AN EXPLORATION OF THE PERCEPTIONS AND EXPERIENCES OF COMMUNITY MEMBERS ON ACCEPTABILITY AND FEASIBILITY OF HIV SELF-TESTING ORAL FLUID TEST IN NETA WARD MBERENGWA DISTRICT, ZIMBABWE.

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- HIV self-testing
- Oral fluid test
- Community Based Distribution Agent
- Acceptability and feasibility
- Facilitators and barriers
- Traditional non-testers
- Qualitative study
- Zimbabwe



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ABSTRACT

Background: The identification of undiagnosed HIV positive individuals through HIV testing services is one of the key measures in ensuring that the UNAIDS/ WHO 90 90 targets are achieved by the year 2020. The identification and subsequent initiation of HIV positive individuals on ART helps to minimise or prevent HIV transmission following viral suppression. Around 25% of people living with HIV globally are unaware of their positive status. In many countries, critical gaps exist in HIV services including prevention, testing and treatment. In Africa, the East and Southern region has a high burden of HIV/ AIDS where 50% of people are living with HIV, with 800,000 new infections in 2017. Despite concerted efforts in rolling out HIV testing services in Zimbabwe, a significant number of the population, especially men and young people, remain with an unknown HIV status, which is hindering progress towards the control and prevention of the HIV pandemic. A recent study confirmed that HIV testing in men is lower as compared to women. Consequently, progress is slower in trying to achieve the year 2020 milestone. The identification of suitable options for reaching out to these groups and the general population is important to achieve a reduction HIV prevalence. HIV self-testing oral fluid sample is thought to have the capacity to increase uptake of HIV testing. However, it still requires evidence on its acceptability and feasibility for those with undiagnosed HIV. Aim: The aim of this study was to explore the perceptions and experiences of the accessibility and feasibility HIV self-testing kits for individuals who received and used this method in Neta ward in Mberengwa District, Zimbabwe. The study identified some key factors that led to individuals accepting the kits and using them. The findings of this study will hopefully be able to inform policy makers' decisionmaking about the importance of rolling out HST in the country.

Method: This exploratory study employed qualitative research methods. The study participants were beneficiaries of the HIV self-testing kit distribution programme within the ward. A non-probability purposive sampling was used to select study participants. Eleven in-depth interviews were conducted among male and female individuals between the ages of 18 to 39 years. Thematic analysis was used to analyse the data.

Findings: Overall, the participants' perceptions and experiences with the HIV self-testing kits were positive. One of the main factors that encouraged the uptake and use

of HIV self-testing kits was the privacy and confidentiality that the self-test offered. Other factors included: the convenience of self-testing including the simple method of doing the test; no pain and drawing of blood; no need to travel to a health facility; and absence of health worker supervision which resulted in the autonomy and empowerment of the individual doing the self-test. The introduction of the programme through use of Community Based Distributors was also a factor in increasing the uptake and use of kits. The Community Based Distributors were able to access traditional non-testers including men in gold panning areas and young people, ensuring that they received kits. The fact that the programme was spearheaded by the Ministry of Health and Child Care led to many community members accepting the programme as legitimate and credible.

Conclusion: The study findings indicate that the potential for HIV self-testing in reaching out to traditional non-testers, relies on its ability to guarantee individuals privacy and confidentiality, convenience and autonomy; the absence of which could prevent them from accessing other means of HIV testing. HIV self-testing can help to increase access to HIV testing and therefore can contribute towards the achievement of the UNAIDS/ WHO 90 90 90 targets by year 2020.

Recommendations: The recommendations in this study include ensuring wide availability of self-testing kits to facilitate access by all population groups to HIV testing. The facilitation of targeted kit distribution especially for men and young people should be made possible with the assistance of Community Based Distributors. Community leaders for example chiefs, headman and councilors could be key in creating awareness and demand for HIVST. It is also recommended that follow up and linkage programmes for self-testers be implemented to ensure that individuals are promptly commenced on ART or supported accordingly. Further research e.g. a randomized controlled trial could be conducted to ascertain evidence on the linkage of clients with reactive self-test results to confirmatory tests and treatment.

DECLARATION

I declare that "An exploration of the perceptions and experiences of community members on acceptability and feasibility of HIV self-testing oral fluid test in Neta ward Mberengwa District, Zimbabwe" is my own work. It has not been submitted for any degree or examination in any university. All the sources that I have used or quoted have been indicated and acknowledged by complete references.

Mboneni Ona Tshuma December 2018 Signed: UNIVERSITY of the WESTERN CAPE

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LIST OF ABBREVIATIONS

CBDA	Community Based Distribution Agent
HIV	Human Immunodeficiency Virus
HIVST	Human Immunodeficiency Virus Self Testing
IDI	In-Depth Interview
MOHCC	Ministry of Health and Child Care
OFT	Oral Fluid Test
WHO	World Health Organisation



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CHAPTER 1

INTRODUCTION

This chapter introduces and orientates the reader to the study. It includes the background to the study, the study setting, the research problem, and an outline of this report.

1.1 Background to the study

Worldwide, 75% of people living with HIV knew their status while 9,4 million people did not know their status in 2017 (UNAIDS, 2017). The remaining 25% need to be reached with HIV Testing Services (HTS) and consequently treatment and care, otherwise the response to the HIV epidemic will be seriously hampered (UNAIDS, 2017). According to MOHCC (2016) survey, knowledge of HIV status facilitates HIV-negative individuals to make informed decisions to reduce their risk and increase safe sex practices to stay disease free. For individuals who are HIV positive, knowledge of their status allows them to act to protect their sexual partners, to access treatment, protect self against reinfection and to plan for a healthy future (Cichocki, 2018; WHO, 2016a).

According to a study by Asaolu *et al* (2016) in Sub-Saharan Africa (SSA), 73% of respondents had never tested for HIV. The study recommended increased HIV counseling and testing efforts to be channeled towards youth and traditional non-testers like men and young people. Similarly, in a report by UNAIDS (2017) in South Africa men and boys are less likely to access HTS as compared to females due to challenges with facility-based testing. The report recommended provision of services to men and boys that are non-discriminatory, in convenient locations and open during hours that suit working people. The WHO (2016b) progress report on HIV/AIDS revealed that despite the increasing number of health facilities offering HTS in SSA, a significant proportion of the population still do not access these services. Most countries in the SSA have long introduced innovative alternatives for HIV testing including community-based HTS (for example mobile outreaches) (Sharma *et al*, 2017). While community-based approaches of HIV-testing reduce barriers for testing, the challenges associated with health facilities, like lack of confidentiality and convenience remain, which may prevent some individuals from accessing HTS

(Sabapathy *et al*, 2018). This is hampering HIV prevention strategies and must be addressed promptly if the pandemic is to be controlled.

In a Zimbabwean study, HIV testing was lower in men (39%) as compared to women (60%) (Takarinda *et al*, 2016), reflecting that men were generally lagging in HIV testing as compared to women. The researchers also posited that low HIV testing can pose a challenge for the MOHCC to achieve the adopted 90 90 90 targets by year 2020 which were set by UNAIDS (2014). The first 90 targets the testing of 90% of HIV positive individuals, the second 90% targets 90% of cases to be initiated on treatment while the last 90% targets 90% of those on treatment to have undetectable viral load or suppressed HIV by the year 2020. This means HIV testing should be reinforced for cases to be diagnosed and initiated on treatment.

The MOHCC 2015 – 2016 survey revealed that 74% of people living with HIV (PLHIV) ages 15 to 64 years reported knowing their HIV status. This requires renewed efforts to increase the number of people who know their HIV status to achieve the 90 90 90 targets by year 2020 (MOHCC, 2016). In the Midlands Province of Zimbabwe where Mberengwa District is located, HIV prevalence is 15% among women and men aged 15 to 49 years old (MOHCC, 2016). The prevalence is higher than the national prevalence of 13%. The MOHCC has adopted a national HIV test and treat all policy and capacitated all health facilities to conduct HTS where every patient diagnosed with HIV is immediately commenced on ART despite their CD4 cell count (MOHCC, 2015). This is one of the efforts to ensure early access to treatment by PLHIV.

Despite, several HIV testing models being employed by many countries in SSA including Zimbabwe to improve access to HIV testing, uptake has been found to remain low (Harichund and Moshabela, 2017). For example, in a study done in Zimbabwe, Takarinda *et al* (2016) confirmed that there remains a high proportion of undiagnosed HIV infected persons and hence there is a need for innovative strategies aimed at increasing HTS particularly for men and in lower-income and lower-educated populations. Harichund and Moshabela (2017) also intimated that HIV Self-Testing (HIVST) could be acceptable in SSA. However, they recommended further research be done among diverse populations citing variable acceptability (22 - 94%) and which was higher among men than women.

The Joint United Nations and WHO Programme on HIV/ AIDS describes HIVST as a process whereby a person who wants to know his or her HIV status personally collects a specimen (this could be either oral fluid or blood sample), performs a test and interprets the test result in private (UNAIDS/ WHO, 2013). The potential benefits of HIVST include increased access to testing and earlier diagnosis (Mugo *et al*, 2017; UNAIDS/WHO, 2013). This study seeks to explore the perceptions and experiences of community members on acceptability and feasibility of HIVST in Mberengwa District.

1.2 Problem Statement

Notwithstanding the effort made by the MOHCC, especially in Mberengwa District, Midlands Province, in ensuring that all health facilities provide HTS, there is still a significant percentage (26%) of PLHIV in the district who are undiagnosed, as estimated by MOHCC in a population-based survey (MOHCC, 2016). HIV testing in the province is low especially among the 15–24 age group with 52% and 36% for men and women respectively who have never tested (MOHCC, 2016). This is a concern for the country especially for the adopted 90 90 90 targets to be achieved by year 2020 (WHO, 2016c). Undiagnosed HIV increases the risk of HIV infection as shown by recent studies (Fan *et al*, 2014; Parsons *et al*, 2006). HIV transmission is also possible for those who are already HIV positive where they can acquire a different strain than or a drug resistant one (Cichocki, 2018). The current HTS programmes in Zimbabwe have partly contributed towards ensuring that individuals with HIV are diagnosed and initiated on treatment to achieve viral suppression as a way of reducing new infections (Takarinda *et al*, 2016).

However, some individuals and groups in the community have not yet accessed HTS and this is impacting negatively on the efforts to control the HIV epidemic (MOHCC, 2016). This problem requires ways of deliberately targeting some population groups with HTS including men, young people and couples among others. The identification of suitable options for reaching out to these groups and the general population is important to achieve a reduction HIV prevalence. HIV self-testing oral fluid sample (OFT) is an innovation for HTS and is thought to have the capacity to increase uptake of HIV testing, but still requires evidence on its acceptability and feasibility in reaching out to individuals or groups with undiagnosed HIV (WHO, 2016a). The

findings of this study will hopefully be able to inform policy makers decision making about the importance of rolling out HST in the country.

1.3 Study Setting

The setting chosen for the study is Neta ward in Mberengwa District which is a rural district within Midlands Province, Zimbabwe. Seasonal farming and gold mining are practiced as major sources of income. There are also illegal mining areas in the ward and district which are regarded as hotspots for HIV and sexually transmitted infections (STI) transmission. Men, including school leavers, spend most of their time conducting gold panning activities sometimes lasting a few days before returning home. Neta ward consists of 1570 households with a total population of 9631 (National Census report, 2012). The ward has one clinic, but some patients travel approximately sixteen kilometres by bus or donkey driven cart to reach the health facility. The study sought to gather information about the pilot programme which was implemented over three months, between May and July 2017 in Neta ward. As part of a national programme, 5490 people were targeted for free HIVST kit distribution. A total of 4084 individuals received HIVST kits between June and July 2017. The distribution programme had 26 Community Based Distribution Agents (CBDAs) who provided the people with self-testing information and kits. The distribution was done at household level, places like business centres and gold panning areas where men and young people are usually found. The CBDA would conduct a health talk with each recipient before issuing them a kit. The CBDA used a runner (vinyl banner with instructions) to disseminate testing information while also showing a video or transferring to the client's phone. Inside the package were also instructions written in Ndebele (local language) and a toll-free number.

1.4 Outline of this report

This study is presented in six chapters as follows:

Chapter 1 gives a background to the study.

Chapter 2 discusses the literature relevant to the study.

Chapter 3 describes the research design and methodology used for data collection, as well as data analysis procedures, ethical considerations and limitations to the study.

Chapter 4 presents the findings of the study.

Chapter 5 discusses the findings together with findings from available literature.

