Syringe Service Programs Indicators Implementation Guide

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SHaRP: SUPPORTING HARM REDUCTION PROGRAMS
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List of Abbreviations

Abbreviation	Definition
CAB	Community advisory board
CDC	Centers for Disease Control and Prevention
FTE	Full Time Employee
HCV	Hepatitis C Virus
HIPAA	Health Insurance Portability and Accountability Act
HIV	Human Immunodeficiency Virus
LGBTQ+	Lesbian, Gay, Bisexual, Transgender, Queer
MAT	Medication Assisted Treatment
MOUD	Medication for Opioid Use Disorder
M&E	Monitoring and evaluation
NACCHO	National Association of County Health Officials
OMB	Office of Management and Budget
PHI	Private Health Information
RFA	Request for applications
RFP	Request for proposals
SHaRP	Supporting Harm Reduction Programs team
SSN	Social Security Number
SSP	Syringe services program
PiTS	Point in time survey
UID	Unique Identifier
UW	University of Washington

Introduction

This guidance is for syringe services programs (SSPs) and for those who regulate and fund SSPs. We provide background for this project, an overview of good data practices for monitoring and evaluation at SSPs, and a guide for collecting and analyzing specific indicators. We know harm reduction regulations and data requirements differ geographically and across funders, so there is no one data model for all programs, but our indicator recommendations provide broad guidelines and a list of indicators we think may be helpful across different programs and locations.

Proposed Use

The SSP Indicators Implementation Guide aims to provide basic data points that could be collected at a wide variety of SSPs, with a focus on basic SSP services (i.e., provision of safe use supplies and naloxone), descriptions of program, descriptions of participants, and participant experiences. These data points are usable for internal program evaluation and external program communication (i.e., advocacy and grant writing).

While the SHaRP team does recommend minimal data collection, we recognize that most programs will collect additional data beyond the indicators listed here. This is intentional. SSPs are incredibly diverse in what services they offer and how they offer services and the data they collect should be carefully considered and tailored to account for factors such as services offered, service model, local context, evaluation goals, and evaluation capacity.

We have attempted to make a comprehensive document for SSPs to think about and adapt these indicators for their own use. It is likely that most users will not read this from start to finish but go specifically to the parts that interest or serve them. We encourage going directly to the parts that interest you and note that for any indicator of interest we recommend reading all the information on that indicator to get the full picture.

Out of Scope

The scope of this project does not include some services that are becoming more common at SSPs, specifically, case management and infectious disease testing because both require identifiable information (e.g., first and last name, contact information, birthdate) and would fall under the Health Insurance Portability and Accountability Act (HIPAA). HIPAA is outside of the scope of this, and nothing in the guidance will tell you whether an organization needs to be HIPAA compliant, that depends on several factors including what data is collected, how the data is collected, and other data that you are collecting with it. This kind of data should be documented separately from SSP data, not linked to SSP services, and needs to be collected and stored in accordance with HIPAA. Ideally, SSP services should be anonymous (i.e., not linked to any identifiable information). If SSP service information is linked to testing or case management information that contains identifiable information, it is confidential, not anonymous. Participants should always be made aware when their data is confidential (i.e., identifiable).

The project does not focus on participant outcomes (e.g., behavior change) for two main reasons. First, participant outcomes are incredibly hard to track, especially within the standards we set for the indicators in this project. The indicators met three standards: flexible (could be collected across a wide swath of SSPs), ethical (data collection is ethical for participants and staff), and quality (able to collect with high confidence of data quality). Most participant outcome data would struggle to meet any of those three standards. The second reason is that tracking participant outcomes requires using unique identifiers and we do not recommend tracking unique participant data. When and where the policy environment allows, anonymous data collection for SSP services is ideal for participant privacy and can improve access to services. We recognize that some programs may at times be asked or required to report on participant outcomes, despite existing evidence. This is beyond the scope of this project.

Lastly, we did not include community level indicators in this project because, as mentioned, this project focuses on internal program evaluation, and community level indicators require external data sources. Currently there are very few national, state, or local publicly available data sources for the community level data that would be useful to SSPs, and therefore it would require significant expertise and funding to collect, which is outside of the scope of most SSPs currently.

SHaRP Guiding Principles for Data

The Supporting Harm Reduction Programs (SHaRP) team at the University of Washington has several guiding principles that inform the current indicators project. First, harm reduction has significant existing evidence[1] and asking or requiring SSPs to continue demonstrating what research has already proven puts burdens on the programs and creates barriers to services for participants. Second, we recommend collecting minimal data, or just enough data to meet internal evaluation goals and external reporting requirements. This minimal data collection lessens the data burden on program staff, who must take time to collect, analyze, and disseminate data, and on participants, who spend time and energy on providing data. We recommend only collecting data that can be used to benefit people who use drugs. Data may be beneficial, but protecting that data is crucial. Programs may want to consider the worst possible outcomes of the data they collect – could the data be used to hurt participants? Could data hurt staff or programs?

Third, data should never be a barrier to services and should not be stigmatizing. We recommend aligning data collection practices with harm reduction principles. Data collection should be transparent, optional, and objective.

Fourth, data security is critical to protecting participants and programs. If possible, all collected data should be anonymous and de-identified (i.e., there is no personal information in the data that can be used to identify someone) due to the criminalization of drug use. If data cannot be anonymous, every effort should be made to keep data secure. For more information on data security, please review our Brief Overview of Data Privacy and Security Considerations at Harm Reduction Programs[2]. Because we recommend anonymous data collection, our team doesn't recommend the use of unique identifiers or identification codes unless they are externally required or provide state or local legal protections[3]. All

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[1] https://www.cdc.gov/syringe-services-programs/php/safety-effectiveness.html

[2] https://www.sharpta.uw.edu/syringe-services-program-monitoring-and-evaluation-resources/brief-overview-of-data-privacy-security-considerations-at-harm-reduction-programs/

[3] For instance, in some jurisdictions, SSP participants are only protected from paraphernalia charges if they can show they use a SSP or are traveling to or from a SSP.

our recommended indicators may be measured anonymously. If your program is required to use unique identifiers, we have a guidance document[4].

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[4] https://www.sharpta.uw.edu/syringe-services-program-monitoring-and-evaluation-resources/using-unique-identifiers-within-syringe-services-programs/

Background

Project Origin

The SHaRP team provides technical assistance to harm reduction programs nationally on issues relating to data. Programs consistently ask the team two questions: what data do we collect? And how do we collect data according to good and ethical practices? We also hear a common complaint – that programs have too many burdensome and changing data reporting requirements from funders and regulators that the programs themselves have no input in creating.

Our team undertook this project because we want to have community-informed recommendations to give programs when they ask about which data to collect and good data practices. We do not have the power to change data requirements, but we wanted to document the burden requirements have on programs.

Methods and Early Findings

The indicators project was divided into three phases. Phase 1 consisted of a literature review and formative conversations with SSPs, state health departments, and non-state funders. The literature review included 41 peer-reviewed articles, white papers, and grey literature from harm reduction programs and drug user organizers. The review, summarized here[5], focused on good and ethical data practices at harm reduction programs and recommended harm reduction data indicators.

For the formative conversations, we spoke with nine harm reduction programs, four health departments in states where SSPs are legal, and four non-state funders about their current data collection practices or data requirements and ways they use their data. We contacted SSPs based on their location in urban versus rural areas, progressive versus conservative states, and whether their programs were small/medium or large/very large, as seen in Table 1. We recruited one program that operates underground, for a total of nine programs. The list of SSPs we contacted was based on our team's previous experiences with or the reputation of the program.

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[5] https://www.sharpta.uw.edu/syringe-services-program-monitoring-and-evaluation-resources/good-practices-and-ethical-data-collection-at-harm-reduction-programs-a-brief-summary/

Table 1. Types and numbers of SSPs recruited

	Urban[6]		**Rural**[7]	
	Small/medium program[8]	**Large/very large program**[9]	**Small/medium program**	**Large/very large program**
Progressive state[10]	1	1	1	1
Conservative state[11]	1	1	1	1

We contacted state health departments based on their population size (under or over five million residents) and their location in progressive versus conservative states, as defined in Table 1. We had conversations with four harm reduction non-state funders/advocacy organizations who operate nationwide.

Conversations lasted approximately one hour and included the participant(s) and two members of the SHaRP team. We conducted all conversations via video. We recorded and transcribed all the conversations. We used the conversation guide in Appendix 5 with SSPs and in Appendix 6 with state health departments and non-state funders/advocacy organizations. A primary and secondary coder coded each transcription in Dedoose (2022). We developed the codebook using emergent codes from the data and from the conversation guides. The following represent themes from the conversations.

Consistently inconsistent. There is little consistency between SSPs, state health departments, and funders in terms of which data they collect or require SSPs to collect or how data is collected.

Underfunded and overworked. There is an overall understanding that there are gaps in services and that data collection is often a barrier to services, but SSPs and funders alike feel limited in what they can do to improve conditions due to limited funding and staff capacity. State health departments and funders also seem frustrated with the data they think they must ask SSPs to collect because of pressure from policy makers, legislators, and higher-level funders.

Multiple challenges for SSPs to collect data. SSPs face challenges in terms of staff and participant time and patience in collecting data. These challenges are decreased when SSPs have funding for dedicated staff time for data collection and analyses.

Potentially useful data. SSPs at times have difficulty thinking about which data they want to collect because they are overwhelmed with collecting the data they think they must for grant applications or that they are required to collect for current funding. They often do not find the required grant and funder data to be useful programmatically. There were some common domains in which SSPs wanted to

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[6] Urban programs are located in an urban area and serve a majority urban population as defined by HRSA (https://www.hrsa.gov/sites/default/files/hrsa/rural-health/resources/forhp-eligible-areas.pdf)

[7] Rural programs are located in or have locations in a rural area and serve a majority rural population in those locations as defined by HRSA (https://www.hrsa.gov/sites/default/files/hrsa/rural-health/resources/forhp-eligible-areas.pdf)

[8] Small/medium program is based on the 2022 Dave Purchase Memorial survey, and distributes less than 128,000 syringes per year

[9] Large/very large program is based on the 2022 Dave Purchase Memorial survey, and distributes 128,000 or more syringes per year

[10] Progressive state has a progressive state legislature based on control of the state senate and house

[11] Conservative state has a conservative state legislature based on control of the state senate and house

collect indicators, including demographics, supplies, and participant interactions with law enforcement, health care providers, and substance use disorder treatment providers.

Lack of communication. There is evidence of a lack of communication between SSPs, state health departments, and non-state funders. SSPs think they are being asked for data without their input and without proper considerations for their needs. Funders think they are only asking for a small amount of data, but when multiple entities are asking SSPs for a small amount of data that is not harmonized with what other entities are requiring, the result is SSPs face accumulating data requirements. SSPs do not understand how their data are being used and are frustrated that they do not receive meaningful report backs from funders about their data.

Location matters. Where health departments and SSPs are located dramatically affects their strategies and experiences. Some health departments and SSPs must meticulously think about policies and public perceptions before acting, while other health departments and SSPs can be more flexible. While operating in unclear policy environments carries potential legal ramifications for SSPs, programs that operate underground or without explicit sanction may experience the easiest data environments because they do not have to contend with state reporting requirements.

In phase 2, we solicited data collection and reporting forms from nine SSPs, five private funders, and thirty states. We solicited data collection tools from the 43 states with a Determination of Need from the Centers for Disease Control and Prevention. Nine states did not share their tools and four did not collect any data from SSPs. We compiled the indicators from these forms, which resulted in over 500 indicators, even after collapsing some indicators that were incredibly similar. When analyzing this compiled list, we found there were inconsistencies in terms of how data were asked about, the frequency of data collection, and the methods for collecting data. There were dozens of indicators that were similar, but not identical, meaning data could not be compared and SSPs may have been asked to collect the same or similar data, but to report those data in different ways.

We grouped the indicators by topical areas into domains. Table 2 shows how many states and non-state funders collected indicators within each domain. Most of the 30 states collected indicators within the service and supply provision (*n*=28), service coverage (*n*=27), demographics (*n*=22), and overdose prevention (*n*=22) domains. All 5 of the non-state funders collected indicators on service and supply provision (*n*=5).

Table 2. Domains collected

Domain	**# of States with Indicators in Domain (*n*=30)**	**# of Non-State Funders with Indicators in Domain (*n*=5)**
Demographics	22 (73%)	3 (60%)
Engagement with People who Use Drugs	4 (13%)	2 (40%)
Health behaviors	13 (43%)	1 (20%)
Health status	8 (27%)	2 (40%)
Overdose prevention	22 (73%)	4 (80%)
Service and supply provision	28 (93%)	5 (100%)
Service coverage	27 (90%)	4 (80%)
Service quality	13 (43%)	3 (60%)
Structural violence	14 (47%)	3 (60%)

To refine the list, we adapted a method frequently used in qualitative research, card sorting, to identify whether indicators met three criteria: ethical, flexible, and would result in quality data. By ethical, we mean a low burden of data collection and analysis for participants and staff that is culturally and structurally relevant, has a clear use, may be securely collected, and if data are breached, minimal harm would occur. By flexible, we mean they would apply to the majority of SSPs in the United States, and some indicators allow for the discovery of unexpected findings. For quality data, we mean that data has an accepted history of use in harm reduction, answers relevant evaluation questions, and collected data could be close to complete, reliable, and accurate.

Each member of our team first sorted indicators out of our list based on whether they were ethical, then sorted indicators out based on flexibility, and finally sorted indicators out based on quality. With the indicators that were remaining, our team met and utilized a consensus process to refine a list of indicators that the SHaRP team felt we could support, based on the community feedback we wanted to receive in phase 3.

Phase 3 began with a convening, followed by a workgroup and public share back. We 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 and funded 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.

The original convening purpose was to identify indicators that would be ethical and potentially useful for harm reduction programs to collect. As a result of dialogue around potential harms of data collection on SSP participants and staff, workgroup members determined that identifying indicators was not the priority for the in-person time, and instead discussed themes around data collection, relationship with funders, programmatic autonomy, and data ethics. These findings have been summarized and informed workgroup meetings.

During follow-up workgroup meetings, we presented the SHaRP team indicator list, formulated in phase 2. We used a REDCap survey to solicit feedback about the indicators on the same criteria (i.e., ethical, flexible, quality) used in phase 2. We asked workgroup participants to comment on any changes they wanted made to indicators and to propose additional indicators. This resulted in eighteen indicators, after we removed, modified, and added indicators.

The 18 indicators were presented in a public share back in November 2023. After the presentation, a REDCap survey was again used to solicit feedback from the public, which informed the current Indicator Implementation Guide.

Limitations

There are several limitations to this project. While we made every effort to include as many voices as possible from the harm reduction community, time and funding limited the amount of feedback we could collect and analyze. While many of the indicators we propose have a long history in harm reduction, we have not pilot tested these indicators or the questions associated with them as a cohesive indicator dataset. Due to external reporting requirements and differences in local contexts, we assume our proposed indicators will not be all the indicators that a program tracks, or a program may only collect a portion of these indicators. Because of said differences, we cannot say whether the proposed indicators will always be helpful or how many indicators should be collected to create a complete evaluation plan for a program.

Indicators

In the next section, before introducing the proposed indicators, we will define a few monitoring and evaluation related terms. These terms may be useful in understanding each indicator and its associated recommendations. Indicators will then be presented and organized by domain: service and supply provision, service coverage, service quality, engagement with people who use drugs, overdose prevention, demographics, and then structural violence.

Monitoring and Evaluation (M&E) 101

Monitoring and evaluation (M&E) involves collecting program data on an ongoing basis to determine if programs are meeting their goals. The indicators included in this guide are a suggested set of data collection points for SSPs to integrate into their data systems for both internal and external use. Below are some brief concepts that are important to creating a M&E system, more detailed information about some of these concepts can be found in our M&E toolkit[12] and Point in Time Survey (PiTS) toolkit[13].

What is an indicator? An indicator is a specific, observable measure of something we want to know about. For example, indicators include the number of syringes distributed in a month or the race and ethnicity of participants. Indicators identify the overall concept being measured but are not the specific wording of a question. In many cases, an indicator can be asked or addressed in multiple ways. For example, participant age is an indicator that could be measured by directly asking a participant's age or by asking which age range they fit into.

The indicators included in this guide are organized into a series of domains. A domain is a category of indicators related to a similar overarching question or purpose. For example, service coverage and demographics are both domains. Service coverage includes indicators related to syringe inventory and the type of supplies a program offers, while demographics includes indicators about race and ethnicity, gender, and age.

