

Acceptability of HIV Oral Self-Test Among Men Having Sex With Men and Transgender Population: A Qualitative Investigation From Pune, India

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ABSTRACT: Globally HIV-self-test is considered as an important tool to end AIDS. However, several countries, including India, are yet to adopt such a strategy. Against this background, we conducted a qualitative inquiry exploring acceptability of an HIV-oral-self-test (HIVOST) among MSM and TG communities in the district of Pune, India. Discussions were facilitated around an HIVOST kit developed in-country. Most of the participants expressed familiarity with the concept of self-test. They realised that confirmatory diagnostic test would be required following a positive HIVOST screening result. Discrimination from health care workers, crowded environment, lack of privacy and delay in getting reports were hurdles faced during HIV testing at public healthcare facilities. Contrastingly, quick results, painless technique and no-blood-draw were perceived advantages of HIVOST. Innovative suggestions were obtained on how-to-do instruction modalities, kit distribution venues and redressing of apprehensions. Such qualitative responses indicated interest and encouraging level of acceptance around HIVOST among study participants.

KEYWORDS: HIV-oral-self-test, MSM, TG, people's voices

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Introduction

HIV prevention interventions in India witnessed exemplary success over the last decade during 2000 to 2010.¹ While in 1980s, some of the states in the country had had generalised HIV epidemic,² the infection now is concentrated mostly among key population groups such as female sex workers (FSW), men having sex with men (MSM), transgender (TG) community and people who inject drugs (PWID).³ Worth noting in this context is that currently, of the 2.14 million estimated people living with HIV (PLHIV) in India,⁴ 1.58 million (74%) know their HIV status of whom 0.88 million have been put on anti-retroviral treatment (ART).⁵

The global ambition of ending AIDS by 2030, rests on 3 program aspirations to be fulfilled by 2020; 90% of the estimated PLHIV will know their HIV status, of whom 90% will receive sustained ART and 90% of those treated with ART will have viral load suppression.⁶ Gaps for India, in this regard, as highlighted above, are of concern. Moreover, the declining trend of new HIV infections has reached a plateau in the country.⁷ HIV self-test, by facilitating detection of new infections and subsequent linkages with ART program⁸ and also by promoting positive behaviour change⁹ has the potential to address some of these gaps. Successful linkages to HIV confirmatory testing and antiretroviral therapy (ART) among MSM, who tested reactive by HIV self-testing, have been reported by studies from resource-limited as well as high-income countries.¹⁰⁻¹²

The World Health Organisation (WHO) defines HIV self-test as a process, in which a person collects his or her specimen (oral fluid or blood) and then performs an HIV test and interprets the result often in private setting, either alone or with someone he or she trusts.¹³ We recognise that HIV self-test has been part of the public health discussion for a considerable period of time.¹⁴ A literature review among key population groups also revealed that most of the studies on HIV self-test were conducted among FSWs and MSM and HIV self-test was acceptable to them as it was convenient, easy to use and privacy could be maintained.¹⁵

However, poor accuracy of early generation HIV self-screening kits, uncertainty around possible responses from the users to positive screening test result and non-availability of effective ART in the early years of HIV epidemic, did not allow its wide acceptance. With subsequent technological developments and availability of low cost highly active antiretroviral therapy (HAART), a renewed interest in HIV self-test has emerged in recent times. For example, Kenya became the first African country to develop national guidelines pertaining to HIV self-testing. Various standards such as for kit quality, counselling, kit outlets, referral services, access, information to be provided by the vendors, how to conduct and interpret HIV self-test results were developed in this regard.¹⁶ These issues were taken into consideration while conducting the current investigation.



Currently, India does not have a program guideline for HIV self-test and kits are not available in pharmacies. In this study we intended to assess how well an HIVOST kit, developed in-country, will be received by the target population and the extent to which it would meet the needs of men having sex with men and transgender community groups. The overall purpose was to generate evidence for intervention¹⁷ and also to appropriately inform the National AIDS Control Program.

