

# Acceptability of HIV self-test among adolescent Men who have Sex with Men, travestis and transgender women in Brazil

*Aceitabilidade ao autoteste de HIV entre adolescentes Homens que fazem Sexo com Homens, travestis e mulheres transexuais em três capitais brasileiras*

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**ABSTRACT** Introduction: The objective of this study is to analyze the acceptability of the HIV self-test among male adolescents who have sex with male and transgender women in three Brazilian capitals. Method: qualitative study, with 6 focus groups and 37 in-depth interviews with 58 participants, from the cities of Belo Horizonte, Salvador and São Paulo, whose thematic analysis was based on the Theoretical Framework of Acceptability. Results: the HIV self-test had good acceptability, although it was not homogeneous among participating adolescents. Positive aspects include, for example, agility, privacy, autonomy, monitoring one's health, and emotional and stigma management. In another direction are concerns about how to deal with an eventual reactive result and whether self-testing is a prevention strategy. The place where self-tests are given out is decisive to improving their use, which depends on cultural competence to accommodate sexual and gender diversities of adolescents. Conclusion: This study has shown that HIV self-testing is a fundamental strategy to increase adolescent autonomy and self-care. These should be considered to better adapt the test to local youth cultures and, consequently, achieve better compliance.

**KEYWORDS** Self-testing. HIV testing. Adolescent. Transgender persons. Sexual and gender minorities.

**RESUMO** *Introdução: O objetivo deste estudo é analisar a aceitabilidade do autoteste de HIV entre adolescentes Homens que fazem Sexo com Homens e mulheres travestis e transexuais em três capitais brasileiras. Método: estudo qualitativo, com 6 Grupos Focais e 37 Entrevistas em profundidade, envolvendo 58 participantes, nas cidades de Belo Horizonte, Salvador e São Paulo, cuja análise temática de conteúdo orientou-se pelo Theoretical Framework of Acceptability. Resultados: boa aceitabilidade do autoteste de HIV, ainda que não homogênea entre participantes. Entre os aspectos positivos dos testes estão, por exemplo, a agilidade, a privacidade, a autonomia no monitoramento da própria saúde e a gestão emocional e de estigma. Em outra direção tem-se a preocupação em como lidar com um eventual resultado reagente e o questionamento do autoteste como estratégia de prevenção. O local de dispensação do autoteste é decisivo para potencializar ou não o uso, a depender da competência cultural para acolher a diversidade sexual e de identidade de gênero de adolescentes. Conclusão: Este estudo identificou o autoteste de HIV como uma estratégia fundamental para o incremento da autonomia e autocuidado entre adolescentes. Estas devem ser consideradas para maior adequação às culturas juvenis locais e, conseqüentemente, maior adesão à testagem.*

**PALAVRAS-CHAVE** Autoteste. Teste de HIV. Adolescentes. Pessoas transgênero. Minorias sexuais e de gênero.

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## Introduction

An estimated 26% of people living with HIV worldwide are unaware of their serologic status<sup>1</sup>. To improve access to testing and timely initiation of treatment, the World Health Organization (WHO) has proposed the HIV self-test (HIVST) since 2016 as a complementary strategy to testing by healthcare professionals, taking into account different contexts of vulnerability<sup>1</sup>. However, the cost and low supply of the test in the market make it difficult to use it on a large scale in low-income countries and/or in countries with strong social inequalities, making the free availability of HIVST by authorities crucial<sup>1</sup>.

In Brazil, the 'Test and Treat component' is part of the Combined Prevention of HIV and Other Sexually Transmitted Infections (STI) strategy, which provides for the provision of prevention methods such as HIV pre-exposure prophylaxis (PrEP), HIV post-exposure prophylaxis (PEP), risk reduction counseling, condom and lubricant use, testing, and treatment<sup>2</sup>. The strategy provides for the selection and combination of methods based on people's interests and their specific vulnerabilities, with an emphasis on support of key groups: gay men and other Men who have Sex with Men (MSM), *travestis* and transgender (TGW), people who use alcohol and other drugs, people deprived of their liberty, and sex workers<sup>2</sup>.

