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

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**SHaRP: SUPPORTING HARM REDUCTION PROGRAMS**

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*This project is supported by the Centers for Disease Control and Prevention of the U.S. Department of Health and Human Services (HHS) as part of the National Harm Reduction Technical Assistance Center (NHRTAC) funded by SAMHSA and the CDC. The contents are those of the author(s) and do not necessarily represent the official views of, nor an endorsement by, CDC/HHS, or the U.S. Government.*

## Notes on Language

The way we talk about data in harm reduction becomes full of jargon quickly. Here are a few helpful terms:

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

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

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

## Good practices for data collection at harm reduction programs

Below is a summary of harm reduction data collection and data use good practices. We included citations and can share the full text of any article if you email us at [sharpta@uw.edu](mailto:sharpta@uw.edu).

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

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

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

*How to pick an indicator* – One of the purposes of this convening is to propose indicators that are helpful for a variety of contexts and SSPs. Here are some things to think about when we discuss what makes a good indicator, adapted from MacDonald<sup>15</sup> (listed in alphabetical order, not according to importance):

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

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

**Ethical data collection at harm reduction programs**

Below is a summary of harm reduction ethical data collection practices. We included citations and can share the full text of any article if you email us at [sharpta@uw.edu](mailto:sharpta@uw.edu).

*Problems with unethical data collection* – Data collection may be intrusive, stigmatizing, exploit peoples’ pain, create fear, and exhaust valuable resources, especially in communities that are over-researched and underserved.<sup>2</sup> Harm reduction data collection often reflects trends of surveilling the individual, instead of measuring inequities and structural violence.<sup>16</sup> Data

collection in programs may decrease trust with participants and deter new participants.<sup>8</sup> Data collection that is intrusive, outsider imposed, or otherwise flawed often results in poor-quality data.<sup>10</sup> For instance, participants may give inaccurate data when questions feel rude and staff may guess at data when collection is too burdensome.<sup>8</sup>

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

*Consent* – Both programs and participants should have the right to refuse to take part in data collection.<sup>2</sup>

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

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

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

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

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

*Compensation* – Programs should work with participants to decide when compensation is necessary and feasible (e.g. according to how long it takes to complete a survey), how compensation compares to local living wage estimates, and the preferred method of compensation, which may be cash, but is unlikely gift cards.<sup>2,9,11</sup> Whether compensation is

provided or not, data collection should never be a barrier to services and all other ethical data collection guidelines should be considered.

*Privacy and security* – Programs should be clear with participants about how data collection may affect participant privacy and security.<sup>25</sup> Data that includes potentially identifying information should be stored in secure databases<sup>1</sup> and data about people who use drugs should never be shared with law enforcement.<sup>26-27</sup>

## Further resources

The literature we reviewed is cited throughout, but here are what we consider the core resources.

[Ricky N. Bluthenthal et al.](#), *Recommended Best Practices for Effective Syringe Exchange Programs in the United States: Results of a Consensus Meeting* (New York: New York City Department of Health and Mental Hygiene, 2009).

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

[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>.

[Drug Policy Alliance](#), “Recommendations for Community Driven Drug Policy Research” ([https://drive.google.com/file/d/10lBcJ-7JigbcHfaO\\_ur4zzxn86lNoED9/view](https://drive.google.com/file/d/10lBcJ-7JigbcHfaO_ur4zzxn86lNoED9/view), 2022).

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

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## Questions to think about for your program

- What isn’t working about past and current data collection practices at our program?
- What makes for good data collection at our program?
- What makes for ethical data collection at our program?
- What are our goals for monitoring and evaluation?
- What are some indicators that can help us reach those goals?

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

Suggested citation:

University of Washington Supporting Harm Reduction Programs (SHaRP) Team. “Good Practices and Ethical Data Collection at Harm Reduction Programs: A Brief Summary,” May 2023.

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<sup>1</sup> Zulqarnain Javed et al., “A Technical Package of Effective Strategies and Approaches for Planning, Design, and Implementation.” (Atlanta: Centers for Disease Control and Prevention, 2020).

<sup>2</sup> Louise Boilevin et al., *Research 101: A Manifesto for Ethical Research in the Downtown Eastside* (Vancouver: Research 101, 2019).

<sup>3</sup> Ruchi M. Sanghani, Alexandra L. Carlin, and Alexander K. Moler, “Assessing Success—a Commentary on the Necessity of Outcomes Measures,” *Substance Abuse Treatment, Prevention, and Policy* 10, no. 1 (2015): 20, <https://doi.org/10.1186/s13011-015-0017-2>.

<sup>4</sup> James L. Sorensen and Thomas Kosten, “Developing the Tools of Implementation Science in Substance Use Disorders Treatment: Applications of the Consolidated Framework for Implementation Research,” *Psychology of Addictive Behaviors: Journal of the Society of Psychologists in Addictive Behaviors* 25, no. 2 (2011): 262–68, <https://doi.org/10.1037/a0022765>.

<sup>5</sup> Lucas Wiessing et al., “Monitoring Quality and Coverage of Harm Reduction Services for People Who Use Drugs: A Consensus Study,” *Harm Reduction Journal* 14, no. 1 (2017): 19, <https://doi.org/10.1186/s12954-017-0141-6>.

<sup>6</sup> Lou Atkins et al., “A Guide to Using the Theoretical Domains Framework of Behaviour Change to Investigate Implementation Problems,” *Implementation Science* 12, no. 1 (2017): 77, <https://doi.org/10.1186/s13012-017-0605-9>.

