FACTORS CONTRIBUTING TO NON-INITIATION OF ART AMONGST ELIGIBLE PRE-ART PATIENTS IN RURAL CLINICS IN SWAZILAND

by

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DECLARATION

I, NOSIPHO GWEBU STORER, DECLARE THIS DISSERTATION LIMITED SCOPE ENTITLED:

"*FACTORS CONTRIBUTING TO NON-INITIATION OF ART AMONGST ELIGIBLE PRE-ART PATIENTS IN RURAL CLINICS IN SWAZILAND.*"

IS ENTIRELY MY WORK IN EXECUTION, FORMULATION AND DELIVERY. IT HAS NEVER BEEN SUBMITTED BY MYSELF, TO THIS UNIVERSITY, OR TO ANY OTHER INSTITUTION OF HIGHER LEARNING. ALL SOURCES AND QUOTES HAVE BEEN CORRECTLY REFERENCED AND ACKNOWLEDGED THROUGHOUT THIS DOCUMENT.

_____ _____

Nosipho Gwebu Storer **Date:**

DEDICATION

I dedicate this Dissertation of Limited Scope to all the people who have fought with steadfast courage and an unbreakable spirit, to conquer HIV in Swaziland.

They have rewritten history.

ACKNOWLEDGEMENTS

I would like to sincerely thank and acknowledge the following:

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- My children, my song of praise. Thank you for making me a better person. I am a lifetime of proud of you both.

- My supervisor, Doctor Janse van Rensburg, who always provided me with encouragement and positive feedback. She saw the finish line long before I did.

ABSTRACT

AIM

The purpose of this study was to explore and describe factors that contribute to the non-initiation of Antiretroviral Therapy (ART) amongst Pre-Antiretroviral Therapy eligible patients and to make recommendations for health care workers to enhance early initiation of pre-ART-eligible patients for primary health care facilities in Swaziland.

METHOD

A qualitative design was applied in rural primary health care (PHC) facilities in the Hhohho region of Swaziland. The target population for this study included nurses who have successfully completed the National Nurse Led Antiretroviral Therapy Initiation in Swaziland (NARTIS) training, and who actively initiated ART to eligible patients in rural PHC facilities. Data was collected through semi-structured interviews and field notes. Purposive, convenient sampling was applied. Eleven respondents were interviewed for the study, and data was collected until data saturation was reached. Data from transcripts and field notes was analysed and categorised with thematic analysis through Tesch's open coding process.

RESULTS

The study identified the following three predominant themes: 1) systematic enablers of prompt ART initiation, 2) barriers to prompt ART initiation, 3) sources of support. Categories included public health care (PHC) factors, community level factors, the interdependence of the health care system, patient centred barriers, individual patient agency, and NARTIS nurse support.

CONCLUSION

The recommendations for health care workers that emerged from the study included continued HIV treatment scale-up and decentralisation to grass roots levels, aggressive treatment prioritisation among pre-ART patients, building the capacity of the local health care system and continued research initiatives. It is hoped that recommendations emerging from the findings of this study will have positive

implications for programming and practice regarding the initiation of ART for eligible pre-ART patients in Swaziland.

Key terms:

Adherence, Human Immunodeficiency Virus (HIV), referral, linkage, eligible, follow-up, National Nurse Led Antiretroviral Therapy Initiation in Swaziland (NARTIS), pre-Antiretroviral Therapy (pre-ART), non-initiation, early initiation, treatment initiation, clinical staging.

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ACRONYMS

AIDS	Acquired Immune Deficiency Syndrome
ANC	Antenatal Care
ART	Antiretroviral Therapy
ARV	Antiretroviral
CD4	Cluster Difference 4
CEC	Community Expert Client
CHAI	Clinton Health Access Initiative
CHW	Community Health Worker
CIHTC	Client Initiated HIV Testing and Counselling
CTX	Cotrimoxazole
CWF	Child Welfare
EC	Expert Client
EGPAF	Elizabeth Glazer Pediatric AIDS Foundation
FBC	Full Blood Count
FP	Family Planning
HIV	Human Immunodeficiency Virus
HTC	HIV Testing and Counselling
ICAP	Global Health Action
PHC	Primary Health Care
PI	Principal Investigator
POC	Point of Care
PIHTC	Provider Initiated HIV Testing and Counselling
LLAPLA	Life Long ART for pregnant and lactating women
LFT	Liver Function Tests
MDT	Multidisciplinary team
MOH	Ministry of Health
NARTIS	Nurse Led ART Initiation in Swaziland
NSTS	National Sample Transportation System
OI	Opportunistic Infections
PLwHA	People Living with HIV/AIDS
PMTCT	Prevention of Mother to Child Transmission

PNC	Postnatal care
PSI	Population Services International
RHM	Rural Health Motivator
SAM	Service Availability Mapping
SDHS	Swaziland Demographic and Health Survey
SHIMS	Swaziland HIV Incidence Measurement Survey
SNAP	Swaziland National AIDS Program
SOP	Standard Operating Procedures
STI	Sexually Transmitted Infection
TB	Tuberculosis
TBA	Traditional Birth Attendants
UNAIDS	Joint United Nations Program on HIV/AIDS
URC	University Research Council
WHO	World Health Organization
VCT	Voluntary Testing and Counselling
VL	Viral Load

CHAPTER 1
ORIENTATION TO THE STUDY

1.1 INTRODUCTION

Swaziland is one of the countries most affected by the Human Immunodeficiency Virus (HIV) and the Acquired Immunodeficiency Syndrome (AIDS) pandemic globally (Swaziland HIV Incidence Measurement Survey (SHIMS) 2012:8). In 2006-7, the Demographic Health Survey of Swaziland (DHS) found that HIV prevalence was 26% amongst the adult population and 38% among pregnant women (Swaziland Demographic Health Survey (SDHS) 2007:221-226). A study conducted in 2012 of HIV incidence in Swaziland, titled *The Swaziland HIV Incidence Measurement Survey* (SHIMS), showed that HIV prevalence in the country had since escalated to 31% within the eighteen to forty-nine year age bracket. It further found that the incidence of HIV in Swaziland was 2.4%, a figure that revealed the large numbers of people in the country who were contracting HIV each year (SHIMS 2012:6-7). In light of this national HIV prevalence and HIV incidence data, the timing for initiation of Antiretroviral Therapy (ART) becomes a possible mitigator to the expanded impact of HIV disease in the country.

The pre-ART stage begins after a person tests positive for HIV. It is the period between an HIV-positive diagnosis and the commencement of ART (Swaziland National AIDS Program Patient Linkage, Retention and Follow-up in HIV Care Standard Operating Procedures (SOP) 2013:4). During this phase, most patients receive a pre-ART package, which consists of enrolment into the pre-ART register, the opening up of a patient chronic care file, a clinical evaluation, psychosocial assessment, TB screening, a cotrimoxazole prescription, and an agreed care plan for of follow-up visits (Swaziland National AIDS Program Patient Linkage, Retention and Follow-up in HIV Care SOP 2013:5). During this pre-ART phase, patients need ongoing support from the health care team to stay healthy. They also need close monitoring to enable the health care team to quickly identify when a patient has reached eligibility for the ART stage so that early treatment initiation can be facilitated.

A person is deemed eligible for ART when their Cluster of Differentiation 4 (CD4) cell count reaches 350 cells/mm3 or below, or if using the World Health Organisation's (WHO) Clinical Staging criteria, they are stage III or IV regardless of their CD4 cell count (Swaziland Ministry of Health National Comprehensive Package of Care for Adults and Adolescents 2010:20). Patients are classified WHO Clinical Stage III when they display conditions such as pulmonary TB, or severe bacterial infection (Swaziland Ministry of Health Integrated HIV Management Guidelines 2015:140). WHO Clinical Stage IV patients exhibit severe, visible signs of physiological deterioration; conditions such as wasting syndrome, HIV encephalopathy and extrapulmonary tuberculosis (Swaziland Ministry of Health Integrated HIV Management Guidelines 2015:141). In resource-limited settings where CD4 testing may not always be available or possible, WHO Clinical Staging assists to give indications for ART initiation.

Eligibility for ART is determined by qualified and registered nurses at public health care (PHC) facilities. Initiation of ART begins when an HIV-positive patient who is not on ARV treatment, is then commenced on ART. Nurse-Led ART in Swaziland (NARTIS) was a strategy that capitated nurses in ART management, a model that has been demonstrated to be successful in other parts of the region (Swaziland Ministry of Health NARTIS Training Curriculum 2015:9). NARTIS trained nurses are the only cadre other than medical doctors that are recognised by the Swaziland Ministry of Health, as qualified to initiate patients on ART. With the growing demand for ART services, nurses were trained in NARTIS to complement the role played by medical doctors in ART management (Swaziland Ministry of Health NARTIS Training Curriculum 2011:9). Although medical doctors were competent, their shortage meant that many patients residing in rural areas were not receiving ART services. Because PHC facilities do not have a medical doctor permanently on-site, these facilities had skills gaps in ART initiation and ART refilling, resulting in many patients being underserviced.

Non-initiation of ART occurs when a pre-ART patient who is determined as being eligible to begin ART (through CD4 or Clinical Staging), does not begin ART. This research aims to explore and describe factors that contribute to this delay.

1.2 BACKGROUND

By December 2010, the Swaziland National AIDS Programme Evaluation (SNAP-E) reported that of the 220, 000 people infected by HIV in Swaziland, only 78, 919 (36%) had started ART (SNAP-E 2012:1). The Swaziland Ministry of Health ART Program Annual Report 2012, further reported an ART coverage of 79.5% in 2011 (Swaziland Ministry of Health ART Program Annual Report 2012:7). Essentially this meant that almost 80% of people who were in need of ART in 2011 received ART. As much as this is a celebrated achievement, there is still a need to determine why the remaining 20% of the population of Swaziland remains outside of this ART coverage.

In 2011, Swaziland adopted a Provider-Initiated HIV Testing and Counselling (PIHTC) approach to HIV testing. This approach mandated that patients presenting at any consultation room within any type of health care facility, or as seen by any health care worker, would be routinely offered HIV testing and counselling as a component of comprehensive health care (Swaziland Ministry of Health National Comprehensive Package of Care for Adults and Adolescents 2010:4). The objective of this approach was to ensure that patients arriving at any health facility in Swaziland were routinely offered an HIV test at every service provision point and by every health care worker that they came into contact with. This was a dynamic change from Swaziland's previous approach of Client Initiated HIV Testing and Counselling (CIHTC), where the patient was 'encouraged to seek out HTC services, ideally before falling ill' (Swaziland Ministry of Health National Comprehensive Package of Care for Adults and Adolescents 2010). This Voluntary Counselling and Testing (VCT) approach left the onus with the patient to voluntarily request an HIV test, rather than being offered one as a routine component of clinical services. As a result of these initiatives, during 2012 a total of 252 678 HIV tests were conducted, an increase from only 180 000 in 2011 (Swaziland National Provider Initiated HIV Testing and Counseling (PIHTC) Standard Operating Procedures 2012:5).

The International Center for AIDS Care and Treatment Programmes (ICAP) Global Health Action, is an entity of the Mailman School of Public Health at Columbia University, New York. The Mailman School of Public Health established ICAP as a Non-Governmental Organisation (NGO) in Swaziland in 2006, whose core mandate

was to support the Ministry of Health in HIV care and treatment services. This includes the decentralisation of ART services from larger, more centralised health facilities to PHC facilities, community groups and the uniformed services. It also involved the provision of supportive supervision to Swaziland Ministry of Health (MOH) staff on the ground, training of facility-based and community-based health care workers, capacity building, research support, renovations, supplying medical equipment and on-site mentoring support. ICAP is currently supporting hospitals (mother facilities), health centres, and PHC facilities (baby facilities) in the country to provide 'high quality, integrated HIV care and treatment services' (ICAP Swaziland Annual Progress Report 2012:1).

The ICAP Monitoring and Evaluation (M & E) database of site-specific ART data from the period of 2009 to 2013 indicates a steady decline in ART initiation at these ICAP supported facilities. It further shows that in Hhohho region, only as little as 67% of pre-ART patients who are eligible for ART, are actually being initiated on ART (ICAP Swaziland Monitoring & Evaluation Database 2013).

Hallett and Eaton (2013:1) describe the HIV continuum as the progression from HIV testing to the attainment of sustained viral suppression on ART. During this cascade, there are areas where patients can fall from care. In June 2012, the Swaziland MOH developed a National Patient Linkage, Retention and Follow-Up in HIV Care Standard Operating Procedure (SOP). This SOP guided health care workers on how to ensure successful patient tracing, and it offered a mechanism to implement patient follow-up for patients who did not return to receive treatment. Before the development of this SOP, it was not clear how to track patients who do not, for various reasons, adhere to their scheduled appointment dates.

This national SOP described an HIV cascade, from the point a patient tested for HIV, to the point of desired viral suppression. This was derived from McNairy and El-Sadr's (2012:1) premise that the overall effectiveness of HIV programmes is severely undermined by attrition of patients across the HIV care continuum, both in resource-rich and resource-limited settings. An illustration of this cascade can be seen in Figure 1.1.

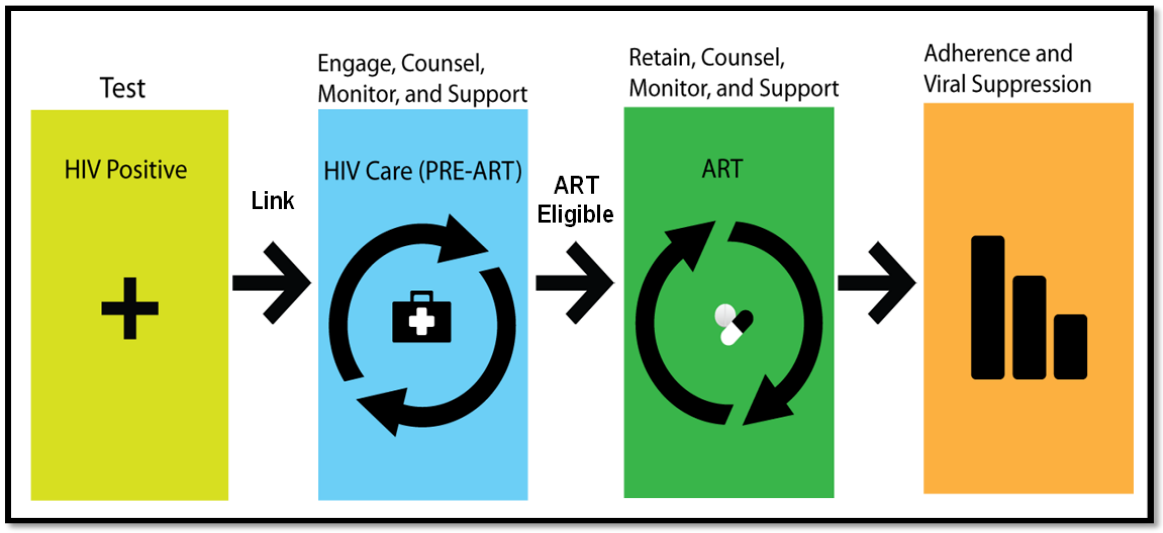

Figure 2.1: HIV Care Cascade (McNairy & El-Sadr 2012)

This cascade emphasises the importance of the sequence of steps that follow on from an HIV-positive diagnosis: *patient linkage* (enrolment into pre-ART and reception of all pre-ART services), *patient retention* (adherence to clinic visits and to the ART treatment plan) and *viral suppression* (viral load undetectable when an antigen test is utilised) (Swaziland National AIDS Program Patient Linkage, Retention and Follow-up in HIV Care SOP 2013:4). In the following section the pre-ART component of the cascade as the major focus area of this research will be discussed.

1.2.1 Pre-ART

In 2010, the Ministry of Health (MOH), with the support of key partners and stakeholders, rolled out a mechanism to actively support and follow-up patients between the time a patient receives a positive HIV diagnosis, to the time they initiate ART drugs. This phase was entitled 'pre-ART.' This pre-ART stage embodies the beginning of the HIV cascade. It is during this phase where waiting for and timing of ART initiation occurs (Swaziland National AIDS Program Patient Linkage, Retention and Follow-up in HIV Care SOP 2013:4).

Patient pre-ART and ART services at PHC facilities in Swaziland are captured through documentation in various national health registers. Each register documents the patient details. Documented patients are assigned a Unique Identifier. Patients testing positive for HIV are also provided with counselling, and are documented in the pre-

ART register to enable health care workers to quickly determine ART eligibility and promptly initiate patients on ART once WHO staged, and CD4 tests are done (Swaziland National AIDS Program Patient Linkage, Retention and Follow-up in HIV Care SOP 2013:8). A 2012 Malawi ART linkage study by MacPherson, Corbett, Makombe, van Oosterhout, Manda, Choko, Thindwa, Squire, Mann and Lalloo (2012:2), followed a prospective cohort of 280 patients for a period of six months. This study assessed the level of completeness of eligibility documentation, and for ART initiation, following the HIV cascade from HIV testing to the treatment initiation phase. At the time this study was conducted in Malawi, ART eligibility was determined by a CD4 cell count of 250cells/mm3 (if the WHO Clinical Stage was I or II), or a WHO Clinical Stating of III or IV (MacPherson et al. 2012:2). The study found that at six months, only 31.1% had initiated ART and 11.4% were lost to follow-up. Of this number, there was a 'higher uptake in participants who were ART-eligible (74.7%) and among participants who received same-day staging (38.8%)'. The study argued that patients who did not receive same-day WHO clinical staging, were less likely to be initiated on ART (MacPherson et al. 2012:3).

This study demonstrated not only the importance of the correct, documented WHO clinical staging as a facilitator to prompt ART initiation, but also highlighted attrition in the HIV cascade between testing for HIV, and finally being initiated on ART.

When patients enrol into pre-ART in PHC facilities in Swaziland, they are documented in the National pre-ART Register. When they are subsequently initiated on ART, their details are then transferred to the National ART Register. In this pre-ART phase, patients are entered into the pre-ART register and are given a pre-ART package, inclusive of screening of other illnesses, the treatment of opportunistic infections (OI) and close monitoring of labs, such as CD4, Full Blood Count (FBT) and Liver Function Tests (LFTs). Further, pre-ART patients are regularly assessed for their psychosocial well-being, their pharmaceutical and lab requirements, their clinical and immunological condition, and their nutritional welfare (Swaziland National AIDS Program Patient Linkage, Retention and Follow-up in HIV Care SOP 2013:5).

MacPherson, MacPherson, Mwale, Bertel Squire, Makombe, Corbett, Lalloo, and Desmond, (2012:1) conducted another study in Malawi on factors that contributed to

whether a pre-ART patient would successfully complete the cascade to ART initiation. Study findings highlighted that determinants of HIV cascade completion included the patients' desire to regain social respect, having lost it due to noticeable physiological deterioration, and the access to support networks. It highlighted overburdened, busy health facilities, weak laboratory services, and inappropriate use of ART tools as factors that could cause weaknesses in ART initiation. These authors emphasised the importance of positive perception, strong health systems and close and consistent support during the pre-ART stage (MacPherson et al. 2012:1).

Pre-ART enables close patient monitoring, early enrolment into ART and early intervention upon disease detection. It also readies patients to be optimally adherent when ART is initiated through ongoing counselling and information sharing within the pre-ART phase. However, the Swaziland National AIDS Programme (SNAP) reports that less than a third of persons testing for HIV subsequently link to ART care (Swaziland National AIDS Program Patient Linkage, Retention and Follow-up in HIV Care SOP 2013:2).

Pre-ART is a critical period because it is within this time that the patient is prepared for lifelong ART treatment. Non-initiation arises where patients who are in pre-ART and are eligible for ART but are not initiated. MacPherson et al. (2012:1) argued that low linkage rates from pre-ART to ART initiation still posed a threat to universal ART coverage, and were still poorly understood. The reasons for these delays may vary, and this research proposes to identify them. These reasons shall be explored further in the next section.

1.3 PROBLEM STATEMENT

A systematic review of risk factors, barriers and facilitators for linkage to ART conducted in 2012 by Govindasamy, Ford and Kranzer (2012:1), found that the most commonly cited factors were transport costs and distance. Other cited factors included stigma and the fear of disclosure, ART side effects, long hours spent waiting for services in the facility, and extended hours needed to take off work to attend clinic visits (Govindasamy et al. 2012:1). However, reasons for non-initiation of ART amongst eligible pre-ART patients in Swaziland has never before been explored. This

study is unique because there have never been any evidence-based findings that have been researched, that can highlight why people in Swaziland are not being initiated on ART when they are eligible pre-ART patients. Reasons for leaks in the HIV cascade for PHC facilities and communities in Swaziland may vary, and the hope is that this research will explore and describe these factors to identify possible leaks to enhance ART initiation in future, especially as 'no national statistics are currently available for linkage to care' (Swaziland National AIDS Program Patient Linkage, Retention and Follow-up in HIV Care SOP 2013:2).

