

GUIDELINES ON HIV SELF-TESTING AND PARTNER NOTIFICATION

SUPPLEMENT TO CONSOLIDATED
GUIDELINES ON HIV TESTING SERVICES

Annex 32. Report on the values and preferences on HIV self-testing and partner notification in Indonesia, Pakistan, Philippines and Thailand

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Contents

Acknowledgements	iv
Acronyms and abbreviations	v
32.1 Background.....	1
32.2 Introduction	1
32.3 Methodology	2
32.3.1 Selection of participants	2
32.3.2 Process, data collection and analysis	2
32.4 Results	3
32.4.1 Characteristics of study population	3
32.4.2 Country-specific findings.....	3
<i>a) Indonesia</i>	3
<i>b) Pakistan</i>	5
<i>c) Philippines</i>	6
<i>d) Thailand</i>	7
32.5 Discussion	9
32.5.1 HIV self-testing	9
32.5.2 Partner notification.....	10
32.6 Strengths and limitations.....	11
32.7 Conclusion.....	11
32.8 Recommendations	12
References	14

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Acronyms and abbreviations

APCOM	Asia-Pacific Coalition on Male Sexual Health
ART	antiretroviral therapy
CBO	community-based organization
FGD	focus group discussion
HIVST	HIV self-testing
HTS	HIV testing services
MSM	men who have sex with men
MSW	male sex workers
NGO	non-governmental organization
PEP	post-exposure prophylaxis
PLHIV	person/people living with HIV
PN	Partner notification for HIV
PrEP	pre-exposure prophylaxis
RDT	Rapid diagnostic test
STI	sexually transmitted infection
TG	transgender people
UNAIDS	Joint United Nations Programme on HIV/AIDS
WHO	World Health Organization
YVC	Youth Voices Count

32.1 Background

In July 2015, WHO published the first Consolidated Guidelines on HIV Testing Services (HTS), which included some discussion of HIV self-testing (HIVST) and partner notification (PN)(1). Countries then requested updated guidance on those two topics.

WHO defines HIVST as a process in which individuals who want to know their HIV status collect their own specimen, perform a test and interpret the result, often in private. HIVST could increase access to testing and play an important role for people who are unable or unwilling to attend formal HTS, or who require repeat HIV testing(1-3).

WHO defines HIV PN as a process where a person diagnosed with HIV is encouraged to voluntarily disclose their status and notify their partner(s); the partner(s) are then confidentially contacted and offered voluntary HTS, prevention, treatment and care (4). PN may also increase HIV testing among partners of people diagnosed with HIV, and facilitate HIV case-finding, early diagnosis and linkage to prevention, treatment and care.

The WHO Western Pacific Regional Office, the Asia-Pacific Coalition on Male Sexual Health (APCOM) and Youth Voices Count (YVC), conducted this study in selected cities in four high-burden countries (Indonesia, Pakistan, Philippines and Thailand), which aimed to:

- Understand knowledge, experiences and views about HIVST and PN through focus group discussions with representatives of two key population groups—men who have sex with men (MSM) and transgender people (TG), specifically young transgender women—and interviews with providers of services and staff of national AIDS programmes, non-governmental organizations (NGO) and community-based organizations (CBO).
- Identify opportunities, benefits, challenges and limitations as perceived by MSM and transgender communities in implementing HIVST and PN at the country level.
- Describe some/potential critical enablers for implementing HIVST and PN for MSM and TG communities at the country level.

32.2 Introduction

According to UNAIDS, there are around 2 million new HIV infections every year worldwide, of which new infections among key populations account for 40%; yet approximately 54% of people living with HIV (PLHIV) are still not on treatment(5), and an estimated 40% remain undiagnosed(6). This is also true in the Asia-Pacific region where there are major gaps in access to HIV testing and awareness of HIV status among MSM and transgender women. The percentage of people living with HIV (PLHIV) in the region that is aware of their HIV status ranges from 14% in Pakistan to 80% in Thailand (7). And while there is an increasing number of HIV tests performed every year, HIV testing coverage for men continues to be lower than for women in most countries(1). Coverage among key populations also remains low; this is due to availability in some settings, but also depends on acceptability of services, and fear of stigma, discrimination and criminalization of behaviour. New approaches to HTS delivery are needed to reach people with HIV who remain undiagnosed—especially those in key populations.

