



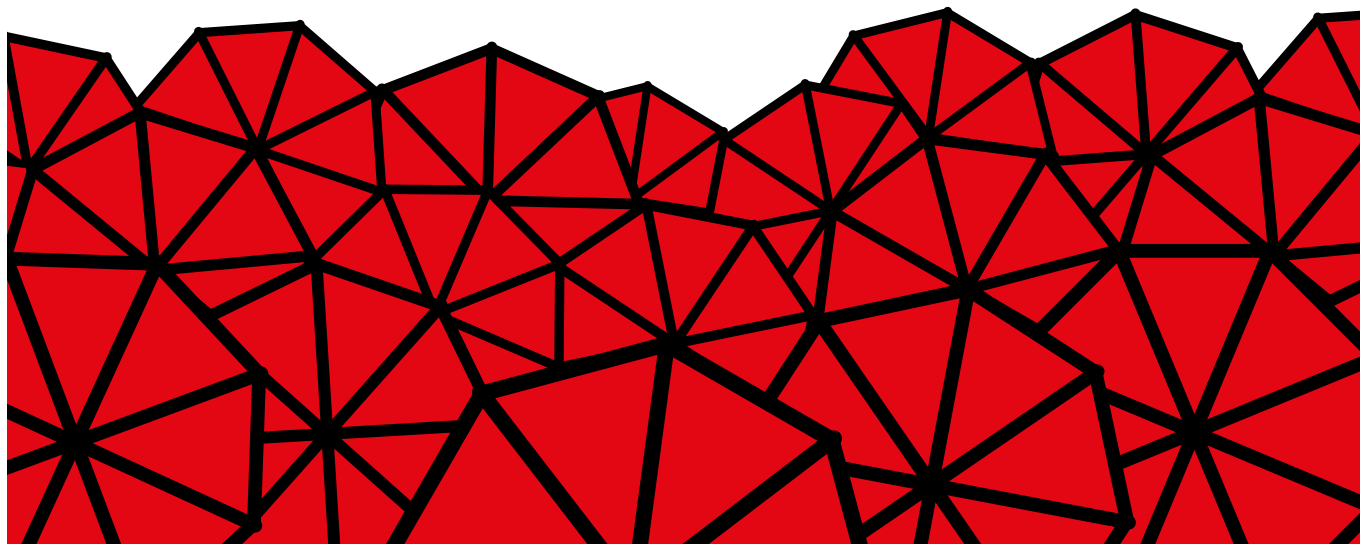
nswp

Global Network of Sex Work Projects
Promoting Health and Human Rights

POLICY BRIEF

Mapping and Population Size Estimates of Sex Workers

**PROCEED WITH
EXTREME CAUTION**



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Introduction

The social, legal and policy environments in which sex workers operate often place them at higher risk of HIV infection. Consequently, the past few decades has seen sex workers and particularly female sex workers become the subject of intensified public health and epidemiological scrutiny. Indeed, female sex workers are routinely associated in research and public discussions with a significant portion of the global HIV burden.^{1, 2, 3, 4} The overall prevalence of HIV among female sex workers in 50 countries is 12% higher than in the general population of women. The probability for female sex workers of getting HIV is 13.5 higher than that of women not involved in sex work.⁵ There are many reasons for this, which include unsafe working conditions, unequal access to health services, and barriers in negotiating condom use. Importantly, sex workers and their communities have faced a disproportionate burden of HIV since the beginning of the epidemic.⁶

More recently, the practices of mapping the places where sex workers live and work, and creating population size estimates, are becoming increasingly routine for community-based organisations, programmers and epidemiologists both at the level of individual programmes and through the creation of national or local population size estimates. In many cases, programmers concentrate on commissioning mapping and population size estimates merely to accumulate more data without plans to provide services. This uses up precious resources which could be used to provide services which actually have an impact upon HIV incidence and prevalence. While these practices have existed in various forms for decades within sex worker-led organisations, they are becoming more common and are often used in ways that negatively impact upon the safety, confidentiality and well-being of sex workers. It is important to note that local mapping for programme planning can inform service delivery directly. That is not the case with mapping done at the national or regional level or with population size estimates that are increasingly used.

- 1 Prüss-Ustün, A., Wolf, J., Driscoll, T., Degenhardt, L., Neira, M., & Calleja, J. M. G. (2013). HIV Due to Female Sex Work: Regional and Global Estimates. *PLoS ONE*, 8(5), e63476.
- 2 Halli, S. S., Ramesh, B. M., O'Neil, J., Moses, S., & Blanchard, J. F. (2006). The role of collectives in STI and HIV/AIDS prevention among female sex workers in Karnataka, India. *AIDS Care*, 18(7), 739–749.
- 3 World Health Organization, United Nations Population Fund, Joint United Nations Programme on HIV/AIDS, Global Network of Sex Work Projects, The World Bank. (2013) Implementing comprehensive HIV/STI programmes with sex workers: practical approaches from collaborative interventions. Geneva, World Health Organization.
- 4 Baral, S., Beyrer, C., Muessig, K., Poteat, T., Wirtz, A. L., Decker, M. R., . . . Kerrigan, D. (2012). Burden of HIV among female sex workers in low-income and middle-income countries: a systematic review and meta-analysis. *The Lancet Infectious Diseases*, 12(7), 538–549.
- 5 Baral, S., Beyrer, C., Muessig, K., Poteat, T., Wirtz, A. L., Decker, M. R., . . . Kerrigan, D. (2012). Burden of HIV among female sex workers in low-income and middle-income countries: a systematic review and meta-analysis. *The Lancet Infectious Diseases*, 12(7), 538–549.
- 6 World Health Organization, United Nations Population Fund, Joint United Nations Programme on HIV/AIDS, Global Network of Sex Work Projects, The World Bank. (2013) Implementing comprehensive HIV/STI programmes with sex workers: practical approaches from collaborative interventions. Geneva, World Health Organization.

