



## Oral HIV self-testing among men who have sex with men in New Delhi, India: Perceptions & apprehensions: A qualitative study

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**Background & objectives:** The overall adult prevalence of HIV in India was estimated to be 0.22 per cent in 2019. The HIV prevalence among men who have sex with men (MSM), a high-risk group for HIV, was estimated to be 4.3 per cent, which is 16 times higher than the national average. In Delhi, the estimated prevalence among MSM was 1.8 per cent. Despite free HIV testing services being made available by the National AIDS Control Programme for more than two decades, many MSM were not aware about their HIV status. Therefore, newer testing strategies are needed. Oral HIV self-testing (HIVST) has proved to be one such promising innovation. At present, there are no programme guidelines on HIVST and oral HIVST kit is not available in India. The aim of this study was to understand the perceived advantages and disadvantages of introduction of oral HIVST strategy among MSM.

**Methods:** MSM who were registered with the selected non-governmental organizations working as targeted intervention sites in Delhi, India, were recruited for focus group discussions (FGDs) between January and May 2021. For the purpose of this study, MSM were defined as males who had anal/oral sex with male/hijra partner in the past one month. A total of six FGDs were conducted using a prepared FGD guide. The FGD guide included questions on problems faced during conventional HIV testing, participants' awareness, acceptability and perceptions of oral HIVST. The data were manually coded and entered in NVivo release 1.5 and themes were identified.

**Results:** A total of 67 respondents participated in the FGDs. A total of 28.4 per cent MSM were beggars at traffic lights, 12 per cent were sex workers and 11.9 per cent were bar/event dancers. Nearly half (50.7%) of the participants had undergone HIV testing less than twice in the preceding one year. None of the MSM were aware about oral HIVST. Perceived advantages of oral HIVST were ease of use, confidentiality and the non-invasive pain-free procedure. Perceived concerns included lack of post-test counselling, linkage to care, poor mental health outcomes and forced testing.

**Interpretation & conclusions:** Most MSM had positive perceptions about oral HIVST. Therefore, it is likely that the introduction of oral HIVST may result in higher uptake of HIV testing among MSM.

**Key words** Delhi - HIV testing - India - men who have sex with men - oral HIV self-testing - qualitative study

Key populations (KPs) and their sexual partners comprised 70 per cent of new HIV infections in 2021<sup>1</sup>.

Of these men who have sex with men (MSM) have 28 times greater risk of acquiring HIV than adult men

(age 15-49 yr) in the general population<sup>1</sup>. In 2019, MSM accounted for an estimated 17 per cent of the new HIV infections globally<sup>2</sup>. In India, HIV prevalence among hijra/transgender people, MSM and female sex workers has been reported to be six to 13 times higher than the adult population<sup>3</sup>. The UNAIDS (Joint United Nations Programme on HIV/AIDS) has advocated the achievement of the 95-95-95 targets which envision that 95 per cent of people living with HIV will know their HIV status by 2030, of those diagnosed 95 per cent should be on antiretroviral therapy and viral suppression should be achieved in 95 per cent of those treated<sup>4</sup>. Furthermore, the 2025 targets and commitments include acknowledging the fact that KPs which include MSM are at particular risk of HIV infection<sup>1</sup>.

Despite global efforts, the HIV testing levels remain suboptimal in many countries. Around 25 per cent of MSM in the UK<sup>5</sup>, 33.2 per cent in China<sup>6</sup> and 14.8 per cent in the United States<sup>7</sup> never got tested for HIV. Among the low- and middle-income countries, only 61.6 per cent of Malaysian MSM<sup>8</sup> and 65 per cent of MSM in Nigeria<sup>9</sup> ever tested for HIV.

In India, HIV care and treatment services are offered free at Integrated Counselling and Testing Centres (ICTCs). These facilities are categorized into screening and confirmatory facilities. At the screening facilities, HIV testing is done using a single rapid test kit. Before and after conducting the test, pre- and post-test counselling is conducted. If the test result turns reactive, further HIV confirmation is done for the individual. Community-based screening for HIV is available at CBOs (community-based organizations)/NGOs (non-governmental organizations)<sup>3</sup>. National AIDS Control Organization (NACO) recommends that all core high-risk groups should be tested for HIV once every six months. A recent study which conducted mapping and size estimation of MSM in virtual platforms in New Delhi, India, cited that 47 per cent of MSM in India had never been tested for HIV<sup>10</sup>. Individuals who are unaware of their HIV status reportedly transmit HIV at a rate 3.5 times higher than individuals who are aware of their status<sup>11</sup>. The uptake of HIV testing services (HTSs) among MSM remains low due to multiple factors such as stigma and discrimination, long distance to HIV testing facilities, long waiting times, crowding, lack of user-friendly testing services, delay in getting reports and fear of having trouble with law enforcement authorities<sup>12-14</sup>.