Materials and Methods

This qualitative inquiry took place during March to June 2019 in the city of Pune in the western State of Maharashtra, India. We have used pseudonyms in this article to present our findings in order to maintain confidentiality of the participants. No direct or indirect personal identifiers such as sex, age, occupation etcetera have been linked with any of the verbatims used for analysis. Approval was obtained from the Institutional Ethics Committee (IEC) of the Indian Council of Medical Research-National AIDS Research Institute (ICMR-NARI). Adult participants (≥ 18 year), self-identifying themselves as MSM or TG, were enrolled in the study. Prior to conducting in-depth-interviews (IDIs) and group discussions (GDs), all the team members including field assistant, moderators and note-takers as well as data analysts underwent orientation training where issues around 'Lesbian Gay Bisexual Transgender Queer and Intersex (LGBTQI)' were discussed. Various aspects of qualitative research constituted other session topics.

Gaining access

Study participants were enrolled from different parts of the city of Pune with the support of a male field assistant. His membership in one of the study communities, and role in organising 'theme celebration parties' for both MSM and TG groups helped in gaining access. We reached out to more participants through snow-balling with the assistance from those getting enrolled at the beginning.

Study settings

This study was conducted across Pune and Pimpri-Chinchwad municipal corporation areas. Locations convenient to the participants, and where they felt safe, were prime considerations during data collection. The premises in which, in-depth interviews (IDI) and group discussions (GD) took place comprised of dating sites, residences of some of the participants and ICMR-NARI campus. Privacy and confidentiality of the participants were kept in consideration while selecting such locations.

Data collection tool

The guides and probes used during interviews and group discussions were prepared in English and then translated to Hindi

and Marathi by native speakers. These tools were tested through trial sessions and further modified for their lucidity, comprehension and correctness of content. Issues around health seeking behaviour, prior HIV test experience, choice of HIV self-test, perceived advantages and apprehensions were explored. Information were also collected on various aspects of the kit such as packaging and presentation, information to go with the kit, how to-do instructions and preferred kit outlets.

Participant interaction

Written informed consent for audio-recording was obtained; INR 150 (US\$ 2.5) per person was provided at the end of each session as compensation for time. An HIV oral self-test (HIVOST) kit named Morcheck, a product of Morsef Lifesciences LPP, and developed in-country by the Bhat Biotech Pvt Ltd, was placed in front of the participants to facilitate reflections around it and to examine its potential acceptability. Ten in-depth-interviews and 4 group discussions were conducted among MSM participants and an equal number of interactions were carried out among TGs as well. Each of the group discussions had 4 MSM participants and 5 to 6 TG members. We ensured that there was no duplication of the participants between IDIs and GDs. Interviews and discussions were conducted in local language (Hindi/Marathi) as per comprehension ability of the participants.

Data analysis

Digitally recorded responses were transcribed exact verbatim, which were then translated in English with pseudonyms to maintain confidentiality. Local phrases and colloquial terms were translated to capture their meaning in a specific context. Analysts reviewed translations for their accuracy and then coded them with the help of a codebook, which was generated through team meetings held at regular intervals. Such meetings further helped in resolving any disagreement related to identifying connection of a narrative content to a theme. Hand written notes and analytical memos were also used as data. Demographic characteristics, prior HIV test experience and familiarity with self-test concept were captured through attribute coding. N-vivo software (version 11) was used for organising and analysing qualitative responses.

Results

Profile of the MSM participants

In-depth-interviewees belonged to the age group 19 to 39 year and each of the IDIs persisted for about an hour. Six of them were graduates, 3 completed 10th standard of school education and 1 completed 12th standard. All were employed except 3, who were pursuing further studies.

Members of the group discussions (GDs) were in the age group 21 to 28 year. In 2 GDs all the participants were employed,

in another all were students and the rest was constituted by working men and students. Educational qualification of the members varied from 12th standard to master's degree. Each of the GDs spanned for approximately 1 hour and 25 minutes.

