

Findings Report: Data Support Needs from Harm Reduction Organizations

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Introduction

While data collection and analysis are essential for informing program development, implementation and evaluation, harm reduction organizations face some critical challenges to these processes.

Even the tenets of the harm reduction model (e.g., “Meet participants where they’re at, even if it means modifying services on the fly,” “Provide lifesaving services first, build infrastructure later”) can be counter to the tenets of robust data collection. Plus, because of the sensitive nature of participants’ substance use and health-related information, organizations require software that protects private individual information.

Many harm reduction organizations have experienced rapid growth in the past three to five years, but the systems they have been using to manage broad organizational structures, including data collection and analysis, have not kept up with the pace of growth. In addition, harm reduction organizations vary in their capacity to conduct data-related activities, due to their size, staff capacity and knowledge, service model and availability of resources, among other reasons.

Given the diversity of data experience, needs and capacity among our subgrantees, the National Council for Mental Wellbeing hosted focus groups to explore and identify options to best support harm reduction organizations in their efforts to improve data collection and analysis.

Methods

Participants representing 15 harm reduction organizations were invited to participate in the focus groups. Each harm reduction organization was a subgrantee for a grant funded by the Centers for Disease Control and Prevention (CDC), “Novel Harm Reduction and Treatment Strategies to Support Individuals with Opioid Use Disorder – COVID-19.” They work as frontline staff, administrators, and data personnel. Three focus groups met, each with three or four participants. The groups were formed based on organization size and their availability. The one-hour focus groups were conducted on Zoom and moderated using a semi-structured topic guide consisting primarily of open-ended questions.



Focus groups were recorded and transcribed. Transcriptions were coded for themes. Five grantee representatives were unable to attend the focus groups and were asked to submit written responses based on questions from the topic guide. Written responses were also coded for themes. Each participant received a \$50 Amazon electronic gift card in gratitude for their participation.

Results

We've summarized our results into four main categories:

- ❑ Methodological issues, including challenges related to the methods of collecting, analyzing and disseminating harm reduction data.
- ❑ Technological issues, including inadequate or insufficient technological tools to support the collection, storage and analysis of data.
- ❑ Personnel and capacity development, including areas where staff needs increased training and support.
- ❑ Systems-level challenges addressing some of the larger structures, often related to funding processes, that can disadvantage harm-reduction organizations.

Methodological Issues

Organizations that perform syringe exchange and other services through more traditional brick-and-mortar locations have, for the most part, identified and developed effective methods of collecting information on participants and interventions, such as intake assessments to capture demographic and drug use information and event-level assessments to capture how many and what types of services are provided. They reported facing challenges, however, collecting individual-level and event-level data in special modes of “non-traditional” service delivery. For example, secondary syringe exchange, or satellite exchange, arose across multiple organizations as a mode of service delivery that is nearly impossible to track at the individual or encounter level. Organizations can often track how many syringes they distribute via secondary exchange in total and by secondary exchanger or “satellite,” and they may be able to track how many unique individuals received syringes, any information beyond that is extremely challenging to collect.



The most challenging part for us is ... satellite distribution. We have about five or six people now who come get supplies once a week and take it to the people they know. I don't want to have to give all of their people unique identifying numbers. I don't even want to give them a unique identifying number. It seems like a lot. I want to have five or six questions that they answer every time they come in to get new supplies. 'How many people?' 'Do you know of any overdose reversals?' 'What are some things that you're seeing in the streets, trends with drugs?' And then there's the question of how do you decide how much [safe use supplies] to give people? ... Not having that information is really frustrating."

Other modes of service delivery that present distinct challenges to collecting individual-level data include mobile delivery and mail-based delivery, where interaction with a participant is minimal, limiting rapport-building, trust-building and time spent with a participant. Event-based service delivery, such as outreach to homeless encampments and pop-up distribution sites, also poses a challenge for individual-level data collection.



We definitely want to stay low-barrier and have data collection be optional if at all possible. In the past, we've done surveys that participants could be a part of, but there is a real lack in being able to engage people to take that survey or other methods as well. It's really hard to be able to get data directly from the people that we want to get it from. I think it's something that is felt everywhere, but I think it's particularly a very strong challenge here in [rural state], since we serve people statewide and the majority of our harm reduction services directly to participants is through the mail-out program."