In the Asia-Pacific region, HIV infections amongst men who have sex with men (MSM) and transgender populations continue to rise, especially in urban settings(8). National HIV prevalence among MSM populations in the region ranges

from 0.7% in Bangladesh, to 12.8% in Indonesia; these rates are usually five to ten times that of the adult male population⁽⁸⁾. HIV rates are even higher among transgender women. Studies conducted from 2011–2014 in India, Pakistan and Malaysia show national HIV prevalence of over 5%, with urban areas such as Jakarta, Indonesia reporting higher levels.

This report summarizes the methodology used to develop the report, documents and analyzes the findings and proposes recommendations for consideration during the guidance development process.

32.3 Methodology

This study used qualitative methods to collect data on target populations and the views of health-care providers, programme implementers and researchers whose work focuses on addressing the needs of those populations in Indonesia, Pakistan, Philippines, Thailand. A total of eight FGDs (two per country) were organized with 64 participants from MSM and transgender communities. In Indonesia and Pakistan focus groups were structured by type of population and broad age groups, one FGD was organized for MSM and the other for transgender women with mixed ages in both groups; in Philippines, there was one mixed group of MSM and transgender women 18-25 years old and another mixed group for participants aged 25 years and above; and in Thailand, there were two mixed groups of MSM and transgender women of different ages.

Fourteen in-depth interviews were conducted with providers of services serving MSM and transgender communities and staff of national AIDS programmes, NGOs and CBOs. They were asked about the acceptability of HIVST and PN and whether there was a place in the 'market' for it; concerns and alignment with national guidelines were also discussed.

Focus group discussions (FGD) and key informant interviews were conducted by country-based consultants who have backgrounds in anthropology, psychology, peer education and research; two of the consultants were peers of FGD participants.

32.3.1 Selection of participants

FGD participants were selected from a list of nominees provided by NGOs and CBOs serving the MSM and transgender communities and participation was voluntary. Selection criteria included: previously tested for HIV or aware of HIVST, or thinking of getting an HIV test in the near future; individuals in a serodiscordant couple; individuals in sexual relationships who were willing to participate.

Key informants were selected on the basis of professional involvement with the study topics. They included a range of professions—physicians, researchers with expertise in HTS and HIVST, National AIDS Programme staff or advisers, leaders of NGOs and CBOs serving MSM populations, CCM representatives, MSM and TG peer counsellors, LGBT and PLHIV activists. A short-list of potential key informants was approved by YVC.

32.3.2 Process, data collection and analysis

FGDs with MSM and TG and interviews with key informants were facilitated by the country consultants and conducted in the local language or in English. All participants gave informed consent; basic demographic information only for FGD participants was recorded. Discussions and interviews were recorded in some cases, and all were transcribed and translated to English as needed. Data extracted from the transcripts was entered into a matrix for analysis. However, the results in this report are summarized as no specific numbers were attributed to the types of responses or the different groups and ages of respondents. Some specification on age and population is provided in the attribution of quotes.

Draft reports were reviewed by YVC and the regional consultant, who then collated the country data, did a further comparative analysis and consolidated the four reports into this regional report. Comments on the draft were provided by YVC, APCOM and WHO.

32.4 Results

32.4.1 Characteristics of study population

Table 1A: Characteristics of the FGD participants

Country	Population*		PLHIV n (%)	Age (in years)		Testing history Had an HIV test	Awareness	
	MSM	TG**		18-25	26+		Aware of HIVST	Aware of PN
Indonesia	9	6	4 (26.7%)	8	7	15	0	0
Pakistan	9	8	3 (17.6%)	n/a	n/a	17	0	5
Philippines	10	6	6 (37.5%)	8	8	15	2	5
Thailand	9	7	0 (0%)	n/a	n/a	12	3	7

* Self-identified

** Also known as 'waria' in Indonesia and 'hijra' in Pakistan

n/a – Not available or not applicable. Age range of participants in Pakistan was 18-41 yrs; age range of participants in Thailand was 18-50yrs.

32.4.2 Country-specific findings

a) Indonesia

HIV Self-testing

The majority of FGD participants reported working in the hospitality and service industries as club performers. Some reported engaging in sex work, and the rest reported being students. None of the participants had previously used HIVST as it was not generally available.