There are various reasons why patients may not return to the facility for ART initiation. In a study conducted by Parkes-Ratanshi, Bufumbo, Nyanzi-Wakholi, Levin, Grosskurth, Lalloo and Kamali (2010:1) in Uganda, it was found that long waits for a home visit by a service provider, domestic issues, moving from the area, and the fear of side effects were statistically significant reasons that caused delays in initiation. Many patients are not ready to be initiated on ART. They are not prepared to begin a lifelong journey of taking medicines on a daily basis, and for a lifelong commitment to health facility visits. Some face denial, and are 'threatened by a previously unknown virus which requires them to talk about, and to change, intimate behaviour, possibly for the rest of their lives' (UNAIDS & WHO 2000:4). Many do not have the time to commit to monthly health facility visits, especially where the clinic refills ART monthly (as opposed to very two or three months). The demand that one adheres optimally to ART (that is, a monthly pill count percentage of >95%<105%) to avoid future risk of liver toxicity means that the journey on ART will need much ongoing support. The high levels of stigma and discrimination in Swaziland may compound fears of getting tested for HIV, and worsen fears of disclosing to family, friends and community members. Unfortunately, these are usually a potential source of support (UNAIDS & WHO 2000:4). Where a patient lacks this kind of support, the prospect of beginning this journey alone can be daunting and may result in poverty of care. Patients who face difficult socio-economic circumstances may not have the funds that would be required to afford the transportation to the facility for continuous follow-up (medicine refill) visits. Where a patient feels or looks healthy, limited family resources may be prioritised in other areas, such as purchasing of food, or care for dependents.

Although most PHC facilities are initiating and refilling ART, there remain few facilities that still refer to other health care centres and large hospitals for ART initiation. Services have been decentralised to PHC facilities, but still need to be decentralised further to community levels. Apart from mobile clinics that travel to communities, community initiation and refills have not taken off in Swaziland.

The role of health care workers in the PHC facilities in the ART initiation process includes preparing and supporting the patient with readiness for lifelong ART. Pre-ART patients who are eligible and stable, are then initiated on ART. Delays in ART predispose patients to advanced disease progression, increased Viral Load (VL) and limited abilities to prevent Opportunistic Infections (OIs). Community levy's, long waiting periods at the clinic, limited youth friendly services and negative attitudes of health care workers can also deter patients from attending the health facilities. Decreased VL further reduced chances of mother-to-child transmission of HIV as seen in a study by Okonji, Zeh, Weidle, Williamson, Akoth, Masaba, Fowler and Thomas (2012:249) conducted in Kenya, which focused on pregnant ART-initiated mothers. The authors found that at twenty-four weeks post-partum, undetectable VL (<400 copies/mL) increased from 6% at baseline to 79%, and that of those with CD4 count <250 cells per microliter decreased from 23% (100) at baseline to 5% (Okonji, et al. 2012:249).

Through this research, the researcher hopes to explore and describe factors associated with non-initiation of ART amongst pre-ART-eligible patients in rural PHC facilities in Swaziland. By so doing the researcher expects to derive recommendations for health care providers, policy developers and strategic health planners that will better promote increased uptake of ART amongst eligible pre-ART patients in PHC facilities in Swaziland.

In Sub-Saharan Africa, it is estimated that approximately 72% of adults living with HIV have not yet received viral suppression as a result of gaps or shortfalls at each stage of the treatment cascade (UNAIDS Global AIDS Report 2013:4). One of the most critical leaks in the treatment cascade, is the continuum from taking a patient from pre-ART, to ART initiation. It is during this pre-ART phase where a patient can either be initiated timeously, or where delays can occur. Earlier initiation of ART would give

patients an opportunity for increased life expectancy, and an improved ability to fight opportunistic infections. Lahuerta, Ue, Hoffman, Elul, Kulkarni, Wu, Nuwagaba-Biribonwoha, Remien, El Sadr and Nash (2013:263) conducted a study on late ART initiation and found that delays in ART initiation are associated with early mortality after ART initiation.

Lahuerta et al. (2013:360) highlight that late ART initiation was associated with a longer infectious period, and that earlier ART initiation substantially reduced onward HIV transmission. These findings highlight that patients who delay in initiating ART are more infectious than those who may be virally suppressed due to their adherence to ART. If these delays are not addressed for Swaziland, the consequence could be that HIV continues to spread. This research will create awareness of the importance of being initiated on ART timeously, and the grave consequences that can be caused by treatment delays. The greatest benefit of this research, from a public health perspective, includes getting patients on ART timeously to stop the progression of HIV disease to others.

The researcher hopes that this research might assist in exploring the problem of non-initiation of ART among pre-ART patients further, and in so doing create awareness of the importance of minimising delays in ART initiation. The researcher also hopes to provide locally derived evidence on how the problem can be combatted.

1.4 RESEARCH AIM

The aim of this research is to enhance the understanding of factors that influence non-initiation of ART amongst pre-ART-eligible patients and to increase the prompt initiation of ART for eligible pre-ART patients in rural PHC facilities in Swaziland.

1.5 RESEARCH OBJECTIVES

The research objectives include:

- To explore and describe factors associated with non-initiation of ART amongst eligible pre-ART patients in rural PHC clinics in Swaziland.

- To make recommendations for health care workers to enhance early initiation of ART amongst eligible pre-ART patients for PHC facilities in Swaziland.

1.5.1 Research questions

The core questions that this study aims to address are:

- What are the factors that might contribute to non-initiation of ART amongst eligible pre-ART patients at rural clinics in Swaziland?

- What recommendations can be made to health care workers to improve the initiation practices of ART for eligible pre-ART patients at rural clinics in Swaziland?

1.6 CLARIFICATION OF CONCEPTS

1.6.1 Adherence

The clinical definition of 'adherence to Antiretroviral (ARV) drugs' according to the Swaziland Ministry of Health National Comprehensive HIV Package of Care (PoC), involves taking the correct medications, the correct way, the correct dosing, and at the correct time (Swaziland Ministry of Health National Comprehensive Package of Care for Adults and Adolescents 2010:45). 'Adherence' in this study involves taking prescribed ARV drugs orally every 12 hours. The treatment is lifelong and requires strict treatment adherence. Missing doses of the ARV drugs could predispose one to develop resistant strains of the HIV.

1.6.2 Antiretroviral therapy (ART)

The World Health Organisation, or WHO (WHO Guidelines 2013:14) defines 'Antiretroviral Therapy' as a combination of at least three antiretroviral (ARV) drugs that are taken as directed by a health care worker, that aim to suppress the HIV virus and reduce the progressive speed of HIV disease. 'ART' refers to the period commencing after an individual is initiated on ARVs (Swaziland National AIDS

Program Patient Linkage, Retention and Follow-up in HIV Care SOP 2013:4). ART is a lifelong therapeutic intervention that requires eligible patients to adhere to complex treatment regimens. Adherence to ART encourages viral load suppression and improvements in CD4 cell counts. This optimises clinical outcomes. The WHO (WHO HIV/AIDs Programme 2012:8) argues that in the early stages of HIV, massive reductions have been seen in rates of mortality and morbidity (especially TB) in persons on prescribed ARV regimens. In this research, 'ART' will be referring to the non-nucleoside reverse transcriptase inhibitors, nucleotide reverse transcriptase inhibitors and protease inhibitors that are given to HIV-positive patients when their CD4 and WHO Clinical Staging levels reach the eligibility criteria. ART proceeds pre-ART, when eligibility has been determined.

1.6.3 ART eligibility assessment

Determining if a patient should be referred to or continue in pre-ART care or whether ART should be initiated, typically occurs through a CD4 count or on the basis of WHO Clinical Staging (Swaziland Ministry of Health National Comprehensive Package of Care for Adults and Adolescents 2010:19). CD4 counts (to be defined below) have to decrease to a threshold of 350 cells/mm3 or below to be eligible for ART initiation. Patients who have a higher CD4 cell count are still classified as being pre-ART patients, they are just not eligible for ART at that stage. Simultaneous assessments used to determine ART eligibility, consists of the WHO Clinical Stages (definition to follow), whereby illness groups are staged by the WHO in order of their severity. Stage III and IV indicate advanced disease progression, and possibly a compromised CD4 cell count. Patients in Swaziland will be initiated at a CD4 count of 350, and or a WHO Clinical Staging of Stage III or IV, regardless of CD4 cell count (WHO HIV/AIDs Programme 2012:9). This criteria is typically used in resource-limited settings, where options for assessment are limited. This is the eligibility criteria that will be utilised for this study. For a full view of the WHO Clinical Staging case definitions, refer to Annexure P.

1.6.4 CD4

‘Cluster of Differentiation 4’ or ‘CD4’, is a variant of T cells that protects against illness and assists the body to fight infection (Centers for Disease Control 2015:1). CD4 cells help in facilitating the immune response (WHO 2007:11). For the purposes of this study, ‘CD4’ will be an indicator for ART eligibility. ART eligibility is determined at a CD4 of 350 cells/ mm3 below. CD4 testing can be done at PHC by running blood samples through a laboratory PIMA device. Health facilities not equipped with a PIMA device need to send their CD4 blood samples to a larger, more equipped laboratory. The latter poses possible consequential delays in ART initiation because of the waiting time for CD4 blood results to return to the PHC. PHC facilities that are able to draw blood samples and immediately check for CD4 cell counts on site are able to facilitate immediate initiation of ART.

1.6.5 Defaulter

A scheduled clinic appointment that is missed by a patient for more than seven days, but less than or equal to ninety days, is known as a ‘defaulter’ (Swaziland National AIDS Program Patient Linkage, Retention and Follow up in HIV Care SOP 2013:25). This definition described in the SOP will be the one that is applied in this research.

1.6.6 Delayed ART initiation

‘Delayed ART initiation’ was defined by Lahuerta et al. (2013:360) as initiating ART in the advanced stages of HIV infection, irrespective of the reason. In this study, ‘delayed ART initiation’ will refer to an initiation that occurs after the pre-ART patient has been determined to be eligible for ART initiation by WHO Clinical Staging, or CD4 cell count, who irrespective of the reason, does not initiate ART. This research will explore the factors contributing to these delays.

1.6.7 HIV

‘Human Immunodeficiency Virus (HIV)’ is a retrovirus that infects cells of the immune system, destroying or impairing their function. Advancement in the progression of the

HIV infection in one's body compromises their ability to fight infection (WHO 2014:1). Health facilities offer on-site daily pre-ART and ART services for people living with HIV. An HIV-positive diagnosis is the beginning of the HIV cascade discussed earlier in this chapter. When a patient tests positive for HIV, they enter into the pre-ART phase of the cascade. They remain in this phase until they are found eligible for ART, at which time they should ideally be initiated on ART treatment.

1.6.8 Initiation

'Initiation' refers to the point whereby a patient commences ART medication because they have been found to be eligible for ART initiation due to their CD4 cell count, or WHO Clinical Staging (Swaziland National AIDS Program Patient Linkage, Retention and Follow up in HIV Care SOP 2013:4). The World Health Organisation recommends that ART should be initiated in all individuals with severe or advanced HIV clinical disease (that is, WHO Clinical Stage III or IV) and individuals with a CD4 count that is less than or equal to 350 cells/mm3 (WHO Guidelines 2013:28). In PHC facilities in Swaziland, ART is initiated by NARTIS trained nurses. This is preceded by them determining the eligibility of ART amongst their pre-ART patients. The timing of ART initiation will form the impetus for this research as the focus will include the possible causes for ART delays.

1.6.9 Non-ART initiation

Non-ART initiation occurs where a pre-ART patient who is eligible to begin ART because they meet the criteria defined by CD4 cell/ mm3 or by the WHO (see definition of ART initiation above), is not initiated on ART. In this research, non-initiation will occur when a pre-ART patient who is eligible for ART is not initiated on ART, regardless of the reason (Lahuerta et al. 2013:360). Non-ART initiation of ART occurs in the pre-ART phase. Role-players who influence non-ART initiation are the NARTIS nurses, who are the ones who both determine ART eligibility and initiates the patient; and the patient themselves, who may, for reasons known only to themselves, not be ready to begin ART.

1.6.10 Linkage

Linkage occurs when a patient who tests positive for HIV is subsequently enrolled in HIV care services through being registered into the National pre-ART register (Swaziland National AIDS Program Patient Linkage, Retention and Follow up in HIV Care SOP 2013:4). This is followed by the issuance of a patient appointment book, and the opening of an HIV chronic care file. In the file, the patient's baseline clinical and laboratory information is placed, as well as the completed and documented psychosocial assessment. This process is completed with the provision of clinical services, such as cotrimoxazole prophylaxis. For this research, the linkage phase is the second phase in the HIV cascade, preceded only by testing HIV-positive. Linked patients are retained in pre-ART, until treatment initiation.

1.6.11 Lost to follow-up

A patient is 'lost to follow-up' when they have not attended an HIV PHC facility for more than ninety days (Swaziland National AIDS Program Patient Linkage, Retention and Follow up in HIV Care SOP 2013:25). In this research, a patient will be viewed as 'lost to follow-up' if they have not attended, and there is no documented service that has been provided at the PHC, for over ninety days.

1.6.12 Nurse-led art initiation in Swaziland (*NARTIS*)

This is a country specific intervention for Swaziland to strengthen the decentralisation of ART access and services. It is aimed primarily at equipping nurses with ART management skills (Mazibuko 2014:7). It entails the training and accreditation of qualified nurses to be able to initiate and refill ART. In this research, before an eligible pre-ART patient can be initiated on ART, the NARTIS nurse needs to determine the clinical eligibility and psychosocial readiness of the patient. Once this is satisfactory, the patient can be initiated on ART. Thus, the NARTIS nurse plays a critical role in being the vehicle that will transport the patient from the pre-ART phase to the ART phase. The NARTIS nurse's assessment holds the largest weight to whether or not an eligible patient will be initiated.

1.6.13 Pre-ART

'Pre-ART' refers to the period commencing at the time an individual tests positive for HIV, to the time they begin ART (Swaziland National AIDS Program Patient Linkage, Retention and Follow up in HIV Care SOP 2013:4). It encompasses all the health related services that are provided by the health care worker, to a patient between the time they test positive for HIV, and the dispensation of their initial dose of ARVs. In this research, there will be much focus on the pre-ART stage and factors that contribute to the non-initiation of ART amongst pre-ART patients will be explored. The pre-ART phase is critical to this research because it is at this time when patients are supported by a team of health care workers to encourage early identification of eligibility for ART. During pre-ART, patient CD4 cell counts and WHO Clinical Staging is closely monitored. Psychosocial counselling services are provided at health facilities to address patient-related reservations to treatment initiation. This is applicable to the research because it is in this phase where factors can positively or negatively influence the timing of one's ART initiation.

1.6.14 Missed appointment

A 'missed appointment' is a scheduled clinic appointment that is missed by more than three days, but less than seven days (Swaziland National AIDS Program Patient Linkage, Retention and Follow up in HIV Care SOP 2013:25). In this research, pre-ART patients who have scheduled appointments at the PHC facility are referred to as a 'missed appointment' if they fall within this three to seven day window, after which they missed their appointment date.

1.6.15 Retention

'Retention' refers to a patient who has attended a health care facility within the last ninety days for medical or pharmaceutical collection, laboratory testing or diagnostics, and or clinical review, and has not been documented to have died, stopped treatment or as a 'lost to follow-up' (Swaziland National AIDS Program Patient Linkage, Retention and Follow up in HIV Care SOP 2013:5). For this research, a patient will be viewed as 'retained' if there are documented health services that were provided to

them within ninety days. Pre-ART patients who have not had a documented clinic visit within ninety days are therefore not considered to be retained. Retention will be applied in this research as it will provide an indication of patients' health-seeking behaviour. ART initiation will demand more frequent visits to the health facility and will not allow patients to be absent from health services for a ninety day period. Health-seeking behaviour will have a bearing on whether a patient will be initiated timeously on ART or not.

1.6.16 WHO Clinical Staging

This refers to the use of a clinical tool that determines a patient's eligibility for ART. It assesses a patient's functional status (Swaziland Ministry of Health National Comprehensive Package of Care for Adults and Adolescents 2010:8). The WHO has classified 'health status' into four components (I, II, III, and IV), each of which give an indication of the level of HIV disease progression and specify the need for ART. WHO Clinical Staging becomes the essential decision-making tool to decide whether or not to initiate a patient on ART. Patients who are defined as WHO Clinical Stage III or IV, are initiated on ART regardless of their CD4 cell count. For this research, ART-eligible patients are those who have clinical stage III or IV. Pre-ART patients who are therefore determined by NARTIS nurses as WHO Clinical Stage III or IV will be eligible for ART initiation. The full WHO Clinical Staging chart can be seen in Annexure P.

1.7 RESEARCH METHODOLOGY

The research methodology describes the research design, setting, population, sampling methods, data collection and data analysis methods.

1.7.1 Research design

The research design employed through this research was a qualitative research design that is explorative and descriptive in nature. This approach was used to enable the researcher to gain a deeper understanding of the factors influencing non-initiation of ART amongst patients who are pre-ART-eligible.

1.7.2 Research setting

The research was conducted in the Hhohho region of Swaziland in eleven PHC clinics, which were diversely spread across the region. All eleven PHC clinics were rural clinics. Each of the PHC clinics where the research was set were providing ART services, including the initiating and refilling of ART.

The Swaziland Ministry of Health Service Availability Mapping (SAM) Report of 2013 reported a total of 287 health facilities in Swaziland, and of these 82 (28.6%) are located in Hhohho region (Swaziland Ministry of Health Service Availability Mapping (SAM) 2013:19). In Hhohho region, there is one National Referral Hospital, one Regional Referral Hospital, and two Health Centres (Swaziland Ministry of Health SAM 2013:27). There are also fifty-eight primary health care clinics in Hhohho region. The WHO recommends that there should be two health facilities per 10 000 population (Swaziland Ministry of Health SAM 2013:28). Currently, Swaziland has a ratio of 2.6 facilities per 10 000 facility population in Hhohho region particularly, the facility population density is 2.7 (Swaziland Ministry of Health SAM 2013:28).

According to the SAM report (2013:75), there are 252 medical doctors in Swaziland, a ratio of 23.1 per 10 000 population. These medical doctors are located primarily in hospitals and health centres, not in the PHC facilities. There are 102.8 staff nurses per 100 000 population (Swaziland Ministry of Health SAM 2013:75-76). There is no regional data available of this ratio. Most PHC clinics will have at least one nurse who is trained in NARTIS. This nurse will provide both ART initiation and ART refill services. In Swaziland, there is a total of 2260 nurses, comprising of matrons, nursing sisters, staff nurses, general nurses and nursing assistants. Seven hundred and forty-three of these are based in Hhohho region (Swaziland Ministry of Health SAM 2013:77). The Swaziland Nursing Council stratifies these nurses hierarchically depending on their levels of nursing preparation. Save for the Nursing Assistant level, all the other nursing levels stated above would require a *Basic Diploma* in Nursing as a minimum requirement to practise as a nurse. This includes qualifications such as a PhD in Nursing, a Masters Degree in Nursing, a Bachelors Degree in Nursing, a Diploma in Advanced Nursing, a Post-basic Diploma in Nursing and a Basic Diploma in Nursing (Swaziland Nursing Council Scope of Practice 2009:8). A nursing assistant, however,

is qualified through a Certificate in Nursing and operates under the direct supervision of a Registered Nurse (Swaziland Nursing Council Scope of Practice 2009:8). For the purposes of this study, Nursing Assistants were not included in the study sample frame as they are not eligible to be trained in NARTIS. This brings the number of nurses down from 1760 and 581 respectively (Swaziland Ministry of Health SAM 2013:76). Not all of these nurses are NARTIS trained.

1.7.3 Study population and sampling

The 'study population' refers to all the individuals or objects with common, defining characteristics (Polit & Beck 2012:59). The study population in this research are qualified nurses in Swaziland who are trained in NARTIS and who are working in any of the fifty-eight rural PHC facilities in the Hhohho region of Swaziland. This would be the population from which the sample was selected. A purposively selected sample (as discussed in 1.8.4) of eleven health care facilities was used for this research. From each of these facilities, one NARTIS trained nurse was interviewed by the researcher using a semi-structured interview guide. This semi-structured interview guide, and the scheduled dates of the interviews, can be viewed in the Annexures. Data was collected until data saturation was reached. For more information on the study population, please refer to Chapter 3.

1.7.4 Sampling methods

Purposive, convenience sampling methods were used in this research. Purposive sampling is used when the researcher uses their own knowledge about the sample to select the sample members (Polit & Beck 2012:279). Convenience samples occurs where the sample is conveniently available for the research (Polit & Beck 2012:276). This method would enable the researcher to control the selection of participants for the study, eliminating a selection that is purely based on chance. This sampling method ensured that nurses who are NARTIS trained and were stationed at rural PHC facilities were included in the sample.

The sampling frame consisted of the PHC facilities and the NARTIS trained nurses. Eleven PHC facilities were purposively sampled out of the fifty-eight primary health care facilities in the region. Each facility had at least one NARTIS trained nurse.

The researcher selected PHC facilities that were located geographically closer to where the researcher resided to make it easier for the researcher to travel to those facilities. The researcher travelled to the facilities to conduct the semi-structured interviews with the nurse trained in NARTIS on-site. The NARTIS nurses were employed and stationed at these PHC clinics. Eleven NARTIS trained nurses, across eleven sample faculties, were interviewed until data saturation was reached – after eleven interviews. The inclusion criteria consisted of nurses who were trained in NARTIS, stationed in rural PHC care facilities, who were actively initiating patients on ART, and who were willing to participate in this research. Exclusion criteria included nurses who were not trained in NARTIS, and who were stationed in health centres and hospital.

1.7.5 Data collection

To collect data for the research, the researcher used semi-structured interviews and field notes. Field notes included taking notes of observations made by the researcher while at the facility. The researcher travelled to the eleven sampled PHC facilities to conduct the semi-structured interviews. All prospective participants were informed of the research. The researcher shared all the information of the research with the participants, explaining the research aims and objectives.

Participants were given an opportunity to ask questions about the research and have these questions addressed before consent was given. Informed consent was obtained from the participants to conduct semi-structured interviews and to audio record the interviews. Permission was also obtained from stakeholders, who included the PHC senior nurse, the Regional Matron, the Regional Health Management team, and ethical clearances was obtained from both Swaziland and South Africa. These can be seen from Annexure B to Annexure G.