Levels of data

The proposed SSP indicators broadly fall into two categories: person-level data and program-level data. When establishing a data collection system, it is important to determine how and from whom data will be collected. Data systems are often a mix of both person-level and program-level data.

Person-level data:

Person-level data collection involves collecting data directly from participants and can include anonymous encounter-level data, encounter data linked with unique IDs, or a point in time survey (PiTS).

With encounter-level data collection, participants are not assigned a unique code, and typically do not complete an enrollment process with your staff. Encounter-level data collected from participants is not

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[12] https://www.sharpta.uw.edu/monitoring-and-evaluation-toolkit-data-collection-methods-and-pilot-testing/
[13] https://www.sharpta.uw.edu/syringe-services-program-monitoring-and-evaluation-resources/pits-toolkit/

linked to them, and data collected over multiple visits from the same person is treated as separate data entries. This is sometimes referred to as “duplicate” data since individuals who receive services multiple times are also represented in the data multiple times. Encounter-level data collection systems allow for anonymous data collection and are generally lower barrier than unique data collection systems.

Data collection systems linked with unique IDs attempt to distinguish unique participants in the system. This is typically done to estimate the number of unique participants and monitor the services used by those participants over time. For most programs, this entails assigning a unique identifier (UID – more information below), and this code is used to monitor participants’ service provision in your program. Depending on your state and local jurisdiction, having a unique identifier may provide some legal protections to harm reduction program participants. With the appropriate analytical support, unique data collection can allow for intensive data analysis. For example, this system allows a program to calculate the average number of supplies or syringes out per unique participant over an extended period of time. However, unique data collection also presents potential barriers for your participants because it typically means you are asking participants for more personal information, often when they are first accessing your services.

Program-level data:

Program-level data includes data about your program rather than participants. This could include supply data, service data, and information about your program’s overall framework/model. Supply data can be gathered by tallying the number of services/supplies provided at each encounter or by using an inventory method. To do this, you keep track of how many syringes, supplies, etc., you took out for services that day, and how many you returned with after services. Service data can be collected similarly to supply data. It can be good for capturing the sorts of services your program provides on a regular basis (i.e., food, referrals, testing) and/or data from special events or activities that may happen on an ad-hoc basis (community naloxone trainings).

Standardizing data

Data standardization relates to the rules and procedures your program develops to ensure that data is collected, recorded, stored, and reviewed in a consistent way. For example, if individual staff record the same indicator differently it may result in data that is inaccurate or hard to fully analyze. One staff member may record the number of naloxone kits distributed while another may record the individual doses. In this situation, if the form only includes tallies with no description of if the number refers to kits or doses, this will result in difficulty reporting how much naloxone you are distributing.

Pilot testing

Pilot testing is a process of testing out your survey and data collection process to ensure they function before you start to collect real data. By testing it, you are trying to work out any problems before you do your real data collection by getting feedback and experience administering the survey to people who are part of, or knowledgeable about, your population.

Pilot testing is an iterative process, meaning that you will test, make revisions, and test again until the survey and/or data collection system is working reliably. Sufficient pilot testing ensures the data you are collecting will meet your needs and that your survey and data collection process are functional and sustainable for your staff and participants.

Data monitoring and quality assurance

As mentioned above, data monitoring and evaluation involves collecting program data on an ongoing basis to determine if programs are meeting their goals. Part of the process is to regularly check in with the data your program has been collecting and determining if it is meeting your goals and expectations. Is data collection being rolled out consistently? Has any data collection efforts impacted provision of services? Is the data being recorded legibly and accurately? Do you have unexpected missing data? Routinely checking your data for consistency and accuracy will help you course correct your data efforts in real time, rather than needing to analyze a huge chunk of data and realizing that it is difficult to decipher.

Service and Supply Provision

The services that a program provides and the supplies that a program distributes.

	Indicator	Format	Recommended Data Source
01	Count of syringes distributed	Reported as a number, could be reported as a daily, weekly, monthly, quarterly, or annual estimate	Inventory, encounter
02	Types of services a program provides	Reported as a list	Program model
03	Types of supplies a program distributes	Reported as a list	Inventory

INDICATOR: Count of Syringes Distributed

Definition:

Count of syringes distributed is an estimate of the number of syringes a program distributes over a given time (e.g., monthly, annually).

Use:

Why indicator was selected:

Count of syringes distributed is a low-barrier indicator for program staff and participants. It does not require staff to ask questions of participants, does not require unique identifiers for participants, and does not pose a risk to participant privacy or autonomy. It is simple to track across different program types and may be tailored to fit the program's services, staff bandwidth, and reporting schedule.

Using it for program improvement:

Count of syringes distributed gives SSPs and funders a sense of participant demand and if tracked over time, may reveal trends. **Count of syringes distributed** may inform inventory (e.g., stocking, ordering) and fundraising (e.g., grant writing) decisions. Stratifying this indicator by site, over time, or by service model (e.g., outreach, brick and mortar, mail) may help programs understand where, when, and how most syringes are distributed.

Using it for advocacy:

Count of syringes distributed may show organizations and local communities the value of a program in preventing the spread of HIV infections and the associated cost savings (Des Jarlais, 2021).[1] This indicator may illustrate the demand for a program when advocating with health authorities, community members, or funders.

Collection:

Two systems could be used to collect **count of syringes distributed**. In an encounter system, staff tally the number of syringes distributed during each participant visit or encounter. How a program notes encounters can vary, ranging from using a tally counter (if there is not supplemental data being documented) to making a tally mark on a paper log to completing a digital form for each encounter. In an inventory system, staff could determine how many syringes were distributed by completing a count or inventory of their syringes at regular intervals. A combination of these methods could be used to cross-check or for different aspects of the program (e.g., encounter system for daily direct service and inventory system for events).

Programs may choose to record type of syringes out to understand participant preferences for inventory. Type of syringes distributed does not need to be reported outside of the program.

Considerations:

On its own, the **count of syringes distributed** cannot tell a program if they are meeting the syringe coverage[14] needs of their participants, i.e., if participants are receiving enough syringes to use a new syringe for each injection.

Count of syringes distributed may be reported as shift, daily, monthly, and/or annual totals. Remember that the **count of syringes distributed** does not indicate if the syringes are distributed to the people most in need, are distributed equitably across participants or populations, or are meeting participants syringe coverage needs. Qualitative data from program staff and/or a point in time survey from participants may offer more insight into those topics. **Count of syringes distributed** does not indicate which type of syringe is distributed. If multiple syringe types are distributed, stratifying by type may assist in revealing participant demand and may inform inventory.

Example:

Syringes distributed by quarter	
January-March	89,520
April-June	110,750
July-September	130,500
October-December	92,630
Annual total	***323,400***

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[14] https://www.sharpta.uw.edu/syringe-services-program-monitoring-and-evaluation-resources/syringe-coverage/

INDICATOR: Types of Services a Program Provides

Definition:

Types of services a program provides is a list of services offered by a SSP to its participants.

Use:

Why indicator was selected:

Types of services a program provides is a low-barrier indicator for program staff and participants. It does not require staff to ask questions of participants, does not require unique identifiers for participants, and does not pose a risk to participant privacy or autonomy. It's fairly simple to track across different program types and may be tailored to fit the program's services, staff bandwidth, and reporting schedule.

Using indicator for program improvement:

Reviewing the **types of services a program provides** allows a SSP to document the overall support they offer participants. It can be a great way to show how a program has expanded over time and identify gaps in services provided and potentially new services that could be offered. **Types of services a program provides** is a useful indicator in funding applications to demonstrate the breadth of programing a SSP offers.

Using indicator for advocacy:

Types of services a program provides demonstrates to organizations and communities the breadth of support a SSP offers and its overall impact. It can be used to expand support of a SSP's existence and/or grow partnerships with other organizations who may provide services that a program does not offer. As a caveat, we recommend that programs are mindful of their environment and do not publicize any services that are illegal or in legal grey areas.

Collection:

We recommend programs update their list of services provided at least yearly or when there has been a major shift in which services are provided (e.g., get a grant to begin HIV/HCV testing and HCV treatment). This update includes adding new services and removing any services your program does not actively provide. We encourage programs to report their model of syringe distribution as part of this indicator. Syringe distribution models vary (e.g., one-for-one, needs-based, etc.) and the differences can impact the effectiveness of SSPs.

Considerations:

Types of services a program provides does not necessarily show how engaged participants are with each individual service nor does it capture the roll-out of specific services. It is simply a list of all possible services a participant can access when coming to the program. It may be beneficial to provide context to each service provided by describing what accessing the service entails and what the service covers. For instance, if your program provides wound care, you may want to say who provides the care. Is there a nurse or doctor on staff? You can also mention what specific wound care services are provided. Are there certain injuries that your program is more adept at addressing and others that you will have to refer out? Does your program also provide first aid kits to participants directly?

Like many of the other indicators, **types of services a program provides** is most useful when additional context is given. It may be helpful to describe what certain services entail. In addition, the services offered are more compelling when the nuances of your program are also present, such as general demographics of participants and location context paired with how your specific services address your community needs.

Example:

Types of services offered
Needs-based syringe access, syringe disposal, safer smoking supplies, wound care, behavioral health, housing referrals and case management, referrals to MOUD, HIV/HCV testing, safer injection education

INDICATOR: Types of Supplies Program Distributes

Definition:

Types of supplies a program distributes is a list of the supplies offered by an SSP to its participants.

Use:

Why indicator was selected:

Types of supplies a program provides is a low-barrier indicator for program staff and participants. It does not require staff to ask questions of participants, does not require unique identifiers for participants, and does not pose a risk to participant privacy or autonomy. It's fairly simple to track across different program types and may be tailored to fit the program's services, staff bandwidth, and reporting schedule.

While it can make sense to provide information about how many of certain supplies are distributed (e.g., syringes, naloxone), some supplies (e.g., cottons, cookers, alcohol wipes) do not need to be counted or reported externally and may only need to be tracked through inventory for internal uses like ordering and budgeting. One important caveat is that programs should be careful when documenting distribution of supplies that are in legal grey areas.

Using indicator for program improvement:

Reviewing the **types of supplies a program provides** allows a SSP and its participants to see the breadth of supplies a program offers. It can be a great way to show how a program has expanded over time (e.g., offering more variety of supplies, offering new supplies to address local changes) and identify gaps in supplies provided and potentially new supplies that could be offered. Some programs use a list of supplies they provide as a "menu" for participants during services so participants can see everything they have access to. If keeping enough supplies in stock is a problem, whether due to budget constraints or supply chain issues, programs may want to document the issue to understand and address it. **Types**

of supplies a program provides is a useful indicator in funding applications to demonstrate the breadth of programing a SSP offers.

Using indicator for advocacy:

Types of supplies a program provides demonstrates to organizations and communities the breadth of support a SSP offers and its overall impact. It can be used to expand support of a SSP's existence and/or grow partnerships with other organizations who may provide supplies that a program does not offer. As a caveat, we recommend that programs are mindful of their environment and do not publicize any services that are illegal or in legal grey areas.

Collection:

We recommend programs update their list of supplies provided at least yearly or when there has been a major shift in which supplies are provided (e.g., received a grant to begin providing smoking supplies). This update includes adding new supplies and removing any supplies your program does not actively provide. Programs may also want to provide information about how they provide supplies (e.g., needs-based, one-for-one, etc.).

Considerations:

Types of supplies a program provides does not necessarily show if the supplies are meeting the goals of a program or the needs of the participants (i.e., are you providing enough cookers so participants have enough to use a new one each time?). Programs would need further data to know whether they were achieving those. Policy and legislation, restrictive funding, and/or supply chain issues may impact a program's ability to fund certain supplies and/or keep them in stock.

Like many of the other indicators, **types of supplies a program provides** is most useful when additional context is given. It may be helpful to look at other sources of data, like staff notes, to assess if your program regularly runs out of certain supplies or if participants are asking for supplies you do not have. Those may present opportunities that could be useful when applying for new funding and/or areas for your program to grow.

Example:

Types of supplies distributed
Syringes, sterile injection supplies (cottons, water, tourniquets, ascorbic acid, alcohol wipes), sharps containers, safe smoking supplies (stems, bubbles, filters, chore boy, foil), fentanyl test strips, overdose reversal supplies (nasal or injectable naloxone, syringes, CPR masks), wound care supplies (antibiotic ointment, gauze, Band-Aids, alcohol wipes), condoms, hygiene products.

Service Coverage

At the population level, service coverage may refer to the reach of a program in a geographic area. At the individual level, service coverage may refer to the level of engagement, level of services, or comprehensiveness of services provided to a participant.

	Indicator	Format	Recommended Data Source
04	Hours per week program operates	Reported as a number	Program model
05	Program's service model(s)	Reported as a list (i.e., fixed site, mobile, mail-based, street outreach, etc.)	Program model
06	Total participant visits	Reported as a number, includes duplicated participants and thus does not require unique identification; could be reported as a daily, weekly, monthly, quarterly, or annual estimate	Encounter

INDICATOR: Hours Per Week a Program Operates

Definition:

Hours per week a program operates is a record of a SSP's in-person schedule and/or the total amount of time a program offers services to participants each week. Vending machines and mail-based services are not included.

Use:

Why indicator was selected:

Hours per week a program operates is a low-barrier indicator for program staff and participants. It does not require staff to ask questions of participants, does not require unique identifiers for participants, and does not pose a risk to participant privacy or autonomy. It's fairly simple to track across different program types and may be tailored to fit the program's services and reporting schedule.

Using indicator for program improvement:

Programs can use **hours per week program operates** to make decisions about hiring or staffing. If, for example, a 5-day-per-week fixed-site program adds a delivery service that operates 12 hours per week, bumping their total number of operating hours across all services to 52, they may weigh hiring additional personnel against restructuring weekly staffing. Programs may also use changes in total hours per week to help assess changes in service delivery. A program might find that expanding to 20 hours per week from 15 hours more than doubles their encounter total, allowing them to justify a budget increase from funders. Especially in the context of other indicators, this indicator can be used to help assess program capacity and service availability to participants.

Using indicator for advocacy:

Programs might find that **hours per week** is useful for showing a program's capacity, growth, or need for expansion. If expanded hours have led to an increase in supplies out or participant visits, a program may use that data to advocate for community support and funding.

Collection:

We recommend documenting and updating **hours per week program operates** annually and revisiting as needed. We caution against documenting total hours for service models that may exist in legal gray areas or are illegal.

Some programs may record their total number of hours across all locations and/or service models. Other programs may simply record the number of hours they are open per week without differentiating among locations and/or service models. (e.g., "33 hours per week;" "10 hours per week"). It can also be helpful to track the days and specific times a program is open to monitor change over time and whether other local programs have complementary hours.

Considerations:

Hours per week a program operates alone cannot illustrate a program's reach or impact. Rather, it is best used in conjunction with other indicators as a way to assess and demonstrate program capacity and need. **Hours per week a program operates** is only useful for in-person services and would not be applicable to vending machines or mailed based services.

Programs using **hours per week** to demonstrate capacity should take note of other relevant contexts. For example, if your program recently changed its schedule, adding a staff member during peak hours but cutting a slower shift short, you may want to see whether the change in hours has correlated with a change in encounters or supplies out. If your program expands hours but has not seen a corresponding change in services or supplies out, you may decide to allocate resources toward a complementary service model and return to your original schedule.

Example:

Site	**Number of hours per week**
Fixed site on 3rd Street	10
Fixed site on Maple Ave	5
Outreach	10
Delivery	8
Total	*33*

INDICATOR: Program Service Models

Definition:

Program service models is a list of models through which SSPs provide services to their participants.

Use:

Why indicator was selected:

Program service models is a low-barrier indicator for program staff and participants. It does not require staff to ask questions of participants, does not require unique identifiers for participants, and does not pose a risk to participant privacy or autonomy. It's fairly simple to track across different program types and may be tailored to fit the program's reporting schedule.

Using indicator for program improvement:

Maintaining a list of **program's service models** demonstrates to organizations and communities the breadth of support a SSP offers and its overall impact. It can be used to expand support of a SSP's existence and/or grow partnerships with other organizations who may provide services via a different model. We recommend that programs are mindful of their environment and do not publicize service models that are illegal or in legal grey areas.

Using indicator for advocacy:

Maintaining a list of **program service models** may help demonstrate your program's impact in the community. It can be used to expand support of your program's existence or grow partnerships with other organizations who provide services via different models. We recommend that programs are mindful of their environment and do not publicize service models that are illegal or in legal grey areas.