The techniques that they use include documenting the specific places and times where sex workers live and work, and where 'risky' behaviours occur.

Recently, organisations such as The Global Fund, the World Bank and government ministries throughout Asia and West Africa have used **geographical mapping** and counting (often referred to as '**enumeration**') of key populations to inform how HIV prevention funding is allocated. The techniques that they use include documenting the specific places and times where sex workers live and work, and where 'risky' behaviours occur. This is happening even in countries where the prevalence of HIV is relatively low.⁷

This paper offers an overview and critique of mapping, population size estimates and **unique identifier codes** and how they are used. Some of the threats associated with these practices, and the strategies that are used to keep people safe and data confidential and secure, are discussed.

Definitions

- ▶ **Epidemiology:** "Studies of the way diseases are distributed in populations and of the factors that influence this distribution".⁸ To identify risk factors and health outcomes, epidemiology uses statistical and screening tools to monitor health conditions and diseases in certain populations.
- ▶ **Epidemiological mapping:** Set of techniques that situate demographic, environmental, behavioural, socio-economic, genetic, and infection risk factors in relation to physical space and populations. This can be geographical mapping of cases of diseases, of locations where high-risk activities may occur for a specific illness or disease, or of locations where health services providers are located.
- ▶ **Geographical mapping or Geo-mapping:** A type of epidemiological mapping that links specific geographical locations to health outcome, risks or status. For example, a neighbourhood where the population generally has fewer economic resources may be related to poorer health outcomes. When it comes to sex workers, epidemiological mapping has been used to indicate on maps where sex workers work, and sometimes where they live, in an effort to locate places where people are at 'high risk' for HIV and other STI transmission.
- ▶ **Population size estimates and enumeration:** Measures that estimate the size of a group of individuals in a specific geographical location, for the purpose of health monitoring and surveillance, using specialised mathematical methods. The word 'enumeration' is often used to describe the counting of each member of a population. That information can be used to plan programmes and service delivery.
- ▶ **Unique identifier codes:** Unique code made of numbers and/or letters used to link individual data to demographic information and other information like health status or health services use. Some variations of unique identifier codes have included biometrics such as fingerprints and retinal scans, which are human rights violations.
- ▶ **Hotspot:** Locations where 'high-risk' activities take place identified through the process of geographical mapping.

⁷ Lorway, R., & Khan, S. (2014). Reassembling epidemiology: Mapping, monitoring and making-up people in the context of HIV prevention in India. *Social Science & Medicine*, 112(0), 51–62.

⁸ Gordis, L. (2009). *Epidemiology*. Philadelphia: Elsevier/Saunders, pp: 3

Mapping and population size estimates

Mapping and the different methodologies it is associated with (such as population size estimates and codes to identify the individuals associated with them) is a tool that has traditionally been used in public health and **epidemiology** to understand the geographic characteristics and distribution of diseases. In recent years, the growing focus on the importance of place and context in HIV and harm reduction has contributed to the increased usage of epidemiological mapping amongst epidemiologists and other academic researchers, funding agencies and sometimes community-based organisations.^{9, 10, 11, 12}

The World Health Organization (WHO), together with UNFPA, UNAIDS, UNDP, NSWP and the World Bank produced in 2013 *Implementing comprehensive HIV/STI programmes with sex workers: practical approaches from collaborative interventions*.¹³ Commonly referred to as the *Sex Worker Implementation Tool (SWIT)*, it was created to detail ways to implement WHO's 2012 recommendations on HIV and sex work.¹⁴ This document emphasises the importance of implementation at a grassroots level, led by local sex workers and sex worker-led organisations. It describes these methods as a step in the development of community-led outreach for sex workers. These methods can be used to develop an effective outreach programme that provides “acceptable and accessible services to the greatest

possible number of community members”. The SWIT emphasises that mapping must be done in a way that respects the needs and safety of sex workers, with local sex workers involved in, indeed leading, the mapping. It also states that the information must be considered confidential, to “guard against the possibility of maps being obtained by law enforcement authorities or other groups who might use them to locate and close sites or otherwise cause harm to sex workers.” Local mapping should be for service delivery use, and not mapping for population size estimates at a national or even regional level. It cautions against sharing collected information that could be used to harm sex workers.

