HIVST in South Africa: How a Qualitative Account of Users' Experiences Can Contribute to HIVST Interventions

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Table of Contents

Abstract

The research proposed in this paper is centered around the emerging approach of HIV self-testing (HIVST) as an intervention to increase the uptake of HIV testing services for under-tested segments of the population in South Africa, a country with the highest number of people living with HIV in the world. Under the STAR (Self-Testing AfRica) initiative program, approximately 1.1 million HIVST kits were distributed in South Africa to increase the access to and use of HIVST. The aim of this study was to discover what users' experiences of HIVST were, in order to understand what factors formed the barriers and facilitators to the uptake of HIVST and entry into care post-use.

A qualitative methodology was used in conducting in-depth interviews with recipients of HIVST from the community-distribution model of the STAR program in South Africa [n=16]. The findings of this paper show that an interest in HIVST as a new form of testing and a perceived risk of HIV motivated the use of HIVST. The main facilitators of HIVST were a preferenced for oral-fluid based testing, the ability to circumvent facility-based barriers, disclosure over one's status and privacy. The main barriers to HIVST that this paper found were a lack of familiarity with HIVST and concerns over the validity of HIVST. Furthermore, this paper found that for users who received a negative result, the HIVST served as a catalyst to engage in preventative health behavior, including more frequent testing. The results showed that users who received a positive result attended confirmatory testing and entered into care. The findings indicate that HIVST facilitated users' motivation to receive treatment for HIV by providing information on the process of entering into care and behavioral control to do so.

The main implication of the results of this study is that HIVST has the potential to facilitate the uptake of testing, and that the benefits of HIVST outweigh the potential deterrents that stem from a lack of familiarity with HIVST. Future research on users' experiences with HIVST should be emphasized and incorporated into the design of interventions to distribute kits, in order for HIVST to effectively increase testing and entry into care for under-tested segments of the population in South Africa.

Introduction

Human immunodeficiency virus, commonly known as HIV, remains one of the most significant threats to global health as of 2020. Although there is no cure for HIV, the virus can be controlled with proper treatment and care, the leading form of treatment being antiretroviral therapy (ART). Untreated, the virus can lead to acquired immunodeficiency syndrome, also known as AIDS. According to the World Health Organization (WHO), around 37.9 million people were living with HIV globally at the end of 2018 (WHO, 2019). In South Africa, the number of people living with HIV (PLHIV) in 2018 was estimated at about 7.52 million. As of 2019, South Africa has one of the highest HIV prevalence rates of any country, with approximately 13.1% of the general population living with HIV and an estimated 19% of the population of adults aged 15-49 years being HIV positive (Statistics South Africa, 2019). The WHO estimates that as of 2018, 90% of PLHIV in South Africa knew their status. However, the number of PLHIV receiving ART the same year was only estimated to be at 65%, and with a new infection rate at 240,000 persons annually, it is clear that gaps and barriers in HIV testing and counseling persist (WHO, 2019).

HIV testing and counseling (HTC) services "allow people to make informed decisions regarding knowledge of their HIV status and the implications of those decisions" (WHO, 2020, p. 1). The uptake of HTC services has important implications at the individual, community, and population levels. HTC enables individuals to make informed choices about their practices and behaviors, reduce their risk of acquiring and transmitting HIV, know their status, and facilitates entry into care for prevention, treatment, and support. Traditional facility-based testing can present barriers, especially for vulnerable individuals, to access HTC services. One of the proposed ways to reduce these potential barriers and persistent testing gaps for priority, under-tested segments of the population in South Africa is the health promotion innovation of HIV self-testing (HIVST) (Majam, Rhagnath, Lalla-Edward, Mahomed, Venter, & Fischer, 2020). This involves a "person collecting their own specimen (oral fluid or blood) and performing and interpreting the results, often in a private setting" (WHO, 2019).

HIVST is an emerging approach to increase the uptake of HIV testing services for those who may not otherwise test, especially for populations with low access and those at a higher risk. Furthermore, early detection of one's HIV status increases the chances that PLHIV can receive proper treatment and care before they become sick (WHO, 2016). As HIVST allows individuals to self-screen and receive an initial diagnosis it facilitates the early detection of one's HIV status and is a promising approach to reduce testing gaps and facilitate entry into care for both prevention and treatment in the high-prevalence context of South Africa. Furthermore, HIVST is a relevant strategy in global efforts to meet the 95-95-95 targets laid out by the UNAIDS, the United Nations' foundation to end the AIDS epidemic by 2030. The targets outlined by the foundation aim to have 95% of all PLHIV to know their status, 95% of those diagnosed to receive ART, and 95% of those receiving ART to achieve viral suppression by 2030 (UNAIDS, 2014). Thus, more research is needed on how HIVST can overcome traditional barriers to testing and facilitate the uptake of HTC services and entry into care in South Africa, and to identify the factors at the individual and community levels which influence this.

Existing Literature

To understand how HIVST can reduce testing gaps and potentially enable faster diagnosis and entry into care for PLHIV, it is important to understand and address what the barriers and facilitators are to the uptake of traditional HTC services. The results of a cross-sectional survey found several factors relevant to traditional HIV testing uptake across health facilities in South Africa. In this survey, 18.1% of the participants had never been tested for HIV, reflecting that large segments of the population in South Africa are still under-tested and indicating that there may be barriers to the uptake of traditional HTC services (Mohlabane, Tutshana, Peltzer, & Mwisongo, 2016). Factors that were expressed as deterrents to the uptake of HTC services included: fear of finding out one's HIV test result, embarrassment, avoidance of divulging personal information to health workers, staff attitudes, lack of knowledge of testing sites, lack of treatment availability, and inconvenient site opening hours. Participants' accounts indicated that stigma surrounding testing and fear of revealing one’s HIV status by initiating treatment after diagnosis were the main barriers to the uptake of traditional HTC services from a user’s perspective (Mohlabane et al., 2016).

Additionally, the results of this survey indicate that emphasizing the benefits of HTC, including the reduction of HIV transmission and the availability of HIV care and treatment, was important in efforts to increase testing uptake (Mohlabane et al., 2016). The results also indicate that HIVST could potentially enable the uptake of HTC by providing the opportunity for household testing and offering users more convenience and privacy.

It is therefore important to examine the existing research on HIVST as an emerging approach to increase the uptake of HTC services and identify any gaps in the existing research which need to be addressed. At the individual level, it is important to identify factors from the user’s perspective which either motivate or deter the behavior of HIVST uptake. At the community level, factors should be identified as they relate to the potential for HIVST to address barriers to traditional HIV testing and facilitate uptake in HTC services and entry into care in under-tested segments of the population in South Africa.

In their systematic review, Njau, Covin, Lisasi, Damian, Mushi, Boulle, and Matthews (2019) identified factors enabling and deterring the uptake of HIVST across various Sub-Saharan African contexts. This review provides qualitative evidence of users’ experiences of HIVST where there has not yet been extensive research. The main deterrents to the uptake of HIVST expressed by users included the cost of self-test kits, the unreliability of self-testing, low literacy, and fear or anxiety of positive test results. The factors that were expressed as enabling the uptake of HIVST included privacy, convenience, disclosure of one’s status, the ability for HIVST to decrease stigma and discrimination, to circumvent facility-based barriers, and perceived autonomy in decision-making to test. These facilitators to HIVST address traditional barriers to the uptake of HTC services such as divulging personal information to health workers, shyness or embarrassment, stigma, inconvenience, and healthcare access.

In one of the few studies conducted on the emerging approach of HIVST in South Africa, Ritchwood, Selin, Pettifor, Lippman, Gilmore, Kimaru, and Khan (2019) aimed to determine whether HIVST could address socio-structural barriers to testing such as confidentiality, healthcare access, and concerns of stigma. This findings of this study indicated that the HIVST has the potential to address important barriers to the uptake of traditional HTC services, namely its ability to provide confidentiality, privacy, convenience, and control over disclosing one's status (Ritchwood et al., 2019). Participants also expressed that the validity of HIVST results and the potential cost of HIVST kits were concerns in the adoption of HIVST. However, the findings this study indicated that participants had an overall favorable attitude towards HIVST in South Africa. Additionally, a study conducted by Moore (2017) focusing on self-testing as an effective means of increasing HIV-testing and awareness among adults in South Africa found that 88% of individuals who refused traditional testing and were offered HIVST accepted.