Collection:

We recommend programs update their list of service models at least annually or when there has been a major shift in how services are provided (e.g., get a grant to begin mail-based distribution). This update includes adding new models and removing any models your program does not actively provide.

Considerations:

Program service models is simply a list and does not necessarily show how engaged participants are with each service model nor does it show how models are implemented. It may be beneficial to provide context to each service model by describing how the model is implemented, and which services are available for each model. For instance, if your program provides mail-based distribution, you may want to say which supplies are provided. You can mention how staff communicate with participants and ways participants can ask staff questions.

Like many of the other indicators, **program service models** is most useful when additional context is given. It may be helpful to describe what models entail. In addition, the service models offered are more compelling when the nuances of your program are present, such as general participant demographics and count of participant visits.

Example:

Service models:
Fixed-site, mail-based, street outreach

INDICATOR: Total Participant Visits

Definition:

Total participant visits is an estimate of the number of non-unique participants a program has encounters with over a given time (e.g., monthly, annually).

Use:

Why indicator was selected:

Total participant visits is a low-barrier indicator for program staff and participants. It does not require staff to ask questions of participants, does not require unique identifiers for participants, and does not pose a risk to participant privacy or autonomy. It's fairly simple to track across different program types and may be tailored to fit the program's services, staff bandwidth, and reporting schedule.

Using indicator for program improvement:

Total participant visits gives SSPs and funders a sense of their service volume and participant demand. **Total participant visits** may inform capacity (e.g., staffing, hours) and fundraising (e.g., grant writing) decisions. Stratifying this indicator by site, over time (e.g., day of the week, month, season), or by service model (e.g., outreach, brick and mortar, mail) may help programs understand where, when, and how most participants are served.

Using indicator for advocacy:

Total participant visits may illustrate the demand for a program when advocating with health authorities, community members, or funders. When used with other indicators, **total participant visits** can help illustrate the impact of policies and community practices. For example, if **total participant visits** are lower than expected on days when local police park nearby, this lower service engagement may be useful in advocating for the police to park elsewhere. If **total participant visits** increase dramatically when a program begins offering pipes, this increase in service engagement may be used to advocate for more funding or policies that allow pipe distribution elsewhere.

Collection:

Note each participant visit as it takes place. Add up the number of visits for each shift. Record and store the sum of each shift's visit as **total participant visits** in a safe, consistent place. Keeping track of numbers of encounters by shift (rather than by weekly totals, for example) may be useful in determining staffing needs, changes in operating hours, or planned closures. Some programs may record their total number of participants across all locations and/or service models. Other programs may simply record the number participant visits they had in a month without differentiating among locations and/or service models. (e.g., 928 participant visits per month).

Depending on a program's processes, noting encounters may be as simple as using a tally counter if there is no supplemental data being documented (such as number of syringes distributed), making a tally mark on a post-it note or more formal paper log, or making an entry in a digital form. We recommend marking down each participant visit as it happens to ensure accuracy and to always have a pen-and-paper method available as backup for any data collection technology staff might use. Make sure to store data in a safe, consistent place after each shift. Mail-based programs would likely consider each supply or resource mailing a "participant visit."

Considerations:

Total participant visits cannot give SSPs an estimate of how many unique individual participants frequent their program or how many people their program indirectly reaches (e.g., through secondary exchange). However, it is consistently more reliable and less burdensome to collect than unique participant numbers or secondary exchange.

Remember that **total participant visits** is not the same as total participants. This type of data is sometimes called "duplicated" because it may include repeat visits from participants. **Total participant visits** alone does not necessarily reflect participant satisfaction or efficacy of service coverage. For example, if a formerly needs-based program implements a syringe cap due to a resource shortage, they may notice an *increase* in total participant visits as participants need more supplies sooner.

Example:

Site	**Number of participant visits per month**
Fixed site on 3rd Street	423
Fixed site on Maple Ave	128
Outreach	305
Delivery	72
Total	*928*

Service Quality

Effectiveness of services at improving the wellbeing and meeting the self-identified expectations of participants, staff, and volunteers.

	Indicator	Format	Recommended Data Source
07	Program activities	Reported as a narrative	Program model, staff
08	Program needs and barriers to service provision	Reported as a narrative	Staff

INDICATOR: Program activities

Definition:

Program activities is a record of the general operations of a SSP over a given time (e.g., monthly, quarterly), including events, services, and experiences.

Use:

Why indicator was selected:

Recording **program activities** is a low-barrier indicator for program staff and participants. It does not require staff to ask questions of participants, does not require unique identifiers for participants, and does not pose a risk to participant privacy or autonomy. It's fairly simple to track across different program types and may be tailored to fit the program's services, staff bandwidth, and reporting schedule.

Using indicator for program improvement:

By regularly recording and reviewing summaries of **program activities** and experiences, SSPs can make iterative changes based on findings. For example, if one month's summary of **program activities** shows that overdose prevention trainings were well attended at a local medication for opioid use disorder (MOUD) clinic, but that no one attended at a local bar, staff may shift where and when they provide trainings. By regularly reviewing narratives of **program activities**, SSPs can better track program growth and gaps over time.

Using indicator for advocacy:

Maintaining a list of **program activities** demonstrates to organizations and communities the breadth of support a SSP offers and its overall impact. It can be used to expand support of a SSP's existence and/or grow partnerships with other organizations who may provide services that are complimentary to a SSPs' **program activities**. Regularly documenting **program activities** and distilling them into a narrative will make it easier to respond to requests for qualitative data about programs. As a caveat, we recommend that programs are mindful of their environment and do not publicize any activities that are illegal or in legal grey areas.

Collection:

We recommend that programs record regular notes as a method to collect **program activities**. You could collect qualitative notes on staff observations and experiences, emerging community partnerships, specific program events, or significant participant/community interactions. Quantitative notes on activities can also be used for **program activities.** For example, recording counts of the number of and type of event/activity held during the month or quarter. In many cases, it is best to pair the quantitative and qualitative data together. For example, a count of the number of overdose trainings during the quarter and a summary of those various events (attendance, reception, impact).

For daily or weekly recording, we recommend that programs implement a staff log for staff and volunteers to fill out on a daily or weekly basis—whichever makes the most sense given your program's personnel and operation structure. Content of the staff log will depend on your program's context, goals, and values. This log could include activities that the program regularly does such as service provision.

For ad-hoc recording, we recommend that programs also take notes on an ad-hoc basis for more seasonal or "rare" events. For instance, if your program hosts events such as overdose prevention trainings, you could keep both qualitative and quantitative notes on the training: topics covered, number of attendees, location, engagement, overall success, etc. In addition, taking notes at staff meetings and integrating them into narratives of your program is a great way to collect qualitative data on your program activities.

Programs often do not have the ability to determine when reports are due to external entities. We do, however, recommend that programs generate reports of their **program activities** semi-regularly to prevent a need for last-minute analysis and compilation of activities. The interval in which a program generates a report of **program activities** may vary depending on audience and mechanism. For instance, providing a monthly newsletter that includes a narrative of the services provided, events held, and notable happenings in your community may be an appropriate reporting mechanism for participants, staff, and other community members. Alternatively, quarterly updates are likely to fit better for grant reporting or to maintain an internal narrative of activities that can be used for future grant applications.

Considerations:

Program activities is primarily a qualitative indicator and thus interpretation of data may be subject to bias. We recommend that more than one person is involved in the analysis or review of findings to reduce some potential biases. Different people from different backgrounds and with different experiences may be primed to interpret the data differently. Having multiple people check the analysis and summaries of the program activity data and discuss their takeaways helps ensure that the narrative of program activities is reflective of your staff's experience.

Example:

Program activities: November

In the month of November, we hosted three overdose prevention training sessions and trained a total of 45 people. The trainings were well received by participants, and many thanked us for hosting the event. The trainings took place on November 2nd, 18th, and 29th. As of now, we have another two training sessions scheduled before the end of the year and hope to train at least 30 individuals. We were not able to schedule our quarterly CAB meeting and are aiming to host it next month.

Staffing and volunteers were consistent this month, but we may be seeing some participant changes. Staff have noted that we are starting to see more and more folks picking up supplies. They have noted that they feel like there have been more unfamiliar faces too. It's unclear if the increase is related to the holidays or maybe more people are hearing about us for the first time. It has also been harder to keep a consistent supply of pipes. We have had five participants over the last few months express that they have had bad experiences with one of our referral MOUD providers. We intend to stop referring to her.

INDICATOR: Program needs and barriers to service provision

Definition:

Program needs and barriers to service provision is a record of a SSP's obstacles, gaps in services, and unmet needs over a given time (e.g., monthly, quarterly).

Use:

Why indicator was selected:

Recording **program needs and barriers to service provision** is a low-barrier indicator for program staff and participants. It does not require staff to ask questions of participants, does not require unique identifiers for participants, and does not pose a risk to participant privacy or autonomy. It's fairly simple to track across different program types and may be tailored to fit the program's services, staff bandwidth, and reporting schedule.

Using indicator for program improvement:

By regularly recording and reviewing summaries of **program needs and barriers to services**, SSPs can make iterative changes based on findings. For example, if one month's summary of **program needs and barriers to services** includes recurring negative experiences related to a treatment referral, it may bring awareness to the ways that a program should update their referral network. By regularly reviewing narratives of **program needs and barriers to services**, SSPs can better track program growth and gaps over time.

Using indicator for advocacy:

Maintaining a record of **program needs and barriers to service provision** demonstrates the potential hurdles a program faces or areas where resources are lacking. Funding applications and community advocacy often require SSPs to explain gaps in services. Regularly documenting **program needs and barriers to service provision** and distilling them into a narrative makes it easier to advocate for needed kinds of support and resources.

This indicator, when regularly documented and summarized, can help provide needed contextual information to explain dips and changes in programs. For example, if a program had a needs-based syringe distribution model but had to shift to capping the number syringes due to lack of funding, and then served 300 fewer participants per month, the program could use this information to advocate to fund a needs-based model.

Documenting **program needs and barriers to service provision** may highlight potential intra-organizational or community issues. For example, consistent negative interactions with the public may show that more advocacy for harm reduction is needed in the broader community.

Collection:

There is not one best way to collect **program needs and barriers to service provision** because this indicator is dependent on your program's context (policy environment, services you offer, geographic location, service model). We recommend that programs record regular notes as a method to collect **program needs and barriers to service provision**. You could collect qualitative notes on staff observations and experiences, emerging community trends, specific obstacles your program is facing, or significant participant/community interactions. Quantitative notes on events can also be used for program needs and barriers to service provision. For example, recording counts of the number of days you ran out of specific supplies, or the number of times you were short-staffed. In many cases, it is best to pair the quantitative and qualitative data together. For example, a count of the number of days you had neighbors complain about your program/participants and descriptions of the nature of these complaints. Over time, this data can be reviewed to determine the best course of action to address the most common complaints (i.e., scheduled pick-up days and documentation of organized effort if syringe litter is an issue).

For daily or weekly recording, we recommend that programs implement a staff log for staff and volunteers to fill out on a daily or weekly basis—whichever makes the most sense given your program's personnel and operation structure. Content of the staff log will depend on your program's context, goals, and values. This log could include activities and experiences that the program regularly deals with such as supplies that the program runs out of during provision of services. Notes or logs should be stored somewhere consistent and known to all staff.

For ad-hoc recording, we recommend that programs also take notes on an ad-hoc basis for more seasonal or "rare" events. For instance, you could keep qualitative notes on events that happened in your community that caused barriers to service provision such as flooding in an area where you do outreach services, or construction on the building where your brick and mortar is located. In addition, taking notes at staff meetings and integrating them into narratives of your program is a great way to collect qualitative data on your needs and barriers to service provision.

We do recommend that programs generate reports of their **program needs and barriers to service provision** on a routine basis to prevent a need for last-minute analysis and compilation of activities. The interval in which a program generates a report of program activities may vary depending on audience and mechanism. For instance, providing a monthly newsletter that includes a narrative of possible interruptions of services (like upcoming construction) and notable happenings in your community may be an appropriate reporting mechanism for participants, staff, and other community members. Alternatively, quarterly updates are likely to fit better for grant reporting or to maintain an internal narrative of **needs and barriers to services** that can be used for future grant applications.

Considerations:

In some cases, there will be **barriers to service provision** that your program is unlikely to be able to fix. A state restriction on purchasing and/or distributing pipes may prevent you from incorporating them into your offered supplies, but documentation that participants request pipes may help inform policy changes over time.

Program needs and barriers to service provision is primarily a qualitative indicator and thus interpretation of data may be subject to bias. We recommend that more than one person is involved in the analysis or review of findings to reduce some potential biases. Different people from different backgrounds, with different experiences, may be primed to interpret the data differently. Having multiple people check the analysis and summaries of the program data and discuss their takeaways helps ensure that the narrative of program activities is reflective of your staff's experience.

Example:

Winter quarter: January-March

We ran out of syringes at least one day each week of this quarter. In mid-February, we altered ordering to prevent running out. This worked for two weeks, and then we ran out of supplies each week in March. Participants were frustrated that we had to cap the number of syringes they could request.

Service hours were regularly very busy. Staff expressed frustration at the amount of data that had to be collected during each encounter. It was difficult to engage with participants, distribute supplies, and accurately record data. Most weeks, when it came time to enter encounter data, a lot of it was missing. This is now the third quarter that staff have complained about the data collection burden related to the new grant we acquired last year.

We were unexpectedly closed 5 service days this quarter due to weather-related interruptions. This may explain why some of the weeks were so busy.

Engagement with People Who Use Drugs

The ways that programs empower people who use drugs, include people who use drugs in decision-making, collect feedback from people who use drugs, and incorporate feedback in programming.

	Indicator	Format	Recommended Data Source
09	How people who use drugs are engaged to give feedback about programs	Reported as a list or narrative	Program model
10	How participants have decision making power in programs	Reported as a list or narrative	Program model

INDICATOR: How People Who Use Drugs are Engaged to Give Feedback About Programs

Definition:

How people who use drugs are engaged to give feedback about programs is a record of a SSP's approach(es) to collecting and recording input from people who use drugs about the overall program, including services, supplies, and structure.

Use:

Why indicator was selected:

Recording **how people who use drugs are engaged to give feedback about programs** is a low-barrier indicator for program staff and participants. It does not require staff to ask questions of participants, does not require unique identifiers for participants, and does not pose a risk to participant privacy or autonomy. It's fairly simple to track across different program types and may be tailored to fit the program's services, staff bandwidth, and reporting schedule.

Using it for program improvement:

The most effective program improvement is directed by participants and people who use drugs. Documenting the ways they are engaged to provide feedback, in addition to their actual feedback, can provide nuance to how program changes are determined. For example, in documenting **ways people who use drugs are engaged to provide feedback** you may find that most of your feedback comes from long-term participants volunteering information during encounters. These interactions may be comprised of only participants who are comfortable at the program, most of whom share similar demographics (e.g., age and race). In documenting this, your program determines that additional engagement methods are needed to reach newer participants and a more demographically representative group of participants. Point-in-time surveys are potentially another method of collecting feedback from a wide array of participants.

Using it for advocacy:

How people who use drugs are engaged to provide feedback shows if SSPs include participants in advocacy priority setting, such as legalizing supplies and services. Sharing the ways participants contribute to advocacy priorities can bolster and demonstrate participant buy-in. Including participants in providing feedback is itself a form of advocacy with people who use drugs. Reporting out to communities and funders on **how people who use drugs are engaged to provide feedback** illustrates the importance of having participant-driven services.

Collection:

We recommend keeping a list of **ways people who use drugs are engaged to provide feedback about programs** that can be used in a program narrative for grant applications and/or in a program's planning documents. When possible, documenting program changes that come about from PWUD feedback can be useful for program improvement, advocacy, and securing funding. Some programs may choose to document the level of participant interest or engagement in each method as well, especially when evaluating what methods work best for their program.

We recommend revisiting, updating, and revising the list of **ways people who use drugs are engaged to give feedback about programs** at least once a year. This can help ensure the list is up to date for internal evaluations and protocols, for promoting to participants, and for funding applications.

Considerations:

A list of the **ways people who use drugs are engaged to provide feedback about programs** cannot indicate actual people who use drugs' level of engagement. On its own, documenting how people who use drugs are encouraged or have the opportunity to provide feedback will not give nuanced information on the scale in which they give feedback. The **ways people who use drugs are engaged to provide feedback about programs** is most meaningful with context, such as method of collection, uptake, or a brief summary of results. For example, a small program with limited funds may not be able to run a participant advisory board, but they may be able to base supply orders on participant requests. Similarly, a program with multiple opportunities for participants to engage in feedback may find that over time, interest and participation shift from one method toward another, which can help them determine where to focus engagement efforts.

