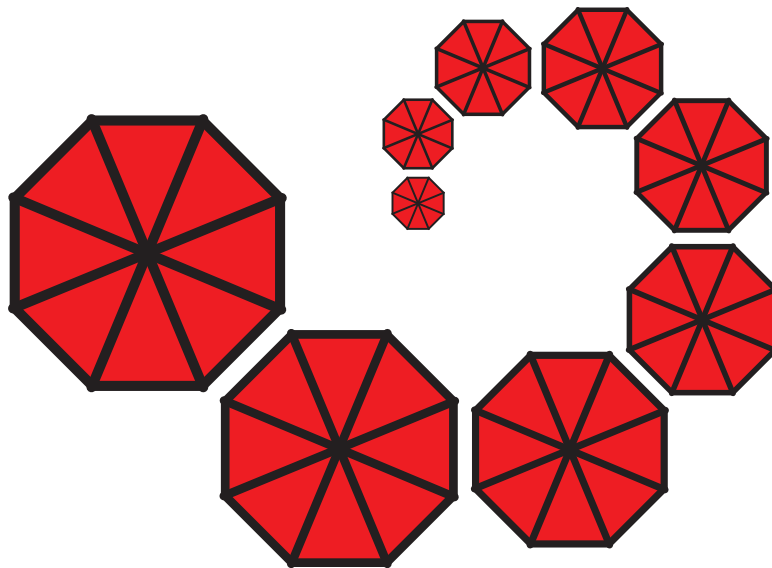




Global Network of Sex Work Projects
Promoting Health and Human Rights

GLOBAL CONSULTATION:

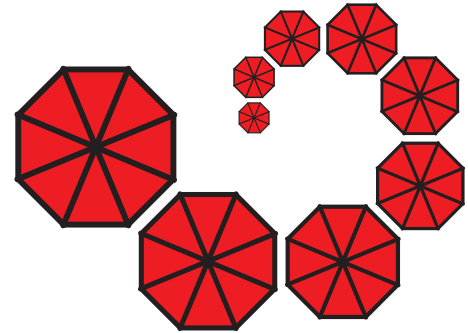
PrEP and Early Treatment as HIV Prevention Strategies



***Sex worker community
experiences and perspectives***



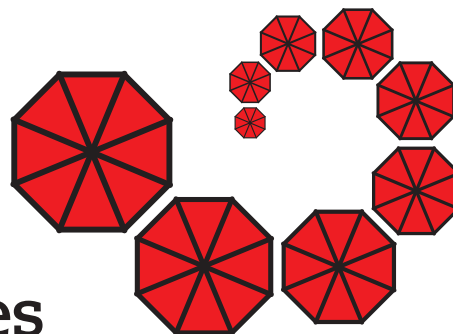
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PrEP and Early Treatment as HIV Prevention Strategies



Sex worker community experiences and perspectives

Foreword

As new medical technologies are increasingly being promoted in the prevention and treatment of HIV, and heralded as interventions to be used within communities of key populations including sex workers, NSWP urges the international HIV community and donors to take the concerns of sex workers presented in this report seriously and continue meaningful engagement with key populations in this shift towards the use of biomedical interventions. For years sex workers around the world have been developing and sustaining sex worker-led HIV prevention, treatment, care and support programmes. The successes of these community-led programmes have been recognised by UN and international partners including the World Health Organization, United Nations Population Fund, Joint United Nations Programme on HIV/AIDS, The World Bank, USAID and the Bill & Melinda Gates Foundation, with their most recent guidelines '**Implementing comprehensive HIV/STI programmes with sex workers: practical approaches from collaborative interventions**' (SWIT, 2013¹) clearly supporting sex worker-led programmes as the most effective in reducing sex workers' vulnerability to HIV. These sex worker-led efforts must be continually supported and not hampered by any biomedical intervention that does not take seriously, and ensure to mitigate, the risks involved of strategies such as PrEP and early treatment as prevention strategies.

NSWP also urges those reading this report to consider the potential benefits and risks of PrEP and early treatment as prevention strategies carefully through the three lenses of impact;

- ▮ impact on the individual sex worker;
- ▮ impact on the wider sex worker community; and
- ▮ impact on wider society and overall HIV prevalence.

Whilst these new prevention technologies may have the potential to significantly reduce HIV prevalence amongst wider society by targeting key populations, the risks to the individual and to sex worker communities' long-term efforts to reduce prevalence through community empowerment must be recognised.

1 World Health Organization, United Nations Population Fund, Joint United Nations Programme on HIV/AIDS, Global Network of Sex Work Projects, The World Bank. Geneva, World Health Organization, 2013.

This report is an initial step in highlighting the experiences and concerns of sex workers around the world in the hope that dialogue and meaningful engagement with key populations will continue. Increased vulnerability amongst key populations is fuelled within structural contexts of criminalisation, stigma and discrimination, particularly in relation to healthcare access. NSWP recognises, in line with the diverse opinions of sex workers across the world, that there is a place for biomedical interventions in the global fight to end HIV. However, these will fail if implemented at the expense of supporting and empowering sex workers and other key populations to take ownership of their health needs, related policies and programmes, and they are not implemented within a rights-based framework. Sex workers must be fully engaged in this growing debate, as noted by NSWP members:

**“Sex workers are not the problem;
we are part of the solution!”**

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Executive summary

HIV and AIDS have affected different population groups in different magnitudes since their emergence. Sex workers, in particular female sex workers, have one of the highest HIV prevalence rates globally. Prevalence rates between regions ranged between 1.7 percent in Middle-East/North Africa to 36.9 percent in sub-Saharan Africa².

New HIV prevention, testing, and treatment approaches such as pre-exposure prophylaxis (PrEP) and early initiation of treatment have the potential to significantly reduce HIV-related vulnerability and improve the health outcomes of those living with HIV. However, great gap exists in the application, including the efficacy and effectiveness of these strategies amongst sex workers despite their demonstrated clinical benefits. There are still many unanswered questions in relation to the use of early treatment initiatives and PrEP for sex workers.