In 2015, WHO produced *Consolidated strategic information guidelines for HIV in the health sector*¹⁵. It recommends the use of population size estimates of key populations affected by HIV/AIDS at regional and national levels to develop and scale-up HIV prevention, treatment and care. Sex workers are one of the populations identified. The methods are presented as helping resource allocation, advocacy and tracking of indicators. While the report does discuss the importance of considering the safety of sex workers and other members of the identified key population when it comes to disclosure, it does not address the dangers associated with such detailed information being collected by government agencies. No discussions of the risks associated with mapping and population size estimates in comparison to their advantages for sex workers is presented. These methods are presented as the only way to effectively plan for HIV-related health services for key populations, and no alternatives are discussed.

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9 Ferguson, A. G., & Morris, C. N. (2007). Mapping transactional sex on the Northern Corridor highway in Kenya. *Health & Place*, 13(2), 504–519.

10 Fulcher, C., & Kaukinen, C. (2005). Mapping and visualizing the location HIV service providers: An exploratory spatial analysis of Toronto neighbourhoods. *AIDS Care*, 17(3), 386–396.

11 Kaukinen, C., & Fulcher, C. (2006). Mapping the social demography and location of HIV services across Toronto neighbourhoods. *Health & Social Care in the Community*, 14(1), 37–48.

12 Weir, S. S., Pailman, C., Mahlalela, X., Coetzee, N., Meidany, F., & Boerma, J. T. (2003). From people to places: Focusing AIDS prevention efforts where it matters most. *Aids*, 17(6), 895–903.

13 World Health Organization, United Nations Population Fund, Joint United Nations Programme on HIV/AIDS, Global Network of Sex Work Projects, The World Bank. (2013) *Implementing comprehensive HIV/STI programmes with sex workers: practical approaches from collaborative interventions*. Geneva, World Health Organization.

14 World Health Organization, United Nations Population Fund, Global Network of Sex Work Projects, The World Bank. (2012). *Prevention and treatment of HIV and other sexually transmitted infections for sex workers in low- and middle-income countries: recommendations for a public health approach*. Geneva, World Health Organization.

15 World Health Organization. (2015). *Consolidated strategic information guidelines for HIV in the health sector*. Geneva, World Health Organization.

It is more problematic when mapping is done for the sole purpose of producing population size estimates without any intention to improve service delivery.

The data from population size estimates relies upon the identification, enumeration and geographical mapping of people who are *assumed* to be at high risk for HIV and other infections in the geographical area that they focus on. The way that they apply the same level of potential risk to a whole population can be problematic, especially if confidentiality is not

respected. It is more problematic when mapping is done for the sole purpose of producing population size estimates without any intention to improve service delivery.

Population size estimates use a variety of different methods to get to a number that is considered a valid estimation of the population. Population size estimates that focus on sex workers communities are based on data collected from the key population directly, even when they are done at the national level.¹⁶ The method known as

‘capture-recapture’ is an indirect estimation of the size of a population. It looks at different sources of information on the size of the population, evaluates the degree of overlap between them using statistical tools to get an estimate of the total population.^{17, 18} Two other methods that are commonly used are census and enumerations. A census counts all members of the population. An enumeration will map an area, count a fraction of the population in a selected area and will extrapolate from the number found to create an estimate.¹⁹ Finally, a method called ‘multiplier’ is also commonly used and works by comparing two independent sources of data on the population and estimating the total number in the population.²⁰

‘Geo-mapping’ is used in many contexts in health research. It is used to record the locations where people engage in ‘high-risk’ behaviour, but also where harm reduction and care services are provided. In Cape Town, for example, a research project on targeted HIV prevention used mapping to identify condom availability and new sites where people look for sexual partners.²¹ In the Canadian city of Toronto, a mapping of HIV service providers identified characteristics of the populations in neighbourhoods where there was less access to these services with the purpose of improving services. These neighbourhoods were associated with concentrated economic disadvantage, concentrated immigration and residential instability.²²

The SWIT recommends that sex worker-led organisations, wherever they exist, should be consulted in the planning and process of mapping. Involving other key informant such as brothel or bar owners and managers must only be done in a way that will not endanger sex workers. Extreme care must be taken with whom has access to the maps containing information about the location and identity of sex workers. It highlights the fact that “the programme would lose the trust of the community” if the confidential materials were disclosed. If the information gathered through mapping was distributed or leaked, sex workers’ safety and well-being would be threatened. This is why it is crucial that the information is kept safe by sex worker-led organisations, but also by the health programmers and researchers associated with these programmes.

16 World Health Organization. (2010). *Guidelines on Estimating the Size of Populations Most at Risk to HIV*. Geneva, World Health Organization.

17 Chao, A., Tsay, P. K., Lin, S. H., Shau, W. Y., & Chao, D. Y. (2001). The applications of capture-recapture models to epidemiological data. *Stat Med*, 20(20), 3123–3157

18 Capture-recapture and multiple-record systems estimation I: History and theoretical development. International Working Group for Disease Monitoring and Forecasting. (1995). *Am J Epidemiol*, 142(10), 1047–1058

19 World Health Organization. (2010). *Guidelines on Estimating the Size of Populations Most at Risk to HIV*. Geneva, World Health Organization.

20 World Health Organization. (2010). *Guidelines on Estimating the Size of Populations Most at Risk to HIV*. Geneva, World Health Organization.

21 Weir, S. S., Pailman, C., Mahlalela, X., Coetzee, N., Meidany, F., & Boerma, J. T. (2003). From people to places: Focusing AIDS prevention efforts where it matters most. *Aids*, 17(6), 895–903.

