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Impacts of mandated data collection on syringe distribution programs in the United States

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Abstract

Objectives.—Syringe Distribution Programs (SDPs) are a well-proven public health response to the spread of HIV and other blood borne illnesses among people who inject drugs. Many SDPs in the United States are required to collect data from service users as a condition of either legal authorization to operate or as a condition of funding. We sought to describe the prevalence of such externally mandated data collection and impact on service delivery at syringe distribution programs (SDPs) in the United States via an online survey.

Methods.—Online survey of SDPs in the US.

Results.—63 SDPs participated. 95·2% collected data about individual service users, with 76·7% being mandated to do so by an external entity as a condition of legal authorization, and/or as a condition of funding. Only 21·7% of mandated respondents received any report back on how data was used. 60·0% reported that data collection acted as a barrier to providing syringes to people who use drugs due to service user fears about loss of anonymity and/or law enforcement. 33·3% reported that the computer literacy and language skills required to collect data meant otherwise appropriate members of the community could not he hired as staff or volunteers.

Conclusions.—Data collection at SDPs may act as a barrier to service provision to populations at high risk for HIV and other blood born viruses, and place considerable logistic burdens on often under-resourced public health programs. Further, it is often unclear to SDPs what purpose their

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Peter Davidson: co-conceptualized the study (with M. Marquesen), designed and implemented data collection device, co-conducted analysis (with P. Chakrabarti), acquired funding, provided overall supervision of project, co-wrote first draft (with P. Chakrabarti), participated in editing with all authors, wrote final draft.
Priya Chakrabarti: assisted in data collection, co-conducted analysis (with P. Davidson), co-wrote first draft (with P. Davidson), participated in editing with all authors, reviewed final manuscript.
Michael Marquesen: co-conceptualized the study (with P. Davidson), contributed to instrument design, participated in editing with all authors, reviewed final manuscript.

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data is being put to. We argue that to be ethical, the purpose of data collection should be carefully considered and regularly reviewed to ensure data is being put to meaningful purpose which is commensurate with impacts on service delivery.

Keywords

Syringe distribution; data collection; people who inject drugs; ethics

Introduction

Syringe Distribution Programs (SDPs) are a well-proven public health response to the spread of HIV and other blood borne illnesses among people who inject drugs (PWID) (Wodak & Cooney, 2005). Despite this, SDPs remain controversial in the United States and it can take considerable political effort to authorize new programs. One common approach used historically to facilitate the introduction of new programs has been for city, county, or state level government to authorize a program on a ‘pilot’ or ‘research’ basis, and to require that the program collect individual-level data from service users to allow an evaluation of the efficacy of the program. However such mandated data collection can then continue for years or even decades after the program has been demonstrably successful (Sherman et al., 2015; Strathdee & Beyrer, 2015). In addition to government entities mandating data collection, funding entities also often require data collection as a condition for funding (in many parts of the US, syringe distribution is funded in whole or in part via private foundations and donations rather than via public funding).

In this paper, we describe results from a survey of SDPs across the United States, focusing on the types of data being collected at SDPs, whether data collection was mandated by an external agency, and what uses those data were being put to, if any. The purpose of the survey was, in part, to explore unintended consequences of continuous data collection on the ability of SDPs to provide services to vulnerable populations. The paper ultimately derives from a series of conversations between the first author (who has served as the chair or member of the advisory boards of three Californian SDPs over the past 15 years) and three executive directors of SDPs in different parts of the country, in which those EDs spontaneously brought up what they felt to be problematic impacts of mandated data collection on their programs and on their program service users. We then discuss these findings and suggest a research ethics framework as one way to determine what data can or should be collected at the point of service delivery.