<sup>7</sup> Simon Baldwin, Neil Boisen, and Robert Power, “Managing Information: Using Systematic Data Collection to Estimate Process and Impact Indicators Related to Harm Reduction Services in Myanmar,” *The International Journal on Drug Policy* 19 Suppl 1 (2008): S74-79, <https://doi.org/10.1016/j.drugpo.2007.12.005>.

<sup>8</sup> 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>.

<sup>9</sup> Drug Policy Alliance, “Recommendations for Community Driven Drug Policy Research” ([https://drive.google.com/file/d/10IBcJ-7JigbcHfaO\\_ur4zxxn86INoED9/view](https://drive.google.com/file/d/10IBcJ-7JigbcHfaO_ur4zxxn86INoED9/view), 2022).

<sup>10</sup> Jules Netherland et al., *Oregon’s Measure 110 Principles and Metrics for Effective Evaluations* (M110 Evaluation Working Group, 2021).

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- <sup>11</sup> Caty Simon et al., “We Are the Researched, the Researchers, and the Discounted: The Experiences of Drug User Activists as Researchers,” *International Journal of Drug Policy* 98 (December 1, 2021): 103364, <https://doi.org/10.1016/j.drugpo.2021.103364>.
- <sup>12</sup> Nadia Safaeinili et al., “CFIR Simplified: Pragmatic Application of and Adaptations to the Consolidated Framework for Implementation Research (CFIR) for Evaluation of a Patient-Centered Care Transformation within a Learning Health System,” *Learning Health Systems* 4, no. 1 (2020): e10201, <https://doi.org/10.1002/lrh2.10201>.
- <sup>13</sup> Carol Strike et al., *Ontario Needle Exchange Programs: Best Practice Recommendations* (Toronto: Ontario Needle Exchange Coordinating Committee, 2006).
- <sup>14</sup> Ricky N. Bluthenthal et al., *Recommended Best Practices for Effective Syringe Exchange Programs in the United States: Results of a Consensus Meeting* (New York: New York City Department of Health and Mental Hygiene, 2009).
- <sup>15</sup> Goldie MacDonald, *Criteria for Selection of High-Performing Indicators: A Checklist to Inform Monitoring and Evaluation* (Atlanta: Centers for Disease Control and Prevention, 2012).
- <sup>16</sup> Brett Wolfson-Stofko et al., “The Portapotty Experiment: Neoliberal Approaches to the Intertwined Epidemics of Opioid-Related Overdose and HIV/HCV, and Why We Need Cultural Anthropologists in the South Bronx,” *Dialectical Anthropology* 40, no. 4 (2016): 395–410, <https://doi.org/10.1007/s10624-016-9443-4>.
- <sup>17</sup> UNAIDS, *The “Three Ones” in Action: Where We Are and Where We Go from Here* (United Nations Programme on HIV/AIDS, 2005).
- <sup>18</sup> Susan Boyd and NAOMI Patients Association, “Yet They Failed to Do so: Recommendations Based on the Experiences of NAOMI Research Survivors and a Call for Action,” *Harm Reduction Journal* 10, no. 1 (April 18, 2013): 6, <https://doi.org/10.1186/1477-7517-10-6>.
- <sup>19</sup> North Carolina Survivors’ Union, “Ethical Research Manifesto,” 2020, <https://docs.google.com/document/d/1UFm5EYCCgr5Shv9TjOCobobF4JwI12i8uN98TV8Fr34/edit?usp=sharing>.
- <sup>20</sup> *Nothing About Us Without Us: A Manifesto by People Who Use Drugs* (Toronto: Canadian HIV/AIDS Legal Network, International HIV/AIDS Alliance, Open Society Institute, and International Network of People Who Use Drugs, 2008).
- <sup>21</sup> Carol Strike et al., “Guidelines for Better Harm Reduction: Evaluating Implementation of Best Practice Recommendations for Needle and Syringe Programs (NSPs),” *International Journal of Drug Policy* 22, no. 1 (2011): 34–40, <https://doi.org/10.1016/j.drugpo.2010.03.007>.
- <sup>22</sup> Terry Ruefli and Susan J. Rogers, “How Do Drug Users Define Their Progress in Harm Reduction Programs? Qualitative Research to Develop User-Generated Outcomes,” *Harm Reduction Journal* 1, no. 1 (2004): 8, <https://doi.org/10.1186/1477-7517-1-8>.
- <sup>23</sup> Merrill Singer, “Knowledge for Use: Anthropology and Community-Centered Substance Abuse Research,” *Social Science & Medicine* 37, no. 1 (1993): 15–25, [https://doi.org/10.1016/0277-9536\(93\)90312-r](https://doi.org/10.1016/0277-9536(93)90312-r).
- <sup>24</sup> Daniel O’Keefe et al., “Measures of Harm Reduction Service Provision for People Who Inject Drugs,” *Bulletin of the World Health Organization* 97, no. 9 (2019): 605–11, <https://doi.org/10.2471/BLT.18.224089>.

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<sup>25</sup> Michael P. Schaub, Ambros Uchtenhagen, and EQUUS Expert Group, “Building a European Consensus on Minimum Quality Standards for Drug Treatment, Rehabilitation and Harm Reduction,” *European Addiction Research* 19, no. 6 (2013): 314–24, <https://doi.org/10.1159/000350740>.

<sup>26</sup> WHO, UNODC, UNAIDS, *Technical Guide for Countries to Set Targets for Universal Access to HIV Prevention, Treatment, and Care for Injecting Drug Users* (World Health Organization, 2012).

<sup>27</sup> Liam Michaud, Emily van der Meulen, and Adrian Guta, “Between Care and Control: Examining Surveillance Practices in Harm Reduction,” *Contemporary Drug Problems* 50, no. 1 (March 2023): 3–24, <https://doi.org/10.1177/00914509221128598>.