All the semi-structured interviews were conducted by the researcher in the PHC facility premises. The interview guide was structured in English but participants were given an opportunity to select the language of their preference to use before the interview began. Many of the participants switched between English and Siswati in their responses. The interviews were all recorded using an audio tape device. The researcher is fluent in both English and siSwati, and was able to translate the siSwati quotes into English when the eleven interviews were later transcribed verbatim by the researcher (view Annexures). Another fluent siSwati speaker, who is also fluent in English, assisted with the translations. These were then back-translated into siSwati. The anonymity of participants was contained as the assistant translator was not informed of the participant's identity, or of the identity of the facility at which they were stationed.

The interviews were conducted until data saturation was reached. This part of the process shall be discussed further in the data analysis section 1.7.6

1.7.6 Data analysis

Data analysis involves grouping qualitative information into a logical and intelligible scheme (Polit & Beck 2012:62). For this study, the data was continuously analysed through the data collection process. The researcher took field notes, and was constantly reflecting on the participant responses during the interviews. The researcher constantly read and re-read the interviews, to identify emerging themes. The field notes and the semi-structured interviews' content analysis was done using Tesch's open coding method (Creswell 2014:198). This method will be explained in more detail in Chapter 3. The researcher engaged an independent coder, who also reviewed the transcribed interviews and independently identified emerging themes. The researcher and the independent coder were unanimous in the themes identified. These themes will be elaborated on in Chapter 4.

1.7.7 Ethical considerations

Observation of ethics involves the protection of study subjects and also the protection of the trust from members of the public (Polit & Beck 2012:168). The researcher

ensured that ethical principles were adhered to by ensuring that both the research participants' and the public's trust were safeguarded. These ethical principles included respect for persons, non-maleficence, beneficence, and justice. These shall be discussed further in Chapter 3.

Before commencement of the research, the researcher was granted approval from the Higher Degrees Committee, Department of Health Studies, University of South Africa (UNISA). After ethical clearance was granted from UNISA (Number: REC 012714-039), the researcher sought ethical approval from the Swaziland Ethics Committee. Letters of approval to conduct the study in the Hhohho region's primary health care clinics was granted by both the Hhohho Regional Health Administrator, and the Hhohho Regional Matron. These approval documents can be viewed from Annexures B to Annexure G.

All the participants in the research were fully informed of the research. The research was comprehensively explained to them verbally, by the researcher, during a private one-to-one session. The one-to-one sessions were conducted in the PHC facility, in a private, confidential location within the clinic premises. Participants were also provided with a written outline of the study. They were given time to ask questions, and these were answered to their satisfaction by the researcher. When all the questions had been answered and when concerns had been fully addressed, participants provided informed consent. Coercion or the use of threat or unwarranted, extreme reward for the purposes of gaining member participation in the research, was not used (Polit & Beck 2012:722). This was prevented by allowing participants to discontinue the semi-structured interview at any time, by allowing them not to answer any question they felt uncomfortable with, and by not including any incentives or rewards for participants in this research. Before acquiring informed consent, the researcher explained that the participation of the respondents was purely voluntary and they were free to exit the interview at any time. They were also not compelled to answer any questions that made them feel any level of discomfort. Here, if a participant felt discomfort, they were free not to answer the question posed or to discontinue the interview. In order to avoid interruptions in service delivery, the researcher conducted the interviews in the afternoons, or during times when the clinic was quiet and when patient volumes were minimal.

The researcher pledged confidentiality to all the participants and ensured them that their identities would be protected. The identity of the facility was also kept confidential. Both participants and facilities were assigned unique identifiers. This was done to safeguard that anonymity, privacy and confidentiality were maintained. The interviews were carried out in a language of the participant's choice, in a quiet, private room. Participants gave consent that the interviews could be audiotaped, prior to the interviews. The audiotaped data was kept securely under lock and key by the researcher. The researcher will securely maintain the data for five years after completion of the research. More detail of the data security will follow in Chapter 3.

1.7.8 Trustworthiness

To ensure the trustworthiness of the study, the researcher adhered to the principles of trustworthiness described in Polit and Beck (2012:62), that the findings of the research accurately represent the perceptions and expressions of the participants. These included credibility, dependability, confirmability, transferability, and authenticity. These principles shall be elaborated on further in Chapter 3.

1.8 SIGNIFICANCE OF STUDY

This research will enable the derivation of delays in ART initiation amongst eligible pre-ART patients, from the perspective of nurses who are trained in NARTIS. Currently, minimal studies have been conducted in Swaziland that focus on pre-ART patients. This particular thematic area is still unearthed. Current national policies and strategic plans have been developed around anecdotal recitals from health care workers of their experience with pre-ART patients, or because of comparisons with countries of similar demographic characteristics, such as Lesotho or Malawi. This study will offer local findings, within a local context. It will fill the existing gap in research around this thematic area and highlight to health care workers, partners and stakeholders, the perceptions and experiences of health care workers that ultimately influence health service delivery. More importantly, it will facilitate the development of local, context-specific recommendations for health care workers, to be applied for patients who are still in the pre-ART phase.

1.9 LIMITATIONS

Few limitations were identified in this research. One key limitation included social desirability bias, where the participants may have provided responses that are more socially acceptable, rather than honest and truthful. Another limitation, typical of most qualitative studies, was the inability to generalise this study as the sample size was small. Limitations will be expanded on in Chapter 5.

1.10 OUTLINE OF THE STUDY

The outline of this research is as follows:

Chapter 1: Orientation of the study
Chapter 2: Literature Review
Chapter 3: Research Methodology
Chapter 4: Discussion of research findings and literature control
Chapter 5: Conclusions, Recommendations and Limitations

1.11 CONCLUSION

This research aims to explore and describe factors that contribute to late, or delayed initiation of ART for pre-ART-eligible patients. Swaziland faces high levels of HIV prevalence and incidence, meaning that more and more people should be enrolled in HIV care and treatment services at an early stage. It further means that once pre-ART patients have been clinically determined by NARTIS trained nurses to be eligible for ART, they will need to be enrolled in HIV treatment services early to enable them to live long and healthy lives. This will prevent unnecessary deaths and the onset of opportunistic infections due to late access to life-saving ARV drugs. Through early access to ART, and treatment adherence, patients could attain viral suppression. This would enable them to live long and productive lives, contributing to their economy, and raising and providing for their children. This study, therefore, aims to identify these factors that contribute to the late initiation of eligible pre-ART patients on ART, so that

recommendations can be formulated for health care workers to be informed and equipped to work towards addressing these factors.

In this chapter, an overview of the study was provided and the background, pre-ART, the problem statement, operational definitions, the research methodology, and the ethical considerations were discussed. In the next chapter, the literature review will be discussed. The chapters that will follow will describe the research methodology, the data management procedures and the interpretation of the findings.

CHAPTER 2
LITERATURE REVIEW

2.1 INTRODUCTION

The primary aim of conducting a literature review is to expand the researcher's understanding of the phenomenon from multiple perspectives (Polit & Beck 2012: 94). Through this literature review, the researcher aims to gain insight into unanswered questions and highlight perceptions around ART initiation globally and in Swaziland. The general vacuity in local research in this area presented the researcher with an opportunity to explore it further. Through this literature review, the researcher plans to review local, regional and international studies that might shed more light on the non-initiation of ART amongst eligible pre-ART patients.

A literature review is typically conducted before data is collected (Polit & Beck 2012: 58). However, the timing of the literature review is debated by many researchers. In some studies, the literature review is conducted after the study. This is done so that the findings of the literature review do not bias the researcher or influence conceptualisation of the focal phenomenon as they conduct the study (Polit & Beck 2012:61). For this research, the researcher felt that it was appropriate to conduct the literature review before the study, in order to bring some context and depth to the importance of pre-ART in HIV care, and also to explore existing literature on the topic of ART initiation amongst eligible pre-ART patients. This research is examining the timing of initiation for the pre-ART phase amongst ART-eligible pre-ART patients. The pre-ART phase focuses on the provision of comprehensive care for patients before they begin on ART. This package of intervention shall be discussed later in this chapter.

The local, regional and international literature on ART initiation will be reviewed in this chapter. It will discuss the perspectives around ART initiation, HIV incidence in Swaziland, and the role of pre-ART. It will also describe the strategies that Swaziland has implemented to facilitate prompt initiation of ART amongst eligible pre-ART

patient, explore the dangers of delayed ART initiation, and the advantages of prompt ART treatment initiation.

2.2 HIV AND ART INITIATION

Before the availability of ART treatment in Swaziland, HIV used to be a death sentence. To date, HIV has no cure, so management and treatment through ART medicines are critical. In Swaziland, eligibility for ART begins at a CD4 cell count of 350cells/mm3, or at WHO Clinical Stage III or IV (Swaziland Ministry of Health National Comprehensive Package of Care for Adults and Adolescents 2010:19). The most recent national study of HIV incidence and HIV prevalence in Swaziland was the Swaziland HIV Incidence Measurement Survey (SHIMS) conducted in 2012. This study found that the prevalence of HIV amongst eighteen to forty-nine-year-olds was 31%. This prevalence was found to be higher for women (38%) than men (23%) (SHIMS 2012:21). With such high rates of prevalence in Swaziland, it is critical to ensure that ART-eligible pre-ART patients are initiated as early as possible.

A study by Lahuerta et al (2013:360) that explored the problem of late initiation of ART in Sub-Saharan Africa, emphasised that early ART treatment initiation significantly reduced onward transmission of HIV. It further described that the benefit of early initiation of ART to the population was HIV transmission being almost entirely interrupted (Lahuerta et al. 2013:365). Another study conducted by Ingle, May, Uebel, Timmerman, Kotze, Bachmann, Sterne, Egger and Fairall (2010:2), that investigated the outcomes of patients waiting for ART treatment in the Free State Province, South Africa, found that 87% of all HIV-related deaths occurred amongst patients who had not been initiated on ART. This study cited pre-treatment mortality in other parts of Sub-Saharan Africa, including 35 deaths per 100 person-years within the first month of screening for ART eligibility in Uganda, 33.3 deaths per 100 person-years in Cape Town, and 57.7 deaths per 100 person-years for patients with a CD4 cell count of under 200 (Ingle et al. 2010:7). The study findings demonstrated that where HIV is left untreated, predisposition to mortality is high.

As such, the 2015 Swaziland Integrated HIV Management Guidelines advocate that *all* patients testing HIV-positive should be referred, linked and enrolled into HIV chronic

care, and that all health facilities should strive to provide the highest quality of chronic care for all HIV-positive patients (Swaziland Ministry of Health Integrated HIV Management Guidelines 2015:48). In so doing, these 2015 guidelines aim to ensure that all patients who test positive for HIV and are deemed to be eligible for ART, are initiated on treatment as early as possible, without delays.

2.3 GLOBAL PERSPECTIVES ON ART INITIATION

In 2015, Joint United Nations Program on HIV/AIDS (UNAIDS) determined that 36.9 million people globally were living with HIV (UNAIDS 2015:1). This prevalence has been steadily increasing, indicating that more people living with HIV are staying alive because of access to Antiretroviral Therapy (ART). The HIV incidence in 2000 was 3.1 million, which dropped to 2 million in 2014, indicating a decline of 35% (UNAIDS 2015:1). According to this report, 2 million people died from AIDS in 2005. In 2014, this number dropped to 1.2 million (UNAIDS 2015:1). Not only does this underscore the fact that there needs to be an ongoing supply of life-saving ART to those who are eligible to receive it, and that ART has to be universally accessible, but it also highlights that if people can access ART treatment, they can stay alive for longer.

This also illustrates the importance of early initiation of ART treatment to those who are eligible to receive it. The UNAIDS report reveals that in Sub-Saharan Africa in 2014, 25.8 million people were living with HIV, and there were 1.4 million new HIV infections (UNAIDS 2015:2). AIDS-related mortality in the region had fallen by 42% since 2004 (UNAIDS 2015:2). It also found that in 2014, 13.5 million people were accessing ART; this number rose to 15.8 million in 2015 (UNAIDS 2015:1). The UNAIDS Gap Report (UNAIDS Gap Report 2014:1) revealed that Nigeria, South Africa and Uganda accounted for 48% of new HIV infections in 2014. Encouragingly, this study also asserts that in Sub-Saharan Africa, almost 90% people who have tested HIV-positive were subsequently initiated on ART. Further, 76% of those on treatment in Sub-Saharan Africa have attained viral suppression (UNAIDS Gap Report 2014:1).

The completion of HIV cascade, which begins at the point of testing for HIV and continues through to the attainment of viral load suppression when on ART, is needed to optimise the health outcomes of people living with HIV (McNairy & El-Sadr 2012:1).

These outcomes are often compromised by the significant levels of attrition along the continuum. McNairy and El-Sadr (2012:1) found that less than a third of people are retained in HIV services from the time of testing HIV-positive to the time they are initiated on ART.

Larson, Brennan, McNamara, Long, Rosen, Sanne and Fox (2010) conducted a study on the early loss to follow-up after enrolment into pre-ART in a large Johannesburg public clinic. They argue that most patients living with HIV present very late at the HIV care and treatment facility with advanced HIV disease and a compromised CD4 cell count, resulting in them being initiated on ART much later than eligibility was determined (Larson et al. 2010:43). Larson et al. (2010:43) attribute such attrition of patients from pre-ART to ART initiation to death and loss to follow-up. This is supported by a study conducted by Gwynn, Fawzy, Viho, Wu, Abrams and Nash (2015:2), who also note high rates of death among non-retention, subsequent death, and LTFU amongst pre-ART patients who are eligible for ART but have not yet started treatment. These findings stress how the patient attrition in the pre-ART phase leads to compromised numbers of pre-ART patients receiving treatment initiation. It describes the terminal risk posed to eligible pre-ART patients who are not initiated on ART. It further stresses the relevance of this research, as essentially this research is exploring the contributing factors for this attrition within the Swaziland context.

The linkages of patients who test positive for HIV – at any HIV testing entry point – to a health facility for enrolment into pre-ART, is also weak in many settings. McNairy and El-Sadr (2012:1) reported that linkage data is not routinely reported in many settings; in Sub-Saharan Africa for example, the medial linkage rate was found to be 59% across a review of twenty-eight studies (McNairy & El-Sadr 2012:2). Before patients can be determined as eligible for ART, they would have to be enrolled into pre-ART. Attrition in this phase of the HIV cascade undermines efforts to ensure that pre-ART patients who need ART, receive ART as early as possible. In Sub-Saharan Africa, only two-thirds of eligible pre-ART patients remain in HIV care up until ART initiation (McNairy & El-Sadr 2012:2). Again, this highlights that within the region there are still high levels of attrition between pre-ART eligibility and ART initiation along the cascade. These findings prompted this research inquiry into the reasons for this attrition along the Swaziland HIV care continuum. Providing support to people living

with HIV requires more than just getting people tested or putting people on ART treatment. It is about retaining them throughout the HIV cascade. McNairy and El-Sadr (2012:3) argue that retention on the HIV continuum is a measure of the quality of HIV services. The researcher wanted to focus on this part of the HIV continuum also as a measure of the quality of the HIV services that are provided in Swaziland.

The World Health Organisation (WHO) has recommended a new public health approach to ART initiation by increasing ART eligibility from Cluster of Differentiation 4 (CD4) 350 cells/mm3 to CD4 500 cells/mm3 (WHO Guidelines 2013:25). This expansion in criteria of ART eligibility was recommended with a view to providing new opportunities to save lives, to improve clinical outcomes and reduce HIV incidence (WHO Guidelines 2013:26). In their study focusing on attrition through multiple stages of pre-treatment and ART HIV care in South Africa, Fox, Shearer, Maskew, Meyer-Rath, Clouse and Sanne (2014:1) allege that although the WHO's increase in the ART eligibility threshold was premised upon the improved benefit it would pose to the patient, and on the decrease in HIV transmission rates, this goal would be significantly undermined if patients were not being retained in pre-ART. Fox et al. (2014:1) further argue that increasing the ART eligibility threshold has resource implications and these resources should not be diverted from strengthening systems of linkages and retention of patients through the HIV cascade, particularly, from HIV testing, to pre-ART, to treatment initiation. Test-and-treat programmes, for example, would need to concentrate efforts on improving retention, especially of pre-ART patients, in order to avoid morbidity, mortality and future transmissions (Fox et al. 2014:9).

Innovations in HIV care and treatment services to advance this expansion include Point of Care (POC) testing and the once daily dose of ART. Point of Care devices enable CD4 results to be determined approximately twenty minutes after drawing a blood sample (Mtapuri-Zinyowera, Chideme, Mangwanya, Mugurungi, Gudukeya, Hatzold, Mangwiro, Bhattacharya, Lehe & Peter 2010:1). This means that contrary to previous practice, patients testing positive for HIV in primary health facilities in the country no longer need to be given a subsequent appointment date at which to collect CD4 results. McNairy and El-Sadr (2012:3) have cited that POC CD4 count testing has yielded promising results for strengthening some of the phases on the HIV cascade. Currently, most patients in Swaziland can be enrolled into pre-ART care on

the day they test positive for HIV. Enrolment into pre-ART enables prompt follow-up action for treatment initiation after the determination of eligibility of ART. If a patient is not enrolled in care, then following them up for ART initiation after having determined eligibility, does not become possible. Thus, the availability of POC CD4 count assists in estimating the HIV incidence in Swaziland.

2.4 HIV INCIDENCE IN SWAZILAND

The Kingdom of Swaziland harbours a population of just over 1 million people (WHO Global Health Observatory 2012). It also has the highest rate of HIV infection in the world, with HIV remaining its most prominent area of public health interest (SHIMS 2012:8). The most recent Swaziland Demographic Health Survey found HIV prevalence to be 26.1% between ages fifteen years to forty-nine years (SDHS 2007:221). Comparable levels of HIV prevalence were found with the Swaziland HIV Incidence Survey (SHIMS), determined to be 31% (SHIMS 2012:6). SHIMS also found an HIV incidence rate of 2.38% amongst adults (SHIMS 2012:7). This data illustrates that there are substantial numbers of people in Swaziland who are acquiring HIV each year. All these people who are testing HIV-positive are at the starting point of the HIV cascade. They should then be enrolled into pre-ART. The SHIMS study reminded the country that pre-ART systems need to be in place, in order to support those acquiring HIV each year. It also reminded us that every person acquiring HIV needed to begin the HIV care and treatment continuum, and receive all the support required to complete it.

2.5 PRE-ART: THE ROLE OF PRE-ART IN ART INITIATION

According to the Swaziland National AIDS Program Patient Linkage, Retention and Follow-up in HIV care Standard Operating Procedures (2013:5), the pre-ART phase entails a comprehensive package of care, including the enrolment of patients into pre-ART, opening a patient chronic care file, a clinical evaluation, a TB screening, a psychosocial assessment, a prescription of cotrimoxazole, the provision of condoms, and the setting up of agreed follow-up visits through the facility's Appointment Register. These pre-ART systems assisted in the prompt identification of ART-eligible pre-ART patients and attempted to avoid delays in treatment initiation. Larson et al.

(2010:46) describe the central goal of pre-ART as being the close monitoring of HIV disease progression so as to safeguard that ART is commenced as early as possible, and avoid the development of potentially acute illnesses.

A pre-ART study conducted by Burtle, Welfare, Elden, Mamvura, Vandelanotte, Petherick, Walley and Wright (2012:1) in a large hospital in Swaziland, followed two patients who tested HIV-positive in 2009 and in 2010 to determine the levels of pre-ART services offered to them. Similar to Larson et al., this study contended that the elevated levels of loss to follow-up of HIV-positive patients was due to their late presentation at the health facility, predisposing them to poor health outcomes (Burtle et al. 2012:1). This study found that in 2009, pre-ART care was not routinely offered at hospitals. Mechanisms of patient follow-up only commenced after ART treatment initiation. Blood samples for CD4 were collected at this hospital, with results only being returned after three days (Burtle et al. 2012:2). Sobering findings of an internal audit of the same hospital in October 2008 found that: more than 153/407 (38%) of patients returned to collect their CD4 cell count result; that the patients were being initiated on ART at an advantaged disease stage with a median CD4 at presentation of 116 cells/mm3; that cotrimoxazole was not routinely supplied for pre-ART patients; and that TB screening was neither routinely documented nor consistently documented and that TB screening results were not followed-up (Burtle et al. 2012:2). This study found an increase between the baseline and group 1 and 2 in the number of pre-ART patients who were assessed for eligibility from 57.5% at baseline to 61.4% and 77.6% respectively (Burtle et al. 2012:5). A significant improvement was also witnessed in the number of ART-eligible pre-ART patients who were being started on ART from baseline and group 1 and 2, going from 52.9% at baseline to 81.1% in group 1 and 81.4% in group 2 (Burtle et al. 2012:5). Although this study was conducted at only one regional hospital, the findings validate the need for a significant exploration of other health facilities and other regions of the factors contributing to the non-initiation of ART amongst pre-ART patients.

Since this study, local strategies have been implemented in Swaziland to attempt to facilitate prompt initiation of ART. These are described below.

2.6 SWAZILAND'S STRATEGIES TO FACILITATE PROMPT ART INITIATION

In an effort to increase uptake of ARVs amongst eligible pre-ART patients, Swaziland continues to implement strategies aimed at attaining universal coverage of ART in the country, particularly ensuring that those who are eligible for ART, are accessing it. These strategies are being strengthened through the development of several key strategic documents and some critical innovations, such as the formation of Technical Working Groups (Swaziland Ministry of Health National Comprehensive Package of Care for Adults and Adolescents 2010:viii). These strategies included the development of the National Comprehensive Package of 2010, the decentralisation of HIV services, NARTIS, Provider Initiated HIV Testing and Counselling (PIHTC), Life Long ART for Pregnant and Lactating Women (LAPLLA), and the Swaziland Integrated Management of HIV Management Guidelines of 2015.

