COMMUNITY PERSPECTIVES ON MAKING HIV SELF-TESTING ACCESSIBLE AS A COMPREHENSIVE PREVENTION PACKAGE

Shruta Rawat[1], Sunil Suhas Solomon[2], Shalini Bharat[3], Alpana Dange[1], Aylur Kailasom Srikrishnan[2], Venkatesan Chakrapani[4], Biji Mohan[3], Shobini Rajan[5], Vinita Verma[5], Joyeeta Mukherjee[6], Nikhil Singla[7]

EXECUTIVE SUMMARY

The WHO guidelines on HIV Self-Testing (HIVST)[1] (2016) emphasize on the need for HIVST to diversify and amplify existing HIV interventions and make them accessible to hard-to-reach communities[2]. With technological advances, communities such as Transgender Women (TGW), Men who have Sex with Men (MSM), and Female Sex Workers (FSW) are increasingly migrating to virtual platforms making them inaccessible to current HIV interventions. Vulnerable communities hesitate to access services from interventions as they perceive stigma and judgemental attitudes but engage in high risk behaviour.

A study supported by National AIDS Control Organisation (NACO) and the study sponsors, International AIDS Vaccine (IAVI), United States Agency for International Development (USAID) and the Accelerate the Development of Vaccines and New Technologies to Combat the AIDS Epidemic (ADVANCE) programme, was implemented by YRG Care, Tata Institute of Social Sciences and The Humsafar Trust in order to understand acceptability and feasibility of HIVST among Key Populations (KP).

The study found that HIVST is highly acceptable to KPs and therefore recommended, particularly for those populations that are hard-to-reach (internet-based, mobile populations). There must be a focus on integrating counselling and linkage to care for those availing HIVST as well as creating awareness and education, particularly emphasizing that HIVST is a screening test.

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[1] *World Health Organisation: HIV Self-Testing and Partner Notification Guidelines (2016)*
[2] *Stevens D, Vrana C, Dlin R, Korte J, A Global Review of HIV Self-Testing: Themes and Implications. AIDS Behaviour (2018) 22:497–512 https://doi.org/10.1007/s10461-017-1707-8*

[1]*The Humsafar Trust, Mumbai* | [2]*Y.R. Gaitonde Centre for AIDS Research and Education, Chennai*
[3]*Tata Institute of Social Sciences, Mumbai* | [4]*Centre for Sexuality and Health Research and Policy (C-SHaRP), Chennai*
[5]*National AIDS Control Organisation, New Delhi* | [6]*International AIDS Vaccine Initiative, New Delhi* | [7]*Former Deputy Director, IAVI, New Delhi*

THE ISSUE

The WHO guidelines on HIVST[3] (2016) emphasize on the need for HIVST to diversify and amplify existing HIV interventions and make them accessible to hard-to-reach communities. Globally, HIVST is being increasingly explored as a strategy to increase testing among communities that are not within the purview of existing HIV interventions[4]. Within India, MSM communities surveyed on the internet[5] report poor testing behaviour and condomless anal sex with over 45% having never tested for HIV and 25% having tested over a year ago. In interactions during the study, over 90% FSWs and 70% Injecting Drug Users (IDU) reported not accessing services from current interventions. With technological advances, communities such as TGW, MSM, and FSW are increasingly migrating to virtual platforms making them inaccessible to current HIV interventions. While consensual same sex relations were recently decriminalized, unfavourable punitive laws governing sex work and substance use are barriers to good health-seeking behaviour. Further, stigma and negative societal attitudes toward non-heteronormative behaviours and actions perceived as immoral/criminal invisibilize communities and contribute to their vulnerability. These vulnerable communities hesitate to access services from existing interventions as they perceive stigma and judgemental attitudes but engage in high risk behaviour. While these communities are primarily at risk, they act as a bridge for HIV infection to their sexual partners, commercial or otherwise.

Strategies thus need to be diversified and tailored toward delivering comprehensive HIV prevention and treatment as a means to achieving 90–90–90.

