

Applying Mixed Methods to Understand Kusolidwa (Stigma) and Psychosocial Barriers to Pre-Exposure  
Prophylaxis (PrEP) Among Women Engaging in Sex Work in Lusaka, Zambia

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**Abstract**

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In Zambia, women engaging in sex work (WESW) are a key population (KP) disproportionately affected by the HIV pandemic, with prevalence significantly higher than the general population. Despite high initiation rates, persistence on pre-exposure prophylaxis (PrEP) remains low among sex workers. This dissertation explores the barriers and enablers to PrEP uptake and persistence among WESW in Lusaka, Zambia, through a mixed-methods approach.

Chapter 2 examines the association between discrimination, multiple types of stigmas, and PrEP persistence among sex workers. Using a prospective cohort design, 298 cis-gendered WESW aged  $\geq 18$  years were enrolled and eligible from two urban community hubs. Surveys assessed chronic discrimination and validated scales for HIV and PrEP stigma, were linked to electronic medical records (N=262) to track PrEP persistence. High levels of chronic discrimination, primarily due to being identified

as a sex worker, were significantly associated with immediate PrEP discontinuation (aPR=1.6; 95%CI:1.07,2.54; p=0.03).

Chapter 3 qualitatively explores perceptions and preferences for oral and long-acting injectable PrEP (LAI-PrEP) among WESW and peer-navigators. Using the COM-B model, the study identified critical factors influencing PrEP engagement. Education by peer navigators and program staff was crucial in building trust and demystifying PrEP among participants, though persistent knowledge gaps, especially about adherence and alcohol use, remained significant barriers. Trustworthy program staff and reliable service provision facilitated continued PrEP use. Long-acting injectable PrEP (LAI-PrEP) was preferred for its reduced stigma and pill burden but concerns about side effects and supply inconsistency emerged as potential barriers.

The findings underscore the need for holistic, person-centered approaches that address psychosocial and structural barriers, while leveraging available peer support and targeted prevention education to enhance PrEP engagement. By implementing stigma reduction interventions and creating trustworthy, KP-led services, HIV prevention efforts among WESW in Zambia can be significantly improved.

## Acknowledgements

During this work I had the honor of caring for *ammama* at the end of her life and caring for *amma* through a cancer diagnosis and treatment. My sister was my partner through this, and courageously persevered to earn her a degree from one of the most prestigious law schools in the country. To each of you and all the women in my ancestral lineage: thank you for making sacrifices, many of which I have no knowledge of, so that I could complete this degree.

I acknowledge the men in my life, *appa* who taught me the greatest lesson a father can teach a daughter: to choose myself. I honor *thatha's* belief that self-discipline is the highest form of self-respect, and *thambi thatha's* lesson: 'your life is in your own two hands.' I am the master of my destiny. Thanks to my extended family in India who supported us as we lost a pillar of the family.

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When we think of wealth, we think of our accumulated assets and resources or ‘capital.’ Community wealth requires its own forms of capital. Marginalized communities require ‘navigational capital’ to survive in an institution that seeks to destroy our ways of knowing and being. The following students and recent graduates invested navigational capital in me: Dr Arthur Sillah, Mohamed Albrair, Fatima Al Shimari, Dr Kidist Zewdie, Kieran Blaikie, Tia ‘Tee’ Benally, and Tanya Libby. The Center for Anti-Racism and Community Health (ARCH), the Deans Advisory Council of Students, and the International Student Support Program are inspiring scholars working for our collective liberation. Special thanks to Dr Natasha Ludwig-Barron who helped me select this university, and like a true sister with Dr Tina Sesay, supported me mind, body, and spirit every step of the journey.

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It takes a village to raise a child, but for Ramya, it took the entire planet.

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I continued even when I was scared, lonely, and exhausted. I didn't quit. I persevered. The only reason I was able to, was through faith in my Creator. God has given me abundant blessings, and I am grateful for all of them.

## Dedication

This work has a dual dedication.

To *ammama*, you taught me to be a citizen of the world, and to expect more from myself, than of others. You embodied the greatest qualities of womanhood: confidence, elegance, intelligence, and grace. Your enduring love and commitment to your worldwide family, friends, community, and your country has been my lifelong inspiration. It was a privilege to be your granddaughter.

*Everything good in me, is a reflection of you.*

To mummy, you are a powerhouse single mother. You raised two girls as an immigrant to America. You have worked every single day of your adult life, even during sickness, to protect and provide for us. You are truly incredible in every sense of the word. You take joy in every aspect of our lives: our friendships, our successes, our adventures. It is an honor to be your daughter, and it is even more special to be your friend.

*Everything that I can become, is thanks to you.*

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## Chapter 1: Introduction

In Zambia, women engaging in sex workers (WESW) are a key population disproportionately affected by the HIV epidemic, with HIV prevalence significantly higher than in the general population. Despite efforts to scale up HIV prevention and treatment services, significant service gaps remain, particularly in reaching marginalized groups like WESW. In 2022, the Zambia Demographic and Health Survey highlighted that 48.8% of WESW are living with HIV, highlighting an unmet need for effective combination HIV prevention, including pre-exposure prophylaxis for HIV (PrEP). While PrEP has been shown to be a highly effective biomedical prevention method, barriers such as stigma, discrimination, and logistical challenges hinder its consistent use among WESW. As a result, persistence on pre-exposure prophylaxis (PrEP) remains low in this population.

The Zambian National HIV/AIDS Strategic Framework emphasizes the need for targeted interventions for key populations, including sex workers, aligning with the UNAIDS 95-95-95 goals to ensure 95% of people living with HIV know their status, 95% of those diagnosed are on antiretroviral therapy (ART), and 95% of those on treatment are virally suppressed. Despite progress, factors such as socio-cultural stigma, discrimination, economic instability, and lack of legal protections continue to drive new HIV infections among WESW[1].

Sex workers in Zambia face intersecting stigmas related to their gender, profession, HIV status, prevention behaviors, and other structural factors and socio-economic vulnerabilities. These stigmas manifest as discrimination, which significantly impacts their health-seeking behaviors like PrEP uptake and persistence. The Key Population Investment Fund (KPIF), implemented by the Centre for Infectious Disease Research in Zambia (CIDRZ) in partnership with the Ministry of Health and key population civil society organizations (KP-CSOs), has been instrumental in providing community-based HIV prevention

and treatment services. However, the persistence of high levels of stigma and discrimination underscores the need for more nuanced and person-centered interventions.

The introduction of long-acting injectable PrEP (LAI-PrEP) offers a promising advancement in HIV prevention. LAI-PrEP, specifically cabotegravir, has been shown to be highly effective in preventing HIV acquisition and is particularly beneficial for individuals who struggle with daily oral PrEP adherence. Recent trials, such as the HPTN 084 study, demonstrated that LAI-PrEP is significantly more effective than oral PrEP in preventing HIV among women in sub-Saharan Africa, including countries like Zimbabwe, South Africa, and Kenya, where high HIV incidence persists among cis-gendered women [2]. In February 2024, Zambia launched the rollout of long-acting injectable cabotegravir (CAB-LA) for HIV prevention, making it the first country in Africa to offer this injectable PrEP outside of a study setting.

This dissertation aims to understand the barriers and enablers to PrEP uptake and persistence among WESW within Lusaka, Zambia, through a mixed-methods approach. [Chapter 2](#) examines the association between discrimination, various types of stigmas, and PrEP persistence, using data from a prospective cohort study of 316 women in sex work. The findings indicate that high levels of chronic discrimination, particularly due to being identified as a sex worker, significantly increase the likelihood of immediate PrEP discontinuation. [Chapter 3](#) explores perceptions and preferences for oral and long-acting injectable PrEP (LAI-PrEP) among WESW who immediately discontinued PrEP after initiation (n=6), continued on PrEP (n=6), and peer-navigators (n=6) using qualitative methods. The study identifies critical factors influencing PrEP engagement, including socio-structural barriers and the potential benefits of LAI-PrEP in reducing stigma and the burden of daily pill adherence. [Chapter 4](#) concludes with policy and service recommendations aiming to improve care for sex workers, with the ultimate goal of working towards community-level reduction in HIV incidence. A list of conceptual definitions is found in [Appendix 1](#).

Importantly, this study was collaboratively developed using community-based participatory research (CBPR), a research paradigm that focuses on relationships between academic and community partners, with principles of co-learning, mutual benefit, and long-term commitment. CBPR incorporates community theories, participation, and practices into the research efforts and plays a role in expanding the reach of implementation science to influence practice and policies for eliminating health disparities[3,4]. A Community Advisory Board (CAB) with two KP-CSOs working in the study sites: the Zambia Sex Workers Alliance and Tithandizeni Umoyo Network worked with the study team to develop trust with people engaging in sex work. The study team worked with the CAB to adapt the study within complex systems of organizational and cultural context and knowledge.

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## **Chapter 2: Enhancing PrEP Persistence – Understanding Stigma and Discrimination Among Women Engaging in Sex Work in Lusaka, Zambia**

### **Abstract**

**Introduction:** Globally, women engaging in sex work (WESW) have 21 times the risk of HIV acquisition compared to the general population, yet persistence on HIV pre-exposure prophylaxis (PrEP) remains low, and the impact of stigma on short-term persistence is poorly understood. This quantitative analysis from a mixed-method study in Lusaka, Zambia, examined the association between discrimination and multiple types of stigmas and PrEP persistence among WESW.

**Methods:** We used a prospective cohort design and community-based participatory research principles, enrolling 316 cis-gendered WESW aged  $\geq 18$  years from two urban hubs (July–October 2023). This study was embedded within a program where key population (KP) civil society organizations provided health services with the Ministry of Health. We administered a survey to assess chronic discrimination using the Everyday Discrimination Scale and validated scales for HIV and PrEP stigma. Routine electronic medical record data was abstracted to assess PrEP outcomes. An adjusted mixed effect regression model, including fixed effects for confounders (community hub, age, education, and duration of sex work) identified from a directed acyclic graph, was used to estimate the likelihood of discrimination on discontinuing PrEP within 3 months of initiation. We report adjusted prevalence ratios (aPR) and 95% confidence intervals (95%CI).

**Results:** We had 97% of enrolled WESW initiate on PrEP and 262 (87.2%) remained in the final analysis set. The median age was 24 years (interquartile range [IQR]: 21,29), with 50.8% aged 18-24 years. Median duration of sex work was 3 years (IQR: 2,4), 70.2% were single or never married, 84% had less than secondary education, 88.5% were not employed outside sex work, and 8% lived in extreme poverty. Prevalence of high chronic discrimination prevalence was 28.2%, PrEP stigma was 22.5%, and HIV

stigma was 20.2%. Immediate discontinuers had higher chronic discrimination (32.2%) than those with refill visits (27.1%). Chronic discrimination in the past year was associated with immediate PrEP discontinuation (aPR=1.6; 95%CI:1.07,2.54; p=0.03), predominantly due to being identified as a sex worker (93.1%). PrEP stigma slightly increased (aPR=1.02; 95%CI:0.58,1.81; p=0.93), and HIV stigma reduced the likelihood of immediate discontinuation (aPR=0.68; 95%CI:0.37,1.26; p=0.22), though not significantly so.

**Conclusion:** Chronic discrimination from being identified as a sex worker is associated with immediate PrEP discontinuation, even in programs designed for KP and run by KP. Stigma reduction interventions aimed at creating societal change and addressing multi-level causes of discrimination are needed to improve HIV prevention services for WESW.

## **Background**

Women who engage in sex work (WESW) are a key population (KP) that is disproportionately affected by HIV. Globally sex workers have 21 times the risk of HIV acquisition compared to the general population [1]. Yet, less than 50% have access to highly effective HIV prevention strategies like HIV pre-exposure prophylaxis (PrEP) [1,2]. Almost two-thirds of total new HIV infections occur on the African continent, and 25% of those are among WESW in the Southern and East African regions [3]. Addressing this disparity necessitates tailored prevention strategies to effectively reduce the HIV burden among African WESW, as well as people in their sexual network, thereby reducing the burden of HIV in Africa[4,5].

WESW often face multiple layers of stigma due to intersecting identities, conditions, and behaviors. For example, being involved in sex work (identity), living with HIV (condition), and taking medications for HIV prevention (behaviour), may result in multiple intersecting stigmas [6,7]. Stigmas — negative beliefs, attitudes and stereotypes about a person or group— behaviorally manifest as discrimination. This complex interplay of stigmas exacerbates the discrimination experienced by WESW, impacting their health-seeking behaviors.

Effective HIV interventions must address the co-occurrence of multiple stigmas to improve health outcomes among WESW. Many HIV interventions that address HIV stigma alone have had limited success in making lasting improvements in health or reducing health disparities [7]. People with multiple stigmatized conditions across low and middle income countries have been found to be less likely to seek help and treatment for any condition when they experience health-related stigma [8]. Ignoring multiple stigmas can hinder health-seeking behaviors, thereby limiting the success of HIV prevention efforts.

Discrimination poses a significant barrier to HIV prevention efforts among WESW in Zambia, affecting their willingness to seek care. The Southern African republic of Zambia has a generalized HIV

epidemic, and the capital city of Lusaka is a major regional transit hub attracting WESW from the region. Approximately 126,000 WESW live in the country, although this is likely an underestimate [9]. Of these women, nearly half (48.8%) are living with HIV, underscoring the need to urgently tailor prevention strategies for this population [9]. WESW within Zambia are subject to discrimination in the form of verbal, physical, and sexual abuse from strangers, acquaintances, clients, intimate partners, and even health care providers [9]. Surveys among WESW in Zambia have shown provider stigma and discrimination, as well as a lack of confidential care were their main barriers to HIV prevention services at public health facilities [9,10]. To develop effective interventions, it is essential to understand the multifaceted stigmas that influence PrEP initiation and persistence among WESW.

Significant progress has been made in Zambia to provide comprehensive HIV prevention services to KPs through initiatives like the PEPFAR-funded Key Population Investment Fund (KPIF). KPIF has been successfully engaging with KPs to provide community-based HIV prevention and treatment services in Lusaka Province. KPIF is implemented by the local Zambian non-governmental organization, the Centre for Infectious Disease Research in Zambia (CIDRZ), in partnership with the Zambian Ministry of Health (MoH), U.S. Centers for Disease Control and Prevention (CDC) and most importantly, Key Population civil society organizations (KP-CSOs). A key objective of the KPIF program is to improve the uptake, persistence, and continuation on PrEP among HIV-negative KP.

Despite high PrEP initiation rates, significant gaps remain in achieving sustained PrEP engagement among WESW in Zambia. Although high numbers of WESW are initiating PrEP through KPIF community-based outreach services, the number of PrEP initiations may not be a very useful indicator for estimating PrEP effectiveness [11]. Although the World Health Organization (WHO) and national PrEP guidelines recommend that PrEP clients are tested for HIV at one and three months after initiation and every three months thereafter, there have been challenges in achieving continued engagement in follow-up visits [12,13]. Despite increasing adoption of PrEP, there is limited data on the

number of WESW in Zambia initiating PrEP who persist on PrEP in the short term. A global systematic review, found high PrEP discontinuation after 1 month [14]. Assessing whether a large percentage of PrEP clients are not returning for the first follow-up visit has important implications for PrEP effectiveness since oral PrEP with emtricitabine and tenofovir disoproxil fumarate (FTC/TDF) reaches maximum effectiveness after about 20 days of daily use. It is important to note, that current prevention strategies do not consider multiple stigmas and the resulting psychosocial stress as important barriers to PrEP persistence. Understanding the barriers to PrEP persistence, particularly those related to stigma and psychosocial stress, is crucial for improving PrEP effectiveness.

The overall goal of this study was to measure the effect of discrimination, and types of stigmas on PrEP uptake and persistence among WESW. Our hypothesis was that discrimination or stigma was associated with PrEP discontinuation.