The findings of Njau et al. (2019) and Ritchwood et al. (2019) suggest that at the individual level, HIVST facilitates the motivation to test by providing privacy, confidentiality, perceived control over one's health choices, and disclosure of one's status. In their findings, the potential barriers to the uptake of HIVST that were commonly expressed by users included: the reliability of the test, the potential cost of the test, and emotional concerns of receiving a positive test result. In line with Njau et al. (2019) and Ritchwoood (2019), the findings of Moore (2017) lend support to the argument that HIVST has the potential to be accepted at the individual and community level and overcome traditional barriers to testing.

While this existing literature provides an overview of the barriers and facilitators to traditional HCT services and HIVST as an emergent approach to testing, there are gaps in the literature in addressing the issues that HIV self-testers experience along the continuum of care from kit usage to entry into care. This is especially in the case in South Africa, where self-testing at a large scale is relatively new. The research proposed in this paper will try to address these gaps in the literature by taking the user's perspective of the barriers, facilitators and other factors that influence the uptake of HIVST and entry into care in the context of South Africa.

Theoretical Framework

This paper will use two models, one from a community-level theory and one from an individual-level theory, as a framework for conceptually understanding the factors that influence the uptake of HIVST and entry into care post-use. At the community level, the diffusion of innovations (DOI) theory provides a framework for understanding how innovations are diffused and adopted by populations (McKenzie, Neiger, & Thackeray, 2017). The diffusion and adoption of an innovation can also be understood as its uptake by a population. In the context of other research, the DOI theory was previously applied to study the adoption (or non-adoption) of the innovation of HIV rapid testing in an intervention trial at a general practice in London (McMullen, Griffiths, Leber, & Greenhalgh, 2015). In their findings, several factors were found which contributed to the effectiveness of the intervention of HIV rapid testing, including adapting the intervention to fit the target population and involving them in the decision-making and implementation process. In using the DOI theory to predict the adoption of HIV rapid testing, this study contributed to a better understanding of the factors that may hinder or promote the uptake and routinization of HIV rapid testing.

While the DOI theory helps frame the factors which shape the potential for the uptake of an innovation, like HIVST, at the community-level, the innovation-decision-process (IDP) model, which stems from the DOI theory, extends this analysis by taking the individual decision-making process in the uptake of an innovation into account. The IDP model, developed by Rogers (1983) outlines the process steps which are involved in the adoption, or uptake of an innovation (Figure 1). This situation-specific decision process results from the five stages of knowledge, persuasion, decision, implementation, and confirmation.

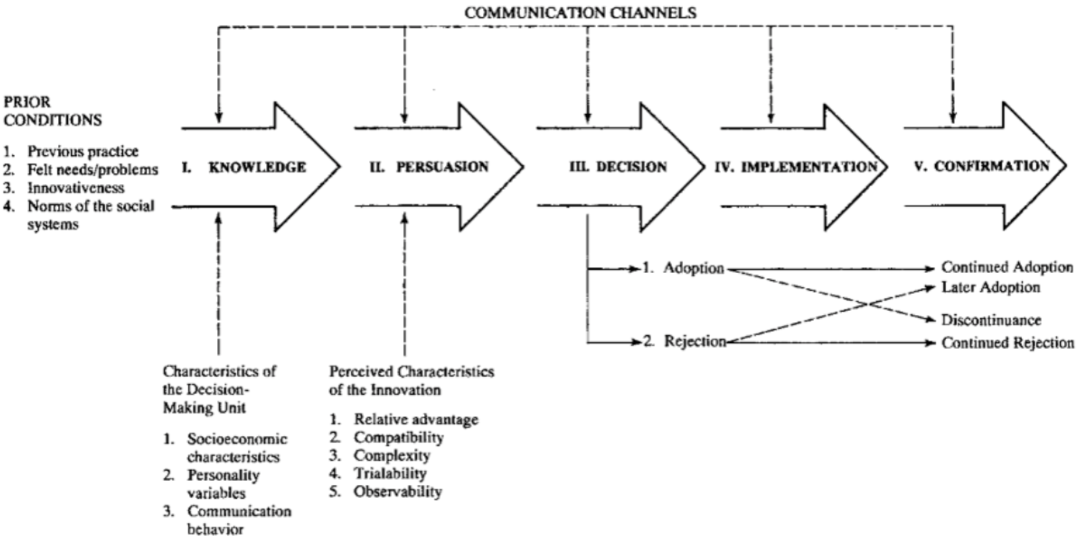

Figure 1: Innovation-Decision Process Model
Source: Rogers (1983)

The IDP model explains the process by which an "individual or organization evaluates a new idea and decides whether or not to incorporate it into ongoing practice" (Rogers, 1983, p. 163). Thus, the variables of this model can be applied to analyze the decision-making process to use HIVST among under-tested segments of the South African population."Knowledge" can be understood as exposure to the innovation of HIVST kits and how they work. "Persuasion", here, relates to the formation of an attitude towards HIVST. "Decision" takes place when the choice to either adopt or reject the concept of HIVST is made, and "implementation" relates to the actual use of the HIVST. The final stage of the IDP model is "confirmation", in which the individual seeks supportive confirmation of their decision to use HIVST, and can be applied in this context to the commitment to follow-up with the use of HIVST (Rogers, 1983). Thus, the IDP model of the DOI theory is useful as it facilitates a meso-level analysis of the factors at the individual level that contribute to the decision to use HIVST which can then inform the development of interventions to more effectively increase the uptake of HIVST.

While the IDP model can be applied to understand the process by which individuals decide to use HIVST, a social-cognitive approach can also be used to understand the mechanisms the behavior of HIVST uptake at the individual level. This body of theories understands individuals' behavior as a function of the subjective value of an outcome and the expectation that a particular action will achieve that outcome (McKenzie et al., 2017). The information-motivation-behavioral (IMB) skills model takes a social cognitive approach in explaining individuals' (preventive) behavior as determined by the development of information, motivation, and behavioral skills. The IMB model explains that individuals not only need to be well informed about a particular health issue but also need to have personal and social motivation to act on it. Furthermore, the model explains that "in addition to being well-informed and motivated to act… that people must possess the behavioral skills" to engage in the desired behavior (McKenzie et al., 2017, p. 168).

The IMB model was initially developed by Fisher and Fisher (1992) to create a theoretical underpinning for understanding HIV preventative behavior. Furthermore, the IMB model has been used as a theoretical framework in studies aimed at promoting the use of HIVST among high-risk youth in the United States (Brown, Carballo-Dieguez, John, & Schnall, 2016). Thus, the IMB model is a suitable theoretical perspective that can be applied to understand the behavior of HIVST uptake in the context of this study.

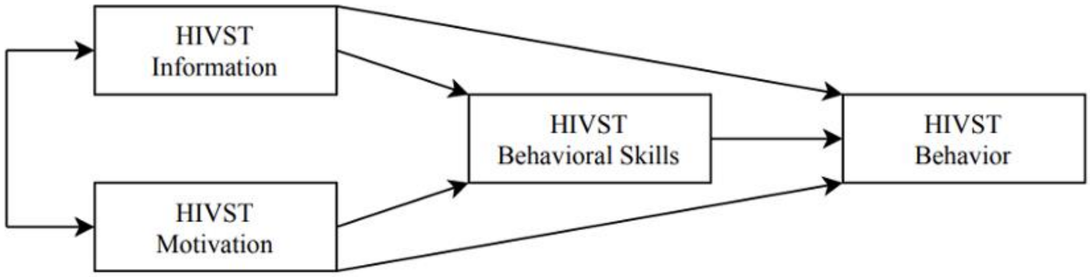

Figure 2: Three fundamental determinants of the decision to use HIV self-test (Information-Motivation-Behavioral (IMB) Skills Model.
Source: Adapted from Fisher & Fisher (1992).

The model by Fisher and Fisher (1992) has been adapted here to understand the behavior of HIVST uptake (Figure 2). The construct of information can be understood as having the relevant knowledge about the health issue of HIV, the importance of HIV testing, and HIVST as a form of testing. The construct of motivation is two-part, with personal motivation relating to an individual's attitude towards HIVST, and social motivation relating to whether there is social support for HIVST. Behavioral skills include both an individual's objective ability and their perceived self-efficacy to perform the behavior of using an HIVST kit. Behavioral skills can also be understood as behavioral control, or the perceived difficulty or ease of performing the behavior of HIVST uptake (McKenzie et al., 2017). Within this model, all three variables are seen as fundamental determinants of an individual's use of an HIVST.