It is in this context that the Global Network of Sex Work Projects (NSWP) conducted a global consultation of sex workers with the aim to gather the diversity of their perspectives on the implementation of PrEP and early treatment as prevention strategies; to identify important issues of concern for the sex worker community in the application of these strategies; and to identify pre-conditions for the implementation of programmes based on the sex worker community’s perspectives and concerns.

440 participants from 40 countries through 20 focus group discussions, 146 key informant interviews, and 33 online surveys, helped inform the findings of this consultation.

² World Bank. The Global HIV Epidemics among Sex Workers. 2013, Washington, WA: International Bank for Reconstruction and Development.

Key findings of the consultation included:

- ▶ Sex workers' awareness and knowledge of PrEP and early treatment was low or limited, especially with regard to PrEP. There was also a general confusion regarding the application of PrEP, including participants mistaking PrEP as post-exposure prophylaxis or as an HIV vaccine.
- ▶ Sex workers expressed great uncertainty toward PrEP and early treatment. The majority of participants were suspicious and sceptical of these strategies and many declared that they would not be willing to adopt PrEP as a prevention strategy.
- ▶ Sex workers expressed concerns with regard to the impact of these strategies on their personal health and human rights, the impact on existing prevention programmes, the accessibility and sustainability of these strategies, and the effect on stigma and discrimination against sex workers:
 - Sex workers worried about the long-term impact of ARVs on their health as a result of PrEP and early treatment. They also highlighted a key limitation of these strategies in addressing the other aspects of their sexual and reproductive health needs.
 - Sex workers questioned the ethics and application of these strategies within legal environments in which the rights of sex workers are often undermined.
 - Sex workers expressed concerns regarding the appropriateness of these strategies for sex workers and the impact of these strategies on the use of condoms amongst sex workers and clients.
 - Accessibility and sustainability of these strategies with regard to the cost, sex workers' ability to adhere to the use of ARVs, and access to the required medications, was also of concern for sex workers.
 - PrEP and early treatment could potentially exacerbate stigma and discrimination against sex workers by targeting and prioritising sex workers for these interventions.

Key recommendations for the development of PrEP and early treatment programmes amongst sex workers included:

- ▶ Ensure that sex workers have **access to accurate knowledge and information** about PrEP and early treatment by strengthening the capacity of the sex worker organisations in educating and training their communities on issues pertaining to their use;
- ▶ Prioritise **research and data collection** on the use of PrEP and early treatment amongst sex workers and ensure all trials and data collection methods used are ethical;
- ▶ Promote and **expand community-based services, in particular sex worker-led HIV testing and treatment services** based on their demonstrated success in increasing testing uptake and promotion of sex workers' health in various settings;
- ▶ Recognise the critical role that sex worker communities have played in addressing the HIV epidemic at both local and global levels and sustain their response through **adequate funding and support of sex worker-led organisations**;
- ▶ Increase political commitment to promoting sex workers' rights through **full decriminalisation of sex work**;
- ▶ Address the critical **impact of stigma and discrimination in healthcare settings** on confidentiality and access to healthcare services for sex workers; and

- ▶ **Engage sex workers in all levels of policy and programmatic discussions** relating to PrEP and early treatment as prevention strategies, including sex worker involvement in the design, implementation and monitoring of these programmes.
- ▶ Programmers must address the concerns raised in this report at the three levels of impact; individual sex workers; the wider sex worker community; and wider society.

Introduction

HIV and AIDS have affected different population groups in different magnitudes since their emergence more than 30 years ago. The key populations including sex workers, men who have sex with men (MSM), transgender people, and people who use drugs among others have been disproportionately affected.

Sex workers, in particular female sex workers, have one of the highest HIV prevalence rates globally. The World Bank's *Global HIV Epidemics among Sex Workers, 2013* report³, which included a systematic analysis of approximately 100,000 sex workers in 50 countries, found an overall HIV prevalence amongst female sex workers of 11.8 percent. While prevalence rates varied between regions, with the Middle-East/North Africa at the lower end of the spectrum at 1.7 percent, the highest prevalence was found in sub-Saharan Africa with a pooled prevalence rate of 36.9 percent.⁴ The lower prevalence rate in the Middle-East/North Africa, however, is believed to be masking a potentially high rate of new infections in countries such as Egypt and Somalia. When compared with the general population of women between 15 to 49 years old, HIV prevalence amongst female sex workers was 13.5 times higher.

A growing body of bio-medical research suggests that new HIV prevention and treatment approaches such as pre-exposure prophylaxis (PrEP) and an early initiation of treatment (also known as treatment as prevention (TasP), or test and treat) have the potential to significantly reduce HIV-related vulnerability and improve the health outcomes of those living with HIV.

Within such a context, in June 2013, the World Health Organization (WHO) released their *Consolidated Guidelines on the Use of Antiretroviral Drugs for Treating and Preventing HIV Infection*. The guidelines realigned the various WHO recommendations on the use of antiretroviral drugs (ARVs) for the treatment of HIV; they also integrated the latest data on the use of ARVs as a prevention strategy. Evidence focused on early treatment and PrEP in reducing HIV transmission was provided and suggested as potential prevention strategies for key populations.

Although at a scientific level, the prevention benefits of ARVs and treatment have been established, great gap exists in the application, including the efficacy and effectiveness of these strategies for sex workers. The viability and potential benefits and harms of prioritising sex workers as a key population in the implementation of such strategies remain critical in the debate. There are still many unanswered questions in relation to early treatment initiatives and PrEP for sex workers. Despite this, sex workers are increasingly being targeted as the intended audience, with demonstration projects already underway around the world. There is a pressing need to understand the context within which HIV programming for sex workers takes place.

3 Ibid.

4 Ibid.

Aims and objectives

Recognising the critical gap in the currently available evidence on the use of PrEP and early treatment in sex workers, including the perspective of sex workers on the use of these strategies, the Global Network of Sex Work Projects (NSWP) conducted a global consultation of sex workers on the use of PrEP and early treatment as prevention strategies between March and May 2014.