## **Methods**

### ***Study Population & Setting***

This quantitative analysis is from a mixed-method study in Lusaka, Zambia, The *Women in Sex work, Stigma, and PrEP* (WiSSPr) study. The overall rationale of the parent study was to understand what the enabling factors and psychosocial barriers were to initiate and persist on PrEP for WESW. By identifying these barriers, we sought to inform the future development of targeted, stigma-reduction interventions to improve PrEP outcomes for WESW in the African region.

The study population was comprised of adult WESW who are living or working in urban Lusaka. We conducted a prospective observational cohort study to characterize PrEP outcomes for adult HIV-negative, PrEP-naive WESW within Lusaka, Zambia. The study enrolled participants from July-October 2023 from two community-based wellness centres within urban Lusaka. Both were successfully providing HIV services in the community since October 2021. These hubs are drop-in centers, but also provide

community-based outreach at venues where sex workers socialize, like bars, brothels, and guesthouses. Hubs are run by Ministry of Health (MOH) personnel trained in KP-friendly services, and KP CSOs. The electronic medical record (EMR) 'SmartCare' is installed in each hub which is linked to a government health 'mother' facility for data management and reporting.

### ***CBPR Approach***

The study was guided by a Community Advisory Board (CAB) comprised of KP-CSOs, MOH, and CIDRZ staff and used community-based participatory research (CBPR) principles to prioritize trust development, essential due to the criminalization and historical marginalization of sex workers in Zambia [15–17]. The CAB guided decision-making, recruitment strategies, with the aim of minimizing participant harms. They also ensured sensitive issues like HIV-related stigma and abuse were handled with care, providing psychosocial support and referrals when necessary.

### ***Data Collection***

A team of trained research assistants (including WESW who were also peer-navigators), administered a one-time survey in English, ChiNyanja, or IchiBemba, based on participant preference. We collected data on demographics, income generated from sex work and other economic activities, intersectional discrimination from the Everyday Discrimination Scale (EDS), and HIV and PrEP stigmas adapted from the Internalized AIDS-Related Stigma Scale and the Community PrEP-related stigma scale respectively [18–21]. Data were entered into an electronic data capture tablet.

We linked participants to the EMR and abstracted routine data on oral PrEP pharmacy dispensations. We defined PrEP uptake as the total number of individuals initiated on PrEP divided by the total number enrolled in the KPIF program and offered PrEP. We conceptualized persistence in two ways: (1) immediate discontinuation for those who initiate on a 30 day supply of PrEP and do not return for any

refills over the 108 day observation period and (2) medication possession ratio (MPR) of total days with medication in client possession to the observation period, as a measure of engagement in services. Coverage greater than 1 (i.e., indicating the client came back for a PrEP refill before the expected date for pills to run out) was truncated to 1.

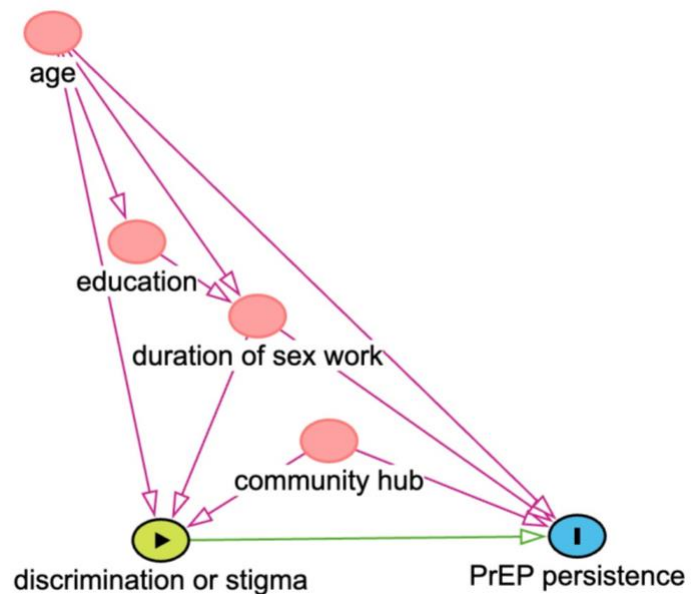
### ***Sample Size***

We used the approaches from Demidenko *et al.* and Witte *et al* to help calculate the minimum sample size for this research [22,23]. Sample size considerations were based on a primary outcome of PrEP initiation and informed through preliminary programmatic data to form assumptions of baseline HIV prevalence and estimated PrEP initiation. We sought to enroll a sample of 300 eligible WESW. Assuming 5% of participant medical records could not be found, a total cohort of 285 PrEP users would allow us to estimate the effect size of stigma on PrEP initiation of 1.98 or higher (positive association) or 0.50 or lower (negative association) with 80% power at a significance level of 0.05.

### Data Analysis

We used the chronicity-based coding approach to the EDS in order to reflect the total number of reported discrimination experiences, standardized on the total number of days per year [24]. 'Never' was coded 0. 'Less than once a year' was coded as the midpoint between 0 and 1 time per year=0.5×/year. 'A few' is generally interpreted as 2–4, so we selected the midpoint=3. We coded 'a few times a year' as 3×/year and 'a few times a month' as 3×12 months=36×/year. We coded 'at least once a week' as 2×52 weeks=104×/year and 'almost every day' as 5×52 weeks=260×/year. Recoded 5 items were summed to represent the total number of EDS experiences annually (range: 0–1300,  $\alpha=0.8829$ ). The anticipated community-level stigmas around HIV (range: 4-13,  $\alpha=0.785$ ), and PrEP (range: 4-15,  $\alpha=0.5885$ ) were measured by summing scores from the 4-item scale, with a value closer to 16 indicating greater stigma. We reverse coded 1 item which had a positive perception. To facilitate comparisons between scales, we collapsed each into tertiles reflecting low, moderate, and high exposure.

We report descriptive statistics for MPR (median and interquartile range [IQR]), and bivariate associations with Pearson's chi-square for immediate discontinuation. Using Stata (v16), we fit an adjusted, mixed effect regression model, including fixed effects for confounders—community hub, age, education, and duration of sex work—which were identified by a directed-acyclic graph (Figure 1), to estimate likelihood of chronic discrimination, PrEP stigma, and HIV stigma on immediate



**Figure 11:** Directed acyclic graph (DAG) illustrating the causal effect of stigma on PrEP persistence. Minimum adjustment to estimate the total effect: community hub, age, duration of sex work, education.

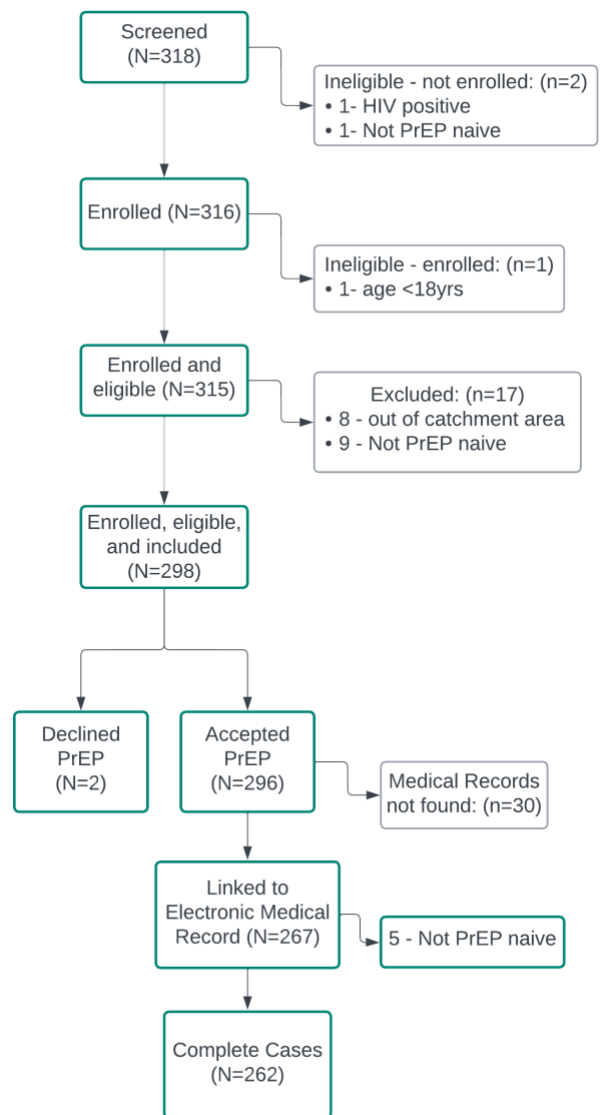
discontinuation of PrEP over a 3-month follow-up period. We report adjusted prevalence ratios (aPR), 95% confidence intervals (CIs) and p-values at the alpha=0.05 significance level.

### Ethics

This study was approved by the University of Zambia Biomedical Research Ethics Committee (UNZABREC; protocol 3650-2023), dated 21/06/2023 and the University of North Carolina (UNC) Biomedical Institutional Review Board (IRB) (22-3147), dated 11/07/2023. University of Washington agreed to rely on UNC IRB for ethical oversight through an IRB Reliance Agreement. All participants provided written informed consent in their preferred language. As added protection for this marginalized population, participants completed an informed consent quiz to ensure that they understood the risks of the study.

### Results

Screening, enrolment and linkage to the EMR are described in the Figure 2 CONSORT diagram (**Figure 2**). Of the 318 participants screened, 298 (93.1%) were eligible. The main reasons for study ineligibility included testing HIV positive, history of PrEP use, or not living or working within the catchment area.



**Figure 2:** Flowchart of enrollment and inclusion in analysis

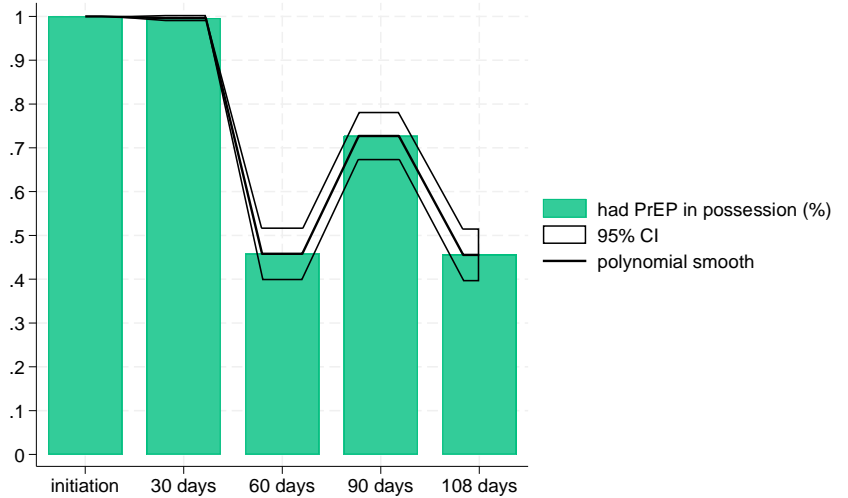
**Participant Characteristics**

Of the enrolled participants, 296 (99.3%) initiated on PrEP and 262 were linked to the EMR. The median age was 24 (IQR: 21, 29) and 50.8% were 18-24 years old. Women were mostly single or never married (70.2%) and had less than a secondary school (84%) education (Table 1). The median duration of sex work was 3 years (IQR: 2, 4). The majority were not employed outside of sex work (88.5%) and 8% were living in extreme poverty as defined by the World Bank indicator of living on <\$2.15 per day. Participant characteristics disaggregated by community hub are available in Supplemental

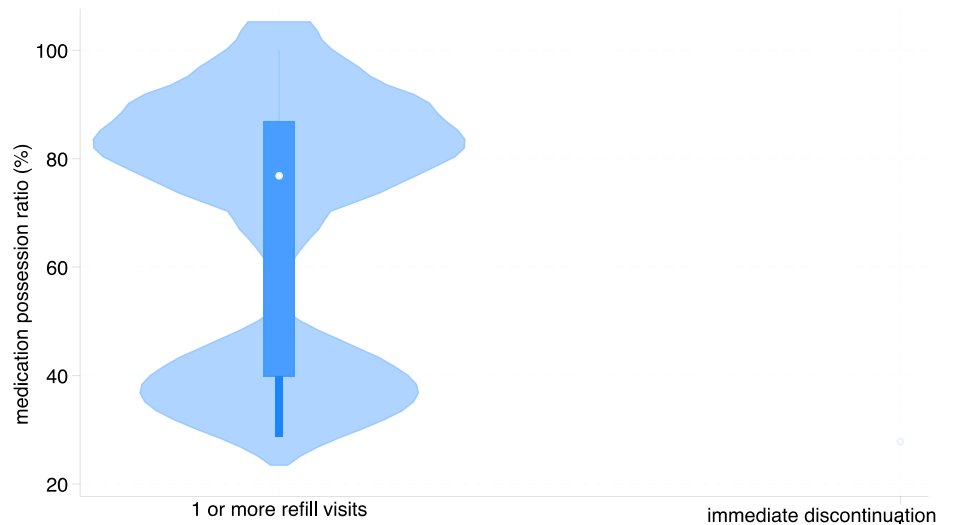
[Table S1](#).

**PrEP Persistence**

We linked 262 (88.5%) participants to the EMR. PrEP uptake was 97%. All study participants had PrEP in their possession at 30 days after initiation, less than half (45%) of participants have PrEP by 60 days, 70% at



**Figure 3:** Bar chart of those with PrEP in possession (%) at time points post initiation (N=262)



**Figure 4:** Violin plots of medication possession ratio for those with one or more refills vs immediate discontinuations (N=262)

90 days, and 45% at 108 days (**Figure 3**). Immediate discontinuation defined as no refill visits during the observation period was high 22.5% (**Table 2**). The MPR exhibited a bimodal distribution among participants who returned for one or more refills, with two distinct groups: MPR values ranging from 20-50%, indicating lower adherence, and the other ranged from 70-100%, indicating higher adherence. This suggests that participants tended to fall into two main adherence groups, either having relatively low or high medication possession rates (**Figure 4**).

#### ***Prevalence of Discrimination, PrEP and HIV Stigmas***

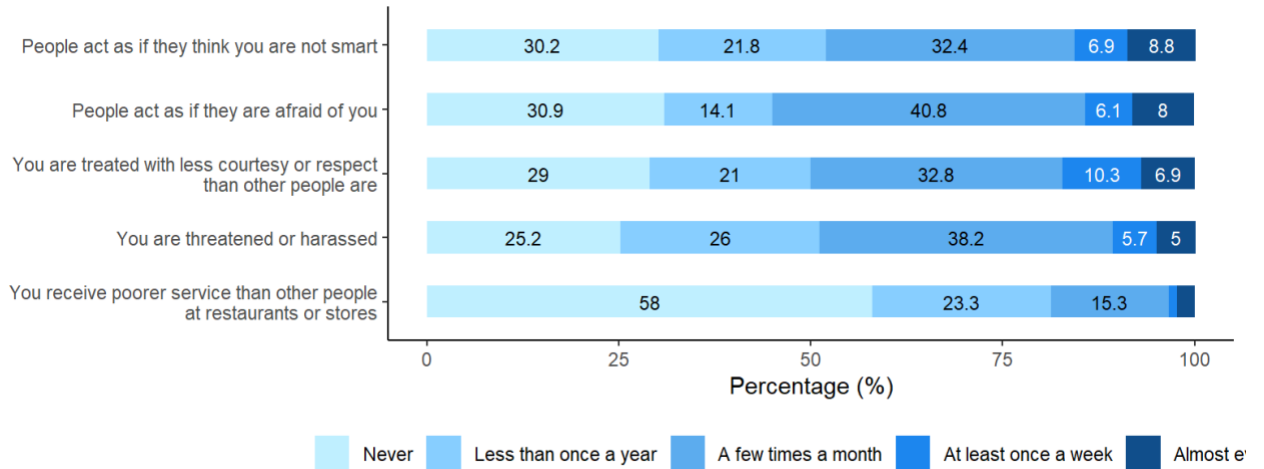
Overall, participants had high discrimination scores on the EDS. Items that most frequently had a response of “at least once a week” or “almost everyday,” indicating a high frequency of discrimination in the last one year, included being treated with "less courtesy or respect (17.2%)," being treated as "not smart (15.7%)," people act "afraid (14.1%)," and feeling "threatened or harassed (10.7%)" by people in general (**Figure 5a**). The EDS demonstrated internal consistency with a Cronbach’s alpha of 0.88.