Example:

People who Use Drugs Engagement 2023:

- Program comment box
    - Method: Left by service desk during operation hours—reviewed monthly
    - Uptake: Not heavily used, mostly positive comments from participants about service appreciation
    - Summary of results: Some feedback about pipes breaking
- Direct feedback from program participants during services
    - Staff notes collected from participant interactions

    - Asked participants about new hours of operation and potential new brick and mortar location
    - Realized through feedback and participant advisory board meetings that mostly white participants sharing feedback—next year prioritize methods to engage native and black participants.
- Direct feedback from hired staff who use drugs
    - Hired one new staff member with lived experience
        - Total employed people with lived expereince is 5
    - PWUD staff piloted new point in time survey questions
    - PWUD staff proposed meeting topics for participant advisory board
- Quarterly PAB meetings: 4 total
    - Attendance ranged from 8-12 people
        - Group mostly comprised of long-term program participants
        - Open invitation to attend to all participants
    - Each lasted ~1 hour
    - Topics discussed each meeting: potential to move locations to new brick and mortar, how to handle running out of syringes (capping number distributed per person or just running out faster), updating Medication Assisted Treatment (MAT) (referral network, new hours of operation

INDICATOR: How participants have decision making power in programs

Definition:

How participants have decision making power in programs is a list and description of ways SSP participants influence and direct program changes, practices, supplies, and services.

Use:

Why indicator was selected:

Importantly, harm reduction began and is most effective as a drug-user-led practice and movement, and documenting **how participants have decision making power in programs** shows the ways a program is led by the people it serves. Recording **how participants have decision making power in programs** is a low-barrier indicator for program staff and participants. It does not require staff to ask questions of participants, does not require unique identifiers for participants, and does not pose a risk to participant privacy or autonomy. It's fairly simple to track across different program types and may be tailored to fit the program's services, staff bandwidth, and reporting schedule.

Using it for program improvement:

Programs tracking **the ways participants have decision making power** over time may find it useful to see if changes in encounters occur after implementing new power-sharing methods or making participant-requested changes. Documenting ways that participants have decision making power in programs can help act as a "check" on internal evaluation or ethical priorities. If programs aim to engage in power-sharing, documenting **the ways participants have decision making power** can help a program assess their own progress.

Documenting **how participants have decision making power in programs** can help programs assess how well (and how often) they listen and respond to participant needs. Over time, this indicator can help programs track their own progress towards shared leadership and participant-driven programming. Programs can report back to participants on participant-driven changes (and ways to get involved in decision making) to help build trust and show evidence that participant involvement makes a difference.

Using it for advocacy:

How participants have decision making power in programs shows if SSPs include participants in advocacy priority setting, such as legalizing supplies and services. Sharing the ways participants contribute to advocacy priorities can bolster and demonstrate participant buy-in. Including participants in decision making is itself a form of advocacy with people who use drugs. Offering a list of ways to engage in SSPs can give participants an idea of opportunities to hone their own advocacy skills. Reporting out to communities and funders on **how participants have decision making power in programs** illustrates the importance of having participant-driven services.

Collection:

We recommend keeping a list of ways participants have decision making power with a program protocol, a program narrative for grant applications, and/or in a program's planning documents. When possible, documenting program changes that come about from participant decisions can be useful for program improvement, advocacy, and securing funding. Some programs may choose to document the level of participant interest or engagement in each method as well, especially when evaluating what methods work best for their program.

We recommend revisiting, updating, and revising the list of ways participants have decision making power in programs at least once a year. This can help ensure the list is up-to-date for internal evaluations and protocols, for promoting to participants, and for applying for funding.

We recommend programs inform participants of ways they can share in decision making in your program, whether through word-of-mouth, social media posts, flyers, or a program announcements board. Close the loop! Be sure to inform participants when changes or decisions they requested come about, and share how the decision was made (e.g., suggestion box requests, advisory board vote, surveys, participant requests during encounters). Report the ways your participants have decision-making power at your program in program narratives when applying for or reporting on funding.

Considerations:

A list of the ways participants have decision making power in programs cannot indicate actual participant engagement. On its own, documenting **how participants have decision making power in programs** will not give information on actual program changes and decisions made by participants. Keep in mind that *engagement* is not *power.* Running focus groups on participants' desires for programs and supplies is *engagement,* but *power* comes from programs implementing those desires (or empowering participants to implement them in the program). In engagement, programs listen to participants and decide whether to implement their input. When participants have power, programs follow their lead.

The ways participants have decision making power in programs is most meaningful with context. For example, a small program with limited funds may not be able to run a participant advisory board, but they may be able to base supply orders on participant requests. Similarly, a program with multiple opportunities for participants to engage in decision making may find that over time, interest and participation shift from one method toward another, which can help them determine where to focus engagement efforts. Tracking ways participants have decision-making powers over time can also show participants' power growing over time within a program.

Example:

Some programs may prefer to keep a running list of ways participants have decision-making power throughout the year. This might look like a document with a bulleted list that programs update as events happen or decisions are made:

- Put out suggestion box Feb 1
    - Checked box Feb 8
        - 5 suggestions for going back to old brand of ties
            - March 1 ordered old brand of ties
        - 3 suggestions for phone chargers in waiting area
    - Checked box Feb 15
        - 2 suggestions for nighttime hours
        - 5 suggestions for phone chargers in waiting area
            - Feb 25 added charging station to waiting area

Programs that base decisions on conversations with participants might keep an ongoing list of participant requests for ordering as needed, and those lists may be useful in identifying ways participants have decision-making power.

For example, a program that keeps (and implements) the following lists might find that they can report that participants decide what snacks they will keep on hand and changes to outreach hours and routes.

- Participant asks for snacks (ongoing)
    - Popcorn (NOT kettle corn), fruit snacks, bananas
- Outreach notes
    - Encampment by 501 asked us to come by closer to 3pm from now on
    - Willie is moving across town on 4/3; can we add a stop near his new place?

Other programs might keep a calendar of events they can refer back to:

Tues March 3	Weds March 4	Thurs March 5	Fri March 6
Participant advisory board meeting (vote on new hours)		Participants interview new hire candidates	Check suggestion box!

Overdose Prevention

Program services and activities directed towards preventing fatal overdose.

	Indicator	Format	Recommended Data Source
11	Count of naloxone doses distributed	Reported as a number, could be reported as a daily, weekly, monthly, quarterly, or annual estimate	Inventory, encounter
12	Participant overdose experience	Reported as a number	Participants via anonymous point in time Survey (PiTS)
13	Reported overdose reversals	Reported as a number	Participants via anonymous point in time survey (PiTS)

INDICATOR: Count of Naloxone Doses Distributed

Definition:

Count of naloxone doses distributed is an estimate of the number of naloxone doses a program distributes over a given time (e.g., monthly, annually). This indicator is a count of naloxone doses, not kits, since different programs may distribute different numbers of naloxone doses in each kit.

Use:

Why indicator was selected:

Count of naloxone doses distributed is a low-barrier indicator for program staff and participants. It does not require staff to ask questions of participants, does not require unique identifiers for participants, and does not pose a risk to participant privacy or autonomy. It's fairly simple to track across different program types and may be tailored to fit the program's services, staff bandwidth, and reporting schedule.

Using indicator for program improvement:

Count of naloxone doses distributed gives SSPs and funders a sense of their overdose prevention efforts and program efficacy, as well as an understanding of participant demand (Javed et al. 2020)[1]. Tracking the **count of naloxone doses distributed** over time may reveal trends relating to local context (e.g., criminalization of naloxone and overdose) and drug supply (e.g., introduction of new drugs) that may affect SSPs. **Count of naloxone doses distributed** may inform inventory (e.g., stocking, ordering) and fundraising (e.g., grant writing) decisions. Stratifying this indicator by site, over time, or by service model (e.g., outreach, brick and mortar, mail) may help programs understand where, when, and how most syringes are distributed.

Using indicator for advocacy:

Count of naloxone doses distributed may show organizations and local communities the value of a program in preventing overdose deaths. This indicator may illustrate the demand for a program when advocating with health authorities, community members, or funders.

Collection:

Two systems could be used to collect **count of naloxone doses distributed**. In an encounter system, staff tally the number of naloxone doses distributed during each participant visit or encounter. Methods for tracking encounters may vary in simplicity, including using a tally counter if there is not supplemental data, making a tally mark on a paper log, or completing a digital form for each encounter. In an inventory system, staff could determine how many doses were distributed by completing a count or inventory of their naloxone doses at regular intervals. A combination of these methods could be used to cross-check or for different aspects of the program (e.g., encounter system for daily direct service and inventory system for events).

For an encounter system, a **count of naloxone doses distributed** will be tallied with each participant visit as it takes place. These tallies may be stored line by line (e.g., one line on paper or spreadsheet per participant) or aggregate (e.g., the number of doses distributed each shift). For an inventory system, the number of naloxone doses that are stocked and how many have distributed may be counted daily or weekly, depending on participant volume.

Considerations:

Count of naloxone doses distributed does not show if those doses were actually used to reverse an overdose. It shows how many doses were distributed, but not if the doses were distributed to people who most need them (i.e., people who use drugs and their acquaintances) or to how many people those doses were distributed.

Count of naloxone doses distributed may be reported as shift, daily, monthly, and/or annual totals. Remember that count of naloxone doses distributed does not indicate if the doses are distributed to the people most in need or are distributed equitably across participants. Qualitative data from program staff may help show that doses are distributed to people who use drugs. **Count of naloxone doses distributed** does not indicate which type of naloxone is distributed (e.g., nasal, intramuscular, low dose). If multiple naloxone types are distributed, stratifying by type of naloxone may assist in revealing participant demand and may inform inventory.

Example:

In 2023, we distributed 9,898 doses of naloxone. All naloxone was distributed via our brick-and-mortar SSP, which primarily serves people who inject drugs.

INDICATOR: Participant Overdose Experience

Definition:

Participant overdose experience is a record of SSP participants' experiences with themselves non-fatally overdosing. This is *not* an indicator to document participant experiences with other people overdosing. This is a sensitive indicator and how data are collected should consider participant trauma, historical trauma, and local context.

Use:

Why indicator was selected:

Although it is a sensitive indicator, **participant overdose experience** may be collected via trauma-informed methods that are tailored to fit unique participant populations, the local context in which people who use drugs live, the program's services, staff bandwidth, and reporting schedule. As with all indicators, but especially with sensitive indicators like this, participants should never be required to answer questions to receive services and quantitative data collected with this indicator should be reported out in aggregate and anonymously (i.e., not attached to a unique ID). Qualitative data should be reported anonymously and de-identified, meaning any information that could be used to recognize individuals is removed.

Due to our system in which the drug supply is contaminated and drug use is criminalized, people who use drugs more often experience nonfatal overdoses. This indicator documents the physical and physiological burden of nonfatal overdose on people who use drugs.

Using indicator for program improvement:

Participant overdose experience may help programs better understand the physical and psychological burdens of overdose that participants face. This information may assist in developing participant and community education (e.g., methods of decreasing overdose risk), creating new services (e.g., overdose grief and support group), or altering existing services (e.g., communicating drug checking results more quickly). We do not recommend asking this question to gauge whether participants need routine services, like naloxone and drug testing. We instead recommend asking participants directly what services they need (i.e., do you need naloxone?).

Using indicator for advocacy:

Participant overdose experience may be used for advocacy within an organization (e.g., advocating for drug checking services). Programs may also use this evidence in advocacy with local, state, and federal policy makers to support decisions and legislation that decrease population level overdose risk (e.g., increasing access to low-barrier methadone, supporting safer consumption spaces). In areas where overdose surveillance data is inadequate or inaccurate, these data may compliment those surveillance data.

Collection:

Programs should decide if they are asking about all overdoses, opioid overdoses, stimulant overdose, etc., recognizing that people may not be able to differentiate between types of overdoses due to the contaminated drug supply and lack of widely available drug testing.

We recommend collecting data on **participant overdose experience** via point-in-time surveys or ad hoc informal qualitative data collection. For a point-in-time survey, data may be collected via quantitative or qualitative questions. Point-in-time surveys may provide a snapshot of participant experiences without requiring every participant to provide data. For ad hoc informal qualitative data collection, staff would not ask participants directly about their overdose. Instead, when a participant began talking about their overdose experience, staff would ask participants if they would like that experience or story documented via anonymous and deidentified staff notes. If the participant confirmed, staff would record notes via paper, electronic document, or database.

More frequent data collection for this indicator may increase risks of retraumatizing participants. If this question is asked at every encounter, then duplicate data may become frequent as someone repeatedly reports their experience.

For a quantitative point-in-time survey, participants may be asked, “Have you overdosed in the last six months?” Possible answers could be, “No,” “Yes,” “Don’t Know,” and “Prefer not to answer.” A qualitative question on a point-in-time survey could be, “Please tell me about your experiences with overdose in the last six months.” Different time frames may be used for this question, but they should remain consistent across a survey. Longer time frames may capture more data but may be more prone to recall bias.

Considerations:

Asking about **participant overdose experience** may be retraumatizing. These data may represent an undercount of overdoses experienced if people do not want to talk about a traumatic event. Depending on how often this question is asked and how the question is asked, there may be duplicates.

If **participant overdose experience** data is collected on a point-in-time survey that also collects demographics data, data could be stratified to show how overdose experience shifts according to participant race/ethnicity, age, gender identity, and housing status.

As mentioned, programs should decide if they are asking about all overdoses, opioid overdoses, stimulant overdose, etc., recognizing that people may not be able to differentiate between types of overdoses due to the contaminated drug supply and lack of widely available drug testing. If asking about overdose in general, like below, the data will likely include both stimulant and opioid overdose. Due to the major limitations with both methods, the recommended question for **participant overdose experience** below would not differentiate and therefore collect data on both opioid and stimulant overdose.

Examples:

Method: Quantitative question on a point-in-time survey

Question: Have you overdosed in the last six months?
1. No 2. Yes 3. Don't know 4. Prefer not to answer

Results:

Answer	**n**	**%**
No	62	62%
Yes	32	32%
Don't know	1	1%
Prefer not to answer	5	5%
TOTAL	100	100%

Method: Findings from ad-hoc informal qualitative data collected via comment box on form labeled "Participant comments about overdose"

Results: From January to June 2023, 128 participants told us their stories of overdosing. Even though our 2022 PiT survey showed that only 15% of our participants are Black/African American, 27% of the stories we documented were from Black/African American participants. Even though the same survey showed that 45% of our participants are cis men, 61% of the stories we documented were from cis men. 60 (47%) were from people who are unsheltered. 98 (77%) said someone else used at least one dose of naloxone on them. Several themes were in people's stories: they more often overdosed when they were using from a new supplier or when their supplier had a new supplier. People overdosed more often after coming out of jail. Folks are also reluctant to call 911 because they have had bad experiences with paramedics, police, and hospitals.

INDICATOR: Reported Overdose Reversals

Definition:

Reported overdose reversals is a record of SSP participants' experiences reversing overdoses. This is *not* an indicator to document an individual's own overdose. This is a sensitive indicator and how data are collected should consider participant trauma, historical trauma, and local context.

Use:

Why indicator was selected:

Although it is a sensitive indicator, **reported overdose reversals** may be collected via trauma-informed methods that are tailored to fit unique participant populations, the local context in which people who use drugs live, the program's services, staff bandwidth, and reporting schedule. As with all indicators, but especially with sensitive indicators like this, participants should never be required to answer questions to receive services and quantitative data collected with this indicator should be reported out in aggregate and anonymously (i.e., not attached to a unique ID). Qualitative data should be reported anonymously and de-identified, meaning any information that could be used to recognize individuals is removed.

Due to close vicinity to other people who use drugs, a contaminated drug supply, and discrimination from first responders and medical professionals, people who use drugs often reverse overdoses among friends, family, and community members. This indicator documents the care that people who use drugs provide to one another as well as the physical and physiological labor of reversing overdoses.

Using indicator for program improvement:

Reported overdose reversals may help programs better understand the magnitude of care that participants provide to people who use drugs in their community. This information may assist in developing participant and community education (e.g., methods of compassionate overdose reversal), creating new services (e.g., support groups), or altering existing services (e.g., providing preferred forms of naloxone). We do not recommend asking this question to gauge whether participants need routine services, like naloxone. We instead recommend asking participants directly what services they need (i.e., do you need naloxone?).