Profile of the TG participants

IDI participants belonged to the age group 23 to 36 year and were from various occupational backgrounds such as call centre-based information services, professional acting, banking and sex work. While 4 of the participants reportedly never attended a school, the remaining had various levels of completed education ranging from fourth standard to graduation. One of the members was pursuing his master's degree. Each of the IDIs lasted for 40 minutes to 1 hour and 15 minutes. Group discussants were in the age range 20 to 31 year. Educational qualifications were diverse from fourth standard to master's degree. Means of livelihood, as reported by the members, in the 3 GDs were either sex work or begging, while in another group, members were either working or pursuing studies. Duration of each GD ranged from 1 hour 10 minutes to 1 hour 30 minutes.

Self-test concept

Majority of the MSM and TG interviewees cited pregnancy test, blood sugar estimation, blood pressure measurement and use of thermometer to measure temperature as examples of self-test. While all the GD participants among MSM were aware of self-test concept, relatively a fewer members from TG communities reported so.

Reasons for participation

Expression of happiness, and active interest in the current research were reflected through some of the verbatims. For example, 'thembe thembe tale sache (*little drops of water, being collected, form a lake*)' – (MSM 02, Kalesh) was articulated by one of the interviewees to underline that opinions thus collected from different individuals would lead to a larger impact. Similarly, interviewees from TG community highlighted that the present research provided them with an opportunity to voice their ideas and concerns, which might contribute to increasing their acceptance in the society.

'I feel good. . . usually no one asks TG for information – I feel good that someone is coming to me and my opinion is being sought. . . I am feeling emotional – for the first time someone is asking me . . . I am very happy that people are asking my opinion. I also have a place in the society.'

-Nita (TG07)

A few of the respondents thought that they would obtain information around HIVOST through their participation in this investigation. Others viewed their involvement as important from the perspective of vulnerability of LGBT community to HIV.

'We are in this field. . . we cannot say. . . we have (sexual) relations sometimes without safety (condom) – we can use this test (HIVOST) at that time'

-Aif (MSM07)

'Now mostly no one talks about HIV. . . there are more risks in the LGBT community. That's why it is important to get information about this self-test. . . they are in multiple partner relationships to earn money – no one uses safety also – we cannot say how the person is – who is in front – that is why there is a high risk'

-Akki (TG05)

Prior HIV test experience

Most of the interviewees from MSM and TG community had tested themselves for HIV in government hospitals at some point in time in the past. Contrastingly, only one of the group discussants from MSM community had prior HIV test experience. Interviewees among MSM expressed their concerns regarding delay in getting reports, feeling hassled and uncertainty about quality of the report. Crowding, long queues, unhygienic environment and difficulties in navigating to the right place for test in government hospitals were problems articulated by TG participants.

Stigmatising behaviour was experienced by both MSM and TGs, while seeking HIV test from public health care settings. 'Being looked at' was a commonly used expression in this regard. Contrastingly, private hospitals, clinics and community-based organisations were mostly preferred for care seeking including HIV testing.

'I will tell you one of my stories. . . last month I went to my village and wanted to take HIV test. . . I went to a Government hospital. . . I told the doctor that I want to take an HIV test – then he said why do you want to take an HIV test? Then I told him I am gay . . . since I lived in the city, I lived freely. So directly I told him – I am gay . . . so he started looking at me. . . I felt so uncomfortable – then he told everyone about me. . . so everyone started looking at me – at that time I felt very uncomfortable . . . that is why most of the time I avoid going to government hospital'

-Ramu (MSM01)

'Crowd is there (government hospital). If people like us (TGs) go to a government hospital, then the other people look at us. If we go there in saree then people look at us again and again till we go away. Even if we are waiting in line for case paper, then people continue to whisper. . . even if men are in front or behind us then they immediately go away. They think that we'll ask for money. . .'

-Ria (TG06)

Perception around HIV self-test and choice of specimen

HIV self-test per se was viewed as advantageous due to associated confidentiality. Quick results, painless technique and avoidance of fear associated with blood draw were the reasons for

preferring saliva over blood. However, a few of the participants valued blood over saliva because HIV was considered by them as an infection of blood and also for the perception that food or drink could adversely impact saliva-based test outcome.

'Because there is a relief from pain. . . if you take test from saliva, then there won't be any pain – I think so – it is confidential – I can take this test (HIVOST) anywhere. . . I can take this test in the washroom. There is no need to discuss with anyone. There will not be any type of hesitation. Anytime I can take the test. I don't need to inform anyone. . . I need to go there (clinic / hospital) to take a test – this tension will not be there. . . on the spot I will get result. . . It is easy to handle. . . because it is only saliva test. . . I do not need to be professional.'