Chapter 6 summarises the key findings from the research and suggests some realistic recommendations based on these findings.



CHAPTER 2

LITERATURE REVIEW

This chapter reviews the literature on HIV Testing Services (HTS) including background of current HTS, advantages of HIVST oral fluid test and concerns with HIVST.

2.1 Background to HIV Testing Services

The WHO (2015) describes HTS as a term used to embrace the full range of services that should be provided together with HIV testing including counselling, linkage to appropriate HIV prevention, treatment and care services and other clinical and support services. The three goals of HTS guidelines include: 1) identification of people living with HIV through provision of quality services for individuals, couples and families: 2) effectively linking individuals and their families to appropriate HIV treatment, care and support; 3) supporting the scale up of high impact interventions to reduce HIV transmission and HIV related morbidity and mortality (WHO, 2015). HIV self-testing was identified as one of the high impact interventions thought to enhance the identification of people with HIV and linking them to treatment, care and support (WHO, 2016a). The WHO's HIV self-testing guidelines stated that HIVST is aimed at achieving the first 90% of diagnosed people with HIV by year 2020.

Despite the admission that HIVST may have the capacity to increase HTS uptake through reaching out to traditional non-testers like men and young people, sex workers and MSM, its effectiveness and acceptability has not been confirmed across all regions (WHO, 2016a). Takarinda *et al*, (2016) also suggested in a study conducted in Zimbabwe that future HIVST studies should further explore the experiences of the different populations especially in hard to reach areas based on social, cultural and geographic factors.

There are three basic types of HIV tests namely the antibody test, combination or fourth generation test and Nucleic Acid Test (WHO/ CDC, 2015). The HIV testing services are usually provided at health facilities and at community level through outreach teams by trained health care workers. There are two types of antibody tests

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to detect HIV antibodies one using blood and the other using oral fluid. The test using blood is administered by a trained health worker and the one using oral fluid is administered by the individual (self-test) who wants to know their HIV status. The fourth-generation test is conducted within a laboratory and is used to diagnose both antibodies and the antigen (HIV) in a single result. The test reduces the test-negative window to approximately 2 weeks as compared to the antibody tests, which may require six weeks after infection (WHO/ CDC, 2015). The Nucleic Acid Test (NAT) detects the ribonucleic acid (RNA) from HIV. It uses a blood sample and is normally conducted for screening donated blood (Food and Drug Administration, 2017) from donors in tertiary or specialist facilities. This test requires personnel with high level training.

2.2 Overview of HIV self-test

HIV self-testing enables individuals to test themselves for HIV in private (WHO/ UNAIDS, 2014). It is a process whereby an individual who wants to know his or her HIV status collects a specimen (oral fluid or blood), performs a test and interprets the test result in private (WHO/UNAIDS, 2014). Pre-test information and post-test counselling, including linkage to clinical services and community support groups, must be accessible and available to all people who use HIV self-testing kits. As with all HIV testing services, no one should be forced or coerced by anyone into taking an HIV self-test. Currently, in Zimbabwe, the self-test kits are given to people who are aged 16 years and above as the MoHCC regards such individuals as being mature and able to consent and request health services on their own (MoHCC, 2016). An HIVST is regarded as a screening test and does not provide an HIV diagnosis. All individuals who receive kits are told that a positive test must be confirmed at a health facility. If their positive test is confirmed, they must be linked to HIV prevention, treatment, care and support services (WHO, 2016a).

Individuals who have had a recent potential HIV exposure should be advised to retest after 6–12 weeks. All people who have regular risk exposure and are at high ongoing risk should be advised to have an HIV test every six months or seek Pre-Exposure Prophylaxis (WHO/UNAIDS, 2014; WHO, 2016a). People who have a non-reactive (negative) HIV self-testing result can consider their result as negative and they do not need to seek confirmatory test at a health facility unless they feel otherwise. However, individuals who have non-reactive tests are still encouraged to go to health facilities to access other services for example cervical cancer screening for females, voluntary medical male circumcision for males and TB screening among others. Potential self-testers should also be warned that HIV self-testing should never be used when an individual is on antiretroviral therapy. This is because antiretroviral drugs work to suppress the virus and thereby reduce the production of HIV antibodies, which may result in false negative HIV test results.

According to Takarinda *et al* (2016), HIVST is expected to bridge the current testing gap by reaching out to key populations for example young men and women, couples, sex workers and MSM. By providing an opportunity for individuals to test themselves discreetly and conveniently, HIVST may provide people who are not currently reached by existing HTS with information about their HIV status (WHO/ UNAIDS, 2014). Current field work on HIVST is expected to inform decision making especially on implementation guidelines and policy formulation by WHO, governments and other stakeholders that can address the barriers that people face when trying to access HTS (WHO/ UNAIDS, 2014).

2.3 Advantage of HIV self-testing to address barriers to HIV testing uptake

2.3.1 Enhanced privacy and confidentiality **TTY** of the

It has been suggested that HIVST can address some barriers due to HIV testing including lack of privacy and confidentiality which may lead to stigma and discrimination (Mugo *et al*, 2017; WHO, 2016a). Fear of stigma and discrimination in the community is undoubtedly one of the barriers to HTS access. HIV/AIDS stigma and discrimination have a crucial impact on the life of people living with HIV/AIDS. It can be an important barrier for voluntary testing (Choi *et al*, 2006; Parker and Aggleton, 2003). For example, in a study conducted in China on 482 males who had sexual intercourse with other males, it was found that 82% of the participants preferred not to ever do HIV tests because of concerns about being seen by fellow community members (Choi *et al*, 2006). In a study in South Africa, a significant number of communities associated HIV testing with being involved in risky sexual behaviour and promiscuity. The labelling of such individuals influences social discrimination and stigma in the community and as a result some individuals avoided testing (Mohlabane *et al*, 2016). Stigma and discrimination may lead one to

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experience feelings of guilt and responsibility for being sick, which can result in some people not accessing HIV testing (Kontomonalis *et al*, 2017).

Studies conducted in Kenya (Mugo *et al*, 2017) and Zimbabwe (Takarinda *et al*, 2016) have confirmed that privacy and other ethical issues have been a challenge for many population groups in HIV testing at health facilities. Kwapong *et al*, (2014) and Rizza *et al* (2012) in studies conducted in Ghana and Switzerland respectively also suggested that privacy at health facilities during and after testing is one of the foreseen barriers towards uptake of HIV testing. In the study in Ghana, pregnant women related that nurses conducted HIV testing in an open area in full view of others, which infringed on the patient's privacy, confidentiality and heightened stigma and discrimination within the community. Kwapong *et al* (2014) suggested that the lack of privacy at counselling centres militated against the efforts to improve utilisation of HTS. In view of this evidence HIVST can ensure privacy, anonymity and most importantly confidentiality among individuals because they perform the test alone which can increase access to HTS by those who have never tested because of privacy and confidentiality issues and can choose whom to disclose the results to (Krause, 2013; Takarinda *et al*, 2016).

Self-testing for HIV provides an environment for clients to test and know their results on their own. The innovation of HIVST also has the potential to address stigma and discrimination surrounding HIV (Takarinda *et al*, 2016; Mavedzenge *et al* (2013). Individuals will begin to take self-test kits and test on their own without the influence of nurses, although they can do this in the presence of a trusted individual. They will be able to keep the results of the test to themselves or choose whom to disclose to. As a result, the authors argued that HIVST could facilitate the reduction of HIV stigma and discrimination (Takarinda *et al*, 2016).

It has been found that apart from the lack of clients' privacy, the other health system barrier to uptake of HTS is fear of breach of confidentiality by some health workers (Dapaah and Senah, 2016). Lack of privacy and confidentiality therefore leads to the stigmatization of clients because they are not able to conceal their status from others and inhibits clients from going to health centres to access an HIV test (Naik *et al*, 2017).

Related to privacy and confidentiality, there is also the fear of mistreatment by health workers. Logie *et al*, (2017) discovered in Kenya that a significant number of individuals refused HIV testing because of fear of perceived mistreatment by health workers. It has been found that mistreatment usually begins after a client has tested positive for HIV especially among young individuals as health workers seeks to shame them for contracting HIV at such a young age (Kwapong *et al*, 2014). Logie *et al*, (2017) further found that complaints of mistreatment by health workers was significant among MSM and transgender clients and assert that it will effectively reduce HTS access by key populations.

Greenwald (2006) argued facility-based testing must remain confidential and private so that people can build trust and confidence in the health system. However, the fact that a nurse must be present during testing casts doubt on the client regarding privacy and confidential issues. The fact that a nurse does not have to be present during HIVST can therefore be viewed as another one of its advantage. However, Harichund and Moshabela (2017) argue that the perceived benefits of enhanced privacy and confidentiality which can lead to increased uptake of HIVST need to be further investigated along cultural and other societal norms of diverse populations seeing that self-testing is still an innovation for HIV testing.

2.3.2 Autonomy and empowerment **ERSITY** of the

It has been shown that HIVST provides personal empowerment in terms of taking charge of one's health. It has also been shown to be autonomous and discreet (Krause *et al*, 2013; Takarinda *et al*, 2016). With HIVST, the individual makes the decision to do an HIV test as opposed to health facilities where a client may be asked to have an HIV test done even if they had come for a different service altogether (Mugo *et al*, 2017; WHO/ UNAIDS, 2014). Furthermore, Mugo *et al* (2017) noted that perceived coercive testing and mistreatment of clients at health facilities could also enhance acceptability of HIVST within the population especially in SSA with high prevalence of HIV.

2.3.3 Convenience

Lippman *et al* (2014) reported that HIV self-testing is convenient to the tester because they decide what time is convenient for them to conduct the test especially if it is

delivered at home. The research, which was conducted in South Africa, concluded that self-testing is done at one's preferred time as compared to the facility-based testing which can only be done during prescribed period. Facility-based testing may be associated with long waiting times and therefore can negatively affect HTS uptake because some clients might not be patient to wait for an HIV test (Hurt and Powers, 2014).

A study by Mohlabane *et al*, (2016) found that health care facilities opening times are inconvenient for some people especially those who work during the day and school going young people. A significant number (18%) of participants complained about inconvenient opening times had never tested for HIV. Similarly, Meremo et al, (2016) argued that even if HTS is one of the confirmed strategies to reduce HIV transmission its uptake remains low in Tanzania like in many other countries in SSA because of inability of some individuals to report at clinics within opening times. The research findings also indicated that a significant number of participants reported spending more than two hours before conducting an HIV test which they thought was too much time wasted. In another study in Zimbabwe, the lack of counsellors and working space was cited as a reason for not offering testing. These resource constraints resulted in long waiting periods for patients, resulting in many clients leaving the health facility before HIV testing could be carried out (Kranzer et al, 2014). The study noted that HIVST could address issues of inconvenience among clients but recommended further research to determine how self-testing can reach out to working men and school going young people who do not usually have time to visit a health facility during working or school hours. These findings indicate that long waiting times at a health care facility could be a challenge in HTS uptake.

Previous studies in Southern Africa have shown various factors associated with lack of HIV testing which includes health system factors where clients are only attended to after long waiting times (Hurt and Powers, 2014; Mohlabane *et al*, 2016). It has been found that health care facilities offering HTS opening times are inconvenient for some people especially those who work during the day and school going young people (Mohlabane *et al*, 2016). A significant number (18%) of participants who complained about inconvenient opening times had never tested for HIV (Mohlabane *et al*, 2016). To address the challenge of inconvenience among clients at health facilities, WHO (2017) stated that HIVST ensures that the individual plans and prepare themselves for the test at their own time; therefore, it is convenient and will meet their expectations.

2.3.4 Accessibility to health care facilities

The distance to a health care facility has been found to be a glaring barrier for community members to access HTS (Naik *et al*, 2017). The participants in the study by Naik *et al* (2017) reported that they did not have enough money to travel to the clinic because of the far distance. Takarinda *et al* (2016) also concurred that most rural clinics in Zimbabwe are difficult to access by some communities due to long distances and sometimes unavailability of bus fare. The authors noted that most HIV patients continued living without being diagnosed until they are symptomatic and sick.

