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'The earlier you go, the longer you live': HIV self-testing in South Africa

In a country where people with HIV suffer hugely from discrimination, the privacy afforded by self-testing is having a positive impact on rates of diagnosis and treatment

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Rebecca Ratcliffe in Johannesburg

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David* is perched on a stool, staring at the table in front of him. On it, a small testing stick stands in a cylinder of liquid.

“I’ve never tested before, so I thought I should,” he says.

David is sitting in a blue tent, in the middle of a busy shopping centre in Johannesburg. A kitchen timer, tied to the side of the tent, shows there are five more minutes to go. Soon, either one or two lines will appear. Two lines would indicate he may be HIV-positive, one that he is virus free.

There is no clinician present because David is using a self-screening kit. It takes 20 minutes, requires only an oral sample and is more than 90% accurate at identifying an HIV-positive result. Experts hope it could transform testing for the virus, increasing the number of people

who know their status. Screening yourself for HIV, it is predicted, will become as normal as a doing a pregnancy test.

As David waits, Mokgadi Mabuela, a counsellor, is handing kits to passersby amid the lunchtime rush in Hillbrow, a deprived and bustling area of the city. “You can either do it here [in a private tent] or take the test home,” she tells a group of men. “Inside [the kit], you find your stand [for the cylinder of liquid], the liquid and testing pen.”

The testing pen has to be swiped across the gums and left in the liquid, she explains.

“Usually we give out 300 kits in one day,” says Mabuela. David, who is 33 and from Zimbabwe, is exactly the kind of person counsellors want to reach. “It hadn’t come into my mind [to get tested],” he says, adding that his girlfriend, who is younger, had a test that came back negative after she recently fell pregnant.

It is not uncommon for Mabuela to encounter people taking their first test. Often, they suspect they are positive but don’t feel ready to find out, she says. “They are just scared to know. It’s just the thing of knowing you could be positive that’s quite scary,” she says. “Especially in a place like Hillbrow where you have your brothels, strip clubs and everything. The discrimination that comes with having HIV is still a huge thing.”

According to government figures, 86% of South Africans know their status. It is hoped self-testing could help the country reach the 90% target set by the UN. About 2.2m kits are being distributed in target areas as part of the HIV self-testing Africa (Star) initiative, a five-year project funded by the Unitaid, a global health organisation that works in six countries across southern Africa. If successful, it is hoped the government or other donors will put up funding to enable self-screening to be offered countrywide.

“Within the next five years this will be really normal,” says Karin Hatzold, director of the Star initiative and director for HIV services at Population Services International, which is implementing the project. Clinics will still offer confirmative testing, she adds, but most people will do an initial test at home. “Zimbabwe, Malawi and Zambia are already a step ahead starting the national roll out,” says Hatzold.

There are plenty of reasons for the growing popularity of self-testing: it is convenient, private and relieves the burden on overstretched clinics. To get a test at a health facility, people are expected to queue for hours, and the stigma attached to HIV means many worry about being seen by friends or neighbours.

“When you get there with all of the anxiety, you’re like number 20 in the queue. You see people walking down the corridors of the facility and others coming out crying,” says Vuyokazi Gonyela, deputy general secretary of Treatment Action Campaign, a civil society group. Many non-South Africans are reluctant to use clinics because they face discrimination by medical staff.

Gonyela welcomes self-testing, but says it must be accompanied by quality counselling. “It has to come in the form of a package. There needs to be education and understanding of what it means,” she says. “We need to be mindful of the psychological state that we put our people into, because this then challenges the extent to which we are able to unpack our treatment, care and support programme.”

Fears that leaving people to test on their own, may lead to self-harm or domestic violence have so far proved unfounded.

To prevent gender-based violence or coercive testing, men are not allowed to take home an extra kit for their partner - although women can do so.



A woman in Hillbrow listens intently as the benefits of HIV self-testing are explained to her. Photograph: Mujahid Safodien/AFP/Getty Images

In Hillbrow, Elizabeth takes a kit for herself and her boyfriend. They talk openly about HIV and test regularly, but she says some men don't like being told to test. "You know how men are, they are very difficult. The ones who are head of the house, they want to be the ones who are bringing decisions. In his mind, he will be thinking, 'OK, maybe this girl has been doing something outside, now she's got a guilty conscience, she wants to force me to go and test."

People who take a self-screening kit in Hillbrow are required to give their details to counsellors first, and are given advice on what to do with their result. Inside, there's a referral sheet with a list of clinics, a card that can be presented to a nurse, and a phone number for Mpumelelo Sibanda, the self-screening site coordinator.

"I get a lot of calls," says Sibanda. "People text me on WhatsApp saying, 'I need to speak to you now' ... People are in a state of panic, so they want to be seen soon."

Normally, says Sibanda, people who have tested positive can be seen the next day. They will be given a confirmative test and - if they are ready - can start antiretroviral treatment.

Ensuring patients are linked to care, and that they stay on treatment, is a struggle for South Africa as it aims to hit the ambitious targets set by the UN. These targets state that, by 2020, 90% of people living with HIV should be diagnosed, 90% of diagnosed people should be put on antiretrovirals, and 90% of people on treatment should have a fully suppressed viral load - the measure of successful treatment. In South Africa, these figures currently stand at 86%, 65% and 85%.

The government has massively expanded access to treatment, and there are now 3.7 million people on antiretroviral treatment. Gonyela, however, worries that chasing numbers could lead to a decline in quality care. Many people already drop out of treatment programmes, with the reasons ranging from side effects to practical issues, such as not being able to take time off work to queue at the clinic.

Regardless of how people test, improving the quality of education and guidance across South Africa's clinics is essential, says Gonyela.

"People get tired [of taking treatment], that's a reality," she says. "But if you get quality information, you can tell that it doesn't matter how many times you get tired in a year - the minute you decide to stay away from your medication, that's the minute you're giving HIV the

opportunity to rise above your CD4. That's the type of information that people really want to understand."

The 20 minutes are up on David's test. He holds out the testing stick and two lines appear: he is likely to be HIV positive. "I'm OK, I'm OK," he says. A counsellor comes over and advises that he now needs to take a confirmatory test. If this is also positive, he can start antiretroviral treatment.

Lewis, who decides to take his kit home, says attitudes towards testing and treatment are changing. "People [taking treatment] are living longer than those who don't report. [Communities] know people who passed away because they kept it secret.

"Now they see, the earlier you go, the longer you are going to live. People are not shy, they go get their treatment," he says. "They know the more they keep quiet, the more HIV attacks them."

** Some names have been changed*

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