

Moments of Uncertainty

Exploring How an App-Based Oral HIV Self-Testing Strategy Fits in Communities ‘Living Under’ HIV Risk

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Received: 30 July 2020; Accepted: 19 March 2021; Published: 3 November 2021

Abstract

Feasibility and acceptability research for HIV self-testing (HIVST) often emphasises the importance of good test conduct and correct test interpretation for knowing one’s HIV result while overlooking the ways in which different uncertainties and meanings emerge around testing. Using empirical examples from a quantitative study assessing an app-based strategy in Cape Town, South Africa, this research article explores the practice of HIVST and how people deal with uncertainties while using the app in question, named ‘HIVSmart!’. We use the concept of ‘living under’ to explore the practices of HIV testing for those who fit the definition of being ‘at risk’ of HIV (note that an individual’s HIV status must be unknown in order for them to fit this definition) and to understand how an app-based HIVST strategy fits within these practices. We show how the app and oral self-test—as well as knowledge around HIV risk behaviours, comparisons between different testing methods, and the guidance and presence of healthcare staff—alleviate as well as generate uncertainty and constitute HIV status as an ongoing process. The effective implementation of new strategies for HIVST requires consideration of multiple aspects of the testing process, including local understandings of HIV risk, access to healthcare staff, and the meaning of certain test methods within a particular context.

Keywords

Digital health, Self-testing, Diagnostics, Screening, Care.

Introduction

The World Health Organisation (WHO) recommends HIV self-testing (HIVST) as a way of encouraging more people to find out their HIV status, which, in the case of a positive test, would lead them to seek confirmatory testing, counselling, and treatment. Although a healthcare provider is necessary to confirm serostatus, part of the allure of HIVST is that it provides people with the opportunity to take tests without assistance from healthcare professionals. However, with the autonomy and freedom promised by home testing methods also comes an increase in tasks and responsibilities, such as good test conduct, for the patient (Lucivero and Dalibert 2013).

Research on the feasibility and acceptability of HIVST emphasises the importance of correct test conduct and interpretation by (lay) users (e.g., Devillé and Tempelman 2019; Jamil et al. 2017; Kurth et al. 2016; Peck et al. 2014; and Volk et al. 2016). Scientific research articles that focus on the feasibility and acceptability of HIVST alone often frame the issue of test conduct and interpretation through discussions of user knowledge, education around conduct, the provision of simple or easy instructions, and/or recommendations that rollouts of HIVST should include education on proper test use (Deville and Tempelman 2019; Jamil et al. 2017; Kurth et al. 2016; Peck et al. 2014). These suggestions aim, firstly, to deal with issues of uncertainty around how a person completes the test and interprets the results and, secondly, to help ensure that people who take the test do the 'right' thing after receiving a result by accessing the appropriate follow-up care.

Although these elements are important, testing and knowing one's HIV result are not necessarily matters solely involving the completion of the test and the reading of results as per the instructions provided; even if one can correctly do and interpret an HIV self-test, other uncertainties may arise. For example: uncertainties about the validity of the testing method, uncertainties about personal risk, and uncertainty about when one should be tested. Uncertainty is part of testing and diagnosis: it is brought on through the availability of different testing options but also allows opportunities for action (in different forms of care) to remain open (Whyte, Whyte, and Kyaddondo 2018; Street 2011). Clinical uncertainty is an innate part of medical practice, and diagnosis requires a person to bring 'order and meaning to a complex series of signs and symptoms' (Gifford et al. 1986, 224). It is vital to understand how people deal with uncertainty and try to make sense of different signs and symptoms if we are to understand how people go about HIVST and make sense of their results, and thus how they make decisions about when to access further testing or care. In this research article, we explore how a smartphone app named HIVSmart!, which was designed (in part) to help people in the process of

performing and interpreting an oral HIV self-test, is used in practice. Additionally, we broaden our focus beyond test conduct and interpretation, aiming to understand how different uncertainties arise during the HIVST process and how these uncertainties contribute to people's understanding of their HIV test results and inform what they 'know' about their HIV status.

This article pulls from ethnographic material gathered through observation of, interviews with, and a focus group made up of staff and participants taking part in a quantitative study evaluating HIVSmart! in Cape Town, South Africa. The qualitative arm of the study, which we draw on here, was embedded within the quantitative cohort study assessing the HIVSmart! app. The aim of the cohort study was to evaluate whether the app-based oral HIVST strategy improved referrals, detected new infections, and/or expedited linkages to care and treatment compared to conventional HIV testing through a healthcare provider (Pai et al. 2018).

In South Africa, Ricky Janssen (RJ) spent time with the study team responsible for implementing the HIVSmart! strategy. While the team on the quantitative arm of the study gathered numerical data on aspects such as the number of new infections detected, preferences regarding HIV self-testing strategies, and linkages to care (Pai et al. 2018), RJ was responsible for gathering qualitative data on participants' experiences using the app and self-test and on study staff's experiences implementing the HIVSmart! strategy. The aim was to understand if and how the app strategy provided counselling and support during self-testing. Here, we repurpose this data to show how the participants constructed understandings of their HIV test result and HIV status.

RJ conducted participant interviews; interviews with healthcare workers, nurses, and doctors on the study team; and a focus group discussion with healthcare workers and nurses while also attending team meetings with the staff from the study's quantitative arm. This study took place in three separate clinics in three different townships around Cape Town, all of which provide health services to the general local population. RJ spent a total of three months in these clinics in 2017 and 2018, observing participants following the HIVSmart! self-testing strategy and having informal discussions with study staff. These informal discussions mostly took place in the clinics, but also at the research office and laboratory at the University of Cape Town, where the team meetings were held.

The intervention in Cape Town provided participants with three different options for completing the app-assisted self-test. Since oral HIVST was approved in South Africa in 2016, participants recruited to participate in the study at each of the three clinic sites could choose between an initial unsupervised option (using the app on their own smartphones to complete the self-test at home or in their offices); a

second unsupervised option, where they completed the test using a tablet provided by the study in private kiosks attached to the clinic (without any direct supervision from trained healthcare staff); or a supervised option, where they completed the test in the same manner as in the second unsupervised option but under the direct supervision of trained healthcare staff.

