Transgender women's experiences using *SMARTtest,* a smartphone application to facilitate self- and partner- HIV/syphilis testing using the INSTI Multiplex: A brief report

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Abstract

We present experiences of transgender women (TW) who have sex with men with *SMARTtest*, a smartphone app to accompany the INSTI Multiplex®, a one-minute, dual blood-based HIV/ syphilis rapid test. TW participants (N=11) received 10 INSTI Multiplex® tests to take home for self- and/or partner-testing and installed the *SMARTtest* app on their phones. The *SMARTtest* app aimed to support INSTI Multiplex users in correctly performing the test, interpreting the results, and connecting with care following a positive HIV or syphilis screening. After 3-months, users completed in-depth interviews on their experiences. A total of n=9 TW used *SMARTtest* with partners. App feedback was positive, but refining is necessary. Specifically, TW reported that: *SMARTtest* is easy to use and convenient; instructions on how to use the INSTI Multiplex presented on the app were helpful to complete procedures correctly; the most frequently used feature on SMARTtest was the information on clinics that offered confirmatory

testing; and participants and their partners were not concerned about app privacy, but reported this could change if INSTI Multiplex detected an HIV-positive result. Further, participants provided recommendations on how to improve *SMARTtest*, and changes were mostly related to features, content, functionality, navigation, and overall "look" of the app. *SMARTtest* is promising to facilitate INSTI Multiplex® use in TW, and user feedback should be integrated in future versions.

Keywords

Transgender women; HIV/AIDS; syphilis; self-testing; partner testing

INTRODUCTION

As HIV self- and partner-testing grows in popularity and acceptability (Carballo-Dieguez et al., 2020), concerns about correct use, results interpretation, and linkage-to care-remain. (Figueroa et al., 2015) In addition to this, although the OraQuick Advance in-Home HIV test remains the only over-the-counter screening available in the United States to-date, different configurations of HIV tests that have the potential to be used at home continue to emerge. Correctly administering self- and partner-tests and follow-up procedures may be especially important for populations disproportionately affected by HIV, such as transgender women (TW).

Existing research shows that TW, a population that shoulders a disproportionate burden of HIV (e.g., in the US, ~14% of TW overall are living with HIV)(Becasen et al., 2018), are willing and able to use HIV self-tests. (Rael et al., 2020) New testing innovations, such as dual, blood-based HIV and syphilis rapid tests (e.g., the INSTI Multiplex®) appeal to end-users, including TW, and could someday be approved for home use. (Balan et al., 2021) However, these tests are different in that they require users to self-collect a blood sample, manipulate multiple testing vials, and interpret a single display window that includes screening results for HIV *and* syphilis. Further, test users who receive a positive result may not already know where and how to seek care.

To simplify the at-home self- and partner-testing experience, facilitate use of correct screening and interpretation practices, and provide an easily accessible linkage-to-care information database (specific to New York City; NYC), we created *SMARTtest* (Balan et al., 2020), a companion smartphone application to the INSTI Multiplex®. To inform the optimization of the content, features, and functionality of *SMARTtest*, we interviewed TW who used this application (app) about their experiences, preferences, and future recommendations.

METHODS

Recruitment

Participants were recruited in NYC in-person and online using geospacial sexual networking apps targeted to sexual and gender minorities. Eligible participants were HIV-negative gay and bisexual men (GBM) and transgender women (TW) who were at least 18 years old and reported all of the following sexual behaviors in the last three months: anal intercourse

with two or more male partners, three or more occasions of condomless anal intercourse with men who were living with HIV or of unknown HIV status, and rarely or never using condoms during anal intercourse. Because the following analysis focuses exclusively on TW, we will only discuss processes and procedures relative to this population.