Participants also exhibited high PrEP stigma scores. Items that most frequently had a response of “strongly agree” or “agree,” indicating a high level of stigma, included perceptions that people taking PrEP are not being “responsible about their health (77.1%),” are viewed as "promiscuous" or "having casual sex (70.6%),” are living with HIV (67.6%), and a belief that PrEP is "not safe for health (60.7%)" (**Figure 5b**). The PrEP Likert stigma scale had low reliability, with a Cronbach’s alpha below 0.60.

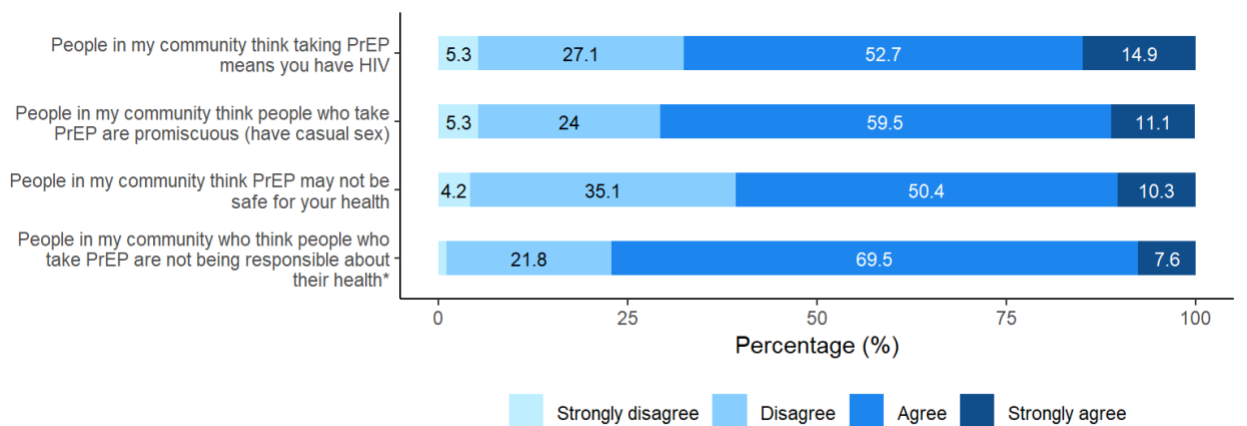
The prevalence of high HIV stigma was lower than that of discrimination and PrEP. Items that most frequently had a response of “strongly agree” or “agree,” indicating a high level of stigma, included disagreement with statements that people living with HIV are treated badly or "sacked" at work (10.8%), or "lose friends" if they acquire HIV (14.2%) (**Figure 5c**). The Likert HIV stigma scale showed internal consistency with a Cronbach’s alpha of 0.81.

The overall prevalence of high chronic discrimination was 28.2%, high PrEP stigma was 22.6%, and high HIV stigma was 20.2% (**Table 2**). Immediate discontinuers experienced higher prevalence of

chronic discrimination (32.2%) compared to those with one or more refill visits (27.1%). Conversely, those with one or more refill visits experienced higher rates of PrEP stigma (23.2% vs. 20.3%) and HIV stigma (21.2% vs. 17.0%) compared to immediate discontinuers.

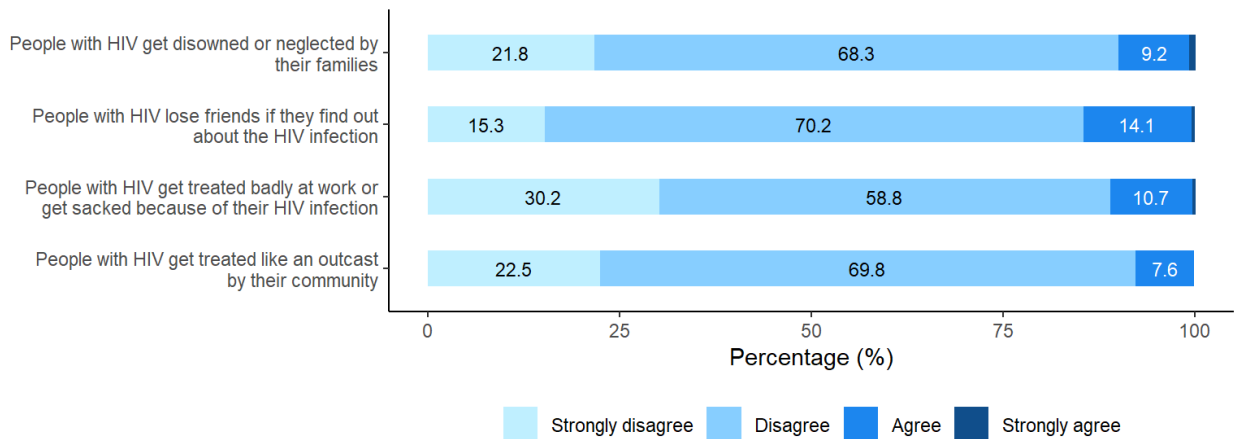


**Figure 5a:** Endorsements of Everyday Discrimination Scale (N=262)



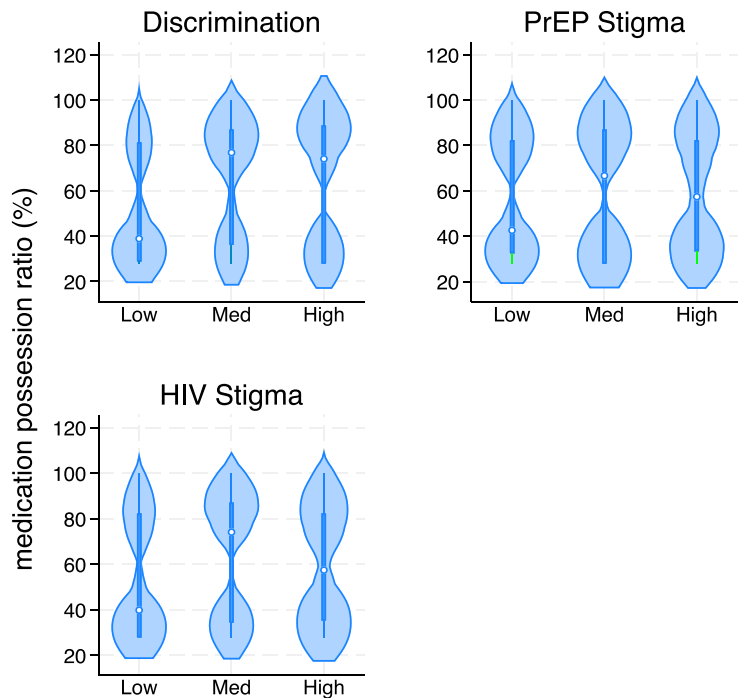
\*Changed wording to reflect reverse scores, original wording in supplementary material

**Figure 5b:** Endorsements of Adapted PrEP Stigma Likert Scale (4-point scale)(N=262)



**Figure 5c:** Endorsements of Adapted HIV Stigma Likert Scale (4-point scale) (N=262)

The overall median MPR was 57.4 (IQR: 30.6, 82.4) (**Table 3**). The median MPR was higher in the highest tertile of discrimination, PrEP stigma, and HIV stigma compared to their respective lowest tertiles (**Figure 6**). For those in the highest tertile of discrimination, the median MPR was 74.0 (IQR: 27.8, 88.9), compared to 38.9 (IQR: 28.7, 81.5) in the lowest tertile. For those in the highest tertile of PrEP stigma, the median MPR was 57.4 (IQR: 33.3, 82.4), compared to 42.6 (IQR: 32.4,



**Figure 6:** Violin plots of medication possession ratio by tertiles of discrimination, PrEP and HIV stigmas (N=262)

82.4) in the lowest tertile. For those in the highest tertile of HIV stigma, the median MPR was 57.4 (IQR: 35.2, 82.4), compared to 39.8 (IQR: 27.8, 82.4) in the lowest tertile.

***Measures of Association between Discrimination, Stigmas and PrEP Persistence***

WESW experiencing high chronic discrimination in the past year had higher likelihood of immediate PrEP discontinuation (aPR=1.60; 95%CI:1.07,2.54; p=0.03) (**Table 4**). This reason for discrimination was predominantly due to being identified as a sex worker (93.1%) ([Supplement Table S2](#)). PrEP stigma slightly increased the likelihood (aPR=1.02; 95%CI:0.58,1.81; p=0.93), and HIV stigma reduced the likelihood of immediate discontinuation (aPR=0.68; 95%CI:0.37,1.26; p=0.22), though not significantly so.

**Table 1: Descriptive Summary of Enrollment Characteristics (N=262)**

	<b>N (%) or median (IQR)</b>
Age	24 (21-29)
Age	
younger (18-24)	133 (50.8%)
older (25+)	129 (49.2%)
Duration of sex work in years, median (IQR)	3 (2-4)
Highest education obtained	
none	9 (3.4%)
incomplete primary	118 (45.0%)
complete primary	36 (13.7%)
incomplete secondary	57 (21.8%)
completed secondary or higher	42 (16.0%)
Marital status	
single/never married	184 (70.2%)
married	3 (1.2%)
divorced/separated	69 (26.3%)
widowed	6 (2.3%)
Number of children, median (IQR)	1 (0-2)
Number of dependents, median (IQR)	3 (2-4)
Self-report employment status independent of sex work	
employed: informal	9 (3.4%)
employed: public/private	3 (1.2%)
employed: self	18 (6.9%)
unemployed	60 (22.9%)
unemployed and seeking work	172 (65.7%)
Income generating activities independent of sex work	
Yes	51 (19.5%)
No	211 (80.5%)
Monthly income from sex work (USD) , median (IQR)	140 (75-210)
Monthly income from other employment (USD) , median (IQR)	0 (0-25)
Monthly income total (USD) , median (IQR)	175 (100-258)

Living in extreme poverty (<\$2.15)*	
Yes	20 (8%)
No	232 (89%)
Missing	10 (4%)

\*World Bank Indicator of <\$2.15 indicates living in extreme poverty

**Table 2:** Frequency Of Discrimination, Prep and HIV Stigmas Among Those Who Immediately Discontinue and Those with One Or More Refill Visits (N=262)

	Overall	Immediate discontinuation	One or more refill visit	p-value
	N (%) or median (IQR)			
	N=262	N=59	N=203	
Age	24 (21-29)	25 (23-30)	24 (21-29)	0.16
Age				0.08
younger (18-24)	133 (50.8%)	24 (40.7%)	109 (53.7%)	
older (25+)	129 (49.%)	35 (59.3%)	94 (46.3%)	
Community hub				<0.001
A	124 (47.33%)	2 (3.4%)	122 (60.1%)	
B	138 (52.7%)	57 (96.6%)	81 (39.9%)	
Discrimination Score	73.5 (1.0-180.0)	73.5 (0.5-212.0)	73.5 (1.5-180.0)	0.79
Discrimination Tertiles				0.33
low	105 (40.1%)	26 (44.1%)	79 (38.9%)	
medium	83 (31.7%)	14 (23.7%)	69 (34.0%)	
high	74 (28.2%)	19 (32.2%)	55 (27.1%)	
PrEP Stigma Score	10.0 (9.0-11.0)	11.0 (9.0-11.0)	10.0 (9.0-11.0)	0.98
PrEP Stigma Tertiles				0.60
low	132 (50.4%)	28 (47.5%)	104 (51.2%)	
medium	71 (27.1%)	19 (32.2%)	52 (25.6%)	
high	59 (22.5%)	12 (20.3%)	47 (23.2%)	
HIV Stigma Score	8.0 (6.0-8.0)	7.0 (6.0-8.0)	8.0 (7.0-8.0)	0.12
HIV Stigma Tertiles				0.07
low	100 (38.2%)	30 (50.9%)	70 (34.5%)	
medium	109 (41.6%)	19 (32.2%)	90 (44.3%)	
high	53 (20.2%)	10 (17.0%)	43 (21.2%)	

**Table 3:** Medication Possession Ratios Overall, and by Tertile of Discrimination and Stigmas (N=262)

	<b>N</b>	<b>Median (IQR)</b>	<b>Range</b>
Overall	262	57.4 (30.6,82.4)	(27.8,100)
Discrimination			
low	105	38.9 (28.7,81.5)	(27.8,100)
medium	83	76.9 (36.1,87)	(27.8,100)
high	74	74.1 (27.8,88.9)	(27.8,100)
PrEP Stigma			
low	132	42.6 (32.4,82.4)	(27.8,100)
medium	71	66.7 (27.8,87)	(27.8,100)
high	59	57.4 (33.3,82.4)	(27.8,100)
HIV Stigma			
low	100	39.8 (27.8,82.4)	(27.8,100)
medium	109	74.1 (34.3,87)	(27.8,100)
high	53	57.4 (35.2,82.4)	(27.8,100)

**Table 4:** Measures of Association between Discrimination, Stigmas and Immediate Discontinuation of PrEP (N=262)

	<b>Crude</b>			<b>Adjusted</b>		
	<b>PR</b>	<b>95%CI:</b>	<b>p-value</b>	<b>aPR</b>	<b>95%CI:</b>	<b>p-value</b>
Discrimination						
low	ref	-	-	ref	-	-
medium	0.68	(0.38,1.22)	0.20	1.20	(0.70,2.06)	0.50
high	1.04	(0.62,1.73)	0.89	1.65	(1.07,2.54)	0.03
PrEP Stigma						
low	ref	-	-	ref	-	-
medium	1.26	(0.76,2.09)	0.37	1.41	(0.91,2.19)	0.13
high	0.96	(0.52,1.75)	0.89	1.02	(0.58,1.81)	0.93
HIV Stigma						
low	ref	-	-	ref	-	-
medium	0.58	(0.35,0.97)	0.04	0.78	(0.48,1.27)	0.32
high	0.63	(0.33,1.19)	0.15	0.68	(0.37,1.26)	0.22

## Discussion

Although PrEP uptake and initiation were high, many women immediately discontinued PrEP. Our study is the first to find that WESW experiencing high levels of chronic discrimination had a higher likelihood of immediate PrEP discontinuation. KP-led programs are successfully reaching WESW and initiating them onto oral PrEP, yet there are varying levels of PrEP engagement in the three month period immediately following initiation. Our study had higher PrEP initiations compared to recent CDC estimates across 27 countries, which found less than 30% of HIV-negative female sex workers initiating PrEP [25]. Consistent with other studies, we observed low short-term persistence: a Kenyan demo project found only 26.3% continued oral PrEP at three months, and 14% at twelve months, while the TAPS study in South Africa found only 43.8% continued at twelve months post-initiation [26,27]. Further understanding the drivers of PrEP discontinuation is needed to improve uptake and continuation of PrEP, along with ongoing community education and demand generation. While innovations like long-acting injectable (LAI) and event-driven PrEP may increase uptake, systemic structural barriers must also be addressed.

Although selling sex itself is legal, the laws in Zambia criminalize activities around sex work such as soliciting, procuring, and living off the earnings of sex work [28,29]. Thus, sex work still takes place in a largely criminalized environment [30]. Police authorities use several nuisance-related offenses in the Penal Code to arrest, detain, and harass sex workers, infringing on their basic human rights and freedoms. This behavior by authorities violates international human rights norms and standards, and a punitive environment affects overall safety and access to HIV prevention and treatment services for WESW [31]. Chronic discrimination against sex workers significantly impacts PrEP discontinuation due to psychological stress, reduced motivation to seek HIV services, and erodes trust in medical professionals and institutions, discouraging regular engagement with HIV care services even within KP-led programs [32–34]. Ongoing discrimination reinforces the stigma associated with PrEP as HIV medication, causing

individuals to fear judgment or ostracism if seen accessing HIV-related care. Sex workers in Zambia report the main barriers to HIV services as a lack of confidential care, and provider stigma and discrimination, with many women being refused health care and denied police assistance because they were assumed to be a sex worker [9,10].