Because this study integrated multiple elements of the testing process at different moments, it provided a unique opportunity to explore how participants constructed understandings of their HIV test result and HIV status. For example, participants who were 'unsupervised' had to read and interpret the test on their own, and then had to wait for later confirmation of a correct interpretation by a healthcare provider after the self-testing process. In addition, even though participants used an app and oral HIV self-test, part of the study protocol dictated that the research staff had to complete a rapid blood test *and* a laboratory-based HIV test to confirm the oral test result for each participant. A healthcare provider (e.g., a nurse or healthcare worker from the cohort study) communicated blood-based results to the participants after they had completed the app-based oral self-test strategy. The study design brought together different testing methods, different moments of communication, and the myriad times and spaces occupied between tests. As we will show in this research article, these different elements, which go beyond the individual participant's test conduct and interpretation, help make visible the process through which people come to understand, and question, their HIV result and status.

We build on the conceptual lens used by Martin (2007) and Manderson (2020) when describing 'living under' diagnosis or description. This term is used to illustrate the role of the diagnostic label in dictating symptom management, monitoring and measurement, directing actions and behaviour, individual diagnostic accuracy, and the possibility of the diagnosis being reversed (Manderson 2020). Manderson unpacks this term, stating: "Living under" emphasises that illness, once named, is an assemblage. It flags that any diagnosed condition is pre-scripted, defining the technologies of management and engineering how life is lived' (idem, 3).

We, however, use this term to investigate what happens on the road to diagnosis. The 'at risk' definition of those deemed at risk of developing a particular disease by their healthcare provider (or public health discourse more broadly) may be experienced as a diagnosis in itself (Gifford et al. 1986). Just as diagnosis defines and brings together an assemblage of technologies and ways of living, so too does living under risk. As we will show, living under the risk of HIV infection means being thrown into a world of healthcare provider dialogue, diagnostic tests and testing routines, health promotion messaging, and behaviours deemed either 'risky' or

'safe'. 'Living under' risk implies only that something *might* happen; diagnosis is only a potential future. The assemblage of technologies, people, and ways of living inscribed by 'living under' HIV risk present moments of uncertainty; these signs and signals could indicate HIV positivity or negativity, but they are not yet brought to order through a diagnosis.

This article examines how the HIVSmart! app and an oral HIV self-test are used in three different township communities around Cape Town. The townships are a mix of informal and formal settlements, established during apartheid, and are characterised by high levels of unemployment, poverty, and poor living conditions, all of which contribute to high HIV prevalence and HIV risk within the community. For those living in informal urban settlements in particular, there is an increased risk of contracting HIV (Gibbs et al. 2020). For many people in these township communities, HIV and HIV risk are a part of daily life. Even when going to the clinic for something other than an HIV test, HIV risk is often made visible through routine medical practice. One research nurse who worked on the study highlighted the chronic nature of HIV testing in the area of Cape Town, stating that anyone who comes for family planning or tuberculosis screening is tested and that 'everybody gets tested all the time'. This even caused problems for the quantitative study because, firstly, the recruitment criteria mandated that a person could not have been tested in the three months prior to enrolment in the study and, secondly, the participant had to be undiagnosed at the study's baseline. This often led to potential participants being turned away. This is not to say that all groups tested this frequently; many of the initiatives that promoted HIV testing, such as family planning, were targeted towards women. Certain groups, such as men, seemed to test less frequently in general.

HIV testing usually includes pre- and post-test counselling, meaning that public health messaging around HIV risk behaviours and routine testing are commonplace in these Cape Town communities. The risk of HIV produces a community that is medically socialised (Pols 2014), meaning that medical knowledge and practice form part of people's experiences and inform the ways in which they engage in and relate to HIV testing.

Here, we aim to explore how the introduction of a new HIVST strategy comes to work alongside these existing HIV testing technologies and routines. Introducing an HIV testing strategy that includes a new kind of diagnostic test (an oral test) in addition to a new method of supporting the tester through the testing process (an app) changes the interactions that occur within the testing encounter. Examples of HIV testing in Uganda and South Africa show how healthcare providers mediate knowledge of HIV status between a testing device and a patient and provide clarification regarding results or repeat testing so as to alleviate uncertainty for the

patient (Engel et al. 2017; Whyte, Whyte, and Kyaddondo 2018). As Whyte describes in the Ugandan context, the counselling aspect of this encounter involves talking about a person's social life and 'risky' behaviours, and this dialogue plays an important role in helping a person relate to their HIV test result (Whyte, Whyte, and Kyaddondo 2018): 'Likewise the simple digital answer from the lab must be synthesized with information about partners, condoms, pregnancy, future tests, and (if the answer is yes) programs of treatment and support. This synthesis begins in the dialogue that occurs in the course of the consultation' (idem, 104). This statement suggests that an HIV test result and its meaning can be constituted through interactions between different actors in practices of testing and patient–practitioner dialogue. But, in the case of the app and self-test being used independently of a human healthcare provider, how might this dialogue and meaning-making process occur?

Medical anthropology and sociology literature illustrates how point-of-care tests (POCTs) take on different meanings in particular contexts. The introduction of rapid diagnostic tests (RDTs) for malaria in small drug shops in Uganda helped legitimise drug sellers in the community, as the tests imbued the drug sellers who performed the tests with meanings of skill and trustworthiness that are generally associated with trained health workers (Hutchinson et al. 2015). Similarly, the use of a C-reactive protein POCT in Thailand helped to legitimise healthcare providers' decisions around whether or not to provide antibiotic treatment (Haenssger et al. 2018). For patients, this POCT took on meanings of good care in a setting where decisions around the provision of antibiotic treatments can be difficult to negotiate (Haenssger et al. 2018). As such, POCTs and the results they provide do not come about in isolation, but in relation to existing medical practices, notions of good care, and notions of disease—both of patients and providers. Again, this highlights the need to go beyond proper test conduct and interpretation and to explore and understand how a new mode of testing, such as an oral self-test used in conjunction with an app, takes on meaning within the context of Cape Town. Furthermore, it is prudent to examine how a new testing method might also contribute to or alleviate uncertainty in the practice of HIV testing.

Our analytical approach regards the knowledge of study participants (or patients/testers) as practical knowledge on the same level as clinical knowledge (Pols 2014). In this way, we acknowledge the entanglement of patient and medical knowledge in the practice of HIV testing as well as the fact that HIV testing is a practical endeavour through which patients aim to find out their HIV status not with the goal of accumulating knowledge, but so that action might be taken in order to achieve an acceptable or healthy life (Pols 2014). Ethnographic methods are suitable for this analytical approach, as they focus on the practice through which patients create knowledge and the techniques they use to make sense of and act

on this knowledge. These methods therefore help us to disentangle the tasks of doing the self-test and reading the result from the ways in which this practice takes on meaning for the tester as either a positive, negative, or uncertain HIV result and/or status. Below, we explore the techniques used by testers for knowing (and/or not knowing) about their HIV results and HIV statuses in the practice of self-testing.