Using indicator for advocacy:

Reported overdose reversals may be used for advocacy within an organization (e.g., advocating for participant requested supplies to assist in reversals). Programs may also use this evidence in advocacy with local, state, and federal policy makers to support decisions and legislation that decrease population level overdose risk (e.g., increasing access to medications for opioid use disorder, supporting a safer drug supply). In areas where overdose surveillance data is inadequate or inaccurate, these data may compliment those surveillance data.

Collection:

Programs should decide if they are asking about all overdoses, opioid overdoses, stimulant overdose, etc., recognizing that people may not be able to differentiate between types of overdoses due to the contaminated drug supply and lack of widely available drug testing. This indicator can include quantitative, qualitative, or both types of data, depending on program needs and staff bandwidth.

If a program is specifically interested in reversals that used naloxone, that should be said clearly in the question, otherwise the reversals may include other types of responses, like rescue breathing as well.

We recommend collecting data on **reported overdose reversals** via point-in-time surveys or ad hoc informal qualitative data collection. For a point-in-time survey, data may be collected via quantitative or qualitative questions. Point-in-time surveys may provide a snapshot of participant experiences without requiring every participant to provide data. For ad hoc informal qualitative data collection, staff would not ask participants directly about the overdose reversal. Instead, when a participant began talking about a reversal, staff would ask participants if they would like that experience or story documented via anonymous and deidentified staff notes. If the participant confirmed, staff would record notes via paper, electronic document, or database.

More frequent data collection for this indicator may increase risks of retraumatizing participants. If this question is asked at every encounter, then duplicate data may be more likely if someone repeatedly reports the same experience.

For a quantitative point-in-time survey, participants may be asked, “Have you reversed an overdose in the last six months?” Possible answers could be, “No,” “Yes,” “Don’t Know,” and “Prefer not to answer.” This would not give an estimate of the number of overdoses reversed but would give an estimate of the number of participants who have reversed an overdose. To collect an estimate of number of overdoses reversed, participants could be asked “How many overdoses have you reversed in the last six months?” This is an estimate because there may be undercounts (e.g., people not wanting to think about traumatic events) and duplicates (e.g., multiple people reporting the same reversal, the same person reporting a reversal multiple times). Different time frames may be used for this question, but they should remain consistent across a survey. Longer time frames may capture more data but may be more prone to recall bias.

Considerations:

Asking about overdose reversals may be retraumatizing. These data may represent an undercount of overdoses experienced if people do not want to talk about a traumatic event. On the other hand, there may be duplicated data (i.e., an overcount) if multiple people are involved in reversing an overdose or a person is asked the same question multiple times during the data collection window.

If overdose reversal data is collected on a point-in-time survey that also collects demographics data, data could be stratified to show the frequency with which participants reverse overdoses according to their race/ethnicity, age, gender identity, and housing status.

Examples:

Method: Quantitative question on a point-in-time survey

Question: Have you reversed an overdose in the last six months?

1. No 2. Yes 3. Don’t know 4. Prefer not to answer

Results:

Answer	**n**	**%**
No	54	54%
Yes	41	41%
Don’t know	1	1%
Prefer not to answer	4	4%
TOTAL	100	100%

Method: Findings from ad-hoc informal qualitative data collected via comment box on form labeled "Participant comments about overdose"

Results: From January to December 2023, 188 participants told us their stories of reversing overdoses. Even though our 2023 PiT survey showed that 25% of our participants are Black/African American, 32% of the stories we documented were from Black/African American participants. Even though the same survey showed that 45% of our participants are cis women, 68% of the stories we documented were from cis women. 104 (55%) were from people who are unsheltered. Several themes were in people's stories: they were most often reversing someone who lived with or close to them. Some people used rescue breathing, but most did not. People were reluctant to call 911 because they have had bad experiences with paramedics, police, and hospitals.

Demographics

Participant characteristics

	Indicator	**Format**	**Recommended Data Source**
14	Participant age range	Reported as a table	Participants via anonymous point in time survey (PiTS)
15	Participant gender	Reported as a table	Participants via anonymous point in time survey (PiTS); only when safe to collect given local context; see guidance for further information
16	Participant race/ethnicity	Reported as a table	Participants via anonymous point in time survey (PiTS)

INDICATOR: Participant Age Range

Definition:

Participant age range is a count of the number of SSP participants in age categories. This can be used to estimate the age range of a participant population.

Use:

Why indicator was selected:

Participant age range may be collected via methods that are tailored to fit unique participant populations, the program's services, staff bandwidth, and reporting schedule. **Participant age range** is an indicator of equity for SSPs to monitor for program evaluation and identification of health inequalities. People who are different ages may benefit from tailored harm reduction services.

Using indicator for program improvement:

Participant age range can be useful for programs to understand the populations they serve and to make programmatic changes accordingly (e.g., creating youth focused programing or outreach). **Participant age range** can be a useful tool for stratifying other data about your participants, such as race, gender, and housing status to help identify who is and is not served by a program. Demographic data can be helpful for programs to compare their participant demographics and the demographic makeup of their staff to ensure their staff is reflective of the community they serve or hope to serve.

Using indicator for advocacy:

Participant age range is an important demographic indicator that can be incorporated into data published about a program (e.g., annual reports, grant applications) to show the range of community members served. Showing that a program serves youth or older participants may help with coalition building across organizations and provide an entryway for harm reduction practices to enter other spaces, such as youth programs and aging programs.

Collection:

Like all the demographic indicators, **participant age range** needs to be collected directly from participants, but there are methods that limit the data collection burden while providing programs with information to understand who they are and are not serving and make appropriate changes. **Participant age range** should be asked openly and directly to participants so they can provide their own response. This applies to all methods of data collection (i.e., point in time survey, enrollment form, or encounter form). At different programs the count may come from different data sources, and it may be a sample or census of participants.

Like all demographic indicators, a point in time survey is the recommended method for collecting **participant age range**. A point in time survey collects data from a sample of participants that programs can use to estimate information about their larger participant population. Because the data is collected at the same time and in a consistent manner, it is often more accurate, complete, and easier to analyze than enrollment or encounter data. Since participant age is mutable, and programs may want to monitor changes in trends, we recommend collecting it at regular intervals, but not more frequently than annually. Lastly, while data does need to be collected directly from participants, a point-in-time survey can be a minimal burden since data collection is done for a short period of time. If unique IDs are not used, point in time surveys can be anonymous and protect participant privacy. With enough demographic information it is possible to triangulate someone’s identity. For this reason, point-in-time survey reporting should be done in aggregate (i.e., proportions, tables) and not report on individuals.

Collecting participant age or age range using an enrollment form or during encounters has several limitations. Since enrollment forms are collected on a rolling basis, it can be difficult to compile and analyze the data. If collecting participant age via an enrollment form, we recommend only reporting that as **participant age range** at enrollment. We do not recommend collecting age or age range via an encounter form, as that would be highly repetitive for participants, creates an additional data collection burden for staff and participants, and is difficult to analyze and report.

The data may be collected directly as an age range (e.g., <30 years) or collected as a single age (e.g., 26 years) and then categorized into a range. Asking participants to select their age range maximizes participant anonymity and confidentiality. A second benefit of collecting age range is that the data do not need to be organized into range; it is already in that form. The main obstacle to collecting age range is that programs may have multiple reporting requirements on age that use different ranges. If your program is asked to report different participant age ranges to different funders, it may be easier to collect age and then convert the answers to the different ranges for reporting. However, this does pose some risk to participant anonymity and confidentiality and requires more data analysis labor from staff.

There is not one right age range for collecting or reporting age. Ensuring that the lowest age range is inclusive of 18 is protective of minors. There may be local contextual factors or questions that a program is trying to answer that dictate how age range is organized. For example, if looking at insurance coverage, it would be important to consider that Medicare eligibility starts at 65. Therefore, you would want to ensure that none of the age ranges crossed 65 to enable you to account for Medicare eligibility in your analysis. Likely, reporting requirements may be the deciding factor.

Recommended question and answer formats

Question	Answer
What is your age?	• 19 and under • 20-29 • 30-39 • 40-49 • 50-59 • 60-64 • 65+ • Prefer not to answer
What is your age?	_____ (enter number)

Considerations:

The main ethical consideration when collecting data for **participant age range** is its potential to be identifiable. Depending on how participant age is collected, it can be highly identifiable, and therefore a risk to participant anonymity and confidentiality. Collecting birthdates in order to calculate participant age is the riskiest and is discouraged. Participant birthdate is highly identifiable and poses a risk to participant privacy and confidentiality. Even age, when collected and stored with other demographic information, can be identifiable and a risk to participant anonymity and confidentiality. Another minor benefit of collecting age range instead of age is that it requires less data cleaning and analyzing than collecting age and then categorizing into age range. The main reason to collect age and not age range is that most programs are asked to submit participant age information in different ranges to different funders and reporting entities. However, there is limited additional useful information a program would gain from analyzing age data in comparison to age range data.

Participants who are 17 and younger may be wary to report their age for fear of being denied services. Additionally, programs that knowingly serve people under the age of 18 and collect this information could be at risk if their jurisdiction prohibits serving minors. For these reasons, the youngest category of age reported should always be inclusive of (at least) 18.

Participant age is mutable, meaning that it changes over time. This is why some programs collect birthdate and then calculate participant age from that. However, birthdate is highly identifiable and, especially when collected with other demographic information, can pose a risk to participant anonymity and confidentiality. For those reasons, we recommend collecting participant age range or age, and never birthdate. We also recommend that it is collected anonymously (i.e., not connected to a unique ID) and stored securely.

Participant age range does not need to be reported more frequently than annually. If data is collected via a point in time survey, using a combination of demographic factors, like race and age, can help a program see who is and is not coming to their program. These data can then be used to offer more targeted or tailored services. In addition, other data points on the survey can be stratified by participant age to understand differences in your population.

Example:

Method: Quantitative question on a point in time survey

Question: What is your age?

1. 19 and under
2. 20-29
3. 30-39
4. 40-49
5. 50-59
6. 60-64
7. 65+
8. Prefer not to answer

Results:

Answer	**n**	**%**
19 and under	5	5%
20-29	12	12%
30-39	24	24%
40-49	32	32%
50-59	15	15%
60-64	5	5%
65+	6	6%
Prefer not to answer	1	1%
Total	100	100%

INDICATOR: Participant Gender

Definition:

Participant gender identity is a count of the number of SSP participants in gender categories. This can be used to estimate the gender identities of a participant population. This is a sensitive indicator and how data are collected should consider participant trauma, historical trauma, and local context.

Use:

Why indicator was selected:

Although it is a sensitive indicator, **participant gender identity** may be collected via trauma-informed methods that are tailored to fit unique participant populations, the local context in which people who use drugs live, the program's services, staff bandwidth, and reporting schedule. As with all indicators, but especially with sensitive indicators like this, participants should never be required to answer questions to receive services and quantitative data collected with this indicator should be reported out in aggregate and anonymously (i.e., not attached to a unique ID). **Participant gender identity** is an indicator of equity for SSPs to monitor for program evaluation and identification of health inequalities. People who are LGBTQIA+ may benefit from tailored harm reduction services.

Using indicator for program improvement:

Participant gender identity can be useful for programs to understand the populations they serve and to make programmatic changes accordingly (e.g., providing services for gender affirming hormone therapy). **Participant gender identity** can be a useful tool for stratifying other data about your participants, such as race, age range, and housing status to help identify who is and is not served by a program. This information can be important in assessing health equity and ensuring services are reaching certain populations. Demographic data can be helpful for programs to compare their participant demographics and the demographic makeup of their staff to ensure their staff is reflective of the community they serve or hope to serve.

Using indicator for advocacy:

Participant gender identity is an important demographic indicator that can be incorporated into data published about a program (e.g., annual reports, grant applications) to show the range of community members served. **Participant gender identity** may be used in advocacy within an organization (e.g., providing trans-affirming care). Showing that a program serves people who are part of the LGBTQ+ community may help with coalition building across organizations and provide an entryway for harm reduction practices to enter other spaces, such as LGBTQ+ centers.

Collection:

Like all the demographic indicators, **participant gender identity** needs to be collected directly from participants, rather than guessed or assumed. There are methods that can limit the data collection burden and still provide programs with the data needed to understand who they are and are not serving and make appropriate changes. As with all indicators, but especially with sensitive indicators like this, participants should never be required to answer questions to receive services. Quantitative data collected with this indicator should be reported out in aggregate and anonymously (i.e., not attached to a unique ID). This estimate can come from a variety of data sources, and it may be based on a sample or census of participants.

Like all person-level indicators, gender identity questions should be asked openly and directly to participants so they can provide their own response. This method of respondent self-determination is preferred over permitting an interviewer to guess or assume a person's gender, which is not respectful to participants and can result in poor data quality due to incorrect assumptions. It is important that participants can answer privately, and not be overheard by anyone, including other participants they may have come with.

A point in time survey is the recommended method for collecting **participant gender identity**. A point in time survey collects data from a sample of participants that programs can then use to estimate information about their larger participant population. Because the data is collected at the same time and in a consistent manner, it is often more accurate, complete, and easier to analyze than enrollment or encounter data. We recommend collecting **participant gender identity** at regular intervals to monitor changes in trends, but not more frequently than annually. While data does need to be collected directly from participants, a point in time survey can be a minimal burden to both participants and SSP staff since data collection is done for a short period of time. These surveys can also be conducted anonymously to protect participant privacy if unique IDs are not used.

Collecting **participant gender identity** using an enrollment form or during encounters has several limitations. Since enrollment forms are collected on a rolling basis, it can be difficult to compile and analyze the data to look at trends. Further some people may not feel comfortable disclosing their gender identity at their first visit and the gender identity recorded at enrollment may change. If collecting **participant gender identity** via an enrollment form, we recommend only reporting that as **participant gender identity** at enrollment. We do not recommend collecting gender identity via an encounter form for several reasons. Gender can be a sensitive question, it would be highly repetitive for participants, it creates an additional data collection burden for staff and participants, and it is difficult to analyze and report.

We do not recommend asking about sex assigned at birth. Instead, we recommend asking about **participant gender identity**, with the option to include a follow up question to assess if an individual identifies as transgender. More question and answer options can be found in our guidance on collecting demographic information[2]. Whatever the list of response options are, they should be alphabetized to present them in an unbiased manner, and include a prefer not to answer option. Which genders are included may differ based on a program's reporting requirements, local context, or what they are trying to understand about their participant population.

Recommended question and answer formats

Question	Answer
What is your current gender identity? (select one)	• Man • Non-binary/gender queer/gender non-conforming person • Woman • Gender not listed (with write in option) • Prefer not to answer
Do you consider yourself to be transgender?	• No • Yes • Other (with write in option) • Prefer not to answer

Considerations:

Participants should always have the right to choose how and how much to disclose about themselves. Gender-based discrimination is common, and participants may not want to disclose information about their gender, especially if the services they are receiving are not related to gender. Another major limitation is that federal standards, set by U.S. Office of Management and Budget (OMB), ask about sex, not gender, and only ask about male and female sex. Other funders may also ask about sex, and not gender. Lastly, there may be instances when multiple demographic data points can be combined and become identifiable, especially in areas with a small population size (i.e., gender with age and race). For that reason, we recommend that **participant gender identity** is collected anonymously (i.e., not connected to a unique ID) and stored securely.

While a person's gender identity is mutable and can change over time, we recommend that **participant gender identity** is not reported more frequently than annually. If data is collected via a point in time survey and in combination with other demographic factors, like race and age, this can help a program see who is and is not coming to their program to offer more targeted or tailored services (e.g., special hours for women or for transgender participant). Other data points on the survey can be stratified by participant gender identity to understand differences in your population as well. Observed differences found in the data between participants with different gender identities may reflect historical biases and discrimination and should be interpreted within this context.

Example:

Method: Quantitative question on a point-in-time survey

Question: What is your current gender identity?

1. Man
2. Non-binary/gender queer/ gender non-conforming
3. Woman
4. Gender not listed
5. Prefer not to answer

Answer	**n**	**%**
Man	46	46%
Non-binary/gender queer/gender non-conforming person	14	14%
Woman	32	32%
Gender not listed	3	3%
Prefer not to answer	5	5%
Total	**100**	**100%**

Question: Do you consider yourself to be transgender?

