



# Visions, voices, and priorities\*



## YOUNG PEOPLE TALK ABOUT SELF-TESTING FOR HIV

1

**Young people want quality sexual and reproductive health services, from ethical and well-trained health service providers, with services tailored to their needs, rights and desires – especially as young people living with and most affected by HIV.**

Young people identified the benefits of self-testing in avoiding judgmental attitudes, stigma, discrimination and breaches of confidentiality by service providers. While self-testing offers a number of benefits, these issues need to be urgently addressed within HIV and sexual and reproductive health services, to make them safe spaces for all young people to access and utilise. Self-testing is not necessarily an easy fix, and can also introduce complicated risks that must be addressed by health service providers and suppliers.

2

**Young people want to enjoy their sexual and reproductive rights, including the freedom to love and be loved safely.**

Self-testing allows young people to choose when, where and how to test for HIV, and may give them a sense of control over their sexuality and sexual health; for individuals, couples and sex workers, it can be used as a tool to enhance trust, pleasure and well-being in sexual relationships. However, it can also be used inappropriately or to reinforce harmful power imbalances, and a rights-based approach will be required for self-testing to be used effectively and equitably.

3

**Young people want full access to information and education on HIV and sexual and reproductive health and rights (SRHR) including on sexual orientation and gender identity.**

Self-testing should be delivered as part of a comprehensive HIV and SRHR package, with appropriate information on HIV prevention, counselling and treatment, as well as information on STI and pregnancy prevention.

4

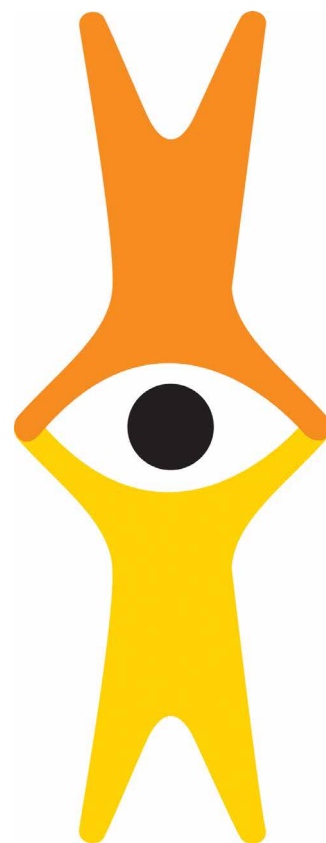
**Young people seek gender equality and to see an end to gender-based violence, including sexual violence, in all its forms, including because of sexual orientation or gender identity.**

There is a potential for self-testing to be used coercively, in order to refuse condom use, or to 'screen' potential partners. Young women and young people most affected by HIV should receive training in rights literacy and life skills to build confidence and agency so that they are able to make their own choices regarding self-testing, as well as the use of male and female condoms for the prevention of HIV, STIs and pregnancy.

5

**Young people, in all their diversity, want to be a meaningful part of the solution, and participate in the decision-making that affects their lives.**

Young people have a key role to play in community education and mobilisation related to self-testing, and are an essential voice in the development of policies and programmes that promote self-testing.



\* The Link Up *Visions, Voices, and Priorities* consultation created a five-point framework for programming and advocacy designed by and for young people living with and most affected by HIV. This issue brief applies the framework to adolescent access to self testing for HIV. See [www.aidsalliance.org/resources/510-report-visions-voices-and-priorities-of-young-people](http://www.aidsalliance.org/resources/510-report-visions-voices-and-priorities-of-young-people)



## Background and introduction

The original *Visions, Voices, and Priorities* report<sup>1</sup> shares the findings of a global consultation carried out by the ATHENA Network and the Global Youth Coalition on HIV and AIDS (GYCA) in partnership with local community-based organisations as part of the Link Up project in 2013. The consultation explored access to and priorities for SRHR for young people living with and most affected by HIV,<sup>2</sup> through an on-line survey and community dialogues involving over 1,200 young people. Near the end of the Link Up project in 2016, three new areas of focus within the HIV and SRHR spheres were identified for further consultation:

- Access to HIV treatment and care among adolescents living with HIV – with attention to adherence and staying in care
- Attitudes toward and perceptions about pre-exposure prophylaxis (PrEP)
- Attitudes toward and perceived benefits and challenges of self-testing for HIV among different key populations and age groups.