Procedures

Participants were pre-screened for eligibility by telephone and invited to the research office for an initial screening visit. At this visit, participants completed a computer-assisted self-interview (CASI) screening questionnaire that included sections on demographics, HIV and STI testing history, HIV and STI knowledge and risk perception, and pre-exposure prophylaxis (PrEP) use. Also during this visit, participants were monitored by study staff as they tested themselves using the INSTI Multiplex® rapid dual HIV and syphilis test. This process, which has been used in other studies (Rael et al., 2020), orients participants to the test so they can more easily use it independently on themselves or with potential sexual partners. Participants tested themselves while following video guidance from the *SMARTtest app*(Balan et al., 2020). *SMARTtest* includes instructions on how to administer the INSTI Multiplex® test, interpret results, and provides information on available services if an INSTI Multiplex® user tests positive for HIV or syphilis. Additionally, *SMARTtest* contains a scanning feature that allows test users to capture an image of their completed test. The app then interprets the results displayed on the test and presents users with a written statement of the HIV and syphilis results (i.e., "positive", "negative", or "invalid"). *SMARTtest* also returns scanned results to the research team through an encrypted, secure connection. It is optimized for use on iOS and Android platforms. Participants received training on how to use *SMARTtest* and scan the results window of the completed INSTI Multiplex® to receive displayed results through the app. A full description of the *SMARTtest* app has been published elsewhere.(Balan et al., 2020)

Participants who screened positive for either syphilis or HIV during the initial screening visit were offered appropriate services on our medical campus. Participants who received negative INSTI Multiplex® results for HIV and syphilis and who were eligible on the CASI were invited to a second enrollment visit. In the second enrollment visit, participants were provided with 10 INSTI Multiplex® kits to use on themselves and potential sexual partners over the next 3 months, had the *SMARTtest* app installed on their personal phones, and were given an orientation on its contents.

Three months after their second enrollment visit, participants were invited back to our research offices, where they completed another CASI on their: sexual behavior, use of INSTI Multiplex® tests, sexual risk factors, motivations to use PrEP (pre-exposure prophylaxis)/remain HIV-negative, and experiences with *SMARTtest*. They also completed an audio-recorded, interviewer-administered in-depth interview (IDI). Specific IDI discussion topics included: experiences using the app (e.g., "What was your experience using the app?"); frequently used resources/features (e.g., "What resources or features did you find yourself using more frequently?"); app security/privacy (e.g., "Did you use the app to save test results to your phone? How did that process go?"); and recommendations to improve the

app in future versions (e.g., "What parts of the app do you think should be improved? What recommendations do you have for improving them?").

Participants received $50 for their initial screening visit, $30 for their enrollment visit, and $70 for their follow-up visit to cover their time and travel expenses. All participants provided written informed consent prior to engaging in study activities, and all procedures were approved by the institutional review board (IRB) at the New York State Psychiatric Institute (NYSPI).

Analyses

The IDI audio recordings were transcribed, and data were analyzed using NVivo Version 11. Two independent coders used a thematic approach to the analysis. The first coder independently defined a list of *a priori* codes, based on topics addressed in the IDI guide. Next, the first coder analyzed text to identify *in vivo* codes (e.g., the language participants used to describe their thoughts/experiences with HIVST) and developed a list of recurring themes that included *a priori* and *in vivo* codes. These codes were intended to represent the presumed meanings underlying participants' responses.

A second coder reviewed the codebook that contained the text excerpts that corresponded to the *a priori* and *in vivo* codes. This coder highlighted content and noted any discrepancies between these excerpts and codes. Then, this second coder reviewed each code output file from NVivo, looking for additional excerpts not included, focusing on excerpts that might provide additional insight, evidence or refutation for a specific code. The first and second coder then compared the text excerpts they had selected for inclusion (or excerpts that had been removed) to discuss discrepancies and new excerpts, eventually reaching consensus.