Always that little doubt...

During her time in Cape Town, Ricky Janssen (RJ) interviewed one of the study's research nurses, who worked across multiple clinic sites. She conducted the interview in the research office at the University of Cape Town, several kilometres from the community clinic sites where the study was being carried out. The research office had a laboratory and several offices; it was an organised and relatively calm place. This was in stark contrast to the loud, crowded, fast-paced clinic environments where the study was taking place. There, nurses and healthcare workers regularly carried out the careful, sometimes messy, business of taking blood and conducting HIV tests. The nurse illustrated the uncertainty people experienced around their HIV status prior to testing while also relating to her own uncertainty as a healthcare provider:

Because I think anybody, anybody, goes through a moment's anxiety of testing. It doesn't matter how much protection you've used, it doesn't matter how good you've been. There's always that little doubt in your head. 'Cause it could have been something small you've done. I mean, for me, [...] I take blood all the time. It could be the slightest mistake. And sometimes, I mean the other day, I took blood and it felt like a drop went on my—you know those big pipettes? And I imagined something splattered on my lip or something. And I was freaked out, I was freaked out by that. But anything can happen, you don't know, so I think there's always that doubt before you test yourself and the possibility it might be.

The nurse gave this statement to explain why she would recommend the HIVSmart! app along with the self-test. She then highlighted the idea of being more 'liberal' about testing and to 'just keep testing and testing', because you just don't ever know. Even when you are 'good' and follow all the rules, you can never be sure. People deal with uncertainty about potential illness in different ways: one person might ignore or deny risk related to a particular illness, while another might take decisive action to monitor or mitigate risk (Gifford et al. 1986). HIV self-testing (HIVST) is perceived as an opportunity for more frequent testing for those experiencing anxiety or doubt around their HIV status—it provides an opportunity to take action (Witzel et al. 2017). People bring their uncertainties around their HIV

status (that one event of exposure to HIV in an occupational setting, the odd one-night stand, perhaps) into the testing process; indeed, these uncertainties are sometimes what encourages or motivates someone to test in the first place. Below, we explore the different aspects of the testing process as it played out in the study assessing this app-based self-testing strategy. We look at how study participants dealt with elements of uncertainty while completing the test, both in relation to existing testing practices and to ideas of risk and time. We then consider how these elements contributed to participants' knowledge of their HIV result.

Doing the test: Conduct and interpretation

The HIVSmart! strategy aims to, among other things, provide support for the conducting and interpretation of the oral HIV self-test. The oral self-test requires that participants swab the upper and lower portion of their gums, put the swab into a buffer liquid, and then wait approximately 20 minutes for the result to appear. Prior to conducting the self-test, each study participant was shown a video at the clinic on how to do the oral self-test. This video was also included in the self-testing app. When one participant was asked if he trusted his ability to do the test correctly, he referred to the app and the instructions it provided in the form of a video tutorial:

Interviewer: 'Did you trust that you did it [the test] right?'

Participant: 'Yeah. Because I saw [it] in the instructions.'

Interviewer: 'Ah, okay. The instructions where?'

Participant: 'In the video.'

The video instructions were flexible in that participants were able to pause or replay the video as needed. This helped participants trust in their ability to do the tests on their own. Another participant said, 'Yes, yes, I had my doubts. I watched the video multiple times—I think two or three times—just to make sure that I'm doing everything correctly: align the apparatus correctly, uh, I dip that stick well and everything. So that's why.'

One unsupervised participant stated:

First it [the app] asked me my age and some personal stuff, and then I answered them. And then there was a video I have to see before I like, before I do the test. And then I saw it. And then I replay it again to go step by step through the test [...] And then after that there was a, there was something, yes, I wait for 20 minutes for it. And then after that I captured [a picture of the result on my phone] and it showed my [HIV] status, and then I was done.

Replaying the video was one strategy testers could use to deal with any uncertainties they had regarding test conduct. Indeed, these examples illustrate that the video played a central role for participants facing potential uncertainty and helped to instil a sense of trust in those doing the test. The previously quoted participant went on to state that the app then showed her that her status was HIV negative.

For many study participants, this was not their first time doing an HIV test; still, oral HIV testing was a new experience for many. People cited different reasons for their previous HIV testing, including the need to access general sexually transmitted infection (STI) testing, family planning services, and pregnancy. People seeking other kinds of sexual and reproductive health services in Cape Town (even without specifically coming for an HIV test) are often required to take an HIV test, implying that those seeking these services are at risk of HIV. In South Africa, this assumption can lead to strained relationships between health workers and patients, who may feel forced to test (Martinez Perez et al. 2016). However, many other participants said they had sought out HIV testing because ‘they wanted to know their status’. Many participants were familiar with other HIV testing methods, such as a ‘finger-prick test’ (rapid blood antibody/antigen test). This became apparent when discussing the ways in which people interpreted their oral test results. Some people relied on the app’s interpretation, while others remembered how to read the test from previous clinical experiences. Others still asked the nurse and healthcare workers at the clinic or knew how oral tests worked due to past experiences with other self-test devices, such as pregnancy tests. Nonetheless, because the HIV test was new, there was uncertainty regarding whether the results would be displayed in the same way as other tests. In this instance, the app provided reassurance regarding the interpretation of results. One participant said in an interview:

Because it was a new test, a new way of testing, I didn’t know if that’s how the results will be showing [...] Maybe negative will show two signs, maybe, um, it’s not conclusive [and] will show two lines. I didn’t know. But from previous experience, I know if it shows two lines then you know it’s positive. So when I saw that, and I compared it to [...] the results on the app and I looked at both the screen and the test [...], then I could compare the negative and the positive [...] to what was happening on the actual test.

When asked what the app told them, the participant added, ‘The app told me if it’s two lines it’s positive and the actual test told two lines and then I knew it was positive.’