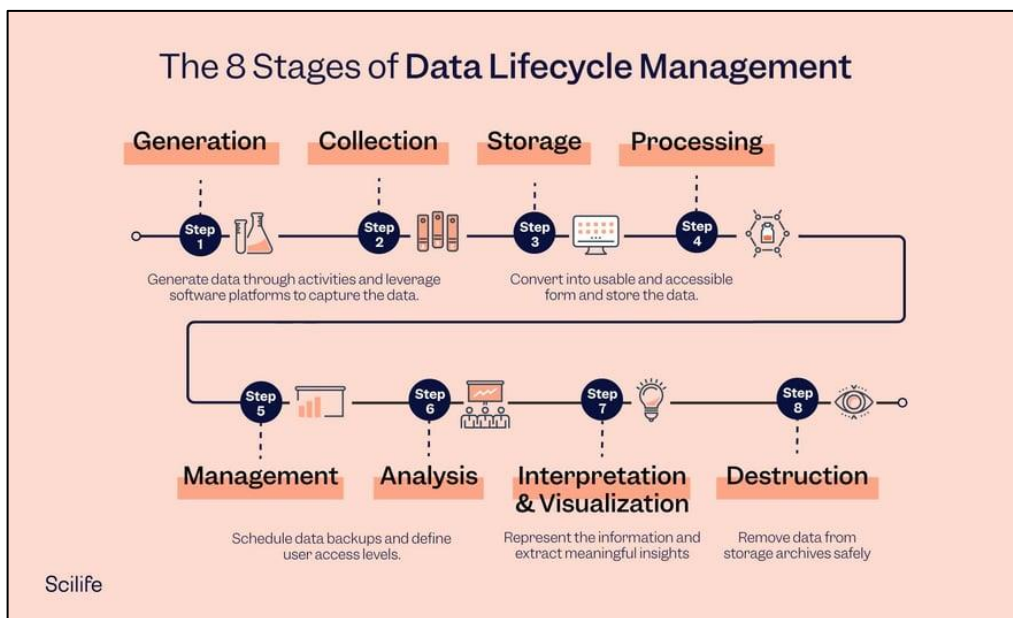
Some organizations discussed an intentional move toward a lower-threshold model of service provision. While successful at increasing the number of participants engaged and receiving life-saving services and supplies, this presents new challenges to collecting individual-level data, as staff don't have lengthy interactions in which to ask multiple questions, and they do not often conduct an in-depth intake interview. Organizations have considered substituting alternative methods of data collection in order to meet this need and understand their participant population better, such as point-in-time, cross sectional surveys. This type of activity, however, requires staff expertise and time in addition to day-to-day job requirements – both of which present challenges to small organizations with minimal staffing.

While organizations generally have systems in place to capture quantitative outputs, some organizations reported struggling to adequately capture the “powerful conversations” staff have with participants they engage in services. Harm reduction at its core is about connection, and staff create powerful therapeutic alliances with participants. Unfortunately, there are no good methods in place to capture those connections and turn the information gained from them into qualitative data that can be used for program improvement and reporting.



We engage in powerful conversations [with clients], and how do we also capture that and really evaluate our program, evaluate the services, and help identify where there are gaps in need?”

When asked about data across the life cycle -- from data generation and collection to cleaning, storage, analysis and eventual destruction – participants largely reported that data collection was the stage where they felt their organization did best, despite the many focus group conversations centering on issues of data collection. Data cleaning, analysis, manipulation, processing and reporting, on the other hand, were areas that nearly all organizations felt needed improvement. Some of the areas specifically mentioned were using program data to measure impact and strategies for presenting data findings to key stakeholder groups, such as participants, funders and the greater community.



¹ Deshpande, R. (2023, March 23). *8 stages of data lifecycle management*. Scilife. <https://www.scilife.io/blog/stages-data-lifecycle-management> .

Consequently, many of the issues that will be discussed in the remainder of this report focus on issues of data storage, management and analysis.