In recent years, self-testing has become increasingly accessible across several countries, and more are likely to follow. While self-testing allows individuals to screen for HIV easily and discreetly, regulations and availability vary widely. This series of community dialogues was undertaken to record the perceptions, priorities and concerns of young people living with and most affected by HIV around self-testing and the potential for its use in their communities. Based on the views expressed through these dialogues, this brief highlights the need for the involvement of young people most impacted by HIV in ongoing dialogue, community education, advocacy and research around self-testing.

### METHODOLOGY

Community dialogues on HIV self-testing, designed with and for young people living with and most affected by HIV, took place in Ethiopia, Burundi, Bangladesh, Myanmar and Uganda during April 2016. Young people living with and most affected by HIV led dialogues with other young people in their communities, facilitated using a standard discussion guide. A total of 49 young people took part in the dialogues, including three groups of young men who have sex with men (Bangladesh, Burundi and Myanmar) one group of young women who sell sex (Burundi), and one group of young people and adolescents living with HIV (Uganda). The results of the dialogue were validated in a meeting in Yangon, Myanmar in June 2016, and further validated among participants virtually in July 2016.

Each community dialogue was facilitated using a discussion guide, which included a set of key questions and a definition of self-testing (see box). The questions were designed to facilitate discussion and to explore knowledge and attitudes about self-testing.

#### WHAT IS HIV SELF TESTING?

HIV self-testing is a method of testing for HIV for person who wants to know his or her HIV status by collecting a small sample of blood, or oral fluid (depending on the type of kit) and performs a test and interprets the result by him or herself, often in private.

Self-testing is an emerging approach that gives the opportunity to test discreetly, at home for instance and for this reason it can be useful to people who may be unable or reluctant to use the more traditional ways of testing for HIV. It may also be useful to people who need to retest frequently.

In some countries, HIV self-testing is becoming increasingly available, both informally and in a regulated manner. It is important to remember that HIV self-testing does not provide a definitive HIV diagnosis. HIV positive status need to be confirmed using a test in a clinic.

1. *HIV and sexual and reproductive health and rights: visions, voices, and priorities of young people living with and most affected by HIV*. Available at: [www.aidsalliance.org/resources/510-report-visions-voices-and-priorities-of-young-people](http://www.aidsalliance.org/resources/510-report-visions-voices-and-priorities-of-young-people)

2. In this case, "most affected" refers to young people at elevated risk of HIV exposure such as young women, young people who sell sex, young people who identify as lesbian, gay, bisexual, or transgender (LGBT), or young men who have sex with men.



"It is very helpful and I think people like MSM and many who fear about their identity can use it and get an instant result."

YOUNG MAN WHO HAS SEX WITH MEN, BANGLADESH

# Key findings

Participants in dialogues on self-testing described a range of opportunities and benefits offered by self-testing.

## CONVENIENCE

Many of the responses cited convenience, speed and cost effectiveness as some of the benefits of self-testing. Participants remarked on the challenges they face reaching clinics for testing and other sexual and reproductive health services. Lack of transportation was compounded by the choice to travel to more distant health clinics where participants were less likely to be recognised. In addition to the inconvenience of traveling, long wait times can translate to lost wages and childcare can be difficult to secure. Utilising self-testing was seen as a way to save time, effort and money by participants.