The barriers to ongoing follow-up will likely persist even with the roll-out of new biomedical interventions. LAIs significantly advance HIV prevention by addressing daily pill adherence issues and reducing stigma associated with oral PrEP, but ongoing follow-up remains essential. The HPTN-083 trial demonstrated cabotegravir effectiveness compared to oral PrEP, yet most HIV transmissions occurred among those missing injection appointments, with many developing resistance to integrase strand transfer inhibitors (INSTIs) [35,36]. This highlights the urgent need to reduce stigma and other healthcare barriers to prevent increased INSTI resistance, especially as LAIs become more widely used [37].

To reduce chronic discrimination and improve support for WESW, interventions must focus on creating trustworthy, KP-led services. These services must prioritize confidentiality, privacy, trustworthiness, and convenient locations to ensure WESW feel safe and supported. Studies with sex workers in Mombassa, Kenya, show that sex workers value these attributes in health services and prefer facilities with friendly providers and a reputation for serving them [38]. Programs may consider using the reachable moment of PrEP initiation as an opportunity to build trustworthiness by linking WESW to other sex-worker-friendly services beyond HIV care, including mental health counseling, substance use services, STI testing and treatment, and reproductive health services.

Policies must integrate stigma reduction into HIV prevention programs. Newly developed conceptual frameworks address how PrEP stigma operates among young women and adolescents, and highlight potential intervention targets at multiple levels in the stigmatization process [39]. Stigma is influenced by factors at multiple levels—policy, health systems, community, and individual—resulting in decreased access to and acceptability of PrEP, limited social support, and negative impacts on mental

health and adherence. Our study suggests that stigma may also be a motivator, and the fear of HIV infection could override other stigmas associated with taking preventive measures, leading to higher adherence to PrEP despite any negative perceptions from peers or society. This heightened fear and motivation to remain HIV-negative could drive consistent use of PrEP as a proactive strategy for health preservation. Recognizing sex work as an identity, along with the intersecting stigmas of HIV and PrEP, as well as gender and sexuality, is crucial for comprehensive stigma reduction efforts.

This study had its limitations. First, the short follow-up duration restricts our ability to observe changes in the relationship between discrimination, stigma and PrEP over time, and the small sample size may have left us underpowered to see statistically significant effects. We lacked electronic adherence monitoring devices or drug level measurements, which are more reliable indicators of PrEP adherence. Recruitment from brothels, bars, and nightclubs may not represent the broader population of sex workers, limiting the generalizability of our findings. Finally, the PrEP stigma scale measured only community stigma, neglecting anticipated or internalized stigma, which may have different effects. This study's strengths include the use of community-based participatory research (CBPR), ensuring the involvement of WESW in the study's design and implementation, which fostered trust and relevance. Zambia's strong sex work activist networks are a valuable resource for sexual health promotion, and PrEP implementation programs should incorporate these networks into programming decisions and peer education initiatives. Additionally, robust data linkage through electronic medical records provided comprehensive "real world" programmatic data on PrEP uptake and persistence.

## **Conclusion**

Even in KP-led programs, while PrEP initiation rates are high, short-term persistence remains low among WESW. Our study identified chronic discrimination related to sex work as a significant factor contributing to immediate PrEP discontinuation. To improve HIV prevention efforts among WESW, it is crucial to implement non-judgmental, and respectful care, as part of a stigma-sensitive, person-centered

approach to public health. Additionally, new stigma-reduction interventions that address the multi-level causes of discrimination and foster societal change are essential. By addressing these barriers, we can enhance PrEP persistence and overall health outcomes for WESW.

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## **Chapter 3: Beyond the Pill: Understanding Barriers and Enablers to Oral and Long-Acting Injectable PrEP for Women in Sex Work in Zambia, a Rapid Qualitative Study**

### **Abstract**

**Introduction:** Women engaging in sex work (WESW) in low- and middle-income countries face a disproportionately high risk of HIV infection. This study explores the enablers and barriers to the uptake and persistence of both oral pre-exposure prophylaxis (PrEP) and long-acting injectable PrEP (LAI-PrEP) among WESW in Lusaka, Zambia.

**Methods:** Our study evaluated Capability, Opportunity, and Motivation behavioral domains, according to the COM-B model, affecting behavioral engagement with PrEP services among newly-initiated WESW from community-based safe spaces. Participants were recruited from July to October 2023, and interviewed utilizing a semi-structured guide to explore barriers and enablers to engagement with HIV prevention. We used a rapid analysis approach, a two-step qualitative method to identify themes aligned with COM-B domains. Interviews were conducted in English, ChiNyanja, or IchiBemba, with all sessions audio-recorded, translated into English when necessary, and transcribed verbatim.

**Results:** Among 18 participants with median age 28 years (IQR:23-33) and 5 years in sex work (IQR:2,7), education provided during outreach by peer navigators and program staff was crucial in building trust and demystifying PrEP. Persistent knowledge gaps and misconceptions, especially about daily adherence and alcohol use, were significant barriers. Trustworthy program staff and reliable service provision facilitated continued use, with women preferring PrEP delivery to them. Social support systems were mixed, offering both aid and competition. Personal empowerment and health protection motivated PrEP use, with LAI-PrEP preferred for eliminating daily pill burdens and associated stigma. However, inconsistent supply and misconceptions about LAI-PrEP posed potential barriers.

**Conclusion:** This study underscores the importance of person-centered care in addressing the complex interplay of individual, community, and programmatic factors influencing PrEP engagement among WESW in Zambia. A holistic focus and adaptive health service delivery approach are crucial to ensure that advances in HIV prevention translate into tangible benefits for KP. Reliable and respectful healthcare programs that provide accurate and trusted information are essential for improving PrEP uptake and persistence.

## **Background**

The global HIV burden among women engaged in sex worker (WESW) is alarmingly high, particularly in regions like Eastern and Southern Africa. In 2022, HIV prevalence was four times as high among sex workers compared with adults in the general population (aged 15-49 years) [1]. Globally, WESW have an HIV prevalence of 10.4%, and among those living in Eastern and Southern Africa, the HIV prevalence is 3 times as high at 33.3% [2]. Failure to protect WESW, a key population (KP) disproportionately affected by HIV, from HIV acquisition will prolong the pandemic indefinitely, at a huge cost to the affected communities and broader societies.

Pre-exposure prophylaxis for HIV (PrEP) is a highly effective biomedical intervention recommended by the World Health Organization for KP at substantial risk of HIV acquisition. The willingness of WESW to use PrEP has been demonstrated in multiple clinical trials, but this willingness does not always translate into actual use in “real world” settings. Several studies show that uptake of PrEP among sex workers is high, but the persistence on PrEP is low [3–5].

Some barriers to uptake and persistence are deeply entrenched in social perceptions and structural barriers. These barriers include socio-structural factors like stigma, discrimination, criminalization, violence, and financial insecurity. Stigma related to PrEP and being perceived as HIV-positive affects uptake and persistence on the drug, even during periods when a person is still at risk. There is additional misinformation about PrEP’s safety, side effects, and efficacy. Logistical and practical barriers to oral PrEP use also remain. These include the need to frequently test for HIV every 3 months while on PrEP, and individual-level challenges like unpredictable schedules for sex work, or having to travel out of town to meet clients, which make clinic visits and consistent PrEP usage difficult.

The introduction of long-acting injectable PrEP (LAI-PrEP) throughout the African continent signifies a potential shift in HIV prevention strategies, though its impact is yet to be fully understood. LAI-

PrEP has shown superior efficacy over daily oral PrEP in clinical trials, offering a new avenue for prevention [6,7]. LAI-PrEP is initially administered once a month for two months and then once every two months as injections, making its discrete and extended-duration formulation especially appealing to adolescents and young women [8–11]. Nevertheless, the most appropriate ways to implement it remains uncertain given the paucity of information on the perceptions and preferences of WESW with regards to PrEP. Healthcare services that neglect the specific preferences of WESW within broader HIV prevention programming for KP could hinder the effectiveness of LAI-PrEP.

Zambia's early adoption of LAI-PrEP marks a significant step in prioritizing advanced HIV prevention methods. Zambia was the first country on the African continent to roll out LAI-PrEP in February 2024. Although the rollout prioritized young women and adolescents in the general population, they may have intersecting identities that qualify them as members of a key population [12]. Programs like the PEPFAR-funded Key Population Investment Fund (KPIF) have been successfully engaging with KPs in Lusaka Province and providing community-based HIV prevention and treatment services to KP including WESW. KPIF is implemented by the local non-governmental organization, the Centre for Infectious Disease Research in Zambia (CIDRZ), in partnership with the Zambian Ministry of Health (MoH), U.S. Centers for Disease Control and Prevention (CDC) and most importantly, Key Population civil society organizations (KP-CSOs). Although programs like KPIF are increasingly reaching sex workers, barriers to PrEP uptake and persistence remain. To address the multilevel barriers that persist in PrEP uptake, health systems must seek to understand these challenges in order to maximize reachable moments by providing highly effective prevention methods.

Our study aimed to understand the perceptions and preferences of oral and LAI-PrEP among cis- and trans-gendered women engaging in sex work as well as peer navigators who identify as WESW employed by the KP CSOs. The objectives of this study were to qualitatively explore the enablers and psychosocial barriers and structural to initiating and persisting on PrEP, and to assess interest and

acceptability of LAI-PrEP. The findings from this research are crucial for refining approaches and ensuring the effectiveness of PrEP interventions, ultimately shaping future HIV prevention policies and community-based programs.

## **Methods**

### ***Study Design***

The WiSSPr parent study was a mixed methods study that used a convergent parallel design to collect quantitative and qualitative data concurrently and separately, prioritizing both strands equally but keeping them independent during analysis. This paper reports the qualitative data only.

### ***Theoretical frameworks***

We used the COM-B model to analyze Capability, Opportunity, and Motivation as drivers of behavioral engagement with PrEP services [13,14]. This framework allowed us to align intervention strategies directly with identified deficits in knowledge or skills (Capability), environmental and social contexts (Opportunity), and personal motivations and attitudes (Motivation). 'Individual' factors are predominantly linked to Capability and Motivation but can overlap with Opportunity when considering the individual's access to resources. 'Environmental' factors are mostly categorized under Opportunity, reflecting how external conditions facilitate or hinder behavior. 'Programmatic' factors influence both Opportunity and Capability by altering the environment or by providing education and support that enable the behavior.

The COM-B model, utilized in HIV prevention, proposes a structured cascade approach to identify and address gaps in motivation, access, and effective use of HIV prevention methods within prioritized populations. This model facilitates routine monitoring, advocacy, and the establishment of clear targets akin to the 95-95-95 goals set for HIV treatment. By analyzing reasons for discrepancies at each stage of the prevention cascade—motivation, access, effective use—it offers a framework to support the

development and implementation of targeted interventions, thereby potentially enhancing the efficacy and reach of HIV prevention programs [15].

In practice, identifying factors at various levels (individual, environment, and programmatic) nested within domains of the COM-B model allows for a comprehensive analysis that addresses the specific barriers and facilitators to PrEP uptake and adherence. This integrated approach ensures that all relevant aspects of behavior change are considered, leading to more effective and sustainable health outcomes.

### ***KPIF Overview***

The WiSSPr parent study was nested within the KPIF program. In the KPIF program, KP CSOs employ women from the sex work community, known as peer-navigators who leverage their own social networks to recruit sex workers to access services at community-based wellness spaces' also referred to as 'drop-in centers'. These drop-in centers have been functioning as community-based outposts of neighboring MoH clinics since October 2021. KPIF also provides venue-based outreach to deliver HIV testing services and prevention services like oral PrEP, condoms and lube at venues where WESW socialize, such as brothels, bars, or the home of a Key Informant (KI). A KI is usually a 'queen mother' leader of WESW or other trusted older woman in the sex work community.

Peer-navigators are involved in all aspects of PrEP delivery together with MoH clinical and laboratory staff trained to be KP-friendly. Together, the teams liaise with the key informants (KIs) who are respected women in the sex work community, providing health education, HIV testing, and PrEP refills, and PrEP adherence support. Their support builds trust and belief in the benefits and effectiveness of PrEP.

Women are sometimes given the date for next PrEP refill, and connected to a peer navigator who is supposed to call and remind them to pick up their next refill at the drop-in center, or the next time the program is making a visit to their preferred venues.

### ***Participant Selection***

From July - October 2023, we recruited WESW who were newly initiated on PrEP from two drop-in centres, and community-based 'safe spaces' in Lusaka, Zambia.

We purposively sampled 18 women: 6 who discontinued PrEP immediately after initiation, 6 who continued on PrEP, and 6 peer navigators who provided the perspectives of women who are 'boundary spanners' at the unique interface of supporters of health service delivery and recipients of care as sex workers themselves. To determine when thematic saturation had been reached, we reviewed interview memos after each interview and extracted themes into a matrix on MS Excel (Redmond, WA, USA).

### ***Data Collection***

We used a semi-structured interview guide ([Appendix 2](#)) with open-ended questions and probes to explore specific themes related to HIV prevention and intersectional stigma. This guide allowed flexibility to follow topics of interest to participants. The themes we explored were informed by our the Socioecological model and the COM-B framework which includes perceived and enacted stigma and discrimination, the impact of intersectional stigmas on health service utilization, service needs, enablers such as psychosocial support or resilience, and building trust in the healthcare system. The guide also included patient education on oral PrEP versus LAI-PrEP, and the interviewer explained that LAI-PrEP is a highly effective HIV prevention method for at-risk adults and adolescents, administered as a bi-monthly injection that maintains protective medication levels in the blood, similar to oral PrEP, and will be available in Zambia in 2024. We did this to assess participants' perceptions on the relative advantages and disadvantages, and willingness to use, these different PrEP options. Participants were asked about their own perceptions as well as those of other sex workers in their community, as this approach has yielded richer responses in other studies with sex workers [16].

All interviews were conducted by a single trained interviewer. JP is a Black cis-gendered Zambian woman, who was not a sex-worker, and was not from the same socioeconomic background or community

as the interviewees. She had previous interaction with the participants, working with the peer-navigators in the hubs on programmatic activities, and from administering a quantitative survey to the women at their baseline visit in the study. Participants were consented and given information that these interviews were to understand what the challenges were for WESW to start using HIV PrEP and to continue using it, to help the program develop appropriate service delivery strategies. The interview guides were developed with input from a community advisory board, and piloted with board members and senior peer-navigators. The interviews were conducted with caution and with the guidance and support of KP-CSOs. The well-being of WESW was the central consideration of the study, which was considered as a driver of the study design and the reasons for the involvement of community advisory board. CSO staff and key informants helped to monitor the emotional reactions of WESW after the interview and provided psychological support to the participants if needed.

Our positionality as researchers, including our socio-cultural backgrounds and professional roles, influenced both the design of the interview questions and our interpretation of the results. We acknowledge that these factors may have shaped the framing of our questions and our understanding of participants' responses, and we sought to address this by incorporating feedback from a community advisory board and peer navigators throughout the research process.

Interviews were conducted in English, ChiNyanja, or IchiBemba based on participant preference. We requested permission to audio record interviews for transcription and translation purposes. The participants had the right to accept or refuse audio-recording, and all participants opted to be audio-recorded. Audio recordings were translated into English and transcribed verbatim in a single step by qualified research staff. The audio-recordings were not marked with any identifying information. Instead, a unique qualitative study identifier was used to label the audio-recordings.