22 Kaukinen, C., & Fulcher, C. (2006). Mapping the social demography and location of HIV services across Toronto neighbourhoods. *Health & Social Care in the Community*, 14(1), 37–48.

What are they used for

The geographic and epidemiologic mapping and population size estimation techniques outlined in this paper are used separately or together in many different ways and for varied purposes. It is important to differentiate between population size estimates and mapping exercises that are done by sex worker-led organisations and other community-based organisations for reasons that relate to service provision, and those done at the regional or national level by health authorities or other governmental agencies. This section discusses some of these uses and purposes.

Aside from the obvious goal of estimating of the number of individual sex workers in a certain location, geographical mapping and population size estimates can also be used to identify differences amongst the

members of the group it targets. For example, it was shown that, in Mexico, undocumented migrant sex workers from South America were more commonly found working in cities along the borders than Mexican women, who tended to be more centrally located.²³

The same methodologies can also allow for the identification of underserved groups, subgroups or groups in a population that have not yet been reached by a programme. For example, the

mapping of truck stops along the Northern Corridor Highway in Kenya identified several **hotspots** where sex work was happening and pointed towards 'vulnerable' groups of sex workers who did not have ready access to HIV prevention and other health services.²⁴ Similarly, a study using mapping in Estonia showed that sex work was a lot more common than previously assumed in residential areas, as opposed to the red light districts.²⁵

Finally, the results from these methods can help explain why programmes or services do not reach some of the groups within the sex worker community. A local social mapping research project based in Vancouver, Canada, highlighted the relationship between health service and needle/syringe availability at a geographic level. It showed how certain places were avoided by sex workers due to violence and policing of outdoor female sex work. The displacement of sex workers to more remote, industrial areas pushed women further from health and social supports and reduced access to safer injection and harm reduction materials.²⁶ Understanding the role of certain places and how people think about them, can be crucial to planning programmes and ultimately to designing policies that focus on keeping sex workers safe. This study is part of the Maka Project, which is a community-based HIV prevention research partnership. The community partner and the peer research team, comprised of past and current sex workers, are part of the conception, design and implementation of the research.

...the results from these methods can help explain why programmes or services do not reach some of the groups within the sex worker community.

23 Uribe-Salas, F., Conde-Glez, C. J., Juarez-Figueroa, L., & Hernandez-Castellanos, A. (2003). Socio-Demographic Characteristics and Sex Practices Related to Herpes Simplex Virus Type 2 Infection in Mexican and Central American Female Sex Workers. *Epidemiology and Infection*, 131(2), 859–865.

24 Ferguson, A. G., & Morris, C. N. (2007). Mapping transactional sex on the Northern Corridor highway in Kenya. *Health & Place*, 13(2), 504–519.

25 Aral, S. O., Lawrence, J. S. S., & Uusküla, A. (2006). Sex work in Tallinn, Estonia: the sociospatial penetration of sex work into society. *Sexually Transmitted Infections*, 82(5), 348–353.

26 Shannon, K., Rusch, M., Shoveller, J., Alexson, D., Gibson, K., & Tyndall, M. W. (2008). Mapping violence and policing as an environmental–structural barrier to health service and syringe availability among substance-using women in street-level sex work. *International Journal of Drug Policy*, 19(2), 140–147.

What makes the biggest difference in reducing the potential harms of these techniques and tools is who is using them and who has control over the data...

The techniques and tools that are discussed in this paper could be extremely useful at a local level and give sex worker-led organisations and service providers access to detailed, complex information that would otherwise be very difficult to put together. However, they also

potentially present significant risks to several of the rights of sex workers outlined in the NSWP *Consensus Statement on Sex Work, Human Rights and the Law*, such as the right to health and the right to privacy and freedom from arbitrary intervention.²⁷ These risks are greatly increased when mapping is done by agencies not led by sex workers or without involving sex workers in every step. When sex workers are not involved, information is more likely to be shared with government

agencies (including health and law enforcement). What makes the biggest difference in reducing the potential harms of these techniques and tools is who is using them and who has control over the data: community-based organisations, service providers, national agencies, or anti-sex work organisations.

Unique identifier codes

UICs have been controversial since the beginning of their use within the HIV/AIDS movement²⁸ as well as in the sex workers' rights movement. They are used to link information about a person's identity with other confidential information, such as their health status or their use of healthcare. For sex worker-led organisations and programmes, UICs link data from each individual sex worker to a unique code. The data they commonly link:

- 1 Describe the personal identity and the demographics of the individual such as age, gender, type of sex work practised, length of time in sex work and;
- 2 Detail "baseline" information such as reported condom use in sex work, estimate of partners in a week, whether voluntarily tested for HIV in the last year, etc.

The rationale presented for collecting this particular information is that it will be useful in estimating the harm reduction services and give an idea of the risks for programme planning²⁹.

The more general justification for the use of UICs focuses on their ability to protect the identity of the individual so that their data can be used in analysis and programme planning without any threat to their confidentiality.^{30, 31} They are also described as preventing duplication of data, contributing to adequate identification of new individuals, and assist in reorienting services to meet needs and attendance patterns for programmes.³² While this rationale is consistently present in academic papers and in official guidelines from organisations such as WHO and UNAIDS, there is no clear evidence that UICs actually preserve the confidentiality of sex workers, nor is there any discussion of how the use of UICs benefits individual sex workers directly.