HIVST was included in the Unified Health System (SUS) in 2018 and was expanded in 2020 to reach populations not reached by health services<sup>3</sup>. According to the guidelines for the service, this has the benefit of expanding access to serologic status, providing a testing option for people who don't want to be tested in front of others in the health service, and promoting autonomy to decide where, when, and how the person wants to be tested<sup>3</sup>.

HIVST is a technology that is little known and little used among youth in Brazil<sup>4</sup>. Despite great progress in the availability of HIVST in

the country, the adolescent public isn't fully involved in the strategy, because the test is only offered in connection with health professionals<sup>5</sup>. The concern in testing this group is related to the increase in HIV infection rates among MSM and TGW in the age group between 15 and 19 years, which is considered adolescent according to the WHO criteria<sup>6</sup>. Between 2009 and 2019, the number of HIV infections among men aged 15 to 19 years in Brazil increased by 64.9%, from 1.1 to 6.1 HIV-infected persons per 100,000 population<sup>7</sup>. The estimated HIV prevalence is 18.4% among MSM<sup>8</sup> and among TGW exceeds 25% in some places in the country<sup>9</sup>.

Worldwide, there are few studies examining HIVST among young people. These suggest high uptake in countries such as Congo<sup>10</sup>, Mozambique<sup>11</sup>, and Nigeria<sup>12</sup>. A study of MSM from Brazil and Peru who were at least 18 years old<sup>13</sup> and a scientific publication with Brazilian adolescents indicate high adherence to HIVST<sup>4</sup>. Although HIVST is presented as of particular interest to vulnerable groups<sup>5</sup>, there remain gaps in understanding the acceptability of this strategy, and to date no article has examined acceptability among MSM and TGW adolescents in Brazil.

The aim of this article is to analyze the acceptability of HIVST among young MSM and TGW in three Brazilian capitals.

## Material and methods

### Participants

Data are from formative research (FR)<sup>14</sup> of the PrEP15-19 study, a trial of the efficacy of HIV pre-exposure prophylaxis (PrEP) in MSM and TGW adolescents aged 15-19 years, developed in Belo Horizonte, São Paulo, and Salvador.

The FR was conducted in 2019 using qualitative methods before enrolling participants to generate knowledge about the target population. It is a research structure common to

other studies whose goal is to include hard-to-reach populations. This includes mapping of social spaces, individual interviews, and group discussions<sup>14</sup>.

In the first phase, a participant observation was conducted by a researcher in each city to map spaces with high concentrations of MSM and TGW youth, both in person – in public and private schools, at parties, in bars – and online – in social networks and apps. Observations were systematized into field diaries that contained information and researchers' impressions of potential participants for the second phase.

In the second phase, interviews and focus groups were conducted in the three cities, allowing for analysis of narratives in individual and group contexts. To ensure diversity of participants, the following criteria were used: 1) diversity of self-declared gender identities and sexual orientation; and 2) socioeconomic and racial diversity. The criteria for inclusion of participants were: being between 15 and 19 years old and with gender identities and sexual orientations that are key HIV prevention groups. Exclusion criteria were any barriers or refusal to sign the informed consent/assent form.

The study complied with the Sex and Gender Equity in Research (SAGER), which advocate the careful use of sex and gender in research and scientific publications and the standardization of these definitions whenever possible for the study<sup>15</sup>. In this study, we describe all gender identities and sexual orientations self-reported by participants as part of the findings. However, we chose to work with the MSM and TGW categories because they allow for grouping of gender identities and sexual orientations and discussion with other studies and public policies.

## Data construction

Fifty-eight adolescents participated in the FR. Six focus groups (FG) and 37 interviews (IN) were conducted, with 26 adolescents

participating in both the interviews and the focus groups.

Of the 37 interviews conducted, 8 took place in Belo Horizonte, 16 in Salvador, and 13 in São Paulo. The interviews were preceded by a semi-structured script that covered the following topics: networks and social spaces; gender identity, sexual orientation, and sexuality; vulnerability to HIV, violence, and discrimination; knowledge of motivation for using PrEP and HIVST; and perceptions of recruitment strategies for the PrEP15-19 trial.