RESULTS

A total of N=11 TW were enrolled in the study and completed IDIs on their experiences using the *SMARTtest* app to support use of the INSTI Multiplex®. Participants had a mean age of 41.5 years. Our sample was racially and ethnically diverse. Specifically, six individuals identified as Latinx (54.5%), five (45.5%) participants identified as Black, and another five (45.5%) identified as more than one race. In the past three months, participants had a mean of 30.6 sexual partners; they used a mean of 4.3 INSTI Multiplex kits to test themselves, and 2.3 kits to test potential sexual partners. Additionally, nine participants (81.8%) reported using the *SMARTtest* app during the 3 month study period. In their IDIs. participants reported on themes including partners' responses to the idea of using *SMARTtest*; *SMARTtest* app likes and dislikes; app privacy concerns; experiences with app instructions; most commonly used resources and features; and users' recommendations for future versions of *SMARTtest*. Table 1 summarizes these themes and text excerpt examples. We note that overall, feedback from TW participants was overwhelmingly similar to that offered by GBM. Images of the *SMARTtest* app are published elsewhere. (Balan et al., 2020)

Participants reported that their partners were open to the idea of using *SMARTtest*. Additionally, feedback about *SMARTtest* was mostly positive, including that the app is easy

to use and convenient. Many participants specifically found the instructions on how to use the INSTI Multiplex® helpful and liked that information on where to find clinics that offered confirmatory testing was readily available; these two domains of information were those that were most frequently used by participants. On the other hand, like with the first version of many apps, *SMARTtest* requires additional refining for optimal functionality. Specifically, participants reported desiring additional functionality (e.g., a notes section), and found that the app responded inadequately to user input (e.g., difficulty downloading test results). For the most part, participants were either unconcerned with privacy when using *SMARTtest*, or disclosed that they would only be concerned if they or their partner had an HIV-positive screening. Users provided multiple recommendations on how to improve future iterations of *SMARTtest*. Suggestions were mainly related to the inclusion of additional features, content and functionality and improved navigation. A minority of participants reported functionality issues or expressed that the app "look" should be revised to look less "institutional."

DISCUSSION

Participants reported that partners were frequently open to the idea of using *SMARTtest*. In this study and others, participants described only proposing use of HIV self-tests to partners they felt would be receptive to the idea, and avoided those they anticipated would become aggressive or angry.(Rael et al., 2021; Rael et al., 2020) It could be that partners who were open to the idea of using the INSTI Multiplex® viewed the use of *SMARTtest* similarly to STI testing. This provides some preliminary evidence that combining HIV tests and supportive apps may be feasible and acceptable for testing partners of transgender women. Future self- and partner-testing studies should consider developing companion smartphone applications for TW and test their acceptability and feasibility on a larger scale.

Because participants found the instructions on how to use the INSTI Multiplex® and on where to find clinics that offered confirmatory testing helpful, these should be retained in future iterations of the app. However, we note that they may need to be modified to better suit target users' unique geographic contexts, and to appear less plain. Interestingly, the comments we received from TW on *SMARTtest* were not dramatically different from those disclosed by GBM.(Balan et al., 2021) Thus, tailoring the app to appeal to specific gender identities may be less important than tailoring it to garner broader visual appeal and geographic utility overall.

Though participants overwhelmingly responded positively to the app, they reported that additional refining is needed to add functionality and solve some technical problems, as is the case with the first version of many apps. Though we can only speculate since our small sample size does not allow us to draw definitive conclusions, it is possible that participants' mobile carrier and/or device type (e.g., iOS vs. Android, and/or their specific model) affected the type and frequency of app issues they experienced. We point out that the present research was intended to preliminarily test *SMARTtest* and that awareness of these issues is key to fixing them. However, there did not appear to be a pattern to these errors; this, too, is likely the result of our small sample size. While the app team will work to understand and resolve the technological issues reported in this work, it is necessary to test *SMARTtest* in a larger and longer trial to understand patterns associated with app problems

and address them in a targeted way. The experiences disclosed by users in this study provide a meaningful starting point for where these assessments should begin.