27 NSWP. (2013). *Consensus Statement on Sex Work, Human Rights and the Law*. Edinburgh.

28 Forbes, A. (1997). An Activist's Guide to Unique Identifiers. *The Active Voice*. Act Up. Accessed online on October 6, 2015 at <http://www.actupny.org/alert/names03.html>

29 World Health Organization, United Nations Population Fund, Joint United Nations Programme on HIV/AIDS, Global Network of Sex Work Projects, The World Bank. (2013) Implementing comprehensive HIV/STI programmes with sex workers: practical approaches from collaborative interventions. Geneva, World Health Organization.

30 World Health Organization, United Nations Population Fund, Joint United Nations Programme on HIV/AIDS, Global Network of Sex Work Projects, The World Bank. (2013) Implementing comprehensive HIV/STI programmes with sex workers: practical approaches from collaborative interventions. Geneva, World Health Organization.

31 Forbes, A. (1997). An Activist's Guide to Unique Identifiers. *The Active Voice*. Act Up. Accessed online on October 6, 2015 at <http://www.actupny.org/alert/names03.html>

32 World Health Organization, United Nations Population Fund, Joint United Nations Programme on HIV/AIDS, Global Network of Sex Work Projects, The World Bank. (2013) Implementing comprehensive HIV/STI programmes with sex workers: practical approaches from collaborative interventions. Geneva, World Health Organization.

The current and potential use of biometrics measures in general and for UICs, such as fingerprints, retina scans and other unique physical identifiers are extremely worrisome and constitute human rights violations. Their use is fraught with potential violations of privacy and increases the risks of tracking and profiling sex workers in contexts where they are often criminalised. Additionally, they require a high level of technology, which might not be sustainable for smaller organisations and that could lead to more errors or breaches of confidentiality. Unique physical identifiers could be used to share information or bridge different sources of information without the consent or knowledge of sex workers or in ways that harm sex workers. While this is possible with any information collected, the specificity of biometric measures increases the risks and consequences of those breaches of confidentiality.

Crucially, their use could also deter some individuals from using essential services because of biometrics' association with criminality (e.g. taking fingerprints) or if they decline to provide biometric information.

The 2015 WHO guidelines³³ encourage health care providers to record whether their clients are part of key populations, to better track coverage, with the use of unique identifier codes (UICs). The guidelines do mention that for safety reasons, "routine collection of such information may not be advisable".³⁴

Considering the various contexts in which sex work is entirely or partially criminalised, it is crucial to consider whether the potential benefits to using UICs outweigh their harms.

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If UICs are used at all, access to and storage of this information must be carefully planned to prevent breach of confidentiality both within organisations and with law enforcement or health agencies. In this sense, the 'master list' where all the codes and the information

associated with them is kept is of crucial importance and should be kept in a safe place within sex worker-led organisations, with limited access and strict guidelines regarding its use.

Threats to safety, confidentiality and well-being

The nature of the information that is gathered by geographical mapping, population size estimates and in some cases UICs, is very sensitive. Any breach in confidentiality can be a direct threat to sex workers' rights to health, safety and privacy. The identification of where sex workers live and work on maps or through publications can lead and has led to harassment and criminalisation. In addition to the risks of increased violence, harassment and social problems such as loss of housing or involvement of social services if the worker has children or other dependants, this can lead to a loss of revenue for sex workers. Furthermore, this can potentially allow for the continued tracking of sex workers by health authorities, law enforcement agencies or anti-sex work groups.

33 World Health Organization. (2015). Consolidated strategic information guidelines for HIV in the health sector. Geneva, World Health Organization.

34 World Health Organization. (2015). Consolidated strategic information guidelines for HIV in the health sector. Geneva, World Health Organization., pp 68.

In Montréal, Canada in 2013, a well-funded anti-sex work organisation, the *Coalition des luttes contre l'exploitation sexuelle* (CLÉS) recklessly mapped out all of the locations of 'sexual exploitation', including exotic dancer clubs, massage parlours, escort agencies and restaurants with 'sexy waitresses', and published it in mainstream newspapers. This directly endangered the livelihoods and safety of sex workers. The map continues to be readily available online over two years after its original publication.

Vignette 1: Kenya

A research project was conducted in Nairobi, Kenya, to estimate the number of sex workers working in the city, using mapping and capture-recapture. Based on this research project an academic article was published in 2013. The article, published in *PLoS One*, not only detailed the results of the study but contained a map that made it evident where the enumeration was conducted and, alarmingly, where sex workers are located. The authors made superficial changes to the map, such as removing street names, but it was still possible for anyone with knowledge of Nairobi to locate the specific locations where sex workers can be found, and in what numbers. After the publication of the article and circulation of the report, there was an increase of negative coverage of sex workers in mainstream media that included the secret and non-consensual filming of sex workers at work. Security agencies conducted raids in some of the hotspots; sex workers and clients were arrested equally. The map was eventually removed from the article, based on the insistence of a collective of international researchers, sex workers, NGOs and public health practitioners from the Global South and the Global North. However, the journal as late as October 2015 still notes that "readers with an academic interest in the information originally displayed in the figure may contact the authors directly in relation to this information". This indicates that the data is still potentially available to anyone who can send an email to the authors.