In each city, there was one FG with TGW participants and one with MSM. In Belo Horizonte there were 4 TGW and 6 MSM, in Salvador 5 TGW and 10 MSM, and in São Paulo 3 TGW and 9 MSM. The FG started with a brief explanation of HIVST, followed by a presentation of possible strategies to disseminate the test (peer interaction, on the Internet, in schools, and in socializing places), with the goal of stimulating discussion about their possible advantages and barriers.

The interview and FG scripts can be found in a previous publication<sup>16</sup>. They were conducted by researchers with experience in qualitative and HIV research in reserved rooms, lasted an average of 63 minutes, were recorded with participant consent, transcribed, and stored in a single digital file. To ensure anonymity of participants, adolescents were identified by numerical coding (J1, J2) and their quotes, which were identified by data collection context (IN or FG), target population (MSM or TGW), age, and study location (BH, SSA, SP).

## Data analysis

Thematic analysis of the interviews and focus groups involved six steps<sup>17</sup>: 1. Familiarization with data; 2. initial coding; 3. Search for themes; 4. Review of themes; 5. Definition of themes; and 6. Writing. These steps were based on discussions among the teams at the three sites, and coding of themes was based on the literature on adolescents and HIV and

the acceptability of health strategies.

We analyzed the prospective acceptability of the HIVST based on the Theoretical Framework of Acceptability (TFA)<sup>18</sup>. In the TFA, acceptability is defined as

a multifaceted construct that reflects the extent to which people who provide or receive a health care intervention believe it to be appropriate, based on expected or experienced cognitive and emotional responses to the intervention<sup>18(4)</sup>.

The analysis of acceptability was prospective because the HIVST was provided by the SUS only to individuals 18 years of age or older and none of the participants had used it.

The categories were selected based on their recurrence and because they allowed us to

access the conceptual world of the participants and the meanings they gave to the subject. Based on the themes in the narratives, we identified thematic categories related to the components of the AFT that were adapted to the present study, namely: 1. Affective attitude, defined as ‘How would the adolescents feel about using the self-test?’ 2. perceived effectiveness and coherence of the intervention, defined as ‘How do adolescents understand the goals of HIVST? And what is needed for HIVST to achieve its goals?’ 3. Self-efficacy and burden of participation: ‘how confident are adolescents that they can use the HIVST? And what effort is required to use the HIVST?’ 4. Ethics, defined as ‘Does HIVST fit the adolescents’ value system?’ (table 1). NVivo12 Plus software was used for data organization.

Table 1. Dimensions of acceptability of the HIV self-test (HIVST) according to the Theoretical Framework of Acceptability (TFA), translated by the authors and adapted to this research

DIMENSION	FOCUS
Affective attitude	How would the teenagers feel when performing the self-test ?
Perceived effectiveness and coherence of the intervention	How do teenagers understand the objectives of the HIVST? And, what would it take for HIVST to achieve its goals?
Efficacy and burden of participation	Are teenagers confident in their own ability to administer the HIVST? And what efforts are needed to carry out the HIVST?
Ethics	Does the HIVST fit the adolescent's value system?

Source: Own work.

## Research ethics

The study was conducted in accordance with the guidelines of Resolution 466/2012, which regulates research standards involving human subjects, and follows the provisions of Resolution 510/2016, which regulates respect for human dignity and the special protection of participants in scientific research involving human subjects. The study was approved by the Research Ethics Committees of the World Health Organization, the Federal University of

Minas Gerais (protocol 17750313.0.0000.5149), the Federal University of Bahia (protocol 01691718.1.0000.5030), and the University of São Paulo (protocol 70798017.3.0000.0065).

Participants were informed of the research objectives and the rights associated with participation. Individuals over the age of 18 signed an informed consent form and those between the ages of 15 and 17 signed an informed assent form. Based on the principle of non-maleficence, the research ethics committees waived consent from family members

or guardians because it could compromise the confidentiality of adolescents regarding their sexual orientation and/or gender identity and allow the risk of discrimination or violence. Anyone could enroll to be part of the PrEP15-19 study cohort, which would give them broad access to PrEP and other combined prevention methods.