[3]*World Health Organisation: HIV Self-Testing and Partner Notification Guidelines (2016)*

[4]*Stevens D, Vrana C, Dlin R, Korte J, A Global Review of HIV Self-Testing: Themes and Implications. AIDS Behav (2018) 22:497–512 https://doi.org/10.1007/s10461-017-1707-8*

[5]*Patel, V.V., Dange, A., Rawat, S., Arnsten, J.H., Piña, C., Golub, S., Pujari, R., Trivedi, A., Harrison-Quintana, J., & Mayer, K.H. (2018). Barriers to HIV testing among MSM in India reached online: implications for interventions. JAIDS 78(4):e30-e34. PMCID: PMC6019173.*

With technological advances, communities such as **TGW, MSM, and FSW** are increasingly migrating to **virtual platforms making them inaccessible and hidden.**

THE STUDY

A study was conducted to understand acceptability and feasibility of HIVST among KPs. The study, among the first such studies, was supported by NACO and the study sponsors, IAVI, USAID and PEPFAR. The study was implemented by YRG Care, Tata Institute of Social Sciences and The Humsafar Trust.

THE METHODOLOGY

Eight Focus Group Discussions (FGDs), Eight In-Depth Interviews (IDIs) and Eight Key Informant Interviews (KIIs) were conducted in local languages/ English by trained interviewers, translate, transcribed, and thematically analysed. Data was collected from four cities – Mumbai, Delhi, Vijaywada and Imphal. The study was approved by institutional review boards of YRG Care, Tata Institute of Social Sciences and The Humsafar Trust.

The study explored awareness and attitudes, acceptability, concerns and challenges, pricing and packaging, modes of communication, delivery of kits and change in risk behavior among the identified target population.

Study Populations

Study Sites

	MSM	TGW	PWID	FSW
Mumbai	**TISS/Humsafar** 4 FGD; 4 IDI; 4 KII	**TISS/Humsafar** 4 FGD; 4 IDI; 4 KII		
Delhi		**TISS/Humsafar** 4 FGD; 4 IDI; 4 KII	**YRG CARE** 4 FGD; 4 IDI; 4 KII	**YRG CARE** 4 FGD; 4 IDI; 4 KII
Vijayawada	**YRG CARE** 4 FGD; 4 IDI; 4 KII			**YRG CARE** 4 FGD; 4 IDI; 4 KII
Imphal			**YRG CARE** 4 FGD; 4 IDI; 4 KII	--
TOTAL	8 FGD; 8 IDI; 8 KII	8 FGD; 8 IDI; 8 KII	8 FGD; 8 IDI; 8 KII	8 FGD; 8 IDI; 8 KII

Study Partners Data Collection Methodology

CONVENIENCE

- "Yes I will do this self-testing because it saves time, saves money, also we don't have to give our blood and there would be no conveyance (travel & money) problem" – Male IDI, Delhi
- "It will not take much time and we can do it according to our own convenience. There is no need to disclose it to anyone that I am going to get tested for HIV. We can do it by ourselves" – MSM, Mumbai

CONFIDENTIALITY

- "This test is very nice. We can do it by ourselves. No Need to go to hospital. No one will know our test result." – MSM, Vijaywada
- There will be benefits like it can be done at home can save time. It will take more time to go to the hospital for tests but we can do the tests within 20 minutes. If any time we have a doubt good for the HRG to do the test quickly without revealing their status." FSW, Vijaywada

INSTITUTIONAL CONSTRAINTS

- "They will feel comfortable and can save money because when they have to go hospital so their full day waste in hospital and income of that day also affected." Home-based FSW, Delhi
- She may say that since you wake up late in the morning and you don't get time so it's better to bring it home and do the self testing to conform it. It is good in that way." – TGW, Mumbai

NO STIGMA

- We will be safe from bad eyes of people. Other thing is even if we go to government offices, hospitals or NGOs, many times there are people in NGO who don't take our work easily – TGW, Delhi
- We will be noticed by others, as we are community if we go out and will face stigma and discrimination. People will have a low look on us if we are tested positive. Instead of taking risk and feeling bad better spend Rs.150.00 and can do the tests at home." FSW, Vijaywada

FINDINGS

- Respondents said that they felt that the kits were convenient, since they could use them at home, and test whenever they were in doubt.
- The tests were thought to be confidential, and there was no fear of being found at a testing centre, additionally there was privacy while conducting HIVST.
- The respondents liked that the tests were non-invasive
- The tests allowed users to avoid institutional barriers such as long waiting time, losing too much time and stigma .
- The concerns expressed were about the cost of the test, which should not be too high.
- The respondents were also concerned as how would illiterate people be able to understand the instructions in order to use the test kit.
- The respondents wanted to know what the validity of the tests would be, whether they would need to repeat the process for confirmation.
- The respondents also wanted linkage to care and pre-post counselling.