### ***Rapid Qualitative Data Analysis***

Given the initial rollout of LAI-PrEP in Zambia in February 2024, and the urgency of releasing these findings to inform implementation, our analysis was conducted in a two-step process using a rapid qualitative analytic approach [17–19]. First, we used a standard template to create a summary memo of each interview, incorporating both the audio recording and the interviewer’s field notes. Second, we created an analysis matrix; each row was a unique question, and each column was the individual interview. *A priori* themes were determined based on the Socioecological model nested within the domains of COM-B. We identified themes and subthemes across all participants for each question. After the initial round of deductive theme identification, we mapped the themes onto the appropriate domains of the COM-B model. Team members met to discuss and reach a consensus on pertinent themes. Members who did not participate in the interview participated in the analysis and reviewed the findings to confirm that the themes reflected their experiences. We present the themes, sub-themes and number of interviews in which themes occurred within a table. We note when a theme was a barrier (–), or enabler (+) to using PrEP, or even both (– / +) depending on the circumstance. The credibility and trustworthiness of qualitative data were assured through member checking by the participants themselves [20].

### ***Critical Reflexivity Statement***

Our research team, comprised of public health experts, epidemiologists, and qualitative researchers, acknowledges the potential biases stemming from our external position to the female sex worker community in Lusaka. Recognizing the power dynamics involved, we engaged KIs in the sex work community, who also routinely work with program staff, to foster trust and enhance data authenticity. As academic orientations may shape data interpretation, we involved a community advisory board to inform our analysis processes. This board included both sex workers and healthcare providers, ensuring that findings resonate with the participants' lived experiences. The socio-legal context of sex work in Zambia likely influenced participant responses, given the stigmatization and criminalization of sex work,

as well as stigma around HIV prevention methods like PrEP. We continually reflected on these dynamics, discussing the influence of our positionalities and the research context on our interactions and findings. Through these efforts, we aimed to conduct our research ethically and effectively, fully aware of the influence our backgrounds and the study environment have on the research outputs.

### ***Ethical Considerations***

Written informed consent in English, or one of two local languages, ChiNyanja or IchiBemba, was obtained before enrolment. As added protection for this marginalized population, participants completed an informed consent quiz to ensure that they understood the potential risks of study participants. Each participant received the Zambian Kwacha equivalent of \$5.50 (US\$1 USD ≈ ZMW18) as compensation for their time and willingness to participate.

This study was approved by the University of Zambia Biomedical Research Ethics Committee (UNZABREC; protocol 3650-2023), dated 21/06/2023 and the University of North Carolina (UNC) Biomedical Institutional Review Board (IRB) (22-3147), dated 11/07/2023.

## **Results**

### ***Overall Summary***

Participants had a median age of 28 years [IQR:23,33] with a median of 5 years in sex work [IQR:2,7]. A complex interplay of factors at individual, community, and programmatic levels influence PrEP engagement among WESW which are summarized in **Table 5**.

**Table 5:** Determinants of PrEP Engagement among Sex Workers (N=18)  
 Key: barriers (−), enablers (+), both (− / +); [occurrences]

Domain	Level	Oral PrEP	LAI-PrEP
Capability	Provider	Education during outreach to venues where sex workers socialize (+) [7]	Misconceptions and knowledge gaps among peers and peer-navigators (−) [3]
	Individual	Knowledge gaps (−) [3]	
		Alcohol use incompatible with daily pill adherence (−) [6]	
Opportunity	Health system	Trust-worthy, and respectful program staff (− / +) [9]	Inconsistent supply chain availability (−) [2]
		Convenience and reliability of service provision (+) [10]	
	Individual	Burdens of opportunity costs, financial strain, and side effects (−) [6]	
	Community	Sex worker social support system (− / +) [3]	Sex worker social support system (− / +) [3]
Motivation	Individual	Observability of Effectiveness (+) [3]	Elimination of pill burden (+) [18]
		Protection in work environment of known HIV acquisition risk (+) [13]	
		Compatible with lifestyle (+) [3]	Compatible with lifestyle (− / +) [8]
	Community	PrEP Stigma (−) [7]	PrEP Stigma (+) [7]

## ***Determinants of Oral PrEP***

### **Capability**

Theme: Education about PrEP from peer-navigators and program staff during outreach visits in the community give WESW the knowledge to initiate on PrEP

The KPIF program's outreach visits to venues where sex workers socialize, has played a crucial role in educating WESW, allowing them to take proactive steps to protect themselves against HIV. These educational initiatives, often facilitated by peer promoters and program staff, provide essential knowledge that demystifies PrEP and builds trust in its efficacy.

*The effectiveness of these outreach visits is illustrated by a participant who decided to take PrEP after understanding its protective benefits:*

*"After I was tested [for HIV], and the result was negative, they told me how PrEP works, so I thought to myself, 'it's good because it protects against HIV'" (4004, 19 years, continuer).*

The trust and reassurance provided by peer promoters and program staff were pivotal for many WESW. One participant reflected on experiences with the program stating,

*"The words I was told, I knew they [program staff] wouldn't lie to me, and I knew PrEP was useful" (6005, 26 years, continuer).*

Approaching sex workers in bars and brothels is a strength of the program's ability to meet people where they are. However trust takes time to develop and not all women initiate on the drug right after the first interaction:

*"They found us in a bar, then talked to us about PrEP, but I didn't start right away because we thought they were lying to us and they give us things that we have never taken before" (6007, 36 years, discontinued).*

Despite this, the education provided in these outreach visits was often the turning point for WESW, as noted by one participant:

*"They taught us about PrEP when they came to my area. After being educated on it, that's when we knew what it's for. That's when we started taking PrEP" (4005, 39 years, discontinued).*

### Theme: Knowledge gaps about oral PrEP

Some participants revealed a fundamental misunderstanding of the purposes and duration of taking PrEP versus antiretroviral therapy (ART), highlighting gaps in knowledge that can hinder effective use of PrEP. One woman's story illustrates a common misconception that PrEP, like ART, must be taken indefinitely, which can discourage uptake and persistence.

*"I just [took oral PrEP] for 2 weeks. I started having stomach cramps, so my friend started telling her friends that I got medicine, and it was prevention for HIV. She [friend of a friend] said ARVs (antiretrovirals) and PrEP are the same because you take it forever until you die. If you stop, then HIV virus enters. So I became scared and I stopped." (6008, 27 year, discontinued).*

Her quote also illustrated stigmatization around HIV-related medication, which further complicates the decision to continue PrEP. The woman describes how her friends gossiped about her PrEP use. Embarrassment and fear of being judged can lead to discontinuation of PrEP use, even among those who initially started it. The persistence of such misinformation and stigma indicates that, although outreach programs are effective in disseminating information, continuous education and support are crucial to address ongoing misconceptions and encourage sustained PrEP adherence.

There are also misconceptions regarding the correct usage of PrEP, including beliefs about its effectiveness if not taken at the same time daily or with alcohol consumption. For instance, one participant remarked,

*"[oral PrEP] wants [to be taken] every day at the same time." (6002, 35 years, peer-navigator)*

Another highlighted concerns related to alcohol consumption:

*"Especially us who drink, we forget, so with the injectable you can't forget because it's already in the body, also taking the pills with beer is not good, so it's better in the body." (6005, 26 years, continuer)*

These beliefs may stem from their experiences with or knowledge of ARV use, even though PrEP does not have to be taken at the same time every day and can be consumed with alcohol and still be effective.

Another WESW became pregnant and went into labor shortly after her interview. This was likely the reason why she discontinued her PrEP regimen soon after initiation. This suggests that programs need to provide comprehensive information about the safety and efficacy of PrEP during pregnancy at the outset of treatment initiation.

This also supports a need for a person-centered approach to HIV prevention programs. Rather than just focusing on HIV, integrating sexual and reproductive health services and family planning ensures the diverse health needs of women are met in a holistic manner. This integrated approach not only reduces the risk of unintended pregnancies and sexually transmitted infections (STIs), but also increases access and convenience for individuals, therefore improving their engagement in the program.

**Theme: Alcohol use is part of the lifestyle, but incompatible with daily pill adherence**

For many sex workers, alcohol is part of the work culture. It is a job requirement for attracting clients at bars, nightclubs, and other venues. Alcohol is served at these venues, and in order to fit in, a woman must buy herself a drink in order to feel relaxed and flirt with clients. Clients will then continue to buy drinks for both themselves and the sex worker. There is a partnership between the owners of these venues, and the sex workers, because the sex worker is encouraging clients to spend on alcohol, thereby increasing profits for the venue owners.

In this way, alcohol use is a fundamental part of the lives of sex workers. Even when interviews took place during the day, women were hungover and still smelled like the alcohol they drank the previous night. Alcohol is also a coping mechanism for the violence, rape, and discrimination that the women face. One sex worker who discontinued PrEP describes how it brings joy:

*“What brings me joy, even when am going through issues ... is alcohol!!! After I take it, I feel very happy, and then I go home to laugh some with my children and then it makes me [more] happy.” (6009, 22 years, discontinued)*

One woman who immediately discontinued PrEP after initiating illustrates this point:

*Interviewer: “When you look at all the challenges that you have mentioned where people call you “a whore”, men refusing to pay you ... What helps you to have less stress from the challenge you have mentioned? Is it the encouragement from your friends?”*

*Participant: “I just drink mooba (term for any drink that contains alcohol)!” (4009, 23 years, discontinued)*

Among women who are consuming substantial amounts of alcohol, their capability to take the drug is compromised, because alcohol impairs cognitive functions like memory, and affects the woman's ability to remember to take their medication as prescribed. One peer-navigator describes why she discontinued PrEP even though she was still at risk:

*“Forgetting when I'm drunk. When I forget I miss doses and PrEP is not supposed to be taken like that. It wants [to be taken] every day at the same time.” (6002, 35 years, peer-navigator)*

### Opportunity

Theme: Trust-worthy, and respectful program staff

Medical mistrust, the lack of trust in healthcare systems and providers, is a significant barrier to accessing and utilizing health services. Negative interactions with healthcare providers, including perceived or actual discrimination, bias, and inadequate communication, can reinforce mistrust. Stories of mistreatment within communities can spread, compounding the sense of distrust.

Many women report profound discrimination where nurses and doctors verbally abused them for being sex workers, and actively chase them away from the clinics where they seek care. Women highlighted demotivating experiences when attempting to access healthcare services from government clinics versus the KPIF program's safe spaces (drop-in centers). As one participant described:

*“[The program] care[s] for us. [unlike] when we go to other [government] clinics, they say things like ‘Get out of here, we are not the ones who taught you prostitution!’ We know we will be given what we want when we go there [to the hub]. They treat us like people.” (6004, 31 years, continuer).*

WESW with high levels of medical mistrust are less likely to seek preventive care, adhere to prevention options, or engage with healthcare providers. One peer-navigator recounts how discrimination at public health care facilities impacted the accessibility and reliability of the health services.

*“I once went to a certain government facility. I didn't hide that I was a [sex worker], Then [the nurse] laughed. Then she went out and brought her friend. She told her colleague that I was a 'whore.' From then on I stopped {going there}. (6002, 35 years, peer-navigator)*

Women were clear about the need for more KP-friendly services and spaces, which play a significant role in their decision to initiate and persist on oral PrEP. As one participant reflected:

*“... the [government] clinics, they are not good. It would be better if they built a clinic for us. That would be much better because you people [the program] understand us. They don't.” (6009, 22 years, discontinued)*

Empathy, respect and effective communication play a critical role in making health services trustworthy. health education, particularly in encouraging the acceptance and use of PrEP among WESW. Women commended the program for their respectful, patient, and clear manner of teaching about PrEP, which not only facilitates learning but also fosters a trusting environment. The rapport that women build with program staff during outreach visits, motivates them to continue using services at the drop-in centers.

*"I chose this space because of how you [program staff] take me. You give me respect, so I feel good, you teach us calmly about PrEP in a proper manner" (4007, 31 years).*

#### Theme: Convenience and reliability of service provision

Women had a strong preference for accessing PrEP from community safe spaces like KI homes, and outreach visits to venues where KP socialize (i.e.: brothels, bars), rather than from public health facilities. Knowing that the KPIF program was reliable and accessible when needed, was a facilitator to PrEP continuation. Although program staff encourage women to travel to the drop-in center to pick up

their refills, staff from the KPIF hub will conduct outreach visits to offer HIV testing and deliver PrEP refills, which relieves women's mental anxiety about having to make the time and find money to travel to a clinic. Taken together, the convenience of a drop-in center close to a home, and the reliable PrEP delivery, if requested, is an important facilitator for PrEP use:

*"It's near yes, it's available, and as for me I don't panic because I know that they will bring for me, even if I have a shortage, they will bring for me." (6006, 21 years, continuer)*

This reliability of services to WESW is due, in part, to the rapport and reliability the peer-navigators had with the government clinic staff who were trained on KP-friendly services and partner with the program. One peer-navigator describes the confidence that she had that the head nurse in charge of the partner government facility would not only be receptive to her requests, but organize the delivery of condoms into the community:

*"There are times when you create a rapport, whereby, you just call, "Sister I want you to bring me condoms." They bring for you. (4002, 26 years, peer-navigator)*

Although HIV testing and oral PrEP services are perceived as reliable and accessible, gaps remain. A significant barrier to discontinuing PrEP was the lack of clear communication regarding the next refill dates, and the absence of reminders. The program is supposed to provide women with a written card of when their next refill is due, and women are told to come to the drop-in center if they run out of drug, and an outreach visit isn't scheduled before that date. One woman describes her confusion on whether the program can deliver to her because she did not know the date of refill, or how to refill their oral PrEP from other places like chemists or pharmacies.

*"Where do we get [PrEP] if they don't bring it for us? We always hope that you will bring for us, but if you become quiet, then that means we will not have. We can't go and register somewhere else for PrEP, because [program staff] don't write the next [refill] date. If they did, we would go." (6007, 36 years, discontinued)*

Additionally, there was a reluctance among women to proactively contact program staff due to a misunderstanding that the program had a systematic way of communicating upcoming refills and delivery.

*"I thought of calling, but I thought you follow 'stage by stage. I used to think about calling, but I just decided to wait." (4005, 39 years, discontinued)*

**Theme: Burdens of opportunity costs, financial strain, and side effects.**

Several women responded they were 'too busy' to call the program and follow up on refills, pointing to an opportunity cost of traveling to a safe space and waiting to receive medication, as well as actual costs of transport. They felt that coming to the program's drop-in centers to pick-up the pills was a burden. This was especially true for women who experienced strong discrimination from government health facilities, and are still building up their trust with the program.

Additionally, side effects such as increased appetite and weight gain were frequently cited as reasons for discontinuing oral PrEP. These physiological changes pose significant challenges, particularly in the context of poverty, as they can exacerbate financial strain by increasing food consumption needs. This economic burden compels some women to discontinue PrEP and seek alternative protective measures, such as condoms freely provided by the program. One woman highlighted this shift in her strategy for protection due to the side effects and her financial situation:

*"[PrEP] gave me appetite too much. Sometimes I didn't have money to buy food so I stopped. But now, whether he [client] wants or he doesn't, I always use protection." (6009, 22 years, discontinued).*

Although this participant has the best of intentions to use condoms, invariably sex workers feel forced to engage in condomless sex either because of fear of violence from clients, or financial stressors that motivate them to engage in condomless sex which pays higher than sex with condoms.

One peer-navigator describes why she is able to decline client requests for condomless sex because of her financial stability from multiple income streams including employment in the program,

*"it's because at least am a bit financially independent ... so even if someone comes, they tell me, "No, let's have sex [and] I'll give you so much, let's not use protection"... it's a 'No' for me. (4001, 23 years, peer-navigator)"*

These experiences highlight the need for tailored support mechanisms within PrEP programs to address and manage side effects, and ensuring that financial or physiological barriers do not impede continued use when women still have the desire to take the drug.