Most participants agreed that having more, free-of-charge options for HIV testing would increase the rates of people choosing to know their status. It was noted that some members of MSM and TG communities might prefer HIVST, such as people whose schedules do not allow time to go to hospitals for HTS. At the same time, most participants were reluctant to support the idea of widespread HIVST as they felt that HIVST would not promote positive behavior change, and testing on one's own could provoke feelings of isolation and loneliness. Some participants suggested that people might be embarrassed to purchase self-test kits at a pharmacy. Concerns were also expressed about test accuracy and reliability of results due to lack of technical knowledge about how to do the self-test. Some participants reported having more confidence in traditional HTS delivered by counsellors at health facilities. In addition, it was reported that poor health-seeking behaviors and the competing priorities and concerns of daily life lead many in the MSM and TG communities to not prioritize HIV prevention;¹ for those people, HIVST would also not be seen as a priority.

The cons seemed to outweigh the pros in the opinions of MSM participants.

¹ It was not clear in the reported findings if the poor health-seeking behaviours were HIV-specific or due to a sense that the respondents did not feel they were at risk of HIV infection, or for some other reasons.

"I think every option is good especially for those who are busy or have no access to normal services. But these people need to be worldly, educated and prepared for any result. They need to understand what "window period" is, and about how HIV is transmitted. I would be worried they might experience depression or denial. Having an HIV test is hard enough let alone doing it [alone]. I don't think Indonesia, including Bali, is prepared for this." MSM, 26+ years old

Transgender participants expressed concern that HIVST may not provide access to counselling and supplementary services such as condoms and lubricants. They worried about cost and the potential for discrimination from pharmacy staff if kits were to be sold over the counter:

"If they are going to sell it at the pharmacy, the pharmacy staff should be trained not to discriminate; it would need to be free." Transgender woman, 18-25 years old

Key Informants felt HIVST would be acceptable to a certain segment of the MSM and transgender communities—those with sufficient knowledge about the test, confidence and concern about confidentiality, and those *"wanting to get over the hurdle for the first time"*. The population who might prefer HIVST is not yet clearly defined, except that they are hard to reach through the usual programmes, or disinclined to seek HIVST. Those already receiving free services for VCCT (or HTS) are unlikely to choose HIVST. There was also concern about monitoring and reporting results.

Partner notification

None of the participants reported having been offered PN, though four were living with HIV. For those in stable or open partnerships, the concept of couples counselling or mediated PN was preferred to anonymous notification through a medium like text/internet messaging. This was because feelings of trust had been built through the relationship and they felt they could handle the information together, compared to an SMS informing the partner. Automated text messaging could be better received, for example a generic message requesting a return call for more information, compared to one that would state the HIV test result.

Fear of retribution and reprisal from the recipient of the notification message was of great concern for transgender women, particularly those that support themselves through sex work.

"For our own partner it is OK. But as a sex worker it could end up really badly." Transgender woman, 26 years

"For me as a sex worker I don't think it is very useful. I can't remember who I slept with last and we don't share contact details." Transgender woman, no age given

For MSM, the nature of the community and the manner in which members of the community interact were raised as concerns. If there is 'gossip' and scandal mongering, the introduction of PN may not be easily accepted.

New technologies have also made it easier to hook up for sex while maintaining anonymity, or constructing an alternative identity or image. These types of relationships make it difficult to consider PN.

"With social media now we can find a sexual partner with no strings attached and we also have no idea of their real name or contact details. No way of tracing them. More often than not the details they provide are fake anyway." Outreach worker, age not given

Key informants supported the idea of PN being introduced along with HIVST. They stressed the need for prudence and circumspection, including the approaches and the ways in which messages are disseminated. Staff and health-care

providers need to be trained to convey the message and to manage data in a way that ensures confidentiality. All participants felt that PN should be voluntary.

b) Pakistan

HIV Self-testing

FGD participants included students, sex workers, dancers, NGO workers, makeup artists, and family business owners. None of the participants had experienced HIVST. The generally low awareness about HIV, misinformation and high levels of stigma in the country were seen as barriers not just to HIVST but to HTS in general.

"...people think HIV is transmitted only through bad sex habits [so] anybody going for [HIV] test would be considered into bad [sexual] activities causing need for [such] tests. Here [in CBO] we are relaxed because this is community serving the community and we are not judged about our sexual activities." MSM and TG, mixed ages

Participants noted that public awareness on HIV is needed to reduce stigma around HIV and HTS. A desire for confidentiality was thought to be the main reason for undergoing HIVST.

Preferences regarding how and where HIVST should be done varied. Most MSM are thought to be affluent, closeted, married and with access to technology. They favored using internet, social media, video links, and group training sessions at the CBO on how to conduct the self-test, how to interpret the results and post-test follow-up. Participants felt that helplines are a useful tool for providing HIV information. Transgender participants, on the other hand, reported a preference for face-to-face interaction with a counsellor for HIVST.