The WHO (2017) consolidated guidelines on HIV testing services which recommend that HIV testing services be available through a wide range of service delivery models and approaches tailored to the epidemiological context to reach all populations, especially those currently being underserved by existing services. The guidelines however state that there are challenges faced by community members to access these services when they require them, and the challenges need to be sufficiently addressed to increase HIV testing among the population. To address this issue, Bowles *et al* (2008) maintains that community or makeshift HIV testing centres can ensure accessibility of HTS in hard to reach areas. However, Jean *et al* (2012) argue that this can be expensive in the long term for the health care system and can only be a temporary relief. Takarinda *et al* (2016) noted that HIVST could address issues of access challenges that clients experienced. In a study conducted across three countries (Kenya, Malawi and South Africa) participants welcomed the idea of an HIV oral fluid self-test which can be delivered at one's doorstep (Rooyen *et al*, 2015).

2.3.5 Easy to perform

The HIV self-testing process is simple and easy to follow and has the capacity to facilitate uptake of HTS (WHO, 2016a) which could be a regarded as another advantage of HIVST. In a study conducted across three countries (Kenya, Malawi and South Africa) participants welcomed the idea of an HIV oral fluid self-test which is easy-to-use (Rooyen *et al*, 2015). The self-test is rapid, has clear instructions which

makes testing easy and does not involve queuing, pre-test and post-test counselling like facility-based testing (Mugo *et al*, 2017).

2.3.6 No pain and loss of blood

The HIVST is an Oral Fluid Test and therefore does not involve finger pricking because a sample is collected through swabbing one's gums. In a report by Population Services International (2016), most clients who received HIVST kits were pleased that the process of testing does not include finger pricking to draw a blood sample. This is in contrast with facility-based testing which requires a finger prick which can be painful. The report further highlighted that this could benefit certain population groups, for example the Apostolic faith sect who usually shuns health facilities and refuse spilling their blood due to religious beliefs. As a result, HIVST could be effective in targeting the Apostolic Sect and other population groups who shun HIV testing because of pain and spilling of blood. In a study conducted in China, Marley et al (2014) also found that most of participants were excited that the HIVST oral fluid test did not involve finger pricking. The study revealed that participants disliked finger pricking done at clinics as it was painful and scary to do. As a result, the authors suggested that HIVST had an upper hand when compared to clinic-based HIV testing among other benefits. Some participants in studies conducted in Australia and United States of America (USA), reported being averse to blood being taken from their bodies (Bond et al, 2005; Conway et al, 2015; Schwarcz et al, 2011). Alemnji et al, (2011), in a study conducted in India, also concurred that a significant number of participants disliked finger pricking to collect blood sample for HIV testing. Knight et al, (2017) also noted in their research in South Africa that a significant number of participants complained that finger pricking to collect a blood sample was scary and painful and can discourage people from HIV testing. Therefore, HIVST can be advantageous to addressing the barrier of pain and blood spilling for increased HIV testing uptake.

2.3.7 Increase of known HIV status

HIVST has been thought to raise an individual's confidence in addressing fear and conducting the self-test. HIV self-testing in the privacy of one's home has long been proposed as a way of increasing the number of people tested (Hurt and Powers, 2014: Marley *et al*, 2014). The authors argued that HIVST has the capacity to reach out to

people who would not usually go to the clinic for HIV testing because of varied reasons such privacy and confidentiality of the test, no need to travel and queue at a health facility and self-empowerment among others. These groups include men, young people and key populations like Sex Workers and Men having Sex with Men (MSM). Recent studies in South Africa which was conducted on individuals who visited targeted health facilities (Mohlabane *et al*, 2016) and South Korea (Sohn *et al*, 2015) which was done among Men who have Sex with Men (MSM) have shown that a significant number of individuals feared knowing their HIV status. While Sohn *et al*, (2015) agree that there is general fear among individuals, they contend that this is heightened by the thought of discrimination once their result (positive) is accidentally disclosed to people. Mohlabane *et al*, (2016) found that in South Africa, the fear among subjects was associated with shyness and embarrassment in front of health workers. Both studies recommended further research into finding possible HIV testing frameworks which address fear among clients. For example, in Asian countries some members of MSM and transgender communities might prefer HIVST (WHO, 2016b).

In a study in Zimbabwe by Takarinda *et al* (2016), the authors found that some people are afraid of knowing their status especially if testing is done at the facility. They suggested that HIVST can significantly increase the number of people who know their HIV status since the test kits are delivered at home or work making it more accessible, for example to people whose schedules do not allow time to go to hospitals for HTS (WHO, 2016b). The WHO (2016b) also noted that having more, free-of-charge options for HIV testing would increase the rates of people choosing to know their HIV status. Making HIVST more accessible can complement the 90 90 90 targets where the first 90 is earmarked to achieve 90% of HIV positive individuals with a known HIV status (WHO, 2016c).

2.3.8 Reduction of costs to health care system

Recent studies have suggested that HIVST has the potential of reducing costs to the health system (Mugo *et al*, 2017; Takarinda *et al*, 2016: WHO/ UNAIDS, 2014). The health department will not have to hire more personnel, for example counsellors and laboratory staff so there could be a reduction of costs (salaries and allowances) (Naik *et al*, 2017). In addition, another saving for the health care system will be that reduced resources will be needed as only reactive self-tests will need to be confirmed (Johnson

et al, 2014). The editorial review by the authors suggested after a cost-effectiveness analysis in Zimbabwe that if HIVST cost US\$3 per test, health services could save US\$53 million over 20 years and have a significant public health impact.

2.4 Some concerns with HIVST

One issue of unsupervised (some are supervised by trained distributor) HIVST identified is the lack of formal or face-to-face counseling (Wood *et al*, 2014). In addition, it has been argued that false-negative tests could lead to false reassurance and that positive results could lead to suicidality and other adverse events (Wood *et al*, 2014). However, Krause *et al* (2013) and Takarinda *et al* (2016) asserted that with the availability and effectiveness of antiretroviral therapy, suicidal thinking after a positive HIV test has become less frequent. The authors added that suicidal attitudes may still occur and may be more likely in resource-limited settings because health services are not readily available and affordable. There is also concern that without face-to-face counseling, clients can miss opportunities to discuss risk prevention with their provider and may not be able to ask relevant questions (Wood *et al*, 2014).

It is accepted that HIVST might empower people and promote autonomy by allowing them to dictate the terms on which they test but there may be potential ethical issues inherent to it (Youngs and Hooper, 2015). Unsupervised HIVST may introduce ethical dilemmas by scaling-up testing where treatment is unavailable, increasing user autonomy without adequate support, and increasing potential risk for coercive testing, inter-partner violence, and psycho-social distress, especially in settings with pre-existing violence and among key populations who fear accessing HIV services (Scot, 2014; Johnson et al, 2014). The authors also acknowledged that these concerns are common for all other HIV testing approaches and not only unique to HIVST but need to be investigated according to socio-cultural contexts. According to Youngs and Hooper (2015), in their study conducted in the United Kingdom, the areas of concern include the possibility of user error with the test kit and the concern that individuals may not present to health services following a reactive result.

False negatives have the potential to cause harm if the 'window period' is not understood by the client and false positives might produce psychological distress on clients (Scot, 2014). Young and Hooper (2015) revealed these ethical issues may lead to litigation by individuals or concerned groups to the manufacturer or distributor of the kit. Bain *et al* (2016) in a later study agreed with Youngs and Hooper but further mentioned that even the educated may not fully understand the decisions they take after conducting an HIVST, and therefore effort must be made to ensure that kit recipients receive adequate testing information. Despite the mentioned concerns, Johnson *et al* (2014) highlighted that provision of suitable regulatory and policy frameworks for HIVST is important because the risks or ethical concerns are likely to be minimal and outweighed by the benefits of HIVST.

Monitoring and reporting systems are important for all approaches to HTS, including HIVST (WHO, 2016a). Because of the discreet, private nature of HIVST, there may be challenges with collecting information on how effective an HIVST programme is or monitoring the experiences of users and tracking possible social harm, for example domestic violence and cohesive testing. Although the instances of harm reported to date have been few, it is essential for programmes to utilize or adapt existing systems to monitor and report on social harm or other adverse events, as well as corrective action and follow-up, to address harm if it occurs (WHO, 2016a).

Despite some concerns as highlighted above, the literature shows that there are significant advantages for the HIVST programme in different geographical areas. The study is therefore seeking to explore these advantages and any other in the Zimbabwean context through exploring the perspectives and experiences of those who were offered the HIVST kit within the community in Neta ward Mberengwa District, Zimbabwe. However, certain disadvantages were also highlighted in the literature and therefore the disadvantages will also be explored in this study. The findings of the acceptability and feasibility of the programme can contribute towards the scale-up of future implementation of HIVST in the control and prevention of HIV/AIDS.

CHAPTER 3

RESEARCH DESIGN AND METHODOLOGY

This chapter describes the methodological approaches to the study and the research design and strategies in detail. These include aim, objectives, study design and setting, description of HIVST kit distribution programme in Neta ward, the study population, sampling, the data collection tools and methods, the data analysis process, the rigour employed during the study and finally the ethical considerations.

3.1 Aim

This study aimed to gain an understanding of the perceptions and experiences of community members on the acceptability and feasibility of HIVST oral fluid test in Neta ward Mberengwa District, Zimbabwe.

3.2 **Objectives**

- 1. To describe the experiences and perceptions of community members who used the HIVST kits
- 2. To explore the facilitators, advantages, disadvantages and barriers of HIVST uptake
- To explore participants' recommendations for improved uptake and use of HIVST kits

3.3 Study Design

The design of this study was exploratory. It utilised qualitative research methods given that it envisaged exploring experiences and perceptions of community members about a phenomenon in natural settings (Cresswell and Miller, 2000; Malterud, 2001). The phenomenon in this study was HIV self-testing, an innovation for testing for HIV using oral fluid. The qualitative approach enabled the researcher to collect non-numeric data suitable for accessing in-depth understanding, knowledge and experiences of the community on HIVST.

3.4 Study Setting

The study was conducted in Neta ward in Mberengwa District, which is a rural district

within Midlands Province, Zimbabwe. Seasonal farming and gold mining are practiced as major sources of income. There are illegal mining areas in the ward and district which are regarded as hotspots for HIV and sexually transmitted infections (STIs) transmission. HIV testing in the province is low especially among the 15–24 age group with 52% and 36% for men and women respectively who have never tested (MOHCC, 2016). This is a concern for the country especially for the adopted 90 90 90 targets to be achieved by year 2020 (WHO, 2016b). Neta ward consists of 1570 households with a total population of 9631 (National Census report, 2012). Health services in this ward are provided by Neta clinic with irregular outreach clinics. Some community members are located far from the clinic and travel approximately 11 kilometres by bus or donkey driven carts to reach the health facility.

3.5 HIVST programme in Neta ward

As part of a national programme, 5490 people were targeted for free HIVST kit distribution between May and July 2017 in Neta ward. A total of 4084 individuals received HIVST kits within a 20-day distribution programme. The targeted number of people could not be reached most likely due to a short period of distribution. The distribution programme had 26 Community Based Distribution Agents (CBDAs) who provided the people with the kits. The distribution was done at household level. The CBDA would first give self-testing information with each recipient before issuing him or her with a kit. The CBDA used a vinyl banner with instructions to disseminate testing information while also showing a video of the self-testing process after the demonstration and or transferring it to the client's phone for future reference. Inside the package were also instructions accompanied with pictures on how one can efficiently conduct the test written in English, Ndebele and Shona (local languages) and a toll-free number for post-test counselling and further support.

3.6 Study population

The study population included individuals aged between 18 and 39 years who were offered a free HIVST kit and performed the test in Neta ward, Mberengwa District. Although the age group 15-49 years is generally considered to be a sexually active group (MOHCC, 2015), the study only recruited participants from 18 years. Those under the age of 18 are considered by the Zimbabwean law as minors and therefore may have posed ethical challenges for the research regarding permission for

participation.

3.7 Sampling and sample size

A non-probability purposive sampling was employed to derive the sample (Robson, 2011). This ensured that the researcher applied expert knowledge of the population to select participants who could provide data needed for the research (Battaglia, 2011). The final sample comprised of eleven participants who were offered test kits and performed the test. The study had proposed to continue recruiting participants beyond eleven if saturation was reached, however at eleven participants no new data was forthcoming from the interviews. The researcher used a HIVST distribution list obtained from the local health office, which contained names of those who were approached and had accepted. Besides names and surnames the list also had gender, age, date of birth, place of residence and phone numbers where applicable. The researcher endeavoured to sample for maximum variation but only managed to sample beneficiaries who had contact numbers on this list.