### Motivation

#### Theme: Observability: Personal experiences of PrEP effectiveness

Women who continued to persist on PrEP perceive the effectiveness and benefits of PrEP in their life, especially in comparison to their peers illustrating its impact on their lives and the lives of others within their community. The following quote from a woman continuing PrEP illustrates the concept of "observability" in the diffusion of innovations theory, where the benefits of a new technology or practice (like PrEP) are visible and influential in encouraging its adoption among others [21].

*"My friends are on [ARVs], but I am not. You will find that I introduce someone to prostitution, because of ignorance; they will start taking [ARVs], but me I will be okay and continue to be fit. She leaves me taking PrEP, then...she starts taking ARVs." (6004, 31 years, continued)*

This comparison underscores the participant's belief in PrEP as a preventive measure that has kept them "fit" and free from the need for lifelong ARVs, despite their high-risk lifestyle. The participant's use of the term "ignorance" highlights a perceived lack of awareness or misunderstanding about the benefits of PrEP among some peers, which they feel has led to poorer health outcomes for others.

As in the previous quote, there is a psychological comfort and security derived from taking PrEP. Women express a sense of reassurance and reduced anxiety about acquiring HIV:

*"I use PrEP because then I know everything is fine with me." (6005, 26 years, continuer).*

PrEP is not only a medical tool but also a means of psychological assurance for those at high risk of HIV. By showcasing tangible health benefits and offering peace of mind, PrEP effectively demonstrates its value, promoting its wider acceptance and use among women engaged in sex work.

**Theme: Oral PrEP offers personal empowerment and health protection in work environments of known HIV acquisition risk**

Oral PrEP is seen by many women as a tool for personal empowerment and health protection in their high-risk work environment. The most salient enablers to initiating and staying on PrEP include internal motivations and perceived personal benefits, such as the desire for personal safety, the acknowledgment of the 'high risk' nature of their job, and the value placed on maintaining a negative HIV status as a form of self-care and empowerment.

For many women, the decision to continue taking PrEP is directly linked to their experiences and the realities of their work. One participant explained,

*"I continued to take PrEP because...sometimes, even if you are not drunk, some clients want 'live' (condomless sex), so if you don't take PrEP, there is nothing [to protect you]" (4006, 31 years, continuer).*

This highlights the immediate risk factors and the protective role PrEP plays in situations where condom use is not always possible.

Understanding the broader health implications, some women also recognize that acquiring other sexually transmitted infections (STIs) increases their risk of HIV. One peer-navigator shared her rationale for starting PrEP:

*"I also used to have a lot of STIs, so I knew that I was also at risk of getting HIV" (6002, 35 years, peer-navigator).*

Furthermore, the uncertainty surrounding the HIV status of their clients adds another layer of risk, which PrEP helps mitigate. As one peer-navigator described,

*"I heard that PrEP helps in protecting against HIV, we are in a chain where we don't know everyone's status, so I started taking it to protect myself" (4002, 26 years, peer-navigator).*

This sentiment reflects the widespread concern about unknowingly being exposed to HIV and the empowerment derived from taking proactive measures.

In summary, the women's reflections and decisions to use PrEP illustrate a clear understanding of their risk environment and a strong drive towards personal health and empowerment. By taking PrEP, they not only protect themselves from HIV but also exercise control over their health and well-being in a high-risk occupation.

#### Theme: Compatible and flexible with lifestyle

The compatibility and flexibility of oral PrEP with the lifestyles of sex workers emerge as strong motivators for its initiation and continued use. One key aspect is the ability to start and stop PrEP based on personal circumstances and perceived risk, which allows for greater control over their health management.

The flexibility of PrEP allows women to adapt its use based on changes in their personal lives, such as finding a stable partner. As one participant noted about her decision to start PrEP and her ongoing motivation: “

*“When I found out that you can stop PrEP when you find a man that wants to marry you”  
(4008, 37 years, continuer)*

This highlights how the ability to discontinue PrEP when entering a committed relationship can be reassuring and practical for some women.

Moreover, the adaptability of PrEP use to their fluctuating risk levels is appealing. One participant shared,

*“I usually stop and start [PrEP] whenever I see that I have stopped running around too much” (4001, 23 years, peer-navigator).*

Here, she implies that she adjusts her PrEP usage based on the number of clients and her perceived risk of HIV acquisition. This adaptability not only supports initial uptake but also motivates sustained use as circumstances change.

### ***Determinants of LAI-PrEP***

#### **Capability**

**Theme: Misconceptions and knowledge gaps among peer-navigators and peers**

Even before LAI-PrEP misconceptions already exist among peer-navigators regarding the relationship between missing LAI-PrEP doses, seroconversion (the period during which HIV antibodies develop and become detectable), and the subsequent effectiveness of ART.

*“We went to a workshop somewhere, they told us once you start then you miss a jab then you seroconvert from PrEP to ART. Meaning ART will never work in your body. That’s what we were taught. So that’s the disadvantage of injectable PrEP.” (6003, 29 years, peer-navigator)*

Women already anticipate misconceptions among their peers and are concerned that LAI- PrEP might conceal the virus, making it undetectable for those already infected with HIV.

*“There may be a lot of misconceptions among people. People may think PrEP hides the [HIV] virus.” (6001, 23 years, peer-navigator)*

Addressing these misconceptions is important, since women recognize their own knowledge gaps on how LAI-PrEP works and would rely on their peers to build trust and understanding.

*“I wouldn’t take the injectable PrEP, unless my friend told me it was OK. Then I would. I’m afraid because I wouldn’t know how it works.” (4006, 31 years, continuer)*

## Opportunity

### Theme: Inconsistent Supply Chain Availability

One participant was concerned about the consistent availability of LAI-PrEP. The fear that dependency on a scheduled injection could be disrupted by supply chain issues leads to anxiety about having to revert to oral pills, which may be seen as a less desirable option. This worry not only highlights logistical challenges within healthcare systems and drug supply chains but also emphasizes the psychological and practical adjustments required from users when transitioning between different forms of PrEP.

*“The injectable PrEP may not be available when you need it ... When it's your date to take it again ... Or it can run out when we are already used to it and that can mean getting back to pills” (4002, 26 years, peer-navigator).*

Inconsistency in the supply of LAI-PrEP can undermine their trust in the healthcare system and disrupt women's work routines. This inconsistency has the potential to cause significant stress as the anticipation of potential shortages creates uncertainty around maintaining effective HIV prevention. Transitioning back to oral pills may be seen as a step backward, both in terms of convenience and perceived efficacy. The process of adjusting back to daily oral medication may be daunting, especially for those who have become accustomed to the less frequent dosing schedule of LAI-PrEP. Suddenly stopping LAI-PrEP can create a window period where individuals are at risk of HIV infection, including resistant strains, due to reduced drug levels in their system. During this time, those who discontinue LAI-PrEP may need to switch back to oral pills to maintain continuous protection, highlighting the importance of consistent PrEP use and proper transition planning to prevent gaps in HIV prevention.

### Theme: Sex Worker social support system

Sex workers operate within complex social networks characterized by both competition and camaraderie. The competitive nature of their environment, driven by the need to secure clients, inherently

fosters instability within these networks. The following quote illustrates how WESW will use the community stigma around PrEP to their advantage in order to entice clients away from sex workers using PrEP.

*“...Friends ...the ones I stay with...they used to say bad things that I am taking ARVs...sometimes even when you are in a bar they would discourage clients from coming to me and tell them, “You are going to the one taking ARVs, and if you want, you can come home, you will find the bottle.” But I was not discouraged, and I didn’t stop taking PrEP.” (6009, 22 years, discontinuer)*

Despite this competition, the shared experiences and challenges unique to sex work create a basis for mutual understanding and support among workers. This solidarity is crucial for navigating the risks associated with their profession, including personal safety and protection from violence and rape. Moreover, within the context of HIV prevention, this solidarity manifests as a practical support system for PrEP adherence. The practice of sharing PrEP pills among peers who may forget or lack access to their medication underscores the role of social support as a key facilitator in maintaining PrEP regimes. However, the transition to LAI-PrEP may potentially challenge this form of solidarity. Unlike pill sharing, injectable PrEP cannot be shared among peers, potentially leading to a loss of a critical support mechanism within these networks.

*“Sometimes we share tablets, but if in jab form, then no sharing.” (6001, 33 years, peer-navigator)*

### Motivation

#### Theme: Alleviates daily pill burden

WESW showed a strong preference for LAI-PrEP, facilitated by KPIF-supported peer networks and service delivery platforms. There was a consistent sense that injectable PrEP would be seamlessly integrated into their lifestyle without the constant reminder or the need for daily action, particularly beneficial for those who are missing doses due to alcohol use.

*“I wouldn't be forgetting” (4009, 23 years, discontinued)*

One peer-navigator describes women reporting pill aversion, and the mention of the oral PrEP pill's size as a deterrent suggests that the physical act of taking pills is a barrier to persistence for some, independent of any associated stigma or lifestyle factors. The preference for an injectable option points to the potential for increased acceptance and persistence on PrEP, particularly among those who are generally resistant to taking pills.

*“Some of us don't like taking pills even when we are sick because of the size of the pills but with injectable it will be good.” (6003, 29 years, peer-navigator)*

**Theme: May or may not be compatible with occupation and fit into lifestyle**

Injectable PrEP acceptance involves weighing the efficacy of the intervention against the side effects, especially those that interfere with their ability to engage in sex work. Most of the concerns about LAI-PrEP included potential side effects such as weight gain which affects their ability to attract clients, and prolonged menstrual periods which reduce the number of days they can engage in vaginal sex. Other side effects of concern were vomiting, diarrhea, nausea, and injection site pain.

There are further challenges and concerns associated with the logistical aspects of using long-acting injectable (LAI) PrEP, particularly concerning the lifestyle and work demands faced by sex workers. There is inherent uncertainty and mobility in the lives of sex workers, who may need to travel frequently and unexpectedly for work. There is anxiety over missed appointments due to travel, and it's clear the preference to receive services through the KPIF program, and an implied reluctance to get the injectable from other government clinics where a woman is traveling.

*“The disadvantage is that maybe that day you have gone on a journey, and your appointment date has come but you're out, what can you do? At least you can carry the pill and go with it.” (4005, 39 years, discontinued)*

This scenario contrasts with the flexibility offered by oral PrEP, which can be taken along on travels, ensuring continuity of protection against HIV without being tied to a specific location or healthcare provider.

#### Theme: PrEP Stigma

The confusion between PrEP drugs and ARVs contributes significantly to PrEP stigma, intertwining it with HIV stigma. PrEP medications contain some of the same active ingredients found in ARVs, leading to misconceptions that individuals on PrEP are HIV-positive or that PrEP is used exclusively by those with high-risk behaviors, thus stigmatizing its use. This misperception can exacerbate the challenges individuals face when deciding to use PrEP, as they may fear being mistakenly perceived as having HIV. The overlap in medication types thus fuels both PrEP and HIV-related stigmas, impacting individuals' willingness to seek and adhere to PrEP as a preventive strategy. One woman describes this phenomenon:

*“When you get a jab, no one can see you or know that you have taken PrEP. With the pills, they can compare bottles and think that you are taking ARVs.” (6008, 27 years, discontinued)*

*“For some men, when they see you take PrEP, they become suspicious and curious, but when you jab, they can’t even know you have taken PrEP. (4005, 39 years, discontinued)*

Women feel empowered by the anonymity when their preventative healthcare choices remain private, safeguarding them from societal judgment and stigma. Many preferred LAI over oral PrEP as *“nobody can know that you are on PrEP” (6006, age: 21 years, continuer)*, potentially reducing anticipated stigma and the ease of regimen persistence and adherence.

WESW described a sense of enhanced safety and well-being with injectables that might not be there with oral PrEP. This highlights the dual aspect of physical health protection from HIV and the reduction of risk from external threats, such as violence, by minimizing visible signs of PrEP usage.

Women discuss the anxiety of missing doses when *“a client gets you and keeps you” (4007, 31 years,*

*continuer*) for several days, and fear of clients “*even beating you*” (4006, 31 years, *continuer*) if they find pills that could be mistaken for antiretrovirals (ARVs).

**Table 6:** Potential PrEP Interventions for the Zambian Key Populations Investment Fund Informed by the COM-B Model

COM-B Component	Intervention	Description
Capability	Educational Workshops	<ul style="list-style-type: none"> <li>- Conduct interactive workshops tailored to different literacy levels in languages spoken by WESW.</li> <li>- Use role-playing and Q&amp;A sessions to educate about PrEP and its effectiveness even with alcohol use or during pregnancy.</li> </ul>
	Peer-led Education Programs	<ul style="list-style-type: none"> <li>- Train peer navigators to provide accurate information and dispel myths about PrEP.</li> <li>- Create talking points or a brochure with popular misconceptions about PrEP.</li> <li>- Facilitate peer-led group discussions to share experiences and learn in a supportive environment.</li> </ul>
Opportunity	Improving Access to Services	<ul style="list-style-type: none"> <li>- Create a schedule to communicate PrEP refill dates via phone calls, and SMS reminders.</li> </ul>
	Convenient Service Delivery	<ul style="list-style-type: none"> <li>- Expand PrEP refill depots to additional community-safe spaces like KI homes.</li> <li>- Conduct more regular outreach visits to venues such as brothels and bars to provide on-site PrEP services.</li> </ul>
Motivation	Counseling and Support	<ul style="list-style-type: none"> <li>- Offer personalized counseling to address individual concerns about PrEP.</li> <li>- Create support groups for WESW to discuss their experiences and challenges.</li> </ul>
	Positive Reinforcement	<ul style="list-style-type: none"> <li>- Share success stories and testimonials from peers who have benefited from PrEP.</li> <li>- Fund more talktime for peer-navigators to call WESW initiating on PrEP 2 weeks before their refill date.</li> <li>- Provide small incentives for follow-up appointment attendance for WESW newly initiating on PrEP.</li> </ul>
	Reducing Stigma	<ul style="list-style-type: none"> <li>- Implement campaigns to reduce stigma associated with PrEP use, involving influential community members to promote positive attitudes towards oral and LAI-PrEP.</li> </ul>
Combined Interventions Addressing Multiple COM-B components	Comprehensive Training Programs	<ul style="list-style-type: none"> <li>- Train healthcare providers to deliver person-centered care.</li> <li>- Provide integrated health services combining PrEP with other sexual and reproductive health, substance use, and mental health services.</li> </ul>
	Enhanced Communication Strategies	<ul style="list-style-type: none"> <li>- Implement regular follow-up via phone calls, SMS reminders, and home visits.</li> <li>- Create feedback mechanisms for WESW to voice concerns and suggestions.</li> </ul>
	Peer Support Networks	<ul style="list-style-type: none"> <li>- Establish buddy systems for mutual support in persisting on PrEP.</li> <li>- Organize community events focused on health education and building a supportive network among WESW.</li> </ul>

## **Discussion**

Our study found that education by peer-navigators and program staff is crucial in providing trustworthy HIV services and promoting PrEP uptake among sex workers who have faced widespread discrimination in government clinics. Our study is the first to highlight the significant impact of persistent knowledge gaps and misconceptions about PrEP adherence and alcohol use as barriers. Also, we found that trust in program staff and reliable service provision facilitated continued use, with a preference for PrEP delivery to them. Social support systems were mixed, providing both aid and competition. Not only that, we further identified that personal empowerment and health protection motivated PrEP use, with LAI-PrEP preferred for reducing daily pill burden and stigma of oral PrEP as HIV medication. However, concerns about inconsistent supply and misconceptions about LAI-PrEP present potential barriers to uptake.

Our findings on the barriers to oral PrEP initiation and persistence among WESW in Lusaka echo similar challenges documented in other African contexts, including stigma, challenges accessing healthcare, and misconceptions about PrEP [16]. The expressed preference for LAI-PrEP over oral formulations aligns with a growing demand for more discreet and convenient HIV prevention methods [16]. This preference underscores a potential shift in prevention strategies that could significantly reduce new HIV infections among sex workers and their sexual partners in Southern Africa. The following subsections discuss recommendations which are summarized in **Table 6**.

