SASOD Guyana
Society Against Sexual Orientation Discrimination

# Assessment of Knowledge, Attitudes and Delivery Preferences for HIV Pre-Exposure Prophylaxis (PrEP) among Key Populations in Guyana

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**Supported by the International HIV and AIDS Alliance's Rapid Response Fund**

**August 2018**

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## Introduction

Guyana has a generalized HIV epidemic with an estimated adult HIV prevalence rate of 1.4%,[(1)] but certain key populations (KPs) face much higher rates of HIV: for example, the 2013/14 Guyana Bio-behavioral Surveillance Survey (BBSS) found rates as high as 4.6% among men who have sex with men (MSM) and 7.8% in transgender (TG) women.[(2)]Daily oral pre-exposure prophylaxis (PrEP) with tenofovir/emtricitabine (TDF/FTC) has been proven effective and safe in high-risk groups, prompting the WHO in 2014 to recommend PrEP as an additional HIV prevention choice for these groups.[(3)] In spite of this recommendation, most persons currently on PrEP are within the United States, and the global target of providing 3 million at-risk persons with PrEP by 2020 stands at 2%. [(4)]For unknown reasons, the Caribbean's uptake of this option has been negligible, although at least two Caribbean countries – Bahamas and Barbados - have started providing free-of-cost PrEP to all high-risk persons. These Caribbean governments, including Guyana, made commitments to increase PrEP demonstration projects at a region-wide forum in 2015,[(5)] but 3 years later, there still has been no move on the part of the Guyanese governmental stakeholders to initiate delivery. Data on the barriers to utilizing PrEP in the region remain anecdotal, vague and undefined, but a lack of awareness, both by prescribers and potential patients is certainly a factor. Given this significant paucity of data and the urgent need to implement supplementary preventative measures in vulnerable populations, the Society Against Sexual Orientation Discrimination (SASOD)conducted a qualitative assessment of the current knowledge, attitudes and preferences with regards to PrEP in Guyanese MSMS and TG persons.

## Methodology

Focus groups were conducted with HIV-negative MSM and TG persons over 18 years old and residing in administrativeRegions 3, 4, 5, 6 and 10 of Guyanato assess the current level of knowledge, attitudes and delivery preferences with regards to PrEP. Participants were purposively selected, striving for broad representations in age, ethnicity, education level and socio-economic status. Additionally, the 'snowballing' method of participant recruitment was utilized to increase access to a population that is otherwise difficult to reach. The focus group discussions used a semi-structured topic guide, were audio-taped, transcribed verbatim and then thematically analyzed. The questions in the discussion covered community HIV prevention, knowledge and attitudes towards PrEP, messaging and service delivery for PrEP. At the end of the focus group discussions, a short, six-question survey was individually administered to each participant to assess their interest in taking PrEP.

## Results

Six focus groups comprising 5 to 10 persons each, were conducted with a total of 47 participants. One focus group each was held in Regions 3, 5, 6 and 10 with both MSM and

TG participants, and two in Region 4 – one for MSM and one for TG persons. The average age of the participants was 29.5 years.There were 17 transgender women (36%) and 30 cisgender men. Table 1 here shows further participant demographics:

| Demographic | Number | % |
|---|---|---|
| **Education** | | |
| Post-secondary | 20 | 42% |
| Completed secondary | 14 | 29% |
| Partial secondary | 12 | 25% |
| Completed primary | 1 | 2% |
| **Ethnicity** | | |
| Afro-Guyanese | 22 | 46% |
| Mixed-Guyanese | 16 | 34% |
| Indo-Guyanese | 8 | 17% |
| **Employment** | | |
| Employed | 32 | 68% |
| Unemployed | 14 | 29% |
| Retired | 1 | 2% |
| **Relationship status** | | |
| In a relationship | 18 | 38% |
| Dating | 10 | 21% |
| Neither | 19 | 40% |
| **Partner HIV Status** | | |
| Negative | 45 | 95% |
| Positive | 2 | 42% |
| **Frequency of condom use** | | |
| Always/Often | 30 | 63% |
| Sometimes/Rarely | 11 | 23% |
| Never | 6 | 12% |

***Knowledge and Attitudes***

60% of the participants had never heard of PrEP before, and even among those who reported they had heard of it before, when they were asked to explain what they understood by the term, it was discovered that some were confusing PrEP and PEP (post-exposure prophylaxis). None of the 6 persons in Region 5 had heard of PrEP before. Conversely, 6 out of 10 MSM in Region 4 had heard of PrEP.

After PrEP was explained to the participants, several persons in all the groups thought it was a "good thing" and some persons openly declared that they would use it if it was available. When probed about their concerns or questions about the medication, issues that arose included cost, side-effects, possibility of interactions with medications or alcohol, duration of use, level of protection offered, effect on pregnant women, and how soon it would become available in Guyana. A significant minority of persons expressed concern about the possibility of the medication increasing sexual promiscuity in both HIV- negative persons and persons living with HIV.