This consultation aimed to help inform the development of appropriate HIV-related prevention and treatment policies, guidelines, and programmes within the current prevention environment for the sex worker community. In particular, it aimed to gather the diversity of sex worker perspectives on the implementation of PrEP and early treatment as prevention strategies; to identify important issues of concern for the sex worker community in the application of these strategies; and to identify preconditions for the implementation of prevention programmes based on these strategies for sex workers.

Methods

Sex worker perspectives were gathered primarily through a mixed-methodology of focus group discussions and key informant interviews from selected countries in five regions – Africa, Asia and the Pacific, Europe, Latin America, and North America and the Caribbean. Online survey was not originally included as a consultation method at the onset of this process but was later added due to its appropriateness, based on the recommendations of the NSWP local partner.

A total of 440 participants from 40 countries through 20 focus group discussions, 146 key informant interviews, and 33 online surveys, helped inform the findings of this consultation.

Consultation and data collection protocol

A simple consultation instrument, including consultation guidelines, semi-structured guiding questions, NSWP PrEP factsheet, and a demographic form was developed jointly by NSWP staff and a team of consultants in November 2013. The guiding questions were designed to help gather the diverse perspectives and concerns related to the application of PrEP and early treatment as prevention strategies for sex workers.

NSWP staff and consultants conducted pilot focus group discussions at the 11th International Congress on AIDS in Asia and the Pacific (ICAAP) and the 17th International Conference on AIDS and STIs in Africa (ICASA) between November and December 2013 using a set of predesigned, semi-structured guiding questions. Consultation objectives, questions, and approach were revised and finalised based on these pilot focus group discussions.

The regional consultation process took place between March and May 2014.

The regional consultations were conducted based on the following process:

- 1 Regional consultants identified
- 2 Focus and number of countries within each region selected
- 3 Number of local focus group discussions and key country informants determined
- 4 Local focus group discussion facilitators and key country informants identified
- 5 Local focus group discussion facilitators and key country informants briefed and provided with consultation guidelines and guiding questions

- 6 Local focus group discussions and key informant interviews carried out by local facilitators and key country informants
- 7 Reports of focus group discussions, including demographic information sent to the regional consultants
- 8 Key country informants interviewed by the regional consultants
- 9 Reports of focus group discussions and key informant interviews collated by the regional consultants and sent to NSWP for analysis.

Focus group discussions

A purposeful selection process utilising referrals and known networks of sex workers was adapted to help identify the focus group participants. The composition of the focus group members reflected the diversity of the sex worker community and included:

- Female, male and trans sex workers
- Sex workers living with HIV
- Sex workers in both rural and urban settings
- Sex workers working in various settings, including brothels, street-based, entertainment venues, and online
- Ages 18 and above

Country focus group discussion facilitators were identified through NSWP local partners and regional consultants. The facilitators used the consultation guidelines and semi-structured guiding questions to help guide the group discussions.

Key informant interviews

Key informant interviews were conducted at two levels:

- Interviews with local informants by key country informants; and
- Interviews with key country informants by the regional consultants

The number of interviews and countries for each region were determined based on the presence and accessibility of sex worker-based organisations, sex workers, and advocates in each of the regions.

A purposeful selection process was also utilised to help identify both local and country-level key informants. To ensure consistency in the consultation process, diversity criteria similar to those used for the focus group discussions were adapted and included:

- Female, male and trans sex workers
- Sex workers living with HIV
- Sex workers in both rural and urban settings
- Sex workers working in various settings, including brothels, street-based, entertainment venues, and online
- Ages 18 and above

Additional criteria were added to the selection of key country informants:

- A demonstrated connection with the broader sex worker community in their local context
- Willingness to undertake semi-structured consultations with their local community prior to the interviews with the regional consultants

Online survey

An online survey via Survey Monkey was setup in Australia by Scarlet Alliance – The Australian Sex Workers’ Association to help capture the perspectives of Australian sex workers on PrEP and early treatment.

A total of 21 questions were set up based on the guiding questions of the consultations and included multiple choices and comment boxes. The survey was distributed to Scarlet Alliance members via its sex worker-only E-list, its individual member email list, and its member organisation contact list. Sex workers were provided with background and context about the consultation, the NSW PrEP factsheet, and were required to give their informed consent before completing the survey. Respondents were informed that they could choose whether or not to participate in the survey, could stop at any time, and that their responses would remain anonymous.

Table 1 provides a brief overview of the data collection process in each of the five regions.

TABLE 1: Data collection process, by region

| Region | # of countries | Country names | # of FGD* | # of KII** | Other |
|--|---------------------|--|---------------|----------------|--------------------------|
| Africa | 11 | Botswana, Congo, Ethiopia, Ghana, Kenya, Mali, Namibia, Nigeria, South Africa, Uganda, Zimbabwe | 8 | 8 | - |
| Asia and the Pacific | 11 | Australia, Cambodia, China, Fiji, India, Indonesia, Malaysia, Myanmar, Papua New Guinea, Thailand, Timor Leste | 7 | 1 | 33 online surveys |
| Europe | 9 | France, Kyrgyzstan, Macedonia, Russia, Sweden, Tajikistan, Turkey, United Kingdom, Ukraine | 2 | 86 | - |
| Latin America | 4 | Brazil, Mexico, Peru, Ecuador | 3 | 42 | - |
| North America and the Caribbean | 5 | Antigua, Canada, Haiti, Jamaica, USA | - | 9 | - |
| Total | 40 Countries | | 20 FGD | 146 KII | 33 online surveys |

* FDG – focus group discussions

** KII – key informant interviews

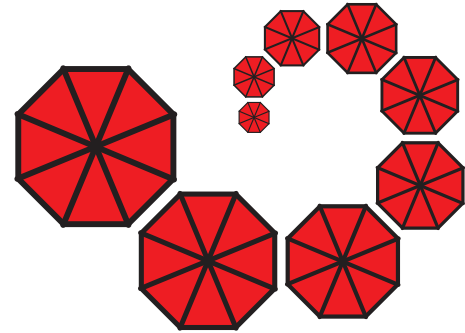
Analysis

An inductive approach was used in the analysis of the information gathered due to its utility in condensing raw textual data into brief summary; adaptability in identifying links between study/research objectives and findings within raw data; and capacity to develop a framework of the underlying structure of experiences and processes evident in the raw data.