Another important aspect of the new test strategy was the change in participant proximity to the test and its interpretation. Many people said they preferred being

able to read the test and result themselves. When asked about why they liked doing the test themselves, one participant said it alleviated fear around whether the results actually belonged to them and expressed his concerns around test ownership: ‘Maybe they [i.e., clinical staff] swapped the results of someone else with mine.’

In the South African environment, where some people are distrustful of healthcare professionals (Martinez Perez et al. 2016), people appreciate the ability to see their test and result in front of them. The self-testing strategy, facilitated by the app, deals with uncertainty in this instance by instilling a sense of trust that the results are authentic and correct, and by giving people a sense of ownership over the testing process. Healthcare providers in South Africa have been shown to use a similar strategy during regular point-of-care testing (POCT) for HIV: they ask patients to read the test results themselves directly from the test strip so as to create a sense of ownership or acceptance of the result (Engel et al. 2017).

However, the process of conducting the test and reading the result was not always straightforward for participants. One participant spoke to me about her experience of testing HIV positive when using the self-test strategy at the clinic. When I asked her how she knew how to read the test results, she said the nurse had helped her. When asked if the app had assisted her in reading the result, she stated yes. However, when asked to elaborate on what the app did to assist her, the participant could not recall and added that she was under so much stress at the time that she did not clearly remember what had happened. The stressful nature of the test process can contribute to a person’s uncertainty around conduct and interpretation, especially in a high-burden setting like South Africa, where the chances are high that an accurate self-test could be a true positive.

One of the nurses also mentioned the impact of stress during the self-testing process when describing a situation with a participant. The nurse described a scenario in which a young female participant had finished watching the video instructions on the app and had then frozen; the video had finished but the participant was still sitting there, waiting. The nurse emphasised that she had followed study protocol prior to the testing by showing the participant the video and explaining that it would replay on the app when she went through the testing process on her own. Another healthcare worker suggested that, despite having the knowledge to complete the testing process, related stress may have led the participant to freeze.

Maybe it was stress or not focusing [...] Sometimes I can talk to you but [Participant 5 says, ‘But you’re not listening.’] I’m not listening [...] I say okay, I’m okay ... When it comes, I have to do it now on my own, I don’t know what

to do because I was just like okay, okay, and not focusing, thinking something else. So I think because it was a young person ...

Another participant added, 'Maybe she knew she was at risk of [HIV].'

The healthcare worker continued: 'So maybe now she was thinking far, not here. So, I think it was that, not because they don't know, because the young ones they always on that. And [...] she did it anyway. So I think that it was just stress or not focusing, feeling something else.'

The nurse had to provide some extra encouragement and double-check that this participant knew what to do. They waited a few extra minutes and, eventually, the participant completed the test on her own. Distress and anxiety can occur during HIVST and is associated with conduct errors during the testing process (Deville and Tempelman 2019). In their study, Devillé and Templeman (2019) assessed HIVST in rural South Africa without a supporting digital strategy. However, it is still important to note that, even after stating that stress and anxiety during the testing process can lead to conduct errors and suggesting that comfort and the presence/absence of healthcare workers might ease this stress, one of the final suggestions in their article is: 'Self-testing remains prone to procedural errors and difficulties requiring a robust test. Self-test instructions and procedures require simple steps, easy devices and simple and clear pictorial instructions to be tested in various target populations' (Deville and Tempelman 2019, 11).

The story told by the healthcare workers and patients in our study contrasts with the conclusion presented in the article excerpt above. The authors still suggest that issues of test conduct and interpretation centre around ensuring participants have the knowledge to complete the self-test through the provision of clear, easy-to-understand instructions. By suggesting this, the authors allow the emotionally loaded or stressful experience of HIV testing to fade into the background. In our examples, the study participants, healthcare workers, and nurse do not suggest lack of knowledge or understanding as the problem, but rather highlight the impact of stress or lack of focus during the testing process. This difference also highlights the continued role of the nurse/healthcare worker in facilitating the self-test process. In addition to the fact that some participants used the app and self-test in kiosks at the clinics, the study protocol in Cape Town included the provision of contact information and enabled direct access to study staff, who were all trained healthcare professionals. Since participants could do the self-test and the app at home, the study protocol dictated that participants needed to return to the clinic (often the following day) to show the nurse or healthcare worker the result of the oral test. The nurse or healthcare worker would then check the oral test result against the rapid finger-prick test administered when the participant enrolled in the study.

In this section, we explored the ways in which our participants dealt with moments of uncertainty during processes of test conduct and interpretation, as well as the roles played by the app, the oral self-test, and the study/healthcare staff and test setting. Yet, as we will show in the following sections, living under risk of HIV means that people have previous experiences and understandings of what HIV testing and prevention entail. The novelty of the self-test method, participants' ideas concerning 'risky' behaviours, the timing of testing, and the development of symptoms also play a role in understanding test results.

Blood and saliva: Validating the test method

The oral test used in this study was an *in vitro* immunoassay test designed to detect HIV antibodies in saliva. The oral HIV test is a relatively novel way of testing for HIV (approved in South Africa in 2016) and most participants in the study were instead accustomed to blood-based test methods. For some participants, the use of a different fluid in the test process lead to uncertainty regarding the validity of the oral test. One participant said:

I think we are all used to testing HIV through the finger prick and the blood. So how will you—and then the information that you can't have HIV in your mouth and all—so how does it work? How does it show in your mouth that you have that or not? So it was kind of a shock.

Later in the interview, she added, 'Because I didn't know, I didn't know. The thing is that, pricking here and the saliva there, like, how can it be the same? Because there is blood and this is water.'

These examples illustrate that, because the use of saliva in the test contradicts what people know about HIV transmission, uncertainty can arise. The novelty of the test led to uncertainty regarding the results provided by the test, even if the person was confident they had performed the test correctly. Consider this extract from an interview transcript:

Interviewer: 'What if you had done the self-test on its own, without the blood test?'

Participant: 'I would not have believed it.'

Interviewer: 'No? Why not?'

Participant: 'I would say, it's new, which [it] is, so I wouldn't have believed it.'

Interviewer: 'Did you trust your ability to do the test? You know you had to do it by yourself. What did you think about that? Did you trust that you could do it?'

Participant: 'Yes.'

Here we see that belief in one's ability to correctly complete and interpret the test does not mean the person actually trusts that the testing method gives a valid result. Other participants echoed concerns about the test, explaining that they had requested confirmation of their results in the form of blood tests and from the nurse. One participant said, 'When the finger-prick one came, of which it tells the very same thing that the oral one was saying, then I was like oh okay, this oral [test] is working.'