Participants raised concerns about the psychological and emotional implications of doing a self-test and getting a reactive result. Both MSM and TG participants reported a concern about an increase in suicide if people test alone without professional help; some recalled receiving a positive result and feeling that they had nowhere to go.

The participants emphasized that HIVST should be available free of charge and through CBOs.

" They [outreach workers] should distribute self-test kits as they distribute condoms. . ." MSM, no age given

"This [CBO] is the only place where we come freely because we know everybody here, they guide us and we make good decisions about our health. We can trust [self-testing] if available here." Transgender woman, no age given

Key informants² thought that there was currently no demand for HIVST.

" [HIVST] is something we cannot even think of happening in Pakistan unless promoted widely." Key informant, age not given

"Lack of awareness about HIV and need for getting tested is a major hurdle. Although HIV is in Pakistan, doctors deny it. Who would accept HIV self-testing in such a bad condition?" Key informant, age not given

² Key informants were providers of services serving MSM and transgender communities and staff of national AIDS programmes, NGOs and CBOs. No identifying information for quotes from key informants was provided.

Participants noted that HIVST is not part of the national strategy for HTS, and this lack of recognition could be a barrier to its introduction.

"HIVST is not mentioned in the new national strategy for HTS. The system is already in transition, and it cannot afford to bear the burden of a completely new thing like HIVST... our AIDS Control managers are not going to even listen...." Key informant, age not given

Partner notification

Five (of 17) FGD participants had been offered or experienced PN; three were HIV-positive. Most participants indicated they would prefer not to disclose their HIV status to their partners. Members of MSM and TG communities change their sex partners frequently, making it difficult for the counsellor to facilitate PN. Participants consider sharing one's HIV-positive status within health-care settings a big risk. They reported that doctors are not well informed about modes of transmission. Furthermore, participants noted that many doctors, while serving known PLHIV, avoid touching patients during examination, thus fueling stigma and misconceptions.

In contrast, key informants stressed the importance of PN as a key factor in the success of HIV prevention programs. One interview participant cited poor quality of counselling in HTS as inimical to PN. This is often due to health staff being overburdened and inadequately trained.

In Pakistan, *hijra* (transgender or 'third gender' people) households, known as '*deras*'; community organizations and NGOs serving the *hijra* population are key stakeholders with a critical role in supporting PN. *Dera* households are headed by '*gurus*', who serve as an important form of family, peer, social and community support for *hijras*. The acceptance or non-acceptance of HIV-positive *hijras*, as well as PN and HIV testing in the *dera*, supported by *gurus* and other leaders, is key to a wider acceptance of both HIVST and PN within these communities.

"We can share with our gurus only . . . when they are completely aware of the sensitivities related to HIV and AIDS. Otherwise, there are chances of social boycott because no one would like to keep an HIV- positive person in her dera due to fear of being isolated from the rest of hijra community. Other than safety, this social boycott can lead to financial loss also..." Hijra, age not given

c) Philippines

HIV Self-testing

FGD groups included students, workers (services, administration, medical), and some people who were unemployed.

Only two participants below 25 years of age had experienced HIVST. They had access to rapid diagnostic tests (RDT) and were familiar with the techniques to perform it. However, they recalled being tense and apprehensive, and they expressed a preference to speak with a counsellor, before and after the test. Most participants were aware of HIVST and the availability of kits online; participants mentioned three websites where HIVST is available.

Participants expressed concerns about test accuracy and about the need for having confirmation of the test results. They wondered if a prescription would be needed to buy the kit at a pharmacy. They also expressed concern about judgmental pharmacy clerks.

Advantages of HIVST mentioned by participants included privacy and confidentiality, and being able to do the test in the comfort of home. However, a disadvantage in the event of a reactive result would be uncertainty about next steps.

Young MSM and TG saw HIVST as “double-edged”—it could be helpful, but if the client is unprepared and is not educated about the test and follow-up, it could cause problems.

Some participants suggested different ways to do the test (e.g., saliva is preferred). Several expressed preference for having the self-test available at the Social Hygiene Clinic testing facilities alongside traditional HTS.

“There should be counselling and proper marketing [of the test, and] referrals [including contact information and next steps] should be part of the package; the packaging must be right, information readable and easily understandable.” TG, 26+ years

Partner notification

Five participants (of 16) had been offered or experienced PN, and six were living with HIV. For young MSM and TG, the context of the relationship and circumstances of notification are important to consider if there is a possibility of abuse or exploitation and protective support is required. Sometimes there is no choice but to disclose, and it can come as a shock, for example, when an opportunistic infection strikes, or the partner is hospitalized.