Methods

The United States has approximately 250 active SDPs providing services in almost every state (NASEN | North American Syringe Exchange Network, n.d.), despite being legally sanctioned in only 33 states (Center for Public Health Research, Temple University, n.d.). A brief email describing the study and containing a link to an online survey was sent to all known SDPs across the United States (contact emails were either already known to the first author through previous work relating to overdose prevention (~50) or obtained from a publicly available list maintained by the North American Syringe Exchange Network

(NASEN | North American Syringe Exchange Network, n.d.)). The same email was also sent to three email mailing lists used by SDPs in the United States to discuss best practices and organize advocacy, and finally was posted by the first author on social media. After approximately a month of data collection, initial responses were organized by state and a second followup email was sent to the contact email addresses of SDPs located in states from which no responses had been received. The survey was closed to new responses after 6 months. All surveys were completed between January and July 2018.

Surveys were conducted using Limesurvey v3.5 (Limesurvey GmbH, n.d.), an open source web-based survey software package, hosted on a server maintained by the University of California, San Diego. The online survey contained 35 questions (see Appendix 1), and included questions on the basic characteristics of the SDP (including the state in which the program was located, the size of the program by volume of syringes distributed, and the main source of funding for the program); what (if any) data was being collected from or about service users; whether data collection was mandated by an external entity; where data was being reported to; and what was known about the uses to which external agencies put the data. Univariate data are presented below.

The survey also included two open ended questions about the perceived impacts of data collection requirements on the willingness of people who use drugs to access the program, and on the impacts of data collection requirements on any other aspect of program operations. These qualitative data were gathered into a single document, read through in their entirety, then coded on a sentence-by-sentence basis into thematic categories that emerged from the data.

The survey was designed to take less than ten minutes to complete. After completing the survey, participants were offered the choice of providing unlinked contact information to allow the authors to send them study results and to contact them in the future for a planned follow-up study. The only potentially identifying information collected was the state in which the program was located and the IP address of the computer from which the survey was completed. After the survey was closed, the survey data set was checked for duplicate IP addresses (which could have indicated inadvertent duplicate responses from the same organization), however no duplicates were found. IP addresses were then deleted from the data set.

Ethics approval for this study was granted by the Institutional Review Board of the University of California, San Diego.

Results

Sixty three surveys were completed between January and July, 2018.

Program and Respondent Characteristics

Twenty seven states were represented in the sample. Almost all of the individuals completing the survey (n = 59; 93·7%) self-reported holding a senior leadership role in their organization (executive director or equivalent). In discussing this project with SDP workers prior to designing the survey, several expressed an interest in knowing what proportion of SDPs in the United States were led by women; in this survey slightly over half of respondents stated the SDP was led by a person identifying as female (n=37, 58·7%), with 19 (30·2%) being led by people identifying as male, 3 (4·8%) being led by people with non-binary gender identities, and 2 (3·2%) having collective or joint leadership.

Of the represented SDPs, 33 (52·4%) were part of a larger organization that served people other than people who use drugs and 30 (47·6%) were stand-alone programs that almost entirely served people who use drugs. SDPs varied considerably in size, distributing syringes to between 3 and 800 people per week (median 80). Respondents were asked the main source of funding for syringe distribution. Twelve (19·0%) were funded by a city or county government; 12 (19·0%) by a state government; 19 (30·2%) by private foundations; 11 (17·5%) by donations; and the remaining 9 (14·3%) by unspecified other means. Note that in the United States, federal law prohibits federal funding being used to “provide individuals with hypodermic needles or syringes so that such individuals may use illegal drugs” (Use of funds to supply hypodermic needles or syringes for illegal drug use; prohibition 42 USC §300ee-5, n.d.)

