

**Title:**

**Understanding Early Uptake of PrEP by Female Sex Workers in Zimbabwe**

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**Title:****Understanding Early Uptake of PrEP by Female Sex Workers in Zimbabwe****Abstract**

Female sex workers (FSW) are prioritised for increased access to pre-exposure prophylaxis (PrEP), although rates of uptake remain sub-optimal, particularly across Southern Africa. In the first two years of its availability in Zimbabwe, 37.1% of FSW in trial sites initiated PrEP and received at least one re-supply. We conducted a qualitative study on perceptions of PrEP among 19 early users selected from sites with varying rates of PrEP initiation. Narrative interviews examined the pathways taken by FSW from hearing about PrEP, through their decision to start taking it, and early experiences. FSW appreciated PrEP's introduction within familiar and trusted "friendly" services tailored for sex workers and valued positive encouragement from clinic staff and peers over negative influence from family members. They also found PrEP difficult to understand at first, and feared side effects and rare adverse complications described in information leaflets. While FSW identified individual strategies for remembering to take their medication, they also relied on structured peer adherence support, leading some FSW to actively promote the method to other FSW as "PrEP champions". Information on how early users experience a new prevention technology such as PrEP can inform design of interventions that leverage existing support structures and target key barriers.

**Keywords**

PrEP; Female Sex Workers; Zimbabwe; Qualitative

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## Introduction

Women in southern Africa have among the highest incidence of HIV globally, with female sex workers (FSW) most vulnerable. Worldwide, HIV prevalence among FSW is 13 times higher than women in the general population (Baral et al., 2012). Increasing FSW's access to routine pre-exposure prophylaxis (PrEP) is part of global commitments to provide PrEP to those at highest risk (Beyrer et al., 2015; Fonner et al., 2016; Syvertsen et al., 2014; WHO, 2016).

Rates of uptake, adherence and retention have proved lower than hoped in many PrEP trials and demonstration projects (Marrazzo et al., 2015; Van Damme et al., 2012). Despite initial enthusiasm, FSW encounter barriers to PrEP use (Eakle et al., 2018; Marrazzo et al., 2015). New users struggle with integrating daily PrEP use into routine practice (Skovdal, 2019), are adversely influenced by family and peers' negative opinions (Van der Elst et al., 2013), and fear PrEP will be confused for ART (Eakle, Bourne, et al., 2017).

Nevertheless, some FSW find PrEP acceptable and are willing to persevere (Eakle, Gomez, et al., 2017; Mugo et al., 2016). Understanding these women's experiences and perceptions is critical for informing interventions to support PrEP uptake (Celum et al., 2015; Cowan et al., 2016). In particular, information on how early users of PrEP are influenced by FSW peers, other social networks and interactions with health staff can help harness existing support structures and target key barriers.

We present the experience of offering PrEP to FSW as part of a complex intervention through the SAPPH-IRe cluster randomised controlled trial (Cowan et al., 2018). The study was conducted in Zimbabwe where mean HIV prevalence among FSW across 14 sites in 2013 ranged from 42.8 – 79.2% (Cowan et al., 2017). Finding effective HIV prevention interventions for FSW is critical to both alleviate their disproportionate burden and lower indirect transmission in the wider population (Bekker et al., 2015).

## Methods

We conducted the SAPPH-IRe trial ("Sisters Antiretroviral Programme for Prevention of HIV – an Integrated Response") between April 2014 and March 2016 (Cowan et al., 2018; Hargreaves et al., 2016). The trial was nested within Zimbabwe's national programme for FSW 'Sisters with a Voice' (*Sisters*). As part of the trial, the *Sisters* programme was strengthened in intervention sites to include more intensive community mobilization, active promotion of regular HIV testing, and on-site provision of ART and PrEP. All FSW on PrEP or ART were invited to join the Adherence Sisters Programme, which encouraged women to pair up with another FSW (or friend/relative) to provide

medication support. Implementation of PrEP was monitored through programme records collecting data on HIV testing, PrEP referral, uptake and continuation.