Participants preferred a gradual process for notifying their partners. They mentioned both passive and assisted notification, or informational seminars, which might motivate a person to seek HTS. One participant felt that the partner would need to know the basics of HIV before s/he would be prepared to have a discussion about getting tested.

“I just tell him to use a condom with any partner...when he begins to ask about HIV, then I feel is the right time...” No identifying information provided

Respondents emphasized that people in discordant relationships, where one is not aware of the other’s status, need to discuss PN. Peers can also support PN. In some cases individuals could be more motivated to have a test or notify partners in a group setting. Participants acknowledged the difficulty of notifying others and concerns about their own readiness to disclose to a partner. They were also concerned about the possibility of criminalization if they failed to disclose their HIV status to a partner—there had been recent discussions in the media about the need to review the AIDS laws and criminalize transmission—and expressed the need for clear guidelines on PN].

Young members of MSM and TG communities in the Philippines now have more opportunities to travel to other countries, and the use of social media and “hook up” applications to meet sexual partners can be a barrier to PN.

“I’m quite sure that I got HIV from a sexual encounter in Viet Nam. I wanted to inform him but I did not know how to get in touch, I only have his first name....” Young MSM, age not given

d) Thailand HIV Self-testing

FGD participants included students, corporate workers, hotel employees, business owners, NGO staff and freelancers. Three participants reported having used HIVST, but most participants had never heard of it. Both FGD and interview participants supported HIVST and preferred purchasing kits at a pharmacy. However, many participants questioned the accuracy of the test results, particularly if done in community settings without assistance and if distributed for free. Some expressed concerns over the lack of psychosocial support such as face-to-face pre-test information and post-test counselling.

Participants mentioned several advantages of HIVST including accessibility, anonymity, confidentiality and short waiting time for results. They felt that HIVST should be available over the counter, at low cost (US\$2.80–8.50). Availability at pharmacies would indicate that safety and accuracy standards are in place. Some participants preferred the option of assisted HIVST with experienced counsellors. There should be clear instructions on use of the kit and clear and up-to-date contacts for referral services (for both negative and reactive results).

"This issue [post-test counselling] is essential to minimize emotional breakdown or even self-harm after clients' positive result is confirmed. Psychological support is integral to private HIVST—both pre- and post-test, in order to help the clients cope with the test results..." Peer educator, age not given

Participants did not think that HIVST would replace HTS, or be popular among those who regularly undergo HTS. They expressed more trust in accuracy of test results delivered through HTS compared to HIVST.

Key informants were knowledgeable about the policy and regulatory framework, and the practical aspects, as a self-testing pilot project was underway at the time of this study. They felt that HIVST in its initial stage should be entirely supervised and assisted. Future availability and accessibility in Thailand will mean changing laws and policies that prohibit non-medical professionals from using HIV testing devices. All HIVST, private or supervised, should be part of the HIV screening strategy, although opinions were divided over financing of HIVST.

"HIVST could be preferred in comparison to HTS because it's easier to use and access, and requires no official registration. Initially, HIVST should be under the supervision of experienced workers. Demand can be created and well documented." Key informant, age not given

"Everyone should have access to HIV testing kit, like a pregnancy test. We've witnessed the benefit of early testing for earliest treatment, that it has dramatically decreased [AIDS-related] morbidity and mortality. HIVST kits must be easy to use, with high accuracy, available and accessible." Key informant, age not given

"This form of testing [HIVST kit] should be individuals' financial responsibility, the same way one needs to pay for a pregnancy test kit. If a person prefers to know their HIV status in private even though there's a 'traditional' HIV testing service available and accessible, they should pay for the extra cost." Key informant, age not given

Partner notification

Seven participants (of 16) had been offered or experienced PN, although none openly admitted living with HIV. Participants with HIV testing experience reported that PN was by client referral, with minimal assistance, such as early treatment information, from counsellors. Most participants would be inclined to notify serious and long-term partners by themselves. Similarly, they preferred to be notified by long-term partners, for the main purpose of getting health services. Fear of rejection is the major obstacle to notifying long-term partners. Participants felt that violence is not likely to happen.

Within casual partnerships, provider referral was preferred. Providers could provide technical information on pre-exposure prophylaxis (PrEP) and early treatment, and emotional support for patients in voluntarily initiating PN.