In 2016, the World Health Organization (WHO) endorsed HIV self-testing (HIVST) as an innovative approach to expand HTSs, particularly among high-risk and underserved populations<sup>15</sup>. There are four WHO pre-qualified HIVST products, of which three (Mylan HIVST, INSTI HIVST and Sure HIVST) are blood based and have a sensitivity ranging from 97 to 99.8 per cent and specificity ranging from 100 to 99.5 per cent. The OraQuick HIV self-test is an oral fluid-based HIV testing product and has a sensitivity of 100 per cent and specificity of 99.2 per cent<sup>16</sup>. The WHO, in 2019, released the updated guidelines on the use of HIVST. As of 2019, around 77 countries across the globe had adopted HIVST strategy policies, while many others were currently developing them<sup>17,18</sup>. Currently, India does not have a formal programme guideline for HIV self-test; neither are the HIVST kits available in the country<sup>10</sup>. HIVST is believed to increase the reach individuals who have limited access to testing services for various reasons. Before introducing the project/strategy, it is important to understand and capture the opinions, perceptions and apprehensions of the people surrounding the project/strategy among which it is planned to be introduced. Therefore, the present study aimed to understand perceptions and concerns about oral HIVST among MSM in Delhi. The objective of this study was to assess the perceptions and apprehensions of the registered MSM about introducing oral HIVST strategy.

## Material & Methods

*Study sites & sampling procedure:* The present study was qualitative in nature, and was conducted through focus group discussions (FGDs) from January to May 2021 in the department of Community Medicine, All India Institute of Medical Sciences, New Delhi, India. In consultation with the Delhi State AIDS Control Society, NGO partners working as targeted intervention (TI) sites for MSM were purposively selected. All these were exclusive NGO partners working for the welfare of MSM. A total of six FGDs were held physically with MSM registered in these selected TI sites. Each FGD included 6-15 participants. The sampling strategy was purposive and convenient. Participants registered with TI sites were recruited with the assistance from outreach workers. Participants, who were aged 18 yr or older, spoke Hindi and were able and willing to provide written informed consent, were included in the study. For the purpose of the study, MSM were defined as males who had anal/oral sex with a male/hijra partner in the past

one month. Permission was obtained to audio record the FGDs, and the data were recorded.

Written informed consent was obtained from each study participant after giving them a detailed description of the study objectives and procedure. All attempts were made to maintain privacy during the conduct of the FGDs that was held at a private place. The confidentiality of the participants was ensured by removing all personal identifiers from the FGD transcripts. The study protocol was approved by the Institutional Ethics Committee of AIIMS, New Delhi, India.

Data collectors included one moderator a female academic research fellow with background in public health and two notetakers. The FGDs were conducted at the TI sites for MSM as per their convenience. The participants were given a brief introduction to the study topic and were then asked to express their opinions. The discussions were audio recorded. Each FGD lasted approximately 45-60 min. There were a total of 67 participants for all the six FGDs included.

*Guide development:* The expertise of the authors in the field of HIV surveillance was drawn upon to achieve the impetus of developing guides to identify how to increase HIV testing among MSM, especially the hidden group. The topic guides included prompt questions, which were pre-tested among the MSM for content validity and comprehension of the language used. Issues explored in FGDs were perception about HIV/AIDS, prior HIV testing, awareness about HIVST strategy, perceptions of oral HIV self-test, perceived benefits and disadvantages of oral HIVST strategy and potential distribution channels for delivery of oral HIVST kits. Prior to the conduct of the FGDs, the participants were sensitized about the topic of the FGD and then asked questions to understand their views about prior HIV testing. They were informed about the method of conduct of HIV testing using the oral HIVST kit. No other information such as advantages or disadvantages of the oral HIVST kit was mentioned to the participants as it could influence their opinion.

*Data analyses:* The investigators transcribed all audio-recorded FGDs in the local language (Hindi). These were handwritten verbatim. The collected data were analyzed in a stepwise manner: free listing of transcribed script, domain formation and coding. The codes were entered manually in the software NVivo Release 1.5 (NVivo 10, QSR International). Similar

group excerpts were collected under a single code. This was followed by categorization till we reached theoretical saturation. Recurring themes identified during data analyses were used for developing a common narrative.