COUNSELLING	LINKAGE TO CARE	COSTS	POTENTIAL COERCION
▪ "Counselling is the most important thing. Because if suppose test result of a person comes positive and if he belongs to our community then he won't be much knowledgeable and hence may go into depression also. Because he won't be able to get counselling at that moment". TGW, Delhi ▪ We will be mentally depressed thinking about the situations of why we have become like this. We will get thoughts of committing suicide at that time instead of dying with the disease." FSW, Vijaywada	▪ If the result comes as positive then you could be properly guided about every step. So it will be beneficial. If unsupervised, you do not know that the hell to do and then again the same stories like depression …" MSM, Mumbai ▪ "If a FSW did her test at home and she found positive so she will not come to NGO to inform about her HIV status then it's difficult for NGO to find positive people and will not able to trace any one." – Home-based FSW, Delhi	▪ "If it cost will be 500 so how can an IDU purchase it so price should be same for everyone either he is earning or not. It should be free in NGO. The price should be under 25 rupees". PWID, Delhi ▪ As we are getting other services from NGO and hospital free of cost so it should be also available free of cost." – FSW, Delhi	▪ "Say, for example, your family gets to know about the availability of such a thing (meaning HIV ST) in the market. They might force you to get tested because they know you are a gay…" -MSM, Mumbai ▪ "In this there will be a problem as well that suppose if there is our personal relationship. I am positive and he does not know that. If I am asking him today to do his test then tomorrow he will ask me to test with this kit and since my ART is going on and then my problem will get opened in front of him." – TGW, Delhi

Community perspectives: Assisted versus unassisted

MSM	TGW	PWID	FSW
▪ Demonstrations should be done. Videos must be played in public areas like market, cinema halls, and shopping malls. Awareness must be created about the usage of kits. It has to be advertised then only people will come to know." MSM, Vijaywada ▪ It this kit is going to come then I think it should be advertised on dating sites… these guys are mostly on PR and Grindr. So we can have this advertised in the dating sites…We can also think that these dating sites care for us too." – MSM, Mumbai	▪ "We will talk about that through the internet, whatsapp, Grindr. These hidden populations are mostly active in social media." TGW Mumbai ▪ "I use WhatsApp. We have group of HIjras in it. Name of group is LNT. I can even put this in the group. Hijras may listen and it may work." – TGW, Delhi	▪ Maybe they can order online because some people can feel hesitation to purchase it from chemist. – Male IDU, Imphal	▪ All the community is using smart phones these days and they have access to what's app and face book compulsorily. Only few do not have access." – FSW, Delhi ▪ "We have to keep them in that area, They need to be made available in the Hot spots, RMP doctor, Hospital, PE, ORW and from there we can take from them." – FSW Vijaywada.

Community perspectives: What, where and how?

MSM	TGW	PWID	FSW
▪ "Self-testing means no one should be there. If someone is accompanying, then they can directly go to the government hospital for testing…" MSM, Vijaywada ▪ As far as I feel about this kit, It can be used at your home, in privacy. You can know about your status and then act upon it. If you are using this kit in front of a doctor or counsellor then there is no meaning in it." – MSM, Mumbai	▪ Unless and until I will not know about anything how will I know? Now as you are explaining me then I will do it. If I will not be knowing about anything I will not be able to do it myself. If I am taking from NGO, then the person who gives counselling in NGO, I will have to ask them and then give counselling like how to use it and what to do" – TGW Mumbai	▪ No for IDUs. Supervision must be compulsory for the IDUs as there is no acceptance amongst them. So, they need proper guidance and supervision post the test – TI Manager, PWID, Delhi ▪ Since our rapport has been built up more with the TI NGOs, I would prefer the counsellors or the peer educators to supervise our testing – Male PWID, Imphal	▪ "Because we are illiterate, we will not be able to see self – test results." – Brothel based FSW, Delhi ▪ "It has to be given at both the times. Before the test, she has to be guided with the proper process of using these kits. Post the test; she has to be guided with the further facilitation depending upon her result, ensuring her proper follow up." – FSW, Delhi

LEARNINGS

- Findings from the community indicate that awareness about HIVST is inadequate
- However, HIVST is highly acceptable to the communities, especially hard-to-reach communities such as those on online spaces and mobile populations.
- Low levels of literacy is a concern in the uptake of HIVST.
- Involvement of community-specific stakeholders (mediators, community-based organisations, gurus) plays an important role in devising effective strategies for ensuring optimal uptake and use of HIVST
- Perceived convenience, confidentiality, non-invasiveness, no/less exposure to stigma, and overcoming structural and monetary challenges are associated with site-based testing centres, thereby making HIVST acceptable to all KPs.
- KPs identified challenges such as absence of pre-post test counsellling, linkage-to-care, costs and potential coercion as barriers to HIVST.
- If the above is addressed, HIVST has the potential to amplify HIV interventions and strengthen outreach to hard-to-reach communities such as MSM, FSW and TGW on virtual platforms, partners of TGW and mobile populations.
- While some KP groups preferred unassisted HIVST, MSMs preferred unassisted HIVST the most. FSWs and TGWs on the other hand preferred assisted HIVST with counselllors and doctors assisting them.