**“It is cost effective and can be done at anytime. It also reduces [exposure to] stigma and discrimination as it encourages confidentiality of information.”**

ADOLESCENT MAN LIVING WITH HIV, UGANDA

**“It’s easier to self-test than to go to the testing centre, which can be far away, or you don’t have the time and then you forget.”**

YOUNG WOMAN WHO SELLS SEX, BURUNDI

## PRIVACY AND CONFIDENTIALITY

The assurance of privacy and confidentiality was also perceived as an important benefit of self-testing. As cited in the original *Visions, Voices, and Priorities* report and confirmed in these dialogues, lack of confidentiality is a consistently significant risk when accessing HIV testing or other sexual and reproductive health services. Many clinic facilities are not designed to ensure private information disclosure, allowing sensitive information to easily be overheard by others. In some cases health service providers themselves violate patients’ rights to confidentiality, openly announcing test results or sharing them with family members or friends without the patient’s consent. With self-testing, the results of the test and the choice whether and when to disclose belongs entirely to the person testing.

**“At home we can use it and keep it secret”**

YOUNG MAN WHO HAS SEX WITH MEN, BANGLADESH

**“The service providers discriminate [MSM] and say why did you come here, you are just a young boy.”**

YOUNG MAN WHO HAS SEX WITH MEN, BANGLADESH

For young LGBT people and young people who sell sex, self-testing was seen as appealing because they could avoid being exposed in a health service facility. If a young person is seen as being a member of a marginalised or discriminated against group, often he or she will face discrimination or judgmental attitudes from health service providers and other members of the community. Health service providers can ask personal or identifying questions that are difficult or embarrassing to answer, or might expose a young person as being a member of a group that is discriminated against. Avoiding a trip to a health service facility can protect a young person from potential discrimination, violence and mistreatment.

**“If I had the self-testing kit I would test myself often without having to talk about my sexuality to strangers who sometimes judge you.”**

YOUNG WOMAN WHO SELLS SEX, BURUNDI

## INCREASED WELL-BEING AND PERCEIVED SAFETY IN HAVING SEX WITHOUT A CONDOM

Some participants felt that self-testing had the potential to increase well-being and safety between intimate partners and between sex workers and their clients. They saw self-testing as a way to enable a safer work environment for sex workers who could ask their clients to test before having sex without a condom, or to allow intimate partners to have sex without condoms.

**“It’s good for everyone especially couples who don’t want to use a condom, or who want to stop [using condoms].”**

YOUNG WOMAN WHO SELLS SEX, BURUNDI



**“Yes, [I would use it] because of the convenience, and also it will lower the ‘ugly’ moment of waiting at the health centre.”**

YOUNG PERSON, ETHIOPIA



**“I would be certain of the confidentiality of my test results because I would be the only one to see them.”**

YOUNG WOMAN WHO SELLS SEX, BURUNDI



**“It would enable [us] to test our clients if they want sex without a condom and once the customer [knows] that you are HIV negative, he will trust you and will be able to return often and without fear and you earn more money. I think the self-test is a good idea for sex workers for their health and for their work “**

YOUNG WOMAN WHO SELLS SEX, BURUNDI



**“For young MSM I know they are very sexually active, so they need to test often. It’s a question of individual will and of way of life.”**

YOUNG MAN WHO HAS SEX WITH MEN, BURUNDI



“The counselling given at the beginning of [HIV] testing helps a lot.

People often lose hope in life once they are told they are HIV positive. When the test comes back positive [the counsellor] knows how to handle the situation and put the individual in perspective.”

YOUNG PERSON, ETHIOPIA



“I would use it to test my clients who don't want to use a condom.”

YOUNG WOMAN WHO SELLS SEX, BURUNDI



“Some fail to interpret results. The testing kit

can fail to react and this can only be interpreted by experienced health workers.”

YOUNG WOMAN LIVING WITH HIV, UGANDA



“People can use it with bad intentions, e.g. if a husband or

wife thinks their partner is cheating it's easy to test them secretly which would be against their will, or maybe couples can do the test together and then it's not guaranteed that the results will remain confidential.”

