



UW SSP Data Indicators Project Share-back

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SHaRP Team Values and Guiding Principles for TA

1. Services first, data second
2. Client confidentiality (anonymity if possible)
3. Minimize burden on programs and participants
4. Only collect data that can be used to benefit people who use drugs and programs
5. No one size fits all



Meeting Objectives

- Share background and goals of the project
- Provide an overview of the project to-date
- Reach common understanding of general M&E terms
- Share preliminary list of recommended ethical indicators
- Present next steps
- Offer time for discussion and Q&A
 - Team members will be answering questions live in the chat throughout and we will then verbally go through questions after the presentation



Project Background and Goals



Project Origins in the TA Center

- Common questions about which data to collect and how to collect it
- Common complaints about burdensome reporting requirements

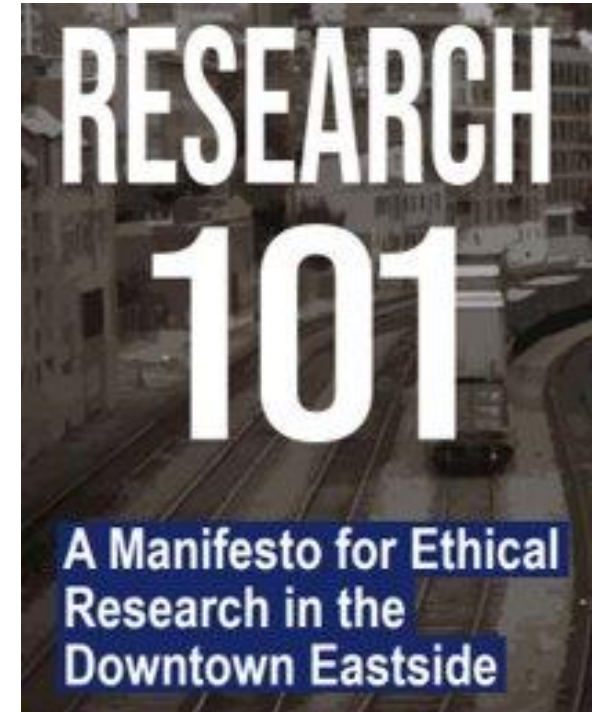


Project Origins in the Community



US Narcotic Farm, Lexington, KY

ACT UP



Monitoring and Evaluation (M&E)



Why Do SSPs Collect and Analyze Data?



What Challenges Do SSPs Face with Data Collection?

Burdensome data collection mandated by funders/reporting entities

Not having a way to opt out of data collection

Collecting more data than is needed (e.g., demographic data at every encounter)

Collecting data that's not relevant to services

Difficulty finding a platform that is flexible for multiple settings and works long-term

Infrastructure/tech

Lack of funding for staff time

Minimal funding for data-focused projects



We are proposing a limited set of indicators that we can recommend to SSPs as ethical, quality, and flexible measures for monitoring and evaluating their programs.

Why Focused, Limited Data Collection Makes Sense for SSPs

- Only collect what is needed/will be used
- Over-researched populations
- Criminalization
- Historical trauma
- Individual trauma
- Lack of \$\$\$ for data infrastructure and staff



A Few Terms...

Indicator vs. question

- Indicator: A specific, observable measure of something we want to know about (e.g., age)
- Question: How we collect data to measure an indicator (e.g., How old are you?)

Anonymity

- Inability to link data to an individual

Unique Identifiers

- Code assigned to a single participant, used to distinguish individual participants

Participant data vs. program data

- Participant data: data about individual people (e.g., age, gender, do you have naloxone)
- Program data: data about services provided (e.g., total naloxone out)

Aggregate vs. individual-level data (or row-by-row data)

- Aggregate data: total number or proportion (e.g., total syringes out in one year)
- Individual-level data: all data provided by a participant at every encounter (e.g., # syringes out)

Data collection frequency

- Intake/enrollment data
- Encounter data
- Point in Time Survey (PiTS) data

Qualitative data

- Non-numerical, descriptive information



Project Overview To Date



Overview

1. Literature Review
2. Formative conversations with SSPs, states, and funders
3. Reviewed data collection & reporting forms to develop a preliminary list
4. Held indicators convening
5. Solicited 2 rounds of feedback on preliminary list