The study protocol dictated that participants would need to have three tests done in order to confirm their HIV result: the oral HIV self-test (HIVST), a rapid blood finger-prick test, and a laboratory blood test. Several participants only trusted the oral test result after receiving a matching result from the rapid blood test. The rapid blood test is a routine HIV test in the Cape Town clinics where we conducted the study, and the rapid blood test's agreement with the oral test imbues confidence in the oral test method.

Sometimes, there was even doubt among those who tested routinely in the blood test method. One participant doubted her past negative HIV results because her partner was HIV positive. She mentioned that she wanted to try the app-based oral test strategy because she wondered if it would give her a different result. This example illustrates that people also have doubts about existing test methods. This participant was able to compare the results between both test results and, in this instance, both results came out positive. The participant said that if the two tests had provided different results, she would have gone for another opinion. The novelty of the oral test in this example reinforces the participant's confidence in the blood test and vice versa—it is not just the blood test confirming the oral test. The above example also shows that how a person understands their personal risk influences their confidence in their test result. In the following section, we explore how understandings of risky behaviour, testing guidelines, symptoms, and time relate to how a person understands their HIVST result.

The chronicity of HIV testing

Timing plays a dominant role in determining the ways in which healthcare guidelines and protocols outline (proper) patient interaction with HIV services. For example, timing in HIV treatment adherence acts as a 'disciplining' tool: good patients plan their daily routines to ensure they take medication on time and in a way that aligns with local, national, and global HIV treatment protocols (Benton, Sangaramoorthy, and Kalofonos 2017). The worsening of a patient's health, then, can be explained away by that patient's inability to abide by this 'adherence time' (ibid.). In the communities explored in our study, we saw that HIV testing is a

regular occurrence. For those living under the risk of HIV, the frequency of their testing is shaped by things such as access to certain healthcare services (e.g., family-planning or STI screening), public health messaging around how frequently people should test (see below points on the ‘window period’), and the meaning of symptoms and risk behaviours. We now explore how time plays a role in the ways in which people understand their oral HIV self-test results, the level of confidence they have in their results, and the ways in which their confidence shapes their testing routines.

The app provided participants with a lot of information about HIV, asked participants questions about their HIV risk, and provided them with a risk score. This encouraged moments of internal dialogue among participants, allowing them to reflect on their behaviour and HIV result. This process is similar to dialogue that would occur as part of conventional HIV testing, where a nurse or healthcare worker might talk to a patient about how they can manage their risk or take better care of themselves. Dialogue around risk and behaviour is a crucial aspect of the testing process, especially when it comes to encouraging participants to relate to their test results. For example, one participant in our study related his trust in the oral test result to his last result and condom use with his partner:

Yeah, I trusted the result, because the last time I did the test I was negative. I continued using a condom with my partner, so I didn't think I could be positive anyway because I'm safe and I'm not doing anything different after, I didn't do anything different with my partner after that test.

In this case, the negative result aligned with the person's risk knowledge and use of condoms, as well as his previous negative result, contributing to his trust in the result. In contrast, there were instances where participants' knowledge of risk behaviours contributed to uncertainty and distrust in their test result. One participant, speaking to us using a translator, illustrated this:

She [the participant] said she doesn't trust the results because when she sleeps with her boyfriend or with a guy she doesn't use a condom [...] So she feels that at a later stage or maybe in a week or two weeks' time or whenever, the results might come back differently.

Here we see that sometimes participants' knowledge of risk and disease transmission contribute to uncertainty. The participant's doubt regarding the test result in relation to her risky behaviour acts as an indication that further action, such as repeat testing, might be necessary. Participants frequently spoke about how often they should test due to ‘window periods’—this term typically refers to the period between HIV exposure and HIV infection becoming detectable due to the development of antibodies (transmission during this period is still possible). The

length of a given window period depends on the type, and thus sensitivity, of test used, with rapid HIV antibody tests such as the OraQuick oral test having longer window periods than antigen tests. RNA tests are more accurate in terms of detecting HIV during the period following HIV infection, but these tests require access to a lab, where both antigen and RNA can be tested. In order to deal with the issue of window periods, healthcare staff, including the clinic staff in Cape Town and those working on the app study, regularly advised patients to come back for a test after three months if they had taken part in high-risk behaviours less than three months prior to receiving the current test result. One participant told us:

Yes. They said you must come there again and you will do the test again. Because if you slept with your boyfriend now the results will come negative of which you didn't use a condom. And then, if you can come back then maybe three weeks or four weeks, then you come and test again, or at six weeks, the results will come. And said if he was positive, then you'll be positive. Yes.

One unsupervised at-home participant illustrated the temporary state of HIV status through the language used to describe their result and the need to test again, saying, 'I feel relief because my results, I see, [are] still negative. Yes. So I must know, after three months I must come to the clinic and check for an HIV test.'

Another unsupervised at-home participant said:

I sort of knew my status and then it [the oral test] was a sort of confirmation. So that's when I was like, yeah, maybe nothing changed. And then I went to the clinic and the nurse told me it was also negative, so I was like yes, yes it's reliable.

This participant's confidence about being HIV negative prior to the test reinforced his confidence of the ability of the test to provide a reliable result. Despite this confidence, this quote still enforces the inherent uncertainty and changeability of his status: 'Maybe nothing has changed.' Health promotion services and peers are shown to reinforce the need for reassurance about continued seronegativity in communities considered high risk (Witzel et al. 2017). Similar to the disciplining effect of time (used to categorise 'good' or 'bad' patients based on how well they adhere to HIV treatment) (Benton, Sangaramoorthy, and Kalofonos 2017), here we see that abiding by timeframes set out in HIV testing guidelines instils confidence or uncertainty in one's current HIV status.

Finally, uncertainty regarding HIV status and potential results also related to the physical symptoms and experiences of the test-taker. Although the supervised self-testing participant quoted below did not trust her result until she saw confirmation (in the form of the blood test), she already had her suspicions

regarding her HIV status because of symptoms and the unfaithfulness of her partner.

When I came here to test, I was [...] having funny things that are coming out to me. So when I came to test, I really have a faith that I'm negative. You see? So, when I was doing it though, [I] told [myself] that I was positive. Because the [...] symptoms that I was seeing in me, I saw them in other persons. Yes.