1. No
2. Yes
3. Other
4. Prefer not to answer

Answer	No	%
No	87	87%
Yes	7	7%
Other	1	1%
Prefer not to answer	5	5%
Total	**100**	**100%**

INDICATOR: Participant Race/Ethnicity

Definition:

Participant race and ethnicity is a count of the number of SSP participants in racial/ethnic categories. This can be used to estimate the racial/ethnic identities of a participant population. This is a sensitive indicator and how data are collected should consider participant trauma, historical trauma, and local context.

Use:

Why indicator was selected:

Although it is a sensitive indicator, **participant race and ethnicity** may be collected via trauma-informed methods that are tailored to fit unique participant populations, the local context in which people who use drugs live, the program's services, staff bandwidth, and reporting schedule. As with all indicators, but especially with sensitive indicators like this, participants should never be required to answer questions to receive services and quantitative data collected with this indicator should be reported out in aggregate and anonymously (i.e., not attached to a unique ID). **Participant race and ethnicity** is an indicator of equity for SSPs to monitor for program evaluation and identification of health inequalities. People in various racial and ethnic communities may benefit from tailored harm reduction services.

Using indicator for program improvement:

Participant race and ethnicity is one of the most critical equity indicators and can be useful for programs to understand the populations they serve and to make programmatic changes accordingly (e.g., hiring staff who speak certain languages). **Participant race and ethnicity** can be a useful tool for stratifying other data about your participants, such as gender identity, age range, and housing status to help identify who is and is not served by a program. This information can be important in assessing health equity and ensuring services are reaching certain populations. Demographic data can be helpful for programs to compare their participant demographics and the demographic makeup of their staff to ensure their staff is reflective of the community they serve or hope to serve.

Using indicator for advocacy:

Participant race and ethnicity is an important demographic indicator that can be incorporated into data published about a program (e.g., annual reports, grant applications) to show the range of community members served. **Participant race and ethnicity** may be used in advocacy within an organization (e.g., hiring bilingual staff). Showing that a program serves people who in various racial and ethnic communities may help with coalition building across organizations and provide an entryway for harm reduction practices to enter other spaces, such cultural centers.

Collection:

Like all the demographic indicators, **participant race and ethnicity** needs to be collected directly from participants, rather than guessed or assumed. Like all participant level indicators, race and ethnicity questions should be asked openly and directly to participants so they can provide their own response. This method of respondent self-determination is preferred over permitting an interviewer to guess or assume a person’s race, which results in poor data quality due to incorrect assumptions. There are methods that limit the data collection burden while providing programs with demographic information to understand who they are and are not serving and make appropriate changes. Different programs may have the count come from different data sources, and it may be based on a sample or census of participants.

A point in time survey is the recommended method for collecting **participant race and ethnicity**. A point in time survey collects data from a sample of participants that programs can then use to estimate information about their larger participant population. Because the data is collected at the same time and in a consistent manner, it is often more accurate, complete, and easier to analyze than enrollment or encounter data. We recommend collecting **participant race and ethnicity** at regular intervals to monitor changes in trends, but not more frequently than annually. While data does need to be collected directly from participants, a point in time survey can be a minimal burden to both participants and SSP staff since data collection is done for a short period of time, and if unique IDs are not used, can be done anonymously to protect participant privacy.

Collecting **participant race and ethnicity** using an enrollment form or during encounters has several limitations. Since enrollment forms are done on a rolling basis, it can be difficult to compile and analyze the data to look at trends. If collecting participant race and ethnicity via an enrollment form, we recommend only reporting that as participant race and ethnicity at enrollment. We do not recommend collecting race and ethnicity via encounter form, as that would be highly repetitive for participants, creates an additional data collection burden for staff and participants, and is difficult to analyze and report.

We recommend that programs ask participants to select all races/ethnicities that apply, rather than having a multi-racial response option. Many people who have multiple racial identities do not identify as multi-racial, rather they may consider each of their identities as distinct. Documenting each separately using a “select all that apply” approach still allows programs to recategorize respondents who selected multiple responses for reporting purposes if needed.

There is not one correct list of race and ethnicity response options. There are two main considerations for programs considering what options to use: local context and reporting requirements. The most commonly used racial categories in the US are often broad, and many identities are collapsed into a single racial category, creating invisible identities within those broad racial categories. For instance, "Asian" often includes people who may be from or have ancestry in China, India, Japan, Vietnam, and many more countries that together represent over 30% of the world's population. To the extent possible, consider your community's racial makeup when determining racial categories and consider offering more nuanced categories based on local statistics, participant input, and pilot testing. Reporting requirements often require the broad categories. If you add additional categories, have a plan for how you will collapse them for reporting requirements. Whatever the list of response options are, they should be alphabetized to present them in an unbiased manner.

Recommended question and answer formats

Question	Answer
What best describes your racial and/or ethic identity? (select all that apply)	• American Indian/Alaska Native • Asian/South Asian • Black/African American • Latinx • Native Hawaiian/Pacific Islander • White • Prefer not to answer

Considerations:

Until recently, U.S. Office of Management and Budget (OMB) guidelines typically required or requested using separate race and ethnicity questions, and hence many programs have been asked to report race and ethnicity this way. However, there was a recent change by the OMB to ask race and ethnicity as a single question[1]. It is unknown how long it will take for these changes to be widely implemented. Multiple demographic data points, when combined, can be identifiable. For that reason, we recommend that participant race and ethnicity is collected anonymously (i.e., not connected to a unique ID) and stored securely.

Participant race and ethnicity does not need to be reported more frequently than annually. If data is collected via a point in time survey, using a combination of demographic factors, like housing status and gender, can help a program see who is and is not coming to their program in order to offer more targeted or tailored services. Other data points on the survey can be stratified by **participant race and ethnicity** to understand differences in your population as well.

There are multiple ways programs may want to look at people who select more than one race. For an overall multiracial category, any participant who selected more than one race could be re-categorized as multi-racial. Depending on local context, programs may want to look at specific multi-racial combinations.

Observed differences found in the data between racial/ethnic groups may reflect historical biases and discrimination (e.g., redlining, medical malpractice), and should be interpreted within this context. For example, SSPs should interpret disparities between Black/African American and white participants' engagement in HIV testing not as a product of race itself, but rather that race is a marker of racism and discrimination, which act as barriers that participants may face when considering HIV testing.

<u>Example:</u>

Method: Quantitative question on a point-in-time survey (n=100)

Question: What best describes your racial and/or ethnic identity? *Select all that apply*

1. American Indian/Alaska Native
2. Asian/South Asian
3. Black/African American
4. Latinx
5. Native Hawaiian/Pacific Islander
6. White
7. Prefer not to answer

Results:

Answer	**n**	**%**
American Indian/Alaska Native	8	8%
Asian/South Asian	2	2%
Black/African American	25	25%
Latinx	12	12%
Native Hawaiian/Pacific Islander	7	7%
White	62	62%
Prefer not to answer	0	0%

Structural Violence

The ways that local, regional, and national systems and institutions, including economic, political, cultural, and legal institutions, affect the lives and health of participants.

	Indicator	Format	Recommended Data Source
17	Participant housing status	Reported as table and/or reported as narrative, with all information de-identified	Participants via anonymous point in time survey (PiTS) or ad-hoc informal qualitative data collection with careful consideration
18	Participant interactions with law enforcement	Reported as table and/or reported as narrative, with all information de-identified	Participants via anonymous point in time survey (PiTS) or ad-hoc informal qualitative data collection with careful consideration

INDICATOR: Participant Housing Status

Definition:

Participant housing status is a count of the number of SSP participants who currently live in certain situations. This can be used to estimate the housing statuses of a participant population. This is a sensitive indicator and how data are collected should consider participant trauma, historical trauma, and local context.

Use:

Why indicator was selected:

Although it is a sensitive indicator, **participant housing status** may be collected via trauma-informed methods that are tailored to fit unique participant populations, the local context in which people who use drugs live, the program's services, staff bandwidth, and reporting schedule. As with all indicators, but especially with sensitive indicators like this, participants should never be required to answer questions to receive services and quantitative data collected with this indicator should be reported out in aggregate and anonymously (i.e., not attached to a unique ID). Qualitative data should be reported anonymously and de-identified, meaning any information that could be used to recognize individuals is removed.

People who use drugs are criminalized in ways that prevent access to housing. **Participant housing status** is an indicator of equity for SSPs to monitor for program evaluation and identification of health inequalities. People who are experiencing housing instability may benefit from tailored harm reduction services that differ from services provided to those who are stably housed.

Using indicator for program improvement:

Monitoring **participant housing status** may help programs better understand the structural constraints and violence that participants face. These data can be useful for programs to understand the populations they serve and to make programmatic changes accordingly. **Participant housing status** can also be a useful tool for stratifying other data about your participants, such as gender identity, age range, and race and ethnicity to help identify who is and is not served by a program. This information can be important in assessing health equity and ensuring services are reaching certain populations.

Participant housing status may be incorporated into data published about a program, such as an annual report, to show the range of participants a program serves. These data may be helpful in grant applications to apply for funding specifically for people who are unhoused or unstably housed. **Participant housing status data** may help programs tailor services as appropriate for certain groups (e.g., people who sleep in cars, people who stay at motels, people who live alone in tents). This information may assist in developing participant and community education (e.g., information on recent legislation against camping), creating new services (e.g., summer hygiene kits), or altering existing services (e.g., not requiring returned syringes, especially after sweeps).

Using indicator for advocacy:

Participant housing status is an important demographic indicator that can be incorporated into data published about a program (e.g., annual reports, grant applications) to show the range of community members served. **Participant housing status** may be used in advocacy within an organization (e.g., not removing people for sleeping onsite). Showing that a program serves people who are unhoused may help with coalition building across organizations and provide an entryway for harm reduction practices to enter other spaces, such as shelters and food pantries. Programs may use these data in advocacy with local, state, and federal policy makers to support decisions and legislation that decrease housing instability and the criminalization of people who are unhoused.

Collection:

We recommend collecting data on **participant housing status** via quantitative questions on annual point-in-time surveys or ad hoc informal qualitative data collection. Point-in-time surveys may provide a snapshot of participant experiences without requiring every participant to provide data. Point-in-time survey data are intended to provide an understanding of what participants in general are experiencing and to inform programmatic decisions, not necessarily to determine an individual's need for immediate services. An individual's need for immediate services would likely be captured in case management or service notes or records. For ad hoc informal qualitative data collection, staff would not ask participants directly about their housing status. Instead, when a participant began talking about their housing status, staff would ask participants if they would like that experience or story documented via anonymous and deidentified staff notes. If the participant confirmed, staff would record notes via paper, electronic document, or database.

A quantitative question could be, "What is your current living situation?" Answer choices could be, "permanent/stably housed," "temporarily/unstably housed," "unhoused/homeless," and "other." Language for questions and response choices should be tailored to program goals and to local context, with participant input. For instance, if a program wants to tailor services to people who are living outside and facing increased sweeps, and to people living in their cars, then those two responses should be represented in a quantitative question. Answers to the "other" option may help create answer choices on a future survey. All questions should have the option of "prefer not to answer."

Considerations:

Asking about **participant housing status** may cause people to feel stigmatized in our society, where people who are unhoused are heavily discriminated against. Housing status is an indicator that may change frequently. There are a wide variety of types of housing status, and categorizing different types may be complex and context specific. What housing status means changes according to location (e.g., in rural versus urban areas). More frequent data collection for this indicator would increase data collection burden for staff and participants and increase risks of making participants feel stigmatized.

If **participant housing status** is being collected on a point-in-time survey that also collects demographics data, data could be stratified to show how participant housing status shifts according to participant race/ethnicity, age, and gender identity. If different types of housing instability are asked about (e.g., living outside, living in cars, staying in motel/hotel, staying temporarily with friend/family), then these categories could be collapsed into "unhoused/homeless" or "temporarily/unstably housed."

Examples:

Method: Quantitative question on a point-in-time survey

Question: What is your current living situation?

1. Stably housed
2. Temporarily staying with a friend/family
3. Staying in a car
4. Staying at a motel/hotel
5. Staying outside
6. Staying in a shelter
7. Prefer not to answer

Results:

Answer	**n**	**%**
Stably housed	35	35%
Temporarily staying with a friend/family	26	26%
Staying outside	24	24%
Staying in a car	8	8%
Staying at a motel/hotel	4	4%
Staying in a shelter	2	2%
Prefer not to answer	1	1%
TOTAL	**100**	**100%**

Method: Findings from ad-hoc informal qualitative data collected via comment box on encounter form that is not required to be completed but is only completed when participants offer information labeled "Participant comments about housing."

Results: From January to June 2023, 99 participants told us about their living situation. Over a third (35%) said they were stably housed. About a quarter (26%) said they were staying with friends or family. The stability around these situations varied – some folks had a set rotation of people they stayed with, some had been staying with family for years with few problems, but about half said the situation was very temporary, likely only to last a few days or weeks before they had to find another place. About a quarter (24%) said they were staying outside. Since sweeps have been frequent in city limits, most either lived with one or two other people and changed spots every day, or they moved to larger camps on the outskirts of town. A few people who lived in city limits and had to move a lot said they had a hard time bringing syringes back to the program, while some of the people in the larger camps had no problem bringing a larger number of syringes back. The people staying in their cars also could not bring syringes back, because they did not want to constantly drive around with syringes. These comments have caused us to decide not to require syringes to be returned to the program. There might be other needs that are different between these groups that could be explored in the next survey.

INDICATOR: Participant Interactions with Law Enforcement

Definition:

Participant interactions with law enforcement is a record of how local law enforcement treat SSP participants. This is a sensitive indicator and how data are collected should consider participant trauma, historical trauma, and local context.

Use:

Why indicator was selected:

Although it is a sensitive indicator, **participant interactions with law enforcement** may be collected via trauma-informed methods that are tailored to fit unique participant populations, the local context in which people who use drugs live, the program's services, staff bandwidth, and reporting schedule. As with all indicators, but especially with sensitive indicators like this, participants should never be required to answer questions to receive services. Quantitative data collected with this indicator should be anonymous (i.e., not attached to a unique ID) to prevent possible negative consequences to participants. Qualitative data should be collected anonymously and should be de-identified, meaning any information that could be used to recognize individuals is removed.

People who use drugs often encounter law enforcement because of activities associated with drug use that have been criminalized. Police encounters often negatively affect the health and well-being of people who use drugs and may result in physical, psychological, and sexual violence (Cooper et al. 2004)[1]. Police activity around SSPs may decrease program participation (Davis et al. 2005)[2] and law enforcement drug seizures have been associated with increased overdose (Ray et al. 2023)[3].

Using indicator for program improvement:

Monitoring **participant interactions with law enforcement** may help programs better understand the structural constraints and violence that participants face. This information may assist in developing participant and community education (e.g., good Samaritan legislation, legality of smoking supplies), creating new services (e.g., taillight clinic, 24-hour supply access), or altering existing services (e.g., not requiring returned syringes).

<u>Using indicator for advocacy:</u>

The most important aspect of **participant interactions with law enforcement** may be advocacy. Advocacy may be completed within an organization (e.g., advocating with management to not require returned syringes). If local law enforcement say they are supportive of harm reduction, negative interactions show where they are failing, and neutral or positive interactions show where they are supportive. Even if local law enforcement are not concerned about negative interactions, other organizations may be, and these data may help with coalition building across social justice movements. Local evidence of people's negative interactions with law enforcement may be used to advocate for the removal of law enforcement from certain settings, such as health care facilities and shelters. Programs may also use this evidence in advocacy with local, state, and federal policy makers to support decisions and legislation that decrease the harm of drug criminalization.

Collection:

We recommend collecting data on **participant interactions with law enforcement** via annual point-in-time surveys or ad hoc informal qualitative data collection. For a point-in-time survey, data may be collected via quantitative or qualitative questions. Point-in-time surveys may provide a snapshot of participant experiences without requiring every participant to provide data. For ad hoc informal qualitative data collection, staff would not ask participants directly about their interactions with law enforcement. Instead, when a participant began talking about their **interactions with law enforcement**, staff would ask participants if they would like that experience or story documented via anonymous and deidentified staff notes. If the participant confirmed, staff would record notes via paper, electronic document, or database.

Language for questions and response choices should be tailored to program goals and to local context. For instance, if a program is expanding to offer smoking supplies, participants may be asked about their experiences of being stopped by law enforcement with pipes. If a program has heard that law enforcement is confiscating naloxone from participants, the program may specifically ask about that experience.

If a program is attempting to assess general interactions with law enforcement via a quantitative question on a point-in-time survey, they may ask a yes/no question like, "Have you been stopped by the police in the last six months?" This question could shift to focusing on arrests (i.e., "Have you been arrested in the last six months?") or incarceration (i.e., "Have you been incarcerated in the last six months?") depending on program goals. A qualitative question on a point-in-time survey could be, "Please tell me about your experiences with police in the last year." All questions should have the option of "prefer not to answer."