Information gathered through the consultation was analysed based on a standard procedure of:

- 1 Preparation of raw data
- 2 Close reading of text
- 3 Categorisation and identification of themes (within a hierarchy)
- 4 Identification of overlapping coding and un-coded text
- 5 Revision and refinement of the category/theme system

Findings and results



Demographic characteristics of the participants

Participants were asked to complete the demographic information forms at the start of each focus group discussions and interviews. Participants also had the right to skip over any questions if they did not wish to provide the information.

Responses were most complete from Asia and the Pacific, Europe, and North America and Caribbean regions.

A total of 440 participants took part in this consultation process. Of the 415 participants that responded to the question of sex work, 411 self-identified as sex workers. The other four participants included a Director and staff from local sex worker organisations and a researcher.

The majority of the participants were between the age of 18 and 40 years old and lived in urban areas.

Of the 219 participants that responded to the question on HIV status, 110, around 50 percent, were HIV-negative; 58 were HIV-positive; and another 51 either did not know their status or chose not to disclose.

TABLE 2: Socio-demographic characteristics of key informants, by region

| Socio-demographic characteristics | Africa | Asia and the Pacific | Europe | Latin America | North America and the Caribbean | TOTAL |
|-----------------------------------|--------|----------------------|--------|---------------|---------------------------------|-------|
| # of participants | 117 | 100 | 114 | 90 | 9 | 440 |
| Occupation | | | | | | |
| Female sex worker | 68 | 49 | 73 | 51 | 5 | 246 |
| Male sex worker | 36 | 35 | 35 | 9 | 3 | 118 |
| Transgender sex worker | 4 | 14 | 6 | 19 | - | 43 |
| Sex worker of other gender | 1 | 3 | - | - | - | 4 |
| Non-sex worker | - | - | - | 3 | 1 | 4 |
| Age | | | | | | |
| 18–30 | 7 | 44 | 34 | n/a | 3 | 88 |
| 31–40 | 5 | 35 | 34 | n/a | 3 | 77 |
| 41–50 | 1 | 13 | 4 | n/a | 1 | 19 |
| 51–60 | - | 6 | - | n/a | - | 6 |
| >60 | - | 1 | - | n/a | - | 1 |
| Residence | | | | | | |
| Urban/city | 98 | 71 | 90 | 84 | 6 | 349 |
| Rural/country | 19 | 11 | 8 | 2 | 1 | 41 |
| HIV status | | | | | | |
| HIV-negative | 4 | 43 | 45 | 15 | 3 | 110 |
| HIV-positive | 8 | 24 | 22 | 4 | - | 58 |
| Don't know | - | 13 | 12 | - | 4 | 29 |
| Prefer not to disclose | 1 | 2 | 8 | 10 | 1 | 22 |

Awareness and understandings of PrEP and early treatment

Most of the participants were familiar with the concept of early treatment or treatment as prevention but had not heard of PrEP prior to this consultation. Many participants commented, for example, “*I am hearing and learning about PrEP for the first time,*” and “*never heard of it [PrEP] until the NSWP global consultation.*”

Participants who considered themselves to be familiar with PrEP and/or early treatment were found to be:

- ▶ Living in a country with an up-to-date HIV prevention, treatment and care healthcare system;
- ▶ Working in urban/city contexts;
- ▶ Linked to sex workers-led organisations; and
- ▶ Known sex worker activists and advocates in their communities.

Specifically, focus group participants and key informants from Australia, North America, Western Europe, and selected Asian and Latin American countries (namely Thailand and Brazil), were more familiar with these strategies. Many attributed their familiarity with the issues to be a direct result of discussions in their countries, including debates around the use and implementation of these strategies, in particular, early treatment as prevention. In a number of countries, early treatment is already being implemented amongst sero-discordant couples and PrEP-related programmes and trials have already been conducted amongst selected MSM and transgender populations.

Sex workers in urban/city settings tend to be more informed about these issues. For example, only 8.3% of rural participants in Africa were aware of PrEP and TasP. Urban-based sex workers highlighted the role of their local sex worker-led organisations in increasing sex workers’ awareness and understanding of these issues. In Africa, Asia and Latin America, participants who were familiar with these strategies obtained their information from meetings and workshops organised by sex worker-led organisations. On the other hand, rural-based sex workers tend to receive information about the new HIV prevention strategies through those working in the city.

Key informants identified as sex worker activists and advocates were much more aware of the various emerging HIV prevention strategies – this was particularly so with activists from Asia, Eastern Europe and Latin America who were connected to the international sex worker rights movement.

There was, however, a general confusion and misunderstanding regarding the basic principles of PrEP, its application, and efficacy among the sex workers. While most participants had accurate knowledge about early treatment as prevention strategy, many expressed confusion between PrEP and post-exposure prophylaxis (PEP). Some sex workers also believed that PrEP is a form of HIV treatment, while others thought of it as an HIV vaccine.

With regard to its application, many expressed the view that PrEP is an alternative, stand-alone strategy, rather than a complementary HIV prevention strategy. Some also held the view that PrEP is a more effective prevention tool than condoms. A key informant from North America considered PrEP to be a harm reduction tool for those who may not have access to condoms. A number of sex workers interviewed commented that, “PrEP might be more protective than a condom, which might break or slip off.”

Attitude toward the new strategies

Sex workers who took part in the consultation process expressed great uncertainty toward PrEP and the strategy of early treatment. The majority of participants were suspicious and sceptical of these strategies and many declared that they would not be willing to use PrEP as “condoms work for us,” and that “sex workers don’t need this strategy.” They considered these strategies to be a ‘medical approach’ toward HIV prevention and that they disregard the reality of sex workers’ lives and experiences.