The IMB model is not only applicable to HIV preventative behavior and the uptake of HIVST, but can also be extended to understand individuals' behavior post-HIVST use (Figure 3). The variables of the IMB model can thus be adapted to conceptually understand what shapes individuals' health behavior post-HIVST use, including entry into care.

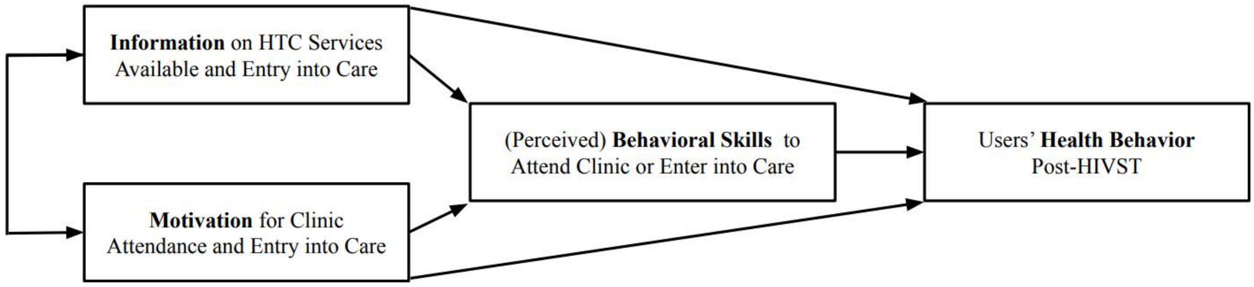

Figure 3: Three fundamental determinants of users' health behavior post-HIVST (Information-Motivation-Behavioral (IMB) Skills Model).
Source: Adapted from Fisher & Fisher (1992)

The variables are similarly defined as they are in the application to the desired behavior of HIVST use. The construct of information is understood as the relevant knowledge that the HIVST user is given about nearby clinics, services available, confirmatory testing, and the process of entering into care. Motivation is both the user's individual attitude towards and social support for clinic attendance and entry into care. Behavioral skills here relates to the user's perceived behavioral control in clinical attendance and engaging in care. These factors are then considered determinants of the desired health behavior of engaging in care post-HIVST use.

Current Study

Under the UNITAID funded STAR (Self-Testing Africa) initiative program, Ezintsha, a sub-division of Wits Reproductive Health and HIV Institute (Wits RHI), distributed approximately 1.1 million HIVST kits in South Africa between November 2017 and April 2020. The STAR program was implemented in the Gauteng, North West, Mpumalanga, Free State and Limpopo provinces of South Africa with the aim of increasing access and use of HIVST among undertested segments of the population (Population Services International, 2017). There are four main distribution models within the research design of this initiative; community-based, public sector facility-based, private sector, and key populations. In the public sector facility-based model, HIVST kits were distributed directly to clients accessing healthcare services at an outpatient clinic and indirectly to high-risk sexually active men, through women partners accessing antenatal care services and exposed sexual partners of HIV positive patients. In the private sector model, HIVST was offered to the general population at workplaces, pharmacies, and in a private practice setting. In the key populations model, HIVST kits were offered directly to high-risk female sex workers and their networks and indirectly to the male partners of female sex workers at sex worker clinics and hotspots. In the community-based distribution model, HIVST kits are offered directly to interested individuals either at transport hubs or at a fixed-point where there is high foot traffic.

This paper will focus on the outcomes of the community-based distribution model, as this model accounts for 74% of all kits distributed between November 2017 and December 2019, representing a wide range of HIVST recipients. This paper will look at the outcomes of the fixed-point modality, in which HIVST kits were distributed at fixed testing sites and individuals had the option to take the test kit home or to test on-site through fixed pop-up tents. Upon receiving the kit, recipients were instructed how to use the test and all HIVST kits included informational pamphlets on nearby clinics and services available to them following HIVST-use. Furthermore, onsite confirmatory testing services were also available for reactive individuals in this distribution model.

After receiving the HIVST kit, individuals were asked by the service providers if they were willing to provide their contact details which were reported in a data collection form onsite. To follow-up the distribution of the HIVST kits, recipients were asked if they consented to be followed-up via telephone by an Ezintsha fieldworker. Recipients were also given the choice to self-report through one of the three mHealth platforms; interactive voice response (IVRS), Whatsapp, and a web-based app. All follow-up platforms prompted the recipients to self-report on test kit use, result, clinical attendance, and initiation of ART. The self-reported data provided information on both test kit use and on the cascade of care for people living with HIV. The cascade of care is an HIV care continuum that provides a summary of the stages of care for people living with HIV. The HIV continuum of care is useful both at the individual-level to assess care outcomes, "as well as a population-level framework to analyze the proportion of people with HIV in a given community who are engaged in each successive step" (CDC, 2019, p.1)

Research Question and Expectations

The research proposed in this paper is nested within the framework of Ezintsha's operational research, embedded in the STAR program, which seeks to gather information on kit use, yield, and entry into HIV care (prevention or treatment) post HIVST distribution in South Africa. An initial quantitative data analysis carried out by Ezintsha identified fluctuations along the stages of care, particularly in the uptake of HIVST and entry into care. The qualitative study proposed in this paper will try to identify explanations for fluctuations in this cascade of care and to produce a descriptive account of users' experience of HIVST. As there is not yet extensive research on HIVST from the user's perspective, this aim of this study is to contribute to the existing literature and research on HIVST as a potential intervention to increase testing among under-tested segments of the population in South Africa. Thus, an analysis of users' experiences can provide a qualitative context to understand fluctuations in uptake and entry into care post-use and contribute to the development of effective HIVST interventions.

The research questions that this paper will address are as follows:

"What are the experiences of HIVST users from the community-based distribution model of the STAR program in South Africa?"

1. *"What are the barriers and facilitators to the uptake of HIVST expressed by users?"*
2. *"What is the influence of HIVST on users' health behavior post-use?"*

In using the IDP model to understand the decision-making process involved in the uptake of HIVST, the expectation is that knowledge and persuasion will be particularly important in the decision and implementation of the HIVST. Following the existing literature, the expectation is that familiarity will be an important factor in the knowledge stage and that convenience and privacy will be an important factor in the formation of a favorable attitude towards HIVST in the persuasion stage (Ritchwood et al., 2019).

In line with the IMB model presented in the theoretical framework of this paper, information on HIVST and behavioral skills (control) to use the HIVST will be prerequisites for the uptake of HIVST. The expectation is that motivation, specifically to get tested and know one's status, will be the main determinant in the decision to use HIVST. Furthermore, the expectation is that behavioral control will mediate the relationship between motivation and uptake of HIVST. In line with the existing literature, the expectation is that the main barrier to the uptake of HIVST will be concerns over the validity of the test. The expectation is that privacy, convenience, control over disclosing one's status and the ability to circumvent facility-based barriers will be the main facilitating factors in the uptake of HIVST, according to the existing literature (Ritchwoood et al., 2019; Njau et al., 2019). These factors are expected to facilitate the uptake of HIVST as they make the behavior of using the HIVST easier, and thus increase the behavioral control of the individual.

Following the theoretical framework, the expectation is that the mechanisms of information, motivation and behavioral control will be the main determinants of the influence of HIVST on users' health behavior. It is expected that behavioral control, or behavioral skills, will mediate the relationship between information, motivation, and users' health behavior. Following the theoretical concepts of the IMB model, the expectation is that motivation to either maintain a negative HIV status or to manage the virus, given a reactive result, by entering into care will be the main determinant of users' health behavior. In line with the existing literature, the expectation is that the intervention of HIVST has the potential to influence users' health behavior through the theoretical concept of information by emphasizing the benefits of HTC, including the reduction of HIV transmission and the availability of care and treatment. The expectation is that the theoretical concept of behavioral control will be negatively affected by facility-based barriers to clinic attendance and this will limit the influence of HIVST on users' health behavior (Mohlabane et al., 2016).

