HIV SELF-TESTING: KEY QUESTIONS, ANSWERS AND MESSAGES FOR COMMUNITY ORGANIZATIONS

What is self-testing?

HIV self-testing is a process in which a person collects his or her own specimen (either oral fluid, sometimes called saliva, or else blood from a finger prick), then performs a rapid HIV test and interprets the result. If the result is positive, the person seeks retesting at a facility to confirm this result or not. If the result of the self-test is negative, no further action is required unless the person has had a recent likely HIV exposure or faces high ongoing risk of HIV infection. In those cases, later repeat testing should be considered.

Some people may want to perform the self-test alone, in private – at home, perhaps. Others may want to use the self-test with a person they trust, such as a friend or sexual partner, or while waiting to be seen in a health facility.

The World Health Organization (WHO) recommends HIV self-testing as an additional approach for delivering HIV testing services and as a safe and effective way to increase access to and uptake of HIV testing services. The rapid HIV tests used for self-testing detect HIV antibodies, which are produced by a person’s body when he or she acquires an HIV infection. HIV antibodies are present in many body fluids including oral fluid, blood, urine and breast milk. (Although HIV antibodies are present in oral fluid if someone has HIV, HIV cannot be transmitted through oral fluid/saliva.)

WHO recommends HIV self-testing as a means to increase uptake of HIV testing.

Why is self-testing being offered and promoted?

Although many people have been tested for HIV in health clinics and community settings, an estimated 30% of people with HIV do not know their HIV status and, therefore, are not obtaining treatment. Self-testing is a new way for people to learn their HIV status and, if confirmed HIV-positive, obtain treatment and prevention services.

Self-tests are accurate – as accurate as many tests used in facilities. They also are easy for most people to perform, and they allow people to test when and where they want. Many people find HIV self-testing empowering and convenient. Others, however, prefer to seek testing from a trained health worker or peer educator. HIV self-testing does not replace these other options. Instead, it provides an additional choice.

Why are communities important to making HIV self-testing safe, acceptable and effective?

HIV self-testing is becoming much more widely available. Programmes are starting in a number of countries. As of July 2018, more than 40 countries report having policies to allow self-testing, many of which are now implementing self-testing programmes to some degree. (For the
HIV self-tests are also available to purchase through the Internet in most countries and in pharmacies in many countries – although these test kits may not be regulated or of high quality. Aware of this, community organizations can encourage the use of quality self-tests that have been approved for use in their countries.

As self-testing becomes more available, it is important for communities to know about HIV self-testing. Community organizations engaged in HIV prevention and care, including faith-based organizations, want to become familiar with this testing option and decide how best to support it.

Some community organizations, particularly in sub-Saharan Africa, have accumulated a great deal of experience and expertise with integrating HIV self-testing into outreach services, as well as into demand creation for HIV treatment and prevention. Community-led implementation has been particularly successful at increasing uptake of HIV self-testing among first-time testers and populations with low testing coverage, including men, adolescents and young people, couples and key populations. Community-led support for HIV self-testing has been especially useful to reach young people, including adolescents, and in rural areas, where literacy may be low.

Community organizations can play a variety of important roles in support of self-testing. It is critical, at a minimum, that community organizations deliver accurate messages to the community about HIV self-testing so that all people can understand and learn how to use this approach. Also, community organizations often have extensive reach and influence. Thus, they can shape community norms to support self-testing and encourage its appropriate use.

Another important role for community organizations include distributing HIV self-test kits and providing information, support and counselling to people who are considering self-testing and who have tested themselves. Those who obtain negative results need information and help with HIV prevention options. For those with positive self-test results, community organizations can underscore that further testing at a clinic is critical and can explain how and where to get further testing and treatment.

Community organizations also can provide demonstrations of how to use HIV self-test kits and support people who find them difficult to use or need help interpreting their results. Video demonstrations also can help. The link https://aidsfree.usaid.gov/resources/hts-kb/ provides tools to support HIV self-testing, including videos that can be adapted and used to help deliver and promote self-testing.