Collection of data by programs

Almost all responding SDPs collected some form of data from or about service users (n=60; 95·2%), with most (n=52; 86·7%) collecting data in ways which involved directly questioning service users, e.g., by asking them their age or what drugs they had used recently (see Table 1 for data types collected). An additional 7 SDPs (11·7%) collected only data that did not require directly asking service users for information, e.g., by counting the number of individuals served and how many syringes had been distributed to them. When asked if data collection was required by an external entity, 46 (76·7%) stated they were required to collect data by either a funding organization as a condition of receiving funding, by a government entity as a condition of legal authorization to operate, or both (2 were required to collect data solely as a condition of legal authorization, 18 were required solely as a condition of receiving funding, and 26 were required to collect data as both a condition of funding and as a condition of legal authorization). Note that for 24 SDPs their primary source of funding was a government entity, all of which collected data, however 2 of these 24 stated they were not required to do so as a condition of either funding or legal authorization. 13 responding SDPs (20·6%) collected data without being required to do so as a condition of funding or legal authorization. Only 3 (4·8%) responding SDPs did not collect any form of data from or about service users.

To evaluate possible regional variation, responses to two questions (main source of funding and whether the program was mandated to collect data) were grouped by U.S. Census Region (West, Midwest, Northeast, and South, data not shown). No obvious regional variation was noted, and no further stratification of response by geographic region was attempted, however our sample size is small enough that such regional differences may still exist.

Uses for data

Respondents were asked if the SDP itself used any of the data they collected for any internal purpose, or if it was solely collected for reporting to external entities. Respondents who had indicated they were mandated by an external agency to collect data were also asked if that external agency a) told them what the data was used for, and b) if the external agency ever reported back to them findings or summaries or other outputs from data analysis.

Of the 44 respondents who stated that at least some of the data they collected was used by the organization itself, the most common uses of data were improving services (n = 40; 90·9%), writing new grant applications for more funding (n = 37; 84·1%) and ordering supplies (n = 33; 75·0%). Of the 14 respondents who stated that they collected data despite not having a formal requirement to do so, in at least two cases data was being reported to an external governmental entity. In 6 cases (10%), the data was not being used by the responding SDP *or* being reported to any external body.

Of the 46 respondents who were mandated to collect data by an external entity as a condition of authorization to operate, or as a condition of funding, or both, only 10 (21·7%) stated that the external agency “report[s] anything back to you which comes from the data you give them.” For 7 of the 10, the external entity was a government agency.

Of the 18 respondents who stated that the agency to whom they reported told them what the data were used for, the most common reasons given were to report to upstream funders (for foundations) and/or justify budget allocations (for government entities). Other reasons given included public health surveillance, evaluating grant impacts, and advocating for policy change. Of the smaller number of respondents who described receiving some form of report back of data or analysis, the most common report back was simply aggregate data from the program itself. In three cases, this aggregate data included data from other SDPs or other surveillance efforts in the state, allowing the agency to see their role and contributions in larger public health efforts.

Program Burden

On average, participating SDPs distributed syringes to 145 clients per week. Per client, SDPs spent an average of 4 minutes collecting data from each client. They averaged 9·6 hours a week on data collection and 10·7 hours a week on other data-related activities such as entering data into electronic systems or preparing data for reporting to governments or funders.

18 respondents (30·0%) reported that a requirement to collect data (whether externally mandated or not) impacted who they could recruit as front-line staff or volunteers. The two most common issues cited in open ended responses were the need for staff or volunteers to be able to read and write in English in order to assist in mandated data collection (6 of 18, 33·3%), and the need for staff or volunteers to be sufficiently computer-literate to be able to accurately enter data in computer-based forms (6 of 18, 33·3%). In some cases, respondents explicitly noted that these requirements meant they were unable to have some otherwise suitable members of the population being served work for the program as volunteers or paid staff.

The other major concern 36 of the 60 participating SDPs (60·0%) had about mandated data collection was that it might act as a barrier for service users to access services. 22 of the 36 SDPs (61·1%) indicated that many clients were reticent to answer questions for fear that the data would not remain anonymous or that law enforcement would have access to their information.

Qualitative comments

Respondents were invited to leave open-ended comments following quantitative questions about burdens caused by data collection, and to respond to a general open-ended question at the end of the survey asking for any additional comments about any of the topics raised. Most respondents entered responses to both questions (41 of 63, 65·1%).