Considerations:

Asking about **participant interactions with law enforcement** may retraumatize people who have been individually harmed by law enforcement or who live in communities that are systematically harmed by law enforcement. If data are not collected anonymously and not deidentified, data breaches may result in further criminalization of people who use drugs. More frequent data collection for this indicator may increase risks of retraumatizing participants.

If **participant interactions with law enforcement** data is being collected on a point-in-time survey that also collects demographics data, data could be stratified to show how **interactions with law enforcement** shift according to participant race/ethnicity, age, gender identity, and housing status.

Examples:

Method: Quantitative question on a point-in-time survey

Question: Have you been stopped by the police in the last six months?

1. No 2. Yes 3. Don't know 4. Prefer not to answer

Results:

Answer	**n**	**%**
No	56	56%
Yes	40	40%
Don't know	1	1%
Prefer not to answer	3	3%
TOTAL	**100**	**100%**

Method: Findings from ad-hoc informal qualitative data collected via comment box on encounter form that is not required to be completed but is only completed when participants offer information labeled "Participant comments about police."

Results:

From January to June 2023, 23 participants told us their stories of having negative interactions with police. No participants had positive stories. Even though our 2022 PiT survey showed that only 15% of our participants are Black/African American, 43% of the stories we documented were from Black/African American participants. Twenty were from people who are unsheltered. Ten stories were about participants' interactions with the County Sheriff's office; the rest were about city police. Four participants were stopped because of minor traffic violations (one taillight, one expired tags, two speeding), police threw away their harm reduction supplies, but they were not arrested. Nineteen participants were arrested, mostly for paraphernalia and possession. Nine were physically assaulted by police. After talking to eight participants, they should not have been charged with paraphernalia according to state law and two only had paraphernalia in their car because they were bringing it back to our program. One older man, who was unsheltered and Black, said, "No matter where I move in this town, I swear they follow me. They stop me at least once a week. There was one guy hanging about a block from here on Tuesdays in his cruiser – that's why I started coming Thursdays."

Appendices

Appendix 1: Glossary

Ad hoc data collection: Ad hoc data collection takes place as needed rather than at a predetermined time. It is a useful data collection tool when there is a straightforward and specific question that needs to be addressed. Instead of setting up routine data collection, ad hoc data collection can be introduced as a flexible, short-term addition in response to a specific event or need. For example, asking participants about their preferred cooker in response to hearing dissatisfaction about the type of cooker supplied. Ad hoc data collection may also be useful in collecting informal qualitative data (see below). If someone consents and wants to share a particular story or experience, these data would be collected when they share these experiences.

Aggregate Data: Aggregate data collection takes place when a program records information as a total or overall description instead of by encounter. For example, a program that tracks syringes out by counting inventory once a week collects aggregate data; they cannot provide an accurate count of syringes out at each visit, but they have a highly accurate count of syringes distributed over time. Similarly, a program that conducts outreach may record a final number of supplies distributed or of participants served without logging each individual interaction; this is also aggregate data collection. Aggregate data reporting is the most common form of reporting harm reduction data. It means reporting totals of participants seen, supplies out, tests conducted, etc., without breaking the numbers down into individual encounters or “line-level" data. It is unethical for funders to require line-level data from SSPs, without SSPs having choice in whether they want to share that level of data. This is especially true if an SSP uses unique IDs or collects anything that could be considered protected health information (PHI) and is potentially identifiable.

Anonymous data: Anonymous data cannot be traced to specific individuals. This occurs when harm reduction programs record services without documentation of individual level data that could be potentially identifying. In these cases, even the service providers would not be able to trace any documentation back to a specific encounter with a specific individual. Any harm reduction program that enrolls participants using an intake form that is linked to a unique ID, or assigns a unique ID by another means, is likely providing confidential, not anonymous services, and therefore has confidential, and not anonymous, data. (This is because many unique IDs are comprised of identifiers or parts of identifiers.) Even without a unique ID, if a harm reduction program collects demographic data and/or health-related data that is connected to services, data may not be anonymous if combinations of participant characteristics can be linked to individuals.

Blanket code: An anonymous code that can be used for any participant seeking services who does not wish to enroll and/or provide their unique ID at that time. It is important that all SSPs who assign unique IDs have a system in place that allows all participants to receive services, even if they do not want to provide the information for a unique ID. Otherwise, the unique ID becomes a deterrent to participation. Some SSPs may elect to utilize a catch-all or unknown blanket code, which would be a code that is the same length as a normal code but cannot be assigned, such as one with all the same digits (e.g., 999999 for a 6-digit code). This also allows for all non-unique encounter data to be removed and analyzed separately from unique data. When describing their data, SSPs should be sure to identify the removal of these encounters and explain how this likely means their data is an undercount of their actual unique contacts.

Card sorting: A common method of qualitative analysis that involves organizing data into piles. Each pile is related to a topic or theme. As one reviews their qualitative data, they can group related data into different piles. This process can be repeated multiple times to refine each pile into further piles related to more granular topics or themes. For example, if reviewing qualitative data related to participant satisfaction receiving harm reduction services, a first pass at the data may result in two piles: one for satisfied comments and one for unsatisfied comments. The next review of data may divide satisfied comments into groups based on satisfaction related to supplies and satisfaction related to staff interactions. This process can be continued until the analyzer can generate some overall conclusions about their dataset.

Collate: The process of organizing or arranging items into a list. For example, a program may collate their data requirements alphabetically, or based on who requires the data. Collating items, such as data or reporting requirements, may make it easier to keep your data, reporting requirements, or documents organized and easier to fully review.

Community-level data: Community level data are measures about a population, rather than an individual. Census data is an example of community-level data.

Confidential data: Confidential data could, in theory, be linked to an individual person. Programs that have confidential data systems record services that are accompanied by documentation of any individual level data that could potentially be identifiable, either alone or when combined with linked information (e.g., collected in the same tool or linked by unique ID). For that reason, confidential data poses a greater risk to a participant than anonymous data. Any harm reduction program that enrolls participants using an intake form that is linked to a unique ID, or assigns a unique ID by another means, is likely providing confidential services. (This is because many unique ID are comprised of identifiers or parts of identifiers.) Even without a unique ID, if a harm reduction program collects demographic data and/or health-related data, data may be confidential (not anonymous) if combinations of participant characteristics can be linked to individuals. When conducting confidential services, providers should never guarantee privacy and security, because even with the best practices, no programs are exempt from risk.

Data standardization: The rules and procedures your program develops to ensure that data is collected, recorded, stored, and reviewed in a consistent way. For example, if individual staff record the same indicator differently it may result in data that is hard to fully analyze. One staff may record the number of naloxone kits distributed while another may record the individual doses. In this situation, if the form only includes tallies with no description of if the number refers to kits or doses, this will result in difficulty reporting how much naloxone you are distributing.

De-duplicated data: De-duplicated data allows you to distinguish individuals in a dataset. At SSPs, this normally happens using a unique ID. When data is collected with a unique ID, participants can be tracked across visits within a dataset. For example, if an SSP had encounter data collection that used an unique ID from 1 year of services, they could use that unique ID to de-duplicate the data and estimate the number of unique participants served. It is noteworthy that unique IDs can be a barrier to services for participants.

De-identified data: De-identified data is data in which personal identifiers have been removed or masked to help protect the identity and privacy of the subject. This is different from anonymous data, where identifiers are not collected at all.

Determination of need: In this document's context, a determination of need[15] refers to the process where a state, tribal, or territorial health department provides evidence to the CDC that their locality is at risk for or actively experiencing an HIV or HCV outbreak related to injection-drug use. This evidence demonstrates that SSPs (and potentially SSP funding) is needed to address the health risks.

Domain: A domain is a category of indicators related to a similar overarching question or purpose. For example, service coverage and demographics are both domains. Service coverage includes indicators related to syringe inventory and the type of supplies a program offers, while demographics includes indicators about race and ethnicity, gender, and age.

Duplicate data: Duplicate data does not distinguish individuals from each other (e.g., does not use a unique ID). For example, encounter data collection without a unique ID would produce duplicate data because you could not take the data and understand how many unique participants you served; people who have had multiple encounters are duplicated in the dataset. Any data collected from a participant cannot be linked to them and data cannot be linked across visits. Duplicate data systems are generally lower-barrier for participants than de-duplicated data systems, where an unique ID is used.

Encounter form: An encounter form records every time supplies and sometimes services that participants receive. It may or may not use a unique identifier. Encounter forms can be a useful tool for evaluating SSP services, especially when they collect minimal data, and can have a minimal burden on staff and participants.

Formal Qualitative Data: A type of qualitative (non-numerical and descriptive) data that can be generated from more traditional research activities. Types of formal qualitative data include in-depth interviews, focus group discussions, or community based participatory research.

Health Insurance Portability and Accountability Act (HIPAA): In this document's context, HIPAA is referenced relating to the type of identifiable health information that is legally protected at health institutions. It is important to note that HIPAA only applies to officially covered entities, so personal health information (PHI) is not inherently protected if it is simply collected by a non-covered entity.

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[15] https://www.cdc.gov/syringe-services-programs/php/need-determination/index.html

Covered entities include individuals and programs such as health care providers, insurance plans, and government programs like Medicaid.

Identifiable data: Identifiable data is data that could be traced back to a specific individual. This can include protected health information (PHI).[16]

Indicator: An indicator is a specific, observable measure of something we want to know about. For example, indicators include the number of syringes distributed in a month or the race and ethnicity of participants. Indicators identify the overall concept being measured but are not the specific wording of a question. In many cases, an indicator can be asked or addressed in multiple ways. For example, participant age is an indicator that could be measured by directly asking a participant's age or by asking their birth date.

Informal Qualitative Data: A type of qualitative (non-numerical and descriptive) data that can be largely generated from routine service interactions as opposed to formal research activities, such as in-depth interviews, focus group discussions, or community based participatory research. Examples of informal qualitative data include notes from meetings, social media posts, verbal feedback from participants, and staff logs from service provision.

Intake form: An enrollment form, or intake form, is usually completed at a participant's first visit. Enrollment forms vary greatly across programs, but they may involve the creation of a unique ID and they may collect information about the participant, for example demographic information and information related to services offered. Enrollment forms are sometimes done once and sometimes updated regularly. Enrollment forms can be useful in identifying a participant's needs, although since there has not been a chance to build rapport or trust it may turn new participants off if they are not ready to share detailed, personal, or sensitive information at a first visit. Further, they have significant limitations as a monitoring and evaluation tool. They often lead to low quality data because they can have low accuracy due to participants not being ready to share their true information at first visit and because the data often collected in them can quickly be out of date (ex. Housing status). Second, it can be very difficult to compare data from enrollment forms because they are collected on a rolling basis which may mask large changes in the environment. For example, enrollment data from before March 2020 may show that 80% of participants were employed, but after March 2020 it would go down significantly. This would not be because the program's population significantly changed, but because of a change in the environment.

Inventory data: Inventory data is a type of program-level data that relates to the supplies at an SSP. Supply data can be gathered by tallying the number of services/supplies provided at each encounter or by using an inventory method. To do this, you keep track of how many syringes, supplies, etc., you took out for services that day, and how many you returned with after services rather than tracking the number of supplies to distributed to each participant.

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[16] https://en.wikipedia.org/wiki/Protected_health_information

Monitoring and Evaluation (M&E): Monitoring and evaluation (M&E) involves collecting program data on an ongoing basis to determine if programs are meeting their goals. It is an iterative process that a program can engage in to ensure that their program is performing in the ways they desire. Data generated can be used internally to update program activities to best respond to participant needs and to track overall progress. Part of the process is to regularly check in with the data your program has been collecting and determining if it is meeting your goals and expectations. Routinely checking your data for consistency and accuracy will help you correct your data efforts in real time, rather than needing to analyze a huge chunk of data and realizing that it is difficult to decipher.

Narrative: In this document's context, a narrative refers to a type of reporting style that involves a written program data description. This reporting style is best suited for non-numerical data such as open-ended feedback from participants or program activities. A narrative report can tell a story of what a program is doing and/or experiencing in a given timeframe.

Person-level data: Person-level data collection involves collecting data directly from participants and can include anonymous encounter-level data, encounter data linked with unique IDs, or a point in time survey (PiTS).

Pilot testing: A method of helping understand if surveys and interview guides are accurate, valid, and relevant to the local context through a staff, volunteer, participant, and/or participant advisory board review process. Pilot testing should be completed when a survey or interview guide is being used for the first time or the first time in a while, when questions have been added or modified, when working with a new population, when using new survey methods, and when using skip logic. Pilot testing may help to ensure that questions make sense, to check the survey flow and timing, to ensure staff have the resources they need to use the survey or interview guide, and to ensure data collection and analysis systems work as intended.

Point-in-Time Survey (PiTS): Often called a cross-sectional survey, a Point in Time Survey (PiTS) allows a SSP to ask a standardized set of questions to a portion of their clients, providing a snapshot of the population that the SSP serves. These surveys can be a quick and low-cost way to learn about the characteristics, needs, and service utilization patterns of their clients. SSPs use PiTs in different ways. Some SSPs implement a regular (annual, bi-annual) PiTS as part of their overall monitoring and evaluation strategy. SSPs may also do a one-time PiTS as needed. These surveys can be a nimble tool for answering urgent questions or providing information in a timely manner. They can also be used as a method for reducing routine data collection.

Programmatic data: A type of data routinely collected and analyzed for internal uses (and potentially reporting requirements) rather than to answer a research question. Programmatic data refers to the information a program monitors to better understand how their services are performing and where they can grow to better serve participants. Programmatic data describes the overall program including the program’s structure and services, the types of participants the program serves, and the unique experiences and challenges the program may face. There are some instances where programmatic data can be used to answer research questions, but the original intent of the data collection is for programmatic monitoring and evaluation.

Unique Identifier (Unique ID or UID): A code assigned to a single participant that some SSPs use to distinguish individual participants. Unique IDs generally consist of elements of a participant's identity, such as a partial date of birth, initials, parents' name(s), etc. (See "Using Unique Identifiers Within Syringe Services Programs",[17] Appendix A for a table of common elements.) When they are derived from personal identifiers, unique IDs are not truly anonymous. A string of letters and digits may not be an obvious identifier to the general public, but a person with more information (such as birth certificate data) could decode it.

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[17] https://www.sharpta.uw.edu/syringe-services-program-monitoring-and-evaluation-resources/using-unique-identifiers-within-syringe-services-programs/

Appendix 2: Implementation Checklist

The checklist included below has been developed to help outline the steps required to begin implementing the suggested indicators. Each phase of implementation includes steps and considerations for integrating the indicators into a program's data collection system.

Before You Begin: Implementation Considerations

Identify your program and staffing models and your technology needs and infrastructure. Program and staffing model will impact how you collect data, how much data is reasonable to collect, and what data you collect. It is important to identify the technological infrastructure your program has readily available, what budget you have, and what you will still need to acquire.

- Consider where you collect data. For example, at a brick-and-mortar location or mobile van, or perhaps both.
- Identify the methods you use to collect data (encounter forms, point in time surveys, Etc.).
- Identify who collects the data, who uploads or organizes it, who analyzes the data, and who synthesizes it into reports.
- Finally, consider how you collect data, for example, pen and paper or digitally. Determine how you organize and store your data as well as How you analyze it.

Phase 1: Identify data needs

Review your reporting requirements—identify the data you are required to collect and collate it one place, like a spreadsheet, where you can track and update as grants begin and end, and as your organization's own internal evaluation goals change

- Collate reporting requirements from any local or state health departments
- Collate reporting requirements from any grants or fundings
- Set internal evaluation goals
    - What are you not currently collecting that you want to?
    - What data do you need to achieve your programmatic goals?

Phase 2: Select and review indicators

Review the list of indicators above and select the ones you would like to implement at your program in addition to the indicators needed for reporting requirements. Consider how much of the data collection listed is necessary and will be used in conjunction with your reporting requirements and evaluation. Minimal data collection can be beneficial for participants and staff.

- Review proposed indicators with staff and participants
- Compare existing data collection with data collection needs
- Compare with the UW recommended indicator list
    - Where do these requirements overlap? Where do they differ?
- Rate what data points are essential and what are not
    - What data is essential? What data would be nice, but is not necessary?
    - Identify ways to minimize the data collected regularly, especially sensitive data, any data directly asked of participants, and data that takes a lot of staff time to collect, record, or analyze.