What types of tests are available?

At this time most self-tests use oral fluid. A person swipes a mouth swab across the upper and lower gums in the mouth to collect oral fluid, puts the swab into a test tube and a few minutes later sees the result.

Self-tests, that test blood from a finger prick, are also available in some countries and will become more available in the next few years. These tests come with simple retractable lancets to collect the blood. Some people who want to self-test will prefer an oral test, while other will prefer a blood test. It is ideal for programmes and countries to provide both options to suit the preferences of potential users.

Which self-test kits should be used?

The HIV self-test kit used in a country should be one approved for use based on national standards. To assure high quality, it is best in resource-limited settings to use self-test kits that WHO has prequalified (that is, reviewed and found to be of high quality). Small-scale implementations and pilot projects also can buy products approved for procurement through the Global Fund. Details on these products are available at:


For sales in the private sector, some countries recognize regulatory approvals acknowledged by the International Medical Device Regulators Forum, such as those of the United States of America’s Food and Drug Administration, Europe’s Certificate of European Conformity (CE) and Australia’s Therapeutic Goods Administration (TGA).

In some countries unregulated self-test kits are available in private pharmacies or through the Internet. The quality of these tests is unknown. Because they are not quality-assured, they may not give reliable or correct results. Thus, it is critical for community organizations to alert people to use only products that have the appropriate national approvals.

Community organizations can significantly shape norms to support self-testing and its appropriate use.
and show the labels and markings of approved products according to the national system. Any product without such markings should be reported to the national regulatory authorities and to WHO using the complaint reporting system: [http://www.who.int/diagnostics_laboratory/procurement/111121_user_complaint_form_for_adverse_events_and_product_problems_reporting_english.pdf?ua=1](http://www.who.int/diagnostics_laboratory/procurement/111121_user_complaint_form_for_adverse_events_and_product_problems_reporting_english.pdf?ua=1)

What are the key messages for anyone who takes an HIV self-test?

Delivering the following messages is an important role for community organizations, including communities of faith and faith leaders, working together with health-care providers.

1. **If the self-test is “reactive” (that is, positive),** a person must always go to a clinic or community testing site for further testing to confirm the result. A self-test alone does not provide a conclusive positive diagnosis. When people who have a positive self-test result go to a testing facility, they should be tested according to the country’s national testing strategy and algorithm (starting with the first test in the algorithm). If retesting confirms the positive self-test result, a health-care provider will link the person to standard treatment, care, counselling and support.

2. **If the test is “non-reactive” (that is, negative),** the person does not have HIV. However, if a person reporting frequent possible exposures to HIV, it is important to give them information and referrals to specific prevention services and to give them condoms, if they want them, in addition to recommending that they retest in six months. Also, a person who reports potential exposure to HIV in the past six weeks should be encouraged to test again after three months.

3. **How soon should someone test after a potential HIV exposure?** HIV self-test kits detect HIV antibodies, which develop in the weeks after acquiring HIV infection. As with any form of HIV testing, a self-test will not detect these and be positive for at least six weeks after an HIV exposure. Therefore, people should be advised to self-test three months after a potential HIV exposure to be sure that the result is accurate.

4. **Not everyone has to self-test.** Someone who cannot perform the self-test or is having difficulty can visit a local clinic, testing centre or community HIV support group that can help them. For those who prefer self-testing, demonstrations and tools, such as video links and telephone hotlines, can support them. Talking with a community member who has self-tested also can help.

5. **A person who has HIV and is taking antiretroviral therapy should not use a self-test kit. It might give a false negative result.** Someone on antiretroviral therapy may have a very low number of HIV antibodies. Since the tests look for these antibodies, an HIV-positive person taking antiretroviral therapy can get a false negative HIV test result. Some people taking antiretroviral therapy may self-test, for a variety of reasons. Some people with HIV may think that they may have been cured and can stop treatment. Some may want to check how they are doing on treatment, confusing the self-test with a viral load test, which can indicate the success of treatment. Others may question whether they have HIV despite having been previously diagnosed with HIV and being on ART.