She then reaffirmed to the interviewer that she already suspected her HIV status.

These examples illustrate the interaction between the oral test, testing guidelines, people's HIV knowledge, and uncertainty around test results. This interaction and those like it indicate whether a participant's result stabilises and solidifies as a concrete HIV status or whether it remains unstable. If the latter, that person may intend to seek further testing. Participants understood individual risk as emerging from their 'subjective feelings about the meaning of scientific and clinical risk mediated by their social and cultural background, context, and experiences. Lay risk is not objective, cannot be quantified or measured, and is not static. Rather, it must be understood as a dynamic experience of personal uncertainty about one's future' (Gifford et al. 1986, 231).

A test result might appear in an instant, but knowing one's status isn't a moment—it's an ongoing process of viewing test results, considering your behaviours and the behaviours of those around you, observing the things your body is doing, keeping track of how long it's been since you last tested, and knowing when you should test again. Even with a positive result comes the next step of confirmatory testing and then pre-treatment counselling.

When Ricky Janssen (RJ) speaks with people who have tested positive, one of the questions she always asks is whether they have started treatment since receiving their result. In the clinic, nurses and participants explained that, before starting treatment, an HIV-positive person should first come for counselling sessions. Not everyone begins this process right away—for example, one participant said she had not started counselling and treatment because she was afraid to disclose her status to her family. However, another participant—an unsupervised self-tester—who had recently been diagnosed told RJ that she had come for her first counselling appointment. She appeared to be in denial, as she did not believe her HIV status, but said that perhaps she would believe it when she started treatment. RJ asked her why she had decided to return for further care. She told RJ that it was because she had started losing weight and that people had started noticing. Her impetus for returning was therefore not just the reception of an HIV-positive result, but was rooted in the fact that she could relate her test result to her symptoms, which were now physically noticeable. Again, these processes

underline the ongoing nature of diagnosis and the process of becoming an HIV-positive person, even after linkage to further care and treatment.

Discussion

Through our results, we show how uncertainty is present in many aspects of the testing process: in wondering about HIV status prior to testing, in working out how to do the test and read the result, and in determining the efficacy of the test and the accuracy of the result it provides. However, we also show how study participants deal with this uncertainty: by considering their risky behaviours, seeking reassurance from the app and clinic staff, and comparing different test methods.

Digital health tools such as apps are changing the relationships and roles of patients and providers in healthcare practices. HIV testing regularly involves a healthcare provider able to construct diagnoses and contextualise the results a device provides through dialogue with patients. Healthcare practitioners often play a role in dealing with the uncertainty of patients during testing in order to move forward with the care process. For example, in cases where patients are uncertain regarding test results, nurses may want to provide additional support or resources (Chiou et al. 2019), and healthcare workers may provide additional or repeated tests (Whyte, Whyte, and Kyaddondo 2018; Engel et al. 2017).

Through our results, we show how the construction of the diagnostic process is redistributed and reconstituted between these human and material actors when a person performs their own test using an oral HIV self-test (HIVST) with the support of a smartphone app. The app does not resolve all uncertainties, but it does play a role in facilitating conduct and interpretation; initiating dialogue around risky behaviours; and encouraging linkage to resources such as clinics, which can help the person/tester address other uncertainties. Interestingly, however, different elements within the study of the app-based strategy (which included multiple HIV testing methods and trained healthcare staff) worked in conjunction with the app to deal with uncertainties surrounding the validity of the oral test and the confirmation of test results. Study participants synthesised different aspects of the study (including varying test methods, multiple test results, guidance from healthcare workers, and the app) along with their own knowledge and experience, to come to conclusions regarding their HIV result. This process indicated either a stable result (an HIV status) or a need for further action, a process very similar to the dialogue and consultation that occurs as part of HIV voluntary counselling and testing (VCT) in Uganda, which involves a trained healthcare professional (Whyte, Whyte, and Kyaddondo 2018). HIV status was not a product of the app or oral self-

test result alone, but emerged through continuing interactions between the participant, multiple testing methods, the app, and healthcare professionals.

Manderson (2020) highlights that illness cannot be divided into discrete blocks such as sickness, diagnosis, treatment, and cure; rather, it is a continuous thing with messy overlaps. She uses the concept of 'living under' diagnosis (Martin 2007) to help illustrate the role of the diagnostic label in dictating symptom management, monitoring and measuring, directing actions and behaviour, individual diagnostic accuracy, and the possibility of the diagnosis being reversed (Manderson 2020). Our article suggests that, in communities where testing for HIV is often a constant (chronic) aspect of daily life, we can use the phrase 'living under' to think about HIV status, conceptualising it as 'living under' your HIV status or risk of HIV. This goes beyond 'living under' diagnosis, as it encompasses both HIV-negative and HIV-positive people: those not diagnosed, yet to be diagnosed, and already diagnosed. The World Health Organisation (WHO) and Unitaid often refer to the importance of knowing one's status in campaigns and reports, as if it could be achieved in a single moment through (access to) testing (STAR Initiative, Unitaid and World Health Organization 2018; WHO 2018). For instance, 'know your status' was the theme of the World AIDS Day in 2018, for which one of the WHO objectives was to 'urge people to know their HIV infection status through testing ...' (WHO 2018).

In practice, however, knowing your HIV status requires many things: the monitoring of potential symptoms; the measurement/detection of HIV antibodies or antigens (viral load measures for HIV-positive people); considering and attending to frequency of testing; management of risky behaviours; the cultivation of trust in the accuracy and validity of test methods and results; and the possibility of either confirming a negative status, diagnosing a positive status, or attaining a controlled viral load resulting in undetectable HIV infection. HIV status is constituted through these different elements, and attending to them is an ongoing process. Once someone has a confirmed diagnosis (HIV-positive status), the door may open to a new assemblage of tests, treatments, and practitioners, but these will still be under the umbrella of, and in relation to, HIV status.