Literature Review

- 41 published articles and white papers (non-journal publications)
- Created a summary report, "Good Practices and Ethical Data Collection at Harm Reduction Programs" that included criteria for ethical indicators
- Identified 4 core readings for indicators process:
 - **Bluthenthal, Ricky N.**, Allan Clear, Don C Des Jarlais, Samuel R. Friedman, Donald Grove, Holly Hagan, Robert Heimer, et al. 2009. **Recommended Best Practices for Effective Syringe Exchange Programs in the United States: Results of a Consensus Meeting.** New York City Department of Health and Mental Hygiene.
 - **Davidson, Peter**, Priya Chakrabarti, and Michael Marquesen. 2020. "Impacts of Mandated Data Collection on Syringe Distribution Programs in the United States." The International Journal on Drug Policy 79: 102725. <https://doi.org/10.1016/j.drugpo.2020.102725>.
 - **MacDonald, Goldie.** 2012. *Criteria for Selection of High-Performing Indicators: A Checklist to Inform Monitoring and Evaluation.* Centers for Disease Control and Prevention.
 - **North Carolina Urban Survivors Union.** 2020. *Ethical Research Manifesto.* Greensboro, NC: North Carolina Urban Survivors Union.

Good Practices and Ethical Data Collection at Harm Reduction Programs: A Brief Summary

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SSP, State, and Funder Conversations

Purpose: To discuss the **context** of data collection/reporting and **how** data is collected and used

Methods:

- SSPs selected for diversity of progressive/conservative state legislatures, program size, urban/rural, underground/sanctioned
 - Participating SSP staff received a \$100 check for their time
- State governments selected for regional diversity, population, and progressive/conservative legislatures; all states had CDC Determination of Need
- Funders selected based on ability to fund a wide swath of programs, a variety of activities, and underground programs

Results: Themes emerged around inconsistency, challenges related to data collection, frustrations around requirements, and more



Reporting Forms Review

5	National private funders
9	SSPs
30	States <ul style="list-style-type: none">Requested forms from all states where SSP is legal (43)Some lacked reporting processes (4) or did not share forms (9)Ranged from under 10 to ~100 within a single state



500+ unique indicators

Huge variability in types of data collected, lack of agreement in frequency/question framing etc.

UW Indicator List

- Viewed the list of 500+ indicators as the current "universe" of SSP indicators
- Assigned indicators to domains (topic areas) based on similarity
- Conducted card sort:
 - Method based on qualitative research
 - Each team member conducted a three-round card sort to eliminate indicators based on considerations related to 1) ethics, 2) flexibility, and 3) quality
- Met and used consensus/"nomination" process to advance indicators



Indicators Convening with Stakeholders

- Brief application to attend, publicized on list-servs
 - Offered compensation to all attendees
 - Wanted to ensure a size that would encourage participation
 - Invited 38 of 200+ applicants to attend, representing a variety of stakeholders
- Developed recommendations for ethical data collection at SSPs and form a working group to elicit feedback on the UW indicators list

In 1-2 sentences, please describe how these roles have informed what you would contribute to this meeting.

Expand

Select all past and current SSP **data** experience you have had:

- Building an SSP data system
- Disseminating SSP data and/or using data in advocacy
- Documenting case management services
- Documenting health care services
- Documenting SSP and/or outreach services
- Grant writing and/or reporting
- Managing a data system
- SSP data analysis
- SSP data cleaning
- Transitioning from a paper to digital data system
- Working in or with an SSP that enrolls participants and/or assigns unique IDs
- Working in or with an SSP that does not enroll participants and/or does not assign unique IDs
- Working in or with an SSP that conducts a point in time survey or other cross-sectional survey
- Other

Please briefly describe

In 3 sentences or less, please describe what perspective related to SSP data collection, grant reporting, and/or data analysis you will bring to the meeting. If you have a philosophy about data within SSPs, please feel free to share that here, too!

Expand



Indicators List Feedback & Revision Process

- Presented proposed indicators to Indicators Working Group (convening attendees) during a follow-up webinar and solicited feedback using REDCap
 - First survey:
 - Approval/rejection of proposed indicators based on ethics, quality, and flexibility
 - Modification to indicators
 - Additional proposed indicators
 - Second survey:
 - Vote on proposed modifications
 - Feedback on proposed (additional) indicators
- Resulted in 18 proposed indicators (we removed, added, and modified indicators from original list)

Below you will have the choices to approve, reject, or suggest changes to each of the UW indicators. If you reject one, you will be asked to provide justification based on one of the following three parameters.