-Kush (MSM03)

'It is good – if it (HIVOST) becomes available then I will also do it at home. If someone brings this for me then – means someone – suppose, the way those ladies come to give polio drop. . . similarly, if someone comes – every six months or once in a year – if they take one round, then [don't mind anything] people will also participate in the campaign'

-Shilpi (TG03)

'Because blood is directly drawn from the body there are many cells in the blood. . . I think, HIV virus is in the blood. . . saliva is changed after drinking water but blood will not change. . . that's why if we take HIV test by using blood then we will get 100% sure result'

-Kavi (MSM09)

Group discussants and in-depth-interviewees appreciated the need for confirmatory diagnostic test following saliva-based HIV positive test result. Importantly, one of the interviewees from the MSM community underscored the need for recall after a time gap and repeat test in case of a negative test result.

'Now, if result comes negative then after some days again you should take the test – a test should be done after a week or 2–3 months. I am also saying that everyone should take HIV test after every six months'

-Rushi (MSM10)

Apprehensions around HIVOST were very few. Only one of the TG participants talked about possible mischievous prank played by marking a test strip with pink colour to indicate positive result. Accuracy of HIVOST kit was a concern raised by one of the MSM participants. Depression and suicide, following unwanted HIVOST result, were other concerns expressed in a group discussion.

Reflections around HIVOST kit

The following domains were explored: (a) information to go with the kit and packaging, (b) appropriate kit outlet, (c) preferred place to undergo HIVOST and (d) cost considerations. Participants mentioned that the word 'HIV' should be written on the kit. A group member from MSM felt that the

size of the packet (referring to the kit, which was developed in-country and presented to the participants to facilitate interviews and group discussions) should be small enough so that one could easily carry it, which was echoed by TG participants as well.

'The box of this test is very big. . . it will be okay if it is kept smaller, we have small small purses. . . it should fit in that'

-Nita (TG07)

The use of social media, campaigns through celebrities and advertisements on television for information dissemination on how-to-do steps were suggested by the participants. A few underlined the importance of physicians explaining the procedure to those who would find it difficult to understand on their own. Instruction leaflet in local language (such as Hindi) was another felt need. Interestingly, one of the group discussants from MSM community suggested to train the vendors on how-to-do steps. A few participants mentioned that printing a helpline number on the packet would help contacting a physician if needed. Restricting age for sale and mentioning expiry date (to be specified on the kit) were 2 rare points of view.

'See how it is . . . people are fans of celebrities. . . . , if they say something then fans listen to it readily. . . and if a transgender like me does an advertisement then also people will watch . . . because I look different. . . they will buy the test'

-Rimple (TG08)

Medical shops, college campuses and sites proximal to information technology (IT) companies were suggested as potential kit outlets. In addition, physicians' clinics and hospitals were other preferred places as it was perceived that one could seek immediate consultation after doing a test.

'Everyone can purchase it. . . from chemist shop and no one will hesitate. . . because now in 21st century no one hesitates to take these things. . . and if you want to create awareness then it should be available in schools and colleges and also in social places where youths assemble'

-Kush (MSM 03)

'The test can be done by anyone. . . like now there are IT companies – where young boys and girls reside as bachelors . . . their age at marriage is increasing. . . getting delayed. . . like 30–32–40 years. . . till that time they can't control (sexual desires). . . all of us know that . . . so at such places it should be available. . . guiding them is also important'

-Shok (MSM04)

Majority of the participants expressed that they would prefer taking an HIV oral self-test in privacy of their homes and in places like bathroom or basement. However, one of the participants from the TG community mentioned that she would

rather like to do it in *khanjara* (toilet). A Non-Government Organisation (NGO) worker would explain the procedure in an easily comprehensible manner – expressed an MSM community member. A few of the participants emphasised that engagement of doctors in laboratories and health camps for HIVOST would be helpful. While HIV self-test with friends was suggested by a group member of TGs, others from the community opposed the view by saying that they would prefer doing it in private to avoid leakage of information that could negatively impact upon their business for livelihood.