3.8 Data collection tool

The researcher developed a semi-structured interview guide for in-depth interviews. The questions were open ended to encourage an active discussion. The interview guides were produced in 3 languages namely English, Ndebele and Shona (Appendices G - I). The broad topics that were covered included experiences and perceptions, advantages and disadvantages of HIVST and recommendations for the programme for future implementation. Not all questions in the interview guide were asked but depended on the responses and how the conversation was flowing. Probing was also used if further clarity was needed from participants. The interview guide was useful for the researcher to refer to ensure that all areas of interest had been satisfactorily addressed during the interview. Some demographic data, which included age and gender, were also collected during the interview.

3.9 Data collection method

Individual in-depth interviews (IDI) were used as data collecting method from the participants to explore experiences and perceptions of HIV self-testing from an individual perspective (Baum, 1995). Individual IDIs helped to address personal sensitive information about participant's experiences on self-testing as compared to

focus group discussions which could have limited the sharing of personal information in the presence of others (Patton, 2002). The IDIs afforded the interviewer not only flexibility in the wording of questions but also allowed for use of probes in questioning. Probing in qualitative research is usually done when the participant has answered a question and the interviewer wants to learn more about the respondent's answer (Barriball and While, 1994). The researcher endeavoured to elicit individual experiences, opinions and feelings about HIVST. The IDIs worked to ensure that the researcher got an interpretive perspective (Robson, 2011), for example, the connections and relationships the researcher saw between HIVST and their values and beliefs.

The researcher personally contacted the participants to make appointments for interviews at their own opportune time. During the telephone conversation with each participant, they agreed on a convenient time, date and venue for the interview. Most participants were met at their households where the rest of the family members were excused, or a private space was sort to enhance privacy and confidentiality. The researcher conducted all the interviews himself. The average time taken during each IDI was 30 to 45 minutes. All interviews began by welcoming of participant and thanking them for taking part in the study. The researcher went on to explain the objectives of the study and ethical considerations after which the participant signed the consent form. An attempt to build rapport for all interviews was ensured through using participant's name, using a friendly tone of voice and maintaining eye contact during introductions. The interviews proceeded when the researcher was satisfied that the participant was ready and started with easy and non-threatening questions first. The interview was done in the local language Ndebele, Shona or English depending on the choice of the participants, as the researcher was fluent in all the three languages. The interview was audio taped and then transcribed verbatim by the researcher. Two audio recorders were used as a precautionary measure in case the other failed.

3.10 Data analysis

Data analysis in qualitative studies starts with data collection. The strength of qualitative methods is that it is open to analysis at any point of the study. As a result, adjustments to the research process can be made to improve data collection process

(Pope *et al*, 2000). Thematic analysis was used to analyse research data (Robson, 2011). The study collated a thick description of participants' experiences and perspectives of self-testing data from the interviews. From the data, the researcher continuously tried to elicit recurring themes and patterns related to the perceptions and experiences of participants about self-testing (Clarke and Braun, 2013). A process described by Clarke and Braun (2013) of coding and categorising the data was followed while ensuring it brought meaning to the responses of participants. This included familiarisation with the data, coding, searching for themes, reviewing themes, defining and naming themes and finally writing up.

The researcher wrote a reflection soon after conducting each IDI and went on to transcribe the interview verbatim himself. Both the reflections and transcriptions for each interview were used during data analysis. The researcher immersed himself in the data to the extent of becoming familiar with the breadth and depth of the data. Familiarisation entailed repeatedly reading through the transcriptions of the individual IDIs. Clarke and Braun (2013) described coding as the categorisation of data to facilitate analysis. The researcher identified broad categories within data after which noted specific words, phrases and or actions that occurred within each category. Each category was assigned a category code which was a descriptive name used as a marker for each category. It is these meaningful categories that laid the basis for interpretation in the study. Themes were then developed by grouping the codes together which formed certain patterns such as similarities and differences which were interpreted further for example codes like doing test alone, testing while one sees you and no nurse involved were grouped to lack of interruption or disturbance theme in self-testing. The identified theme was refined at a later stage called reviewing themes to privacy of self-testing. The final step was when the researcher consolidated his interpretation of the data for presentation.

3.11 Rigour for this study

Rigour in qualitative study refers to the quality of being valid and trustworthy (Begley, 1996). Rigour was partly achieved through the researcher summarising key points at the end of each individual in-depth interview to verify with the participants that his understanding and interpretation of their perceptions and experiences of HIVST was accurate. This helped to confirm data and ensure that it was complete and trustworthy (Begley, 1996; Casey and Murphy, 2009; Shih, 1998). To further enhance rigour in the study, the researcher transcribed the interview soon as possible after each interview, while he could still remember facial expressions and gestures.

To ensure further rigour in the study, a thorough account of study setting, population and sampling method and rationale is available so that anyone can understand the context of the research. A detailed account of the study processes was maintained also to enable others to make informed decisions on the replicability of the study by providing an audit trail (Leininger, 1994). A reflective diary was also kept as an important tool for expression of reflexivity which supports the confirmability of the research (Rodgers and Cowles, 1993). The researcher kept a reflective diary which was used to document how the researchers' history and interest brought him to the research. The diary provided the rationale for decisions made, instincts and personal challenges faced during the study. The researcher was a field team supervisor in the kit distribution programme. The duties were: coordinating with the field team regarding replenishment of kits and other logistics, facilitating weekly field meetings, training of distributors and providing feedback to district stakeholders.

To enhance the credibility of the research, the researcher transcribed the verbatim which ensured minimal distortion of data. The researcher also took notes during interviews on body language and reflected on these after each interview. Each reflection of the IDI was sent to the supervisor for comments and recommendations, which were implemented in upcoming interviews.

3.12 Ethics considerations

The study protocol was submitted for ethical approval to the University of Western Cape Biomedical Research Ethics Committee. The ethical clearance was then submitted to the Ministry of Health and Child Care to obtain a permission letter to conduct the study. The two documents with a support letter from the supervisor were submitted together with application for ethical clearance at the Medical Research Council of Zimbabwe. Data collection endorsement was also sought at the Midlands Provincial Director and Mberengwa District Medical Officer. All the permissions and approvals were granted.

Participation in the study by participants was voluntary. The participants were

provided with an information sheet in English, Ndebele and Shona (Appendices A, B and C) explaining the study and requesting participation including being audiorecorded during interview. The information sheet stated that participation is voluntary, and participants can withdraw at any stage of the research without any anticipated negative consequences to them. The participants were requested to sign a consent form (Appendices D, E and F) which was available in English, Ndebele and Shona. Data was anonymised and kept confidential using computer passwords only known by the researcher. This meant the identity of data sources will be kept confidential even when research findings are published. The transcriptions were only shared with the research supervisor. The hard copies of the data will be stored in a locked cabinet only accessible to the researcher and will be destroyed after five years.



CHAPTER 4

FINDINGS

This chapter presents the findings from 11 in-depth interviews that were conducted for gathering data on the perceptions and experiences of individuals who received and used HIVST kits. The findings include how kit recipients received information on HIVST, their motivation for using kits, their HIV self-testing process, their post-test experiences and finally their recommendations for the future implementation of the programme.

4.1 Demographic descriptions of study participants

Participant Number	Age (Yrs)	Gender	Marital Status	Education Level	Occupation	Testing History
		F			Ē	before self- testing
IDI 2	23	F	Married	Secondary	House Wife	Tested
IDI 3	18	M	Single	Secondary	Student	Never
IDI 4	39	M	Married	Primary	Farmer	Tested
IDI 5	25	M U	Married	Primary 0	Farmer	Never
		W	ESTE	RN CA	Office	
IDI 6	28	М	Married	Secondary	Clerk	Tested
IDI 7	20	F	Single	Secondary	Sch Leaver	Tested
IDI 8	22	F	Married	Primary	House Wife	Tested
IDI 9	18	F	Single	Secondary	Student	Never
IDI 10	34	F	Married	Secondary	House Wife	Tested
					Gold	
IDI 11	21	М	Single	Secondary	Panner	Tested
					Gold	
IDI 12	22	М	Married	Secondary	Panner	Tested

Table 4.1: Information of study participants.

Most participants (seven)) were young people between the age of 18 to 23 years (5 females, 2 males). Three of the female young people were housewives, 2 males were gold panners and 2 male adults were farmers. One adult male was formally employed

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in the nearby Zvishavane town while two young males were involved illegal gold panning as a source of income within the ward. The only adult female completed primary school before getting married. Seven study participants were married where one male had never tested for HIV.

4.2 Sources of information on HIVST

The findings show that the participants received information on HIVST from different sources including Community Based Distribution Agents (CBDA), Local community leaders and Information, Education and Communication (IEC) material.

The CBDAs assisted most of the participants in accepting the programme. Participants even commended the approach and willingness of the distributor to make sure people understood the programme.

"I think the distributors did a great job in helping people understand selftesting. I appreciate their efforts especially the lady who took me through the process of testing." (20-year-old female)

"The lady [distributor] who stays in our village told me about this programme and made me take the kit...she was gentle and ready to help." (22-year-old male) UNIVERSITY of the

"For I knew the person [distributor] and she has always been good to me...so I took the kit because I saw that she was confident I will take one and after all why not, the kit came at no cost plus I did not buy it or go to clinic to collect." (23-year-old female)

Some individuals received information about HIVST through community leaders including the chief, the councilor and village heads who convened meetings to introduce self-testing. The participants believed that because the programme was promoted by these leaders it had to be genuine and therefore wanted to be involved in it.

"The councilor and village heads conducted meetings where I first learnt about this self-testing programme...[I] had no idea what it was but later on understood it." (23-year-old female) "The programme was first introduced by the councilor and people know that it is genuine programme from government and most people will accept it." 39year-old male)

Information, Education and Communication (IEC) materials, accessed at various venues, also contributed to creating awareness on the HIVST kit distribution programme.

"I picked a paper (flyer) at the shops and started reading...it contained information about the programme." (18-year-old female)

"I think I came across a short video about self-testing and it amazed me because I had never heard that I can actually test myself for HIV... so I began to have interest until I received the kit to test myself." (21-year-old male)

4.3 How clients were approached to accept kits

Participants were approached in different ways to take the kits. Some were met at their homes, shops, and in the streets while others were approached at workplaces.

"The distributor came to our home and introduced herself before telling us her mission. She asked to talk to my parents first about self-testing before she came to me alone." (18-year-old female)

Most of the male participants were approached while at their workplaces and areas of leisure. They seemed to be pleased with how they were approached. They acknowledged that the message was delivered in such a way that it was clearly understood.

"We do mining here, so the distributor came with the kits and held a demonstration of self-testing and showed us the video as a group. Many guys were interested and took kits. We were all men, so we also asked him questions which he answered well." (28-year-old male)

"Gold panning is our life [source of income] as men here, we don't have time to do many things like going to the clinic for tests. If they did not come here we were not going to get the kits because sometimes we spend days here, you know...it is difficult to go home without money." (21-year-old male).
"The distributor came to the shops where I was having drinks with friends. He showed us a banner which had steps for self-testing while explaining in isiNdebele. He was clear in what he was saying and that made us take the kits." (25-year-old male)

The male participants also confirmed that because they were only males they felt comfortable asking the distributor questions freely.

We were all men, so we also asked him questions which he answered well." (28-year-old male)

Some school going participants were pleased that they were approached at school by distributors. One participant highlighted how by approaching them at the school, it ensured her privacy as she did not want her parents to know that she had taken the HIVST.

"I was happy that the distributors came to our school because I don't think my parents were going to allow me to take the kit...so they talked to us on selftesting before they gave us the kits but those under 16 years were denied." (18-year-old female)

Another male participant confirmed this even though he had reservations about sharing his personal information for fear of being found out by his mother.

"They came to our school and most of us were excited about the programme although I wasn't comfortable with them collecting my details...I feared my mom would know that I tested for HIV and she would start asking me questions that am indulging in sexual intercourse while still at school." (18year-old male)

One participant could not wait for the distributor to come and introduce the programme to her and therefore took the initiative to approach the distributor herself.

"I heard about self-testing at the councilor's meeting where we were told that distributors will come with kits to our households but they were delaying...imagine I have heard about all the good things about self-testing and am feeling like this is taking a lot of time, like 4, 5 days...so I had to go to

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his (distributor) *place where he showed me how to do it and took the kit to my home.* "(34-year-old female)

Some distributors were directly approached on the streets.

"I approached him [distributor] on the road, they used to go around putting on branded t-shirts, so it was easy for me to see him. He explained everything to me and when I got home I read the instructions which said that I must test before taking food, so I decided to do it in the morning." (23-year-old female)

One participant declined the kit in front of family members because he thought it was not the right environment to accept the kit but accepted it elsewhere. He was concerned about the negative impression would create in his family if he accepted the kit and therefore preferred to accept it elsewhere.