RECOMMENDATIONS

- HIVST is recommended for KPs, particularly those that are hard-to-reach (internet-based, mobile populations).
- As awareness of HIVST is low, programmes must first focus on increasing awareness of HIVST among KPs via regular platforms (meetings, hoardings, posters, advertisements on TV and radio) as well as technology-based platforms (internet-based messaging apps, social media platforms, app-based dating platforms, electronic IEC, helplines).
- Material on different aspects of HIVST (use, interpretation, window period, disposal) must be created taking into account literacy levels of the intended population. Educational materials must be easy to understand, in multiple languages, pictorial/video-based and must be uniquely developed for and field tested with different KPs.
- Once HIVST kits are certified for use and distribution in India, delivery options such as Community Based Organizations (CBOs) / Non-Governmental Organizations (NGOs), chemists, internet-based platforms need to be explored for uptake and use.
- HIVST could be integrated into existing HIV interventions toward providing enhanced comprehensive prevention for hard-to-reach communities and as a step toward achieving 90–90–90.
- Communities could be provided with an option of seeking assisted or unassisted HIVST based on their comfort and familiarity with the technique.
- While KPs would be more inclined to use HIVST if provided free, social marketing can be explored as well. However, different models of marketing need to be explored as higher costs will adversely affect uptake.
- Adequate care must be taken to keep kit dimensions small and the branding discrete to allow easy carrying and concealment.
- While national programmes may choose to implement HIVST with a generalised approach, KP groups need to be focused on to ensure reaching the unreached.

	FSWs	PWID	MSM	TGW
Awareness about HIVST	Most of the community participants were not aware of or had not heard of HIVST			
Attitude towards HIVST	Positive – Convenient, maintains confidentiality, time & money saver, non invasive. Skeptical - Test accuracy and linkage to care. Negative – Illiteracy, privacy breach at home	Positive – non-invasive, no issues of stigma and discrimination, time and money saver. Skeptical - Concerns around window period, accuracy of the result, lack of pre/-post-test counsellling and linkage to care	Highly positive – Empowering, convenient, fast, confidential. Some concerns included test accuracy, lack of pre and post-test counsellling and linkage to care	Positive – Convenient, confidential, time and money saver, potential avoidance of stigma. Skeptical - Concerns around use of HIVST by minors and non-acceptance of the results at the ART centres; wastage
Acceptability of HIVST	Oral kit preferred – least invasive			
Target Population	Hard-to-reach population on online/virtual networks, home based, educated, and legal minor sex workers	Male and female drug users, wives and children of IDUs	Educated MSM, MSMs on dating apps/internet platforms, MSMs in sex work, married MSM	TGW in sex work, older TGW, TGW on online platforms, mobile hijras
Pricing of the test kit	Rs 10 – Rs 50	Rs 5 – Rs 50	Rs 50 – Rs 100	Rs 50 – Rs 200
Packaging of the test kit	Smaller dimensions, discrete, instructions in multiple languages, easy to dispose, not pointed	Should be small to be carried around in pockets, should have pictorial instructions for use and discard after use.	Should have full instructions on the use and actions to be taken afterwards.	Smaller dimensions, discrete, should not be too HIV, should have in-built disposal mechanism.
Preferred ways of communication/ promotion of HIVST	On-line websites, YouTube and social media, mass media, through peers as well as electronic media and fixed spot.	Word of mouth and advertisements on TV/other channels; NGOs will reach out to both online and general population.	Advertisements, videos in market place, cinema halls and shopping malls; Online - advertisement on dating sites such as Planet Romeo and Grindr, WhatsApp/other SM apps	TGW were open to exploring social media options such as Whatsapp, Grinder, Tinder, Planet Romeo and Facebook
Delivery of HIVST kits	• NGO or govt. hospitals and health facilities such as Revised National Tuberculosis Control Program. Directly observed therapy (RNTCP –DOT) centre; • Chemist/ medical shops, grocer, other outlets; • Among people, pimp, RMP doctor, peer educator, ORW and even Anganwadi worker's names were suggested; • Online ordering had low preference	• Targeted Interventions NGOs • Health facilities like Primary Health Centres (PHCs) or Community Health Centres (CHCs), pharmacies • Online	• Community-based set ups like NGOs, PHCs/CHCs; • Hospitals, private clinics, pharmacies; • Internet-based shopping sites such as Amazon. • Pharmacies	
Need for (pre-/ post-test) counsellling	Nearly all the participants unanimously voiced the need for counselling pre-post HIVST. Most opinions around counselling stressed on the importance of pre-post-test counsellling for either guidance on using the HIVST kits correctly or providing support in case of a positive test.			
Influence of HIVST on risk behaviour	In general, there will be no change in the sexual behaviors of KPs. KPs were unanimous that it will result into positive health seeking behavior. Some expressed that it could go both ways– of being careful or careless with the sexual risk.			
Supervised/ unsupervised HIVST	Participants strongly recommended HIVST supervised by NGO/ CBO counsellor, community leader or nurse/doctor.	Participants felt that people needed guidance at least initially.	MSM participants dismissed the need for supervision and felt that assisted HIVST would be pointless	Supervised testing was strongly recommended
Support after positive test	Most of the PWID participants cited need for care and support services and medication related services. In addition to the usual care and support for a positive person, TGW in general required support in securing their social entitlements and pension for old Hijras			