### ***Addressing Misconceptions and Education Gaps***

Increasing uptake and engagement with both oral PrEP and LAI-PrEP requires targeted education for all program staff, including healthcare providers and peer navigators. This education should

clearly differentiate the mechanisms and actions of PrEP and ART, and dispel myths about PrEP.

Providing program staff with talking points or brochures on common misconceptions during HIV testing and counseling can enhance understanding. Techniques like role-playing and Q&A sessions can educate about PrEP's effectiveness, even when taken with alcohol or during pregnancy. These initiatives are crucial for correcting misinformation, alleviating fears about discontinuing PrEP, and maintaining trust in ART, particularly as PrEP initiation may be the first interaction WESW have with the program.

As LAI-PrEP becomes more widely available, peer-led education programs can further clarify its role, address its side effects, and emphasize the need for adherence to dosing schedules. Peer navigators and "PrEP champions" who have benefited from oral PrEP could lead interactive workshops tailored to different literacy levels and languages. Facilitating peer-led group discussions allows for sharing experiences and learning in a supportive environment.

#### ***Enhancing PrEP Delivery Systems***

Considering the preference for LAI-PrEP, it is critical for policymakers and healthcare providers to develop effective rollout strategies. These should ensure an adequate supply of injectables, proper training for healthcare workers, and protocols that accommodate the specific needs of WESW. Addressing fears of inconsistent supply and ensuring clear communication about alternative options can mitigate concerns. Providing standardized refill cards and using phone calls and SMS reminders to communicate PrEP refill dates can enhance engagement. Additional counseling on the importance of persistence during one-month follow-ups post-PrEP initiation has also been effective in programs tailored for sex workers in South Africa [22,23].

Younger women who sell sex often face greater adherence challenges, necessitating support tailored to their age group and lifestyle [24]. PrEP delivery programs for adolescent girls and young women should offer a choice of adherence support methods, including counselor- and peer-based options, as well as in-person and mHealth options, to suit individual preferences and circumstances [25].

### ***Make PrEP Delivery More Convenient***

Confidentiality, privacy, and worthiness are key qualities sex workers seek in PrEP services [26]. The program can cultivate this trust by making PrEP service delivery more convenient. This includes providing PrEP and HIV testing services at times and locations that do not conflict with WESW work schedules, especially since travel is a lifestyle factor that is known to interfere with proper medication intake among sex workers [23]. Venue-based outreach offering injectable PrEP at locations like KI homes can align with their needs. Integrating financial support mechanisms like transport vouchers can reduce the opportunity costs of accessing PrEP services, shown to create demand for family planning and HIV self-testing [27–29]. Offering flexible service hours, multiple discreet locations, and adaptable refill schedules can further support PrEP adherence. Developing these strategies with input from WESW and their advocacy groups ensures interventions are not only contextually relevant, but also have the buy-in necessary for effectiveness.

### ***Integrating Socioeconomic Considerations into Health Programs***

The side effects of PrEP, combined with the opportunity costs and logistical barriers to accessing refills, illustrate the need for holistic health programs. Women in Africa often engage in sex work due to poverty and insecurity, making HIV prevention a lower priority than basic needs [30]. Holistic health programs should address both medical and economic challenges to ensure sustainable intervention strategies, particularly for LAI-PrEP. Failure to adhere to LAI-PrEP schedules can risk HIV drug resistance. Practical solutions include holistic health education beyond HIV prevention, teaching financial literacy and nutrition, and offering microfinance loans or grants to empower women economically and provide alternative income sources.

### ***Navigating Alcohol Use and Persistence Challenges***

Alcohol use significantly impacts PrEP adherence, as indicated by studies in Kenya where substance use disorders hinder timely medication intake [31]. Educational programs should stress

maintaining medication effectiveness and include strategies like peer support, buddy systems, and behavioral regulation tactics linking medication intake with daily activities that are less likely to be disrupted by alcohol, like wearing a wig or putting on clothes. A person-centered approach to healthcare would provide substance use and mental health counseling alongside HIV prevention services.

### ***Societal Influence on Health Decisions***

The interplay between societal stigma and personal health decision-making highlights the unique challenges faced by WESW in Zambia. Despite the competitive nature of their social networks, support from these networks is crucial for enhancing personal safety and facilitating PrEP persistence. PrEP stigma is driven by ongoing stigma around HIV, low knowledge of PrEP and HIV, and ongoing stigma around adolescence or being a single woman, and sexuality [32]. Social support encourages open discussion of stigma and discrimination, reducing distress. Engaging influential community members as opinion leaders can promote positive attitudes towards PrEP, and this may include brothel leadership who have played facilitatory roles in condom use among WESW and their clients [33]. Successful digital stigma reduction interventions among Black women in the US and Brazil show that involving trusted individuals can foster confidence in PrEP [34,35].

### ***Limitations***

This study offers significant insights but has several limitations that affect the breadth of its applicability. Primarily, our research focused on sex workers in Lusaka, Zambia, who solicit clients from streets, brothels, bars, and nightclubs. This does not encompass the experiences of 'high-class' sex workers who operate from more discrete venues such as massage parlors, hotels, professional offices, or university settings. Consequently, our findings may not be generalizable to all sex worker demographics within Zambia or other regions.

The relevance and importance of barriers and facilitators are context-dependent, and no barrier or facilitator is universally applicable [36]. As injectable PrEP becomes more accessible, further qualitative

research is essential. Collaboration with community advisory boards can help assess the adoption, adherence, and effectiveness of injectable PrEP among different sub-groups of women in sex work. Such studies will clarify the full potential of injectable PrEP in HIV prevention and address gaps identified in this initial research.

## **Conclusion**

This study reveals the multifaceted dynamics influencing PrEP engagement among WESW in Lusaka. While individual motivations and programmatic supports significantly promote uptake, substantial socio-economic and logistical barriers hinder sustained use. The preference for LAI-PrEP, due to its discretion and elimination of pill burden, aligns with a broader trend towards more manageable HIV prevention strategies. However, WESW are concerned about the new complexities with LAI-PrEP, including scheduling constraints and potential supply interruptions, which must be navigated carefully to maximize its effectiveness.

Future interventions should focus on expanding access to PrEP through targeted, context-specific strategies that address both the medical and social needs of sex workers. This includes improving education around PrEP to prevent misinformation, particularly concerning its distinction from ART, and enhancing service delivery to accommodate the unpredictable lifestyles of sex workers. As PrEP options evolve, continuous research is required to assess their impact and acceptance, ensuring that advances in HIV prevention translate into tangible benefits for those at the highest risk.

Adopting person-centered care approaches is crucial. This includes integrating holistic strategies that address both health and socio-economic challenges, such as providing comprehensive support services, financial assistance, and flexible scheduling tailored to the unique needs of WESW. Such holistic approaches are vital for the broader integration of PrEP into HIV prevention programs in Zambia and similar settings, potentially setting a precedent for global health practices.

This research not only sheds light on a marginalized community but also urges policymakers, healthcare professionals, and social support systems to acknowledge and address the unique challenges faced by sex workers in Lusaka. It is a call to action for a more inclusive and empathetic approach towards a group too often overlooked and underserved.

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## Chapter 4: Concluding Statements

### Summary

These two studies leveraged the strengths of both qualitative and quantitative methods to understand pragmatic research questions related to HIV prevention women engaging in sex work in Zambia, focusing on barriers and enablers to PrEP uptake and persistence. By applying theoretical frameworks such as the [COM-B model](#) and using data triangulation, we identified key factors influencing PrEP engagement among WESW. [Chapter 2](#) utilized a prospective cohort study to measure the prevalence of PrEP and HIV stigmas and discrimination from being identified as a sex worker. We presented [measures of their associations with PrEP persistence](#), revealing that chronic discrimination significantly increases the risk of discontinuing oral PrEP immediately after initiation. [Chapter 3](#) employed qualitative methods to explore perceptions of oral and long-acting injectable PrEP (LAI-PrEP) among WESW, highlighting the potential benefits of LAI-PrEP in reducing stigma and daily pill burdens, while also identifying concerns about supply inconsistency and misconceptions. This data informed practical recommendations to improve PrEP service delivery within the Zambian Key Populations Investment Fund.

The study was guided by a Community Advisory Board (CAB) of Key Population Civil Society Organizations, Zambian Ministry of Health, and the Centre for Infectious Disease Research in Zambia and used community-based participatory research (CBPR) principles to prioritize trust development, essential due to the criminalization and historical marginalization of sex workers in Zambia. The CAB guided decision-making, recruitment strategies, with the aim of minimizing participant harms. They also ensured sensitive issues like HIV-related stigma and abuse were handled with care, providing psychosocial support and referrals when necessary. Additionally, peer navigators offered unique

perspectives, providing both lived and professional experiences on barriers and facilitators to HIV prevention services, and resource recommendations to improve service uptake.

Considered together, our findings underscore the importance of addressing socio-structural barriers and implementing stigma reduction interventions to enhance PrEP engagement and adherence among women in sex work. The novel approach of integrating both qualitative and quantitative data provides a comprehensive understanding of the challenges faced by sex workers in Lusaka and offers actionable insights for modifying HIV prevention programs and services.

## **Key Findings**

1. Barriers and Facilitators to PrEP Engagement: Education provided by peer navigators and program staff is crucial for building trust and demystifying PrEP. Persistent knowledge gaps and misconceptions, especially about daily adherence and alcohol use, remain significant barriers. Trustworthy program staff and reliable service provision facilitate continued PrEP use, but inconsistent supply and misconceptions about LAI-PrEP pose potential challenges.

2. Impact of Stigma and Discrimination: High levels of chronic discrimination, primarily due to being identified as a sex worker, significantly increases the risk of immediate PrEP discontinuation. This finding highlights the need for targeted interventions that address multi-level causes of discrimination and foster societal change to improve HIV prevention among women in sex work.

3. Preference for LAI-PrEP: The introduction of LAI-PrEP offers a promising advancement in HIV prevention, with many sex workers preferring it for its reduced stigma and elimination of daily pill burdens.

However, concerns about supply consistency and potential side effects need to be addressed to ensure successful implementation.

## **Recommendations**

1. Implement Multi-Levelled Interventions: HIV prevention programs should incorporate structural and community-based interventions that go beyond individual-level behavior change. This includes stigma reduction strategies, improving access to confidential, and non-judgmental healthcare services.

2. Enhance Education and Support Systems: Continuous education and support from peer navigators and Key Population Investment Fund program staff are essential to address knowledge gaps and misconceptions about PrEP. Providing accurate information about the safety and efficacy of PrEP, including LAI-PrEP, as well as regular communication on refills, can improve adherence and persistence.

3. Foster Trust and Engagement: Building trust between sex workers and healthcare providers is key to improving PrEP engagement. Continued community outreach and engagement in key informant homes and venues that sex workers socialize, makes women feel respected and supported, which can encourage continued use of HIV prevention methods.

4. Provide Holistic Services: Expand HIV prevention programs for KP to provide holistic and convenient services that include substance use and mental health counseling, family planning, STI treatment, and other reproductive health services. Ensure confidentiality, privacy, and convenience by aligning service delivery with sex workers' schedules, offering venue-based outreach, integrating financial support mechanisms like transport vouchers, and providing flexible service hours and adaptable refill schedules to enhance PrEP persistence and effectiveness.

## **Future Directions**

Global targets aim for 10 million PrEP initiations by 2025, but progress has only reached half of this goal. To bridge this gap, it is crucial to expand oral PrEP programs and rapidly implement long-acting injectable PrEP (LAI-PrEP) and other delivery methods like the dapivirine vaginal ring. Engaging key populations (KPs) in the design, planning, and rollout of these programs is essential for ensuring inclusivity and effectiveness.

To address the limitations of this study, future research should include a broader demographic of sex workers, encompassing those who operate in more discrete venues such as massage parlors, hotels, professional offices, or university settings. This approach will help in understanding the unique barriers and facilitators to PrEP use in various contexts, providing a more comprehensive picture of the challenges faced by all segments of sex workers. Additionally, research should consider geographic variability within Zambia and other regions, as socio-cultural and economic factors influencing PrEP use may differ significantly.

As injectable PrEP becomes more accessible, further qualitative research is crucial to understand its adoption, adherence, and effectiveness among diverse sub-groups of women in sex work. Collaboration with community advisory boards in designing and implementing these studies will ensure they are contextually relevant and sensitive to the needs of different sub-populations. This approach will help clarify the full potential of LAI-PrEP in HIV prevention and address gaps identified in this initial research.

Extending follow-up durations in future studies will allow for better observation of the long-term relationship between discrimination, stigma, and PrEP adherence. Longer follow-up periods will provide more robust data on the sustainability of PrEP use and the evolving impact of stigma over time.

Increasing the sample size will also enhance the statistical power of the studies, allowing for the detection of significant effects and the generalization of findings to a broader population.

Developing and validating more comprehensive stigma scales for sex workers that measure not only community stigma but also anticipated and internalized stigma is essential. Understanding the different dimensions of stigma will provide deeper insights into how stigma affects PrEP use and how interventions can be tailored to address these specific aspects. This nuanced approach to measuring stigma will contribute to the development of more effective stigma reduction strategies, ultimately improving PrEP adherence and health outcomes for sex workers.

The introduction of additional HIV prevention methods adds complexity for women in sex work, yet the same structural barriers persist. HIV prevention programs for KP must expand to provide more holistic and convenient services. A person-centered approach to healthcare should also provide substance use and mental health counseling, as well as family planning, STI treatment, and other reproductive services alongside HIV prevention services. To further enhance trust in PrEP services among sex workers, the program should ensure confidentiality, privacy, and convenience by aligning service delivery with their work schedules and providing venue-based outreach at familiar locations like KI homes. Integrating financial support mechanisms like transport vouchers and offering flexible service hours, multiple discreet locations, and adaptable refill schedules will further support PrEP adherence and effectiveness.

KP programs should enhance demand generation efforts while tailoring outreach to specific KP segments. To scale up all safe and effective HIV prevention methods, including oral and LAI-PrEP and the dapivirine ring, a choice-centered approach and inclusive language must be adopted in all KP-serving sites. Integrating community health workers and peer navigators into service design and delivery will enhance the relevance and effectiveness of HIV prevention programs. Additionally, researchers and KP

implementers should design operational studies to facilitate PrEP access beyond clinics, exploring task-shifting, self-initiation on PrEP, and HIV self-testing.

By addressing these recommendations and building on the insights from this research, we can develop a more holistic understanding of the barriers and facilitators to PrEP use among sex workers. This knowledge will inform the design of more effective, inclusive, and sustainable HIV prevention programs, supporting the health and well-being of sex workers in Zambia and beyond.