Efforts to achieve universal coverage of ART in Swaziland began with the decentralisation of HIV care and treatment services.

2.6.1 Decentralisation of HIV services

Between 2003 and 2004, antiretroviral (ARV) drugs became available in Swaziland. These were availed centrally at the main hospitals and health centres. In 2005 and 2006, ART was decentralised to primary health care (PHC) level facilities. Here, doctors would travel to the PHC level facilities to initiate patients on ART, and also to refill patients who were already on ART. In 2011, nurses were capacitated in ART management through the Nurse-Led ART Initiation in Swaziland (NARTIS) training (Swaziland Ministry of Health NARTIS Training Curriculum 2015:6). This lifted the need for a doctor's visit for ART initiation to occur. Currently, patients are able to initiate or refill ART in most facilities in the country, on any working day of the week. Nurses are now able to provide ongoing pre-ART care for patients closer to their homes. NARTIS also enabled closer monitoring of ART patients, facilitating that ART eligibility amongst pre-ART patients could be determined earlier. This research then presented an opportunity to explore the success of the established systems of pre-ART that are currently implemented in the country, and examine whether or not these systems were creating an enabling environment for prompt ART initiation amongst pre-ART patients.

Another strategy to facilitate prompt ART initiation in Swaziland includes the National Comprehensive Package of Care.

2.6.2 National Comprehensive HIV Package of Care (PoC) 2010

In the Swaziland Ministry of Health National Comprehensive Package of Care (PoC) for Adults and Adolescents' 2010 document, the role of pre-ART is described as a package of services which facilitates that ART-eligible pre-ART patients are initiated as soon as possible. This PoC guides health care workers in the provision of comprehensive, quality health care and support throughout the HIV care cascade (Swaziland Ministry of Health National Comprehensive Package of Care for Adults and Adolescents 2010:2).

The Swaziland Ministry of Health National Comprehensive Package of Care (PoC) advised that ART eligibility is determined through the use of clinical and immunological criteria (Swaziland Ministry of Health National Comprehensive Package of Care for Adults and Adolescents 2010:19). There are two primary conditions for ART initiation in Swaziland. Firstly, patients who present with a WHO HIV Clinical Staging of III or IV are initiated on ART, regardless of their CD4 count because these stages indicate serious conditions such as TB, renal disease or HIV-associated nephropathy. Secondly, patients are initiated on ART when they have a CD4 cell count of 350 cells/mm3 or below (Swaziland Ministry of Health National Comprehensive Package of Care for Adults and Adolescents 2010:19). The PoC guided that all patients who tested HIV-positive should immediately be enrolled into pre-ART and follow-ups should take place routinely, regardless of ART eligibility status (Swaziland Ministry of Health National Comprehensive Package of Care for Adults and Adolescents 2010:5). The pre-ART package as defined by the PoCs included registering a patient into a pre-ART register, the issuance of a pre-ART appointment booklet, the opening of a patient pre-ART file, and a baseline clinical, laboratory and psychosocial assessment (Swaziland Ministry of Health National Comprehensive Package of Care for Adults and Adolescents 2010:6). This PoC laid the onus on the facility itself to ensure that they routinely follow-up with pre-ART patients. This PoC tried to enable that pre-ART support structures were in place so that eligibility for ART could quickly be determined. This research will examine factors contributing to the non-initiation of ART amongst

eligible pre-ART patients in light of these support structures. The Swaziland National Comprehensive PoC paved the foundation for the NARTIS intervention that would emerge in later years and created a receptive platform for nurses to initiate ART under the management of doctors.

2.6.3 Nurse-led ART Initiation in Swaziland (NARTIS)

The Nurse Led ART Initiation of Swaziland (NARTIS) model began in March 2011 (Swaziland Ministry of Health NARTIS Training Curriculum 2015:6). It was a strategy to bring ART services to the rural clinics, and bring HIV services closer to the homes of people who need it (Swaziland Ministry of Health NARTIS Training Curriculum 2015:6). This approach was adapted from the model used in Malawi and Ethiopia, where ART is initiated by nurses (WHO Treat Train Retain 2007:40) in an effort to decentralise HIV care and treatment services through shifting tasks from the medical doctors to the nurses. The aim of this was to reduce the level of burden on medical doctors and to enable them to concentrate on complex clinical cases and the mentorship of nurses (Swaziland Ministry of Health NARTIS Training Curriculum 2015:6). A pre-requisite for enrolment into the NARTIS training is the completion of WHO recommended Integrated Management of Adolescent and Adult Illness (IMAI) training, coupled with six months experience in refilling ART. Successful completion of the NARTIS training was succeeded by a clinical attachment in the trainees' preferred health facility (Swaziland Ministry of Health NARTIS Training Curriculum 2015:11).

The aim of NARTIS was to build nurses' competencies in the preparation, initiation and monitoring of ART in adults and children (Swaziland Ministry of Health NARTIS Training Curriculum 2015:7). The NARTIS approach assists in relieving system bottlenecks that became a hindrance to access to health services, by using existing resources (WHO Treat Train Retain 2007:7). NARTIS empowered nurses in the country to have the technical skills and the competencies to manage ART. This included their capacity in routinely initiating ART to eligible pre-ART patients, which meant that nurses trained in NARTIS who were stationed in the rural primary health facilities, could bring ART initiation services closer to their communities. NARTIS,

essentially, brought ART initiation and refilling services closer to the people and addressed barriers of long, costly travels to distant health facilities for ART initiation.

As a result, the researcher felt that nurses trained in NARTIS would be key informants to this study. They had experience of residing in the rural areas and had first-hand information on the reasons why ART-eligible pre-ART patients did not initiate ART. It meant that the NARTIS might shed light on this phenomenon since delays in ART initiation were not a result of lack of capacity in the health facilities. The researcher felt that this leak in the HIV-cascade from pre-ART enrolment to ART initiation was an area that needed further exploring.

Provider-initiated HIV testing and counselling was another strategy of Swaziland to encourage prompt ART initiation.

2.6.4 Provider-Initiated HIV Testing and Counselling (PIHTC)

Provider-Initiated HIV Testing and Counselling (PIHTC) was a Ministry of Health strategy that was aimed at ensuring that all patients who were seen by a health care worker were offered HIV testing and counselling (HTC), and linked to relevant HIV services (Swaziland National Provider Initiated HIV Testing and Counseling (PIHTC) Standard Operating Procedures 2012:2).

This approach was adopted because of the observed weaknesses in the provision of comprehensive access to HIV testing in Swaziland (Swaziland National Provider Initiated HIV Testing and Counseling (PIHTC) Standard Operating Procedures 2012:1). One of Swaziland's core objectives was to increase patients' understanding of the benefits of knowing their HIV status and having an HIV test conducted regularly.

This approach advocated that health care workers routinely offer HIV tests to patients who present at the health facility, on every patient contact. This strategy is relevant to this research because it enabled health care workers to proactively identify and enrol pre-ART patients, and facilitate speedier initiation onto ART if eligible. This was done through the enrolment of patients in the Ministry of Health Pre-ART Register, and the appointing of a follow-up appointment in the Ministry of Health National Appointment

Register after an HIV test. Patients who then missed an appointment would be given a three-day window in which to return to the facility. If the patient did not arrive within three days, the facility would follow-up with them. This enabled pre-ART patients who were eligible for ART to be initiated within the shortest possible turnaround time. Again, this highlights the systems that were put in place to expedite ART treatment initiation. This research will examine the factors that continue to contribute to the non-initiation of ART amongst eligible pre-ART patients, in spite of established systems such as this one.

Another approach employed by the Swaziland Ministry of Health to promote early ART initiation is LLAPLA, which will be discussed below.

2.6.5 Life Long ART for Pregnant and Lactating Women (LLAPLA)

In 2010 Swaziland boasted a Mother to Child Transmission rate of <5% at six to eight weeks (Swaziland Ministry of Health Integrated HIV Management Guidelines 2015:2). In 2014, the Swaziland Ministry of Health began rolling out Life Long ART for Pregnant and Lactating Women (LLAPLA) in the country. Through LLAPLA, all pregnant and lactating women testing positive for HIV would be initiated on ART, regardless of their CD4 count. This strategy provided wider coverage of ART for PMTCT. It also facilitated early initiation of ART amongst pregnant and lactating women testing HIV-positive. It was aimed at minimising the consequences of delayed ART initiation to pregnant women and their unborn child, and instead maximised the health benefits of prompt ART initiation to both these groups.

The Swaziland Integrated HIV Management Guidelines (2015) enhanced the supportive intervention to pre-ART patients.

2.6.6 Swaziland Integrated HIV Management Guidelines of 2015

In 2015, The Swaziland Ministry of Health released the Swaziland Integrated HIV Management Guidelines which guided the implementation of an increase in the national ART eligibility criteria from CD4 350cells/mm3 to CD4 500cells/mm3 (Swaziland Ministry of Health Integrated HIV Management Guidelines 2015:18). This

aimed to provide a more supportive intervention to pre-ART patients, and further minimise delays in ART initiation. This shift in eligibility would mean that people who are currently in the pre-ART phase with a CD4 cell count of over 350 cells/mm3 but under 500 cells/mm3, would become eligible for ART initiation. It would also mean that those patients who may test positive for HIV but have a CD4 count of over 500 cells/mm3 would be receiving the pre-ART package of HIV services.

However, at the time of conducting the semi-structured interviews for this research, these guidelines had not yet been implemented, so ART eligibility was still at CD4 350cells/mm3. Delays in ART initiation predispose patients to increased health risks, which shall be discussed below.

2.7 DANGERS OF DELAYED ART INITIATION

Delayed or late ART initiation was defined by Lahuerta, et al. (2013:360) as initiating an ART intervention in the advanced stages of HIV infection, irrespective of the reason or regimen. The existing literature focusing on the dangers of delayed initiation of ART will be discussed below, while the advantages of prompt ART initiation will be discussed in the next section.

Lahuerta et al. (2013:360) found that late ART initiation was associated with a longer infectious period, and that earlier ART initiation substantially reduced onward HIV transmission. The study observed high mortality rates prior to ART initiation among [pre-ART] people already diagnosed and enrolled in [pre-ART] care (Lahuerta et al. 2013:360). What this emphasised was that deaths caused by delays in ART initiation can be prevented if pre-ART patients are initiated on ART on time. This finding only highlighted the relevance of this research, because if factors that contributed to the non-initiation of ART amongst eligible pre-ART patients in Hhohho could be identified, they could then be addressed and prevented.

Lahuerta et al. (2013:365) also found that late ART initiation can cause mortality after the initiation of ART due to already advanced HIV disease progression and poor prognosis on ART initiation. This indicates that delayed ART initiation may still result in poor health prognosis in patients once they have begun ART treatment. This

essentially means that severe delays in treatment initiation pose risks to patients in pre-ART, and to those already on ART. A 2013 retrospective cohort study conducted in Swaziland (SNAP-E, 2013), which explored treatment outcomes of HIV-infected adults, found that the median CD4 count at ART initiation was 143 cells/mm3. This was stratified between males (cells 114/mm3) and females (158 cells/mm3) (SNAP-E, 2013). The study was conducted when eligibility for ART initiation for Swaziland was still at a CD4 of 200 cells/mm3 and it found that 69% of patients who were initiated on ART had a CD4 cell count that was equal to or less than 200 cells/mm3 (SNAP-E, 2013). This study illustrated that most pre-ART patients were initiating ART at a very low CD4, predisposing them to the threats posed by HIV. Studies conducted in South Africa have also found that mortality rates amongst pre-ART patients are very high (Lawn, Myer, Orrell, Bekker & Wood 2005:2146; Fairall, Bachmann, Louwagie, van Vuuren, Chikobvu, Steyn, Staniland, Timmerman, Msimanga, Seebregts & Boulle 2008:4). A study in Cape Town found that deaths amongst pre-ART patients accounted for 66% of deaths in the entire population (Lawn et al. 2005:2146). In the Free State, a study conducted in 2008 found that deaths among pre-ART patients accounted for 87% of all deaths (Fairall et al. 2008:4).

Again, this highlights the applicability and uniqueness of this research, because if factors that contribute to the non-initiation of ART amongst eligible pre-ART patients can be identified, recommendations for health care workers and health planners can be made to enable early initiation of ART; and ART initiation occurring at advanced HIV disease stages can be avoided.

A systematic review of retention rates in Sub-Saharan Africa, conducted by Rosen and Fox (2011:7), found that only 68% of patients who are eligible for ART end up initiating ART. This denoted 32% attrition rate amongst eligible pre-ART patients who move into the treatment initiation phase of the HIV cascade. Unfortunately, if patients are not being retained in pre-ART systems, efforts to trace them and encourage earlier enrolment into ART when they are determined eligible for ART become undermined.

2.8 ADVANTAGES OF PROMPT INITIATION OF ART

Although there are few studies from Sub-Saharan Africa around retention levels in pre-ART, there are key ones describing extraordinary evidence-based findings of the advantages of earlier initiation of ART. Lahuerta et al. (2013:365) describe, for example, how the HPTN 052 clinical trial found that timely ART initiation was advantageous because it resulted in almost complete interruption of HIV transmission, with a 96% reduction in HIV transmission in serodiscordant couples. A serodiscordant couple is a couple where one partner is living with HIV, and the other is HIV-negative (Swaziland Ministry of Health Integrated HIV Management Guidelines 2015:11). The advantages of early initiation of ART to serodiscordant couples cannot be overestimated.

As described earlier in this chapter, advanced stages of HIV infection are associated with higher rates of HIV transmission due to elevated viral loads (Lahuerta et al. 2013:366). When dealing with couples, the health care system is particularly under pressure to address their unique needs. This is because studies have found that approximately two to three new infections occur for every person placed on ART (Lahuerta et al. 2013:366). This means that although we are taking a step forward, we are often also taking three steps back. Another study in Uganda that followed a cohort of discordant couples found that the probability of HIV transmission during late stages of HIV infection increased by four to eight times during the two years before death (Lahuerta et al. 2013:366). This finding shows that prompt ART initiation becomes a crucial advantage to such couples because it can interrupt future HIV transmission.

2.9 SUMMARY

In this chapter existing studies that looked at pre-ART patients and factors that influence their timing of initiating ART was reviewed. Global perspectives on ART initiation was discussed and national processes of ART initiation was considered. Additionally, the strategies that Swaziland has employed to try and facilitate early ART initiation was examined. The following chapter will look at the methodology used in this study.

CHAPTER 3
RESEARCH METHODOLOGY

3.1 INTRODUCTION

In this chapter the research methodology will be discussed, and the approach that the researcher took in addressing the research questions and for reaching the objectives of the study, will be explained.

Since, at primary health care level, it is the NARTIS trained nurses who make the decision for a patient to be initiated on ART, the researcher felt it would be insightful to gain their perceptions of the factors contributing to non-initiation of ART amongst eligible pre-ART patients in rural primary health care clinics. Understanding these factors can significantly assist in ensuring that pre-ART patients who are eligible for ART are then promptly initiated.

3.2 RESEARCH DESIGN

This study is structured as a qualitative research design that is explorative, descriptive, and contextual. A qualitative study is one that enables the researcher to explore the perceptions of a phenomenon being studied in depth.

3.2.1 Qualitative design

Creswell (2014:4) describes qualitative research as an approach where the researcher explores the meanings that are ascribed to social phenomenon. Qualitative studies are conducted in a natural environment, where the researcher becomes the tool to collect and analyse data through intimate engagement with the environment, continually reflecting on the processes. It enables in-depth understanding of the phenomenon being studied. This qualitative approach will better enable the researcher to gain deep and broad insight into the factors that enhance or compound non-initiation of ART. This will be done by asking open-ended questions and allowing NARTIS trained nurse participants to expand on their perceptions of factors contributing to the

non-initiation of ART amongst eligible pre-ART patients in rural public health clinics. These participants, who are most familiar with health systems within the PHC facilities they are engaged in, would be able to provide varying perceptions on the multi-faceted contributors of non-initiation of ART. Because of their vast experience and long exposure in the health sector, and especially within ART settings, the researcher felt that they could provide sound judgment and varying suppositions around the research questions. A qualitative inquiry would enable these perceptions to be accrued first hand, and rich qualitative information could then be derived. This information will be used to make recommendations for health care workers, to enhance processes of ART initiation.

The researcher will now discuss the exploratory, descriptive and contextual design.

3.2.2 Exploratory design

An essential component of qualitative research methods is that it enables the researcher to extensively explore the subject matter. Exploratory qualitative research is intended to shed light on the various ways in which a phenomenon manifests and underlying processes (Polit & Beck 2012:18).

Exploratory research begins with a phenomenon of interest, but rather than simply observing and describing it, exploratory research investigates the full nature of the phenomenon, the manner in which it is manifested, and the other factors to which it is related (Polit & Beck 2012:18). For this research, the researcher will engage closely with the health facilities, interviewing NARTIS trained nurses using a semi-structured interview guide, and taking observational field notes. The research's objectives are:

- To explore and describe factors associated with non-initiation of ART amongst eligible pre-ART patients in rural clinics in Swaziland.

  To make recommendations for health care workers to enhance early initiation of ART-eligible patients for PHC facilities in Swaziland.

3.2.3 Descriptive design

A qualitative descriptive research design describes the dimensions, meanings, and the importance of phenomena (Polit & Beck 2012:18).

The findings of descriptive studies are often utilised by health planners to record prevalence data, to study disease trends and health conditions, and to develop relevant health interventions (Polit & Beck 2012:229). This research will describe how different factors may become a hindrance to timely ART initiation. It will be set in a rural area, and will explore the dimensions of health operations from the perspective of a primary health care setting.

3.2.4 Contextual design

Contextual designs are research designs that aim to provide an appreciation of the context of a lived experience, by way of close enquiry and engagement (Polit & Beck 2012:524). The research will be conducted in a real life setting and a natural context.

The researcher travelled to PHC health facilities in the Hhohho region Swaziland, and engaged with NARTIS trained nurses who were based in the rural PHC facilities. This was because the researcher wanted to capture their perspectives within their natural, rural, clinic setting. Rural clinics were selected for this research as they serve the larger community to which most of their patients reside. This is opposed to an urban clinic setting where the patients may be more mobile, residing in communities outside of the one serviced by the clinic. The researcher also selected nurses trained in NARTIS because they were competent at ART initiation, and they were familiar with the community dynamics that could either facilitate early treatment initiation or contribute to non-initiation of ART amongst eligible pre-ART patients.

To ensure that the participants remained within their familiar environment, and the research was contextualized, all the interviews were conducted within the PHC facility itself, and none of the participants were interviewed at another location.

3.2.5 Resources

The researcher also explored the differing resources that each of the PHC facilities had. These are described in this section.

3.2.6 Primary Health Care (PHC) facility

Eleven of the fifty-eight PHC facilities from Hhohho region were purposively sampled and represented in this study (Swaziland Ministry of Health SAM 2013:28). All of them were based in Hhohho region, a region that is home to 309 184 people (Swaziland Ministry of Health SAM 2013:4). They all serviced large rural communities.

Stratified by facility type, seven facilities were government facilities, three were mission facilities, and one was a non-governmental organisation (NGO) facilities. PHC facilities needed staff members for ART initiation and the NARTIS trained nurses played a key role.

3.2.7 Nurse staffing

Nurses play a fundamental role in service delivery in PHC facilities. The researcher explored the staffing composition of the facilities to understand the health facility's capacity to deliver health services and the burden of workload for the various facilities. In March 2011, the Nurse-Led ART Initiation in Swaziland (NARTIS) was initially piloted in fifteen health facilities in the country. This included six rural clinics, four Public Health Units (PHUs) and five TB facilities. Training of NARTIS nurses has been ongoing since then. By the end of 2013, there were over 100 NARTIS trained nurses in the country, distributed amongst all health facilities, including hospitals, health centres and PHUs (Swaziland Ministry of Health NARTIS Training Curriculum 2015:6).

According to the participant responses, the average number of NARTIS trained nurses per PHC facility was three per facility. Most PHC facilities in the sample ranged between a number of three to four NARTIS trained nurses, but one of the facilities in the sample, a government facility, had only one NARTIS trained nurse. Another

government facility had two NARTIS trained nurses. There was one facility, a mission facility that had up to seven NARTIS trained nurses.

All the facilities in the sample were confirmed as sites that were both initiating and refilling ART. This means that patients could receive services for HIV pre-ART care and ART treatment initiation once they were determined ART-eligible. This pre-ART care included the opening of a patient Chronic Care File, and enrolment into the National pre-ART Register (Swaziland National AIDS Program Patient Linkage, Retention and Follow up in HIV Care SOP 2013:5).

According to the participants, the majority of the facilities (64%) were entirely funded by the Swaziland government. Three (27%) facilities were affiliated with religious institutions but were still functioning as rural PHC facilities that served large numbers of patients within a large, rural catchment area. These facilities were not significantly advantaged in terms of resources. One facility (9%) was affiliated to NGOs. This affiliation provided little if no advantage to the facility in terms of resources; tangible, technical and human.

Another resource area that the researcher inquired into was the issue of cell phones within the facility. Cell phones were the tools that some facilities were using to provide follow-up care to pre-ART-eligible patients.

3.2.8 Cell phone distribution

Cell phone distribution was relevant since some PHC facilities in Swaziland do not have a landline, and some health facilities that *do* have a landline, have inconsistent functionality. The cell phone then provides a tool that the facility can call patients to remind them of upcoming clinic appointments, or to follow-up with patients who have missed their appointments (Swaziland National AIDS Program Patient Linkage, Retention and Follow up in HIV Care SOP 2013:35).