To explore FSW perceptions and experiences of PrEP, we conducted a qualitative study in 3 of the 7 intervention sites, representing high, mid-range and low rates of registration for use (41.7% of eligible FSW; 22.0%; and 15.1% respectively) over the first six months of the trial (July-December 2014). We sought to purposively recruit 20 women with varying degrees of PrEP uptake (e.g. registered for use but did not start, initiated PrEP but did not continue, maintained PrEP with good/poor adherence) and retention in care (low and high appointment attendance rates). Staff from the *Sisters* programme contacted selected FSW, explained the study and arranged interviews with a qualitative researcher. Interviews were conducted at project sites (e.g. following a community mobilisation session or clinic appointment). We were unable to locate most women sampled for loss to clinical follow up. We tried to contact them by phone 3 times but received no answer or their number was inactive. We recruited 19 new users of PrEP of whom only 1 had defaulted contributing to a bias toward FSW more likely to engage with services and less likely to migrate out of the area.

Interviews followed a narrative approach. FSW were asked to describe their pathways from learning about PrEP through registration, uptake and continuation, focusing on facilitators and barriers to initiation. Interviews also explored personal circumstances such as mobility, relationships and family structure, and type of sex work, exploring how these interacted with PrEP uptake. Respondents provided written informed consent and received US \$5 compensation. Interviewers translated interviews into English prior to transcripts being entered into NVIVO for thematic content analysis. The first author conducted initial broad-brush coding by themes identified *a priori* as “decision making process,” “facilitators of PrEP use” and “barriers to PrEP use.” The study team reviewed coded text to identify additional data-driven themes, comparing these across cases and stages of PrEP use (registration only, registration plus initiation, high/low adherence or retention).

The SAPPH-IRE trial, including these analyses, received approval from the Medical Research Council Zimbabwe, University College London, the London School of Hygiene and Tropical Medicine, and RTI International.

### **3. Results**

A total of 1403 women in 7 intervention sites underwent initial screening, of whom 1061 had a second screening visit, and 639 women initiated PrEP. 521 women (82%) returned for at least one follow-up appointment. Thus, among women who expressed initial interest when PrEP was described to them during the trial, 37.1% underwent the entire screening and prescription process

and returned for a check-up and repeat supply, which we consider a proxy measure for the maximum proportion motivated to use PrEP in the early stages of its availability.

We present qualitative findings chronologically, from hearing about PrEP through eligibility screening, decision to initiate or not, and experiences of adherence or defaulting. Table 1 summarises respondent characteristics.

**Table 1 here**

*Learning about PrEP*

Thirteen respondents first heard about PrEP when attending a *Sisters* clinic and testing for HIV. FSW identified PrEP as one of many freely available services at *Sisters* described by nurses during medical appointments.

*The nurses asked me why I had come. I was having stomach [pelvic] pains, so they helped me, they checked everything, so they knew what was going on, they checked my cervix and everything was fine, so they tested me and the results were negative, and then they talked about PrEP (#19)*

*I decided to come to the clinic after my husband died, so when I came, I had my blood tested, so when that was done it was found that I did not have HIV and that is when they told me about PrEP (#05)*

The other respondents heard about PrEP from other FSW or, in one case, an outreach worker. These women expressed enthusiasm for an additional HIV prevention strategy and attended the clinic specifically to obtain PrEP.

*I heard my mates saying that there is a tablet that you can get from this clinic ... they said that you can be given a tablet that will help reduce your chances of getting infected with HIV if you test negative. ... It did not take time for me, I heard about it on the 26th ... then I came on the 2nd (#04)*

*I was told by others ... they said there is a pill that prevents 'what what' [HIV]. ... I just thought: I want it. I just said 'if I don't have the virus I want that pill' - that's what came into my mind (#12)*

*Decision-Making*

While 4 FSW came to the clinic specifically for PrEP, others took time to consider it, requesting additional information, studying provided leaflets, and consulting family members and other FSW. Nurses proved instrumental in respondents' decision to initiate PrEP.

*They explained to me that PrEP means that when you are not infected, you have to take it every day and never forget. If you have sex with someone who is infected or even if you bathe them with bare hands touching their wounds ... [if] you have forgotten to wear gloves and you just rush to clean someone who is infected, you will not catch it. That is what PrEP means, for sure it is helping us, we used to be scared back then but now we are no longer scared (#01)*

*They told me that this tablet helps the soldiers in my body [T cells], so that it will not be easy for me to get infected with HIV ... I can go for a long time without getting infected. (#16)*

FSW were also reassured by talking to family members and peers, both those who were HIV-negative and HIV-positive. ART-users endorsed PrEP, which was considered closely related to PrEP.