Ethical	
Criteria	Description
Burden of Data Collection	The ease or difficulty of collecting data in terms of the time, effort, and emotional labor on participants and staff
Burden of Data Analysis	The ease or difficulty of analyzing data in terms of the quality, timeliness, and resources required for data analysis
Cultural and Structural Relevancy	Is an indicator appropriate for the people, places, and systems where it's collected?
Minimalist Approach	Data collection should never be a barrier to services and should not consume the resources of underfunded programs
Pathway for Data Use	All ways that data may be used, by whom, and the consequences of that use. All data collected should have a clear use
Privacy and Security	The degree to which data may be kept secure and if it was revealed, the harm it could do to those whose confidentiality is breached

Quality	
Criteria	Description
Accepted History of Evidence-Based Use	Includes a discussion of advantages and limitations of using the indicator and peoples' experiences using the indicator
Data Quality	Can the data collected be complete, reliable, and accurate?
Relevance to Evaluation Questions	Does an indicator answer evaluation questions and represent what is being evaluated?
Value within a Set of Indicators	Decide if there is enough diversity of indicators to answer evaluation questions and if a single indicator adds meaning to sets of indicators. This may help identify redundancies in data collection

Flexibility	
Criteria	Description
Applicability in Different Settings	The ability to collect comparable and consistent data across diverse settings (e.g. mobile programs, underground programs, rural programs, etc.)
Opportunity to Detect Unexpected Findings	Some indicators should be flexible enough to include unexpected or unintended findings



Proposed Indicators



Domains

Service and supply provision (28 states)

Service coverage (27 states)

Service quality (13 states)

Engagement with people who use drugs (4 states)

Demographics (22 states)

Structural violence (14 states)

Overdose prevention (22 states)



None of our proposed indicators are framed as encounter-level, although we know a lot of programs choose (or are required) to collect it this way

Program-Level Indicators

Service & Supply Provision

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

Indicator	Notes
Count of syringes distributed	Could be collected as a daily, weekly, monthly, quarterly, or annual estimate
Types of services program provides	Reported as a list
Types of supplies program distributes	Reported as a list



Service Coverage

The reach of a program in a geographic area + the level of engagement, level of services, or comprehensiveness of services provided to a participant

Indicator	Notes
Hours per week program operates	Reported as a total
Program's service model(s)	Reported as a list (i.e. fixed site, mobile, mail-based, street outreach)
Total participant visits	Includes duplicated participants and thus does not require unique identification; could be collected as a daily, weekly, monthly, quarterly, or annual estimate



Service Quality

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

Indicator	Notes
Program activities	Narrative with examples
Program needs and barriers to service provision	Narrative with examples



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	Notes
How participants are engaged to give feedback about programs	Reported as a narrative with examples
How participants have decision making power in programs	Reported as a narrative with examples



Individual-Level Indicators

Demographics

Participant Characteristics

Indicator	Notes
Participant age range	Recommended to be collected anonymously (i.e. not connected to unique identifiers) from participants via point in time surveys and reported out categorized as under 30 and over 30
Participant gender identity	Recommended to be collected anonymously from participants via point in time surveys and only when safe to collect given local context
Participant race/ethnicity	Recommended to be collected anonymously from participants via point in time surveys as a single question with instructions to select all that apply



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	Notes
Participant housing status	Recommended to be collected anonymously from participants via point in time surveys with careful considerations about how data are collected
Participant interactions with law enforcement	Recommended to be collected anonymously from participants via point in time surveys or informal qualitative data with careful considerations about how data are collected



Overdose Prevention

Program services and activities directed towards preventing fatal overdose as well as measures of overdose burden. **This was our only hybrid program/individual level domain.**

Indicator	Notes
Count of naloxone doses distributed	Could be collected as a daily, weekly, monthly, quarterly, or annual estimate
Participant overdose experience	Recommended to be collected anonymously from participants via point in time surveys with careful considerations about how data are collected
Reported overdose reversals	Could be collected at encounters or via point in time surveys with careful considerations about how data are collected



Next Steps



Public Feedback

Survey open to:

- People who use drugs
- People who work at SSPs
- Entities that collect data from SSPs (health departments, private funders, etc.)

Survey will be open until next Wednesday, 11/22/2023



Public Feedback

We want to learn about:

- Opinions on ethics and data quality for indicators on overdose experience and overdoses reversed
- If SSPs could easily collect and report out on the indicators
- If SSPs could use them internally (examples include tracking progress or milestones over time, evaluating internal goals or quality of service, for grant writing, or advocacy)
- If entities that collect data from SSPs could accept indicator data for their reporting needs.
- How comfortable people who use drugs feel about being asked the indicators that require participant data

The survey responses we receive will be included in the findings from this project. The input will also be used to contextualize the indicator list and provide insight into what implementation considerations and the ramifications of collecting these data might be.



Next Steps

- Create guidance for implementation
- Support and capacity building to SSPs
 - Providing TA and recommendations to SSPs
 - More organized trainings



QUESTIONS?