Technological Issues

A significant number of challenges related to electronic collection and storage of data arose. Perhaps more so than other types of social services, harm reduction organizations often still rely on the use of paper data collection, for a variety of very valid reasons. For staff, many of whom come with a history of lived experience and may have little traditional office job experience, paper data collection may be less intimidating and offer an easier way of capturing data accurately. Staff may also feel that connecting with participants is easier without a screen between them, particularly if the participant has experienced a history of extractive or exploitative data practices or has a mistrust of social services. For them, it makes good sense to capture data on paper first while with the client and transfer it to an electronic system later. And for mobile services delivery, even in urban metropolitan areas such as New York City, harm reduction organizations report unreliable mobile internet availability, which can create challenges when collecting data solely electronically via tablet or smartphone.

When identifying the right software for data collection and management, harm reduction organizations struggle to identify a single product -- which often needs to be different than a typical electronic case management product -- that fits their program model and services and is easy for frontline staff and volunteers to use.



We've tried a bunch of different programs because we do collect so much data, and we haven't found one that we can use successfully, to collect all of the data that we need and then extract it when we need it."



Harm reduction work is so unique and I think what we would really need, what we really need, is a customizable, relational database that is cheap, that is easy to operate, and that can evolve with the needs of the harm reduction universe."

Keep in mind, harm reduction organizations collect information that is highly confidential and/or legally incriminating, such as mental health and infectious disease information, and illicit drug use. Therefore, it is paramount that their data storage systems are secure and are hosted on a safe server. One participant

said they had to travel across several states before finding an organization willing to host their server safely. Another challenge is finding software products that adequately protect sensitive information while meeting other needs such as affordability and user-friendliness.

Finally, most harm reduction organizations are supported by a patchwork of grants and funding streams, each with its own data reporting requirements. As a result, they often found themselves duplicating data entry and/or analysis to meet the specific demands of each funder, but the data systems they commonly used did not adequately meet the multiple demands of funders' differing reporting requirements.



We need to be able to do customizable queries so that we can satisfy each funder at the click of a button, as opposed to kind of backing our data into five different data categories that different funders want. Instead of taking three days to do a data run, it could take 10 minutes.”

Personnel and Capacity Development

Across focus groups, participants underscored the need for more personnel to support increasing data needs. While most named specific needs around data management, analysis and dissemination, there were some needs related to data collection as well. For example, to consistently collect accurate data at each participant encounter, direct service staff and volunteers have buy into the value of the data and understand how to collect and record data accurately. This requires ongoing staff training and support, given frequent staff turnover and the ever-changing needs of the programs.



Technology training [as it relates to data collection] isn't like a one-and-done thing. It would be really great if it was. But people need like consistent support, making sure that what they learned in the technology training, that they're applying it in their work later. And if they have questions, like if they need a training refresh, it just seems like it's something that constantly needs worked on. And if you don't have a person to do that, then it's going to fall under the radar. And that's when we start seeing data entry issues.”

One program that provides services in a rural area via mobile delivery noted that when there is only one staff or volunteer on the van, it is nearly impossible to manage all of the tasks that are required, such as putting together orders, managing delivery schedules, mapping routes, calling or messaging participants and delivering orders. And when there is only one person on duty, data collection often is the first task dropped.

Programs that rely heavily on volunteers -- a substantial subset of the organizations we heard from -- face unique data collection challenges that may not be relevant to paid staff. When data collection is electronic, there is often not funding to purchase tablets or phones for volunteers, who will then rely on their own devices, as compared to staff that have company-issued tablets or phones. Training and quality assurance is also more challenging with a volunteer workforce that may not be as consistently present as paid staff: It can be more difficult to get volunteers to attend data collection trainings or receive feedback on data quality if they are not regularly present.

Unsurprisingly, nearly all organizations arrived at the same conclusion: More resources are needed to support paid, in-house data personnel. This person or team would be responsible for training and capacity building of all data collectors, as well as quality assurance, cleaning, storage and management of data systems. Even the several larger organizations that did in fact have in-house data personnel on staff expressed a need for more resources. They found that data personnel were entirely consumed by the day-to-day needs of data management and lacked the time and resources for other data-related tasks, such as thinking more expansively about using data to measure program impact and developing messaging and results based on data for key stakeholder groups.



Because my role is with data and reporting, but also that kind of turned into grants and grant writing and grant development. And it's kind of merging into a few different things, and also technical support. I do the technology training. And so I think we could use another person or more support, and ... localize more. Somebody's role could just be for data. Somebody's role could just be for technical support. I think that we could, yeah, like everybody else has said, just use more support in those areas."