In general, as information about PrEP and early treatment was introduced in the consultation, many were surprised about the existence of such strategies. Except for the African sex workers, most sex workers expressed a more positive attitude toward the strategy of early treatment but were largely distrustful of PrEP despite the perceived potential benefits of this strategy. Sex workers in Africa, a region with one of the highest HIV infection rates amongst sex workers, were encouraged by the addition of these strategies as ‘new tools’ in their efforts to reduce HIV infections in their communities. Yet many also indicated that, on an individual level, they would be reluctant to use these strategies, especially PrEP, as the potential harms of these strategies seem to outweigh their potential benefits.

For the most part, participants felt that there was a limited benefit to sex workers in the use of these prevention strategies, especially PrEP. “There’s hardly any benefit [in the use of PrEP] due to the health risks involved” was a statement shared by a large number of informants. Some informants also stated, “I think the only benefit is to the drug companies.”

Whilst recognising the simple added benefit of having new tools against HIV infections especially in the case of condom breakage, rape or other risky situations faced by sex workers amongst others engaging in sexual activities, participants also noted the availability of post-exposure prophylaxis (PEP) in mitigating their risk of HIV infections in those situations. Participants saw a role for PrEP and early treatment in situations where condom negotiations might be difficult, including sex with regular sexual partners, when clients refuse condom use and when drugs and alcohol are involved. They also saw the potential of early treatment to reduce the ‘infectiousness’ of HIV-positive sex workers and at the same time promote their health and ability to continue to work. Many participants also felt that male, transgender, and HIV-positive sex workers could greatly benefit from these strategies due to their additional vulnerabilities.

Whilst HIV testing is an integral, essential component of these strategies, participants were split in their view about the potential impact of these strategies on testing uptake among sex workers. Some saw it as an opportunity to help promote regular testing within sex worker communities, while others saw [mandatory] early treatment as detrimental to sex workers’ willingness to find out about their status. Underlying the various concerns regarding HIV testing amongst sex workers is the risk of “excessive testing of sex workers that sometimes does not necessary match their risk level.”

Informants greatly questioned the rationale and impact of long-term use of ARVs as a preventive measure; some flatly called PrEP a “bull-shit” strategy, while others were critical about the potential “hidden agenda behind the push of these strategies in sex workers” given that “PrEP is being pushed by the HIV sector quite strongly.”

Sex workers also expressed uncertainty regarding the ‘real’ aim of early treatment. A number of sex workers also firmly believed that, “... test and treat [early treatment] is a strategy about the number and quality of HIV testing and counseling, and much less about the follow-up of those who are screened as positive.”

Concerns related to PrEP and early treatment

Despite the potential benefits of PrEP and early treatment, the majority of the sex workers indicated that they would not be willing to use these prevention strategies, particularly PrEP. They expressed concerns related to the potential impact on their health and human rights; the impact on existing prevention strategies and programmes; the accessibility and sustainability of these strategies; and the impact on stigma and discrimination against sex workers. Their concerns were multi-faceted, expressed at individual, community, and societal levels, shared across regional boundaries, and grounded in the reality of sex workers' experiences.

Impact on Health

Sex workers expressed deep concern about the safety of PrEP and early treatment in relation to their long-term health. They questioned the safety of these strategies, in particular, the impact of the long-term use of ARVs by HIV-negative individuals and the necessity of early treatment for people living with HIV with an otherwise healthy immune system.

Many sex workers asked about the potential impact of PrEP on their health and physical appearance.

“Our look and our health are our most important asset in this trade” was a sentiment shared by many sex workers across all regions. In countries where stavudine (d4T) was used widely in first-line treatment regimens until the most recent WHO recommendation to phase out its use, many sex workers witnessed the negative impact of ARVs on their friends' and peers' physical appearance. The loss of body fat on the faces, arms and legs, resulting in sulking cheeks, round body, stick-like limbs have contributed greatly to a general mistrust and concern about anything related to the use of ARVs.

Such mistrust of ARVs was also reflected in a comment made by an HIV-positive sex worker,

“Why would I want to start treatment early? It is more likely that the drugs [ARVs] will kill me, not HIV, and that might be because of drug side effects rather than HIV-related illness.”

In addition to drug safety concerns, participants pointed out that PrEP and early treatment address only one aspect of their sexual and reproductive health needs – HIV infection – and viewed it as a key limitation of these prevention strategies.

Impact on human rights

Of fundamental concern were the ethical standards around the use of PrEP and early treatment within the context of sex workers' rights. Specifically, sex workers across the regions questioned how ethical the use of ARVs in HIV-negative people is and providing these medications as a preventive measure in the context of ARVs as life-saving medications.

As a participant said,

“I do not understand why are we asking healthy sex workers to take medications that could potentially damage their health just so we can prevent a potential infection of one disease when condoms also work the same...and more”

A related concern was the view of early treatment as “unnecessary use of medications and treatment in people who are still healthy.”

Participants in Africa, Asia, the Caribbean, Eastern Europe, and Latin America pointed out the difficulty in developing a justification for providing ARVs to HIV-negative sex workers in the context of evidence showing there is already a treatment coverage gap amongst sex workers in their respective regions.

In addition to the ethical concerns, sex workers also worried about the potential impact of these strategies in legal environments in which sex workers in general, or in some countries HIV-positive sex workers, are criminalised.

Participants noted that these technologies increase surveillance of sex workers and heighten the risk of rights violations, including mandatory registration, testing, and treatment of sex workers. Many suggested that given HIV testing is an essential component of these strategies and that mandatory testing of sex workers is already a common, and to a certain extent in many countries an 'accepted' practice, these strategies could be further used to justify testing of sex workers and that it would not be "such a stretch to assume that mandated treatment may be the next step."

They also highlighted the fact that police and law enforcement are already using condoms as evidence of sex work and as the basis for the detention of sex workers in many countries. Many sex workers believed that it is likely that Truvada could also then be treated as evidence of sexual activity if PrEP becomes mandatory in this population.

Within that context, the majority of sex workers expressed concern around the possibility of these strategies being rolled out and implemented in their countries without the full informed consent of sex workers. They were generally distrustful of their governments and healthcare systems, including healthcare providers, and shared a similar view that "if they are going to make me take it, they probably won't inform me how harmful it might be."

