The Art of Privacy in the Quest for HIV Eradication

The Art of Privacy in the Quest for HIV Eradication: How Self-Testing Can Change the Course of the Epidemic

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At the onset of the HIV epidemic, when a patient discovered he was positive ? likely via a diagnosis of full-blown AIDS ? he often had mere months to live. They were painful months, with a range of opportunistic infections, healthcare workers who felt helpless, and a fear that was overwhelming for both patient and physician.

Now, in 2018, anti-retroviral therapy offers that patient a normal, healthy lifespan.

But there?s a barrier to becoming that healthy HIV-positive person on treatment ? you have to actually know your status.

By blood draw or oral swab, it?s not *finding where* to get tested for HIV that?s terribly difficult. Community-based clinics, emergency departments in hospitals, via your own physician ? over time, the tests have gotten easier to give, easier to take, and easier to interpret.

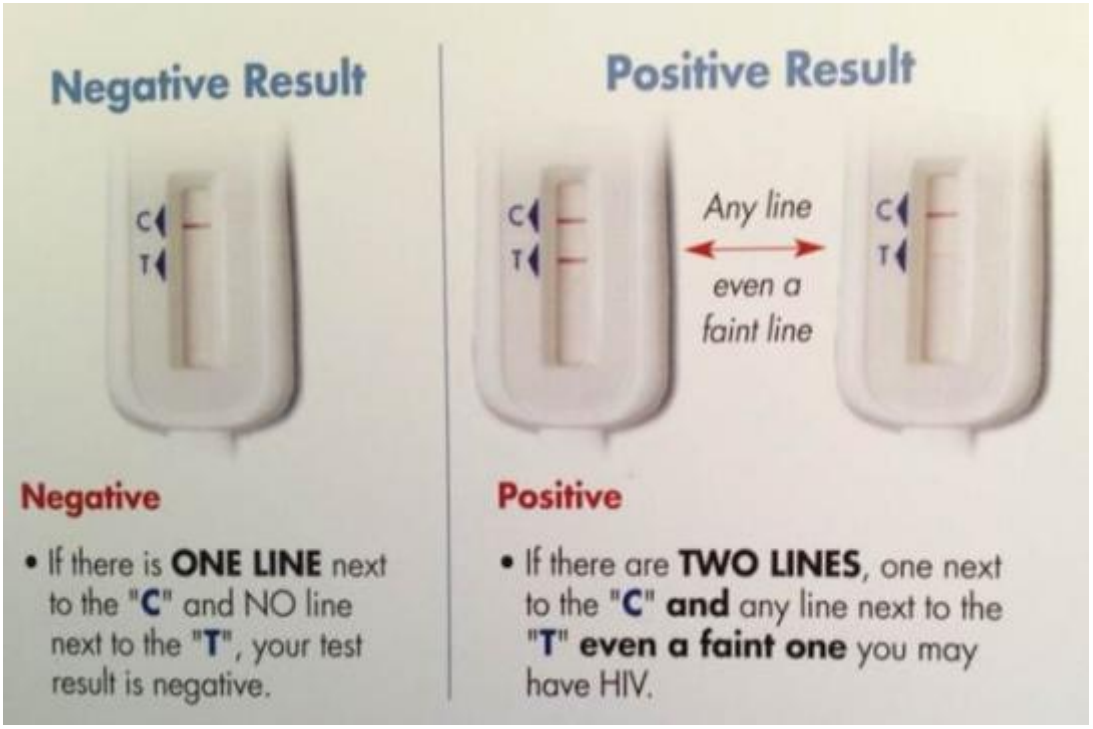
It wasn?t until recently, though, that you could add ?my home? to the list of places where one could test for the virus. Approved by the FDA in 2012, it was slow to gain mainstream popularity (or recognition), but the story of self-testing evolved ? it?s easy to do, by taking a drop of blood from your finger or swabbing your gums, with results that appear in minutes.

The ?at home? is the key, say experts, and it?s starting to be understood why that is. HIVST can be especially effective among key populations for whom HIV stigma is high and privacy is essential ? and therefore, clinic testing is avoided, positive diagnoses go undetected, and treatment is stalled. These ?key pops? ? which includes men who have sex with men (MSM), communities of color, sex workers, and others ? experience multiple layers of stigma related to their behavior and how they are classified (i.e., as a sex worker), in addition to the possibility of being HIV-positive.

Exemplifying this, ?pre-test counseling can actually be a barrier to care,? says UCSF Center for AIDS Prevention Studies researcher Dr. Sheri Lippman. ?People don?t want to get [to a clinic] and get lectured, or be judged for their sexual preferences or behaviors.?

Domestic interventions had proved this ? a study led by UCSF researchers Dr. Marguerita Lightfoot, Lippman, and colleagues, indicated that African-American and Latino MSM who accessed HIVST kits were more likely to actually test, more likely to be HIV-positive, and

more likely to be HIV+ even if their last test was negative, compared to those who screened for HIV through a local public health targeted testing program.



OraSure's OraQuick Rapid Antibody Test

For Dr. Lippman, who works extensively in South Africa, the next question was whether it would work among MSM in South Africa. And with results being published in the March 1 issue of JAIDS [1], the answer was a resounding yes.