Research Methods

Study Design and Procedures

A qualitative research design was used as this method is best suited for the exploratory nature of this research and provides more flexibility and thus the opportunity for richer data collection (Mack & Woodsong, 2005). Post-distribution, potential participants from the community-based distribution model who consented to be followed-up were contacted telephonically and were informed that they were eligible to participate in a qualitative research study regarding their experience with HIVST. (Appendix A). If the HIVST recipient was willing to participate in the study, they were provided with information regarding the purpose of the study and subsequently asked if they were willing to provide informed consent (Appendix B). If the HIVST recipient met the inclusion criteria and agreed to provide informed consent to participate in the study, an interview date was arranged. At the time of the interview, the interviewee was asked to fill out a demographic questionnaire for the semi-structured interview (Appendix C). Next, the interviewee will be asked if they were willing to provide consent for the interview to be audibly recorded (Appendix D). If further consent for the interview to be recorded was obtained, the interview was conducted by trained interviewers using a piloted interview guide (Appendix E). After each interview, participants were provided with information on the availability of counseling services, if needed.

Participant Sample and Recruitment

The STAR program's target population consisted of under-tested segments of the population, which were then divided into specific target populations for each of the distribution models. This study focused on the community-based distribution model in which the target population that participants were sampled from included: high-risk sexually active men (ages 20+) and adolescent girls and young women (ages 15-24). The participants of this study were selected based on the following inclusion criteria: 18 years or older, the primary recipient of an HIVST kit and able to recall receiving an HIVST kit, consented to follow-up on at least one self-reporting platform, provided consent to be contacted with follow-up questions, and willingness to provide informed consent to participate in this qualitative study.

Convenience sampling was the method used to distribute the HIVST kits in high foot-traffic areas, to recruit recipients to self-report their data via one of the four platforms, and to contact potential participants for this study. Sixteen study participants were identified from the Wits RHI STAR program distribution database as recipients of HIVST kits from the community-distribution channel. Of the sixteen participants, ten participants were women between the ages of 20-49, and six participants were men between the ages of 22-48 (Appendix F).

Data Collection and Operationalization

A semi-structured interview guide was the primary data collection instrument. This instrument is best suited to the research questions of this study, as in-depth interviews are optimal for collecting data on individuals' experiences, particularly in relation to sensitive topics, such as HIV (Mack et al., 2005). The in-depth interviews were originally planned to be conducted face-to-face, however due to COVID-19 only the first two interviews were conducted face-to-face and the remaining fourteen interviews were conducted telephonically. Consenting participants were given the choice to have the interview at the initial point of telephonic contact or to schedule the interview for a later time. The interviews lasted on average 30-60 minutes. Participants were paid a reimbursement for mobile data usage of 150 Rand, which they received through an e-wallet. The interviews were conducted in the language of choice: English, Zulu, or Setswana. The interview questions were first developed in English and then translated into Zulu and Setswana. Furthermore, the content validity of the original questions was assessed using back translations (Appendix E).

In the semi-structured interview guide, the domains for discussion consisted of open-ended questions that sought to elicit barriers and facilitators to HIVST kit use and entry into care post-HIVST use as they related to individual and program factors (Appendix E). The main barriers and facilitators to using HIVST kits as they related to individual factors included questions on participants' knowledge, attitudes, and beliefs regarding HIVST. With regards to HIVST kit use as it related to program factors, participants were asked questions about the quality of service they received at the HIVST kit distribution point. In eliciting the main barriers and facilitators to entering into care related to individual factors, participants were asked about their motivation to access healthcare and their response and coping strategies to HIV diagnosis. Participants were also asked to discuss elements of the program that influenced their decision to attend a clinic for confirmatory testing or prevention services, or not, as it related to program-level factors that influenced the decision to enter into care post-HIVST use.

Data Analysis

The interviews were digitally recorded, transcribed in the original language, and translated into English. A thematic analysis approach was used to analyze the data. This method involved "identifying, analyzing, and reporting patterns (themes) within qualitative data" and allowed the researcher to organize and describe the data in detail (Braun & Clarke, 2006, p. 79). This approach was best suited to analyze this data as the research proposed intended to produce a descriptive account rather than a theory. In the context of this qualitative study, thematic analysis involved; transcribing the data, systematically coding interesting features of the data, categorizing relevant codes into potential themes, comparing and adjusting potential themes with the thesis supervisor in order to ensure external validity of the constructs, and summarizing the data for each theme. Weekly meetings were held with the thesis supervisor to debrief and troubleshoot any problems that arose and as a part of an ongoing analysis to discuss emerging themes.

Data analysis was supported by the use of N-Vivo 12 quality analysis software. This program assisted the researcher in coding textual data, manipulating and searching for combinations of coding or words in the text, and categorizing and identifying the most frequently reported themes. Thus, this software helped to manage the qualitative data of the transcribed interviews and identify themes and was complementary to the thematic analysis approach of this study. At the Ezintsha office where the interviews were transcribed, data was stored according to the organizational data management standards; digitally held data was stored in encrypted folders on the access-restricted Ezintsha STAR program shared drive. Hard-copy data, such as interviewer notes, were kept secured in a locked cabinet in a data room. No linking information was stored together to ensure participant anonymity. However, due to the fact that the analysis of the interview transcript had to be done remotely. the transcript data was shared to my Utrecht University access-restricted email, however these files were deleted once the analysis was finished.

Ethical Considerations

The STAR program was implemented in adherence to the ethical principles for medical research involving human subjects of the Declaration of Helsinki. Ethics approval for the qualitative study was obtained from the Research Ethics Committees of the University of Witwatersrand and no data was collected prior to this approval.

Results

In this section the results of the data analysis are presented, participants are referenced only by a given interview number that is not linked to participants' information in order to ensure anonymity. The results are presented by order of research question and the findings of each research question are organized by the identified themes that resulted from the data analysis.

Uptake of HIVST

All sixteen participants in this study used the HIVST that they received. The uptake of HIVST was ultimately shaped by the following themes: interest in HIVST, perceived risk of HIV, perceived role of distributors in the HIV care continuum, the barriers to HIVST, and the facilitators of HIVST.

Interest in HIVST

Participants expressed that an initial interest in HIVST as a new form of testing evoked curiosity to know more about HIVST and how it works. This contributed to their decision to receive the HIVST kit from distributors and was a prerequisite for the uptake of HIVST. Additionally, a gap since the last time participants had tested and the opportunity to check one's HIV status at home was linked to the decision to receive the test, with one participant explaining:

> *"They showed us how it works. It was something new, and my sister and I, who I was with on the day, didn't know you could test outside the clinic without using blood." – Participant 5*

Perceived Risk of HIV

Users' health behavior was linked to their perceived risk of HIV and motivated the decision to use the HIVST. Participants explained that sexual risk behaviors such as having unprotected sex or engaging in sexual activity with more than one partner contributed to their perceived risk of HIV and ultimately influenced their decision to receive and use the HIVST kit, in order to know their HIV status. When asked about their perceived HIV risk during interviews, many participants expressed the possibility of their partners having contracted HIV as a risk factor that contributed to their decision to use the HIVST. Many participants expressed concerns of infidelity, with one participant explaining:

> *"So, it had been a while without testing, and I needed to know my status, I prefer safe than sorry, you understand, unlike (not) 2/3 years down the line. I don't know, my partner and I were not having safe sex, so... it's very important to know yours and the other person's status because you don't know what they do when you aren't there [next to them]" – Participant 8*

Some participants also explained that they were encouraged to test by friends or family members who provided a social motivation to use the HIVST, with one participant explaining:

> *"I wasn't on my own when I took my test. I have a good relationship with my brother so when I picked it up we had been traveling together. We each took one, so we motivated each other." – Participant 2*

Perceived Role of Distributors in HIV Care Continuum

An interesting finding of this study was the perceived role that participants had of distributors as providing support in the use of the HIVST, as a support system post-use, and as a link to entry into care. When asked about the follow-up of recipients post-distribution of the HIVST, one participant expressed:

> *"It made me feel encouraged cause it showed me that what you guys are doing is good and then doing follow up is part of their jobs and it gave me confidence that let me trust this person because this person is giving me the kit and they want to know the results, so that she can help me if I found out that I'm positive and be able to take the second step to see where I go and how do I go about that." – Participant 17*

Barriers to HIVST uptake

During the course of the interviews, the most commonly cited factors that initially deterred the use of the HIVST kit were: lack of familiarity with HIVST and concerns related to the validity of the HIVST. A perception of blood-based testing as having a higher accuracy were also related to concerns of the validity of the HIVST.