Point-of-care tests (POCTs) play a prominent role in constituting HIV status and, following their introduction, new practices and trust relations emerge (Lucivero and Dalibert 2013). Previous research has reported participant concerns around the validity of results from both oral and blood-based HIVSTs (Ritchwood et al. 2019). They reported that this distrust was resolved through actually using the test; they found that participants unanimously trusted their test results after using the HIVST. However, in the study by Ritchwood and colleagues, a nurse was present to confirm the participant's interpretation of the test result and participants were

referred to a local clinic for confirmatory testing. Our results suggest that, instead of using the HIVST alone, it is confirmation by the nurse and other confirmatory testing methods *in addition to* the self-test that plays a role in constructing participant trust in new methods such as oral HIVST. Using methodologies that more carefully explore how different elements of testing and diagnosis create trust in and legitimise new methods is crucial. As the WHO makes changes to testing standards, aiming to increase the number of confirmatory tests necessary for positive HIV diagnosis in countries with a high proportion of people already tested and treated (WHO 2019), it is important to consider these trust-building processes and the ways in which local relationships with test practices might change. Furthermore, the COVID-19 pandemic highlights the importance of understanding these trust-building processes, in part due to public scrutiny and distrust in the legitimacy of certain test methods, as well as the recent introduction and increasing availability of COVID-19 self-tests. COVID-19 also highlights the increasing role played by digital health in disease surveillance, as well as concerns around privacy and public trust, which these technologies evoke.

Conclusion

Self-testing brings the promise of more flexible, accessible, and widespread HIV testing to help more people ‘know their status’. Yet, as we see in the communities in which the HIVSmart! study took place, HIV status is constituted through existing testing technologies, healthcare providers, health messaging, risk behaviours, and timings pre-scribed by what it means to ‘live under’ risk of HIV infection. Therefore, as we have revealed in our research article, the new HIVSmart! strategy needs to work as part of and in relation to this existing assemblage, at certain moments providing reassurance or clarity around HIV test results and HIV status while in other moments contributing to further uncertainty. This uncertainty is not necessarily a bad thing, as it can prompt persons/testers to turn to other parts of the assemblage for support or clarification.

Research into the feasibility and acceptability of HIV self-tests (HIVSTs) as screening/diagnostic tools often puts emphasis on people properly using and interpreting HIVSTs. However, by focusing on methods that ensure good conduct and interpretation as key aspects of effective HIV self-testing implementation, the other ways in which uncertainties emerge or recede following the introduction of new diagnostic and digital health technologies become less visible. Furthermore, focusing primarily on the oral self-test alone (i.e., without considering the role of other actors built into a study protocol and HIV testing experience) obscures the ways in which people use their own experiences, existing technologies, and the expertise of healthcare workers to validate new (potentially untrustworthy) technologies in practice.

The app-based oral self-testing strategy we have explored in this article means to address user uncertainties around interpretation and test conduct in addition to other aspects of HIV care, such as linkage to care and counselling. Our study illustrates that digital strategies such as HIVSmart! can play a key role in alleviating some of the uncertainties associated with HIVST. However, we suggest that any attempt to implement HIVST, even with supporting digital strategies, should also consider the knowledge and experience of the people testing in a given context, as well as the ways in which their testing experiences are shaped by ‘living under’ their unknown HIV status and the risk of HIV. We show that the effective implementation of digital strategies for HIVST, as well as HIVST in general, require the consideration of multiple aspects in the testing process, including local understandings of HIV risk, access to healthcare staff, and the meaning of certain test methods within a particular context.

Acknowledgements

We sincerely thank the staff and participants at each of the study sites for their time and for sharing their experiences. We also thank our reviewers and editors, whose feedback and suggestions were so helpful in producing this piece. The South Africa project was funded by a Transition to Scale grant from Grand Challenges Canada, #0732-05 (awarded to Dr Pant Pai); the Department of Science & Technology, South Africa (awarded to Dr Dheda and Dr Pant Pai); the South African Medical Research Council SHIP (awarded to Dr Dheda and Dr Pant Pai); the RI-MUHC; and the MUHC Foundation. The test kits were purchased and donated by OraSure Technologies (PA, USA). Dr Pant Pai also acknowledges the support of the Fonds de recherche du Québec—Santé Research Scholar Award (Senior) and CIHR operating grants (HHP 137872 and PJT 153149).

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References

- Benton, Adia, Thurka Sangaramoorthy, and Ippolytos Kalofonos. 2017. 'Temporality and Positive Living in the Age of HIV/AIDS—A Multi-Sited Ethnography'. *Current Anthropology* 58 (4): 454–76. <https://doi.org/10.1086/692825>.
- Chiou, Piao-Yi, Chih-Yin Chien, Amanda Lee, Hayter Mark, and Nai-Ying Ko. 2019. 'Experiential Learning of HIV Self-Test among Student Nurses: A Qualitative Study'. *Nurse Education Today* 79: 111–16. <https://doi.org/10.1016/j.nedt.2018.11.012>.
- Devillé, Walter, and Hugo Tempelman. 2019. 'Feasibility and Robustness of an Oral HIV Self-Test in a Rural Community in South-Africa: An Observational Diagnostic Study'. *PLoS One* 14 (4): 1–13. <https://doi.org/10.1371/journal.pone.0215353>.
- Engel, Nora, Malika Davids, Nadine Blankvoort, Keertan Dheda, Nitika Pant Pai, and Madhukar Pai. 2017. 'Making HIV Testing Work at the Point of Care in South Africa: A Qualitative Study of Diagnostic Practices'. *BMC Health Services Research* 17(1): 1–11. <https://doi.org/10.1186/s12913-017-2353-6>.
- Gifford, Sandra M. 1986. 'The Meaning of Lumps: A Case Study of the Ambiguities of Risk'. Janes, Craig R., Ron Stall, and Sandra M. Gifford (eds). *Anthropology and Epidemiology*. Dordrecht: Springer. 213–46. https://doi.org/10.1007/978-94-009-3723-9_8.
- Gibbs, Andrew, Tarylee Reddy, Kristin Dunkle, and Rachel Jewkes. 2020. 'HIV-Prevalence in South Africa by Settlement Type: A Repeat Population-Based Cross-Sectional Analysis of Men and Women'. *PLoS One* 15 (3): e0230105. <https://doi.org/10.1371/journal.pone.0230105>.
- Haenssger, Marco J., Nutch Charoenboon, Thomas Althaus, Rachel C. Greer, Daranee Intralawan, and Yoel Lubell. 2018. 'The Social Role of C-Reactive Protein Point-of-Care Testing to Guide Antibiotic Prescription in Northern Thailand'. *Social Science & Medicine* 202: 1–12. <https://doi.org/10.1016/j.socscimed.2018.02.018>.
- Hutchinson, Eleanor, Clare Chandler, Siân Clarke, Sham Lal, Pascal Magnussen, Miriam Kayendeke, Christine Nabirye, James Kizito, and Anthony Mbonye. 2015. "It Puts Life in Us and We Feel Big": Shifts in the Local Health Care System during the Introduction of Rapid Diagnostic Tests for Malaria into Drug Shops in Uganda'.