As this example shows, the production of population size estimates and mapping the places where sex workers live and work has the potential to be a direct, very serious threat to sex workers' rights to be free from

The reckless attitude of the researchers is more proof of the risks associated with mapping and population size estimates.

discrimination, to privacy, and freedom from arbitrary interference. Even though the data was gathered with the consent of the individuals, the way in which it was handled and shared endangered and continues to endanger sex workers. The reckless attitude of the researchers is more proof of the risks associated with mapping and population size estimates. This case raises the question of whether the benefit to developing programmes is worth the risks that are associated with collecting such information. Sex workers should not only have the right to consent to divulging this information individually, but also be made aware of and consent to how their information is used and where it is shared.

Overreliance on statistics

Even putting aside the alarming threats of epidemiological mapping and population size estimates, the methodology used, and its overreliance on statistical methods does not always provide an adequate portrait of what can make sex workers more vulnerable to increased risks of HIV and other STIs.

The concept of 'risk' in epidemiology is often simplified to consider the biological risk associated with sexual practices only. It often neglects to take into account the ways in which policies, laws and stigma shape the specific vulnerabilities that can expose people to more risks in their sexual activities. The political and legal context that criminalises and stigmatises sex workers, and the local organisation of sex work are often just as important in mapping the risks associated with sex work. The use of qualitative methods and data can provide rich information that can inform programme planning or at least complement the quantitative data.

For example, as part of the same Canadian research mentioned above³⁵, focus group discussions, designed and led in collaboration with sex workers, identified the role of social and structural violence and power relations in shaping the HIV risk environment and prevention practices of a sub-group of women in sex work³⁶. An initiative was undertaken in 2007 in Winnipeg, Canada aiming to map locations where people were vulnerable to HIV and other sexually transmitted infections, to assess the type of activities happening there and the number of people involved in these activities³⁷. To get a better understanding of the differences between very diverse neighbourhoods of the city, a qualitative tool was developed to document the community context and to gather information that was otherwise unavailable through the use of statistical mapping methods. The tool recorded information on the communication style, mobility, social norms, community features, culture, economy, police presence, and resources/services available in each of the neighbourhoods. These examples are in no way perfect, but they illustrated the positive ways that qualitative data can render a more accurate portrait of what happens in sex work.

Depending on the methodology used, some estimations are not based on surveying the whole population, but rather on asking some members of the population to estimate how many sex workers work in certain places and when they come there.^{38, 39} While this may provide adequate information in some contexts where no other sources of information is available, it is unclear whether this information is sufficient to inform, initiate or improve service delivery, or if it is even accurate. For example, in situations where sex work is particularly hidden, sex workers themselves may not know where other sex workers work. More importantly, depending on who is conducting the research, sex workers may be very reluctant to share this type of information and may not provide an accurate estimation. Sex workers may want to hide that information for valid reasons that relate to their safety and the safety of their communities.

35 Shannon, K., Rusch, M., Shoveller, J., Alexson, D., Gibson, K., & Tyndall, M. W. (2008). Mapping violence and policing as an environmental-structural barrier to health service and syringe availability among substance-using women in street-level sex work. *International Journal of Drug Policy*, 19(2), 140–147.

36 Shannon, K., Strathdee, S. A. P., Shoveller, J., Rusch, M., Kerr, T., & Tyndall, M. W. M. D. S. (2009). Structural and Environmental Barriers to Condom Use Negotiation With Clients Among Female Sex Workers: Implications for HIV-Prevention Strategies and Policy. *American Journal of Public Health*, 99(4), 659–665.

37 Ormond, M. L. E. (2008). WIN-MAP: A Feasibility Study of Geographic Mapping of Places in Winnipeg with High Levels of HIV-Related Risk Activity. Winnipeg.

38 Emmanuel, F., Blanchard, J., Zaheer, H. A., Reza, T., & Holte-Mckenzie, M. (2010). The HIV/AIDS Surveillance Project mapping approach: An innovative approach for mapping and size estimation for groups at a higher risk of HIV in Pakistan. *Aids*, 24(SUPPL. 2), S77–S84.

39 Elmore-Meegan, M., Conroy, R. M., & Agala, B. C. (2004). Sex workers in Kenya, numbers of clients and associated risks: An exploratory survey. *Reproductive Health Matters*, 12(23), 50–57.

In some cases, the data presents all the places where sex work happens as being places where ‘high-risk behaviours’ occur. That is how the research is often justified and how the data is analysed. We know that sex workers can be at higher risk of acquiring HIV and other STIs,

This framing of the results of population size estimates and mapping, and even conducting these studies, can contribute to stigma for sex workers and reinforces the political and social climate that creates harms for sex workers.

but we also know that this risk is not equal for all sex workers, in all areas of sex work and in all settings.^{40, 41, 42} This framing of the results of population size estimates and mapping, and even conducting these studies, can contribute to stigma for sex workers and reinforces the political and social climate that creates harms for sex workers.