The semi-structured interview guide enquired into cell phone usage and maintenance within the clinic facility. The data reflected that all of the facilities (11) purposively selected for the sample had a cell phone. All the cell phones were fully funded by

partners who ensured that the maintenance was upheld, and the airtime provision for the cell phone was uninterrupted. Thus, communication was enabled at no cost to the facility.

The cell phones were all used to track pre-ART-eligible patients who had missed their appointments. It was a crucial tool that facilitated the second step in the patient follow-up procedure, following the appointment register tool.

Another on-site resource that was explored by the researcher was the availability of Point of Care (POC) devices. POC machines provided on-site, almost immediate CD4 count blood results. This minimised the turnaround time on the HIV cascade between HIV testing and ART eligibility.

3.2.9 PIMA Point of Care (POC) machine distribution

A PIMA Point of Care (POC) machine is a CD4 count testing device that enumerates the absolute number of CD4 cells/mm3 in a blood sample (Mtapuri-Zinyowera et al. 2010:3). This device enumerates the CD4 count of the blood sample within twenty minutes after collection from the drop of blood, often obtained from a finger prick (Mtapuri-Zinyowera et al. 2010:1). The POC machines – also known as a PIMA POC machine, a term which will be used henceforth – enable health care workers to monitor the progress of HIV immunosuppression caused by HIV, and to demonstrate the impact on the CD4 cells after initiation of ART (Alere 2015:1). The PIMA POC machine can be used by trained, non-laboratory staff, and its placement does not require any laboratory infrastructure (Mtapuri-Zinyowera et al. 2010:1).

This research found that four of the eleven (34%) facilities had a PIMA POC machine on-site. Seven had no PIMA POC machine on-site and would send lab samples to larger, fully equipped laboratory facilities for lab determinations. For the purposes of the research, it was important to determine whether or not a PHC facility was equipped with an on-site PIMA POC machine for the follow-up of pre-ART-eligible patients who had not yet been initiated on ART. Participants who were stationed at PHC facilities that did not have a PIMA indicated a need for a PIMA POC machine on site, and identified it as a required resource.

The largest number of HIV tests reported by participants to have been conducted by a clinic per day was ten. The highest number of HIV tests being done each month by one of the clinics within the sample, was reported to be thirty per day.

The researcher then explored the ART initiating and refilling services that were available within the sample facilities.

3.3 RESEARCH METHODOLOGY

The research method is the procedure used by the researcher to construct the research, collect information on the research question, and analyse this information using appropriate analytical techniques (Polit & Beck 2012:12). It reflects the research setting, population, sampling process and sample size, data collection, and data analysis.

3.3.1 Research setting

According to the most recent Swaziland Ministry of Health Service Availability Mapping Report (SAM) of 2013, Hhohho region housed a population of 282 734 in 2007; this was projected to rise to 309 184 in 2013, contributing to 27.8% of the total population of Swaziland (Swaziland Ministry of Health SAM 2013:4). There are eighty-two health facilities in Hhohho region, of which fifty-eight are primary health care clinics (PHC) (Swaziland Ministry of Health AM 2013:28). The study was set in rural PHC facilities within the Hhohho region of Swaziland, where the prevalence of HIV is 28.9% (SDHS 2007:223). These facilities were selected because the researcher felt that rural PHC facilities often serve a larger population than the private sector PHC, as the majority of people cannot afford private sector health services. The researcher thus felt that this rural setting would be where the information from this study would be more needed and that emerging recommendations from this study could benefit a larger number of people.

Nurses and nursing assistants predominantly manage PHC facilities in the country. Most of these PHC facilities will have at least one nurse who is trained in NARTIS.

3.3.2 Population

The ‘study population’ can be defined as *all* the individuals or objects with common, defining characteristics (Polit & Beck 2012:59). The population possess certain characteristics through which the data from the research is derived. For this research, the population are all qualified nurses who are trained in NARTIS, working in rural PHC clinic in Swaziland.

The accessible population within this target population were nurses who are trained in NARTIS, initiating patients on ART and working in rural PHC facilities in the Hhohho region. Nurses were selected from those who fit this criteria, who were willing and available to participate in the study.

3.3.3 Sampling

According to Creswell (2014:189), random sampling is not always appropriate for qualitative studies as it involves the selection of participants who will best inform the researcher of the phenomenon under study. Because of the need to carefully select participants, qualitative studies almost always use small, non-random samples (Polit & Beck 2012:515). Unlike quantitative studies, the objective of qualitative studies is not to generalise to a general target population, but to discover *meaning* and to uncover multiple realities (Polit & Beck 2012:515). In this research, the sample was purposively drawn from NARTIS (Nurse Led ART Initiation in Swaziland) trained nurses, who were stationed at rural PHC facilities in the Hhohho region of Swaziland.

3.3.4 Sampling techniques

Due to the need to collect as much information as possible from a small number of participants, the researcher needed to draw a sample that would best benefit the research (Polit & Beck 2012:517). As such, the researcher used a purposive, convenient sampling method. Purposive sampling is a sampling method whereby the researcher controls the selection of participants for the study, chance selecting people who are particularly knowledgeable about the phenomenon under study (Polit & Beck

2012:279). Purposive, convenient sampling methods were used for this research to ensure that NARTIS trained nurses who are specifically stationed at rural PHC facilities (NARTIS trained nurses who are working in the private health sector are excluded) are included in the sample, rather than the broader population. This sampling method allowed the researcher to engage with this key population and gain insight of factors contributing to non-initiation of ART amongst eligible pre-ART patients from their perspective.

Currently, there are approximately 300 NARTIS trained nurses in Swaziland. Most of these nurses are based in rural areas, and service patients who reside far from larger health facilities. Since this research focused on rural PHC facilities, they were purposively selected from these particular facilities, specifically PHC facilities in one region, namely Hhohho region. Hhohho region houses fifty-eight PHC facilities (Swaziland Ministry of Health SAM 2013:28). So far, Swaziland has no national database of the distribution of NARTIS trained nurses in the country.

The researcher conducted semi-structured interviews with the NARTIS trained nurses until data saturation was reached. The Hhohho Regional Health Management Team and clinic facility staff were informed of the research before initiation. They also gave authorisation for the research to be conducted at their facilities.

Polit and Beck (2012:521) emphasise that with good informants who are able to reflect on their experiences and communicate effectively, saturation can be achieved with a relatively small sample. Because the sampling was purposive, and only NARTIS trained nurses were selected for the research, the small number of participants provided data saturation and eliminated redundancy of findings.

In order to diversify the perspectives shared by the participants, their nationality was not a restrictive factor. As long as the participants were NARTIS trained, and met the inclusion criteria, foreign country of origin was not excluded from the research. The researcher felt that the origin of the participant might allow diversity in the NARTIS nurses' perspectives and perceptions of factors that contributed to non-ART initiation amongst eligible pre-ART patients.

The sample frame for this research was all nurses who were trained in NARTIS and stationed at PHC facilities. One NARTIS nurse was purposively selected from each of the eleven of fifty-eight PHC facilities in the Hhohho region. These eleven PHC facilities were facilities that were accessible to the researcher.

The researcher purposively sampled NARTIS trained nurses for this research. Data was collected until data saturation was reached; at the eleventh interview. These participants were selected because they would provide much information and a wealth of data on the phenomenon being studied.

3.3.4.1 Inclusion criteria

- Professional nurses who are qualified with a nursing diploma or a nursing degree that was awarded by an accredited training institution.

- Nurses who are working in a public rural PHC facility in the Hhohho region of the country.

- Nurses who have completed the IMAI training.

- Nurses who are trained in Nurse Led ART Initiative in Swaziland (NARTIS).

- NARTIS trained nurses who are actively initiating patients on ART.

- NARTIS trained nurses who have been stationed at the PHC facility for more than one year to ensure that they had the relevant experience and exposure to ART initiation.

- NARTIS trained nurses who have initiated a patient on ART in the last three months.

- NARTIS trained nurses who are fluent in Siswati or English to enhance communication.

3.3.4.2 Exclusion criteria

- Nursing cadres other than professional nurses, for example, Nursing Assistants.
- Nurses who are not NARTIS trained.
- NARTIS trained nurses who are not initiating patients on ART.
- Nurses who are employed in private sector health facilities.
- Nurses who are employed in company-run health facilities.
- Nurses who are employed in hospitals and urban PHC facilities.

3.3.5 Sample size

Polit and Beck (2012:742) define ‘sample size’ as the number of people who participate in the research. The researcher wanted a number of participants who would give as much information to the research question as possible, and who would articulate meanings attached to the phenomenon. The number of participants that would be interviewed would be determined by when the data saturation is reached. ‘Data saturation’ can be defined as sampling to the point at which no new information is obtained and redundancy is achieved (Polit & Beck 2012:521). The researcher reached data saturation with the eleventh interview conducted with NARTIS trained nurses who met the inclusion criteria for the research.

3.4 DATA COLLECTION METHODS AND PROCEDURES

Before data was collected for the research, informed consent was obtained from the research participants. Ethical clearance was obtained, and permission was granted from stakeholders. NARTIS trained nurses from the sample facilities were informed of the research by the researcher. They were also informed that the interviews would be recorded with their permission. The research was explained to the participants, and

they were given an opportunity to ask questions, seek clarity and have concerns addressed prior to providing their consent. They were free to choose if they wanted to participate in the study or not.

Data is collected to organise, provide structure to, and elicit meaning from research (Polit & Beck 2012:556). A semi-structured interview format was used as a data collection tool in this research. The researcher selected this interview format because it allowed the participants to answer questions that the researcher had deliberately structured, freely. This interview method is used when researchers know what they want to ask, but cannot predict what the answers will be (Polit & Beck 2012:537). The advantages of this interview style are that it permitted participants to speak openly and freely, talking as much as they needed to elaborate on the questions posed. This interview style was befitting of the research because it allowed the participants to express their experiences of eligible pre-ART patients not receiving ART in depth. The interview schedule is available in Annexure J.

Data collection began on the 7th of April 2015 and ended on the 23rd of May 2015. The interviews were all conducted in a quiet room in the rural PHC facility, to avoid distractions of other staff and patients. They were scheduled for the late afternoon or at a time stipulated by the participant. This was done in the hope that the NARTIS trained nurse would have finished seeing patients, and would have more time to dedicate to the interview. An attempt was made to avoid interruptions in service provision for the patients who were at the PHC facility and also prevent the participants' colleagues feeling overburdened with additional responsibilities because the participants were in the semi-structured interview. Further, it was done to minimise noise pollution and distractions. If, at the scheduled time of the interview, the NARTIS trained nurse still had patients, the researcher would wait for the nurse to complete all consultations before the interview began.

During the engagement with the participants, the researcher took field notes to describe personal observations, experiences, and interpretations while in the field. These field notes serve as an additional data collection method to enhance and triangulate the data. Field notes also assisted the researcher not only to record perceptions but also to reflect and understand the information (Polit & Beck 2012:548).

The researcher used both descriptive field notes and reflective field notes to enable a process of continuous reflection on the content of the participant feedback. Descriptive field notes involve objective descriptions of what is seen in the field (Polit & Beck 2012:548). The researcher also took reflective field notes, documenting her personal reflections and experiences while in the field (Polit & Beck 2012:549). The researcher's reflective notes were predominately theoretical and personal. Through the theoretical field notes the researcher attempted to gain an understanding of the surroundings and observations within the PHC facility. This included observations of patient flow, of the waiting rooms, and of the ART services available. The personal field notes involved documentation of the researcher's own experiences and sentiments while in the PHC facilities. The data that was yielded from the semi-structured interview guide was carefully scrutinised to identify emerging themes and derive meaning.

3.4.1 Researcher as an instrument

Throughout the research, the researcher was a data collection instrument. This was by virtue of the process of continuously reflecting on how the researcher collects the data. Polit and Beck (2012:543) highlight that non-verbal communication skills are essential to convey to the participant that you are concerned and interested in what they are saying.

Successful interviewers are those who empathise and see the circumstance from the perspective of the participant. The researcher used communication skills such as open-ended questions, attentive listening, maintaining consistency with emotion, breathing, tone of voice, facial expression and nodding (Polit & Beck 2012:543). The researcher also used probing communication techniques such as nodding of the head, leaning forward, eye contact, and encouraging the participants to continue speaking by validating responses with sounds such as "uhm," or "oh…" to encourage the participants to elaborate and expand further. Additionally, the researcher used the participants' preferred language and stayed focused on the research topic throughout the interview by using some structured questions. This was done in order to try and prevent the participant from digressing from the research topic, or from being distracted during the interview. The researcher also probed for elaboration and asked

for clarity when needed. This was done to acquire as many responses and as much data from the participants as possible.

The following section will elaborate in more detail on the interview process.

3.5 THE INTERVIEW PROCESS

3.5.1 Pilot testing of the interview guide

Before using the semi-structured interview guide with the NARTIS trained participants, the researcher tested the guide on three NARTIS trained nurses to ensure clarity of questions and reliability. These three NARTIS trained nurses were excluded from the study findings. Feedback from the practice interviews further guided the researcher in terms of whether the questions were understood by the participants, whether they were phrased coherently, whether the chronology of questions made sense, whether it asked what it was intended to ask, and also if the tool captured the information that it was designed to capture. The pilot testing process indicated that the tool was asking the correct questions, in the correct manner. The phrasing was coherent, and the chronology made sense. The core feedback given was that the tool needed to allow for predominantly open-ended questions so that participants could talk freely and without inhibition about their experiences of pre-ART-eligible patients requiring initiation on ART. The tool was then modified to include this feedback derived from these NARTIS trained nurses.

3.5.2 Preparing the interview participants

Being a health care worker herself, the researcher was easily able to create rapport with the NARTIS trained participants. This was advantageous because it facilitated that participants were able to open up, and feel comfortable and elaborate extensively on the research topic. To build trust, the researcher also explained the objective of the research, and pledged confidentiality for all the participants. Participants were shown the approval letters from both the Higher Degrees Committee (University of South Africa), the Swaziland Ethics Committee, and from the Hhohho Regional Management Team. These approval letters can be found in Annexures A to C. In preparing for the

semi-structured interviews, the researcher ensured that all vital instruments were available, including the audio recording device, a pen, a notepad, a business card, and consent forms.

3.6 DURING THE INTERVIEW

3.6.1 Language

The semi-structured interview guide was designed in English and siSwati to allow the participants to feel comfortable with their language choice. Both these semi-structured interview guides can be found in the Annexures K and L Participants were asked which language they were most comfortable conducting the interview in. All of the participants selected English as the language to be used when conducting the interviews, but some participants used siSwati to express some words or phrases when responding. Since the researcher is fluent in both languages, this did not impact negatively on the interview process. The interviews were transcribed verbatim. An assistant translator, who is also fluent in both English and siSwati, assisted with the translation. Anonymity was managed as the assistant translator was not informed of with the identity of the participants, or of the facilities from which they were stationed.

In the following section, the processes used when ending the interviews are described.

3.7 ENDING THE INTERVIEW

After the participant had responded to the last question of the semi-structured interview, they were given another opportunity to ask any questions they may have. The participants were thanked for participating in the study. Confidentiality was also reinforced at the end of the interview by reminding the participants of how there would be no disclosure of the information they shared, and no divulgence of their identity or the identity of their facility. The interviews lasted approximately between twenty to sixty minutes each.

The data analysis processes are described next.

3.8 DATA ANALYSIS

Qualitative data analysis is an inductive process that involves putting segments together into meaningful conceptual patterns (Polit & Beck 2012:562). To analyse this content of the semi-structured interviews, the researcher used Tesch's method of open coding (Creswell 2014:198), adhering to the following steps in the coding process:

1. The researcher aimed to get a sense of the whole through reading and re-reading the transcripts.
2. The researcher selected one completed interview guide and explored its underlying meaning. The researcher asked the question, *"what is this all about?",* noting points throughout the process.
3. The researcher repeated this process for several more interviews, listing the topics and themes that emerged from each interview, and that cut across the interviews. This is where the researcher began the process of identifying emerging themes and developing a category scheme. This thematic analysis ascribed meaning across a dataset that assisted to provide an answer to the phenomenon being explored.
4. The researcher then listed these topics, and going back to the transcribed interviews, was able to identify the segments where these topics emerged.
5. The researcher then coded the topics into categories and sub-categories. Coded themes were indexed and filed. This assisted the researcher to continuously review each file to revisit key topics and recurring themes in the data that emerge throughout the study. This reductionist approach enabled that the data be converted to smaller, more manageable units that can be retrieved and reviewed by the researcher (Polit & Beck 2012:558).
6. The researcher finalised all the coding, organising the categories and sub-categories.
7. The researcher then began to review and analyse the data within each category.
8. During analysis of the data within each category, the researcher found opportunities to re-code the existing data

Eleven NARTIS nurses were interviewed using a semi-structured interview tool. These interviews were then transcribed verbatim. The researcher read and re-read the transcriptions to identify key ideas, meanings, emerging themes and categories.

Reading the transcripts over multiple times enabled new themes to be discovered. The researcher identified categories, sub-categories and themes that emerged during the interviews. An independent coder was also utilised for this research. The independent coder was given the transcribed interviews to code and provide some objective categorising and thematising. This independent coder was a research study manager for qualitative research conducted in Swaziland. She was selected by the researcher because of her vast experience with qualitative research, especially with qualitative tools development, siSwati and English translations, leading focus group discussions, transcriptions and coding. The independent coder also adhered to Tesch's process of open coding. Upon completion, the researcher and the independent coder had a consensus discussion to clarify the categories and themes that they had both identified. Consensus was reached by the researcher and independent coder on the categorisations and themes identified by data to enhance inter-coder reliability.

The analysis of the data is described below.

3.8.1 Data analysis steps

After completing the semi-structured interviews with the eleven eligible participants, the researcher moved on to the transcription phase. All the interviews were transcribed verbatim. Polit and Beck (2012:621) emphasise that this is a critical step in preparing for data analysis and the foundation for a coding structure. Once the transcription was complete, the researcher was able to review and critique the data, going over it multiple times. The researcher then applied Tesch's coding method (Creswell 2014:198). This way the qualitative data gathered was analysed through transcription, coding and categorising the data into themes. Data was interpreted through a literature control in order to place the findings in the context with existing literature on the topic. The biographic data was used to gain an understanding of the clinic characteristics and level of service provision that may influence the research question. It was also used to determine the level of experience the participant had in HIV and ART service provision.

3.9 MEASURES TO ENSURE TRUSTWORTHINESS

The rigour of the study was strengthened by reinforcing trustworthiness. Polit and Beck (2012:584) refer to Lincoln and Guba's (1985) framework for describing how trustworthiness in qualitative studies is strengthened through credibility, dependability, confirmability, transferability, and authenticity. These shall follow as sub-headings below.

3.9.1 Credibility

Credibility assesses the degree to which confidence in the data results and in the data interpretation can be propagated from the research methods that were employed by the researcher (Polit & Beck 2012:196). Credibility of the study was enhanced as the researcher used prolonged engagement, and also through triangulation. Prolonged engagement occurred as the researcher spent time with the different NARTIS trained nurses who were based at various PHC facilities in the Hhohho region. The data collection process lasted just under two-months. The process began on 7 April 2015 and ended on 23 May 2015. The interviews lasted between twenty and sixty minutes each. Engagement was prolonged until data saturation was reached. In order to build rapport and trust with the participants during the interviews, the researcher began by introducing herself, and the study. To put them at ease, she then shared the aim of the study, addressed issues of confidentiality, and collected the biographic data first.

Triangulation involves the use of multiple methods to collect and interpret data to reach the same conclusion about the phenomenon being studied (Polit & Beck 2012:590). It avoids the potential bias that can emerge if the researcher, being a single observer, were to have only a single perspective of what constitutes the truth. For this research, data was triangulated as it was sourced from the participants themselves, from the semi-structured interviews, and the field notes. Inter-coder reliability was determined by using an independent coder.

Through the semi-structured interviews, the researcher engaged in member checking, which occurs when the researcher gives feedback to the participant on the themes, ideas and interpretations that emerge from the information the participant is providing

(Polit & Beck 2012:591). The researcher did this by probing, checking for understanding and summarising throughout the interviews. The researcher also used the field notes to document interpretations emerging from the interviews. The researcher's audit trail, or the materials needed for another party to develop a conclusion about the data (Polit & Beck 2012:591), included resources about ART initiation, the semi-structured interview tool, and the raw transcribed data. Lastly, the researcher holds an Honours degree in Psychology, and a Diploma in Advanced Health Management from the Foundation of Professional Development (Yale). She has been working in the field of HIV for over thirteen years.

3.9.2 Dependability

'Dependability' can be defined as the stability of the study findings over different conditions, and over time (Polit & Beck 2012:599). Dependability in this research would be obtained if the same findings of this study were also obtainable over time, and also if another researcher, when scrutinising the data, had similar results. Dependability of the data was enhanced through an *inquiry audit*, whereby an external independent co-coder carefully reviewed the collected data. This external co-coder was able to review the data, and independently identified emergent themes and categories. This provided an objective eye when scrutinising the data, and also enhanced confirmability. Further, all the documents pertaining to this study were kept in a locked cabinet. The researcher was the only individual with a key to this cabinet. The researcher will keep the documents locked away for five years after completion of the study. Finally, a thick description of the methodology was provided by the researcher to indicate all the research processes followed.

3.9.3 Confirmability

'Confirmability' can be defined as the extent to which the results of the study are results of the participants and the research itself, rather than being derived from the researchers' own personal biases (Polit & Beck 2012:175). The close engagements, quoting and transcribing of the NARTIS trained nurses' interviews prevented the researcher from incorporating her own beliefs, thoughts and perceptions into the study findings. It was enhanced by the fact that *different* NARTIS trained nurses were

interviewed. Although they are all stationed at PHC facilities, they work in different clinical setting, contexts, and communities. They would all share their diverse perspectives on why pre-ART patients who are eligible for ART were not being initiated on ART.