- Expanding existing programmes to include community-based internet-outreach, inclusion of Post Exposure Prophylaxis (PEP) and Pre Exposure Prophylaxis (PrEP) provision under national programmes, as well as expanding HIV testing to community-specific social platforms (events, parties) could be one of the strategies toward HIV prevention and treatment, being viewed by communities as a comprehensive package that enhances outreach and service delivery.
- There must be focus on integrating counsellling and linkage to care for those availing HIVST as well as creating awareness and education, particularly emphasising that HIVST is a screening test. This needs to be ensured even if integrating HIVST into national programmes.
- Technology such as web-/cloud-/internet-based calling with video-based tutorials could potentially serve to address this.
- Diverse strategies (video-, pictorial- and voice-based IEC) and platforms (YouTube©, internet-based messaging apps, social media platforms, and dating/partner-seeking platforms) accompanied by standard methods should be explored.
- Involvement of community-specific stakeholders (mediators, community-based organisations, gurus) would aid the national programme in devising effective strategies for ensuring optimal uptake and use of HIVST thus furthering the programme's goal by accomplishing the first step of 90–90–90 and reaching KPs not accessing services from national programmes.
- HIVST kits should be made available and tracked via community-based settings and internet-based platforms, and private-sector channels such as pharmacists need to be approached to ensure follow-up and linkage to care.
- Information on HIVST must be made available in multiple languages and must take into account literacy challenges associated with KPs.
- Education and awareness of HIVST is key and should address technical (window period, kit usage and disposal) and social (pre-/post-test counsellling, linkage to care) aspects

Increasing Awareness about HIVST

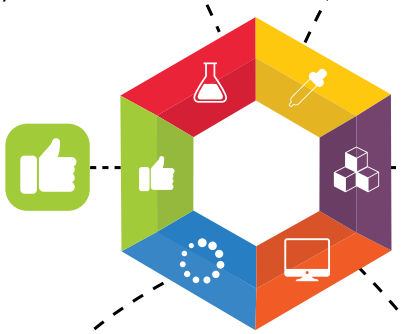
- Physical means (community meetings, publicity events, hoardings, posters);
- Virtual platforms (social media, television, text messages, telephone helplines, internet)

Delivery Points

Venues such as the chemists/medical stores, small shops like paan shops, NGOs/CBOs and health care facilitiescould be the potential venues for obtaining priced HIVST kits.

Counselling Needs

- Pre-test counselling
- Post-test counselling
- Virtual counselling



Preferred HIVST kit features

Small with illustrative kit inserts in local languages with instructions for use and disposal. No HIV-centric packaging.

Target Population

- KPs particularly not covered under the government led Targeted intervention;
- Hidden and hard to reach population by use of social media; mobile population

Preferred Pilot Sites

MSM - Mumbai/Vijaywada
TGW - Delhi/Mumbai
PWID - Imphal
FSW - Delhi/Vijaywada

Do bear in mind...

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Note: *For any information on the study, kindly contact Dr Shalini Bharat, Director & Professor, TISS, Mumbai at sbharat@tiss.edu, Dr Sunil Solomon, Chairman, YRG CARE at sss@yrgcare.org and/or Ms Vinita Verma, Programme Officer (Evaluation & Operational Research), National AIDS Control Organisation at vinitaverma.naco@gmail.com*

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