- Critical Public Health* 25 (1): 48–62.
<https://doi.org/10.1080/09581596.2014.886762>.
- Jamil, Muhammad S., Garrett Prestage, Christopher K. Fairley, Andrew E. Grulich, Kirsty S. Smith, Marcus Chen, Martin Holt, et al. 2017. 'Effect of Availability of HIV Self-Testing on HIV Testing Frequency in Gay and Bisexual Men at High Risk of Infection (FORTH): A Waiting-List Randomised Controlled Trial'. *The Lancet HIV* 4 (6): e241–e250. [https://doi.org/10.1016/S2352-3018\(17\)30023-1](https://doi.org/10.1016/S2352-3018(17)30023-1).
- Kurth, Ann E., Charles M. Cleland, Nok Chhun, John E. Sidle, Edwin Were, Violet Naanyu, Wilfred Emonyi, et al. 2016. 'Accuracy and Acceptability of Oral Fluid HIV Self-Testing in a General Adult Population in Kenya'. *AIDS and Behavior* 20 (4): 870–79. <https://doi.org/10.1007/s10461-015-1213-9>.
- Lucivero, Federica, and Lucie Dalibert. 2013. 'Should I Trust My Gut Feelings or Keep Them at a Distance: A Prospective Analysis of Point-of-Care Diagnostics Practice'. Leenes, Ronald E., and Eleni Kosta (eds). *Bridging Distances in Technology and Regulation*, 151–63. Oisterwijk: Wolf Legal Publishers.
- Manderson, Lenore. 2020. 'After Illness, under Diagnosis'. *Medicine Anthropology Theory* 7 (2): 1–9. <https://doi.org/10.17157/mat.7.2.685>.
- Martin, Emily. 2007. *Bipolar expeditions: Mania and depression in American culture*. Princeton, NJ: Princeton University Press.
- Martínez Pérez, Guillermo, Vivian Cox, Tom Ellman, Ann Moore, Gabriela Patten, Amir Shroufi, Kathryn Stinson, Gilles Van Cutsem, and Maryrene Ibeto. 2016. "I Know That I Do Have HIV but Nobody Saw Me": Oral HIV Self-Testing in an Informal Settlement in South Africa'. *PloS One* 11 (4): 1–15. <https://doi.org/10.1371/journal.pone.0152653>.
- Pai, Nitika Pant, Ali Esmail, Gayatri Marathe, Suzette Oelofse, Marietjie Pretorius, Megan Smallwood, Jana Daher, et al. 2018. '1275. Will an App-Optimized HIV Self-testing Strategy Work for South Africans? Results From a Large Cohort Study'. *Open Forum Infectious Diseases* 5 (S1): S388. <https://doi.org/10.1093/ofid/ofy210.1108>.
- Peck, Roger B., Jeanette M. Lim, Heidi van Rooyen, Wanjiru Mukoma, Lignet Chepuka, Pooja Bansil, Lucia C. Knight, et al. 2014. 'What Should the Ideal HIV Self-Test Look Like? A Usability Study of Test Prototypes in Unsupervised HIV Self-Testing in Kenya, Malawi, and South Africa'. *AIDS and Behavior* 18 (S4): 422–32. <https://doi.org/10.1007/s10461-014-0818-8>.
- Pols, Jeannette. 2014. 'Knowing Patients: Turning Patient Knowledge into Science'. *Science, Technology, & Human Values* 39 (1): 73–97. <https://doi.org/10.1177/0162243913504306>.
- Ritchwood, Tiarnay D., Amanda Selin, Audrey Pettifor, Sheri A. Lippman, Hailey Gilmore, Linda Kimaru, Jennifer Hove, et al. 2019. 'HIV Self-Testing: South African Young Adults' Recommendations for Ease of Use, Test Kit Contents, Accessibility, and

- Supportive Resources'. *BMC Public Health* 19 (1): 1–10. <https://doi.org/10.1186/s12889-019-6402-4>.
- STAR Initiative, UNITAID and World Health Organization (WHO). 2018. 'Knowing your status—then and now: Realizing the potential of HIV self-testing.' November 30, 2018. <https://unitaid.org/assets/STAR-Initiative-Report-Knowing-your-status%E2%80%93then-and-now.pdf>
- Street, Alice. 2011. 'Artefacts of Not-Knowing: The Medical Record, the Diagnosis and the Production of Uncertainty in Papua New Guinean Biomedicine'. *Social Studies of Science* 41 (6): 815–34. <https://doi.org/10.1177/0306312711419974>.
- Volk, Jonathan E., Sheri A. Lippman, Beatriz Grinsztejn, Javier R. Lama, Nilo M. Fernandes, Pedro Gonzales, Nancy A. Hessel, and Susan Buchbinder. 2016. 'Acceptability and Feasibility of HIV Self-Testing among Men Who Have Sex with Men in Peru and Brazil'. *International Journal of STD & AIDS* 27 (7): 531–36. <https://doi.org/10.1177/0956462415586676>.
- Whyte, Susan Reynolds, Michael Whyte, and David Kyaddondo. 2018. 'Technologies of Inquiry: HIV Tests and Divination'. *HAU: Journal of Ethnographic Theory* 8 (1–2): 97–108. <https://doi.org/10.1086/698359>.
- Witzel, T. Charles, Peter Weatherburn, Alison J. Rodger, Adam H. Bourne, and Fiona M. Burns. 2017. 'Risk, Reassurance and Routine: A Qualitative Study of Narrative Understandings of the Potential for HIV Self-Testing among Men Who Have Sex with Men in England'. *BMC Public Health* 17 (1): 1–10. <https://doi.org/10.1186/s12889-017-4370-0>.
- World Health Organization (WHO). 2019. 'Innovative WHO HIV Testing Recommendations Aim to Expand Treatment Coverage'. *Newsroom*. Web. 27 November, 2019. <https://www.who.int/news-room/detail/27-11-2019-innovative-who-hiv-testing-recommendations-aim-to-expand-treatment-coverage>.
- World Health Organization (WHO). 2018. 'World AIDS Day 2018.' Web. December 1, 2018. <https://www.who.int/campaigns/world-aids-day/2018>.