Because people with HIV who are on ART may have a false negative self-test result, it is important to advise them not to use self-tests. If they want to retest, they should discuss this with a health-care worker who can advise what to do. For example, the health worker may offer a viral load test. They should understand that HIV does not have a cure, but an undetectable viral load shows that they are healthy and their treatment is working well.

If a person with HIV on treatment does perform a self-test and the result is negative, she or he must be advised to continue HIV treatment without interruption and to talk to a provider or counsellor.

A person who self-tests positive always should go to a facility for further testing.

A person who takes pre-exposure prophylaxis (PrEP) to prevent HIV acquisition may want to self-test in addition to HIV testing at a facility every three months. Community organizations can encourage and support people using PrEP to retest periodically and also to advise that self-testing cannot replace quarterly retesting during facility visits.

[Photo: Albin Hillert/WCC]

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[Photo: Albin Hillert/WCC]
Should people offer self-tests to others?

Offering a self-test kit and encouraging a sexual partner, friend or adult family member to self-test is often a great way to help people learn their HIV status. But it is important that people never force someone else to take a self-test or pressure them unduly if they do not want to self-test. The decision to take an HIV test is always a personal decision. WHO never supports forced or compulsory testing.

Should parents or guardians test their babies or children?

WHO does not recommend parents or guardians use HIV self-tests to test their babies or children. HIV self-tests will not provide correct results in children under two years because the mother’s antibodies may still be present in the child.

It is critical that children with HIV are linked as soon as possible to a clinic where they can receive further testing and treatment. If a parent or guardian has concerns that a child in their care may have been exposed to HIV, they should consult a health worker. It is always recommended that mothers, particularly those who have HIV, seek testing for babies soon after birth and have further testing according to national policies with final testing once the breastfeeding period has ended. A specifically trained health or community worker should conduct the testing.

Should HIV self-testing be available for adolescents?

Most countries have policies stating the age at which adolescents can access HIV testing without the consent of parents. While this varies by country, it is common for the age of consent to be around 15 or 16 years.

Self-testing has been popular with adolescents, who otherwise have been slow to access HIV testing.

Self-testing programmes for adolescents have been very popular and successful, reaching adolescents who do not seek testing through clinics and other testing sites. Because access and uptake remain low in these age groups, it is important to make this option available to higher-risk young people. Through their existing outreach and services, community-based organizations, and faith-based organizations in particular, may be well positioned to help young people and also provide follow-on support.

Can HIV self-testing be harmful?

There are many benefits to self-testing. Millions of people have used HIV self-testing without harm such as suicide or intimate partner violence. Many users report self-testing has enabled them to obtain HIV treatment or that learning they do not have HIV helped them to make choices about HIV prevention. There have been no indications that people increase risky behaviours after a negative self-test result.

Despite the many benefits, it is important community organizations provide messages, training and advocacy to mitigate any potential for harm, such as people with HIV testing while on treatment and discontinuing treatment, coercion or partner violence. Systems in the community to identify and respond to any harm are important. Community organisations can also continue to play a role in counselling people who have an HIV-positive test result and encouraging them to link to treatment and counselling people with a negative result about HIV prevention.

Learning that you have HIV is never easy. But having HIV, and not knowing that you do, keeps you from treatment that can help you live a long and healthy life. HIV testing offers the opportunity to know your HIV status and, if HIV-positive, to start treatment as soon as possible. Self-testing is an easy, quick and private way to learn one’s HIV status that many people will prefer.

RESOURCES


HIV self-testing research and policy hub: www.hivst.org

AIDSfree HIV testing services knowledge base: https://aidsfree.usaid.gov/resources/hts-kb/


WHO user compliant form for reporting problems and/or adverse events to diagnostic products: http://www.who.int/diagnostics_laboratory/procurement/111121_user_complaint_form_for_adverse_events_and_product_problems_reporting_english.pdf?ua=1

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Q&A

HIV TESTING SERVICES