Participants who were not familiar with the HIVST as a form of testing expressed an initial skepticism of its accuracy, saying for instance that:

> *"Eh, you know I was very skeptical, not sure if the test was accurate or not. I did not trust it." – Participant 9*

Participants who expressed a lack of familiarity with HIVST also explained that it might not be readily accepted as an accurate form of testing in the community-level:

> *"You know, to be honest with you, it didn't feel real because, like I said before, we only know one process of testing for HIV, which is through blood. Blood needs to be taken out in order to check if it's there or not. Even when I gave it to my partner, he was like no we are not used to this thing we have to go like for an actual blood- no. Because a lot of people don't know it and even if I were to pass by someone here and asked them about it, they would be like we don't know it's not really familiar" – Participant 5*

Concerns about the validity of the HIVST were shared by many participants, with one participant explaining their initial perception of HIVST as:

> *"Ok so this might sound negative or something, I just thought this thing is not going to work… because, like I said it's not a blood test so I wouldn't think that it will be, it could be, accurate" – Participant 1*

What was commonly expressed by participants was the fact that the test was oral-fluid based rather than a blood-based form of testing, and this was the main factor which contributed to their concerns of the validity of the HIVST. One participant explained that an oral fluid-based method of testing might deter use of the HIVST due to the fact that HIV education focuses on the fact that HIV is transmissible by blood, and not oral fluids. The participant stressed that:

> *"In our community so it was so unbelievable I felt like even if I did it, I will still want to go for an blood one you know… because, I'm sorry to say this but as a black person, you want to do things that you are used to/the way you are used to and you don't believe it's in your saliva. Do you remember when we were taught about it they tell you, you can use a spoon and share a spoon with a person who is positive because HIV is not in the saliva, it's not in your mouth, it's something like in the blood so now when you come back and say you can test with oral then it comes a question how but then does it mean that it is, you know what I'm saying?" – Participant 5*

Facilitators of HIVST Uptake

In discussing which factors facilitated the use of the HIVST, the most commonly cited factors were: a preference for an oral-based method of testing, the ability to circumvent facility-based barriers, control over the disclosure of one's status, and privacy in testing at home.

A preference for oral-based testing was commonly cited as a practical feature of the HIVST which facilitated its use among users, with one user summarizing:

> *"The test where you must rub your gums [oral test] is much easier [to use]. It doesn't require you to go anywhere, it saves you time, so you won't have to go back and forth to the clinic, it's convenient." – Participant 8*

The ability to circumvent facility-based barriers was a feature of the HIVST that was cited by the majority of participants as a facilitating factor in HIVST uptake. This included the ability to circumvent practical and social facility-based barriers. The facilitating factors to circumvent practical facility-based barriers included the convenience that HIVST provided by allowing users to test at home, the avoidance of long waiting times and overcrowding experienced at clinics. One participant explained that:

> *"I don't have enough time to go to the clinic especially because of how packed it gets there. The treatment is not the same at different clinics. When I am at home, the clinic is very far, I get lazy. But then, when I took the test I saw that it was especially good for me because I can use it anytime, in my own space or I can ask anyone I know and trust to be with me when I do." – Participant 2*

The facilitating factors to circumvent social facility-based barriers included the avoidance of negative staff attitudes, stigma, and gender stereotypes. With one participant explaining:

> *"You can use this test and test yourself alone or with your partner. Some people do not like testing in front of sisters because they think they will gossip about them… so they'd like it to be private." – Participant 8*

Control over the disclosure of one's status was frequently explained as facilitating the use of HIVST. Some participants expressed that they felt that staff at clinics discussed their status behind their backs, and feared that their results might be inadvertently disclosed to someone else while testing at the clinic. Participants also explained that they felt that other patients may become aware that they are testing for HIV when they have attended clinics in the past. One participant described this when explaining how HIVST enabled them to test, saying:

> *"I think that the benefit at the time was the fact that I can do it in my room or wherever. For me, that was beneficial, you know, I don't have to walk out and even if the results were not what I was expecting I knew that when I go outside, I don't have to feel like everyone knows. So, the fact that I'm alone, that was beneficial to me." – Participant 5*

Similarly, privacy was a commonly cited facilitating factor of HIVST, with participants emphasizing that the ability to decide where to use the HIVST provided them with more freedom in testing. The ability to test alone, without the presence of clinic staff, was also mentioned as contributing to participants' perceived autonomy over testing. When asked about their experience with using the HIVST, one participant mentioned that the HIVST offered both convenience and privacy, saying that:

> *"So, basically, this whole thing [HIVST] saves time you know. For anyone who's scared of going to the clinic, I think that is why I'd recommend a self-test to someone who wants to be private." – Participant 1*

Furthermore, in explaining why privacy was a facilitating factor of HIVST, one participant also expressed that the ability to test at home with a trusted person contributed to their favorable attitude towards HIVST:

> *"I can use it anytime, in my own space, or I can ask anyone I know and trust to be with me when I do." – Participant 2*

Influence of HIVST on User's Health Behavior

All sixteen participants consented to disclose their HIVST result during the interviews: fourteen received a negative result and two received a reactive result. Participants that received a non-reactive result were asked about the influence of HIVST on their health behavior post-use and users that received a reactive HIVST result were asked about their entry into care for treatment post-use.

Negative HIVST Result as a Catalyst for Engaging in Preventative Health Behavior

Participants who received a negative result explained that the HIVST influenced their health behavior post-use by encouraging them to test more frequently, engage in preventative behavior, and adopt a healthier lifestyle.

Participants who tested HIV negative stressed that the convenience of HIVST encouraged them to test more frequently in the future. However, when asked whether the HIVST motivated users to attend a clinic for general checkups or to test for other infections or illnesses, the majority of those who received negative results said no, it did not impact their plans for future clinic attendance. One participant expressed that although encouraged by the HIVST, prevailing gender stereotypes that associate clinics as a "woman's place" still deterred him from attending the clinic regularly. He explained that he would prefer to only use HIVST opposed to other HTC services:

> *"It encourages me to go but it becomes difficult for a man to go to the clinic and queue for HIV testing. So, it would be great if we get them [HIVST] after 3 months because for going to the clinic for testing, I will not lie to you it's difficult. You see?" – Participant 15*

Participants also explained that their negative HIVST result served as a catalyst to engage in preventative health behavior, by using condoms and being faithful to one sexual partner as a means to reduce their risk for HIV. In discussing the impact HIVST had on them, many participants mentioned wanting to protect their partners as a motivation for their future health behavior and to lead a healthier lifestyle, with one user saying:

> *"Mostly, I now have to take even better care of myself, more especially (for) the person I am with even though we do not live together. I needed to be more careful about who I touch, as we know HIV can be transferred though blood and sexually, and these needles. I just have to be more accurate about my life and take good care myself..." – Participant 2*

Experience of Entering into Care for HIV Treatment

The two participants that received a reactive HIVST result were linked to follow-up care. Both participants who received a reactive result attended confirmatory testing where there HIV result was confirmed positive. Both participants who tested positive also received counselling services in which they were advised to seek social support, such as contacting a close friend or trusted person. Furthermore both participants remained in care and received further health services, such as CD4 counts, and discussed ART initiation with their healthcare provider. One user described how their HIV diagnosis influenced their subsequent health behavior, saying that:

> *"When I have sex now, I always use condoms and if I get a cut, I make sure that no one touches my blood, yea, so that I may prevent others from getting infected. Even when I get a cough, I go there to check my CD4 count."* – Participant 14

When asked about their experiences post-HIVST use, both participants who tested positive for HIV expressed that they felt comfortable in receiving counselling services after they attended confirmatory testing. They also explained that they felt they were given good advice on the subsequent steps in being retained in care and receiving treatment (ART). With one participant explaining how the health care provider was monitoring their treatment:

> *"Yes, I take my weight and then after a few months you will have your blood tests to check your blood cells… yes for your CD4 count. They check whether or not it is low and ask why you are (or aren't) adhering to your treatment."* – Participant 14

In describing their own well-being, both participants explained that they felt comfortable with the progress of their care and the status of their health.The participants described that as a result of their diagnosis post-HIVST use allowed them to act quickly and enter into care, and that they had continued to engage with their healthcare provider and were retained in care. When asked what they would suggest for other recipients of HIVST that may experience anxiety around testing, one participant said:

> *"I would encourage them and let them know it isn't the end of their life, life goes on, they need not fear."* – Participant 14

Discussion

The aim of this study was to take an account of the experiences of HIVST as expressed by users from the community-based distribution model of the STAR program in South Africa. This was done using in-depth interviews to address and highlight the factors that shape the uptake of HIVST, including the barriers and facilitators to HIVST, and the influence of HIVST on users' health behavior post-use.