Overall, answers to open ended questions mirrored quantitative answers – a small number of respondents described value or utility for their SDP in collecting data (whether mandated or not) but most used the space to list ways in which data collection was a burden or did actual harm to service delivery. Even where respondents reported useful outcomes from data collection, most respondents described the positive role data collection and reporting had in terms of its utility in obtaining funding and in maintaining good relations with funders, or the value of having data to support efforts to advocate for policy change. Only two SDPs described asking questions of service users for the explicit purpose of answering a question the SDP itself had about the needs of their users or the changing environment in which they were operating, for example by asking questions about the prevalence of synthetic opioid use or about non-medical prescription opioid use.

The vast majority of responses to open ended questions about the impact of data collection on service delivery saw data collection in negative terms. These negative comments fell into three loose categories: harming relationships with service users; logistic burdens and lack of in-house expertise; and the weaknesses of the data.

Respondents described data collection as invasive of service user privacy (one respondent also explicitly criticized an unnamed foundation which routinely asks agencies to report the HIV status and sexual identity of agency board members as part of their funding applications, with the respondent clearly regarding this as an invasive abuse of power), and described how such questions erode the trust of existing service users, deter new service users, and may prevent some individuals from using the service at all.

Several described the considerable time burdens of data entry, noting “we often have to decide between providing the service or spending time in the office to enter data.” Respondents described their lack of in-house expertise in data management, which added to the burden of successfully collecting and reporting data. One respondent explicitly noted that they “don’t have the security to collect data like that [i.e., protected health information] and protect clients.” Others complained about funders repeatedly changing data requirements and collection systems without input from the service level staff expected to use new systems, placing a repeated and ongoing training burden on agencies.

Finally, several made comments which collectively point to the weaknesses of data collected solely due to external mandates: stating that program staff frequently guessed or estimated data to reduce the burdens associated with data collection and/or because they had no investment in the accuracy of the data as they never saw it again; that service users might or did routinely give inaccurate information out of paranoia or fear; and that language barriers, while not necessarily a barrier to distributing syringes, are a significant barrier for data collection.

Discussion

We surveyed 63 SDPs whose primary goal is to distribute syringes to people who use drugs to reduce the spread of blood borne viruses and reduce other harms related to injecting with non-sterile equipment. 95·2% of respondents reported that their SDP collected data on service users with 76·7% reporting that they were required to collect such data as a condition of legal authority to operate or a condition of funding or both. However less than a quarter (21·7%) of SDPs mandated to collect data received any information back from mandating entities on how the data was being used. 86·7% collected data directly from service users, although most (82·7%) did so ‘anonymously’, i.e., without collecting explicit identifiers. Respondents described non-trivial negative impacts of data collection on service delivery, including reducing trust with a hard to reach population at high risk for HIV and other blood borne viruses (the very purpose of establishing such programs as distinct from ‘traditional’ health care organizations in the first place), and logistic burdens on programs. Respondents also alluded to or explicitly reflected on the fact that where data collection is externally mandated and is not of direct use to the SDP, front-line staff have little incentive to ensure accurate data collection and hence data collected under these circumstances may be so inaccurate as to be of dubious value for their putative purpose of driving funding and policy decisions.

The survey has a number of limitations. Response rates were relatively low – 63 out of approximately 250 known SDPs (approximately 25%) – which may mean the sample is not representative. The professional and personal connections between the first author and some prospective participants may have influenced who chose to respond and potentially how they responded. Likewise, the use of social media as one way to advertise the survey may have influenced who responded and potentially how they responded. In particular, SDPs where data collection is seen as particularly burdensome or problematic may have been more likely to respond to a survey seeking to document such burdens. However even if this is the case, these survey results still reflect a nontrivial absolute number of SDPs for whom mandated data collection is experienced as problematic. As the survey was conducted on the internet, and as we did not collect identifying information, we had no way to verify if people completing the survey were senior enough in their organizations to be able to answer questions about data collection and use accurately, or even if a given respondent was currently associated with an active program.