Participants felt that these strategies disregard their individual rights and were especially worried about their ability to refuse these strategies if they are rolled out by their national governments.

Impact on existing prevention programmes

Participants were very much surprised about the lack of research around the application and effectiveness of these strategies within the sex worker community. Many feared that these strategies could be misinterpreted and misconstrued as the "silver bullet" to HIV and as a result, hamper existing programmes and achievements in HIV prevention within their communities.

In most regions, participants found it difficult to comprehend the need for a long-term use of potentially harmful medications on top of a prevention strategy with proven success and effectiveness in reducing HIV transmission among sex workers – condoms. They were sceptical about the potential, of PrEP especially, to be an easy to use and effective prevention strategy and were uncertain of its role as a complementary or contradictory strategy in their efforts to increase sex workers' ability to negotiate for condom use.

Of critical concern was the potential impact on condom negotiations with clients as a result of "a sense of false security." They feared that clients "won't be scared of HIV anymore" and will want unprotected services and will want sex workers to be on PrEP. Condom negotiation may become harder as clients' perception of risk is reduced.

Respondents noted that there could be a perception that PrEP and early treatment had 'replaced' condoms. Sex workers pointed out that they are already receiving more requests for 'bareback' on the basis of undetectable viral load and one's HIV status (also known as sero-sorting). Implementation of these strategies could potentially lead to more pressure to provide unprotected vaginal and anal intercourse. Clients aware of the existence of PrEP in particular could push for sex workers to use PrEP instead of condoms. Where sex workers currently won't offer unprotected sex, in a context where those using PrEP do, unprotected sex could potentially become the norm.

Transgender sex workers in particular, talked about the critical need to increase access to, and availability of, female condoms.

Most participants agreed that, “the message about the safety and effectiveness of condom use must not be eroded as a result of introduction of PrEP and early treatment because condom use should still be seen as the primary protection.”

In general, participants felt that the current discussions around the use of these strategies disregard other aspects of sex workers’ sexual and reproductive health and expressed the view that “everything is too HIV focused these days.” Many shared a similar concern that:

“If not implemented properly, PrEP could detract from the current effort toward a comprehensive, human rights-based approach to sexual and reproductive health of sex workers.”

A related issue was the possibility that PrEP could result in a decreased number of individuals being tested due to a perception that transmission has not occurred where PrEP has been used, despite the prerequisite of regular HIV testing.

Accessibility and sustainability

Another area of concern raised by the participants relates to accessibility and sustainability of PrEP and early treatment. They spoke about the potential cost of these strategies to sex workers, points of access, the overlapping issue of rights’ violations and their willingness and desire to access related services, and the challenges of adherence for sex workers. For many, their basic daily needs of food and shelter and the basic needs of their family will always take precedent over paying for any medications. Sex workers in Eastern Europe felt that “PrEP is not for poor people.”

The majority of the participants agreed with the statement that, “unless PrEP and ART are provided for free, it won’t work in the sex worker community.” For many, the cost of any prevention strategy plays a critical role in their decision regarding its usage. A number of the sex workers made the distinction between ‘indoor’ and ‘outdoor’ sex workers and their potential ability to afford such strategies, with outdoor sex workers considered to be more resource-limited and marginalised. Participants also questioned the ability of any government programme to provide and sustain such prevention strategies in the face of funding cuts for HIV treatment programmes.

The statement “sex workers can’t even connect with primary care let alone disease specific services and treatment” reflects the reality of many sex workers’ lives irrespective of their country of residency and place of employment. Informants shared extensively their negative experiences in accessing health services in public healthcare settings and preference for sex worker-led, community-based organisations and services. Sex workers spoke about their reluctance to access services, including HIV testing and treatment due to fear of disclosure and particularly in contexts where sex work is criminalised. In many countries, HIV-positive sex workers are cut off from their treatment when they are arrested.

Stigma and discrimination within the healthcare setting, including the potential breach of confidentiality, have also greatly discouraged participants from seeking healthcare services and support.

As reflected in a comment made by an informant from Latin America,

“There is such a disconnect between medical providers and sex workers. Stigma and discrimination in healthcare setting create such barrier to access of services with populations such as sex workers. Going to a doctor to receive PrEP is unlikely with this population.”

Accessibility and sustainability of these strategies in the context of a highly mobile population, including in countries with a high number of migrant sex workers, will also be another major hurdle that programme implementers, policy makers and the sex worker community would need to collectively overcome prior to any consideration of the use of PrEP and early treatment.

Overlapping the issues of cost, accessibility, and sustainability is the need for PrEP and early treatment users to maintain a certain level, if not a complete adherence to ARVs. HIV-positive sex workers shared their difficulties (and stresses) relating to treatment adherence within the context of their work schedules and locations, and their fear of “being found out about their HIV status and treatment” by brothel and bar owners, and clients. Informants highlighted the already challenging work around treatment adherence and support for HIV-positive sex workers and questioned if the existing healthcare system and community will have the capacity and the support to deal with additional adherence challenges associated with PrEP and early treatment.

Stigma and discrimination

Participants feared that the prioritisation of sex workers as a key population for PrEP and early treatment might further reinforce the stigma against sex workers as the source of HIV transmission, perpetuate discriminatory attitudes and behaviour toward them and consequently impact the uptake of these strategies.

Many spoke about the various types of stigma already faced by sex workers and expressed concern about the potential for these strategies to be taken as evidence to support the common misperception that “sex workers are responsible for the spread of HIV in society,” that “they engage in unsafe sexual behaviours,” and that “they needed to be provided with another form of protection against HIV.” In countries where HIV prevalence rates amongst sex workers are the lowest among the key populations, sex workers worried about the potential negative impact on their effort towards social acceptance of sex work as work.

A related concern is the potential for sex workers on PrEP to be stigmatised by being perceived as HIV-positive. An HIV-positive status greatly hinders a sex worker’s work opportunities and comes with serious financial implications. Participants talked about incidents of sex workers disclosing other’s HIV status as a way to compete for clients in certain situations; in some countries, HIV-positive sex workers are prohibited from sex work and could be prosecuted if found to be selling sex.