Participants found the *SMARTtest* instructions on how to use the INSTI Multiplex® helpful to ensure they completed testing procedures correctly. This was critical, since INSTI Multiplex® requires a specific series of steps that can appear complicated to some users, particularly at first. Based on self-report from other users (e.g., gay and bisexual men; GBM), instructions are necessary the first few times users complete the test and become less important as their testing skills improve. For this reason, current iterations of *SMARTtest* have made testing support content optional, based on users' familiarity with the test.(Balan et al., 2020)

Additionally, TW in our study reported that the app content they most frequently accessed was the list of clinic resources on confirmatory testing and treatment for syphilis and HIV. Because this study tested a beta version of *SMARTtest*, clinic resources were presented as a list. Our other *SMARTtest* findings showed that the gay and bisexual men (GBM) enrolled in this study wanted this resource further broken down to specify providers and/or clinics who are known to be "friendly" to same sex couples, provide HIV care, are low/no-cost, and do not have restrictions on insurance type.(Balan et al., 2020) This might also be helpful for transgender women. Specifically, discrimination in health settings is a persistent threat for transgender women,(Kcomt, 2019) and the shock or sadness associated with having a positive HIV screening could compound the trauma of accessing care for these individuals. Having an easily accessible roster of providers who are known to welcome transgender patients and endorse affordable, gender affirming practices in their clinic could help to reassure preliminarily HIV positive transgender women during this vulnerable time.

Mostly, participants in our study were either not concerned about app privacy or reported that they would only be concerned if they or a partner were to discover they are living with HIV. In our review of the literature, we found that few studies have systematically explored end-user preferences on app or mobile phone-based HIV content security/privacy. However, one study found that participants in a rectal microbicide trial (MTN-017) were not concerned about message privacy when receiving automated study-related short messaging system (SMS) texts about their participation in US and international settings.(Giguere et al., 2018) However, as smartphone-based strategies for HIV prevention continue to proliferate, it is critical to be mindful of the context in which such technology will be used. For example, as recently as 2013, same-sex partnerships are punishable with the death penalty in 5 countries, and possible imprisonment in another 70 countries.(Itaborahy & Zhu, 2013) Additionally, in the United States, 37 States have laws that criminalize exposing another person to HIV.(CDC, 2021) In these settings, strong app security and privacy is critical, since having HIV-related content on one's phone could "out" participants as gay, transgender, or a person living with HIV, putting their life or freedom at risk.

Users provided multiple recommendations on how to improve future iterations of *SMARTtest*. This feedback is congruent with the types of user suggestions typically mentioned in studies to beta test mHealth products. However, because of our small sample size, it is difficult to identify the specific aspects within these broad categories that should be

addressed. Instead, future studies to revise and alpha test *SMARTtest* should pay particular attention to the aforementioned categories to determine specific attributes that should be targeted for change.

LIMITATIONS

Our small sample size of N=11 (where n=9 participants reported using the *SMARTtest* app) limits the generalizations we can make about the *SMARTtest* app. We were unable to identify patterns related to particular targets for improvement (e.g., functionality issues, difficulties caused by phone carriers, specific navigation challenges). However, this is a relatively common issue in app testing and will require assessing *SMARTtest* in a larger and longer trial in the next phase of research. Given the favorability of the app among users in this study, we believe it is important to advance *SMARTtest* to the next phase of development.

Further, we recognize that apps exclude an important subset of transgender women from participation. Since using apps requires the use of a smartphone or tablet, only those individuals who can purchase these devices will be able to access *SMARTtest*. While this may be true in some circumstances, unpublished data from an unrelated formative study to assess barriers and facilitators to existing and emerging forms of PrEP among transgender women (Rael et al., 2018) showed that all transgender woman participants (N=30) owned a smartphone that uses apps. This was not limited to high socioeconomic status (SES) transgender women; participants' median weekly pre-tax income was $301; 20% of participants (N=6) were employed full time; 23% (N=7) had not completed high school or a GED. This highlights the growing ubiquity of smartphone ownership, even in economically marginalized groups. Lastly, we note the possible that participants enrolled in this study could be particularly open to research participation/procedures, which could influence their opinions on themes such as privacy.

CONCLUSIONS

In its initial testing run, *SMARTtest* is a promising tool to support the correct use and interpretation of the INSTI Multiplex® test among initial transgender women users. Participants in this study reported likes and dislikes about the app; at this time, dislikes appear to be solvable, and further testing in a larger and longer trial will help us to pinpoint specifically what they are and how to address them. Future study will also allow for the incorporation and testing of additional features, recommended by current participants. Overall, participants reported that partners were open to the idea of partner testing, and there were no major privacy concerns. Taken together, this suggests the utility of continued *SMARTtest,* development to further test and refine the app. This could be particularly useful if *SMARTtest* is to be used in other, culturally or geographically unique settings.