"I denied the kit in front of my family because I feared they will think am sleeping around, so I met the distributor at the shops and took the kit." (20-year-old female)

4.4 Initial reaction on hearing about HIVST

Participants shared their initial responses to the HIVST before they became fully aware of what it entailed. One reaction described by participants was that even though they knew they were going to do the HIVST they were still apprehensive about what the result would be.

"You know just hearing the word HIV makes you wonder whether you are positive or negative...I started to have this sort of fear and my heart began beating faster than normal." (28-year-old male)

"My brother, HIV is a deadly disease, once you have it you know that death is near." (18-year-old male)

Some participants questioned the credibility of the test upon being introduced to the programme. They could not believe that HIV can be detected using oral fluid.

"I know that HIV is tested using blood, it is difficult to accept this test which uses saliva." (25-year-old male)

"I thought that was a joke... how can HIV be tested in the saliva? Does it mean that kissing can now spread the virus?" (34-year-old female)

"To me the test looked too simply because no nurse, no needle, no blood...it was somehow difficult for me to believe it." (18-year-old female)

One participant admitted that his first reaction was one of mistrust as the test was offered at no cost which implied negative connotations.

"I think I was bit suspicious when the programme was introduced to me particularly around the kit being offered for free. I thought there were underhand things." (20-year-old female)

There were also some misconceptions related to self-testing and Satanism as some participants thought that it was a way of initiating them into cults. They also suspected that the collection of oral fluid sample through wiping gums with a test pad will cause their teeth to fall off.

4.5 Motivation for using HIVST kit

The participants were asked what convinced them to accept the kits upon receiving information about the programme. Some of the factors which led to participants receiving and using kits included privacy and confidentiality, convenience, non-use of the needle, autonomy of the test and that it could address stigma and discrimination issues.

4.5.1 Enhanced privacy, confidentiality and autonomy

Some individuals liked the idea of privacy and the confidentiality afforded by the HIVST when reading the result of the test which is not always possible at health facilities.

"In my own view, privacy was the main advantage for self-testing because myself and friends took the kits because we were going to test alone." (18year-old male)

"It was clear that self-testing was different from testing at the clinic. So, what I liked most was privacy of testing because I have heard people talking about

some people's results and I don't like it...it hurts." (21-year-old male)

The young participants were particularly appreciative that they could do the test without the knowledge of their parents.

"I was not going to ask things about HIV in front of my parents... even taking the kit because they were going to think I am now engaging in sex at a young age." (18-year-old female)

Some participants mentioned that they took the kit because they felt that the privacy and confidentially offered by the self-testing tended to reduce stigma and discrimination.

"I took the kit and tested because no one will know that I tested...no one will look at me with the corner of an eye or start calling me names." (20-year-old female)

"Sometimes when people see you at the clinic for HIV test they just think you have HIV...I think that shows stigma and discrimination. So self-testing makes me test away without anyone seeing me and "labelling" me." (34-year-old female)

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Some participants liked the fact that self-testing gave them a sense of autonomy because the person testing decides when to do the test and who to disclose the results to.

"It is just good...I mean you do it at your own time, no one is rushing you or telling you what to do like at the clinic, you are your own boss [giggles]." (34year-old female)

"I liked the test because the distributor told me that the results are going to be seen by me only, if I want to tell anyone it's up to me." (18-year-old female)

4.5.2 Convenience of HIVST

Most participants acknowledged that HIVST was convenient for them as compared to clinic-based testing. Some highlighted that they could do the test at a time that was convenient to them.

"Self-testing is good and convenient for me because I don't have time to go to the clinic to do an HIV test." (18-year-old female)

"I was so excited to be part of this exciting programme...testing is done at your own time, even if you want to do it in the middle of the night, at work during break time, at school it's all up to the individual." (21-year-old male)

Some participants acknowledged that self-testing made them feel at ease as they did not need to be in the presence of a nurse.

"The test does not need a nurse close by, so I was very comfortable to do it alone..." (28-year-old male)

Some participants also acknowledged the advantage of not having to travel to health facilities to be tested thereby making it more accessible and cost effective.

"... plus, there is no need to travel to the clinic, you just do the test from the comfort of your home." (28-year-old male)

"That programme was nice to me because you know we use buses to travel to clinic, so it saved my money, I did not travel but still got my test [kit] and tested myself. Transport costs much here" (34-year-old female)

4.5.3 Test is pain and blood free **STERN CAPE**

Some individuals accepted the kits because they like the fact that the test used oral fluid instead of blood as in clinic-based testing. They mentioned that self-testing does not have the pain of a finger prick and addresses aversion to being exposed to blood.

"One of the things I liked most about the program is that it didn't use the needle (pricking) method, which is painful and scary." (28-year-old male)

"I think I have a phobia about seeing blood... I mean it's worse if it's coming from my body. So, I was very happy to be part of self-testing and will want another kit in future." (22-year-old female)

"I have noticed that many people shun the needle test because it creates some reluctance to testing...so too I think opting to use saliva is the best." (20-year-

old female)

4.6 HIV self-testing process

4.6.1 Preparation for the test

Participants reported being able to remember the important points in preparation for the test.

"I made sure that I did not drink, eat or brush my teeth for 30 minutes before doing the test otherwise the test will be spoiled...this is what I was told by the distributor" (18-year-old female)

"I remembered that I needed a private place with light and a watch for seeing time for the test." (20-year-old female)

"I read the paper inside before doing the test so that I would be able to see my result right, in fact the photos on the sheet helped me to tell what result I got. I felt so great doing this for myself" (34-year-old female)

4.6.2 Collecting the sample

Most participants had no major difficulties in collecting the oral fluid sample for the test. **UNIVERSITY** of the

"I managed to collect sample by swabbing first, upper gum once then lower gum once again. I felt it was not adequate but the spoon (test pad) was already wet with oral fluid. I then remembered the distributor saying swabbing once is enough for the spoon to collect adequate fluid" (22-year-old female)

One young male participant admitted that he was rather nervous a he was apprehensive about the outcome, but he carried on with the test regardless.

"Somehow, I was feeling a bit jittery, but I managed to collect the sample. The fear of a positive result was striking me." (18-year-old male)

A few respondents acknowledged the simplicity of being able to collect the sample.

"Yah that was fairly simple to do...wiping gums on once on the top and once on the bottom part before inserting into the bottle with chemical." (28-yearold male)

While agreeing that the test was simple and rapid, some participants mentioned that the instruction sheet in the kit was beneficial but that there was too much information given.

"It was fine because there were instructions written in language which I understood, although I felt the information in the insert was bit bulky, needing significant time to go through it." (39-year-old male)

"I did the test in a short time, like between 25 to 30 minutes. This one is better than the clinic-based test which sometimes takes close to an hour." (28-yearold male)

4.6.3 Waiting for results

Waiting for the results seemed to be one of the challenges for participants, mainly because of the fear of a positive result.

"Waiting for results was like tormenting for me because I was afraid of seeing a positive result. The 20 minutes waiting for results were a psychological torture I tell you..." (34-year-old female)

"...I was just curious thinking what if am HIV positive, so I kept on peeping on the test, so at first it was red all the way and was wondering what is happening...but the distributor had discouraged checking the test before time." (18-year-old male)

"Self-testing was my first test so was full of anxiety...what if am HIV positive. I sat there seated quietly until time for the test was up." (18-year-old female)

For other participants waiting for results was time to become occupied with other things.

"I was told that I must check results after 20 minutes, so I take that time to do my Maths homework... I had set alarm, so I knew when it went on that the results are ready." 18-year-old male) "I was a bit nervous, but I took courage because I wanted to know my HIV status...I had to leave the test to do some house chores and came back after time was up." (23-year-old female)

4.6.4 Reading results

Reading results did not appear to be a challenge for the participants. However, some of them admitted that they double-checked their results to confirm the result again.

"I had no problems reading my results and I was satisfied that I got the correct result." (39-year-old male)

"I saw one red line then I referred again to the instruction sheet which showed me that am negative..." (21-year-old male)

"I took my test pad outside to check if there was another faint line on the T...because even a faint line on T shows that you are positive." (22-year-old female)

4.7 **Post-test experience**

Participants had differing experiences after the test. This related to what their experiences and resolutions were and what actions they were going to take. One young participant expressed her satisfaction with her first experience of testing for HIV and for not having to test at a health facility due to access challenges.

"To me I think the test was so fulfilling because it was my first test and have always been wanting to test...it was difficult for me to go to the clinic." (18year-old female)

HIVST also seemed to facilitate couple testing as it was more accessible.

"I tested with my husband, am happy...he has always said he is busy and doesn't have time to go to the clinic." (34-year-old female)

The positive experience with the HIVST encouraged participants to share the experience with others as way of exposing them to HIV ST too.

"I now know my HIV status can plan my future well, I realized that the test is

good and began to encourage my peers to take the kits. I did not want to enjoy this new technology alone." (25-year-old male)

4.8 Participants' recommendations for implementation of HIVST

Some participants observed that self-testing was a good innovation for HIV testing and people should embrace it to ensure the control and prevention of the HIV/ AIDS pandemic. They mentioned that it was a programme introduced by the government through the Ministry of Health and Child Care which meant that it was legitimate and credible; therefore, people should not shun it but accept the HIVST kits.

"We were told during the meeting with councilor that the programme was an initiative of the government, so people must accept it and take kits...for our good health and that we fight HIV/ AIDS." (34-year-old female)

Most participants highlighted the need for kits to be accessible all the time and widely available to those who need or want them.

"The kits need to be available every time so people who want to test get them without difficulties. I think they can be put at the shops, schools and clinics. Again, these distributors must continue to give kits to the people." (25-yearold male)

Others thought the availability of self-testing will encourage traditional non-testers to take up HIV testing.

"The program is good and can ensure that those who don't test can test themselves now, this is a new way for testing, so people are excited about it...the government and donors must bring more kits, maybe this pandemic can be contained." (39-year-old male)

Some participants recommended that the kits be readily available in the community (beyond the health facilities). This would make HIV testing more accessible to young people and men who do not normally attend health facilities.

"Am not sure what they can do but this programme must reach more men, girls and boys because they are the people who don't want to go to the clinic for tests, us women test for HIV most times we go to the clinic even when pregnant." (34-year-old female)

"Distributors must continue to give kits especially to men and young people... they are usually found at gold mining areas, beer spots, they can be seen there because most of them they won't take kits in the presence of their spouses." (23-year-old female)

One participant felt strongly that self-testing to those under the age of 16 years should be considered because they are also affected by HIV.

"I also need my children to be tested, why don't they [Ministry of Health] want them to test using self-testing...are they not affected by this disease?" (34-year-old female)

One participant felt that for the sake of privacy, people could buy the kits at an affordable price at a place where they did not have to be in contact with anyone that might be familiar to them.

"I think other people can buy kits from the shops if they are affordable... because some may want to just buy the kit and go without talking to anyone. They don't want to be seen accessing kits especially married guys, they fear people will say they have a side relationship." (28-year-old male)

From the above findings there are several factors which promoted the acceptance and use of self-testing kits among the participants. The main factor was privacy and confidentiality of the test. Privacy and confidentiality meant the ability of the participant to test and interpret results alone and in privacy. This ensured a reduction in stigma and discrimination following being seen at a health facility accessing HIV testing. Convenience was also a factor as there was no need to travel to the clinic, no cost of accessing HIV testing as kits were delivered at home and the fact that there was absence of pain and blood spilling. The proceeding chapter discusses the findings together with related literature to establish differences and similarities.

CHAPTER 5

DISCUSSION

This study explored the factors which led to individuals accepting and using HIVST kits after accessing information on HIVST from distributors, traditional leaders and others involved in the HIVST programme. It included gathering of experiences and perceptions of participants on the programme. This chapter discusses the findings of the study in relation to available literature.

5.1 Factors contributing to uptake of kits

5.1.1 Enhanced privacy and confidentiality

The study findings showed that privacy and confidentiality was one of the main factors which convinced individuals to accept HIVST kits. The participants liked self-testing because it offered privacy and confidentiality as compared to clinic-based testing where privacy and confidentiality could not be ensured. In support of this finding, Kwapong *et al* (2014) also observed that respondents embraced self-testing because they felt that it guaranteed them privacy and confidentiality. Other studies confirmed that privacy and confidentiality were key in increasing access to HIV testing (Krause *et al*, 2013; Pai *et al*, 2018; Makusha *et al*, 2015) which self-testing afforded.