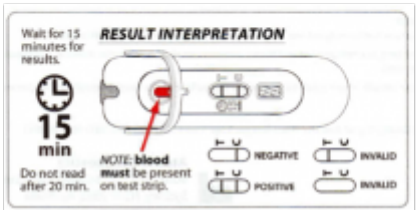
Working with ANOVA [2], a comprehensive HIV/AIDS capacity building, education, research, and advocacy organization based in South Africa ? and with a UCSF co-investigator, Dr. Tim Lane ? Lippman and colleagues were able to reach 127 HIV-negative MSM who subsequently self-tested for the virus. ANOVA does remarkable empowerment work among vulnerable key populations, and with self-testing being a keystone of empowerment, the projects dovetailed nicely.

They enrolled in a longitudinal study that included being given 9 self-test kits (blood fingerstick kits from Atomo [3] Diagnostics, and OraQuick [4], the most widely distributed oral swab test from Ora-Sure), and taking 3- and 6- month post-enrollment surveys that queried participants about their experiences, preferences, and utilization of the HIVST. These men were also able to take test kits back to their communities, to friends, partners, and family ? who were not participating in the study.

Remarkably, ninety-one percent of participants self-tested ? even more importantly, all participants who self-tested reported being likely to self-test again, with over 80% preferring HIVST to clinic-based testing.

The power of these networks was evident in that returning participants distributed 728 tests to sexual partners (18.5% of kits), friends (51.6%), and family (29.8%) ? surprisingly positive findings, as they include a cache of men who may otherwise not have been tested, but also indicates greater acceptance of HIV screening and status among friends and family for MSM.

?People literally showed up at the office asking for more,? Lippman noted, which highlights not only the privacy factor, but convenience factor. ?Can you imagine, especially in a place like South Africa, where it?s a four hour wait, and you?re sitting in a clinic all day ? when all you need is a quick blood draw or swab of the gums??



AtomoRapid HIV Test

Perhaps the most important finding of all? At the start of the study, 37.8% of men indicated they tested semi-annually ? by the end, 84.5% noted they were testing twice a year. And *all the men* participating noted they would test twice in the coming year (which is the recommendation of HIV experts) if HIVST were available, compared with 84% if only clinic-testing were available in the coming year.

Lippman?s work is unique for a few reasons. Earlier HIVST studies have stalled over concerns about participants being given self-test kits without other support mechanisms, or only allowing HIVST use with a counselor present. Researchers have historically been worried about a couple specific social harms ? mainly, the individual perhaps not being able to handle positive results if alone and absent the support of a counselor, and the individual not doing a follow-up confirmatory test at a healthcare facility (which all HIVST underscore as the essential next step).

But these concerns proved to be unwarranted. ?We had an incredible response,? says Lippman. ?Virtually everyone wanted to do it.? Self-testers were given phone numbers of counselors to call if needed, and encouraged to choose supportive friends or family to be present while testing.

Frankly, says Lippman, this makes a lot of sense ? ?testing with someone you care about, instead of sitting in a cold clinic room with someone you don?t know is much more appealing. Populations that don?t want to test in clinics may still want to test themselves ? and they should have that option.?

An especially surprising finding was that most participants preferred the blood tests over the oral swabs ? to the tune of 2:1, and despite what one may assume about the ease and painless nature of a swab. Dr. Lippman thinks this is a nod to the understanding of HIV being

a disease of the blood ? and though the swabs are nearly equal in their accuracy, many participants have more trust in the blood tests.

Making no difference to the study team which test the participants used, the only problem that arose from this was that not only did participants prefer the blood tests, they were blowing through them almost faster than they could be distributed.

?The only real social harm we discovered,? Lippman admitted with a laugh, ?was the pressure participants were getting from their community to get more tests.?

The bottom line, Lippman explains, is making self-test kits easy to get so patients can perform them when and where they?re ready. ?They really need to be accessible and discrete.?

This includes among heterosexual couples and networks, and it led Lippman and colleagues at UNC and the University of the Witwatersrand to the next study question ? whether or not distributing self-test kits to young women ? who are at an elevated risk for infection, accounting for 25% [5] of new infections in the South Africa ? may be a good way to get their male partners tested. Men are far less likely to utilize traditional healthcare services (they do so at a quarter the rate of women, notes Lippman), but they still represent a high burden of new infections ? particularly in South Africa, which battles a national HIV prevalence [5] of nearly 1 in 5 adults. Getting men tested and linked to care if positive, while linked to prevention strategies if negative, is essential.

Might young women offering tests to their male partners at home increase the testing rate, thereby decreasing the incidence and prevalence? Lippman hopes so. Those results will be revealed next month at CROI 2018 *(?HIV Self-testing increases testing in young South African women: Results of an RCT?*).

Getting tests out to those who need them remains the biggest challenge, and while things are moving, they?re moving slowly. The South African government hasn?t yet finalized official programming for HIVST, though they have issued a policy guidance brief [6] and over-the-counter sales have been legalized. An agreement [7] between OraSure [8] and the Gates Foundation [9] has assured OraQuick tests will be available in a few sub-Saharan countries at significantly reduced prices. Getting WHO approved pre-qualified fingerstick tests and into the market with reliable distribution is the next step.

?The real barrier is access,? Dr. Lippman emphasizes.

?Most people who don?t test ? but want to ? are worried about confidentiality, privacy, and facing logistical barriers in [getting to a clinic]. Fear of a positive result may be there no matter what, so we should make everything else as easy as possible. Putting tools in the hands of the user is an incredibly powerful thing.?

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Links
[1] https://www.ncbi.nlm.nih.gov/pubmed/29210826
[2] http://www.anovahealth.co.za/about/
[3] http://atomodiagnostics.com/products/atomo-hiv-self-test/
[4] http://www.oraquick.com/
[5] https://www.avert.org/professionals/hiv-around-world/sub-saharan-africa/south-africa
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