Participants were not enthusiastic about dual referrals, insisting that partner notification should be client-initiated, especially in longer-term and/or committed relationships. Trust between provider and client plays a key role. Some participants felt that decisions to notify a partner, or accessing services after being notified, can take time, and they would prefer to make decisions on the timing of the process, which might be less feasible with dual referrals.

"PN is our right. There are times when we don't want our status known. Notifying your partner of your HIV status takes a lot trust and the ability to cope with the consequences [for] both parties, which should be solely done by clients. Providers have no rights to intervene." Young TG woman, age not provided

32.5 Discussion

32.5.1 HIV self-testing

In general, participants from Indonesia, Thailand and the Philippines supported introducing HIVST as another option to increasing testing uptake among MSM and transgender populations not usually reached by HTS. Acceptance of HIVST by stakeholders was more likely in countries where HIV is less stigmatized and there is better access to HTS. Where HTS uptake is still low, introducing a new way of testing might not be acceptable at present.

Since only five of 59 participants had used HIVST, most viewed HIVST through their own experience with HTS. Those who had had supportive and positive experiences expected that HIVST without pre-test information and post-test counselling, referrals and provision of condoms and lubricants could lead to social harms (suicides, depression, etc.) particularly when a test becomes reactive for the first time.

Perceived advantages of HIVST were convenience, privacy, confidentiality, and ease. A few respondents were concerned about the accuracy of the test or the technical specifications of use. Some expressed worry about getting a reactive test and having no access to a counsellor, ancillary services, or information on "what to do next". Some disadvantages were the perception of HIVST being less accurate than the tests performed in traditional HTS.

Some participants suggested that HIVST kits could be distributed through existing user-friendly facilities, such as CBOs and HTS or STI clinics, rather than pharmacies (with the notable exception of Thailand). Public perceptions of better quality commodities being available at pharmacies in Thailand indicate general confidence in the government's drug regulatory capacity and its implementation of standards. This may not be the case in other countries where pharmacies are poorly regulated and the prevalence of fake and adulterated drugs and questionable test kits are high.

Younger people fear discrimination and judgmental attitudes from pharmacy staff. Young participants felt providers would be judgmental, and would assume they were "immoral", and that they might have HIV. These views were expressed by Philippine participants and may be more common in countries with more conservative attitudes toward sexuality, earlier sexual activity, and/or diverse SOGIE (sexual orientation and gender identity and expression).

Little is known about the potential population who will opt to have HIVST, but given gaps in the HIV "Continuum of Care" cascade, it would seem that potentially, many more could be reached and could have access to the first step in the continuum—knowing one's HIV status. Key informants expressed concern about the possibility of people "falling off" before getting a confirmatory test, (they might not get a confirmatory test if reactive, and may fail to test regularly) and that other conditions closely linked to the sexual transmission of HIV, such as the more commonly occurring STIs would be neglected. This could be a missed opportunity for improved STI screening and treatment.

Countries differ in terms of their experiences and policy responses to this new testing modality. In some countries starting out with HIVST, such as Indonesia, Pakistan and the Philippines, there is no mention of HIVST in national policies and guidelines (mainly because this is a new technological development). Other countries specify that an HIV test can only be done in a clinic or laboratory, with a counsellor, and confirmed using a specific procedure. Where HIVST is recognized, its use is currently limited to research or to certain types of medical professionals.

Policy barriers need to be overcome before government and health officials can endorse HIVST. In countries where HIVST pilots are ongoing (Thailand), there is a clear direction for policy advocacy, for recognition of the test, allowing its use beyond research and pilot studies, and quality assurance regulation. There are also lessons to learn from the marketing of similar self-test kits, such as pregnancy tests.

The private sector does not seem to be involved in the policy discussions, but the distribution channels are present and active, and anyone with a credit card and a delivery address can receive a kit at their convenience.

HIVST is not likely to replace HTS, but supplement it. Increasing the proportion of people who go for a test, whether HTS or HIVST, thus depends on a supportive policy environment and better awareness both within the general public, advocates and NGO and community groups working with MSM and TG, HTS counsellors, and health care providers.

32.5.2 Partner notification

Preferences for PN among MSM and TG in 4 countries in Asia depend on the types of partners one has—casual or long-term, the context in which one met partners (sex work, cruising, or through hook-up applications). Having both types of partner relationships at the same time is not uncommon for many MSM and transgender women.