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Available of data and material

Not applicable

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Table 1:

Participant themes about experiences with the SMARTtest app and illustrative text examples

Description of theme (n=participants that endorsed the given theme)	Text example
	Partners' responses to the idea of using the SMARTtest app (n=5 used SMARTtest with partners)
Partners were open to the idea of using SMARTtest (n=5)	I just tell them, 'The computer is going to tell us. It's an artificial intelligence thing that tells us'… I'm saying it's all about the street talk, girl. Mama is all about the talk… It's an AI. It's going to tell us your [INSTI Multiplex® result] -- they were like, "For real?" Yeah. It is… (laughter) (1079)
	… [He was] Easygoing [about the test results displaying on the SMARTtest app]. It was just the wait period for the dots to show up -- whatever dot was going to show up because he was nervous. (1083)
	Participant "likes" and "dislikes" about the SMARTtest app (n=8 reported on this topic)
SMARTtest is easy to use and convenient (n=6)	"It's easy to navigate, you know? And like, you're very patient and you went, and you downloaded, and you showed me like what the videos are. And then, like, if you forget where the video's located to kind of like watch it and listen to it, because, you know, to play it again… The color is like bold, you know. It's bold and it's easily readable. It's not like difficult language, you know?" (1118)
	"So before I even did the test -- because I did it here and I looked at the video, but it's different because when you get home you might if you get [stressed?] and they let me watch the video again. So I watched the video, [had the video?], I just went through the process and just did it. And it's so easy. It's the easiest thing in the world to do. I mean -- a child could do it. The instructions are so clear. It's not like you have to guess on anything. Three tubes. Prick your finger. The tubes are numbered. So it's not like you have to guess about anything. Once it goes down, pour. Goes down, pour. And just wait for the results. That's it." (1121)
Like with many first versions of smartphone apps, SMARTtest requires additional refining for optimal functionality (n=7)	The app was very difficult.… It didn't work… Because, again, it comes down to who your cellphone company's with and it's not compatible with all phones just quite yet… Because you got a lot of different phones out there… A lot of hard -- I had an issue with downloading the results… It wouldn't take. And I have a Stylo 4. I know somebody else that had an iPhone and had no problems with it…So it's also based on the phone. (1080)
	It doesn't let you -- it says take notes or resources. When you hit resources, nothing happens. And then it's too much video -- paper that you got to hit next, next, next, next, next, next, next while you were doing with the number one, number two, number three, open this, open that, put this to the side. It's -- you re-- it gets repetitive so many times that close it and it's a turn off. (1079)
	Experiences with app instructions on how to use the INSTI Multiplex® and app features and resources (n=7 reported on this topic)
Participants found the instructions presented on the SMARTtest app helpful to complete the test procedures correctly (n=5)	"With him I definitely used the instructions because before that I had only tested twice, and the first time was here. So it was just like I ran through it, not really maintain it. And then the second time I did it on my own, I totally forgot everything I was told, so I had to look at it." (1102)
	It's [instructions presented on the SMARTtest app] much more easy to understand than instructions [presented with the INSTI Multiplex® kit]" (1081)
Participants reported the most frequently used feature on the SMARTtest app was the information on clinics that offered confirmatory testing (n=5)	Oh I looked at clinics – which is actually helpful. The clinics. Because it explains to you if this is going on this is where you can go. So it's good featured that's in there because some people they don't want to go to their primary care. Some people don't have a primary care doctor. So it lets you know exactly where you can go if it says negative. You know for all positive – for anything – because it's giving you posi–it's for syphilis and HIV. So if you see the syphilis sign you can go get tested – go get treated. (1121)
	Clinics, yeah. That one I used the clinic part for like referrals, if anyone asked… Like instead of Googling, you know. Just like, I go into the app and I know where clinics are. (1102)
	Privacy (n=8 reported on this topic)
Participants and their partners did not have privacy concerns related to SMARTtest (n=6)	"…the app is very private. It's ID number, results, date, delete it or not and that's it. It was very convenient. It was very private. It was very discrete." (1089),
	"…I just told them, 'Look, it's a app. I found the app.' And they wanted me to try out stuff.." (1124)