In addressing the factors that shaped the uptake of HIVST, the main findings show that the initial decision to receive the kit from distributors was mainly driven by an interest of HIVST as a new form of testing. While most research on HIVST has focused on the acceptability of HIVST, such as Moore's (2017), a new aspect about this finding is that it acknowledges the initial stages of how individuals form an attitude towards HIVST, beginning with a curiosity over HIVST as a form of testing. The findings of this paper also show that users' health behavior and that of their partners contributed to their perceived risk of HIV, and was a main explanation given by participants in their decision to use the HIVST. Concerns over partners' fidelity also contributed to the perceived risk of HIV. Similarly, concerns over potentially infecting their partners due to personal risk behaviors also contributed to the decision to use the HIVST. This finding on the influence of participants' perceived partner risk on the decision to use HIVST is an interesting aspect to take into account when looking at the factors that shape HIVST uptake. A further finding of this paper that is novel, to the best of my knowledge, was the perception of distributors in playing a role not only in the use of the HIVST, but also along the continuum of care as a form of support and link to entry into care.

Following the theoretical framework of this paper, the expectation was that familiarity with HIVST and positive perception of HIVST as a new form of testing would shape recipients' decision and ultimate use of the HIVST. The findings of this study agree with the theoretical expectation of this paper, in that familiarity with HIVST (knowledge) was a prerequisite for HIVST use and that convenience would be an important factor in the formation of a favorable attitude towards HIVST as a form of testing (persuasion). Furthermore, what the findings of this study show in relation to the IDP model, is the importance of the supportive role of distributors in the knowledge and persuasion stage. The role of distributors was especially salient in the confirmation stage, where users' expressed that distributors' role in the follow-up strengthened not only in the decision to test but in the commitment to follow-up. The IDP model thus provides a connection between individuals' decision making to use HIVST and underscores the importance of the distributors to meet the organizational goal of the STAR program to increase HIVST uptake by the target population.

While the IDP provides a framework to conceptually understand the stages involved in the decision-making process for HIVST use, the IMB model also distinguishes the motivational and behavioral mechanisms which influence HIVST uptake at the individual level. Similarly, information on HIVST was a prerequisite for HIVST uptake. In line with the expectation of this paper, wanting to know one's HIV status was the main motivation for the uptake of HIVST. Furthermore, facilitating factors of HIVST which enabled more behavioral control, such as convenience and perceived autonomy in the decision to test, did mediate the relationship between information, motivation and the behavior of HIVST uptake.

In line with the existing literature, the findings of this paper show that the ability to circumvent facility-based barriers, privacy, disclosure over one's status, and the perceived autonomy in the decision-making to test were facilitating factors for the behavior of HIVST uptake. Additional factors which this study found as contributing to the uptake of HIVST included a preference for oral-based testing and the behavioral control which HIVST provides in facilitating the ease of performing the behavior of testing. Similarly, the finding of this paper that concerns of validity would be the main barrier to the uptake of HIVST, corresponds to the research of Njau et al. (2019) and Ritchwood et al. (2019) Additionally, a lack of familiarity with HIVST and a higher acceptability of blood-based testing constituted barriers to the uptake of HIVST were factors that deterred the use of HIVST and were novel to the findings of this paper. In the context of the other research, an expected deterrent for the uptake of HIVST was the cost of the HIVST. As the HIVST was distributed free of charge this was not a relevant barrier in the context of this study. The findings of this study fit neatly into the context of Njau et al. (2019) and Ritchwood et al.’s (2019) findings on the barriers and facilitators of HIVST. In the context of their research, a factor which they determined as facilitating the use of HIVST which did not emerge in the findings of this research were the ability of HIVST to decrease discrimination.

With regards to the second research question, the findings show that the HIVST did influence users’ health behavior post-HIVST use. For participants who received a negative result, the HIVST served as a catalyst to engage in preventative behavior in order to maintain a negative HIV status, and this was illustrated in the desire to continue frequent testing for HIV. However, facility-based barriers negatively affected the perceived behavioral control of individuals and limited the influence of HIVST on clinic attendance for those who tested negative, as was the expectation of this paper. It is however important to note that when receiving the HIVST, recipients were told that they only needed to attend the clinic for confirmatory testing if they received a positive result, and thus, the importance of clinic attendance post-use was a point of confusion for participants.

The relationship between information on entering into care and motivation to maintain a negative HIV status or enter into treatment for HIV was mediated by perceived behavioral control to enter into care. For participants that received a positive HIVST result, behavioral control positively mediated the relationship between information on HTC services available, motivation to initiate treatment post-diagnosis and the behavior of entering into care. This was illustrated in the findings, where both users who received a positive HIVST result attended confirmatory testing, engaged in care, and had plans to initiate and be retained in ART. In the context of the IMB theory, the desired behavior of engaging in care post-HIVST was mainly influenced by motivation to maintain a negative HIV status or to receive treatment for HIV, which aligns with the theoretical expectation of this. Information provided from the HIVST program on nearby clinics, services available, confirmatory testing, and the process of entering into care also played a role in users' health behavior post-HIVST use.

Strengths and Limitations

A main strength of this study is that the findings are derived directly from the reported experiences of HIVST users in South Africa, and therefore have high ecological validity and are relevant to the intended population. A further strength of this study was the use of semi-structured in-depth interviews in exploring participants' thoughts, feelings, and beliefs about the topic of HIVST. The flexibility in the interview format allowed for the discovery of factors at different levels of influence that contributed to users' experience of HIVST along the stages of care. The inductive thematic approach to data analysis is a strength in the construct validity of this study as the findings derive from the themes that emerged in the interviews.

A limitation on the internal validity of this study is the possibility for social desirability bias during the interviews. This is especially true with relation to the topic of this paper as interviewees may feel inclined to over-report good health behavior such as attending the clinic post-HIVST. A social desirability bias could also stem from the fact that participants were interviewed by the HIVST distribution organization, and therefore may feel compelled to exhibit a favorable attitude towards HIVST or to report having used the kit after receiving it.

A further limitation of this paper was the way in which the semi-structured interviews were operationalized in practice. Interviews were outsourced and conducted by two persons from the organization who, prior to the interviews,were not directly involved in this study. This is in part due to external factors, namely the lockdown restrictions that resulted from COVID-19, which affected who was able to participate in conducting the interviews and how much space there was for regular review of the interview guide. It is recommended that in the future, the importance of training in qualitative interviews is highlighted, in order to improve internal validity and reduce the potential for bias in interview responses, by avoiding leading, double-barreled, or confusing questions. A limitation on the external validity of this study is its relatively small sample size of sixteen participants. The number of interviewees for this distribution model had been pre-determined by the organization through which the data was collected. It may be recommended that future qualitative research on this topic have a larger sample size of twenty to thirty participants.

Research Implications

An important implication of this study is that all sixteen participants demonstrated a favorable attitude towards the innovation of HIVST. Furthermore, many participants also expressed that they would prefer to have continued access to, and would test more frequently, with HIVST as their primary form of testing, rather than attend the clinic for traditional testing services. The high acceptability of HIVST found in this study implies that it is an effective strategy to reduce testing gaps in South Africa.

As this was the last year of distribution under the STAR program, the Department of Health will be overtaking future HIVST distribution at the national level in South Africa (Majam, 2020). There are two implications, related to the distribution and follow-up components of the program which could be used to guide future HIVST interventions. The first being that according to HVST users, the factors of HIVST which facilitated them to test did outweigh the barriers to HIVST, the main barriers being concern over the validity of the test. In future distribution of HIVST kits, an increased effort to disseminate information about the validity of HIVST, also at the clinic and pharmacy or facility-based level, would make the implementation of HIVST more effective. As HIVST becomes a more familiar form of testing, it is expected that concerns of validity will also decrease.