Understanding data collection

A number of reasons for collecting data at the point of service delivery were given by respondents. Among those who described making use of collected data internally, these included improving services, ordering supplies, and writing new grant applications. Among those reporting data to an external agency who had some knowledge of what uses the external agency put the data to, the single most common use was, in essence, to justify future funding (either by reporting to upstream funders for foundations, or to justify budget allocations for government entities). Other uses given by external agencies included public health surveillance, evaluating the impacts of grants, and advocating for policy change.

One framework for understanding the reasoning behind data collection at the point of service is provided by the literature on ‘audit culture’. Audit culture has been defined as “the process by which the principles and techniques of accountancy and financial management are applied to the governance of people and organisations – and, more importantly, the social and cultural consequences of that translation.” (Shore & Wright, 2015, p. 24) Audit culture literature has previously been applied to data collection at SDPs by Wolfson-Stofko et al, who draw attention to the fact that the data funders and others typically require of SDPs is almost always individual level data: “—like the number of syringes and condoms distributed, the number of referrals to detox, or the number of people who are tested for HIV —rather than community-level indices that represent the wider culture of drug use.” (Wolfson-Stofko et al., 2016, p. 405). However, collecting such metrics does not seem to be convincing to those opposed to syringe distribution on moral or other non-science based grounds – in 2018 alone two programs with extensive data collection were shut down in the United States, one in Orange County California (Brazil, 2018), and one in Kanawha County, West Virginia (Katz, 2018) (in the latter case, the adjacent county subsequently became the center of a HIV cluster among people who use drugs (Herald-Dispatch, 2019)).

Others writing within an audit culture framework have noted that externally mandated data collection tends to devalue aspects of service provision which cannot easily be quantified (e.g., the building of effective trust relationships with service users), “even if the unmeasurable is what is ultimately the most important to patients.” (Adams, 2016, p. 81) Likewise, in our data, none of the respondents describe collecting data which could, for example, be used to describe the impact of their program’s existence on reducing the experience of stigma among people who use drugs, or the impact of their program on changing narratives about the most appropriate ways of responding to drug use in the community, or any other structural or community-level question relating to the impacts of overarching policy approaches to drug use, such as criminalisation and supply reduction. Worse still, the kinds of data most SDPs described collecting (see Table 1) are poor indicators of the *quality* of the relationship between the SDP and those it serves – an SDP whose staff regularly treat service users in stigmatizing or demeaning ways and which regularly attempts to make inappropriately-timed referrals to other services such as drug treatment could easily look superior by metrics such as ‘how many people did you refer to drug treatment’ than an SDP which is deeply grounded in and responsive to the community it serves.

While the audit culture framework provides valuable insight into the reasons externally mandated data collection occurs and even why some types of data are collected rather than others, its focus on the power relations present in such situations and on the aims and ends of those mandating data collection runs the risk of obscuring agency on the part of SDPs and the ways the act of collecting data can be used by SDPs (whether mandated or not). As an example, one of the great successes of syringe distribution has been the well-documented impact of SDPs on HIV incidence rates (Wodak & Cooney, 2006). Given the contentious nature of syringe distribution in many parts of the world, such research findings provide valuable justifications for the continued existence of existing programs and the introduction of new programs. We suggest that in at least some cases, data collection at the point of service delivery can act as a way of symbolically incorporating or at least linking the program to the broader world of 'legitimate' empirically practiced public health, even if the data itself is not being used for any meaningful purpose. In our data, 6 respondents (10%) described collecting individual-level data from service users despite not using that data for any purpose themselves and not reporting it to any external entity, which makes little sense unless the *practice* of data collection itself had value, such as helping to construct and locate the SDPs concerned as being a legitimate component of 'public health'. In earlier work of some of our team on NIMBYism and syringe distribution, we noted that one argument sometimes used by opponents of a specific program was to attack its legitimacy by accusing it of not following 'correct' public health practices by, for example, not limiting the number of syringes distributed per person where local ordinance required a limit (Davidson & Howe, 2014).