For those in sex work or meeting partners casually at the outset, with no expectations of a longer-term relationship, PN was not thought to be realistic or practical, given the nature of the sexual encounter (quick, hidden, furtive, frequent, not likely to be repeated, often anonymous, no exchange of personal or even identifying information). The lack of a stronger personal and emotional relationship, and perceived irrelevance of contact details, between casual sex partners, as well as sex workers and clients, may be a barrier to providing notification. Increased mobility (fewer visa requirements, cheap air travel), and new technology that facilitates hooking up between various countries in the ASEAN region is another challenge to providing PN for some casual partners.

Participants felt that a priority for notification was long-term partners, or where a stronger relationship bond exists. Long-term partners are more likely to be notified, for reasons related to concerns about health of the partner and improving access to services. The possibility of rejection by the partner following notification is a barrier to PN.

The HIV-positive status of the notifying partner was seen as an important factor to consider, as this could be a “game changer” for the relationship. Thus, those living with HIV and in discordant relationships are likely to need more support if they are considering PN. Participants felt that in cases where PN is considered, it should be gradually done, over a period of time, and when both partners are perceived to be “ready”. Indications of readiness are very personal and contextual. The shock of a notification, such as being forced to admit having HIV when taken seriously ill, can be potentially avoided with professional assistance. Most participants preferred to be notified directly by their partners rather than by a counsellor or health-care provider. Little was mentioned about the type of services that might be needed to support PN.

There was ambivalence about the role that community groups could play in the notification process itself; if there was lack of trust in community groups, and gossip, this could be detrimental to PN efforts. It appears that PN can be discussed more openly in groups of people living with HIV.

PN should always be voluntary and done only with the consent of the person providing the names and contact details of the partner(s) to be notified. In the case of assisted PN, or with provider-initiated notification, the health staff should be properly trained on how to handle the situation. Providing automated and generic text messages could serve as reminders, rather than specific messages addressed to a particular person.

32.6 Strengths and limitations

All of the FGD participants were identified and contacted by NGOs and CBOs that specialize in serving MSM and TG populations, which assured participants of sensitivity and confidentiality. None of the FGD participants were younger than 18 years; this may have implications on the findings of the study as many young MSM and transgender people report sexual debut before the age of 18, and many may be unreachable through the NGOs, or may need parental consent before any form of HTS. FGD groups were organized by country consultants were based on their assessment of suitability and acceptability in their particular contexts. Thus, some FGDs were separated according to age, or according to self-identification as MSM or transgender females, while others were mixed. This method of organizing FGD groups could differ in other cities or locations, and could limit sub-group analysis. Some participants felt comfortable disclosing their own HIV status or that of their partners, while others may have chosen not to disclose.

Findings and conclusions from this study may not be transferable to the country or region, given the size, geography, and cultural and language diversity of each of the four countries' MSM and transgender populations. FGDs were done in urban areas, mostly capital cities; consequently, specific issues of members of these communities in more rural areas may not be reflected in this report.

There may have been some variability in the quality of documentation, transcription, translation and interpretation of data, but not more so than any other qualitative study that requires language translation. Some of the quotes that appear in the report have been edited for length and clarity.

32.7 Conclusion

HIV self-testing

In general, FGD participants and key informants from Indonesia, Philippines and Thailand were open to the introduction of HIVST as another option for HIV testing services, that could improve uptake of HIV testing. However, as HIVST has only recently been introduced, only five persons (about 10% of those who had taken an HIV test) had actually experienced self-testing. There was general consensus in all countries on the benefits of HIVST, preferences around distribution, cost considerations and the critical role of counselling and other ancillary services that are important for any form of HIVST.

- HIVST was reported to be more convenient, private and confidential, although some participants reported concerns about getting a reactive test and having no access to a counsellor, ancillary services, or information on what to do next.
- In general, HIVST kits could be distributed through existing user-friendly facilities, such as CBOs and social hygiene (STI or sexual health) clinics, rather than pharmacies. In some settings, pharmacies may be more acceptable than in others. However, younger participants feared discrimination and judgmental attitudes from pharmacy staff, in the event that HIVST kits would be available in pharmacies.
- HIVST should be provided for free or a small charge. Most participants were willing try HIVST and to pay a nominal fee (range cited in local currency the equivalent of US\$ 0.30–8.50)
- Training of health-care providers and potential users in performing HIVST procedures is needed.
- Counselling, whether face-to-face, through hotlines, or online, has an especially critical role to play for HIVST.
- All participants agreed that HIVST is not likely to replace traditional HTS.