Participants mentioned that using PrEP might also stigmatise one’s sexual partners.

Table 3 summarises the specific themes and sub-themes raised during the focus group discussions with regard to concerns related to PrEP and early treatment as prevention strategies.

TABLE 3: Summary of key concerns and examples

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| SEX WORKERS' HEALTH | Drug safety | <ul style="list-style-type: none"> ▸ We still do not have data on the long-term use of Truvada in HIV-negative persons. ▸ I would not want to take PrEP because of the potential side effects ▸ Why would I want to start treatment early? It is more likely that the drugs [ARVs] will kill me, not HIV, and that might be because of drug side effects. |
| | Sexual and reproductive health | <ul style="list-style-type: none"> ▸ Why use PrEP when it can only protect us from HIV and not STIs or pregnancy? |
| SEX WORKERS' HUMAN RIGHTS | Ethics of the strategies | <ul style="list-style-type: none"> ▸ I do not understand why we are asking healthy sex workers to take medications that could potentially damage their health just to prevent a potential infection of one disease. ▸ Is it ethical to provide ARVs to HIV-negative sex workers when there are still so many HIV-positive sex workers who need treatment? ▸ How do we justify providing treatment to someone who doesn't really need it over someone who urgently requires treatment, if we provide treatment to everyone? |
| | Testing as a precondition | <ul style="list-style-type: none"> ▸ Since regular testing is part of the requirement under PrEP, I am really concerned about government imposing mandatory testing of sex workers without full consent. ▸ Will this [PrEP] be another way for government to force testing and registration of sex workers? |
| | Police harassment/ violence and evidence of sex work | <ul style="list-style-type: none"> ▸ Polices currently use condoms as evidence of sex work – will they also start using possession of Truvada as evidence too? |
| | Right to say 'no' and confidentiality | <ul style="list-style-type: none"> ▸ Will sex workers have the right to refuse PrEP, testing, and treatment? ▸ It seems like there's a great pressure to force HIV-positive sex workers onto treatment – not for their benefits but to 'reduce community viral load' and protect the society. ▸ How can confidentiality be ensured given that sex workers are already facing forced registration of sex worker identity in many countries? |
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| IMPACT ON EXISTING PREVENTION PROGRAMMES | Appropriateness of the strategy in sex worker community | <ul style="list-style-type: none"> PrEP has not been tested in sex workers, how do we know it is an appropriate strategy to be used in our community? [Female] sex workers have the lowest HIV infection rate and highest condom use in my country. Why are we all being treated equally in risk level? If not implemented properly, PrEP could detract the current effort toward a comprehensive, human rights-based approach to sexual and reproductive health of sex workers. |
| | Devaluation of condom use | <ul style="list-style-type: none"> What is the rationale for the use of a very toxic drug on top of condom which has 96–97% efficacy? We have worked so hard to establish a culture of condom use and safer sex practice, PrEP might undo all this work and devalue condom use in both sex workers and their clients. Sex workers are now used to protecting themselves with condoms, test and treat might undermine this [because they and their clients will think they are not infectious.] |
| | Ability to negotiate safer sexual practices, including condom use | <ul style="list-style-type: none"> Sex workers might face more pressure from their clients to have unprotected sex. Male sex workers are already facing great pressure to provide unprotected anal intercourse and workers are already receiving more requests to bareback even in the absence of the new prevention strategies. |
| | Reduction in HIV testing | <ul style="list-style-type: none"> These strategies could result in decreased numbers of individuals being tested due to a perception that transmission has not occurred. |
| | Adherence | <ul style="list-style-type: none"> We often move around, work odd hours and use alcohol and drugs which will greatly impact our adherence. Sometimes people are afraid to carry their ARVs out to their places of work for fear of the bar owners seeing or the clients and finding out their status. |
| ACCESSIBILITY AND SUSTAINABILITY | Cost | <ul style="list-style-type: none"> Unless PrEP and ART are provided for free, it won't work in the sex worker community. But who will pay for it and how? Governments are already having difficulties sustaining the current treatment programmes, how will they be able to pay for the additional number of people if test and treat is implemented? |

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| ACCESSIBILITY AND SUSTAINABILITY | Hostile legal environment | <ul style="list-style-type: none"> ▸ Sex workers don't have the incentive to get tested or to go on treatment because of legal policies that criminalise sex work and/or criminalise HIV-positive sex workers. ▸ Why would I want to risk carrying anything that could be used against me in case of arrest? It is already problematic with condoms, who's to say Truvada might not be treated the same? ▸ Access and adherence to HIV treatment have been a great challenge for us because sex workers often have to work away from home and move around (both internally and internationally) – access, when possible, to ARVs are often based on our residency registries. ▸ When we get arrested, we don't get access to the medications we needed. ▸ Benefits of treatment as prevention will not have much impact on communities that are marginalised and removed from services. |
| | Healthcare setting | <ul style="list-style-type: none"> ▸ Sex workers can't even connect with primary care let alone disease specific services and treatment. ▸ There is such a disconnect between medical providers and sex workers. Stigma and discrimination in healthcare settings create barriers to access of services with populations such as sex workers. Going to a doctor to receive PrEP is unlikely with this population. |
| STIGMA AND DISCRIMINATION | Key population = source of HIV transmissions | <ul style="list-style-type: none"> ▸ Targeting of sex workers as a 'key population' for PrEP will further perpetuate the image of sex workers as the source of HIV transmissions. |
| | PrEP = HIV-infected | <ul style="list-style-type: none"> ▸ Even if we are using it as PrEP, they might assume we are HIV-positive. |

Testing as a pre-condition

Specific questions were developed around sex workers' experiences of testing given that HIV testing is an integral and critical component of PrEP and early treatment.

Many sex workers were resistant to the idea of mandatory and/or regular HIV testing. They reported negative experiences related to HIV testing, especially in a public healthcare setting, and fear of the added stigma as a result of an HIV-positive result was noted. The majority of participants, with prior experience and access to community-based, sex worker-led testing services, reported positive experiences and there was a great preference for such services to allow for sex workers to manage their own health without judgment and discrimination.