## Results

*Characteristics of participants:* In total, 67 MSM participated in the FGDs. The age of the participants ranged from 18 to 68 yr. A total of 19 (28.4%) participants were panhandlers, that is, those who resorted to begging at traffic signals and trains, 12 per cent were sex workers and 11.9 per cent were bar/event dancers. Most of the participants, 43 (63.2%), were not married and nearly half had tested less than twice in a year for HIV. Of the 67 participants, 30 (44.8%) had completed graduation and 26 (38.2%) had completed studies till higher school (upto 10<sup>th</sup> standard).

*Perception of HIV/AIDS:* Majority of the MSM believed that the general community disapproves HIV/AIDS and looks at people living with HIV/AIDS with contempt. Some MSM also stated that for most people in the community, being a MSM is synonymous with HIV/AIDS.

*'People think it is a very bad disease, and people think wrong about it as they believe it spreads only through sex'.  
(MSM, 38 yr)*

A few MSM believed that HIV/AIDS is not a dangerous disease as viewed by many. People are no longer scared of this disease as medicines have led to better and long-term survival of people living with HIV.

*Awareness about HIV self-testing (HIVST) strategy:* None of the participants were aware that HIV tests could be conducted by themselves. The concept of oral fluid-based HIVST seemed impossible to them. They felt that since HIV does not spread by saliva, thus detection is also not possible.

*'But we are told that HIV does not spread by saliva, by sharing food, so how can you test it with saliva'?  
(MSM, 21 yr)*

*Perceived benefits of HIV self-testing (HIVST):* The concept of HIVST strategy (both blood based and oral fluid based) was introduced to the participants and their opinions about it were then sought. Majority of the participants opined that they were scared of needles

and blood during withdrawal of blood samples. They felt that since the oral HIVST is non-invasive, free of pain and venepuncture was not involved, more MSM would be willing to undertake the test. They unanimously agreed that the oral HIVST would be a better method of HIV testing and would be acceptable to the majority of MSM.

*'Here people start crying. One came, his eyes were filled with tears on seeing the syringe. I told him, its ok, get it done later. So with this saliva based test, these type of people will be more than happy'. (MSM, 32 yr)*

Some MSM believed that more MSM, especially hidden/unregistered MSM, will be able to conduct their own HIV test confidentially. They were happy with the idea of oral HIVST as they felt that the kits could be taken home for their partners who were either busy or reluctant to come to TI sites for conducting HIV test. Participants felt that the test would be easy to use and confidential and can be done by themselves. Some preferred trying both oral and blood tests as they felt that the reliability of the oral test may be questionable.

*'I think both the tests are okay. Blood test may be more reliable'. (MSM, 39 yr)*

*Perceived disadvantages of oral HIV self-testing (HIVST):* Most of the MSM felt that if the oral HIVST was conducted at home, then most people would not share their results, especially if it turns out to be positive. The result will be hidden and there will be no linkage to care. Some of them might go into depression or self-harm in the absence of emotional support on getting a reactive result. Non-availability of pre- and post-test counselling was identified as the potential drawback with oral HIVST. Majority of the MSM said that they would need counselling before and after testing, including training on how to use HIVST.

*'If someone turns out to be positive, he will be shaken and shocked, he will not tell anyone, he will be stressed and tensed, why this has happened to me? He will not eat anything and will go into depression'. (MSM, 32 yr)*

According to a few MSM, some may try to forcefully conduct the test on their partners before every sexual act. A laboratory technician, an MSM, expressed concern stating that many users may not be aware of the correct storage practices of the HIVST kits, which might result in false-positive or false-negative results.

*Preferable testing place for HIV self-testing (HIVST):* The preferred place for conducting the oral HIVST was the TI site under the supervision of/assisted by the laboratory technician/counsellor. As per the participants, conducting the test at TI site under supervision would have triple advantage of counselling, correct interpretation of results and further linkage to care, if necessary. They also suggested that fellow MSM or peer educators of TI site would be ideal persons to distribute the oral HIVST kits.

*'Here at NGO, people will talk to him, make him understand, will sympathise with him, give him treatment and counsel him. Thus, it's better to get tested here at NGO'. (MSM, 41 yr)*

*'I feel more at comfort here. All know me, I know everyone. We can come at our own time as per convenience, I don't have to hide'. (MSM, 35 yr)*

When enquired about alternate method of delivery of HIVST kits, some suggested online delivery of the kits. However, majority of the MSM were not in favour of this mode. The main fear pertaining to the online delivery mechanism was that the package may be opened by family members in their absence which may result in revealing their sexual identity or activity. Many MSM felt that most were not technologically literate to order the kits correctly.

*'Oh, it's my brother's courier. Oh, it's my child's courier. Let's open it and see. And there your entire secret is in front of them. As a result you will be thrown out of house, and suddenly you will be without money, food and place to stay'. (MSM, 23 yr)*

The MSM did not want to purchase the kits from the pharmacy. They preferred a free rapid blood test at TI site over purchasing the oral HIVST kit.