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The current study reported that issues of privacy may key to increasing uptake of selftesting kits especially among young people. Similarly, one of the main motivations for people in sub Saharan Africa to self-test was thought to be privacy of the test (Indravudh *et al* (2017). Some male participants in the current study also felt that selftesting provided an opportunity for them to test privately without supervision of the health workers. Health workers were thought to be harsh and sometimes perceived as breaching principles of confidentiality (Pando *et al*, 2017). This could be a possible factor in men not accessing HTS. The findings are similar to a study on MSM where the respondents applauded self-testing for offering privacy as opposed to clinic-based testing where nurses labelled them as gay (Pando *et al* 2017). As a result, the findings of this study and others suggest that self-testing could be effective in increasing HIVST access among men and young people. Greenwald (2006) asserted that HTS provided to people must always remain private and confidential so that people can build trust and confidence in the health care system. However, one participant related that some people can conclude or judge that one has HIV by merely seeing them at the clinic. As a result, they seized the opportunity of conducting HIV testing using a self-test kit in private. However, although other studies concurred that privacy and confidentiality is key to achieving increased uptake of HIV testing, they reported that it could lead to poor linkage to care treatment for those with reactive tests (Lippman *et al*, 2016; Johnson *et al*, 2017). This could then be regarded as one of the challenges of HIVST.

Privacy and confidentiality were not only pronounced around testing but also how some individuals accessed the kits in this study. Most young people were not comfortable in accessing the kits in the presence of parents and other individuals. They indicated that it was also difficult for them to be seen at the clinic for HIV testing. Similarly, it was found elsewhere that some young people shun accessing HTS in public or open areas because of fear of being thought to be engaging in sexual and delinquent activities at a young age (Naik *et al*, 2017). The current study reported self-testing provided the young people with an opportunity to test for HIV by meeting the distributor and collecting the kits in private. HIV testing was also conducted away from parents and guardians thereby providing young people with privacy and autonomy. Young people are targeted for HTS as they are thought to be key to achieving the first 90 of the 90 90 90 targets by the year 2020 (WHO, 2017). HIVST therefore can provide an opportunity for achieving this target as this study shows that young people readily took up the HIVST kits.

This study showed that distribution of self-testing kits will be more effective if it is targeted to settings where men work or frequent. This is because some people (men and young people) usually do not have time to go to the clinic in addition to having reservations about privacy and confidentiality and therefore targeted distribution will ensure increased uptake of HIV testing. The findings seem to confirm the current thrust of MOHCC (2016) guidelines which emphasise targeting or reaching out to traditional non-tester (like men and young people) with HIV testing. The current study also reported that young people were not keen to discuss HIV issues and even accessing kits in the presence of parents or guardians due to fears of being

misunderstood. Targeting them is key to addressing the HIV pandemic as Schnall *et al* (2016) argued that many young people, even those with high-risk behaviors for HIV have never been tested for HIV and are unaware of their HIV status. Probably it would help to also target the young people in areas where they are likely found alone, for example tertiary institutions and youth clubs. Other studies have also shown that men have a poor health seeking behaviour; they rarely seek health services, including HIV testing from health facilities therefore targeting them in areas which they frequent could increase uptake of HTS (Camlin *et al*, 2016; UNAIDS, 2017).

The willingness of participants in the study to accept kits was also encouraged by the fact that results were first going to be seen by the individual testing. Recent studies have also shown that some self-test kit recipients preferred seeing results on their own (Mavedzenge *et al*, 2013; Gagnon *et al*, 2018). This finding is important because privacy of results suggests a way () to create demand for self-testing in future as it has been suggested as one of the main advantages for self-testing and has the potential to increase uptake for HIV testing (Mugo *et al*, 2017).

While the participants in this study liked the autonomy offered by HIVST of interpreting results own their own, they also felt empowered to be able to choose whom to disclose the results to. Recent studies have also shown that many individuals wanted to maintain confidentiality of their results (Krause, 2013; Takarinda *et al*, 2016). However, this has a potential risk of a delay in reporting reactive result at a health facility by the self-tester to access care and treatment (Conserve *et al*, 2018). The current study shows that self-testing empowered some participants to be responsible for their health because they implored the government to continue distributing the kits, so they could retest in future.

The perceived reduction in stigma and discrimination in this study seemed to have influenced more people to accept kits. A study in Zambia also concurred that reduced stigma and discrimination in self-testing facilitated accessing of kits (Oldenburg *et al*, 2016). The ability of self-testing to address stigma and discrimination could therefore help to reach out to traditional non-testers who shunned being seen at a facility for an HIV test.

5.1.2 Convenience and accessibility

The fact that individuals were able to choose their own time to test seems to have been a factor in increasing access to HIV testing. The study participants reported that self-testing was convenient since they could plan and prepare for the test at their own time as compared to clinic-based testing where they had no control. Other studies have also shown that self-testing provides choices for individuals to test at their own time without the pressure and perceived inconvenient opening times of health facilities which is thought to contribute towards increased HIV testing (Mohlabane *et al*, 2016; WHO, 2017; Gagnon, 2018). In the study by Mohlabane *et al* (2016) conducted in South Africa, 18% of participants complained of inconvenient opening times at health facilities which meant that access to HTS was a challenge. Their findings seem to be compatible with this study although they were conducted in different settings.

Despite the availability of HTS at the local clinic in Neta ward and surrounding areas, some study participants related that there was no need to travel to a health facility when doing HIVST. This advantage of not having to travel could be related to unaffordable transport cost. Earlier studies show that transport costs to the health facilities are sometimes not affordable to many community members and may lead to low HIV testing outputs in the health system (Takarinda *et al.*, 2016; Zanolini *et al.*, 2018). In Neta ward, self-testing kits were distributed using a door-to-door model and this seemed to be in the best interest of the recipients. The HIVST programme therefore saved the beneficiaries' time and transport expenses to the health facility. Even though it was somehow difficult for some participants to refuse kits because they knew the distributors, they lauded the fact that HIVST had come to them at no cost.

The study showed that some male participants in the study indicated that the coming of distributors to gold panning areas with kits was a factor in ensuring that they also benefited from the programme because sometimes they spend several days at the sites making access to HTS difficult. Men who usually work during the day and have no time to go for HIV testing at health facilities can access self-test kits either at workplace or after hours within the neighborhood from peers or distributors (Conserve *et al*, 2018). Camlin *et al*, (2016) also concurred in a study in Kenya and

Uganda that most men spent the day at work (plantations, sea fishing) and would not bother about HIV testing. The two studies (Camlin *et al*, 2016; Conserve *et al*, 2018) together with the findings of this study therefore suggest that self-testing delivered by distributors or peers to men at their areas of work or wherever they are found could be effective in ensuring HIV testing uptake among working men.

Another key finding of this study related to convenience was that the self-test was easy and simple to perform in which has the potential increase access to the HIVST. Recent studies have also shown that the HIVST is easy and simple to perform and has the capacity to reach out to people who are usually occupied and cannot get to a health facility for an HIV test (Peck *et al*, 2014; Schnall *et al*, 2016; WHO, 2016a). Peck *et al* (2014) further described the test as being quick and helps one to escape the "hassles" of dealing with the health facility. The participants in this study were also generally keen with the idea of escaping the need to go to the facility for HIV test.

5.1.3 Absence of pain and drawing of blood

The study findings suggest that the absence of pain in sample collection is a factor that attracted the participants to accept the self-test kit. A recent study by PSI (2016) in Zimbabwe noted that some HIV clients were not happy with finger pricking expressing that it was painful and scary. The current study confirms that finger pricking could be a concern in the uptake of HIV testing. As a result, the implementation of the OFT test could reach out to traditional non-testers and ensure increase in the uptake of HIVST testing. Earlier studies concluded that self-testing had an advantage over clinic-based testing which uses finger pricking to obtain a blood sample (Marley *et al*, 2014; Takarinda *et al*, 2016). However, while self-testing using oral fluid is favorable in this case, it is less sensitive than blood-based tests (Mavedzenge *et al*, 2018) which could be one of the disadvantages of HIVST.

While self-testing does not cause pain during sample collection, the fact that selftesting uses oral fluid instead of blood was a factor in ensuring kit acceptance by some individuals who have an aversion to blood in this study. The Association for Public Health Laboratories (2013) also reported that self-testing using oral fluid has an advantage over blood-based HIV tests owing to aversion of some individuals having their blood drawn. As a result, self-testing using oral fluid has an advantage over blood tests and it may be important to gather data on the preferences of the community before implementing similar programmes or to at least provide choices for the clients. Oral HIVST can therefore enhance the reach of testing to community groups who would not usually accept blood HIV testing (Bauserman, *et al*, 2001). For example, Neta ward has a religious group, the Johane Wemasowe sect, which is opposed to seeking health services and testing for HIV by drawing of blood.

5.1.4 Usability of self-test

A contributing factor in the positive uptake and use of the kits in this study was the fact that the test was easy and simple to execute. The participants reported that they did not face challenges in setting up, collecting the sample and reading results. This was possibly due to the comprehensive information given by the distributor during kit delivery and/or the ability of the participant to understand the process through reading the instructions. One of the participants reported that the instructions for use were somehow "bulky" requiring significant time to read through and therefore needed to be reviewed or simplified so that they are simple to follow. Pictorial messages accompanied by text are usually better than text only messages as reported in Zambia by Zanolini *et al* (2018) in a study for the comprehension of self-testing instructions. This finding suggests that instructions for use be reviewed to largely consist of pictures accompanied by simple text to make following the instructions even easier and quicker for use.

5.1.5 Encouraging peers to take kits

The study shows that the participants were pleased with the self-testing programme and some even encouraged peers to take kits too, using their own experiences of testing. This finding can be interpreted as positively spreading awareness on selftesting and increasing the uptake of kits. Choko *et al* (2017) reported that the receipt and use of self-test kit led their participants to immediately encourage their peers to also access the kits. It was however not known if this was motivated by an incentive of food hamper which was given to recipients or was out of wanting to ensure that peers begin to know their HIV status. The kit distribution programme at Neta ward did not give incentives for taking a kit suggesting that the latter reason could possibly apply in the current study.

5.2 Legitimate and credible test

Some participants of this study regarded the self-testing programme as legitimate and credible because it was introduced by the government through MOHCC. This implies that the community in Neta ward trusted programmes which are initiated by the government. The MOHCC took a leading role in the distribution of self-testing kits. The findings confirm the Zimbabwe National Guidelines on HIV Testing and Counselling (2014) which mandates the MOHCC to be the main provider of HIV testing services in the country, even though there are NGOs supporting the programme. The findings of the current study suggest that programmes which are led by the government through MOHCC might have an impact because people seem to trust them as compared to NGOs which are short-lived within the community (Chevo and Bhatasara, 2012).

5.3 Support structures

CBDAs were trained on HIVST and kit distribution before they embarked on the programme. The study showed that CBDAs were important in convincing participants to accept kits as the support rendered by them was critical in ensuring that clients accepted kits voluntarily. A recent study in Nigeria reported that the use of trained distributors has the capacity to ensure clients easily understand self-testing and take up HIV testing (Population Council, 2018). With these findings, it will be prudent in future to maintain and reinforce the use of trained distributors to effectively distribute self-test kits.

The study revealed that the use of CBDAs from the same setting facilitated availability of support and assistance even after testing. A similar finding was also reported by Indravudh *et al* (2017) in Malawi and Zimbabwe and by Neuman *et al* (2018) in Malawi and Zambia. The current study found that at the same time, CBDAs seemed to be creating a strong environment for demand creation for self-testing in Neta ward. However other studies argue that distributors from the same setting might raise concerns regarding confidentiality issues (MOHCC, 2016; Zanolini *et al*, 2017). The authors noted that some testers may request help to the point where the distributor interprets the result, and this can compromise the confidentiality of the results. To address this confidentiality issue, the MOHCC, in its manual for the training of community volunteers for self-test kit distribution, highlighted the need to reinforce

http://etd.uwc.ac.za/

training especially on ethics and confidentiality. The advantages and disadvantages of the use of CBDAs need to be investigated further in different cultural and social settings before implementing community distribution programmes.