## Results

### Participants

All characteristics of the 58 respondents were self-reported. Forty percent were between 16 and 17 years old and most had incomplete (47%) or complete high school (38%). In terms

of ethnic-racial identity, 55% described themselves as black (brown and black) and 38% as white. In terms of gender identity, 53% described themselves as cisgender men, 22% as transgender women, and 13% as trans and other genders. Nearly half (52%) described their sexual orientation as homosexual or gay (all men), 17% as bisexual, 12% as pansexual, and 12% as heterosexual (all TGW). By gender identities and self-reported sexual orientations, participants were classified as 55% MSM and 35% TGW.

### Dimensions of acceptability

The results in *table 2* indicate a good acceptability of HIVST and show specifics regarding the offer of this strategy for the MSM and TGW adolescent public.

Table 2. Acceptability of the HIV self-test (HIVST) from the perspective of Men who have Sex with Men (MSM) and *travestis* and transgender (TGW) adolescents

DIMENSION	RESULTS
Affective attitude	<ul style="list-style-type: none"> <li>• Agility and privacy;</li> <li>• Autonomy for monitoring one's health.</li> </ul>
Perceived effectiveness and coherence of the intervention	<ul style="list-style-type: none"> <li>• Suitable for early diagnosis and treatment of HIV;</li> <li>• Poorly suited for HIV prevention;</li> <li>• Finger prick is more reliable than oral fluid;</li> <li>• Dispensing at LGBTQIA+ friendly locations is required.</li> </ul>
Efficacy and burden of participation	<ul style="list-style-type: none"> <li>• Trust their ability to perform HIVST, with privacy advantages;</li> <li>• Barriers to getting the HIVST in some locations such as public services;</li> <li>• Fear of doing the HIVST by finger prick;</li> <li>• Problematicize the ability to receive the result on their own.</li> </ul>
Ethics	<ul style="list-style-type: none"> <li>• Compatible with prevention and self-care values;</li> <li>• Little compatible with spontaneity in sexual intercourse, which is valued among these young people.</li> </ul>

Source: Own work.

### (1) AFFECTIVE ATTITUDE

Most adolescents indicate that they would feel satisfaction when doing the HIVST:

(a) because it can be done quickly and privately;

*Like, if I had a risk relationship but didn't prevent it, I let it go, that would help a lot. Because the sooner you know, the better. (J1, IN, TGW, 19 years old, SP).*

*It would make me better in terms of my conscience and it would be something private [...]. I first deal with myself with this situation. (J2, IN, MSM, 19 years old, SP).*

(b) and because of the autonomy they would gain to monitor their own health.

*For me to monitor my health [...] even if I wouldn't give up prevention. That would make people always follow up, take care of themselves. (J3, IN, MSM, 17 years old, SSA).*

*You have autonomy. I think I would do a self-test every day. (J4, IN, TGW, 19 years old, SP).*

### (2) PERCEIVED EFFECTIVENESS AND COHERENCE OF THE INTERVENTION

According to adolescents' narratives, the HIVST is:

(a) suitable for early diagnosis and treatment of HIV;

*Because like, as I told you, I'm paranoid about this disease thing. If I had exposed myself to the risk of contracting the HIV virus, I would go to the pharmacy and buy my self-test, do it and if it were positive, it would be much faster to refer, start the treatment procedures. (J5, FG, TGW, 19 years old, SSA).*

(b) not very suitable if the goal is prevention, since in this case it fits better for people with steady partners;

*The thought [...] is not like 'I'm going to do the test to prevent it'. It's: 'Oh, I'm going to do the test because I think I'm [positive]'. (J6, IN, MSM, 17 years old, SSA).*

*If it's a steady partner, yes, because you can do this check casually. (J7, IN, MSM, 17 years old, BH).*

In order for HIVST to achieve its objectives, adolescents consider that:

(a) the HIVST via finger prick is 'more reliable' than HIVST via oral fluid;

*It's not that I don't trust saliva, because there are several things there, but the fact that I take a little cotton swab and put it in my mouth and I don't know... maybe I wouldn't take it so seriously. (J8, FG, MSM, 19 years old, SSA).*

*I think both are [reliable], but I think it's expected, even psychologically, we feel more confident with the little finger test, the blood test, right?. (J9, FG, MSM, 17 years old, SSA).*

(b) HIVST is more effective when dispensed in LGBTQIA+-friendly venues, as in the PrEP15-19 Project, where peer educators work.