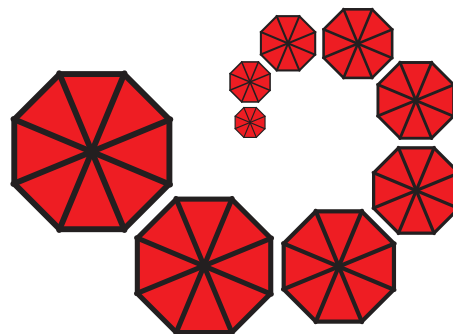
Negative experiences of testing in public healthcare settings were often due to stigma and discrimination by healthcare providers. Participants provided examples of being made to feel ashamed of their profession, being 'lectured' about their 'behaviours', and being made to feel more like a 'pin cushion' than a human being during the process of testing. Sex workers also shared concerns related to confidentiality in public health facilities, where sometimes one's test results and medical files are easily accessible to others.

On the other hand, community-based, sex worker-led testing services were considered to be more friendly, flexible, and understanding of sex workers' needs. However, they also noted the limited availability of such services, largely due to a lack of government support and limitations in funding.

Other challenges related to testing of sex workers concerned access and availability of the testing facilities. Sex workers, in Asia, Africa and Latin America in particular, highlighted the lack of testing facilities for rural sex workers.

Sex workers strongly argued that testing of sex workers must be implemented from a rights-based perspective that protects, respects and fulfils the human rights of sex workers in health programming. Participants spoke extensively about the need for testing to be provided and conducted on a voluntary basis, be anonymous, with strict confidentiality, free, in a friendly, unthreatening environment and be readily available in terms of locations and operating hours. The quality of pre and post-test counselling was also of critical importance to the participants.

Discussion and Recommendations



At the current juncture, most sex workers retain the view that the harms of PrEP and early treatment greatly outweigh their potential benefits, if use is encouraged within the sex worker community. Concerns related to the use of these strategies are grounded and derived from their perception of risk and the complex reality of their lives as sex workers. They are multi-faceted and despite their contextual differences, shared similar themes around impact on personal health; individual and community rights; existing prevention programmes; accessibility and sustainability of these strategies; and stigma and discrimination.

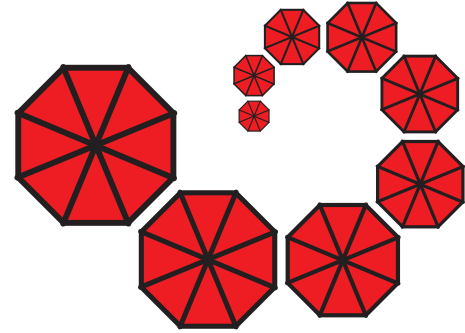
The findings from this consultation highlighted the need to engage sex workers in all discussions and decisions regarding the implementation of PrEP and early treatment in their communities; however, fundamental to any meaningful engagement of sex workers in the discussions of these strategies is the critical need to urgently and rapidly increase awareness and understanding of PrEP and early treatment in sex worker communities around the world. In many countries, sex worker-led organisations have played an important role in educating their members regarding their health and rights and could and should continue to take the key role in this area and be supported in this through international HIV funding.

At the individual level, sex workers were very concerned about the side effects of ARVs and the limitations of PrEP and early treatment as a sexual and reproductive health strategy for sex workers. As a community, they were extremely worried about the potential negative impacts of these strategies on their historical efforts around condom promotion amongst sex workers and clients. Sex workers expressed concern about the likelihood of them being able to freely choose prevention methods within a legal environment that has largely undermined their rights. The cost of, and ability to adhere to the strict requirements of, PrEP and HIV treatment, were also of great concern to the community – in terms of the accessibility and sustainability of these strategies. Lastly, the potential negative impact of these strategies on fueling stigma and discrimination towards sex workers should not be forgotten.

In moving forward with any discussions regarding the development of PrEP and early treatment programmes for sex workers, participants made the following recommendations:

- ▶ Ensure that sex workers have access to accurate knowledge and information about PrEP and early treatment by strengthening the capacity of the sex worker organisations in educating and training their communities on issues pertaining to their use;
- ▶ Prioritise research and data collection on the use of PrEP and early treatment amongst sex workers and ensure all trials and data collection methods used are ethical;
- ▶ Promote and expand community-based services, in particular sex worker-led HIV testing and treatment services based on their demonstrated success in increasing testing uptake and promotion of sex workers' health in various settings;
- ▶ Recognise the critical role that sex worker communities have played in addressing the HIV epidemic at both local and global levels and sustain their response through adequate funding and support of sex worker-led organisations;
- ▶ Increase political commitment to promoting sex workers' rights through full decriminalisation of sex work;
- ▶ Address the critical impact of stigma and discrimination in healthcare settings on confidentiality and access to healthcare services for sex workers; and
- ▶ Engage sex workers in all levels of policy and programmatic discussions relating to PrEP and early treatment as prevention strategies, including sex worker involvement in the design, implementation, and monitoring of these programmes.
- ▶ Programmers must address the concerns raised in this report at the three levels of impact; individual sex workers; the wider sex worker community; and wider society.

Conclusion



This report attempts to capture the diverse, but shared, perspectives and concerns of sex workers relating to the use of PrEP and early treatment as prevention strategies. It highlights the great need to consult and engage the sex worker community in all discussions regarding the potential use of these strategies, including implementation of related policies and programmes with this population. In particular, the development of programmes based on these strategies must first address the various concerns shared by sex workers throughout this consultation process, and as they relate to the impact on individual sex workers, the wider sex worker community, and the wider population.

This consultation also attempts to address the inequitable access to participation and engagement of sex workers in processes and issues that often affect their personal health and lives and the overall wellbeing of the sex worker community. Sex workers call for policy-makers, programmers, researchers, donors, advocates, and the community to work jointly in ensuring that the health and human rights of sex workers are prioritised and protected within the new HIV prevention landscape.



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