The participants confirmed that local leaders were involved in creating awareness for self-testing and the programme. This indicates their support for the programme and confirms findings from other studies where the involvement of community leaders was shown to be important for effective HIV /AIDS programmes (Campbell, 2012; Szekeres, 2012). Therefore, the involvement of local leaders can play an important role in HIVST programmes too. The participants liked the fact that community leaders introduced the programme to them which meant that people were more likely to accept the kits. A study in Malawi also revealed that community leaders were key in ensuring that individuals accessed self-test kits (UNITAID, 2016). These findings show that community leaders can ensure the programme is embraced by the community because of the power and influence their status brings. Therefore, an important consideration for such programmes would be to first seek buy-in from the community leaders before introducing it to the people.

It is evident from the discussion of the study findings that the advantages of HIVST can be associated with the uptake of kits. These include among others enhanced privacy of the test and confidentiality of the test result especially among men and young people. Convenience of self-testing was also major advantage and it encompassed easiness of conducting the test, absence of pain and blood spilling, no need for travelling to health facility and doing the test under the watch of health workers. The use of CBDAs and the fact that self-testing programme was introduced through the government (MOHCC) was a factor in ensuring the kits uptake. Targeted distribution of self-testing kits to areas where men and young people can be found is thought to facilitate increased access to HIV testing.

5.4 Study limitations

The researcher noted that most of the adults were not keen to participate in the study even after explaining the objectives of the research. Some of the potential participants were either busy with their work, had no time and or simple did not want to participate. As a result, most of the study participants (seven) recruited were young people, which brought a potential limitation of the study.

The presence of the researcher during data gathering is also mostly unavoidable in qualitative research. Anderson (2010) argues that it can affect the respondent's responses and consequently the quality of data collected. The researcher therefore endeavored to take time to create rapport with participants while also ensuring further clarification of questions, asking a question in different way and using probing during interviews.

The researcher had been involved in the HIVST programme and this might have formed bias in the study because of knowledge and experience in the programme. However, the researcher endeavored to strictly follow the thesis protocol and conducted the study objectively and continually reflected on his own understanding and perceptions of HIVST.

Most of the participants were young people and therefore a potential limitation of the study because the perceptions and experiences beyond the age group of the participants could be different. Because of the nature of qualitative research, the findings of this study cannot be generalizable to the broader population of young people.

The following chapter derives the conclusion and recommendations according to the findings of this study.

CHAPTER 6

CONCLUSION AND RECOMMENDATIONS

6.1 Conclusion

The study set out to explore the perceptions and experiences of community members on acceptability and feasibility of HIV self-testing oral fluid test as an innovation for increasing the uptake of HIV testing. The programme may be effective in reaching out to those who have never tested for HIV for various reasons. It brings a good alternative for people to access HIV testing without visiting health facilities if this option is not possible for them.

While self-testing was generally well received by the community, the fact that it provided enhanced privacy and confidentiality was key in ensuring people received and used test kits. Most beneficiaries of the programme lauded the extent to which self-testing ensured privacy and confidentiality in HIV testing. This ensured that more individuals accessed the kits and tested for HIV. It was clear in the study that some individuals like men and adolescents shunned visiting the health facilities for HIV tests because of the challenges of privacy and confidentiality. Local health facilities were not ideal for some individuals who knew the facility staff and thought they might compromise their privacy and confidentiality of the results. As a result, self-testing provided a relief to these traditional non-testing groups in the community.

The provision of guaranteed convenience by self-testing was a new and phenomenal experience which worked to ensure that more people accessed kits. Self-testing afforded the beneficiaries to test for HIV at their own time and place. The kits were delivered by distributors at their households, workplaces and other leisure areas. This was helpful for men and other individuals who found themselves busy during working hours. In contrast with testing conducted at health facilities where it is done within working hours, self-test kit distributors could provide the service even after hours. The fact that some people will be at work during the day, compromised their need to access HTS at the health facilities. Self-testing provided the much-needed convenience to the community of Neta ward to still conduct an HIV test without having to go to the health facility initially.

Self-testing also provided convenience in the form of savings on transport costs and time taken at a health facility waiting for an HIV test on the part of beneficiaries of the programme. This also helped those who had never tested for HIV citing accessibility challenges. The continued distribution of self-testing kits in Neta ward and other similar areas may afford the community repeat tests in future. This will ensure that those individuals who were missed by the programme can also receive kits and this can lead to initiation to ART for those with positive tests. The fact that self-testing provided a pain free sample collection and involved no drawing of blood encouraged people to accept the kits. The sample collection method of swabbing gums and lack of finger pricking ensured that many people accepted the programme through taking kits.

6.2 Recommendations

Considering the findings of the research and other studies it is evident that self-testing can enhance access to HTS. It is an innovation that can be embraced by the health system, include health workers, to realise gains in achieving the 90 90 90 targets on HIV/ AIDS. Regarding the findings from this study and related literature, the following recommendations are made when designing effective and sustainable HIV self-testing programmes:

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- Ensure wide availability of self-testing kits in the community, workplaces such as the panning mines and places which men and young people frequent. This will afford people a variety of choices on where to access kits and possibly facilitate repeat regular testing through self-testing.
- Facilitate targeted distribution of self-test kits to reach out to traditional nontesters like men and young people. The distribution process can be modelled in a way that the targeted people are addressed in groups e.g. of young people or gold panners, to take advantage of peer influence.
- Implement regular education or awareness campaign programmes to create awareness and raise demand for HIVST in the community. The campaigns can be done through utilizing local community support groups for examples women clubs, youth friendly centres and sport events. Local community leaders for example chiefs, headman and councilors may also be key in

addressing gatherings to increase awareness and acceptance of HIVST and ensure its legitimacy.

- Review the information for use to cover essential details only to ensure clients are not overwhelmed by too much information
- Conduct further research to ascertain evidence on linkage of clients with reactive self-test results to confirmatory tests and treatment. This could be done through a randomized controlled trial.



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WESTERN CAPE

APPENDICES

Appendix A: English Information sheet



UNIVERSITY OF THE WESTERN CAPE

Private Bag X 17, Bellville 7535, South Africa *Tel: +27 21-959 2809, Fax: 27 21-959 2872* E-mail: <u>soph-comm@uwc.ac.za</u>

INFORMATION SHEET

Project Title: An exploration of the perceptions and experiences of community members on acceptability and feasibility of HIV self-testing oral fluid test in Neta ward Mberengwa District, Zimbabwe.

What is this study about?

This is a research project being conducted by Mboneni Ona Tshuma from the University of the Western Cape. We are inviting you to participate in this research project because we feel you can provide us with information the study is looking for. The research seeks to explore the perceptions of community members who received free HIV self- testing (HIVST) oral fluid test kits. It is hoped that HIVST will help in increasing the number of individuals who know their HIV status, reach out to those who do not usually test and provide an opportunity for those with reactive tests to link with health care facilities. The findings of the study are expected to contribute to HIVST guidelines and policy formulation by health authorities. The study is being done to provide information for the control and prevention of HIV/ AIDS among the population.

What will I be asked to do if I agree to participate?

You will be asked to participate in an individual interview. The interview will be guided by a set of questions. These will include among others your experience and perception of HIVST. The discussion will take about at a convenient place and time to be identified in Neta ward, Mberengwa District.

Would my participation in this study be kept confidential?

The researcher undertakes to protect your identity and the nature of your contribution. To ensure your anonymity, your name will be kept confidential at all times. To ensure your confidentiality, all the records of your participation will be locked away at all times. This will be destroyed when the study has been completed. Should you accept to participate in the research, you will be requested to complete a consent form which will also be kept confidentially. If we write a report or article about this research project, your identity will be protected.

What are the risks of this research?

All human interactions and talking about self or others carry some amount of risks. We will nevertheless minimise such risks and act promptly to assist you if you experience any discomfort, psychological or otherwise during the process of your participation in this study. Where necessary, an appropriate referral will be made to a suitable professional for further assistance or intervention.

What are the benefits of this research?

This research is not designed to help you personally, but the results may help the investigator learn more about HIVST in your community. We hope that, in the future, other people might benefit from this study through improved HIV/ AIDS control and prevention strategies.

Do I have to be in this research and may I stop participating at any time?

Your participation in this research is completely voluntary. You may choose not to take part at all. If you decide to participate in this research, you may stop participating at any time when you want to. If you decide not to participate in this study or if you stop participating at any time, you will not be penalized or lose any benefits to which you otherwise qualify.

What if I have questions?

This research is being conducted by Mboneni Ona Tshuma and School of Public Health at the University of the Western Cape. If you have any questions about the research study itself, please contact:

Mboneni Ona Tshuma Student Number: 3610395 Cell phone Number: +263 712 389 211 Email: <u>mbonenitshuma@yahoo.co.uk</u>

Prof Uta Lehmann School of Public Health Head of Department University of the Western Cape Private Bag X17 Bellville 7535 soph-comm@uwc.ac.za

Prof Anthea Rhoda Acting Dean of the Faculty of Community and Health Sciences University of the Western Cape Private Bag X17 Bellville 7535 <u>chs-deansoffice@uwc.ac.za</u>
This research has been approved by:

BIOMEDICAL RESEARCH ETHICS ADMINISTRATION Research Office New Arts Building, C-Block, Top Floor, Room 28 University of the Western Cape, Private Bag X17, Bellville 7535 APPENDIX B: Ndebele Information sheet



UNIVERSITY of the WESTERN CAPE

Appendix B: Ndebele Information Sheet



UNIVERSITY OF THE WESTERN CAPE

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UGWALO OLUCHASISA NGENHLOLISISO

Inhloko: Inhlolisiso yokudinga imibono lemicabango yabantu abamukela inhlolisiso yokuzihlola I HIV wedwa esigabeni seNeta eMberengwa, Zimbabwe.

Lungani loluhlelo?

Uhlelo lolu luqhutshwa nguMboneni Ona Tshuma owe University of the Western Cape. Siyakunxusa ukuthi uphatheke enhlolisisweni le ngoba sicabanga ukuthi ulakho ukusitshela ulwazi esiludingayo. Uhlelo lujonge ukufunda ngemibono yabantu abamukela kumbe abangamukelanga ama sef-test kit okuzihlola Ihiv kusetshenziswa amanzi atholakala ensinini. Kukhangelelwe ukuthi inhlolisiso izanceda ukuphakamisa inano Labantu asebesazi ukuthi baleHIV kumbe hatshi, ukufinyelela kulabo abangathandiyo ukuya ekilinika lokuphathisa labo abazaphuma beleHIV ukuthi baye ncediswa ekilinika. Okuzaphuma kunhlolisiso kukhangelelwe ukuthi kuphathise ekubumbeni imithetho ephathelene lokulwisana le HIV/ AIDS.

Kuyini engizakubuzwa nxa ngingavuma?

Uzacelwa ukuthi uphatheke ku interview. I interview le izabe ilemibuzo ehleliweyo eyokuncedisa kodwa kuvunyelwe ukuchasisa kabanzi. Lokhu kuzahlanganisa imibono yakho nge HIVST. Ingxoxo le izaphathwa endaweni ehleliweyo khonapha eNeta ward eMberengwa District.

Ukuphatheka kwami kunhlolisiso kuzagcinwa kuyimfihlo na?

Siyazinikela ukuthi ibizo lakho kalisoze likhulunywe kuloba ngubani. Ibizo lakho lizagcinwa emfihlweni izikhathi zonke. Zonke ingwalo ezilebizo lakho zizahlala zikhiyelwe izikhathi zonke. Nxa ungazinikela ukuphatheka ehlelweni lolu, sizakucela ukuthi usayine ugwalo lokuvuma ukuphatheka. Loba singaloba ugwalo lwenhlolisiso le ibizo lakho alisoze lilotshwe lapho.

Yiziphi ingozi zokuphatheka kulenhlolisiso?

Konke ukuxoxa kwabantu kuvame ukuba lokuphambaniseka. Sizazama ukwehlisa loba yiphi ingozi engaba khona ngesikhathi siqhuba uhlelo lolu. Silethemba lokuthi abanye abantu bazaphathiseka ngohlelo lolu ikize kwehliswe I HIV le AIDS.

Nxa ngingaphatheka enhlolisisweni ngilakho ukutshiya loba ngasiphi isikhathi na?

Ukuphatheka kwakho ehlelweni ngokokuzifunela wena wena ungabanjwa ngamandla. Ungacabanga ukuphatheka enhlolisisweni ulakho ukutshiya loba ngasiphi isikhathi osifunayo. Ungacabanga ukungaphatheki kuhlelo lakho kulungile ngoba awusoze uhlangane lobunzima kumbe ukulahlekelwa.

Nxa ngilemibuzo ke?