*Knowing that the person at the table is a transwoman, a travesti who is working. They're people just like me. They're people who won't see it as taboo and... 'Oh my God, he's infected, help, get this person out of here. Don't touch him, he's going to give you AIDS'. We wouldn't hear things like that, for example. We know that in the Unified Health System, we'd certainly hear that, including from professionals. (J10, FG, MSM, 19 years old, SSA).*

### (3) SELF-EFFICACY AND PARTICIPATION BURDEN

In this study, adolescents demonstrate:

(a) confidence in their ability to do the HIVST, with privacy advantages;

*Yes, I'd feel more comfortable alone than with other people. Of course, with a professional and everything it wouldn't be a problem [...], but I think alone is always more comfortable. (J11, FG, MSM, 17 years old, SSA).*

*You aren't embarrassed by another person. And if the result [...] is positive, you'll suffer, of course, but it'll be something that will be only you. (J12, FG, TGW, 19 years old, SSA).*

Most cite as possible barriers to doing the HIVST:

(b) 'Shame' or 'fear of stigma' in places where HIVST is provided, especially if in public health services;

*People are afraid to test themselves in public places [...], even young people don't go to public places for fear that someone will see them when they enter and think they're leaving because they have [HIV]. (J13, FG, MSM, 19 years old, SSA).*

*[Receiving the HIVST] is better at home, by mail, or on the Internet to overcome the stigma of appearing in public health facilities. (J14, FG, MSM, 19 years old, BH).*

Few cite as burdens in doing the HIVST:

(c) fear of pain and blood associated with the finger prick;

*It's better to prick your finger. But I'm afraid of being pricked, which hurts, so I preferred the [oral] fluid... (J16, FG, MT, 16 years old, BH).*

(d) fear of getting the result alone if it's reactive. The situation is alleviated if the HIVST is considered the first phase of the testing procedure, which must be supplemented by the conventional test performed by a specialist.

*Receiving the positive result at home will be a little more difficult. Because the CTA [Testing and Counseling Center] has a social worker. I do the test alone and it's positive. Then how am I supposed to seek help? [...] The CTA shows ways, talks to*

*you [...] it should direct you to undergo treatment. (J17, FG, MSM, 18 years old, BH).*

*You have to do both, the self-test at home and, at the center, you do the blood test. (J18, FG, MSM, 19 years old, SSA).*

#### (4) ETHICS

The narratives show that HIVST:

(a) coincides with prevention and self-care being recognized as group values, although structural and cultural difficulties in putting these values into practice are considered;

*First, I would feel more confident about my health, knowing if I have a problem or not. (J19, IN, MSM, 19 years old, BH).*

*Like, if I had a risk relationship, but I didn't protect myself. And I let it happen. That was a month ago now. I think that would help a lot. Because the sooner you know, the better, right? (J20, IN, TGW, 19 years old, SP).*

(b) is in conflict with the spontaneity of sexual practices if it's intended as a prevention strategy, since it introduces a rational planning element that is foreign to the sexual culture of these young people.

*There are people who would say that this would make them go limp and everything [doing the HIVST before having intercourse]. (J21, IN, MSM, 17 years old, SSA).*

## Discussion

The results suggest good prospective acceptability of the HIVST among MSM and TGW adolescents, similar to what has already been found in a study in Brazil<sup>4</sup> and in other countries<sup>10-12</sup>. However, for the promotion of HIVST, the specific components of acceptability that emerge in the narratives of these adolescents need to be considered<sup>15</sup>.