Another important implication of this study which should be used to guide future HIVST interventions is the perceived role of the HIVST distributor as providing support in the uptake of HIVST and as a link to enter into care post-use. HIVST users stressed that there would be less fluctuations along the stages of care if distributors played a more active role in engaging with follow-up post-distribution.This implies that in the implementation of HIVST as a supplement to South Africa's national HIV testing strategies, there should be a continued focus on providing support in the follow-up of distribution in order to optimize HIVST as an intervention.

Conclusion

The STAR program and the operational research on the distribution, uptake, and entry into care constitutes one of the first large-scale HIVST interventions in South Africa. As large-scale programs to distribute HIVST are relatively new, there are gaps in the existing literature on the acceptability and effectiveness of HIVST as a health promotion innovation, including in the context of South Africa. This qualitative study on the experiences of HIVST users contributes to current and future efforts to diffuse HIVST as an innovation that can address barriers to testing for under-tested segments of the population. Overall, the experience of progressing through the steps of HIV self-testing: from receiving the kit, deciding to test, following-up, and entering into care post-use were described by users as positive. The main implication of this study is that HIVST has the potential to facilitate the uptake of testing, and that the perceived benefits of HIVST outweigh potential barriers that stem from a lack of familiarity with HIVST. Future research on users' experiences with HIVST should be emphasized and incorporated into the design of interventions to distribute kits, in order for HIVST to effectively increase testing and entry into care for under-tested segments of the population in South Africa. The distribution of HIVST, free of cost, should continue to be emphasized in national policies to meet the 95-95-95 targets laid out by UNAIDS to end the AIDS epidemic by 2030.

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Appendices

Appendix A: Follow-up Guidelines

FOLLOW-UP GUIDELINES

Purpose of the study

Hello, my name is ___________________________. I work at Ezintsha a sub-division of the Wits Reproductive Health and HIV Institute (Wits RHI). As part of this study, I am talking to individuals like yourself who are primary recipients of HIV Self-Testing (HIVST) kits and had consented to follow-up. I am calling to find individuals who would be willing to participate in interviews which are part of a study that is aiming to explore the barriers and enablers for HIV self-testers to use test kits, self-report and enter into care. The interviews will take between 60-90 minutes and will be conducted at the Ezintsha/Wits RHI STAR program offices in Hillbrow, Johannesburg. Furthermore, participants will be paid a travel reimbursement fee of R150. The interviews will be conducted in a language of choice offered between English, Zulu, Setswana and Afrikaans. The interview will be recorded and your personal identifiers will not be used during the interview and during analysis of the information you will provide.

Inclusion Criteria

- ☐ First, can you verify for me if you recall receiving an HIVST kit and providing consent to be contacted with follow-up questions?
- ☐ If so, were you the primary recipient of the kit and are you 18 years or older?
- ☐ Would you be willing to provide informed consent for this qualitative study?

Arranging the Interview

If the individual provides consent to participate in the qualitative study, arrangements can be made for the face-to-face interviews.

Date of interview ___ /___ / _____
Time of interview ____:____
Interview language _______________

Things to bring to the interview:

1. Identity document (required for transport reimbursement processes)
2. Preferred method of reimbursement – e-wallet or cash – if e-wallet we will need to participate to validate their cell number & sign

Reminder

After arranging the interview date and time, plan a reminder call or SMS 2 days before the date of the interview to verify that the individual remembers consenting to participate and the accurate time and place of the interview.

Date of interview reminder ___ /___ / _____
Time of interview reminder/call if SMS ____:____

Further Questions

At the end of the call, ask the potential participant if they have any further questions about the study. Furthermore, should they have any further questions regarding this study at a later time provide them with the contact details of ______________.

Contact Details

Ezintsha a Division of Wits Reproductive Health & HIV Institute (RHI)
T: +27 (0) 11 358 5300 **E**: vzishiri@wrhi.ac.za

Appendix B: Informed Sheet and Consent Form for Semi-Structured Interview for the Qualitative Study

Purpose of the study

Hello, my name is __________________________. I work at Ezintsha a sub-division of the Wits Reproductive Health and HIV Institute (Wits RHI). As part of this study, I am talking to individuals like yourself who are primary recipients of HIV Self-Testing (HIVST) kits and had consented to follow-up.

Through this interview, the researcher of this study/ I would like to find out:

1. What made you use / not use the HIVST kit after accepting the offer to take the kit for yourself or partner(s)?
2. What made you use or not use current digital self-reporting platforms provided under the HIVST programme.
3. How we can improve your use of the current self-reporting platforms for the HIVST programme?
4. What made you attend (or not) a health care facility for HIV confirmatory testing or prevention or treatment services as part of the client journey in the HIVST programme?
5. How we can promote clinic attendance for clients who receive HIVST?

Procedures

If you agree to participate, I will talk to you for about 60 - 90 minutes. At the end of the interview you will be requested to complete a demographic questionnaire. This will be administered by yourself or me should you require assistance. Your participation in this interview is completely voluntary (this means you, and only you, can choose whether you would like to join this study). You may refuse to answer any specific question if you feel uncomfortable with that question. You do not have to give me a reason for refusing to answer specific questions. You can also decide to stop participating at any time. If you decide that you don’t want to be part of this study, there will be no negative consequences for you, and it will have no impact on your accessing HIVST or any health care services provided by Ezintsha/Wits RHI or anywhere else. There are no right or wrong answers to any of the questions. I only want to know about your experiences, opinions and ideas.

Confidentiality

We don’t record your full name in this study. To help us to remember what you say here today, I will take notes and will record today’s session on audio-tape. Only our research team will review the tapes. After transcription, the tapes will be safely stored for six years and all personal identifiers will be removed from the transcript. Your name will not be recorded and if necessary a false name will be used (you can choose a name yourself). The only place your real name will be recorded is on this information sheet and informed consent form. These sheets are kept in a locked cabinet and your name will never be used in any of the research outputs.

Discomforts and risk

There is a slight risk that you may feel uncomfortable talking about some of the topic areas. We do not wish this to happen, and you may refuse to answer any question, or any part of a question, at any time.

Reimbursement

There is no financial compensation for your participation. You will however be provided with a travel reimbursement fee of R150 for attending the interview.

Benefits

There are no direct benefits to you at this stage, but your participation will help us find out more about why people who have experience with HIV self-tests chose to use or not use them and follow the processes of care for HIV. With the information gained from these interviews we will try to make changes to the STAR HIVST implementing strategies and make HIVST and linkage to care more appropriate for HIVST users. Further the information gained will assist with improving access to self-reporting and support platforms for HIV self-testers.

Offer to answer questions and freedom to withdraw from the study

If you have questions about the study you may ask them now or you can call: Vincent Zishiri on 011 358 5300

If you don't have any questions and agree to participate in this study then I will go ahead and begin. But first, I will ask you to sign this form stating that I, the interviewer, have informed you of your rights as a participant and that you have agreed to participate in today's interview. This is the only place where your name will be entered. If you cannot sign your name, you may simply mark the space with an 'X'.

Volunteer's statement

THE INTERVIEW HAS BEEN EXPLAINED TO ME. I HAVE BEEN GIVEN A CHANCE TO ASK ANY QUESTIONS I MAY HAVE AND I AM CONTENT WITH THE ANSWERS TO ALL OF MY QUESTIONS.

I ALSO KNOW THAT:
MY RECORDS WILL BE KEPT PRIVATE AND CONFIDENTIAL;
I CAN CHOOSE NOT TO BE INTERVIEWED, NOT TO ANSWER CERTAIN QUESTIONS, OR TO STOP THE INTERVIEW AT ANY TIME;
IF I REFUSE TO BE INTERVIEWED, IT WILL NOT AFFECT MY MEDICAL CARE / ROLE AT THE CLINIC.
I GIVE CONSENT THAT MY INTERVIEW CAN BE TAPE-RECORDED.
I UNDERSTAND THAT THE INTERVIEWS FROM APPROXIMATELY 64 PRIMARY RECIPIENTS OF HIV SELF-TESTING KITS WILL BE ANALYSED WITH MINE AND REPORTED ON AS FINDINGS OF THE STUDY.

I thank you for your time.

______/______/______	______________________	_________________________________
Date	Name of volunteer	Signature or Mark of Volunteer
______/______/______	______________________	_________________________________
Date	Name of witness	Signature of Witness (If participant is illiterate)

Interviewer's statement

I, the undersigned, have defined and explained to the volunteer in a language that he/she understands the procedures to be followed, the risks and benefits involved, and the obligations of the interviewer.