*My brother's daughter, she is the one who made me come back [for PrEP] because ... she is on ART, so she is the one who strengthened me and said '...look at some of us, we are already in this [HIV-positive], but as for you, this may be your chance to protect yourself' (#05)*

*I had been told about it by my friend who also comes here, she said 'my friend since you ... are just like me, there is a clinic where you can go and get help, they will do a blood test and when you test positive they will give you tablets, if you test negative they will also give you some tablets so that when you have sex with someone with HIV and the condom breaks you will not contract AIDS' (#11)*

We interviewed 3 women who decided against PrEP, out of fear of side effects, previous bad experiences with medication, or concerns about taking a daily pill. The information leaflet caused particular concern with its long list of potential adverse effects, as described below by FSW who sought additional reassurance from nurses.

*There is a paper about Truvada that they gave us to read and it says that there are [bad] things that can happen to me, so I asked if it will happen as soon as I start taking it, and then they told me that it is just writing about the tablets. Ever since they started giving it to people no one has experienced those things (#17)*

*So I looked at the side effects and started asking myself, what if I get sick with all those ailments mentioned there? (#02)*

In response to the frequency of such reactions, the leaflet was re-written in 2015, reducing emphasis on extremely rare complications, reflecting a growing evidence base for the lack of serious adverse events (Pilkington et al., 2018).

#### *Early Use of PrEP*

FSW discussed several challenges to maintaining PrEP use. First, 7 FSW reported experiencing side effects during the first few days or weeks, usually dizziness or headaches, stomach pain and nausea, sleepiness and general malaise/weakness. FSW with more serious side effects considered stopping the drug, but were persuaded to persevere by clinic staff, and no longer experienced difficulties.

*But I had this dizziness that I felt, I would get dizzy... but that did not happen for a long time. Ah, it was just for 2 weeks. ... I can say that there was a time when I wanted to stop taking them, so I first came here to ask what would happen if I stop ... [now] this is how I am living, there is no side effect that I can say I have (#06)*

Not all side effects were considered negative, however, as increased appetite and weight gain could be positively interpreted. For example, one FSW proudly talked about breaking the scales soon after initiating PrEP, which she considered a good health.

*PrEP does work and when you take it you will be healthy all the time, yes, you will want food all the time, and for sure you will not stay long with your food. And talking about food - my weight had [previously] reduced but from the time I started taking PrEP, I broke the weighing machine, I am now at 93 kgs! (#15)*

Other respondents struggled to return monthly for follow-up appointments, particularly if they travelled. At first, women could only receive a month's supply at a time, which caused some frustration (and eventual relief when they "graduated" to 2- or 3-monthly prescriptions). The frustration was exacerbated by what was perceived to be a prolonged period of medical testing and eligibility screening prior to initiation.

*We spent about 3 months ... At first they took blood samples...we went back the next week and they checked if we had other diseases before they started testing us. That is when they gave us a 2 week supply of tablets, so that time it took long for us to continue coming back (#15)*

*Yes, I am graduating, so when they gave me [2 months' supply] last time I was so happy (laughter) and I said at least I will rest [from] coming here. ... Because at times we will have other things to do or places to visit. I will know that I have my supply so that I can use until I come back (#06)*

Almost all respondents reported good adherence. Women listed strategies to remember their pills i.e. setting a phone alarm, keeping pills in the same bag as the phone, taking PrEP alongside oral contraceptives, and linking drug taking to a daily event such as preparing an evening meal or brushing teeth.

*No, I never forget to take my tablets, I make sure that when I cook, my tin of tablets will be on my side (#03)*

*I always put them together with my toothpaste because I brush my teeth in the morning, that is the first thing I do when I wake up, so it will be obvious that I see them when I brush my teeth and then I will remember (#05)*

Most also praised the Adherence Sisters programme, where they chose a peer to share reminders. FSW found that while they didn't solely rely on the Adherence Sister to remind them, they liked the "back-up" security and social support.

*I even call my friend and ask her what she is doing, if she has eaten, and she will also answer and ask if I have eaten, and I will tell her that I am eating, and she will say 'open your tablet and take it or after you have finished taking it then you beep me so that I can see that it is time to take mine also' - so we beep each other. ... she is the only person who can tell me her secrets and I can also tell her my secrets (#01)*

#### *Encouraging Others*

Several FSW described pride in being among the first acceptors of PrEP. One referred to her cohort as "pioneers" and others talked about recruiting peers and siblings.