*'We look for free ration distribution... And in this COVID time, my work has suffered, no begging, no dancing... Why should I pay? This NGO test is better than'. (MSM, 28 yr)*

## Discussion

This study brings out the common perceptions and apprehensions of MSM regarding the use of oral HIVST. The findings of this study suggest that participants were unaware of the concept of HIV self-testing, including oral HIVST. Other studies have also reported low awareness about HIVST<sup>19</sup>. Rawat *et al*<sup>19</sup> in their qualitative study, also reported low awareness. However, since they included both blood

and oral HIVST, some participants' were familiar with it, but this awareness might have been due to the blood test kits used in TI site. India does not have a guideline for HIV self-testing and the requisite kits are not available anywhere in the country. Our study findings suggest high perceived acceptability of HIVST among MSM in Delhi. This is consistent with the findings from two other studies conducted in India<sup>10,19</sup>. Almost all participants preferred oral HIVST, mainly because it provided confidentiality and was non-invasive and convenient. Similar findings of confidentiality, convenience of testing and a pain-free testing were also reported by other studies<sup>12-14,19-23</sup>. High perceived acceptability suggests that oral HIVST has the potential to increase the uptake of HIV testing. The 'hidden MSM' who have not yet disclosed their sexuality were likely to benefit the most by oral HIVST as opined by the registered MSM participants. A study conducted among truckers and youths in Pune, showed the acceptance of the HIVST<sup>24</sup>.

Participants expressed concerns regarding the lack of post-test counselling which might lead to adverse psychological outcomes such as depression, anger, resentment or suicidal tendencies and lack of linkage to care on having a reactive result. Similar results were also reported in other studies<sup>23,25</sup>. Other potential drawbacks cited were regarding lack of reliability of the test, lack of knowledge on correct storage of kits and forceful testing of partners. Similar perceived potential drawbacks, especially the lack of pre- and post-test counselling, were cited by participants from other studies as well<sup>14,19,20,26</sup>. However, in the reviews conducted on the studies where HIVST was implemented, participants did not report any social harm<sup>27,28</sup>. Most participants were comfortable with the idea of testing in the presence of a laboratory technician/counsellor from the NGO. Assisted or supervised testing presently seems to be the choice of oral HIVST. A study by Tun *et al*<sup>9</sup> reported that assisted HIVST may reduce invalid test results, and a 24 h hotline or mobile app is needed to better assist testers. Since participants had just heard about the new technology from the investigators and had not witnessed/used HIVST, apprehensions on its use and reliability arose. The provision of post-test counselling in any form, face-to-face counselling or through telephone/hotline would hitherto instil confidence and provide emotional support to the MSM.

We found that the preferred place for conducting the oral HIVST was at TI site and the delivery of kits through their own community members was acceptable.

Online delivery mode and purchasing the kit from the pharmacies were not acceptable to most MSM as they did not want to spend their hard-earned money on the kits. Price emerged as an important factor in determining the uptake of self-test, which is a common constraint in resource-poor settings. Pal *et al*<sup>25</sup> reported that in low-income countries where HIV testing is available free of cost, people are not willing to pay even the nominal price for the kits. Radebe *et al*<sup>29</sup> reported a clear preference of MSM for distribution of HIVST kits through CBOs. Involvement of NGOs and CBOs may ensure effective uptake of HIVST among MSM. Online delivery may be considered for the hidden MSM once the HIVST is introduced on a larger scale in the country and shows promising results. As most MSM have started using online gay apps and are on virtual platform<sup>10</sup>, further research into online delivery mechanisms is, however, required.

This study is among the first few studies to explore the awareness, acceptability and concerns of oral HIVST among MSM in Delhi, India. The high perceived acceptability of oral HIVST among registered MSM suggests that the HIVST may be implemented with pre- and post-test counselling. The evidence generated by our study among the registered MSM may be of help in guiding the national programme in implementation of oral HIVST for key populations, especially MSM.

Despite the benefits, there certain limitations. As this study was qualitative in design, it may further benefit from quantitative research as the results cannot be generalized. The participants provided their perceptions about oral HIVST though they did not undertake the HIV test. The participants in the study were all registered with NGOs, however, the non-registered MSM may have different preferences for the oral HIVST. It would have added value if some participants who were not registered with any NGO were out purely reached through the MSMs network to participate in this study. This approach could have provided of the perspective of hard-to-reach MSM.

Overall, for most of the MSM, the HIVST was acceptable if provided free of cost. If the concern regarding post-test counselling is addressed, then HIVST has a potential to increase the uptake of HIV tests.

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