Satisfaction with the HIVST is related to the speed of technology to ‘dispel uncertainty’<sup>19(517)</sup> after a situation of risk of HIV infection. Convenience in reducing the fear of waiting or possible invasion of privacy with traditional testing methods is also highlighted, similar to the findings of other studies<sup>12,20,21</sup>.

The gain in autonomy for private health surveillance refers to the use of HIVST as a tool for controlling stigmatization, which has also been observed among sex workers in Brazil<sup>22</sup>. Stigma, particularly in health care settings, is a barrier to adolescent testing in this and other studies<sup>10-12,23,24</sup> so overcoming stigma may be beneficial for scaling up testing. However, these data need to be critically analyzed. It’s important to note that the provision of HIVST in HIV/AIDS programs cannot be considered in isolation from interventions to address stigma<sup>25</sup>.

It’s important that the locations where HIVST is offered are well considered, and the adolescents in this study suggest that HIVST is useful when offered in settings that cater to the LGBTQIA+ population or are LGBTQIA+ friendly, similar to what is described in the literature<sup>4,23,26-28</sup>. The Brazilian HIVST protocol for adults includes distribution in locations where PrEP is dispensed, as well as at social locations for key populations<sup>3</sup>. Previous studies have been successful with self-testing and distribution booths in places frequented by adolescents<sup>29</sup> and point to the importance of warning labels adapted to different educational levels, languages, and contexts<sup>11</sup>.

The adolescents in this study indicate that they feel able to perform the HIVST on their own, with gains in privacy, similar to other studies<sup>13,15</sup>. Because the HIVST prevents compromise of confidentiality, adolescents can test themselves more often and, consequently, improve their ability to do test<sup>15</sup>. Although HIVST via finger prick has been shown to be more reliable than via oral fluid, some adolescents report fear of pain or of contact with blood. A cross-sectional study of 18- and 24-year-old TGW and MSM also

found a preference for blood-based HIVST and found no problems with implementation of this strategy in the general population<sup>29</sup>.

Most adolescents in this study appreciated the opportunity to be tested unsupervised, similar to a systematic review and meta-analysis summarizing 25 studies<sup>30</sup>. Some participants believe it’s necessary to supplement HIVST with supervised conventional testing and express fear of a possible reactive outcome. Therefore, it’s emphasized that efforts to provide high-quality counseling and follow-up need to be intensified<sup>12,29</sup>. Similar to a previous study, participants show positive expectations for post-test counseling despite fear of stigmatization in health centers, which may be related to the reputation of the Brazilian program to combat AIDS<sup>30</sup>.

HIVST is perceived by adolescents as a method that would contribute to self-care. It should be noted that self-care in this case may be related to efforts to minimize risks without necessarily involving changes in sexual practices, so the increase in self-care is often not perceived by health professionals who are guided by less specific perspectives. Testing as a prevention strategy has also been contested by some participants because it introduces a rational element of planning into sexual practices that is foreign to their sexual culture. This leads us to consider the importance of discussing the issue of testing and youth culture – a key topic for dialog between peer educators and youth and for further exploration in new studies.

## Conclusions

This study demonstrates that HIVST is a fundamental strategy to enhance adolescent autonomy and self-care. It identifies elements of HIVST acceptability and characteristics of MSM and TGW youth. It describes fear of stigma in health care settings as a factor to consider when implementing HIVST delivery, as HIVST doesn’t require support from health



care professionals. And it highlights elements -of acceptability such as ‘type of test: oral or finger prick’ and ‘purpose of test: diagnosis or prevention’ as central to dialogs aimed at making HIVST more appropriate for youth cultures and, consequently, achieving higher uptake and adherence to testing.

We believe the findings support the current literature on HIV prevention and strengthen the perspective of adolescents from low- and middle-income countries in this literature. As a potential limitation of the study, we note that participants had no prior knowledge of HIVST, so it’s necessary to consider the impact of receiving new information at the time of study.

The good acceptability of HIVST underscores the relevance of its delivery in the SUS,

accompanied by culturally sensitive and appropriate strategies for the target population, as well as the continuity of public policies aimed at addressing the stigmatization of these social groups.

## Collaborators

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