The researcher also had to continuously reflect on her own prejudices, preconceptions, and ideas that could bias her interpretation of the data. This was done through bracketing that was aimed at making sure the researcher was always conscious of her own beliefs and kept these beliefs in abeyance so that they did not influence her interpretation of, or the meanings she ascribed, to the participants' experiences (Polit & Beck 2012:495). The researcher bracketed through continuous reflection and self-reflection throughout in the data analysis process. This was in an effort to make the findings neutral, rather than being the result or the influence of the researcher's own bias and presumptions.

3.9.4 Transferability

'Transferability' refers to the degree to which the findings of qualitative studies can be transferred to other studies in other settings (Polit & Beck 2012:197). In qualitative studies, transferability is not always feasible because they are context specific. However, the researcher provided a thick description of the research methodology and findings to enhance the transferability. The researcher, therefore, must ensure that detailed information about the study that can enable judgements on the similarity of the context, is provided (Pilot & Beck 2012:595). To conduct this research, the researcher purposively sampled NARTIS trained nurses employed in rural primary health clinics in the Hhohho region of Swaziland. A semi-structured interview guide was used to collect their views, thoughts and perceptions around the factors that contribute to the non-initiation of ART amongst eligible pre-ART patients. All the participants provided informed consent, and the researcher pledged to maintain confidentiality. All the interviews were conducted at the health facility where the participant was employed, maintaining the natural context of their work environment. Because this research is contextual, researchers intending to conduct similar studies can use these findings where the environments and the contexts are similar. A literature control was done to place the findings in context with existing studies and literature.

3.9.5 Authenticity

Authenticity aims at depicting and adequately expressing the tone of the real life experiences of individuals as they are lived (Polit & Beck 2012:585). Through the verbatim transcription of the semi-structured interview guides, the researcher captured the tone of the perspectives shared by NARTIS trained nurses.

Ethical considerations applied during the research will be discussed in the following section.

3.10 ETHICAL CONSIDERATIONS

Polit and Beck (2012:150) emphasise that when humans are used as study participants, care must be exercised to ensure that their rights are protected. To guarantee that the research was conducted in an ethical manner, the researcher ensured that informed consent, beneficence, respect for human dignity, confidentiality, justice, autonomy and voluntary participation were adhered to (Creswell 2014:93). These shall be discussed further below.

3.10.1 Principles of beneficence and non-maleficence

Beneficence mandates that the researcher does some good, and protect the participants from any form of harm and exploitation; either physical or psychological (Polit & Beck 2012:172). Non-maleficence urges that participants are not deliberately harmed, and that throughout the research, deliberate efforts are made to protect them. Both beneficence and non-maleficence comply with the Hippocratic Oath clause of '*do no harm'.*

Beneficence was applied in this study as the NARTIS trained nurses in the sample were not identified by name. Data codes in the form of a unique identifier was assigned to each study participant, ensuring that their identity was protected and that there is no threat to their person by virtue of them participating in this study. Further, the name of the PHC facility where the study was performed was not identified. In this way, the

participant was protected from any possible retribution from colleagues or supervisors by their participation in the study. If, for example, a clinic supervisor saw a criticism in this research about a facility they supervise in a publication, they may victimise the NARTIS trained nurse who was stationed at their facility at the time the interviews were conducted. Further, the integrity of the facility was kept untainted. Identifying the facilities in this research may have drawn negative public responses, such as patients deciding to seek ART services at alternative PHC facilities if the research findings were unfavourable. Identification of the facilities would also compromise the protection of the staff working there.

There were no monetary incentives or benefits given to study participants. However, study participants were informed that a copy of the final, approved research would be shared with them. Lastly, all the data collected through the semi-structured interview guides were kept securely under lock and key.

Participants were protected as ethical clearance was obtained from both the Higher Degrees Committee of UNISA and the Swaziland Ethics Committee to conduct this research. To manage emotional discomfort, participants were free to withdraw from the study at any time, and were not compelled to answer interview questions that made them uncomfortable. Informed consent was provided by potential participants for this research, and will now be discussed.

3.10.2 Informed consent

The principle of 'informed consent' is one of the fundamental principles that demonstrate the ethical integrity of a study. Informed consent is the process of informing potential study participants of the risk and benefits of their inclusion in research, and of subsequently acquiring their voluntary participation (Polit & Beck 2012:730). There may have been a risk, for example, that being interviewed during busy clinic days may have an adverse impact on patient flow and may be perceived negatively by colleagues. This was managed by ensuring that the semi-structured interviews were held late in the afternoons when the patients were all seen, or at a time stipulated by the participant. The NARTIS trained nurses who are included in the sample were treated equally, given the same information, given the same opportunity

to consent before inclusion in the study and an option to withdraw from the study at any time. All the input given by the NARTIS trained nurses – their thoughts, perceptions, attitudes and judgments – were respected and validated (nothing was dismissed) and included in the data findings. All the contributions from the NARTIS trained nurses were quoted and transcribed verbatim. The participants were informed that field notes would also be taken throughout the research process.

All applicants were above the age of eighteen years. The informed consent form information sheet was read by the study participants. They were given time to ask questions and have these questions addressed. Participants provided written consent for participation in the study. Participation in the study was purely voluntary, and at any point the participants were free to exit the study if they desire to do so.

The objective of the research was explained to the participants. The researcher also shared the contact information for the Swaziland Ethics Committee, for the participants to contact if they felt they had been in any way harmed or injured by their participation in the research.

3.10.3 Anonymity and confidentiality

Confidentiality is a pledge that any information participants provide will not be publicly reported in a manner that identifies them, and will not be accessible to others (Polit & Beck 2012:162). In safeguarding confidentiality and anonymity, the researcher assigned unique identifiers to study participants. This is described at length earlier in this chapter.

A confidentiality pledge was made by the researcher to all participants before the interview process. This occurs where participants are assured that their privacy will at all times be protected (Polit & Beck 2012:158). Prior to the commencement of the interview, participants were ensured that their personal information, and the identification of their PHC facility, would be kept completely confidential. This was done through the removal of participant and facility names, and by the assignment of unique identifiers instead. They were also assured that no one else would have any access to their responses, and that the completed interview guides and transcripts

would be locked away by the researcher for a period of five years after the conclusion of the research. The co-coder who assisted in coding the transcripts did not have access to this participant and PHC facility information, as the unique identifiers had already been assigned by the time the co-coder was engaged.

The interviews were all recorded with the permission of participants by using an audio recording device. Each recording noted the time, date, duration of the interview, the name of the interviewer, the unique identifiers assigned to each participant, and each facility.

To ensure the confidentiality of the process, all participants were informed that their identity would be kept anonymous and no participant identifiers would be used. To ensure this, all participants were assigned a unique study identifier. This was also done to limit social desirability bias, where the participants tend to misrepresent themselves by giving answers that are congruent with prevailing social values (Polit & Beck 2012:313).

3.10.4 Potential risk or harm to study participants

Participants may feel that they put their welfare at risk when they talk honestly about the challenges in their workplace, in their community, and with their patients. To address this issue, the participant's names were not documented during the semi-structured interviews. Primary health care facilities in the country generally have more than one NARTIS trained nurse, meaning that even if the name of the facility where the interview was being conducted is named, it would not be easy to decipher which NARTIS trained nurse provided the documented responses. Even so, facilities in this research were not named but instead were also assigned a unique identifier. Further, facilities named during the interviews were removed. The use of different facilities during the research ensured that the identity of the participant could not be traced back to any specific facility, in this way reducing the potential to risk or harm. Also, to further secure confidentiality and avoid emotional discomfort, no photographs were taken throughout the interview process. If a participant was uncomfortable responding to any of the questions, they were free not to do so. All the information shared by the participant was kept in the strictest confidence.

3.10.5 Principle of respect for human dignity

Human dignity was ensured as none of the study participants were coerced or forced to participate in the research. Also, the research observed principles of self-determination and voluntary participation. Self-determination occurs where research participants can voluntarily choose not to participate in the research, and experience no negative or prejudicial treatment because of this decision (Polit & Beck 2012:154). It also refers to the fact that research participants are at liberty to ask questions about the research and to seek further clarity. Further, participants can withhold any information or responses and can pull out of the research at any time (Polit & Beck 2012:154).

The idea behind voluntary participation in research is that participants have the right and the freedom to control their own actions (Polit & Beck 2012:172). The participation of the NARTIS trained nurses in the research was voluntary. No incentives or gifts were provided for participation. Prior to the interviews, the researcher informed these participants that their participation was on a voluntary basis, and that they were free to withdraw from the interview at any time. During this research, no participant withdrew. Participants were also advised that they were not compelled to answer any questions that made them feel uncomfortable. The researcher advised that if such a question arose, participants could request to continue to the next question. During the semi-structured interviews, there was no participant who made such a request. Informed consent was obtained before the semi-structured interviews and audio recording began. Participants were also encouraged to ask questions at any time, and the researcher addressed these to their satisfaction.

Another component of ethical compliance in research is the adherence to principles of justice.

3.10.6 Principles of justice

‘Justice’ refers to the participants’ right to fair treatment, and their right to privacy (Polit & Beck 2012:155). Justice was adhered to as the participants were not selected on

the basis of any vulnerability of low social ranking. They were not exploited or unfairly engaged. Additionally, participants were free to withdraw from the study at any time, without any consequence of retribution or prejudice. Participants were also informed of their privacy being protected. This included their identity and the identity of the PHC facility they worked in. They were informed that all interview data would not be accessible to anyone else, and would be kept under lock and key for five years after the conclusion of the research.

3.11 ETHICAL CLEARANCE

The researcher ensured that approvals from the relevant national and international ethical review boards, including the Higher Degrees Committee of the Department of Health Studies, UNISA (Number: REC 012714-039) and the Swaziland Ethics Committee, was given before beginning the research. These certificates can be seen in Annexures F and G.

3.12 SIGNIFICANCE OF THE STUDY

The aim of this research was to identify contributing factors that influence non-initiation of ART amongst pre-ART-eligible patients. These factors can create awareness and enhance sensitivities of the factors that are preventing early ART initiation. Once the factors are identified, solutions can be explored. A further aim was that recommendations for health care providers, strategic planners and health developers to increase the prompt initiation of ART for eligible pre-ART patients in rural PHC facilities in Swaziland, could be derived.

3.13 SUMMARY

In this chapter the methodology that was used to conduct the research was discussed. This included the research design, inclusion criteria, the sampling methods, data collection and analysis, and the adherence to ethical standards.

The following chapter expounds on the management of the data, and will offer some data interpretation. It provides categories, sub-categories and themes that were identified in the data.

CHAPTER 4
DISCUSSION OF RESEARCH FINDINGS AND LITERATURE CONTROL

4.1 INTRODUCTION

In the previous chapter the research methodology was discussed. In this chapter the research findings and the literature control will be deliberated and the findings from data collected will be described to address the objectives:

- To explore and describe factors associated with non-initiation of ART amongst eligible pre-ART patients in rural PHC clinics in Swaziland.

- To make recommendations for health care workers to enhance early initiation of ART amongst eligible pre-ART patients in rural PHC clinics in Swaziland.

The researcher read and re-read through the transcribed semi-structured interviews to acquire and analyse the data from the NARTIS trained nurses. The researcher further used thematic coding (Tesch in Creswell 2014:198) as described in Chapter 3, to identify the meanings of the data. The researcher engaged an external coder also to code the data using the same technique. In this chapter the research findings, including the demographics, themes identified, substantiating quotes from the participants and the field notes, will be discussed.

4.2 DESCRIPTION OF DEMOGRAPHIC DATA

The Swaziland Ministry of Health Service Availability Mapping Report of 2013, reported a total of 2260 nurses, of varying cadres, in the country (Swaziland Ministry of Health SAM 2013:77). Of this number, 743 of 2260 nurses (i.e. 33%) are based in the Hhohho region. This region also accounted for the highest number of nurses, compared to the other three regions (Swaziland Ministry of Health SAM 2013:77).

The participants were NARTIS trained nurses, stationed in rural PHC facilities in the Hhohho region of Swaziland. There were eleven participants in the research; nine were female and two were male. Three participants had been stationed at their PHC facility for over a year. Four had been stationed at their facility for over three years. The rest of the participants had been at their facility for between five years and fourteen years, averaging nine years at their facility

The researcher inquired into the number of patients the participants were initiating each month. Two participants reported to be initiating between one to five patients each month. Two participants reported to be initiating between six to ten patients. Three participants reported to be initiating between eleven and fifteen patients. Two participants claimed to be initiating between sixteen to twenty patients each month. Lastly, two participants reported to be initiating between twenty-six and thirty patients a month. The researcher felt that the participants' experiences of working in the field gave them insight into factors contributing to non-initiation of ART amongst eligible pre-ART patients in rural PHC clinics. They also would be well versed in their community dynamics, understanding the intricate and complex systems that translate into community members' health seeking behaviour. NARTIS trained nurses formed part of the HIV-related resources in PHC facilities, as discussed under resources below.

4.2.1 ART initiation and refilling services

All of the sites sampled for this study initiated ART and refilled ART on a daily basis, namely Monday to Friday. Patients of these PHC facilities could receive ART services any day of the working week. They open as early as 7 am, and close at 4 pm.

NARTIS trained nurses were initiating a varied number of patients on ART each day. The highest reported number of patients seen in one facility in a day was seven, and the largest number of patients initiated on ART per month in a different PHC facility was thirty. Please refer to Figure 4.1 below to view the graphical depiction of these numbers.

The bar graph in Figure 4.1 illustrates the number of people initiated on ARV per facility per day. This is juxtaposed against the number of people initiated on ARVs each month.

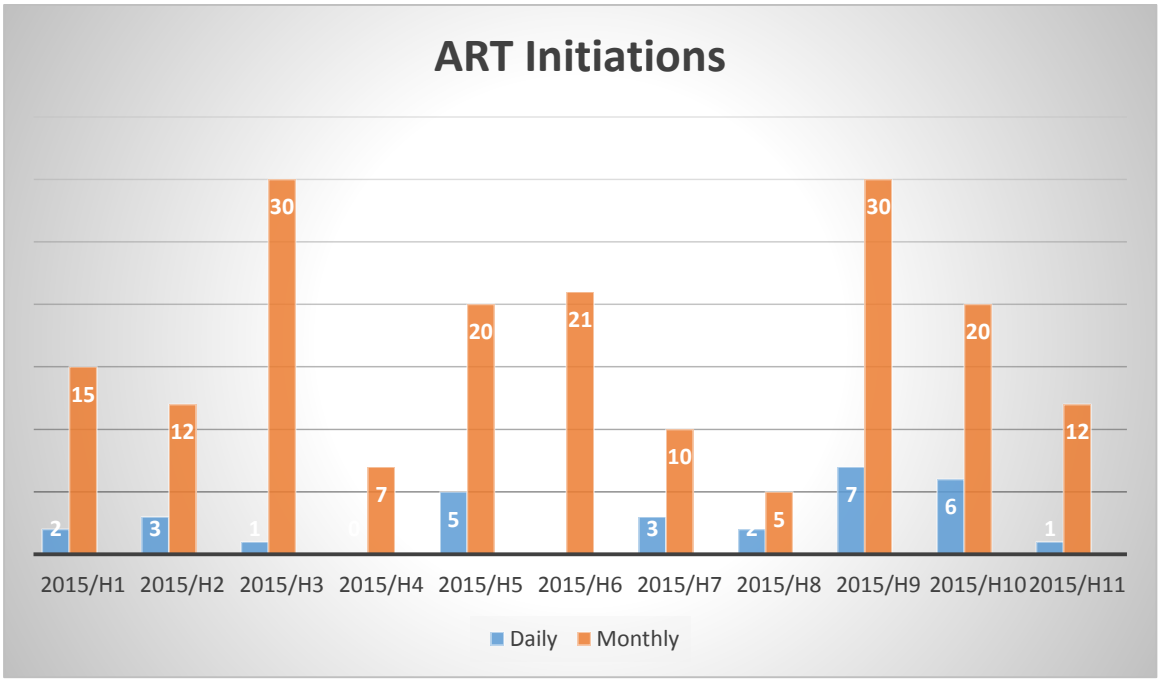

Figure 4.1: ***Graphical depiction of ART initiations and refills for PHC facilities*** **(*Where there is no daily value indicated above, the participant was not sure and could not provide an answer)**

The findings in terms of the themes, categories and sub-categories that emerged from the semi-structured interviews, are described below.

4.3 FINDINGS: THEMES, CATEGORIES AND SUB-CATEGORIES

There were four main themes identified from the data. These were systematic enablers of prompt ART initiation, barriers to prompt ART initiation, use of personal agency, and sources of support. From these four themes, categories and sub-categories emerged.

In Table 4.1, ART initiation refers only to the initiation of ART amongst eligible pre-ART patients. The term 'participants' will be referring to NARTIS trained nurses who participated in this study. Each participant was assigned a unique identifier number, preceded by the letter "H" which stood for 'health facility'.

Table 4.1: Themes, categories, sub-categories

THEME 1	CATEGORY	SUB-CATEGORY
1. SYSTEMIC ENABLERS OF PROMPT ART INITIATION	1. Primary health care level factors	1. Service availability
		2. Multidisciplinary team approach
		3. Health education
	2. Community level factors	1. Patient Factors
		2. Community-based outreach support
THEME 2	**CATEGORIES**	**SUB-CATEGORIES**
2. BARRIERS TO PROMPT ART INITIATION	1. Interdependence of health systems	1. PIMA machine for the timely provision of CD4 results
		2. Scheduled blood sample submission
	2. Patient-centred barriers	1. Mandatory pre-ART counselling sessions
		2. Need for a treatment supporter
		3. Patient readiness
		4. Health status
THEME 3	**CATEGORY**	**SUB-CATEGORY**
3. SOURCES OF SUPPORT	1. Individual patient support	1. Patient resources
		2. Non-disclosure
		3. Workplace support
	2. Limited NARTIS nurse support	1. Resource shortages

4.3.1 THEME 1: SYSTEMATIC ENABLERS OF PROMPT ART INITIATION

The participants reflected on the key enablers of early initiation to ART amongst eligible pre-ART patients. These enablers were recognised as structures within the PHC system, and structures within the community, that created favourable conditions for early ART amongst eligible pre-ART patients. The categories of these enablers, according to participants, were the *primary health care level factors* and *community level factors*.

4.3.1.1 Primary health care level factors

This category identified characteristics of the PHC facility system that created an enabling environment for prompt initiation of ART. These *enablers* served as a productive foundation in which timeous ART initiation could be established. These were identified by the participants as service availability, multidisciplinary team (MDT) approach, and health education.

a) Service availability

Participants elaborated on the supportive services that are available to assist patients in accessing good quality health services at their PHC facilities. This included lab work, on-site prescription drugs, and counselling. For example, participants indicated that all the facilities were connected to the National Sample Transportation (NST) Service. This was a service under the Swaziland Ministry of Health, which was mandated to transport laboratory samples from patients in public PHC facilities, and ensure that these samples were safely delivered to larger, central laboratory service for testing. It was also responsible for the delivery of laboratory results. One nurse described the schedule with the NST as follows:

> *"Let me make an example of Monday. On Monday the samples would go, same time. But Thursday we will be sure that that sample would have returned." (Participant #H5)*

Another participant explained how certain services were provided on certain days in her facility:

"Return dates are given on Wednesdays, as this is the day when labs are done and results are brought to us." (Participant #H1)

A participant mentioned support services in her facility, such as cell phone and airtime support, and she described how the airtime was procured from the MOH through a PEPFAR implementing partner.

"They [the facility staff] always ask for it [cell phone air time] before it finishes. It has never finished on us this year." (Participant #H4)

The researcher noted in the field notes that each facility had an ART room or designated area within the facility where ART services were being provided. They further had a NARTIS trained nurse working within the ART room at the time of the interviews, providing ART services. When enquiry was made into who calls the patients for follow-up, one participant explained that it was the ART nurse who was working within the ART department. This participant denoted the following:

"It's the focal person for ART, but usually it's the nurse who is in the ART department for that week. So if for example today there are patients who have not come, after 2 to 3 days she calls them. But there is a focal person who needs to ensure that there is still airtime in the phone, that the phone is still ok and that the services are still ok." (Participant #H5)

Having ART services on-site was another facility-based service that supported patients in accessing good quality health care. According to participants, the presence of ART on-site meant that patients who desired to initiate for ART were not compelled to travel to a distant larger facility; they could be initiated at their local PHC facility, at any day of the working week. Facilities were all equipped with a cell phone that was maintained and equipped with airtime. These cell phones assisted the PHC staff to actively remind patients, trace patients and encourage them to return to care, for prompt ART initiation.

The researcher observed in the field notes that all the PHC facilities had resources such as clean water, hygiene amenities, and a kitchen. The PHC facilities were also open daily during the working week, and had health care workers available each day to provide services to their patients.

The availability of these multiple services on-site, demonstrates comprehension, cohesion and integration of health services. The Ministry of Health Annual HIV Programmes Report (2014) indicated that the Ministry of Health has placed much emphasis in the recent years on the provision of comprehensive services in health facilities (Ministry of Health Annual Report 2014:6). This *supermarket* approach aimed at providing comprehensive services within a single visit. A study conducted by Kerschberger, Hilderbrand, Boulle, Coetzee, Goemaere, De Azevedo and Van Cutsem (2012:4) that investigated the effect of complete integration of TB and HIV services, found that service integration was associated with reduced timing to ART initiation. After integration, the median time between TB treatment initiation and ART initiation was reduced from 147 days to 75 days. This study further found that patients who received integrated HIV/TB services were 60% more likely to initiate on ART, compared to patients who received non-integrated HIV/TB services (Kerschberger et al. 2012:4). An integrated approach to HIV services can facilitate earlier ART initiation, and avoid duplication of health interventions (Kerschberger et al. 2012:4).