Description of theme (n=participants that endorsed the given theme)	Text example
Participants anticipated that they or their partners could have privacy concerns if INSTI Multiplex® detected a positive result (n=4)	"Well, for me personally, it [displaying a positive result on the SMARTtest app] doesn't bother me. But I would assume it would fuck with everybody else, you know?" (1126)
	"…I mean, they just told me, if – 'Don't be afraid that somebody share your results some day and if it'll be positive?' I mean personally, I'm fine with it, you know? Data fixed everywhere. Because – I have nothing to hide, actually… But, yeah, I think it can be another problem, when they upload the result and people can – I know – I know like 10% of my friends are worrying about privacy. And even one of them would -- so she is a trans woman. For example, I ask her, 'Why are you so worrying if your data's – What are you hiding' And she told me we should just resist and to make it hard. And, yeah, maybe she's right. I don't know. (laughs). Yeah. I'm not, personally [concerned about the privacy of SMARTtest], but I'm not sure. There is 10%, certainly they do have a concern." (1081)
	Users' recommendations for future versions of SMARTtest (n=9 reported on this topic)
Participants provided recommendations on additional features, content, or functionality to be incorporated (n=6)	Yes. Like, I feel like for the results that indicate that syphilis is positive, it should have a little something under that says, you know, like 'Secondary testing should be done to confirm if it is active or previously treated.' Something like that… You know, like how they do for the HIV, like if it comes up positive? 'Secondary testing should be performed.' (1102)
	Leave it [save participant login information to the SMARTtest login screen] on the app on the phone like that because people can get their cell phones and that's where they can keep everything, all the information and everything you need. You can go to the app and say, "Look. Boom, boom, boom." Instead of writing it on a piece of paper and you got it in your bag, "Oh my God, I lost the paper. Now I don't have the paper with me." But everything is right on your phone it's like one, two, three and A, B, Cs and that. It's much better. (1083)
Participants provided ideas on how to improve existing *SMARTtest* navigation and functionality (n=5)	I would like to have the results -- get started, results, and everything that's at the bottom of the other pages should be right here [the resources page] instead. And also at the bottom of each page, like the resources and all of that. Because it's -- this is like OK, boom… Yes, yes, yes, yes, instead of having to go through all this [scroll through the screens on how to use the INSTI Multiplex®] because I already know how to use the test. And by the time I get to be right here [the main page], all of this is already done. So, the only thing I need to do is take the picture and it's like I've got to go through all of this to take the picture. (1089)
	…I always had to put in -- you know when the -- when you open up the app and it says, "Who are you testing, you or your partner?", and then it says "You cannot save partner." That is so useless. If you're going to test partner, you want that to be saved… I used to take a little notepad and write the third test I did was the guy I met in [place of work]. That's where I work. The -- it says that you could take notes. You can't take notes. So you got to fix that. Please fix that. (1079)
A minority of participants wanted to modify the overall "look" of the *SMARTtest* app to improve its visual appeal to users (n=2)	…it looks like a fucking -- what you call it? It looks like a test app. It doesn't look like an app that you would put out there. It's like the font, the language, the pictures, all of that needs to be like in one…. (1089)
	Put bright colors. Use nice fonts. It's so institutional. It feels institutional. And when -- well me -- dealing with me, I don't like things to feel institutional… I'm not really homey, I'm not sort of -- with my lifestyle. Put the [transgender pride] flag up in a corner -- a little corner with the flag, and maybe a girl with long hair, and a hand with long fingernails. Tonterías [silly things] like that. Stupid little things that'll make you laugh and giggle. Especially when you're about to suck a dick. You don't want it to seem -- shit, I'm fucking doing an institutional thing -- I feel like I got the Feds hearing me. (1079)