YOUNG MAN WHO HAS SEX WITH MEN, BURUNDI

## INCREASED FREQUENCY AND AVAILABILITY OF TESTING

Some participants saw the option of self-testing as particularly relevant for people who may want to be tested frequently, but are not because of the challenges of accessing services. For example, young people who have multiple sexual partners, sell sex, or are otherwise at elevated risk of HIV exposure might benefit from frequent and convenient testing.

Participants also described a number of potential challenges that might be posed by making self-testing available to young people from key populations, and barriers to access and uptake.

## LACK OF COUNSELLING AND SUPPORT

Lack of counselling and support in connection with self-testing was raised most often as a concern – particularly since pre- and post-test counselling is typically seen as an integral part of HIV testing. Participants cited concerns regarding the emotional fallout that can accompany a positive result, and fears that indication of an HIV-positive result might leave the person who self-tested feeling isolated, depressed or at risk of self harm.

“I wouldn't use it ... if I find I am HIV positive I risk getting depressed and committing suicide, so I'd rather do the classic test with a counsellor there to counsel, support and accompany me.”

YOUNG MAN WHO HAS SEX WITH MEN, BURUNDI

“With pregnancy test one has the option of abortion, but with a self-test many when they get the positive results they think it's the end of life and think of committing suicide.”

ADOLESCENT MAN LIVING WITH HIV, UGANDA

## RELIABILITY

Some participants expressed concerns about challenges in actually using self-test kits accurately and appropriately. These included self-testing kit failure, misinterpretation of results, or the possibility of false kits being produced to make money from self-testers who may not be able to tell the difference.

“There's an issue about real kit and false kit. If we get it from local market, a group of bad people will make and distribute false kits.”

YOUNG MAN WHO HAS SEX WITH MEN, BANGLADESH

## TESTING (WITH) OTHERS

Participants described scenarios in which the kit could be used to test others without their knowledge, including partners or clients, or coerce others into testing against their will. This also compromises the confidentiality of individuals who test with others. In a context of gender inequality and high prevalence of intimate partner violence – including in association with HIV disclosure – this scenario also poses physical and emotional risks, especially for young women.

Others described concerns which are familiar from other biomedical innovations such as the contraceptive pill or HIV pre-exposure prophylaxis (PrEP): that self-testing would create a sense of permissiveness or false protection that would lead to an increase in unprotected sex or number of sexual partners.

“When self-testing is available young people will test themselves and their partners and if they are both HIV negative they will have more unprotected sex and more STIs and unintended pregnancies.”

YOUNG WOMAN WHO SELLS SEX, BURUNDI

# LINKUP

Link Up has improved the sexual and reproductive health and rights (SRHR) of almost 940,000 young people affected by HIV across five countries in Africa and Asia. The project is being implemented by a consortium of partners led by the International HIV/AIDS Alliance. For more information visit: [www.aidsalliance.org/linkup](http://www.aidsalliance.org/linkup)

Special thanks to our country partners who led the dialogues: **Bangladesh:** Rokonol Rabbi (GYCA) and Moly Farhana (ATHENA Network). **Burundi:** Cédric Nininahazwe and Mona Ndayizeye (HUMURE). **Ethiopia:** Yoadan Workneh Shiferaw and Akililu Guulay (Talent Youth Association); Hanna Hagos (Nikat Charitable Association). **Myanmar:** Chan Aye San, Ei Mon Kyaw, Moe Kyaw and Myo Thet Oo, (Myanmar Youth Stars). **Uganda:** Allen Kyendikuwa, Mariam Nassaka and Charles Bwire (Uganda Youth Coalition on Adolescent SRHR and HIV (CYSRA-Uganda)); Brian Ssensalire, Stanley Nsubuga and Resty Nalwanga, (Uganda Network of Young People Living With HIV (UNYPA)).  
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