The suggested kit-costs varied from INR 50 (US \$ 0.7) to INR 500 (US \$7). However, most of the participants thought that if HIVOST kits were made available, free of cost, it would lead to increased usage. Others voiced their concerns around possible hoarding of kits by unscrupulous businessmen in such scenario and also about people not valuing kits that could be available free of cost:

‘Why should it be free – money should be there – now how it is – company has spent money for making this (HIVOST) – they are working hard for this. The company that manufactured this. . . they should also get the money – we will commit a mistake and why company should provide it for free’

–Aif (MSM07)

‘Yes dear, our ‘kothis’ will run to bring this (HIVOST kit), free means ‘God gift’ – all will pick up and bring – our ‘kothis’ and ‘panthis’ will do the test also . . . it is good for them if they get it free.’

–Nita (TG07)

A businessman (MSM04) stated *‘If it is made available free . . . then acquiring trust is more important’*. Table 1 summarises domain specific findings presented above.

Discussion

The current investigation on acceptability of oral HIV self-screening test among MSM and TG population, shed light on an important area, which as yet, remained inadequately addressed in India. It provides insights into the perspectives of the study population groups on HIV self-screening and outlines related program issues. Currently, MSM and TG populations in India are infected with HIV at a prevalence of 4.2% and 7.5%, respectively.¹⁸ However, HIV prevalence among these groups differs considerably across the states. For example, an investigation in 12 cities of the country highlighted that tremendous diversity existed in prevalence, incidence and risk behaviours among MSM communities.¹⁹ It is therefore important to identify newly occurring infections at the earliest in various geographical pockets and in respective groups, so that they could in turn be linked with appropriate prevention services including ART.

Our study captured unequivocal keenness among MSM and TG populations to accept HIV self-screening tools.

Table 1. Domain specific findings.

DOMAINS EXPLORED	FINDINGS
Perceived kit utility	Easy to do
	Early detection
	Opportunity to exert self-agency
	Maintenance of confidentiality
	Quick results
Information to go with the kit	Physicians' helpline number
	Linking with ART services
	HIVOST positive result requires subsequent confirmation
Kit access outlets	Medical shop
	Grocery shop
	Schools and colleges
	IT companies
'How to do it' steps – HIVOST	Assisted HIV self-test
	Live demonstration
	Advertisements/Social Media
	Instruction in local languages
Kit cost related issues	Investment versus reasonable pricing
	Low cost till the kit gains popularity
	Hoarding free kits and unscrupulous sell
Apprehensions	Price tag may deter people to buy and do the test
	Mischievous use
	Possible aftermath (depression/self-harm) following a positive HIVOST result
	Accuracy of HIVOST kit

Another qualitative study, conducted a few years ago in the brothels of Pune, revealed positive attitude of female sex workers towards HIV self-test.²⁰ While the latter investigation involved HIV sero-reactive and non-reactive peer educators and FSWs, to whom the concept of self-test was verbally explained, the uniqueness of the present study rested with an HIV oral self-test kit, which was placed in front of the participants to facilitate interviews and discussions around it. It is important to note that some low and middle income countries like Peru and Brazil have also recorded high acceptability of HIV self test among MSM and TG population groups.^{21,22}

During the present investigation, participants highlighted some of the barriers encountered by them while seeking HIV test from existing public healthcare facilities. Crowded environment, discriminatory behaviour from health care staff and delay in getting reports were hurdles that they cited in this regard. Similar findings emerged from qualitative investigations, conducted in South India, which explored barriers and facilitators to HIV testing.^{23,24} The study by Woodford et al was conducted among men who have sex with men, transgender women, cisgender female sex workers and injecting drug users in the city of Chennai and revealed that the participants identified advantages associated with HIV self-tests after they were explained about it. People hesitant to give blood sample, or with damaged veins such as PWID, were viewed by them as potential beneficiaries of HIV self-test. Moreover, non-invasive nature of the test, quick results and feasibility of undertaking such a test in field setting were other perceived advantages.²⁴ On the other hand, Beattie et al explored the interpersonal and structural barriers faced by MSM and FSW communities while seeking HIV test from voluntary counselling and testing centres. The participants in this investigation feared discrimination from families, neighbours, landlords and others following inadvertent disclosure of sex-work, homosexuality and/or HIV positive status.²³