Phase 3: Create forms

Organize indicators and other reporting requirement data points into forms based on when and from who you will be collecting data. Pilot test your systems after drafting them to ensure they work for staff and participants. Find more about piloting testing here[18].

- Identify which indicators will be collected routinely, versus those which will be captured weekly, monthly, quarterly, yearly
- Consider your methodology.
    - What methods will you be using to collect data? Encounter forms? Inventory? Point in time surveys?
- Determine who will be providing the data
    - Are these forms for staff to fill out based on inventory or encounters? Are some forms for staff to ask directly to participants? What data is gathered from staff notes?
    - Pilot test all forms Pilot test forms with staff to assess usability and flow.
        - Does the organization of the form make sense for staff? Is it easy for staff to use and administer? Do staff understand what is trying to be communicated and collected?
    - Pilot test forms with participants to assess sensitivity and literacy.
        - Are participants comfortable answering the questions? Do they understand what the questions mean?
    - Pilot testing should mimic data collection.
        - Try to implement the forms to understand how effectively they will be used during data collection.

Phase 4: Train staff and volunteers

Train those who will be involved in data collection, both staff and volunteers. The training should cover administering the forms, using any relevant software, managing the database, and any other tools that will be used in data collection. There should also be training on nonjudgmental survey administration and data privacy.

- Consider who will be collecting data directly from participants and will need to be trained
- Provide training, feedback, and practice with staff and volunteers on nonjudgemental data collection
- Review data collected to look for errors and provide additional training/changes to the system as needed

Phase 5: Implement

Implementation includes data collection, data storage, and quality assurance to ensure your systems are functioning as intended.

- Begin collecting data!
    - For program-level indicators, this is as simple as finding a place where you will store baseline data and update if/when it changes, e.g., operating hours or supplies offered.
    - For all other level indicators, this involves utilizing forms, documenting the data, uploading and monitoring the data, and eventually analyzing.
- Perform ongoing quality assurance and update training as needed
- Analyze data and report out to staff and participants
- Maintain consistent data collection

Phase 6: Reevaluate

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[18] https://www.sharpta.uw.edu/monitoring-and-evaluation-toolkit-data-collection-methods-and-pilot-testing/

No system lasts forever, consider how often you will need to re-evaluate. This may be planned (e.g., annually) or as needed (i.e., new reporting requirements with new grant activities)

- Determine intervals to revisit how data is being collected
    - Consider whether it is being used or if the phrasing needs to be updated
- Remove any indicators that are not being used

Appendix 3: Considerations for Funders

Throughout this toolkit, we have discussed the importance of identifying indicators that can be collected ethically, are likely to result in quality data, and can be implemented flexibly in diverse environments. One of the guiding principles of this toolkit that is geared toward programs is to minimize data collection wherever possible, to respect the autonomy of participants, and to minimize barriers to access services.

Accordingly, it is important to us to address the realities of government or funder-mandated data collection, as the variety and intensity of reporting requirements impacts the ability of harm reduction programs to implement ethical data collection practices. We acknowledge that harm reduction funders have rationale for collecting certain data from funding recipients, including facing their own requirements for specific data and a desire to evaluate their own efforts. However, disparate and potentially unethical requirements have a substantive impact on programs, and in particular, programs with relatively fewer resources.

Below are some suggested considerations for funders of harm reduction services as they implement new or explore alternate methods for collecting data from funding recipients. They were derived in part from a breakout session held during the SSP Indicators Workgroup Convening in June 2023 in Schaumburg, Illinois, and have been updated based on feedback from the SHaRP Salon series[19], three community conversations that the UW SHaRP team facilitated, in February and March 2024.

Consideration 1: Funders should articulate which data collection activities will be required of grantees, including a description of all variables, an overview of any required databases, and the frequency of reporting, in their requests for applications (RFAs) or proposals (RFPs). In addition, funders should be explicit about what potential applicants should know if they do not already collect these data. Including information about what these applicants can do to be competitive with other applicants, since they may be at a disadvantage, may be particularly useful.

> Because SSPs are typically under-resourced, they may experience pressure to pursue any funding that seems relevant to their services. Since many funding applications do not include information about reporting requirements, SSPs that are awarded funding may find themselves in challenging positions after the contracts have been executed. If reporting requirements are announced after the fact, programs may need to overhaul their systems, which would impact both staff and participants by leading to changes to the service model and increased/unexpected costs related to software, hardware, training, and person-time (FTE) related to increases in data entry and analysis.
>
> And finally, funders should be aware that any data collection activities they publicize as "optional" may still be burdensome to programs, as power dynamics may lead programs to fear that any future applications or renewals will be less compelling without a history of completing all suggested data collection activities.

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[19] https://www.sharpta.uw.edu/ssp-indicators/

Consideration 2: Offer technical assistance and resources for recipients who did not previously collect data that will be required moving forward.

> Funders should offer specific, targeted guidance to programs who are new to certain data collection activities. They may consider earmarking funds for SSPs who have less infrastructure and may need to purchase software or hardware or invest in training for staff. They may also retain subject matter experts in-house to be available to funding recipients if questions arise as they are scaling.

Consideration 3: Extend flexibility with data requirements to funding recipients. Where possible, funders should endeavor to accept data that the funding recipient already collects.

> Because there is no one-size-fits-all data system or set of data points that meets the needs of every SSP, funders may consider whether there are ways to adjust data requirements based on individual organizations' systems, data collection methods, and preferences, rather than requiring the same data from all recipients. While this may impact data comparability somewhat, not all funders aggregate data across funding recipients and therefore have the ability to let each recipient's data stand on their own.

Consideration 4: Minimize data requirements. Accept duplicate data wherever possible and ensure any required person-level data is ethical. By ethical, we mean there is limited burden to staff and participants, cultural and social relevancy, a pathway for use, and a high level of privacy.

> Funders should be sure there is a clearly articulated purpose for and benefit to every data point they require funding recipients to report on. Most funders who seek to understand the impact their monies are having can measure success primarily with program-level indicators. These are indicators that assess the types and quantity of services provided by the funding recipient. Many funders default to requiring a count of the number of individuals a program serves; however, this requires SSPs to use a unique ID with participants. This is a very challenging thing for most SSPs to measure and this should only be required if there is a specific value to knowing it. Similarly, collecting potentially identifiable personal health information is generally not necessary for program monitoring and evaluation, and as such each person-level data point merits specific justification. And finally, funders should consider giving programs the opportunity to pilot any new data points with participants to gather feedback and ensure appropriate implementation.

Consideration 5: Consider coordinating application and reporting requirements with other funders. Because SSPs often have multiple funding streams they frequently have heterogenous yet overlapping data reporting requirements, particularly if funders require use of different databases. This can lead to duplicate data entry, multiple similar analyses, and complex reporting.

> There is some precedent in other fields for aligning data collection requirements across different types of funders; this effort is more novel among harm reduction programs in part because of the various service models. However, multiple researchers and experts[20], including SHaRP, have

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[20] 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.

advocated for a minimal and ethical standard dataset that funders could accept, which could reduce overall burden on programs and participants.

Because applying for funding is a time intensive activity and many SSPs have limited staff time to dedicate to it, SSPs may also benefit if funders standardized aspects of their applications, such as budget templates and/or narrative components.

Consideration 6: Understand that SSPs cannot and should not be required to conduct data collection activities as a proxy for epidemiological surveillance.

While public health systems may struggle to measure health outcomes of people who inject drugs, SSPs are responsible for providing effective and tailored services to participants – not to serve as researchers or extensions of public health systems. Instead, their data collection activities should focus on their own internal evaluation goals, which will have a lower impact on participants and staff and a greater impact on service quality and operational success.
There may be instances where funded SSPs have sufficient infrastructure and resources to conduct higher threshold data collection activities that are not directly tied to program goals. However, these activities should not be routine and should instead be tied to specific, time-limited projects, and most importantly, respondents to more intensive interviews or questionnaires should be compensated for their time.

Consideration 7: Funders should ensure that funding recipients remain the owners of their data and should avoid requiring line-level data to be submitted in order to limit risks to privacy and security.

Any participant level data that a funder or governmental entity requires an SSP to submit should only be required in aggregate. For example, if a funder requires housing status, then funding recipients should be able to submit totals, or proportions, and not housing status parsed out by participant. This protects participant privacy and allows the SSP to put security safeguards in place to reduce the risk of unauthorized data access.

Consideration 8: Consider how funders' data requirements may impact the quality of data collected by SSPs.

There are two main ways that funders' data requirements can negatively impact the quality of data SSPs collect. The first is that the amount of data required by funders can be so substantial, either by one funder or multiple funders with different requirements, that the quality of the data collected decreases. This is usually because a SSP doesn't have the funding to create or maintain the kind of infrastructure necessary to collect that level of data, because collecting that quantity of data would negatively impact services, and/or because participants and staff may become weary from long surveys and rush through or leave surveys incomplete.

The second is that the data required to be collected is sensitive (i.e., it may be traumatizing, stigmatizing, or offensive to participants), so SSPs are put in the position of either asking their participants for data that may make them uncomfortable or meeting their grant requirements.

Appendix 4: Resources

All resources may be found on our website, sharpta.uw.edu, and are linked below.

Brief Overview of Data Privacy and Security Considerations at Harm Reduction Programs: This document introduces data privacy and security considerations for SSPs and harm reduction programs, including the defining anonymous services and confidential services, a brief overview of HIPAA and covered entities, good practices for data privacy and security, considerations for linkage to care data, and considerations when reporting out data. This may be of particular use to programs implementing data collection on sensitive indicators or any programs with potentially identifiable data.

Collecting Demographic Data at Syringe Services Programs: This document introduces some issues for SSPs to consider when writing questions to collect data about race, ethnicity, and gender in order to improve accuracy, in accordance with good practices to prioritize participant safety and protect their privacy. The document also includes tips for training staff and conducting analyses.

Estimating Individual Syringe Coverage at Syringe Services Programs: Syringe coverage is an indicator that can help SSPs and other stakeholders estimate if people who inject drugs have enough syringes to reduce risks of infections and vein damage. This guidance is focused on calculating syringe coverage for the participants of one program and for sub-groups of participants of a program (e.g. participants who are unhoused). Health departments and researchers who work with SSPs could use this information to meaningfully engage with harm reduction staff to survey people who inject drugs and assess resource gaps. This guidance is supplemented by an example spreadsheet and a brief summary of the evidence to support needs-based syringe distribution.

Good Practices and Ethical Data Collection at Harm Reduction Programs: A Brief Summary: This guidance is for harm reduction programs and for funders and others who require data from programs. This is a brief summary of good and ethical data collection and data use practices in harm reduction programs. The guidance may help programs evaluate their data collection and use practices as well as help funders and others who require harm reduction data to review which data they require.

Leveraging Informal Qualitative Data Collection and Use at Syringe Services Programs: This document provides a brief overview of some informal approaches to qualitative data collection and analysis. Specifically, this document focuses on suggestions for how to create potential systems for informal qualitative data collection and analysis at syringe services programs (SSPs), including how to develop an overall objective for data collection. By "informal" data collection, we mean data that can be largely generated from routine service interactions as opposed to formal research activities, such as in-depth interviews, focus group discussions, or community based participatory research.

Monitoring and Evaluation Toolkit: Data Collection Methods and Pilot Testing: The purpose of this guidance is to help syringe services programs (SSPs) and other harm reduction programs in establishing and maintaining data collection practices for program monitoring and evaluation. Programs may find this information useful if they have questions about the types of data they might collect, how they might record it, and how they might test out their methods with staff and participants. This guidance is part of a larger Monitoring and Evaluation Toolkit for SSPs that will serve as a resource for programs in all stages of the monitoring and evaluation process.

Participant Input in Harm Reduction Programs: This short document offers an overview of participant input at SSPs and a range of resources for harm reduction programs to consult when building or changing their participant input processes.

Point in Time Survey (PiTS) Toolkit for Use at Syringe Services Programs: A Point in Time Survey (PiTS) allows a syringe services program (SSP) to ask a standardized set of questions from a portion of their clients, providing a snapshot of the population that the SSP serves. These surveys can be a quick and low-cost way to learn about the characteristics, needs, and service utilization patterns of their clients. This toolkit includes resources, tools, and examples for each stage of the PiTS implementation process for programs to consider when designing and implementing their own surveys.

Population Size Estimation of People Who Inject Drugs: An Overview of Methodologies: This document provides an overview of the different methods and considerations for estimating the size of the population who injects drugs. It is primarily intended for local health departments, academia, and other community-based organizations.

SSP Indicators Project: This Indicators Implementation Guidance is the result of the SHaRP team's larger SSP Indicators Project. This project was developed based on ongoing requests for technical assistance related to ethical, reliable, and useful data that could be collected within SSPs. Our team set out to develop community-informed indicators that could be recommended. Our overarching aim is to advocate for good data collection practices that help make programs better, instead of being a burden to SSP staff or participants.

Using Unique Identifiers Within Syringe Services Programs: This guide is intended for syringe services programs (SSPs) and SSP funders to support their understanding of data collection and monitoring. It provides an overview of the benefits and drawbacks of implementing unique identifiers (UID) as a method of data collection. The guide includes considerations for SSPs considering implementing a UID system and considerations for funders who are considering requiring individual-level data from grant recipients.

Appendix 5: SSP Conversation Guide

Below is the interview guide used for our formative conversations with SSPs on their data requirements.

1. Please tell us a little bit about your program.
    a. Where do you operate? Fixed or mobile?
    b. What services do you provide?
    c. Do you have any funding that specifically supports data collection or analysis?
    d. How many syringes did you distribute in 2022?
2. How do you collect data?
    a. Paper or digital? Do you have wi-fi?
    b. Who collects data?
    c. When do you collect data? Intake, encounter, PiTS?
3. How do you store data?
    a. Paper forms?
    b. Digital data?
4. How do you analyze data?
    a. Who does the analysis?
5. Which data are you required to collect?
    a. Who requires these data?
    b. What are the barriers to collecting these data?
        i. What are the specific questions or pieces of data that are hardest to get?
        ii. How do you deal with these barriers?
    c. What makes collecting these data easy or efficient? What's working well?
6. If you had no requirements to collect certain data, which data would be most useful for your program?
7. What else do you want to know about your participants or your program that you're not currently collecting data on?
8. Again, we are creating SSP data collection guidelines. How could we make these guidelines the most useful for you?
9. Overall, how valuable is the data you collect for your program?
10. How do you currently use the data that you collect (e.g. grants, annual reports, expanding services)?
11. How do you think the data that you collect could be better used to support your program?
12. Is there anything else you'd like to add about data, data collection, or using data at your SSP?

Appendix 6: State Health Department and Non-State Funder/Advocacy Conversation Guide

Below is the interview guide for the formative conversations with state health departments and non-state funders on their data requirements for funded SSPs.

1. In which states or territories do these programs operate?
2. For state-level funders
    a. What are the approval processes for SSPs in your state?
    b. How do you fund or otherwise support SSPs?
3. For other funders
    a. How do you fund or otherwise support SSPs?
    b. How do you fund or support unauthorized SSPs?
4. What services do they usually provide?
    a. Which of those services can you explicitly fund?
5. What are your overall goals in funding/supporting SSPs?
    a. Who sets these goals?
6. How do you measure these harm reduction goals?
7. What are SSP data reporting requirements?
    a. Do you require unique counts?
    b. Is any data identifiable (e.g. contain names, full birth data, SSN)?
    c. What are the policies that require collection of certain data?
        i. Where did these reporting requirements come from?
    d. How flexible are these reporting requirements?
8. How do you collect data from programs?
    a. How often do you collect data?
    b. What is the system in which SSPs submit data?
        i. Do you provide a system for SSPs to enter and store data?
            1. Can they opt out/choose to use their own system?
            2. Who owns/has access to the data in that system?
            3. What is the system?
    c. In what format are SSPs required to submit data (e.g. summary, row by row)?
9. How do you store data?
10. Who has access to the data?
11. In what ways have you used the data that you get from programs?
    a. How is data reported out?
        i. Reported back to SSPs? To the public? To other agencies? To legislators?
    b. What are other ways the data could be used that maybe you don't have the time or bandwidth to do currently?
12. How have programs responded to the data that you collect?
    a. What are the barriers they cite in collecting data?
    b. Which data do SSPs report as hardest to collect? Easiest?
    c. How do you work with programs who encounter barriers in data collection?
13. Is there anything else you'd like to add about SSPs, data, monitoring and evaluation?