Another study conducted by O'Brien, Mills, Hamel, Ford and Pottie (2009), explored the benefits and challenges of bringing integrated HIV services to isolated, conflict-prone areas of the Republic of Congo. This study found that integration provided opportunities for HIV services to be offered through other health programmes within the facility, and also facilitated cohesiveness of medical services that may have once been vertically provided (O'Brien et al. 2009:5). This aligned with aims to provide universal access to HIV care and treatment services, and would enable earlier initiation of patients to ART.

Another component of service integration is a multidisciplinary approach. This sub-category is described below.

b) Multidisciplinary (MDT) approach

The Multi-Disciplinary Team (MDT) approach is an approach where team members provide comprehensive care to their patients by working together in a collaborative and complementary fashion. The provision of comprehensive care for HIV rests upon the MDT (Swaziland Ministry of Health National Comprehensive Package of Care for Adults and Adolescents 2010:2). Multidisciplinary team members within PHC facilities can include, for example, the nurses, expert clients, phlebotomists, pharmacists, TB screening officers, HTC counsellors, data clerks, receptionists, orderlies, and groundsmen. Their roles are unique, but complementary of each other. For example, nurses would provide clinical care to the patients, the HTC counsellor would provide psychosocial support and follow-up services to TB patients, phlebotomists would draw laboratory samples from patients, and data clerks would ensure that data of services were being recorded accordingly. This approach enables strong integration of health services within a single HIV care model. An MDT, composing of a mix of skills and talents, could all play a part in facilitating prompt ART initiation.

According to the participants, an MDT approach is undertaken whereby all the different cadres of the heath facility work collaboratively to provide comprehensive care to each of their patients. The aim of this approach is to reach a common goal for the patient, and they work towards this goal by working together in a coordinated fashion. The person responsible for making follow-up phone calls with patients was described by one participant as:

> "*ECs [Expert Clients] and assigned nurses, depending on the circulating system [the rotating schedule of the facility staff]" (Participant H2)*

When asked who in the PHC facility conducted patient follow-up, a participant explained:

> *"All of us. Because the cough Officers follow-up the sputum, the EC calls to follow- up patients who haven't come for tier appointments. The nurses also call to follow- up*

patients…its everybody. The only people who don't use the phone it's the orderly's." (Participant #H3)

According to the participants, each MDT member had a designated role that they would play in the PHC facility for the benefit of the client. Further, the researcher reflected in the field notes that it was the nurses in the facility who enroled patients into the pre-ART Register. Another member of the MDT were Expert Clients. Expert Clients (EC) are patients who are also role models who motivate patients on adherence to HIV care and treatment (Torpey Kabaso, Mutale, Kamanga, Mwango, Simpungwe, Suzuki & Mukadi 2008:7). ECs are capacitated to increase awareness and impart knowledge of HIV, and also encourage positive changes in behaviour amongst people living with HIV (Medley, Kennedy, O'Reilly & Sweat 2009:1). ECs are employed by the facility to demonstrate how to live a healthy life with HIV, provide psychosocial services and conduct patient follow-up of patients who miss appointments. ECs were the ones to appoint patients in the Appointment register, and would also be the ones to identify patients who had missed their clinic appointments. For patients who were not returning to the clinic on the appointed dates, they would be followed up by a community Expert Client. This is an Exert Client who provides community-based adherence support and works within communities to locate and re-engage patients who are lost to care. The researcher's field notes also reflected cohesion in the facilities, where each person knew their role, and where skills were carried out in a systematic and routine practice within the facility, which enabled patients who became eligible to be identified and followed-up.

One participant described how, even if staff shortages result in the designated community MDT member (such as the Mothers2Mothers and the Expert Client) not being able to conduct home visits, this would be undertaken by the nurses. This is reflective of an MDT approach. She described the following:

"…it's mostly the M2M [i.e. Mothers to Mothers] and the Expert Client. But if it does happen that lets say we have enough staff, when it does happen, sometimes the nurse will go and see the clients who cannot come here, so she can go and see them." (Participant #H5)

This described how MDT members' roles complemented each other, so that if someone was absent, another MDT member would take on their responsibilities, ensuring that service delivery is not interrupted and that flexibility was permitted.

Rural Health Motivators (RHMs) are a cadre of community health volunteers who are elected by their community leaders to serve their community (Swaziland Ministry of Health Standard Operating Guidelines for Community Based Health Volunteers in Swaziland 2015:5). Their roles include periodically visiting households within their communities, providing health information, promoting health services uptake, and referring ill patients to the PHC facility. On enquiry into to the utilisation of a RHM for closer engagement with patients within the community, one respondent said:

> *"This facility works with 10 of them." (Participant #H2)*

Another participant described that in her facility there were few RHMs, and they used ECs. However, she further explained that when the ECs were not available, the nurses themselves would assume the role of community workers:

> *"They are not many… most of them are not active… we don't have the figure. But they are able to communicate with the community EC [Expert Client]. Us we usually talk to the Community EC because they are the ones who know who is residing where. With the help of World Vision [Word Vision is a community-based NGO that supports efforts to follow up clients who are lost in care]. But in cases…do go, after we have identified the clients because they live in the community we know them." (Participant #H5)*

This participant described how the MDT approach best enabled her PHC facility to support their patients. Increased variation in staffing roles translated into more comprehensive support potential that could be given to patients attending services for HIV. In a Zambian study conducted by Torpey, K., Kabaso, M., Kasonde, P., Dirks, R., Bweupe, M., Thompson, C. & Mukadi, Y.D. (2010) that described methods of increasing the uptake of prevention of mother to child transmission of HIV (PMTCT) in resource-limited settings, the MDT approach to service provision is articulated. Here, community workers and lay counselors were trained to provide health talks, some PMTCT services, psychosocial support in HIV testing, adherence support, and making

referrals (Torpey et al. 2010:3). These authors argue that the MDT approach includes the skills transference to lower cadres, and building the capacity of existing personnel to provide services (Torpey et al. 2010:3). This is reinforced by the World Health Organisation ART Guidelines (2013), that argue that patient health outcomes were improved where facilities offered systems of support, outreach activities, peer educators (in Swaziland this would be Expert Clients), and, most importantly, where teams of health care professionals offered ongoing multidisciplinary services (WHO Guidelines 2013:178).

One critical form of support provided by PHC facilities was health education. This is described in the following section.

c) Health education

Health education is a forum whereby information transference occurs between health care members of a facility, to the patient. Health education is a powerful weapon used by health care workers to promote healthy behaviour and prevent mortality and morbidity (Nutbeam 2006:259). Health education provides a forum for health care workers to educate patients on health related topics.

Through these fora, health education contributes to the increased understanding and knowledge base of patients about the risk factors for illnesses and disease (Nutbeam 2006:261). The health facility staff gave health education sessions every morning, and each session lasted approximately twenty minutes. The topic of the health talk was always health related, and varied. These sessions were very interactive and gave the patients an opportunity to ask questions, seek clarity and make their own recommendations. Health education sessions presented an opportunity to encourage early ART initiation by creating awareness and sharing information. Participants in this study reported that their facilities were providing morning health education talks to their patients. Health education was seen as an enabler by participants because it gave the PHC facility a platform to frequently inform, reinforce and emphasise the importance of early initiation of ART. It also provided a forum for patients to express any concerns around ART initiation, and to seek clarity and new information on ART.

Health education provided information and motivated patients for HTC. One participant mentioned:

> *"Ok sometimes it's the health education we are providing in the clinic. Some people they have come here for… just they are sick, but after hearing the health education they are… encouraged for HTC [HIV Testing and Counselling]." (Participant #H7)*

Another participant supported this view by saying:

> *"They [participants] come for HTC. I think its friends and health education." Participant #H5*

Another participant described how health talks were the vehicle to share information about sex and sexuality, and how this tool became a stimulus for behaviour change. She said:

> *"…when you talk to them about sexual issues they say "Hey you, you are playing with us" They are still forbidden …. to talk about those kind of topics. Even though they say to me "ahh it's true this one is crazy" but at least they get to hear. So issues around sex are not easy. And nurses, they also don't talk about sex easily. I have noted, It's not all nurses are comfortable with [talking about]sex." Participant #H3)*

Participants perceived health education as a platform to promote uptake of health services, and this could include encouragement and support to eligible patients to enrol into ART early. In a study conducted by Torpey et al. (2010:3), one of the strategies used was to engage lay-health service providers to offer group educational talks to patients. This study demonstrates the impact of health talks to patients as a motivator for behaviour change. It observed an increase of HIV testing from 45% to 90% within a one year period (Torpey et al. 2010:4).

Enablers referred to PHC levels as well as community levels. In the following section, community level systematic enablers of prompt ART initiation will be discussed.

4.3.1.2 Community level factors

The second category – community level factors – was identified by participants as systematic enablers of prompt ART initiation. According to participants, these are factors from within the patient's own community that can positively or negatively influence the timing of ART treatment initiation. Sub-categories that were identified under this category included patient factors and community-based outreach support. These will be expanded on further.

a) Patient factors

The researcher explored what motivated some patients to come to the facility for HIV services, without prompting or referral. This included patient-level factors that enabled patients to take control and make decisions about their own health care, without them being pushed to do so. Participants expressed that patients were motivated by different aspects, including being empowered, or by their health status.

Participants indicated that different factors encourage patients to walk into the facility for services, without having to be prompted by a call to visit the facility. They reported that some patients do this because they have returned for another HIV test, having previously tested HIV-negative. Other participants felt that it was because of empowerment qualities the patient possessed.

One participant justified this as follows:

> *"They [patients] are simply empowered. They have the information. They know the benefits of testing and knowing your HIV status." (Participant #H10)*

This participant described the behaviour of a pre-ART patient who was empowered because of their community. A study was conducted by Mavhu, Dauya, Bandason, Munyati, Cowan, Hart, Corbett and Chikovore (2010:575) that explored reasons why patients who reported coughing for over two weeks had not engaged in clinical services. The results indicated that the predominant reason why patients avoided PHC

facility visits were fear of HIV and TB. They hoped it would resolve itself or they had had a previous negative experience in the health facility where treatment was provided (Mavhu et al. 2010:575). These authors highlight how the lack of patient knowledge and motivation can cause delays in seeking treatment for diseases within health facilities. Johnson (2011:268) defines 'empowerment' as the opposite of powerless. Johnson links empowerment with health literacy as a personal resource that empowers patients. Similar to what this participant was sharing about patients being empowered, patients who have knowledge and information on the importance of knowing their HV status would not necessarily need prompting before going to the health facility to seek services. They would simply seek these services, including early ART initiation if they are pre-ART-eligible.

Participants in this study further indicated that a patient's health conditions influence their health seeking behaviour. Asymptomatic patients, for example, may not seek health services as aggressively as symptomatic patients.

One participant expressed how the deterioration of a patient's own health status positively influence health seeking behaviour:

> *"Sometimes they are sick. Somebody is sick, now they want to test. Another thing is that seeing other people taking the ART, and they say "Eh let me go and test, people are living." (Participant #H7)*

This impact of deterioration of health status was also expressed by another participant who said:

> *"…they come here when they are sick so they just accept the situation. They come here because they know they are sick." (Participant #H7)*

This sentiment was supported by another participant:

> *"People who have tested before and there is a change in their lives. They have started falling sick." (Participant #H6)*

These contributions describe how, when patients feel unwell or observe others' health deteriorating, they are triggered to seek further services. A study conducted by Abaynew, Deribew and Deribe (2011:4) in Ethiopia, explored factors associated with late presentation to HIV/AIDs care. These authors found that feeling well was associated with low rates of linkage in care once a patient had been diagnosed as HIV-positive. The authors further found that patients living with HIV who were displaying symptoms of ill health at HIV diagnosis were associated with late presentation into care (Abaynew et al. 2011:5). This highlights the impact of stigma and discrimination as a contributor of delayed ART initiation. Displaying symptoms of sickness may prevent HIV-positive people from continuing to seek health services at their facility, delaying treatment initiation.

A Malawi study conducted by McGuire, Munyenyembe, Szumilin, Heinzelmann, Le Paih, Bouithy and Pujades-Rodrıguez (2010:58), explored the reasons why patients default from pre-ART and ART. The study discovered that 28.3% of pre-ART patients defaulted due to perceived improved health status. These authors also stressed how feeling healthy may deter patients from being retained in pre-ART services. This was echoed by a participant who said:

> "*Some because they are now well. They feel there is no need to be serious in taking their treatment." (Participant #H7)*

Another participant highlighted the impact it had on a patient to witness the health status of someone they know worsen, saying:

> *"Other say that they saw a sick relative who died, and they were suspicious of themselves..." (Participant #H8)*

This participant highlights how the observation of physical deterioration of health of others had a similar impact on a patient's positive health seeking behaviour related to HIV.

The second theme identified under community level systematic enablers of prompt ART initiation, was community-based outreach support.

b) Community-based outreach support

The participants in this study cited that the PHC facilities had outreach services, including affiliations to support groups and community cadres that enabled community level support to their patients. Participants indicated that these outreach services served as an arm of the PHC facility to provide health services outside of their facility, including providing targeted and community level support to patients who may be facing delays in ART initiation.

Participants identified Ministry of Health programmes such as the Expert Client (EC) Programme and the Rural Health Motivator (RHM) Programme, as strong supportive mechanisms for patients in pre-ART.

Another nurse expressed the need to have community-based support services for the patients they were seeing in the PHC facility. When asked what she felt would be required to facilitate earlier patient initiation for those who are pre-ART-eligible, she responded:

> *"Even the Community. We need someone who could be in the community and encourage them to come. There are those who need someone in the community to encourage them." (Participant #H4)*

Both ECs and RHMS providers were lay and trained; they provided basic health information to patients within the facility, and also within the community. The Expert Client Programme was established in 2007 as a national commitment towards Greater Involvement of People with HIV (GIPA) (Ministry of Health EC Programme 2008:1). It was the umbrella body that provided oversight for all EC activities in the country. They were the unit to which all ECs reported, and sourced support while providing health services. The Rural Health Motivator (RHM) Programme was the unit that supported all of the Rural Health Motivators in the country. The National RHM Review (2012) argues that RHMs play a crucial role in the provision of support and follow-up for people living with HIV in Swaziland communities (Ministry of Health RHM Review 2012:10). Both the EC Programme and the RHM Programme mandate their staff to

actively support patients through the provision of adherence counselling, health information, follow-up and home visits. Patients visiting facilities for HIV services will be seen by an EC, attached to an RHM.

Community cadres included Rural Health Motivators (RHM), and Community Expert Clients (CEC) that could take their services to the community, including health education and adherence to pre-ART care. The latter would include close monitoring of patient eligibility status, addressing patients' concerns around ART initiation, and encouraging eligible patients to enrol for ART. Community support groups also served as a safe and confidential forum for patients to collectively access support and encouragement for why early treatment initiation was beneficial.

Such adherence support units can positively influence the health-seeking behaviour of patients, promoting pre-ART retention levels, and are catalysts for treatment initiation. A study conducted by Torpey et al. (2008:6) in Zambia, revealed that the engagements of lay-teams, such as Adherence Support Workers (ASW), had a positive impact on reduced waiting times, reduced workload for health care workers, and improved the streamlining of patient flow. The study argued that the presence of lay-cadres, such as ECs, RHMs or ASW, meant that patients were ensured of receiving individualised and specialised psychosocial support and counselling (Torpey et al. 2008:7).

Community-based outreach services were mandated because of the challenges faced by patients in coming to the PHC facility. One nurse explained this by saying:

> *"Others say they stay far. But there is no transport here. The bus leaves in the morning at 7am. And then again at 4pm, so it's hard." (Participant #H4)*

Another participant supported this view:

> *"Also the socio-economic status of the people. I don't know what can be done because some you find they really don't have the money. They don't have the money. To come to the clinic. Then you find that it delays." (Participant H7)*

These experiences support findings from a study by Van Dijk, Sutcliffe, Munsanje, Hamangaba, Thuma and Moss (2009:3) conducted in Zambia, who argue that access to health care facilities continues to be the biggest barrier to care in rural Sub-Saharan Africa. This study explored the specific barriers to care amongst children residing in rural Zambia, and found these to predominantly include a lack of transportation modalities, poor road condition, and limited resources (Van Dijk et al. 2009:3). These authors highlight the critical role that community-based outreach services and support play in bringing services closer to the patient in light of such challenges to access.

Another study by Fatti, Meintjies, Shea, Eley and Grimwood (2012:57) found that community-based adherence support enabled patients to overcome denial, improve their understanding and knowledge base about HIV, assist them with adherence to care and treatment, and improve their psychosocial problems. This, in turn, resulted in improved adherence behaviours. These authors highlighted the crucial supportive role that community-based entities played in facilitating positive changes in patient behaviour. One participant described the influence of friends and community activities and events conducted by organisations in prompting patients to visit PHC health facilities, saying:

> *"Recently there was an event by [name of organisation], and others who have come to teach in the communities. Others are assisted by their friends." (Participant #H4)*

Participants identified patients who resided in communities where there was greater support for HIV as having greater support to seek health care, and to accept an HIV-positive diagnosis. Some of the participants attributed a patients' willingness to attend services at the PHC facility without prompting, to supportive community structures. Community health campaigns often resulted in heightened levels of community awareness about HIV and AIDS. Although one might assume that communities with greater awareness became a motivator for many patients to visit the PHC facility, research informs that this is not the case. A study by Karau, Winnie, Geoffrey and Mwenda (2014:167) conducted in Kenya, looked at the responsiveness of HIV education and VCT services amongst rural women and found that HIV/AIDS information is widespread. However, the primary problem was not awareness, but rather the continued resistance and indifference to testing in light of this awareness.

Negin, Wariero, Mutuo, Jan and Pronyk (2009:851) carried out a study where a community awareness initiative was implemented to mobilise a rural area of Kenya on home-based VCT. In an area with a population of 3180 persons aged fifteen to forty-nine years, only 63.9% went for an HIV test (Negin et al. 2009:851). This reinforces the observation that although this participant was attributing positive health seeking behaviour to community campaigns, existing research highlights that there is still an observed lull between HIV diagnosis and treatment initiation despite these interventions.

Another participant said:

> *"Another thing that influences is the community M2M, because they go into people's homes. So when they go in the homestead they don't only look at the babies, but they also [do] counselling. Also, in the community meetings, they go to educate them."(Participant #H5)*

Again, this emphasised how services, messaging and interventions that were based within the community where the patient was residing contributed to positive health seeking behaviour in HIV and may prompt someone to seek ART services early. Having this source of support closer to the patient, assists in prompting them to seek HIV care, as seen by one participant who said:

> *"Others reside in company camps. Men. Then they are able to encourage each other to go and test. Also supporters end up supporting each other. When you ask the patient who they will come back with, they say they will come with the one they stay within the same room. So they return with their roommate, all to find that the roommate is on ART. So they end up both being on treatment, supporting one another. They are able to really support each other." Participant #H8)*

The outreach services personnel and support groups described in the participant quotes provided much support to patients within communities. This community-based outreach support also offered an enabling environment for re-entry into services for patients who were facing challenges or disruptions in access to relevant care.

According to the participants, these services include receiving visits from community health workers who are sent by the PHC facility to follow-up on patients and provide necessary home-based support. They could include facility-based medical practitioners who dedicate time in their calendar to visit their patients at home and provide them with necessary medical support. Further, these services could include the facilitation of patients to support groups as a source of support. These support groups are often backed by the facility team itself, in conjunction with the community leadership. These activities were necessary for timely ART initiation because these outreach services could be the pivot for eligible pre-ART patients to begin treatment initiation.

One participant identified the PHC facility's community follow-up activities as being wholly dependent on Expert Clients, saying that:

> *"Yes we have follow-up of patients on ART and TB. [patients are followed up by] the Expert Client" (Participant #H7)*

Another participant expressed their appreciation for the role of RHMs in the following quote:

> *"We have RHMs. We have probably 100. We use them specifically for tracing clients. ART clients and Pre-ART clients. And for dissemination of information." (Participant #H11)*

Where there was no community-based outreach activity, participants expressed frustration. One participant described:

> *"We need strengthened follow-up. The nurses are too busy. We also need a CEC to conduct the home visits." (Participant #H3)*

Contrary to this view, another participant described her appreciation of the PHC facility's implementation of a community outreach programme as an extension of PHC services. She shared her feelings as a member of the community team that aided in

the provision of community outreach services, who travel to communities to provide care. She shared the following:

> *"We have seen a lot of activities being done by [clinic name] in the community. We actually go out into the community to check our patients. Because as [clinic name] we are servicing in this community….and we normally go out there to consult with our patients." (Participant #H10)*

In this quote, she describes how the PHC facility's outreach implementation brought supportive health services closer to the patient at home and complemented the services that the patients were receiving at the PHC facility.

As some of the participants spoke about their outreach services, the researcher noted in the field notes that they seemed relieved to have these services. They also appeared to be very reassured that community services were taken care of because of the presence of the clinics community cadres: relieved that this department existed in the face of very real staff shortages within the facility. Participants perceived these outreach services positively and identified them as a source of support for themselves, and for their patients. For pre-ART patients who are eligible for ART, this service is the targeted psychosocial support that may be required to expedite ART initiation.