A research ethics framework

We would like to suggest an alternative framework to assist SDPs (and those who fund or provide legal authorization for them) in deciding what data (if any) should be collected and how that data should be collected, namely, a 'research ethics' framework.

In research settings, ethics approval to collect data from humans is predicated in part on a risk analysis which examines the potential risks associated with data collection and compares those to the potential benefits of the research. Proposed data collection which carries risks substantially in excess of any putative benefit is not ethical. While service providers collecting data for the purpose of evaluating and improving their own service delivery do not fall under US Federal Regulations governing human subjects research, we suggest that the same basic ethical principle that data collection should not in itself cause harm or risk of harm out of proportion to the putative benefit can and should still hold.

As such, while data collection at SDPs may be ethically acceptable when the data is being used for a valid scientific or program improvement purpose and where the benefits of the research or program improvement are commensurate with the risks to individuals and to service delivery, data collection with no explicit purpose could be regarded as inherently unethical, and data collection with known harms whose only explicit purpose is an audit-culture oriented 'documenting for the sake of documenting' should similarly be considered inherently unethical.

Syringe distribution programs are an essential public health tool for reducing the spread of HIV and other blood borne viruses, and are a critical part of responding to the current opioid crisis. They exist to serve populations at high risk who are not being reached effectively by other health services. Our survey results suggest that mandating data collection from users of such services as a condition of either funding or legal authorization may act as barriers to service provision, and that the purpose of such data collection should be careful considered and regularly reviewed to ensure data collected is being put to meaningful purpose. We suggest that best practices should require that where funders or government entities mandate data collection from syringe distribution programs, those entities should, as a bare minimum, provide a clear and transparent explanation as to what purpose the data is used for. Data collection mandates should be periodically reviewed to ensure the original purpose of the data collection is still valid, and that the minimum amount of data is collected which can meet that purpose. This latter point includes both checking every variable being collected has actual utility, and that consideration be given to restricting data collection to variables which can be collected without directly questioning service users (e.g., number of syringes distributed per person). Likewise, consideration should be given to conducting periodic data collection rather than continuous data collection (e.g., by having a two week period where data is collected every three months, allowing the same ongoing monitoring of changes to the service environment provided by continuous data collection without the burden to the program and to service users of continuous data collection).

Finally, this preliminary exploration of impacts of data collection on SDP service delivery relied entirely on the perspectives of the senior leadership of SDPs; future research in this area needs to include the perspectives of people SDPs are intended to serve, including both those who currently use such services and those who are not willing to use such services.

Supplementary Material

Refer to Web version on PubMed Central for supplementary material.

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Bibliography

Adams V (Ed.). (2016). Metrics: what counts in global health. Duke University Press.

Brazil B (2018, 2 1). Orange County's only needle exchange shuts down after Santa Ana denies permit. Los Angeles Times. https://www.latimes.com/socal/daily-pilot/news/tn-wknd-et-oc-needle-exchange-20180201-story.html

Center for Public Health Research, Temple University. (n.d.). Syringe Distribution Laws. Retrieved November 13, 2018, from http://lawatlas.org/datasets/syringe-policies-laws-regulating-non-retail-distribution-of-drug-paraphernа

Davidson PJ, & Howe M (2014). Beyond NIMBYism: Understanding community antipathy toward needle distribution services. International Journal of Drug Policy, 25(3), 624–632. 10.1016/j.drugpo.2013.10.012 [PubMed: 24309432]

Herald-Dispatch BNT (2019, 3 5). HIV cluster confirmed in Cabell County. Charleston Gazette-Mail. https://www.wvgazettemail.com/news/health/hiv-cluster-confirmed-in-cabell-county/article_4a53f052-af0e-5172-83e4-faab25ccfc82.html