_______________	__________________	________________________
Date	Name of interviewer	Signature of interview

Interview Consent Form #: ____

Appendix C: Demographic Questionnaire for Semi-Structured Interview for the Qualitative Study

Date of interview: ______/______/______

Through which distribution model did you receive an HIVST? (Please tick one)

Model	Please tick one
Community based	
Public Sector Facility based	
Private Sector- Workplace	
Key Populations (Sex Workers Project)	

Demographic Information

1. What is your age? ____________________

2. Are you male or female? _________________________

3. What is your highest educational level?

Category	Please tick one
Some primary school	
Completed primary school	
Some secondary school	
Completed secondary school	
Any tertiary education/post-secondary school	

4. What is your current employment status?

Category	Please tick one
Full-time employed	
Part-time employed	
Self employed	
Other (specify)	

5. What is your monthly income?

Category	Please tick one
< R5000 / < $500	
R5000 – R10 000 / $500 - $1000	
>R10 000 / > $1000	

6. What nationality are you? _________________________

7. Where do you reside? _________________________

8. What is your marital status?

Category	Please tick one
Married	
Single	

Widowed	
Cohabiting	
Divorced	
Other (specify)	

9. If “married” or “cohabitating” is your spouse/partner a man or a woman?

Category	Please tick one
Male	
Female	

10. If “single’, “widowed” or “divorced” do you mostly date men or women?

Category	Please tick one
Male	
Female	

11.Do you have children?

Category	Please tick one
Yes	
No	

12. If “yes”, how many? ________________________
Demographic questionnaire # _________________

Appendix D: Consent Form for Audio Recording of Semi-Structured Interview for the Qualitative Study

I will record the interview using an audio recorder to help me remember all the information from our conversation. This will only be done however with your consent. Thereafter what you have said will be transcribed (written out). Our discussion will be confidential and your name will not be recorded with the tape recording. There will be no way of linking what you say in this interview to who you are. Only the research study team will see this information.

The tape records will be stored in Johannesburg and the only people who will have access to the tapes will be the principle investigator of this study. Six years after the research has been finalised, the tapes will be destroyed.

Should you have any further questions regarding this research project please feel free to contact the Principal Investigator Vincent Zishiri. The contact details are provided below.

If you agree to this interview being audio recorded please provide me with your full name and signature.

I, ____ have been explained and understand the reason for the audio recording. I agree to this in-depth interview being recorded.

Research participant:

Date: ________/_______/_______ Signature: ____

Interviewer:

Date_______/_______/_______ Signature: ____

Consent Form #: ____

Contact Details
Principal Investigator: Dr Vincent Zishiri
Senior Programme Manager: HIV Self Testing
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Appendix E: Demographic Questionnaire for Semi-Structured Interview for the Qualitative Study

Date of interview: ______/______/______

Through which distribution model did you receive an HIVST? (Please tick one)

Model	Please tick one
Community based	
Public Sector Facility based	
Private Sector- Workplace	
Key Populations (Sex Workers Project)	

Demographic Information

13. What is your age? ____________________

14. Are you male or female? _________________________

15.What is your highest educational level?

Category	Please tick one
Some primary school	
Completed primary school	
Some secondary school	
Completed secondary school	
Any tertiary education/post-secondary school	

16. What is your current employment status?

Category	Please tick one
Full-time employed	
Part-time employed	
Self employed	
Other (specify)	

17.What is your monthly income?

Category	Please tick one
< R5000 / < $500	
R5000 – R10 000 / $500 - $1000	
>R10 000 / > $1000	

18. What nationality are you? _________________________

19. Where do you reside? _________________________

20.What is your marital status?

Category	Please tick one
Married	
Single	

Widowed	
Cohabiting	
Divorced	
Other (specify)	

21. If “married” or “cohabitating” is your spouse/partner a man or a woman?

Category	Please tick one
Male	
Female	

22. If “single’, “widowed” or “divorced” do you mostly date men or women?

Category	Please tick one
Male	
Female	

23.Do you have children?

Category	Please tick one
Yes	
No	

24. If “yes”, how many? ________________________

Demographic questionnaire # _________________

Appendix E: Semi-Structured Interview for Data Collection for the Qualitative Study

INSTRUCTIONS

1. This interview is intended to be an informal conversation to collect information on end user experiences with accessing HIV Self-Testing kits, as well self-reporting on results and clinic attendance
2. Each interview must be audio recorded ONLY after the informed consent form has been signed.
3. There are two levels of questions:
    a. **# Main questions: the questions that the principal investigator want to get answers to**
    b. **<u>Probes</u>: the questions that you as the moderator could ask respondent in order to get greater clarity on certain issues and more information about the main question**
4. *Instructions/suggestions to the moderator are in italics.*
5. The guide is divided into four columns.
6. **<u>The left-hand column</u>** contains the main questions.
7. **<u>The second column from left</u>** contains moderator instructions/questions.
8. **<u>The third column from the left</u>** contains the domain of the discussion
9. **<u>The right-hand column</u>** is for summarising the main points and general impressions. Include information on body language/ non-verbal cues. These summaries should be more than just yes/no, but not longer than a few sentences of bullet points. They do not need to be detailed, as the details are captured on the recording.

Research question	**Specific questions**	**Domain of discussion**	**Summary of main points**
1. **What are the main barriers and facilitators to using HIVST?**	*Get the participants to talk about their knowledge of the HIVST kit use and next steps* *Probe:* - *Why they took the HIVST?* - *Where they received the HIV self-testing kit?* - *Where they aware of the benefits of HIVST. If so what they are?* - *Decision to use / not use the HIVST* - *If the HIVST kit was used, their feelings about the process of using oral fluid to test for HIV* - *Where they administered the test?* - *Were they offered or did they request HIVST kits for their partner(s) and were these provided?* - *If he/she took a partner test kit did they test together with their partner, Why?*	Individual factors: a. Knowledge, attitudes and beliefs regarding HIVST	
	Get the participants to talk about the quality of service they received at HIVST kit distribution *Probes:* - *Did they know what they were receiving?* - *Were they made aware of any circumstances under which a person could not use an HIVST, if yes what where they?* - *Were they told steps to be followed after using HIVST, if yes what were they?* - *Main reasons for use / non-usage of the HIVST kit you received* -	Programme factors: a. Quality of services pre & post distribution counselling. b. Accessibility of post self-testing care. c. Availability of equipment and providers	

	- *Did they receive any contact information if they needed help using the kit?*		
2. What are the barriers & facilitators for clinic attendance post HIVST use	*Get the participant to discuss what motivates him/her to come to access health care* *Probe:* - *The meaning of knowing their HIV status* - *Before taking the HIVST, what was their plan of action after taking the test* - *How did knowing their status influence what healthcare steps they did or did not take?* [I would like to ask you a few more questions but only if you are comfortable with sharing your HIV status with me] *Dependent on status:* - *Did they think that they were at risk for HIV infection? Now that they are positive/negative - has this influenced their decision to attend a clinic?* - *What they think are the benefits of entering care after taking HIVST* - *What they think are the risks to attending a clinic after taking HIVST*	Individual factors a. Coping models and response to HIV diagnosis b. Stigma, Social Support and Disclosure c. Health / Wellness perceptions	
	Get the participants to discuss elements of the programme that motivates for attending a clinic for confirmatory testing or prevention services *Probes:* - *Awareness of nearby clinics and services available to help them attend a clinic; if so, what those services are?* - *Did they access healthcare, for what and their experiences?* - *Have they continued to access healthcare and why?*	Programme factors a. Quality of services pre & post distribution counselling b. Accessibility of post self-testing care c. Availability of equipment and providers	

	If no healthcare was accessed – find out why and whether there are intensions to visit the clinic		

Appendix F Demographic Characteristics of Interview Participants

Participant	Age (Years)	Gender
Participant 1	22	Male
Participant 2	27	Male
Participant 3	45	Female
Participant 4	48	Male
Participant 5	28	Female
Participant 6	23	Female
Participant 7	26	Female
Participant 8	27	Female
Participant 9	23	Female
Participant 10	48	Female
Participant 11	40	Male
Participant 12	30	Female
Participant 13	49	Female
Participant 14	43	Male
Participant 15	31	Male
Participant 16	20	Female