Some of the information created through population size estimates and mapping can certainly be useful to programme planning. However, it is dangerous to gather this information without taking into account what shapes the particular vulnerabilities

associated with some sex work. It is also dangerous to assume that the risk is the same across settings and types of sex work, or that this information alone can truly represent what is happening with sex work in a particular context. The increasing reliance on methods mostly informed by statistics serves funders in organising data and monitoring what is happening with the funds they provide, but how is it safeguarding sex workers’ rights?

Application of methodologies independently of social, political and legal context

These methodologies are presented as ‘tools’ that can be used anywhere in the same easy process. However, the ways in which sex work is organised is very different from one setting to another. If these tools are used at all, they need to take into account the very different social, political and legal contexts in which sex work exists. This is crucial to make sure that the data produced does not endanger sex workers, but also to ensure that the data is valid and representative. Gathering information about the places where sex workers work in a context where sex work is criminalised and the laws are enforced can be extremely dangerous, even if the goal is to develop HIV prevention and treatment programmes for sex workers. Additionally, the quality of the data produced may be negatively impacted if the local context is not considered.

40 Spittal, P. M., Bruneau, J., Craib, K. J., Miller, C., Lamothe, F., Weber, A. E., . . . Schechter, M. T. (2003). Surviving the sex trade: a comparison of HIV risk behaviours among street-involved women in two Canadian cities who inject drugs. *AIDS Care*, 15(2), 187–195.

41 Day, S.E., and Ward, H. (2007). British policy makes sex workers vulnerable. *BMJ* 334:187–187. ?

42 Rekart, M. L. (2005). Sex-work harm reduction. *Lancet*, 366(9503), 2123–2134.

Keeping people safe and data secured

Most sex worker-led organisations and other organisations that provide services to sex workers keep some form of information on their members. Some of the ways in which they gather this information are closely related to or follow the same techniques of geographic mapping and population size estimates. This information can be valuable for planning purposes, and is sometimes required by their funding agencies. This data can also be necessary to be accountable to their members,

Some NSWP members [...] identified the complete control of the data by the community organisation as a successful strategy and key factor in reducing the risks associated with collecting and storing this type of information.

to track the services that are being provided. However, the data that is provided to funders or that is made public is usually collective data that does not endanger the safety of sex workers.

Some NSWP members who shared their experience with population size estimates and mapping identified the complete control of the data by the community organisation as a successful strategy and key factor in reducing the risks associated with collecting and storing this type of information. Depending on the legal and social context, other groups opt to avoid gathering any personal information about the people they provide services to in order to protect the safety

of the people who access their services. UICs are lauded by international organisations as a strategy to protect sex workers' confidentiality and they can be safe. However, their safety relies entirely on the data being kept safe, confidential and in the hands of organisations or agencies that will not share them without consent.

Vignette 2: Ashodaya Samithi, Mysore, India

Ashodaya Samithi is a sex worker-led organisation that has been offering advocacy, health services, condom distribution and HIV prevention services for their members and the broader community of the South Indian city of Mysore since 2004. In the past, in collaboration with different national and international agencies, research centres and academics, they have used various methodologies to estimate the size of their community, locate where people are working, plan for services, and monitor new sex work practices.

Using a variety of technologies has been an important strategy for Ashodaya members and staff to get a more complete picture of what is happening with their community and to make sure that they reach as many sex workers as possible, not simply the ones they already know. They also recognise that different technologies might be more useful to identify and address the varying needs of different groups within their community. The founding members and staff described how essential they believe it is to 'link science to community' and how there is a reciprocal relationship where the community members will let the outreach workers know about changes that could require adaptation of service delivery. This close relationship has allowed Ashodaya to record changes in sex work such as a sharp move from street-based work to overwhelmingly home-based working, as it currently is. Ashodaya uses different community-led techniques such as social network-based mapping, capture-recapture, site profiling, contact mapping etc. to enumerate the number of sex workers as well as to document the field changes.

The increasing use of social media and apps for sex work, especially among male and transgender members of their community, is also something that has changed the way they provide services and required new ways of collecting information.

The monitoring and data collection that is carried out by Ashodaya is done by the community, for the community, in collaboration with researchers and others who work with them. This is also closely monitored by the Board. The information that they gather serves the purpose of identifying the needs of their community. Ashodaya

Ashodaya members agree to answer questions because they trust Ashodaya to only ask questions that are essential and because they know that their information will be kept confidential and stored safely.

members agree to answer questions because they **trust** Ashodaya to only ask questions that are essential and because they know that their information will be kept confidential and stored safely. Ashodaya is confident that the data they collect is high quality because of that relationship of trust. Confidentiality is also essential for Ashodaya to be able to provide the services it offers to its members safely.

Ashodaya uses UICs to identify each sex worker using their services. The UICs are linked in a file that contains some basic contact information and demographic data about their members.

This information is kept in hard and digital copies. Access to the file that connects the information is very strictly monitored by the Programme Directors (community members), with only certain essential staff members (namely Counsellors and clinical staff) having access to it. All digital copies are password protected and hard copies are kept under lock and key. Ashodaya has always refused requests to share their records or any additional information with donors, law enforcement, national and international agencies. The use of UICs has allowed them to provide information on the project outputs measured (number of members who accessed services, types of services, number of contacts in the field, follow-up etc.) while protecting the anonymity and safety of their members.