Several participants in 3 different groups thought that "anybody who was HIV negative, having sex and willing to take it" should be on PrEP. Almost everyone thought PrEP should be taken by sex workers and persons in sero-discordant relationships. In Regions 5 and 6, however, three persons commented on how the use of PrEP in a sero-discordant relationship could hurt the relationship and the sero-positive partner.For example, as P606 said, "HIV-negative persons who might want to say let me go on PrEP could face questions from the person who is positive and say but why you want to take this PrEP if you love me?" Participants also identified transgender persons, MSM, bisexual persons, persons with an STI in the past, persons with multiple sex partners and 'young people' as potential beneficiaries of PrEP.

Persons spoke about some barriers that could impede PrEP uptake and these included the fact that it is a pill ("if you doan like drinking pills everyday") that has to be remembered to be taken daily, side effects, denial about risk, lack of education, and frequency of blood work (although some participants explicitly stated that the frequency of this was a good thing since it would enable them to regularly know their status and get checked up). Two major barriers were the cost of the medication, if it had to be bought, and the continued stigma around HIV.Even though PrEP will be used by HIV-negative persons, it would still be associated with the infection. These barriers could be overcome by providing the medication free-of-cost, promoting large-scale education on PrEP via influencers, mass media and online; empowering persons to feel confident about asking for the medication; and having alternative forms to the tablet, such as liquids or injections.

When asked what they thought the effect of introducing PrEP would be, apart from the positive effects on persons who could most benefit from it, such as sex workers and sero-discordant couples, participants mentioned that it would bring peace of mind, hope, a better future and voiced support for further workshops and community campaigns on the topic.

***Messaging and Delivery***

MSM in Region 4 met partners and socialised mostly online via social media and dating apps, but in the other regions there was a mixture of online socialization and in-person at entertainment venues or personal residences. Participants had a variety of suggestions for how they would like to receive information on HIV and sexual health in general, including via social media, mass media, anonymous, personalised home deliveries, home visits, mobile health services and via non-governmental organizations (NGOs). When asked how they would like to receive information on PrEP specifically, persons in 4 different groups preferred NGOs, especially persons in Region 6 who overwhelmingly preferred to interact with the NGO the focus group was held at - Family Awareness Consciousness Togetherness (FACT). Many persons also preferred the utilisation of a multi-pronged dissemination strategy utilizing mass media, social media, accessing flyers, pamphlets etc. at physical locations, and being informed at health services. Less common suggestions included the use of peer educators, emailing, calling on the phone, and texting, although at least two persons noted "no one texts anymore since WhatsApp and Facebook."

The majority of persons in each group reported they would be comfortable asking their doctor about PrEP: "I would definitely feel comfortable. I think your doctor would feel more happy to advise you more on the programme because remember it is a prevention pill…even a public doctor I will ask about it" (P605). Those who didn't feel comfortable enquiring about

the medication stated it was because these enquiries run the risk of exposing their KP status or because of the stigma surrounding anything related to HIV. In four groups, most participants preferred that PrEP be delivered either via NGOs or the government. As one participant in Region 4 noted: "I think the government, because even if they don't work, it get out there, it does touch the base…the government has that umbrella (so that) everyone is targeted." In the other two groups the preference was for delivery via all three modes - private health care, NGOs and the government. Some persons thought that any'PrEP clinic' and advertising about PrEP should be accessible and targeted to the wider population and not just KPs in order to avoid the stigmatization that could be attached to it.

At the end of the focus groups, almost all the participants said they had learnt 'a lot' (84%), and were either very interested or somewhat interested in taking PrEP (80%). However, only 60% were very interested in paying for it while 81% would be very interested if it were available for free (and only 2 persons were not interested at all if available for free).

**Recommendations**

The results of this qualitative assessment are not generalizable due to the small sample size. However, this type of research is not meant to provide statistically significant estimates but to generate a base for further research and record a range of perspectives with regards to PrEP. The discussions successfully achieved these aims and has led to the following recommendations:

- There is the need for sensitization and education on PrEP in KPs, especially in regions other than Region 4. Consideration should be given to conducting mass educational efforts that address the facts and selection criteria regarding the preventative measure.
- Recent reports indicate that there is a worrying uptick in the incidence of HIV in Guyana, signalling that current prevention methods are not working optimally.[(6)]The government should follow up on its commitment and initiate the provision of PrEP as an additional prevention measure, at no cost, to overcome the major financial barrier present especially amongst lower-income persons who might most benefit from it. The government could follow the example of Barbados, where the need for a more varied prevention combination approachwas recognized and free PrEP was commenced in March 2018 at the island'scentral care centre.[(7)]Barbados' guidelines closely follow recommendations from the CDC and WHO, and states that PrEP may be offered to any person who is deemed to be at substantial risk for HIV.[(8)]
- A less desirable, but possibly more feasible alternative would be to start offering free PrEP to sero-discordant couples, as has been reported as the practice in St. Lucia, Suriname and Grenada.[(9)]
- Engaging NGOs serving KPs would be essential in rolling out PrEP provision among this population, especially in Regions 5 and 6 where there is a significant preference for delivery through an NGO. These NGOs could also be supported in providing education and sensitization for PrEP through virtual and physical channels.

A similar study involving sex workers as another KP group should be conducted to provide insights in relation to sex workers' knowledge, attitudes and delivery preferences for PrEP.

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