System-level Challenges

While some of the fixes to the challenges organizations face are relatively easy, many represent larger problems with the underlying systems and ways in which harm reduction organizations are commonly funded. At times, one-time only funding or short-term funding becomes available to build a specific database or for another finite activity, but consistent ongoing funding to support these activities is lacking. For example, organizations often lack consistent, ongoing funding to support software and licenses for programs such as databases, SQL and ArcGIS.

This same lack of consistent funding for data-related activities contributes to a shortage of data personnel (monitoring and evaluation, informatics, etc.), as described earlier. While technical assistance is available through programs such as the [National Harm Reduction Technical Assistance Center \(NHRTAC\)](#) and, specific to monitoring and evaluation, the Supporting Harm Reduction Program (SHaRP) at the [University of Washington](#), organizations expressed a critical need for ongoing, in-house support from staff who

intimately understood the program model, mission, vision and data collection strategies of the organization.

Focus group participants also expressed frustration about the large amount of detailed data required by funders, which often conflicted with the organizations' ability to provide services. And as mentioned earlier, funders often request different data or the same data aggregated in different ways, which puts more of a burden on programs. Participants expressed a desire for a common, mainstream or aggregated data collection tool, like the common application used in college admissions.

Another challenge named was the way funding and requests for proposals, perhaps unwittingly, often favor larger organizations and health care systems over smaller, grassroots, homegrown and sometimes volunteer-run organizations. Participants noted that because of this dynamic, smaller harm reduction organizations struggle to win the funding needed to build the data systems they need to collect and synthesize programmatic data for grant applications, prompting a cycle that systematically disadvantages smaller organizations.

Last, some organizations connected the challenges of data collection and reporting to the lack of representation of people with lived experience in positions of decision-making power at funding entities. When the data elements requested come from a position or funder not informed by PWUD's lived experiences, they can be poorly worded, improperly quantified or categorized, or irrelevant.



If these individuals were in positions where their experiential knowledge could influence the execution of funding, I think harm reduction programs/grantees would benefit tremendously."

Recommendations for Funders

Some of the most important needs expressed in focus groups spoke to funders specifically. It can behoove funders – primarily public funders, but also private funders – to address some of these concerns.

- Provide consistent, stable, ongoing funding to support data-related activities, personnel and software. Funding could be used to:
 - Fully support in-house data personnel, the biggest need identified by focus group participants.
 - Pay for a portion of all frontline staff members' time, supporting their data collection and recording activities.
 - Train staff on data collection and use of tools.

- Fill key gaps in data collection with extra staffing support and participant incentives to do point-in-time data collection.
- Purchase software, licenses and hosting on secure servers.
- Develop RFP processes that are more inclusive and prioritize smaller, grassroots harm reduction organizations.
- Coordinate with other major funders to align data requests where possible. At a minimum, establish variables and answer categories that are consistent across funders. Ideally, provide one portal to submit data for multiple funders.
- Include people with lived experience in the decisions related to data requirements.
- Seek input and recommendations from grantees regarding which indicators to track and how to track them so the data collected effectively matches program goals and operations.

Other Recommendations

- While organizations devote much of their resources to data collection, they need technical assistance in the areas of data storage, processing, management, analysis and dissemination.
- Organizations need more centralized guidance – from NHRTAC or another hosting entity – on key issues in data management for harm reduction. Standards for safely collecting, storing and maintaining confidential data could be used across the field, rather than each organization investigating the issues and identifying solutions independently.
- While much of the training frontline staff require is specific to each organization’s data collection methods, a centralized training body could provide training on key universal elements, such as the importance of data to harm reduction, basics of monitoring and evaluation in harm reduction and the data life cycle, key standards in accurate and efficient data collection and management, and methods of quality assurance.
- Software developers could support harm reduction by building products, such as case management software, that specifically cater to the unique needs of harm reduction organizations, and provide them to nonprofit organizations at low or no cost.
- Evaluators and applied harm reduction researchers may be able to assist harm reduction organizations in developing creative data collection mechanisms for some of the more challenging modalities, such as secondary exchange, and for qualitative participant data.

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