Katz J (2018, 4 27). Why a City at the Center of the Opioid Crisis Gave Up a Tool to Fight It. The New York Times. https://www.nytimes.com/interactive/2018/04/27/upshot/charleston-opioid-crisis-needle-exchange.html, https://www.nytimes.com/interactive/2018/04/27/upshot/charleston-opioid-crisis-needle-exchange.html

Limesurvey GmbH. (n.d.). LimeSurvey. Retrieved February 4, 2016, from https://www.limesurvey.org/

NASEN | North American Syringe Exchange Network. (n.d.). Retrieved June 26, 2018, from https://nasen.org/

Sherman SG, Patel SA, Ramachandran DV, Galai N, Chaulk P, Serio-Chapman C, & Gindi RM (2015). Consequences of a restrictive syringe exchange policy on utilisation patterns of a syringe exchange program in Baltimore, Maryland: Implications for HIV risk. Drug and Alcohol Review, 34(6), 637–644. 10.1111/dar.12276 [PubMed: 25919590]

Shore C, & Wright S (2015). Governing by numbers: audit culture, rankings and the new world order. Social Anthropology, 23(1), 22–28. 10.1111/1469-8676.12098

Strathdee SA, & Beyrer C (2015). Threading the Needle — How to Stop the HIV Outbreak in Rural Indiana. New England Journal of Medicine, 373(5), 397–399. 10.1056/NEJMp1507252 [PubMed: 26106947]

Use of funds to supply hypodermic needles or syringes for illegal drug use; prohibition. 42 USC §300ee-5, Pub. L. No. 42 USC §300ee-5, §300ee-5 42 USC.

Wodak A, & Cooney A (2005). Effectiveness of sterile needle and syringe programmes. International Journal of Drug Policy, 16(Supplement 1), 31–44. 10.1016/j.drugpo.2005.02.004

Wodak A, & Cooney A (2006). Do Needle Syringe Programs Reduce HIV Infection Among Injecting Drug Users: A Comprehensive Review of the International Evidence. Substance Use & Misuse, 41(6–7), 777–813. 10.1080/10826080600669579 [PubMed: 16809167]

Wolfson-Stofko B, Curtis R, Fuentes F, Manchess E, Del Rio-Cumba A, & Bennett AS (2016). 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(4), 395–410. 10.1007/s10624-016-9443-4 [PubMed: 27917016]

Table 1:

Types of data collected (Note: 12 ‘Other’ responses re-coded)

Data type (n=60)	Number of SDPs collecting this data n (%)
Other services you provided to that person, such as naloxone, other medical or social services, or referrals to other services	60 (100)
Number of syringes given out and/or brought in	57 (95·0)
Basic demographics, such as age, gender, ethnicity	53 (88·3)
A non-identifying unique identifier, such as a membership number or letters from their name or date of birth	40 (66·7)
Information about behaviors, such as how often someone is injecting drugs, or what drugs they’re using or whether they’ve overdosed recently or been in drug treatment recently	32 (53·3)
Information about other parts of peoples lives, such as whether they’ve been arrested recently, or used a ER recently	21 (35·0)
Information about whether the person has been in drug treatment recently	15 (25·0)
Personally identifying information, such as names or dates of birth	9 (15·0)
Other	3 (5·0)

Table 2:

Uses of data and respondent knowledge of external uses of data

	SDP uses data for internal purposes n(%)	External mandating organization describes purpose for which data is used n (%)	External mandating organization reports back data or analysis to program n (%)
Data collection mandated for legal authorization only (n=2)	0 (0·0)	1 (50·0)	1 (50·0)
Data collection mandated for funding only (n=18)	15 (83·3)	4 (22·2)	2 (11·1)
Data collection mandated for both funding and authorization (n=26)	22 (84·6)	11 (42·3)	5 (19·2)
Data collection not mandated but still conducted (n=14)	7 (50·0)	2 (14·2)	2 (14·2)
Total (n=60)	44 (73·3)	18 (30·0)	10 (16·7)