## Supplemental Materials

**Table S1:** Descriptive Summary of Enrollment Characteristics By Community Hub, (N=262)

	<b>Overall N=262</b>	<b>Matero N=138</b>	<b>Kamwala N=124</b>	<b>p-value</b>
	<b>n (%) or median (IQR)</b>			
Age	24 (21-29)	24 (22-29)	24 (21-29)	0.71
Age				0.79
younger (18-24)	133 (50.76%)	69 (50.00%)	64 (51.61%)	
older (25+)	129 (49.24%)	69 (50.00%)	60 (48.39%)	
Duration of sex work (years)	3.0 (2.0-4.0)	3.0 (1.8-5.0)	2.0 (2.0-4.0)	0.055 *
Highest education obtained				0.015 **
none	9 (3.44%)	4 (2.90%)	5 (4.03%)	
incomplete primary	118 (45.04%)	53 (38.41%)	65 (52.42%)	
complete primary	36 (13.74%)	25 (18.12%)	11 (8.87%)	
incomplete secondary	57 (21.76%)	27 (19.57%)	30 (24.19%)	
completed secondary or higher	42 (16.03%)	29 (21.01%)	13 (10.48%)	
Marital status				0.76
single/never married	184 (70.23%)	98 (71.01%)	86 (69.35%)	
married	3 (1.15%)	2 (1.45%)	1 (0.81%)	
divorced/separated	69 (26.34%)	36 (26.09%)	33 (26.61%)	
widowed	6 (2.29%)	2 (1.45%)	4 (3.23%)	
Number of children	1 (0-2)	1 (0-2)	1 (1-2)	0.12
Number of dependents	3 (2-4)	3 (2-4)	3 (2-4)	0.76
Self-report employment status independent of sex work				0.056 *
employed: informal	9 (3.44%)	4 (2.90%)	5 (4.03%)	
employed: public/private	3 (1.15%)	2 (1.45%)	1 (0.81%)	
employed: self	18 (6.87%)	12 (8.70%)	6 (4.84%)	
unemployed	60 (22.90%)	40 (28.99%)	20 (16.13%)	
unemployed and seeking work	172 (65.65%)	80 (57.97%)	92 (74.19%)	
Income generating activities independent of sex work				0.50
Yes	51 (19%)	29 (21%)	22 (18%)	
No	211 (81%)	109 (79%)	102 (82%)	
Monthly income from sex work (USD)	140 (75-210)	150 (80-210)	125 (75-200)	0.27

Monthly income from employment other than sex work (USD)	0 (0-25)	0 (0-0)	0 (0-75)	<0.001 ***
Monthly income total (USD)	175 (100-258)	162 (92-245)	175 (122-265)	0.12
Living in extreme poverty (<\$2.15)*				0.005 ***
Yes	20 (8%)	15 (11%)	5 (4%)	
No	232 (89%)	114 (83%)	118 (95%)	
Missing	10 (4%)	9 (7%)	1 (1%)	

\*World Bank Indicator of <\$2.15 indicates living in extreme poverty

**Table S2:** Intersectional Stigma measured by the Everyday Discrimination Scale (N=262)

<b>Reason for Discrimination</b>	<b>N=262</b>
Sex Worker	212 (81%)
Sex Worker + Appearance	17 (6%)
Sex Worker + Age	5 (2%)
Sex Worker + Age + Appearance	2 (1%)
Sex Worker + Gender	2 (1%)
Sex Worker + Age + Height	1 (0%)
Sex Worker + Appearance + Alcohol use	1 (0%)
Sex Worker + Gender + Education	1 (0%)
Sex Worker + Single	1 (0%)
Sex Worker + Single Mom	1 (0%)
Sex Worker + Skin color shade	1 (0%)
Age	1 (0%)
Single	8 (3%)
Single Mom	9 (3%)



**Table S3:** Measures of Association between Discrimination, Stigmas and Immediate Discontinuation of PrEP with splines (N=262)

	crude			adjusted		
	PR	95%CI:	p-value	aPR	95%CI:	p-value
Discrimination score	1.00	(1.00,1.00)	0.76	1.00	(1.00,1.00)	0.01
spline1	1.00	(1.00,1.00)	0.87	1.00	(1.00,1.01)	0.32
spline2	1.00	(0.99,1.01)	0.82	1.00	(0.99,1.01)	0.51
PrEP Stigma score	1.00	(0.89,1.13)	0.97	1.05	(0.94,1.17)	0.39
spline1	1.05	(0.79,1.39)	0.73	1.13	(0.85,1.49)	0.40
spline2	0.92	(0.60,1.41)	0.71	0.89	(0.60,1.32)	0.56
HIV Stigma score	0.94	(0.82,1.09)	0.415	0.96	(0.85,1.07)	0.46
spline1	0.86	(0.67,1.10)	0.24	1.02	(0.76,1.38)	0.88
spline2	1.08	(0.88,1.33)	0.45	0.95	(0.77,1.17)	0.61

Associations between outcome and tertiles of stigma and discrimination showed evidence of non-linearity. Thus, we included restricted cubic splines with 3 knots for continuous scores (*stata mkspline*). In a restricted cubic spline, one obtains a continuous smooth function that is linear before the first knot, a piecewise cubic polynomial between adjacent knots, and linear again after the last knot.

There is a positive association between PrEP stigma and immediate discontinuation of PrEP, though not significant. On average, for every 1 unit increase in PrEP stigma score, there is a 13% higher likelihood of immediate discontinuation (aPR=1.05; 95%CI:0.94, 1.17). The direction of association changes within windows of the PrEP score. Knots were placed at scores of 8, 10, and 13. For every 1 unit increase in PrEP stigma scores between 9-10, there was a 13% higher likelihood of immediate discontinuation compared to scores 0 – 8 (aPR=1.13; 95%CI(0.85, 1.49). However, for every 1 unit increase in PrEP stigma scores between 11-13, there was a 11% lower likelihood of immediate discontinuation compared to scores 0 – 8 (aPR=0.89; 95%CI:0.60, 1.32).

## Appendix 1: Conceptual Definitions

**High-incidence population** or **affected population** is used rather than “high-risk people/population/group” because people and communities are not inherently risky. The preferred terms acknowledge societal challenges and accurately reflect disease dynamics.<sup>1</sup>

**Intersectional stigma** occurs when an individual or group experience(s) multiple stigmas that are not only overlapping but also co-constitutive. It denotes the synergistic effect produced by systems of oppression at the intersection of these stigmatized identities, behaviors and/or

**Key populations** are defined groups who, due to specific higher-risk behaviors, are at increased risk of HIV irrespective of the epidemic type or local context. Also, they often have legal and social issues related to their behaviors that increase their vulnerability to HIV. The key populations are important to the dynamics of HIV transmission and prevention in Zambia and other countries with concentrated or generalized HIV epidemics globally.

**Psychosocial** refers to the intersection and interaction of social, cultural, and environmental influences on the mind and behavior.

**Stigma** refers to negative beliefs, attitudes and stereotypes about a person or group.

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<sup>1</sup>National Institute of Allergy and Infectious Diseases (NIAID). NIAID HIV Language Guide [Internet].

National Institute of Allergy and Infectious Diseases (NIAID); 2020. Available from:

<https://www.hptn.org/sites/default/files/inline-files/NIAID%20HIV%20Language%20Guide%20-%20March%202020.pdf>

**Stress** is the physiological or psychological response to internal or external stressors. Stress involves changes affecting nearly every system of the body, influencing how people feel and behave. By causing these mind–body changes, stress contributes directly to psychological and physiological disorder and disease and affects mental and physical health, reducing quality of life.

**Unsuccessfully engaged populations/individuals** is used rather than “hard to reach,” in order to put the onus to improve access on the health sector rather than the individual.<sup>1</sup>

**Women engaged in sex work** also known as female sex workers, refers to adults (18 years of age and above) identifying as women who receive money or goods in exchange for sexual services, either regularly or occasionally. As defined in the Convention on the Rights of the Child (CRC), children and adolescents under the age of 18 who exchange sex for money, goods or favours are “sexually exploited” and not defined as sex workers.<sup>2</sup>

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<sup>2</sup> UNAIDS Guidance Note on HIV and Sex Work, 2012, at p 3, available at [http://files.unaids.org/en/media/unaids/contentassets/ documents/unaidspublication/2009/JC2306\\_UNAIDS-guidance-note-HIV-sex-work\\_en.pdf](http://files.unaids.org/en/media/unaids/contentassets/documents/unaidspublication/2009/JC2306_UNAIDS-guidance-note-HIV-sex-work_en.pdf) (accessed 16 July 2016).

## Appendix 2: In-Depth Interview Guide

Interview ID: \_\_\_\_\_

Category:            Women Engaged in Sex Work            Peer-navigator

Date of the Interview: \_\_\_\_/\_\_\_\_/\_\_\_\_ (mm/dd/yy)

Start time of interview (24 h clock, hh:mm): \_\_\_\_: \_\_\_\_

End time of interview (24 h clock, hh:mm): \_\_\_\_: \_\_\_\_

Interviewer name: \_\_\_\_\_

Notetaker name: \_\_\_\_\_

### INTRODUCTION

Hello, my name is **[insert your name]** and this is **[insert the name]**. We want to thank you for agreeing to take part in this interview.

I will be leading the interview and **[insert the note taker's names]** will be taking notes.

**[What is the study?]** This study seeks to interview you to find out how women who engage in sex work make decisions about HIV prevention. What we gather will help develop appropriate service delivery strategies to customize HIV prevention services to their needs.

**[Why have I been invited to take part?]** You have been being asked to take part because you are eligible for HIV prevention services under the KPIF program, **or** you are someone who has helped women doing sex work connect to HIV prevention services. If you are someone who has helped women doing sex work, imagine you are speaking about their experience.

During the interview, we will discuss several topics with you, including your experience of the things that help you get HIV prevention medicine, and the things that are challenges for you getting the same medicine.

Do you have any questions before we start?

**[Take time to address all questions and concerns]**

With your permission, I would like to turn on the tape recorder and begin the interview?

[TURN ON TAPE RECORDER if permission granted]

[INTERVIEWER: START RECORDING]

## **DEMOGRAPHICS**

What is your age?

What is your gender?

What is the highest level of education you have completed?

What is your marital status?

## **ICEBREAKER**

**What is your favorite food?**

**What is bringing you joy lately?**

## **PSYCHOSOCIAL STRESS**

**Q1:** Tell me your story, starting from how you started doing sex *work*?

**[PURPOSE OF QUESTION:** To allow the participant to become comfortable with the interviewer, and to tell their story in their own words.

**Q2:** What are some of the challenges of sex *work*?

**[PURPOSE OF QUESTION:** To allow the participant to discuss any stressors as a result of sex work]

**Q3:** How are these challenges different from those faced by men doing sex work?

**Probe:**

- **Stress related to setting where you work (eg: rest house, bottle store without much security)**
- **Family care for the children and stay where they work**

**[PURPOSE OF QUESTION:** To show vulnerabilities unique to women vs men involved in sex work?]

**Q4:** Of the challenges you mentioned, which stress you a lot?

**[PURPOSE OF QUESTION:** To allow the participant to explain what they feel are the most important stressors in their life. This also provides context for how this person makes decisions around their health.]

**Q5:** What has made those stressors better?

**Probe:**

- **Support from other women engaged in sex work, for example a queen mother**
- **Peer-navigators**
- **Services at KPIF**

**[PURPOSE OF QUESTION:** To find out about social capital and pathways of resiliency]

## **HISTORY OF HIV PREVENTION**

**Q6:** What are the different things you use to prevent HIV?

**Probes:**

- Understanding of available HIV prevention tools
  - o (ex: condoms, or PrEP, PostExposure Prophylaxis (PEP) especially for victims of violence and sexual abuse – Zambian National Guideline states it should be taken within 72 hours of the unwanted sexual encounter)

**[PURPOSE OF QUESTION: To establish baseline knowledge of HIV prevention measures]**

**Q7:** How do you go about getting these prevention services?

**[PURPOSE OF QUESTION: To prompt the participant to think of places where they accessed HIV prevention services]**

**Q8:** What has been your experience in getting these prevention services?

- good experiences
- bad experiences

**[PURPOSE OF QUESTION: To prompt the participant to think of the quality of HIV prevention services they received]**

**Q9:** Based on your experiences, how do you feel about the health care services that are available to you?

**Probes:**

- Being refused health services
- Uncomfortable revealing your identity to health providers

**[PURPOSE OF QUESTION: To prompt the participant to think of instances that created distrust in health care services]**

**Q10.** How did you happen to choose this space for your health services?

**Probes:**

- Social network referred you,
- Convenience - less wait time, drugs are stocked,
- friendly, non-stigmatizing, non-discriminating

**[PURPOSE OF QUESTION: To encourage the participant to think of what positive qualities prompted them to give the program a chance and access this space]**

### **PrEP-SPECIFIC QUESTIONS**

**Note to Interviewer:** This study is recruiting women who were eligible to initiate on PrEP in the last 3 months and asking them to reflect on their experience.

**Q11. Did you start taking PrEP?**

**Q12.** You said you did not start PrEP, what factors stopped you from starting PrEP?

**[PURPOSE OF QUESTION: To understand barriers to initiating PrEP]**

**Probes:**

- Was not offered PrEP.
- Did not receive enough information about it.

**Q13.** You said you did start PrEP, what made you decide to take PrEP?

**Probes:**

- wanted to protect myself,
- protect my partner,

- stay healthy,
- continue care-taking for those who depend on me

**[PURPOSE OF QUESTION: To understand motivating factors for decision to initiate PrEP]**

**Q14.** What helped you to start taking PrEP?

**Probe:**

- peer network,
- support from health workers,
- convenience of site,
- site had drugs in stock,

**[PURPOSE OF QUESTION: To identify what the enabling factors to initiating PrEP]**

**Q15.** The most common ways of getting infected with HIV are sex without condoms, injecting drugs. Tell me about your risk of HIV exposure in the last 3 months. Were they what you envisioned when you started PrEP?

**[PURPOSE OF QUESTION: To understand whether PrEP use was aligned with perception of risk]**

**Q16.** If you are still taking PrEP, what makes you continue taking it?

**[PURPOSE OF QUESTION: To identify enablers to continuing to persist on PrEP over time]**

**Q17:** If you are not still taking PrEP, what made you stop taking it?

**[PURPOSE OF QUESTION: To identify the barriers to persisting on PrEP over time]**

**Probe:**

- Stigma

## **INJECTABLE PREP**

### **INSTRUCTION:**

Give patient education on oral PrEP vs long acting injectable PrEP.

Injectable PrEP is very effective at protecting people from HIV and is for adults and adolescents who are at risk of getting HIV through sex. It is a jab given every 2 months instead of taking pills everyday. The medicine in the jab is in your blood for 2 months and prevents HIV infection. The medicine is the same type of medicine as in the pills. Injectable PrEP is being used in other countries, and will be available in Zambia in the next year.

**Q18a.** What do you think are the advantages of taking injectable PrEP for women who exchange sex for money?

**Q18b.** What are the disadvantages?

**[PURPOSE OF QUESTION: To gauge advantages and disadvantages of injectable PrEP which will be newly available in Zambia.]**

**Q19a.** What are some reasons why women who exchange sex for money would like the jab every 2 months to prevent HIV?

**Q19b.** What are some reasons why they would not like the jab every 2 months?

**[PURPOSE OF QUESTION: To gauge acceptability of injectable PrEP which will be newly available in Zambia.]**

## **SERVICE IMPROVEMENT**

**Q20a.** What factors may lead you to trust any clinic or health care providers less?

**Q20b.** What made you trust the clinic or health providers more?

**Probe:**

- Closed vs Open spaces
- Women vs men
- Privacy / confidentiality
- Having a peer from the community assist me
- Having someone who has had experience in sex work

**[PURPOSE OF QUESTION: To understand what makes services trustworthy to the participant.]**

**Q21.** What should we change in this space to make it more supportive for you to get HIV prevention services? How will this help you?

**Probes:**

- Getting a one-stop shop of services (family planning, STIs, substance use, mental health)
- Information on economic / training opportunities / women's empowerment
- Food packages/ nutritional assistance
- Transportation assistance to make it to health appointments

**[PURPOSE OF QUESTION: To understand specific services women would want from a 'safe space' and understand how they perceive the provision of those services would affect their health]**

**Q22.** Who would you want supporting you to stay on PrEP when you feel you need to be on PrEP?

**[PURPOSE OF QUESTION: To understand who is best to deliver prevention services ]**

## **STIGMA-SPECIFIC QUESTIONS**

**Q23:** Earlier you referred to stigma from XX and XX. What are ways we can reduce stigma?

**Probes:**

- Stigma training programs for health care workers
- Is there anything we can do for you?

**[PURPOSE OF QUESTION: To identify stigma reduction interventions]**

**Q24:** Is there anyone within your work network who attitudes we could change if there was a program to reduce stigma?

**[PURPOSE OF QUESTION: To identify people who would benefit from stigma reduction interventions. To assess efficacy, is there anything we could do to change this? ]**

*Please read verbatim:*

**[“Thank you for taking the time to share your story with me today. Do you have any questions or things you would like to talk about before we end the interview?”]**