In the current study, saliva was preferred over blood as specimen of choice for HIV self-test. Most of the study participants were afraid of needles. Women, in active labour in a rural tertiary teaching hospital at Sevagram in the western state of Maharashtra, expressed similar preference. In this study, while majority of the women opted for HIV oral self-test, about a fourth of them preferred finger stick and rarely a venous blood draw.²⁵

In the present investigation, participants appreciated the difference between a screening and a diagnostic test. They underlined that confirmation of HIV status would be required following a positive HIVOST result. A few raised concerns around accuracy of the HIV self-screening test.

The need for engaging social media platforms for awareness generation and dissemination of how-to-do instructions were 2 other highlights of our study. Pictorial presentation and use of local languages were considered necessary in this regard. A helpline number – linked with a physician – was another expressed service need. Researchers from Cambodia brought out similar issues to the fore while conducting qualitative investigations in 4 provinces that engaged transgender women, men having sex with men and female entertainment workers. Counselling, in the Cambodian study, was cited by the participants as one of the service needs, which could be provided through face-to-face interactions or telephonically on hotline numbers. Transgender women, in this investigation, mentioned that following a positive HIV self-test result, they would seek doctors' advice on treatment provided confidentiality was ensured. Akin to our findings, high

acceptability of HIV self-test among all the 3 key population groups was identified in Cambodia.²⁶

In addition to the traditional health product outlets, such as chemist shops, participants during the current investigation provided justification for innovative kit access venues such as college campuses or information technology (IT) offices. The importance of engaging private pharmacy shops was highlighted in a study from Uganda where MSM community mentioned that anonymity would be maintained while approaching a big pharmacy shop for procurement of HIV self-test kits. Long opening hours of such shops was another perceived advantage. Peer network-based distribution of HIV self-test to the vulnerable and stigmatised communities was suggested to increase access in this Ugandan study.²⁷ A similar view point was echoed by the participants we interacted with. They narrated that a peer worker would have more time to explain how-to-do an HIV self-test and would do so better in an easily comprehensible manner.

Conclusion

We conclude that our findings reflect a reassuring level of acceptance of HIVOST among MSM and TG communities. The participants in the current qualitative investigation, in addition to expressing keenness to use such a test, viewed the scope of obtaining quick result as one of the advantages of HIVOST. The proponents of self-test urge that an HIV self-test kit (using oral saliva or a drop of blood obtained through fingerstick) could serve as an important public health tool. Empirical evidence appears to confirm such notion by demonstrating positive impact of a rapid HIV test on 4 counts, (a) acceptance of such a test by clients, (b) collection of test reports, (c) entry into medical care and (d) the efficacy of prevention counselling after testing.²⁸ We further realised that HIVOST offered a platform to the participants where not only quick result but also opportunity for exerting self-agency made it more appealing. Programming HIV self-test through public and private healthcare facilities would however require certain considerations. The current study was able to address them through voices and reflections of key population groups. We identified support to our assertion in the responses of government officials from the neighbouring country of Nepal, who embraced community-based assisted HIV self-test due to its ability to reach out to hard to reach population and to provide service in non-stigmatising manner.²⁹

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Amrita Rao: Supervision, Validation, Formal Analysis & Writing original draft, Sandip Patil : Supervision, Validation, Formal Analysis & Writing original draft, Sharmila Aheibam: Validation, Software application & Formal Analysis, Prajkta Kshirsagar: Investigation, Project administration & Formal

Analysis, Pranoti Hemade : Investigation, Project administration & Formal Analysis; Samiran Panda: Conceptualization, Methodology, Supervision, Project Administration, Formal Analysis, Writing original draft & Funding acquisition

Research Data for This Article

Due to the sensitive nature of the questions asked in this study, survey respondents were assured that the raw data would remain confidential and would not be shared. Data not available/The data that has been used is confidential.

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