*I will encourage them [FSW] to come ...I will for look for a friend, we are "birds of the same feather," doing the same thing. Our minds will be thinking alike ... I will come [to the clinic] with her (#10)*

*You need to plead with them (reluctant SW) like I did to my friend. She wanted to give up, so I [was] telling her 'no my friend, you should not do that, let us go together' (#12)*

FSW were keen to dispel fears and hold themselves up as positive role models, who had successful experiences. Some volunteered to be 'PrEP Champions', which formalised their promotion of PrEP among FSW.

*Because I can see that it's working for me so I want to help others because it's scary. (#09)*

*We would talk to them [other FSW] and say 'I am on PrEP' ... they would ask 'is there anything that will happen to you?' and I said 'no, look at me. I am actually taking it' (#02)*

#### **4. Discussion**

This study examined experiences of among the first female sex workers who initiated PrEP in Zimbabwe. We found the national Zimbabwean HIV programme for FSW, *Sisters with a Voice*,

provided an enabling environment for PrEP. Most FSW heard about PrEP from the programme or from peers attending *Sisters*. We have previously documented high levels of trust FSW put in the *Sisters* programme (Cowan et al., 2019; Cowan et al., 2018) and it is likely that its “friendliness” contributed to FSWs’ willingness to try PrEP. Other programmes have noted the importance of the service delivery context for early use of new health technologies, such as family planning (Murphy, 2004). This is particularly true for marginalised populations for whom health services are often stigmatising and feared for potential harm to sex workers (Mtetwa et al., 2013; Nyblade et al., 2017; Scorgie et al., 2011; Wanyenze et al., 2017; Wong et al., 2011). FSW in South Africa also credited non-stigmatising, tailored services for encouraging PrEP use (Eakle et al., 2018).

Perhaps as a result of trust in the programme, FSW took seriously medical literature on PrEP side effects. Some were frightened by descriptions of rare but serious complications; this was addressed by re-phrasing the information leaflet to more realistically reflect risk while adhering to the manufacturer’s warnings. We also found that while FSW consulted family members, they found interactions with nurses and peers particularly influential, and appreciated the Adherence Sisters programme for structured peer support. Perhaps due to the success of peer support, study participants did not highlight difficulties in taking daily pills as one of their main challenges, as has been commonly found elsewhere (Glick et al., 2020). Using early PrEP adopters as mentors to later users could be an approach worth adapting and expanding, particularly given the pride some FSW felt in taking a proactive role as “PrEP champions” who travelled throughout Zimbabwe to “give testimony” and promote uptake.

The main limitation of our study was difficulty in recruiting FSW who refused PrEP or defaulted. We unsuccessfully tried to contact these FSW using mobile phone numbers provided at the time of registration. We are thus not able to characterise negative perceptions and experiences of PrEP among those declining or dropping-out, nor explore how they had been influenced during decision-making. Nonetheless, we feel that our study takes a “positive deviance” approach (Rose & McCullough, 2017) that usefully highlights types of PrEP-related knowledge, characteristics, and early experiences encouraging a significant minority of FSW to use PrEP. These can be harnessed in future peer outreach and community dialogue activities to maintain growing momentum for uptake.

## **Conclusion**

In the first two years of PrEP availability within Zimbabwe’s nationally scaled sex worker HIV prevention and treatment programme, close to 40% of FSW approached through the programme initiated and received at least one re-supply. Learning from the motivations, decision-making process, and experiences of these first users can help inform programme adaptations and

improvements to support wider uptake among highly vulnerable populations, both in Zimbabwe and other contexts.

## Tables

Table 1: Respondents' characteristics in high (42% uptake), mid-range (22%) and low (15%) rates of PrEP registration

Interview number	Age	Experience with PrEP at time of interview	Study Site PrEP Acceptance
01	60	Taking PrEP and reporting adherence	High
02	25	Taking PrEP and reporting adherence	High
03	47	Taking PrEP and reporting adherence	High
04	20	Underwent initial screening and has returned to initiate	High
05	43	Registered but never initiated	Medium
06	38	Taking PrEP and reporting adherence	Medium
07	24	Defaulted previously but returning to re-initiate	Medium
08	29	Registering	Medium
09	31	Taking PrEP and reporting adherence	Medium
10	45	Registering	Medium
11	30	Registering	High
12	29	Taking PrEP and reporting adherence	High
13	38	Defaulted	High
14	39	Underwent initial screening and has returned to initiate	Low
15	26	Taking PrEP and reporting adherence	Low
16	33	Registered but never initiated	Low
17	42	Initiated	Low
18	35	Registered but never initiated	Low
19	23	Taking PrEP and reporting adherence	Low

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