Importantly, there has never been a breach of confidentiality in the organisation's history. Ashodaya members are adamant that sex worker-led organisations should collect their own data and provide only essential information to health, research or governmental agencies, in order to prevent dangerous interventions from police forces or anti-sex work agencies who may then get access to the data.

Vignette 3: Stella, l'amie de Maimie, Montréal, Canada

Stella, l'amie de Maimie is a sex worker-led organisation based in Montréal, Canada which is currently celebrating its 20th year. Outreach workers record service statistics such as the number of condoms and other harm reduction materials that they distribute, and the number of people that they interact with in person, or on the phone. However, they never record any health information about the people that they speak to nor the names of the people who use Stella's services. Basic demographic information is recorded about the area of the city in which they reside (no precise addresses), age group and self-identified gender of the people that they interact with, giving Stella an overall idea of who is accessing their services. The information that is recorded serves to meet the demands of their funders, and also supports accountability to their members and supporters to ensure they are fulfilling their organisation's mission. It is mainly used to represent the work that they do, and to be able to keep track of what is happening in the industry at different moments. Extra precaution is taken in presenting the data in their annual reports so that no sensitive information can be identified. They do not use unique identifier codes. The repression that sex workers experience is closely monitored to understand why people move around.

For Ashodaya Samithi, the information that they gather using mapping and population size estimates has allowed them to continuously improve their services and to reach out to new sex workers. For Stella,

the information that they gather, although not as extensive, allows them to monitor the work that they do and who they are in contact with. In the two cases discussed above, complete control over the data collection and who has access to it was a successful strategy to keep people safe and the data secured. However, having complete control over data collection for population size estimates and mapping requires a great deal of research capacity and resources and may not be available

to every programme. Alternatively, the case of Stella shows that refusing to link basic demographic information and service use can also work to make sure that their members are safe.

In the two cases discussed above, complete control over the data collection and who has access to it was a successful strategy to keep people safe and the data secured.

Recommendations

Population size estimates and mapping methodologies discussed here have the potential to be particularly dangerous to sex workers and their communities, if they are not approached with extreme caution and

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with strict rules around ownership of data and confidentiality. They are increasingly common, and it may be difficult to avoid participating in them or using them, even if that may not be the ideal solution for your organisation. However, it is possible to refuse to participate altogether and to propose alternative ways of collecting and managing data safely. Here are recommendations that can help to frame safer and more ethical use of these methodologies:

Unique identifier codes:

- ▮ There is a lack of evidence that the information provided by linking demographic and health data (service utilisation or health status) is the only or the best way to design programmes that benefit sex workers. More importantly, it is unclear that the direct benefits to sex workers of UICs outweigh the risks associated with their existence.
- ▮ If they are used, the control of the data and the 'master list' (where confidential information that could lead to the identification of sex workers is kept) must be placed with the sex workers' organisation.
- ▮ If they are used, do not link data sets (describing personal identity and demographics and describing health information) together.
- ▮ If they are used, UICs should not contain personally identifying information such as birthdates.
- ▮ If they are used, biometrics measures, such as fingerprints, should not be used.

Context must be considered in data collection, analysis and dissemination:

- ▮ Sex workers must fully understand and have control and input over the process of data collection, analysis, and dissemination of the information.
- ▮ Use of qualitative data should be included in data collection to improve the quality of the data, and help to assess the risks of collecting this information.

Accountability to sex workers and sex worker-led organisations means focusing on safety and protecting the rights of sex workers.

- ▮ Mapping and population size estimates should serve to initiate or improve services and support offered to sex workers.
- ▮ Only information that directly informs service provision and safety of sex workers should be collected.
- ▮ Data collection, analysis, use and dissemination of the information must be controlled by sex worker-led organisation.

Conclusion

Geographical mapping and population size estimates can be useful for organisations to monitor the changes in their communities and with the people that they serve, as well as for effective programme planning. In the right context, they can provide valuable information that lead to better services. However, their increased use by governments and multilateral agencies to establish national population size estimates is extremely worrying. The potential harms to sex workers' safety, confidentiality and health should not be underestimated or ignored. The use of these methodologies is increasingly seen as essential to develop national strategic plans, and concept notes for The Global Fund and other international donors, however, they present serious risks to the safety and well-being of sex workers.

It is crucial that we reframe the discussion to focus on how this is helping to protect sex workers' rights to be free from discrimination, to privacy, and freedom from arbitrary interference and their right to the highest attainable standard of health...

Without the collection of data relevant to service planning and delivery, and the guarantee that confidential information that these methods produce will be safeguarded, these methodologies are unethical and dangerous. It is crucial that we reframe the discussion to focus on how this is helping to protect sex workers' rights to be free from discrimination, to privacy, and freedom from arbitrary interference and their right to the highest attainable standard of health, as outlined in the *NSWP Consensus Statement*⁴³ and reflected in the *United Nations Universal Declaration of Human Rights*⁴⁴.

43 NSWP.(2013). *Consensus Statement on Sex Work, Human Rights and the Law*. Edinburgh.

44 The United Nations. (1948). *Universal Declaration of Human Rights*. Available at: <http://www.un.org/en/documents/udhr/>

This community guide is the result of desk research and gathering case studies from NSWP members.



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