Uhlelo lolu luqhutshwa nguMboneni Ona Tshuma owe School of Public Health eUniversity of the Western Cape. Nxa ulemibuzo dinga:

Mboneni Ona Tshuma Student Number: 3610395 Cell phone Number: +263 712 389 211 Email: <u>mbonenitshuma@yahoo.co.uk</u>

Prof Uta Lehmann School of Public Health Head of Department University of the Western Cape Private Bag X17 Bellville 7535 soph-comm@uwc.ac.za Prof Anthea Rhoda Acting Dean of the Faculty of Community and Health Sciences University of the Western Cape Private Bag X17 Bellville 7535 chs-deansoffice@uwc.ac.za

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Appendix C: Shona Information Sheet



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Gwaro Rwetsananguro

Zita retsvakiridzo: Tsvakiridzo yemaonero nengarwa kubva munharaunda, kuzvitambira nekugoneka kwekuzviongorora zve HIV kubva mumvura dzekumatadza ku dunhu re Neta ku Mberengwa mu Zimbabwe.

Tsvakiridzo iyi ndeye chii?

Iyi itsvakiridzo iri kuitwa na Mboneni Ona Tshuma neku University of the Western Cape. Tinokukokai kuti mupinde mutsvakiridzo iyi nekuti tinzwisise kuti muchatipa mashoko ano tsanangura nezvetsvakiridzo iyi. Tsvakiridzo iyi inoda kubudisa pfungwa dzevagari ve nharaunda iyi vakawana ongororo yekuzviongorora hutachiona hwe HIV pachena. Zvinotarisirwa kuti HIVST ichabatsira maererano ne HIV kusvika kune vaya vanganetseka kuwana mukana wekuzviongorora HIV uye kupa mukana vaya vanenge vazvibata HIV kuti vasvike kuchipatara. Zvabuda mutsvakiridzo zvinotarisirwa kuti avichabatsira kugadzira nzira dzemutemo we HIVST mumabato ezvehutano.Tsvakiridzo iri kuitirwa kuti ibudise mashoko ekudzivirira hutachiona hwe HIV ne AIDS muvanhu.

Chii chandichakumbirwa kuita ndikabvuma kupinda mutsvakiridzo?

Uchakumbirwa kuti ubvunzwe mibvunzo wakazvimiririra. Mibvunzo yacho ichange yakati wandeyi kusanganisira ruzivo nepfungwa dzako maererano ne HIVST. Nhaurirano ichaitika panzvimbo nenguva yakafanira mudunhu re Neta, munzvimbo ye Mberengwa.

Mashoko andichataura mutsvakiridzo aka chengetedzeka here? Mutsvakiridzi anozvipira kuchengetedza chimiro chemhunhu apinda mutsvakiridzo uye nezvaachataura. Zita remunhu achapinda mutsvakiridzo richachengetedzwa nguva dzose. Umbowo uyu ucha huchapisira panoperera tsvakiridzo. Kana mukabvuma kupinda mutsvakiridzo muchakumbirwa kunyora moga pasi kuti munobvuma kubatsira uye runyoro urwu ruchachengetedzeka nguva dzose. Kana tikanyora gwaro pamusoro petsvakiridzo iyi zita renyu richachengetedzwa.

Ndedzipi njodzi dzetsvakiridzo iyi?

Nhaurirano dzese dzinosanganisira vanhu mukati dzine njodzi, asi tichazama nepatinogona napo kuti njodzi idzi dzisaitika kana kukuvatsira kana musina kusununguka pane chipi zvacho nenguva ichaitwa tsvakiridzo. Kana zvichibvira vana mazvikokota vanobatsira kutaura nevanhu vangadanwa kuti dambudziko rinenge raitika rigadziriswe.

Ndezvipi zvinobatsira pakuitika kwetsvakiridzo iyi?

Tsvakiridzo iyi haina kugadzirirwa kuti ibatsire iwe wabvunzwa mibvunzo asi ichabatsira asi inobatsira mutsvakiridzi kuti anzwisise zvakawanda maererano ne HIVST munharaunda yenyu. Tinovimba kuti mukupinda kwenyu nevamwe vanhu kuchabatsira vachabatsirika netsvakiridzo iyi mukusimudzira kudzivirira kwe HIV/ AIDS.

Ndinomanhikidza kupinda mutsvakiridzo here kana kuti ndinogona kubuda mairi chero nguva zvayo?

Kubatsira kwenyu mutsvakiridzo isarudzo yako. Unogona kusarudza kusapinda mutsvakiridzo iyi. Kana wasarudza kupinda mutsvakiriszo iyi unogona kumira chero ipi nguva zvayo. Kana wasarudza kusapinda kana kumira hapana zvirango zvamopihwa kana kutorerwa kodzero dzawakafanira.

Ko kana ndine mibvonzo?

Tsvakiridzo iyi irikuitwa naMboneni Ona Tshuma pachikoro chezvehutanho paUniversity of the Western Cape. Kana une mibvunzo patsvakiridzo iyi, tinokumbira mubate:

Mboneni Ona Tshuma Student Number: 3610395 Cell phone Number: +263 712 389 211 Email: <u>mbonenitshuma@yahoo.co.uk</u>

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Prof Anthea Rhoda Acting Dean of the Faculty of Community and Health Sciences University of the Western Cape Private Bag X17 Bellville 7535 chs-deansoffice@uwc.ac.za

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Appendix D: English Consent form



$University of the Western \, Cape$

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CONSENT FORM

Title of Research Project:

An exploration of the perceptions and experiences of community members on acceptability and feasibility of HIV self-testing oral fluid test in Neta ward Mberengwa District, Zimbabwe

The study has been described to me in language that I understand. My questions about the study have been answered. I understand what my participation will involve and I agree to participate of my own choice and free will. I also agree to being audiorecorded. I understand that my identity will not be disclosed to anyone. I understand that I may withdraw from the study at any time without giving a reason and without fear of negative consequences or loss of benefits.

Particinant's name	<u></u>
Participant's signature	UNIVERSITY of the
i ai ticipant s signature	WESTERN CAPE
Date	

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Appendix E: Ndebele Consent Form



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ISIVUMELWANO SEMFIHLO

Inhloko yenhlolisiso:

Inhlolisiso yokudinga imibono lemicabango yabantu abamukela inhlolisiso yokuzihlola I HIV wedwa esigabeni seNeta eMberengwa, Zimbabwe.

Inhlolisiso ichasisiwe kimi ngolimi engiluzwayo. Imibuzo ebe ngilayo iphenduliwe futhi. Ngiyazwisisa ukuphatheka kwami enhlolisisweni njalo ngiyavuma ukuphatheka ngokwentando yami. Ngiyavuma futhi ukuthi ingxoxo izagcinwa ngamazwi okukhuluma. Ngiyazwisisa ukuthi ibizo lami alisoze likhulunywe iloba kubani. Ngilakho ukuthi ngingatshiya inhlolisiso loba ngasiphi isikhathi nginganiki imbangela futhi kungela lutho olubi olungenzeka kimi kumbe olungangilahlekela.

Ibizo lophathekayo..... Isayinetsha yophathekayo..... Ilanga.....

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Appendix F: Shona Consent Form



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Chitsidzo Chetsindidzo

Zita Retsvakiridzo:

Tsvakiridzo yemaonero nengarwa kubva munharaunda, kuzvitambira nekugoneka kwekuzviongorora zve HIV kubva mumvura dzekumatadza ku dunhu re Neta ku Mberengwa mu Zimbabwe.

Tsvakiridzo iyi yatsanangudzwa kwandiri nerurimi gwandinonzwisisa. Mivhunzo yangu pamusoro petsvakiridzo iyi yapindurwa. Ndinonzwisisa kuti sei kuvamutsvakiridzo iyi kwangu kunosanganisira chipi nechipi, ndinozvipira kuva mutsvakiridzo iyi. Ndonzwisisa kuti zita rangu haribuditsvi kana kuna ani zvake. Ndinonzwisisa kuti ndinogona kusarudza kubuda mutsvakiridzo iyi chero nguva ipi zvayo yandada ndisina kupa chikonzero kana tsanangudzo, uyezve pasina kutya kumbundikidzwa kana kurasikirwa nezviwanikwa.

Zita Remubvunzwa.....INIVERSITY of the Runyoro RwemubvunzwaWESTERN CAPE Zuva Ranhasi.....

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Appendix G: English Interview Guide

- 1. What do you understand about HIVST?
- 2. How was HIVST introduced to you?

Tell me what your first reaction was

- 3. Explain to me why you agreed to do the test
- 4. Could you please relate how you conducted the self-test

Probe:

- What is needed to conduct the HIVST at home? Why?
- Setting up and preparation to conduct the test.
- Reading results.
- 5. What do you think are the advantages of HIVST to you?

Probes:

- Which advantages do you like most and why?
- How do you think HIVST can benefit you as an individual?
- What about to your village or community?
- Motivation to conduct the test?
- 6. How does HIVST compare to the current HIV testing at health facilities?
- 7. How can HIVST reach out to those who do not usually test?
- 8. Do you think HIVST would help to link one to access treatment and other services? Why do you say so?
- 9. Would you recommend HIVST to someone? Why/why not?
- 10. What is your recommendation about implementation of HIVST in future?

Probes:

- Comment on the easiness of following instructions for conducting the test.
- How would you want to be supported when conducting the test?

Appendix H: Ndebele Interview Guide

- 1 Uzwisisani nge HIVST?
- 2 Ungangitshela ukuthi wanikwa njani ikit
- 3 Wezwa njani nxa wawutshelwa mgohlelo
- 4 ungangitshela ukuthi yindaba wathanda ukuzihlola
- 5 Ungasitshela ukuthi wayenza njani uhlelo lokuzihlola?

Probes:

- Kuyini okudingekayo ukuthi wenze I test ngekhaya? Yindaba?
- Ukulungisa okokuzihlola.
- Ukubala ama results.
- 6 Kuyini ubuhle bokuzihlola ngekhaya?

Probes:

- Uhlelo lokuzihlola ngekhaya lungakunceda njani wena?
- Isigaba sakho kumbe indawo ohlala kuyo ke?
- Kuyini okwakufuqa ukuthi uzihlole wedwa?
- 7 Ungayiqathanisa njani I HIVST lalakho okuhlolwa ngakho ekilinika?
- 8 I HIVST ingafinyelela njani kulabo abangajwayelanga ukuya ekilinika?
- 9 Ubona angani I HIVST izancedisa ukuthi abantu bethole ukwelatshwa masinyane emakilinika? Yindaba?
- 10 Ungathanda ukutshela omunye ngohlelo lwe HIVST? Chasisa/ Chasisa yindaba?
- 11 Uhlelo lolu lungenziwa njani nxa sikhangele isikhathi esizayo?

Probes:

- Ungathini ngezixwayiso ezikhona nxa uzihlola?
- Ungathanda ukuncediswa njani esikhathini esizayo nxa uzihlola?

Appendix I: Shona Interview Guide

- 1. Chii chaunonzwisisa maererano ne HIVST?
- 2. Wakaziva sei nezve HIVST?
 - Wakazvitambira sei pawakatanga kunzwa nezve HIVST?
- 3. Unganditsanangurirawo kuti nei wakabvuma kuzviongorora uchishandisa HIVST?
- 4. Unganditsanangurira here kuti wakazvifambisa sei pakuzviongorora wega HIV?
- Chii chinodikwa pakushandisa HIVST mudzimba? Sei uchidaro? Kugadzirira nekurongedzera kuzviongorora Kuverenga zvabuda pakuongorora
- 6. Ndezvpi zvakanakira HIVST kwauri?
 Ndezvipi zvamunonyanya kufarira uye sei uchizvifarira?
 Unofunga kuti HIVST ingakubatsira sei sedungamunhu?
 Ingabatsira sei dunhu?
 Kurudziro kuti uzviongorore
- 7. HIVST inotarisirwa sei pane imwe nzira yekuongorora utachiona hwe HIV kuchipatara?
- 8. HIVST ingasvika seikune vasina kubvira vaongororwa utachiona hweHIV?
- 9. HIVST ingabatsira here kudhonzera munhu kuti apiwe mishonga nezvimwe zvingamubatsira. Sei uchidaro?
- 10. Ungakurudzira mumwe kuti aongororwe neHIVST here?
- 11. Ndezvipi zvingaitwa kuti HIVST ifambiswe zvakanaka mungova inotevera? Zvakanyoreka here kutevedzera nzira dzekuongorora uchishandisa HIVST?