In addition to the above, key informants raised other issues:

- The need to have a better understanding of the target groups for HIVST; they felt that individuals with higher levels of education, who are better prepared to do self-testing and to understand the implications, who are concerned about confidentiality, and who have the means to pay would be the target group for HIVST
- They felt that MSM and TG who may already be accessing routine HTS would be unlikely to choose HIVST.
- In countries where HIVST pilots are ongoing (e.g. Thailand), there is a clear direction for policy advocacy, and for legalization and regulation of HIVST.

Partner notification

For members of MSM and TG communities, the type of PN approach chosen depends on the types of partners one has—casual or long-term, and the context in which people met those partners (sex work, cruising, or through hook-up applications). Having different types of partner relationships at the same time is common. For those in sex work or meeting partners casually at the outset, with no expectations of a longer-term relationship, PN was not considered by participants to be realistic or practical.

Participants noted that social and cultural environments and relationship contexts affect an individual's decision to notify their partner(s) and should be taken into account when discussing PN methods and strategies. However, the provider does not select the method for the client—it is important that all methods available are discussed with each client, and they should be allowed to choose. Participants felt that PN should be client-initiated, with minimal assistance from providers. Some participants stated that trust between provider and patients must be firmly established before PN is discussed and initiated. Furthermore, participants felt that PN should be voluntary and done only with the consent of the person providing the names and contact details of the partners. In cases of assisted PN, or with provider-initiated notification, proper training for health staff was considered by participants to be important.

The HIV-positive status of the notifying partner was seen as a very important factor to consider, as this could affect the nature of the relationship of the partners. There was ambivalence about the role that community groups could play in the notification process itself; if there was lack of trust in community groups and gossip was suspected, this could be detrimental to PN efforts. However, it seemed that PN was discussed more openly in PLHIV groups. Participants felt that automated mechanisms (i.e., generic messaging) might also have a role in PN.

32.8 Recommendations

HIV Self-testing

1. Continue HTS advocacy and include HIVST as an option and alternative way of knowing one's status. Integrate HIVST into HTS where possible.
2. Cost of HIVST kits should be affordable or partly subsidized to reduce barriers to access.
3. Regulation and quality assurance of HIVST kits and the information and instructions provided, including local contact information for referrals.
4. Back-up support (assisted HIVST) should be available. Options for access to counsellors and/or medical and health professionals, either online or face-to-face can be made available prior to the test and after the results are received, regardless of whether reactive or non-reactive.
5. Helplines should be considered.
6. There need to be clear referral pathways into the "care cascade" and linkages to ancillary services (STI diagnosis and treatment, SRH services)

7. Individual profiling at point-of-purchase, to provide information on customers, as this is a relatively 'unknown' population. Such information should be collected voluntarily and anonymously, to include:
 - Demographic information such as age, sex, gender, occupation/work, education level, income level
 - Date and instance of last risk behavior
 - Knowledge of 'window period'
 - Previous experience of HTS; previous self-testing experience
 - Knowledge of what to do if test result is reactive or non-reactive
8. Orient face-to-face distributors of HIVST kits to treat all customers equally, and to reduce judgmental attitudes towards young customers, particularly gay or other MSM and transgender people.
9. Review legal and age requirements for HTS, including circumstances under which RDTs and HIVST can be carried out.
10. Develop monitoring mechanisms (such as online sales, sites, costs, utilization).
11. Ensure that HIVST is not used coercively (i.e., where people may be tested against their will and without consent).

Partner notification

1. Social and cultural environments and relationship contexts should be taken into account when discussing PN methods/strategies with HIV-positive clients, so that a preferred notification type is chosen by the client for each partner.
2. Acknowledge that PN strategies may be based on relationship status (i.e., permanent/long-term partner relationships and short-term or casual relationships) but that these may be fluid, and that for many, these types of relationships co-exist at the same time.
3. Trained counsellors should acknowledge, help verbalize and allay fears and concerns, offer support for assisted notification if necessary.
4. Involve key stakeholders in specific communities (i.e., *gurus*, *dera*, peer educators and leaders) in advocacy for supportive environments for PN and for sensitization about treatment and other support services
5. PN should be done with the index person's consent, with assistance to be offered from providers.
6. Trust between provider and clients must be firmly established before PN is discussed and initiated.
7. There is a role for automated, generic text messaging to inform partners about the need to seek advice, or link with a counsellor. Specific messages to individuals that specify a HIV test result, for example, are not recommended.
8. PN should be linked to support services: counselling, PEP, PrEP, ART, STI treatment and other interventions and commodities for HIV prevention, care, support and treatment.

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