The participants felt that the community was a source of support not just for the patients, but also for them because it complemented the services that they provided to patients from the PHC facility. They felt that the support they provided to patients was often strengthened because of the concurrent support provided by the community. Thus, the community offered increased support to the health care worker in the PHC facility. As a result, the community was identified as the provider of a dual form of support: for both the NARTIS nurse and also for the patient from the community.

This is reinforced in a study by Fatti et al. (2012:57) that looked at the impact of community-based adherence support. These authors argued that community support reduces levels of HIV-related stigma, and leads to increased community assets, such as relationships. It further asserted that community support strengthens a patient's community as their safety net, and increases levels of social responsibility. This, in

turn, has a positive knock-on effect towards the patient's level of adherence to their clinic visits and health behaviour.

In a deeply traditional country such as Swaziland, the role that the community networks, perceptions and support systems play in the patients' lives who attend rural PHC health facilities, cannot be overlooked. Through the semi-structured interviews, the theme of community support on personal health behaviour was a recurring theme.

The second theme identified from the data was barriers to prompt ART initiation. This will be discussed below.

4.3.2 THEME 2: BARRIERS TO PROMPT ART INITIATION

According to participants, there were definite barriers that hindered eligible pre-ART patients from starting ART when they needed to. The barriers that will be described in this section were further stratified into the following categories: the interdependence of health systems, and patient-centred barriers.

4.3.2.1 Interdependence of health systems

During semi-structured interviews with participants, it emerged that within the PHC system, services were provided in an interdependent manner. This would often mean, for example, that the provision of one service may be dependent on the provision of a preceding service. For instance, calling patients who have not returned to the PHC facility on their appointment day is dependent upon whether the clinic has a cell phone and airtime. The sub-categories identified under this category included the provision of CD4 lab results and scheduled blood sample submission. A further discussion will follow.

a) PIMA machine for the timely provision of CD4 results

According to participants, PIMA machines enable facilities to determine a CD4 count within approximately twenty minutes of conducting an HIV test. PHC facilities that have this device are therefore not faced with barriers of over-reliance on the National

Sample Transportation (NST) vehicle, or lack or reagents. This apparatus enables escapism from those challenges and the convenience of timely ART treatment initiation.

According to participants, the presence of a PIMA machine and the efficiency of the NST system positively impacts on the CD4 turnaround time and prompt provision of CD4 blood results to the patient. One participant described how, in her facility, provision of CD4 blood results was immediate by virtue of their onsite PIMA machine. She said:

> *"[Patients are informed of their CD4] at the very same time because we have PIMA. We can take their CD4 count." (Participant #H9)*

Conversely, it was noted by other participants that the delivery of the CD4 blood results presented as barriers to timely ART initiation. Because they did not have a PIMA machine in these PHC facilities, CD4 tests needed to be conducted in a larger, more equipped health facility. One participant explained this by saying:

> *"Unfortunately we don't have a PIMA and we actually love to have that. Because I would like to believe that we do qualify to be regarded or considered as a high volume site [this is, a facility with large volume of patients]. We have been challenged with CD4, where suppose the machine is down at our Mother Facility, it's quite a challenge. So if we could have a PIMA machine we would really really appreciate." (Participant #H10)*

Other participants experiencing this challenge expressed a need for a PIMA machine. One participant said:

> *"I wish we had a PIMA, but a PIMA also comes with a person who can work with the PIMA."(Participant #H4)*

Another participant supported this by saying:

"If only our facility had a PIMA. Then patients would be started on time. We would be starting more patients on ART than we do now …" (Participant #H6)

Another said:

"We also need a mini-lab. So that the results can come back quickly….because sometimes you have to look at the chemistry, how is the liver how is the kidney. Before we can start." (Participant #H7)

Another stated:

"I would say I would be very happy to have a PIMA, because then we could take bloods daily." (Participant #H11)

These findings supported a study conducted by Mtapuri-Zinyowera et al. (2010:5) in Zimbabwe that found facilities that had both HIV testing and PIMA POC machines on-site, were able to rapidly diagnose HIV and determine ART eligibility in a single visit. The availability of a PIMA machine on-site meant that subsequent services could be expedited, prioritised and followed up (Mtapuri-Zinyowera et al. 2010:5).

Blood for CD4 counts was taken at the PHC facility and transported to a more equipped laboratory in the absence of the PIMA machine. The vehicle that is utilised to transport blood samples and sample results between facilities, is the National Sample Transportation (NST) vehicle. Hence, the disclosure of CD4 blood results to the patient would depend on the arrival of the NST vehicle at the facility. The NST vehicles would return the bulk of CD4 test results to the PHC facility on a designated day – or days – of the week. Only from that day could a patient be deemed eligible for ART initiation. When describing the time it takes between taking CD4 tests and ART initiation, one participant explained the implications of the designated days for the arrival of NST, saying:

"By the way, you test. You test, you take CD4 some the same day, then return on Monday or on a Wednesday. You can take a CD4 and baselines when it's not the right day. So I would say 2 to 3 weeks… when we test the patient and take CD4 we tell the

patient that it is possible that you need to start ARV. If we have to wait for the CD4, that is what will tell us what to tell the patient." (Participant #H4)

Many of the participants identified the unreliability of the NST as a barrier to prompt initiation of ART. When asked about their perceptions on why patients do not attend their appointments, one participant said:

"Most patients say they were busy. Others say they had no money. Some arrive after the sample transportation have gone, they leave at 10am." (Participant #H4)

This time-bound restriction of the arrival of the NST vehicle results in patients having to return to the PHC facility on another day, incurring further transportation costs, and compromising the goal to provide integrated, comprehensive services within a single visit. In the face of these challenges, it is easy for health care workers to feel demoralised and disenabled to provide the services they need to maintain their community. This is resonated by a study conducted by Justman, Koblavi-Deme, Tanuri, Goldberg, Gonzalez and Gwynn (2009:31) that investigated the development of laboratory systems and infrastructure for HIV scale up, which describes how infrastructural improvements within the work environment can also improve morale and enhance the level of retention.

Unfortunately, vehicle breakdowns or challenges with vehicle maintenance were cited by participants to frequently interrupt sample transportation systems, and result in laboratory results not being delivered. In some instances, it was sighted that the sample transportation would be expected by the PHC facility, but would not arrive at all, compromising the quality of care given to the patients. This was articulated by another participant who said:

"For CD4 we need LFTs [Liver Function Tests]. Sometimes the car to collect the bloods does not come." (Participant #H1)

In Swaziland, the limitations in both phlebotomists and laboratories within the PHC facilities has resulted in a dependence on laboratory sample transportation systems to health facilities with better-equipped personnel and laboratory infrastructure. This

finding is echoed by a participant who described the movement of CD4 blood samples between facilities as a result of an inability of the facilities to follow-up laboratory results. She said:

> *"Now the CD4 is not being done. As much as we do them with the PIMA, we cannot do follow-ups. Then labs also paused as well. Now [Facility A] is not doing them. [Facility B] is not doing them. So they are only being done at [Facility C]. And at [Facility C] for them to be done we have to send them to [Facility A], then [Facility A] will take theirs and their babies to. [Facility C]. [Facility C] also has their own babies. So there is now a queue." (Participant #H5)*

The participants of the study also gave anecdotal quotes of the lack of reagents; the chemical solution needed to enable identification of CD4 cells in a blood sample. With no reagents, it is not feasible to acquire a CD4 test result from a blood sample. This negatively impacted the PHC facilities, since blood samples would be drawn and the NST vehicle *would* arrive, but the chemical solution required to do confirmatory HIV testing on the blood sample was lacking at the laboratory site where the diagnostics were being done. This was indicated by one of the participants, who said:

> *"Sometimes there are no reagents at [our main hospital], so CD4 cannot be done." (Participant #H1)*

Another reiterated:

> *"There are no reagents at the moment, so we are using [WHO] clinical staging." (Participant #H2)*

The frustration of no reagents was further expressed by another participant, who said:

> *"Patients do come, is interested, but would like to know [their HIV status] but are not able to do it because reagents are out of order. So they come when they are really sick. Sometimes a patient will come, and you would find that the patient would like to know more about the CD 4 count."(Participant #H6)*

In a 2010 study conducted by Losina, Bassett, Giddy, Chetty, Regan, Walensky, Ross, Scott, Uhler, Katz, Holst and Freedberg (2010:3), that evaluated the reasons for pre-treatment loss, found that 15% of patients who had a CD4 cell count within eight weeks did not return to the health facility for those results. This stresses the need for Point of Care CD4 testing that would avoid having to wait for NST to bring the results back, or for patients to collect results. A study on the implemented use of motorbikes to transport laboratory samples from facilities with no on-site laboratory equipment as a mean of improving facility infrastructure and capacity was carried out by Torpey et al. (2010:3). This innovation may address the challenges expressed by many of the participants of this study, with the NST.

The frustrations expressed by the participants was further compounded by the stringent schedules around blood collection. This is described below.

b) Scheduled blood sample submission

Patient blood samples that were collected from the PHC facilities were collected by the National Sample Transportation (NST) vehicle. This NST vehicle also returned patient blood sample results to the PHC facility. According to the participants, the vehicle adhered to a strict, scheduled timeline of when blood samples could be taken, and when results would return.

Participants indicated that in the PHC facilities where they worked, blood samples were only drawn on certain days. The scheduling to take blood samples was strict and allowed no flexibility for when a patient could take blood or receive CD4 blood results, and be subsequently initiated on ART if necessary.
This was evident in the following participant's response:

> *"Some arrive after the sample transportation have gone, they leave at 10am" (Participant #H2)*

It was also supported by another participant, who said:

"We need more people to test people for HIV, and a phlebotomist to take bloods. To be onsite. Because the sample transportation comes at 9am. Because of problems of transport, many people are not here by then. To take bloods. So it means that they have to return on another day." (Participant H11)

This quotation demonstrate how this designation of blood work on certain days would translate to a patient having to commit to additional PHC facility visits, additional time spent waiting for services, and additional transport costs incurred to travel to the facility and again return on a follow-up visit for results. Facilities with a PIMA machine would still have to rely on the stringent calendar schedules of the NST vehicles for blood submissions of laboratory tests other than CD4. However, facilities that had no PIMA machine were wholly reliant on the NST vehicle for every type of laboratory test needed. One participant explained how patients were choosing to take blood in facilities where the turnaround time was quicker, rather than adhering to the strict submission deadlines of the NST:

"Some, when you talk about the labs, they opt to go to (Facility A) themselves. You find that they would rather go to (Facility A) on a Tuesday than come [here] to (Facility B) on a Wednesday because their results are given same day. They would rather take them, wait for them, and then return with them. Most of them prefer to go to (Facility C). Take them and wait for them. Then the day they need to return they come with them. Then they are initiated. We do tell them that they can continue with (Facility C) if they wish. We write a lab request form for them, and they take it to (Facility C)." (Participant #H5)

In the field notes, the researcher noted that this participant spoke with passion and zeal about her patients, and about the services they provided in an effort to offer the best services for them. One participant demonstrated this as she described how her facility developed an innovation whereby they proceeded with the initiation of patients on ART regardless of the presence or the absence of blood sample results. This mitigated the long turnaround times for laboratory results while awaiting the NST. She said:

"We do take [bloods on a certain day]. But we don't wait. We do take, like we only take specimen on a Wednesday. But also the client will come let's say on a Friday and then will return let's say on Monday. We cannot say we will wait for him. We will initiate them. Wednesday they will come and get their specimen. The initiation will follow…… The rest will follow because it is the same. The CD4 is not there, there are no reagents. There is no what what I mean really. The patients waits for a long time now."(Participant #H3)

This highlighted how some participants, faced with the challenges of the strict scheduling of the NST, were using it as an opportunity to be innovative. In this case, presenting limitations in laboratory services did not stop them from providing critical services and developing innovations for their patients. Justman et al. (2009:32), emphasise that laboratory systems of collecting testing samples and returning results should be reflective of laboratory and clinical management systems, and it should also reflect the structures of the laboratory network systems. To address these experiences of the participants of the challenges of the NST scheduling time, Justman et al. (2009:32) recommend Point of Care testing for simpler, more frequent laboratory tests such as HIV, haemoglobin and glucose; thus, bypassing the dependence on the NST for the collection and returning of blood sample results.

The second category was patient-centred barriers to prompt ART initiation. This shall be discussed in the subsequent section.

4.3.2.2 Patient-centred barriers

According to participants, this category identified barriers to early ART initiation that were centred on the patient themselves. These were the characteristics concerning the patients that presented as a barrier to timely ART initiation when they were pre-ART-eligible. Sub-categories under this category included the mandatory counselling classes before ART initiation, patient readiness, and the need for a treatment supporter.

a) Mandatory pre-ART counselling sessions

Participants highlighted that in their facilities, patients undergo up to three pre-ART counselling sessions as a pre-requisite to being initiated on ART. These pre-ART sessions involve information sharing and targeted counselling for the patient. Through these platforms, patients would be assessed for pre-ART eligibility, and their questions and concerns could be addressed to their satisfaction. It would also be the forum under which eligibility criteria, such as CD4 blood results, or WHO Clinical Staging, would be discussed. Pre-ART counselling content was described by one participant, who said:

> *"During the 1st counselling session, the eligibility criteria is explained. It is done by the EC." (Participant #H1)*

This requirement for pre-ART counselling mandated that some patients would have to attend three PHC facility visits before they could be initiated on ART, causing some delays. The implication being increased transport costs to the PHC facility, and increased time spent at the facility. This deterrent posed a barrier to prompt initiation of ART, as described by one participant:

> *"… as long as their CD4 is below 350, or they have been staged and they are stage 3 or stage 4, they are told that we have to start on ARVs. And counselling again is needed. Maximum of 2 sessions….Maximum of 3. And on the third day, we initiate." (Participant #H10)*

A study by Faal, Naidoo, Glencross, Venter and Osih (2011:58) conducted in South Africa, argues that health care workers and patients may perceive pre-ART care as less important than ART care.

Contrary to this perception, endorsing mandatory pre-ART sessions before ART initiation, demonstrates that health care workers identify this stage as being critical for future adherence to ART. One participant described how the facility attempted to expedite pre-ART counselling sessions, to avoid delays in ART initiation. She said:

"Let's say they came for counselling. They will go to the nurse counsellor, who counsels him and everything. Then they will go to lab. So what happens when they get to the lab, will depend on the queue that side and the day; what day is it. But if they have go to HTC [HIV testing and counselling], HTC doesn't take as much time as others. So they squeeze them in to see if they are reactive. They run the PIMA. While they PIMA is running, they will enrol and counsel the patient. By the time the CD4 result comes, they are in ongoing counselling. It takes about 20 minutes. So by that time they have done the physical exam, and have been counselled, by the time they come, because she has to determine there if she needs to prepare him for ART or continue him for Cotrim. So when the patient come he is in- between so it's simple. You just check the CD4. If it's below 350, you just counsel the patient towards ART." (Participant #H5)

With the likely increase in ART eligibility for Swaziland to a CD4 blood count of 500mm3, there will be increased numbers of pre-ART patients who need targeted counselling and support as they prepare for lifelong ARVs. This is particularly significant because patients with a high CD4 blood count may generally feel well, and may not appreciate the need for engaging in care, or for attending pre-ART counselling sessions (Faal et al 2011:58). Another factor that impacted the timing of ART initiation was the observed deterioration of health status. A Uganda study conducted by Siedner, Lankowski, Haberer, Kembabazi, Emenyonu, Tsai Muzoora, Geng Martin and Bangberg (2012:3), exploring the impact of pre-ART counselling sessions on ART, found that pre-ART counselling given before commencing ART was associated with delays in treatment initiation. However, this study also found that levels of adherence and viral suppression were high regardless of whether or not patients in the cohort received pre-ART counselling (Siedner et al. 2012:3). Another study conducted by Chung, Richardson, Tapia, Benki-Nugent, Kiarie, Simoni, Overbough, Attwa and John-Stewart (2011:4) looked at the effects of pre-ART counselling on adherence and virological failure. These authors found that patients who received pre-ART counselling had a higher CD4 cell blood count than those who did not. The study further describes how participants who received pre-ART counselling were 59% less likely to experience treatment failure (Chung et al. 2011:4).

One of the core components of pre-ART counselling is the assessment of patient readiness. This shall be discussed below.

b) Patient readiness

Patient readiness for utilising HIV services was frequently mentioned by the participants as a factor that influenced a patient's acceptability of HIV services, and timing of treatment initiation. When responding to the nature of patients' reactions to the disclosure of an HIV-positive test result, one participant expressed that:

> *"People have now accepted. Most of them because when you talk of initiation or if being on ART or adherence, most will say "anything that will make me be right." They are ready now. They have the readiness I think. It's rare to find someone who is very hard. They are now right." (Participant #H5)*

This was supported by another participant, who said:

> *"Aaaahh, it depends on the individuals. Others are ready, they know. They don't have a problem. They are very few who you find they take it badly." (Participants #H9)*

When asked what the facility was using to determine eligibility for ART, another participant responded with:

> *"Readiness!" (Participant #H3)*

Another participant believed that patient's readied themselves before coming to PHC facilities for HIV testing services, elaborating that:

> *"What I have noted: when somebody comes to test, they would have already counselled themselves. Do you know… And I have always thought that is the reason why once the result is positive, they are able to cope. Somehow their coping mechanism, it's not that bad. They easily accept. Though because yes it would come as a surprise. But the reason why somebody has come to test is… there is something they have picked. Something has actually promoted them for testing. And when they come they are expecting anything. Of course a positive result will obviously shock them, but the coping mechanism it's there." (Participant #H10)*

Similarly, another participant described:

> *"Others maybe had heard that there are testing services at this clinic. Or others we may have told that they needed to test, but they were not ready. Then when they are ready, they come to the facility."(Participant #H9)*

According to another participant, patients would sometimes come to the PHC facility for other services, but HIV testing would only occur when that patient was ready:

> *"Others have been treated for … STI. They come for treatment, but they don't want to test on that day. Then they return for … HIV test when they are ready." (Participant #H11)*

One participant described how patient readiness was a determinant to when a patient could be initiated on ART, saying:

> *"We start with the post-test, and we look at the readiness of the clients. We see how far is the readiness. We look at the readiness of the client and we ask them before if they are ready. They we can see if the client themselves are ready to start." (Participant #H5)*

Another participant shared a similar view:

> *"AAhhhh I think if you were just diagnosed today and you are eligible we start the same week. Maybe on Monday, you find that on Thursday we are starting. We don't wait. If somebody is ready… because we are initiating every day." (Participant #H7)*

According to another participant, the weight held by patient readiness was significant. She described how readiness formed part of the ART eligibility, as ART initiation could not proceed unless patient readiness was determined:

"…Because you feel that you go back and forth to ensure that this patient is ready. If then she is not, you feel that you did it justice, they will come again on another day." (Participant #H8)

This was supported by another participant, who felt:

"Or some of them they are just not yet ready to start ARVs. And some its provider initiated you have seen your client is sick. Because maybe you have seen your client is sick, they have fever, diarrhoea, they have herpes zoster. When you initiated the test as the health care provider. They do test, only to be shocked that they are positive. And when you start talking about ART initiation, they say they are just not ready." (Participant #H10)

One participant attributed missing PHC facility appointments to a lack of readiness for services. She expressed that:

"…there are few that will say, would turn up and say they were not ready." (Participant #H6)

Interestingly, one participant leant towards the belief that some patients are becoming increasingly desensitised to HIV, stating that:

"People still feel that HIV is far from them. They feel it is not with me." (Participant #H2)

This quote described how patients distancing themselves from HIV becomes a barrier because such patients do not adopt healthy behaviour or health seeking behaviour. Such denial may inhibit a patient who has tested HIV-positive to acknowledge the need for ART. Notably, in their Free State Province study that explored the outcomes of patients waiting for ART, Ingle et al. (2010:7) argued that most immune compromised patients will not survive the delays caused by the need for patient readiness training. These authors emphasised that although patient readiness improved patient adherence, it simultaneously increased waiting times. This was found to have adverse implications for patients who were immune compromised, who needed early

intervention and could not afford extended pre-ART readiness assessment counselling (Ingle et al. 2010:7). In the field notes, the researcher observed the amount of waiting done by the patients for ART services, including patient readiness assessments.

Another patient-centred barrier that emerged from the data was the mandatory need for a treatment supporter.

c) Need for a treatment supporter

A 'treatment supporter' can be defined as a person who directly observes a patient while they take their pre-ART and or ART medication until barriers to adherence are overcome (Swaziland Ministry of Health Integrated HIV Management Guidelines 2015:92). This is a person to whom a patient has disclosed their HIV status, and who is committed and willing to provide that patient with close and ongoing support in HIV care and treatment. One participant described how in the PHC facility there was a need for the pre-ART patient to return for a follow-up visit with their treatment supporter before they could be initiated on ART. This was done so that the PHC facility could ensure that the index patient had a close, reliable supporter who was committed to assisting, reminding and encouraging them along their treatment journey. She said:

> *"You need to give yourself time and be sure that everything that [the patients] were supposed to learn they learned, and that they came with a treatment supporter…You have talked so much that side, the treatment supporter has asked all their questions, and the patient themselves have also asked all their questions. On some days you feel so tired. You feel like after a single initiation, you just go and sleep. Because you feel that you go back and forth to ensure that this patient is ready. If then she is not, you feel that you did it justice, they will come again on another day." (Participant #H8)*

Another participant described the same, saying:

> *"Well there are those who say I will come back tomorrow, and then again the next day. But we feel that we want them to be at peace and rest. Because others have known their status for a long time, but are shocked by the CD4. They it's like their will be some kind*

of magic because of the ARVs. But 3 weeks does not finish before we have initiated them. If they come Monday and Wednesday…. Friday if they have a treatment supporter, then we will start them." (Participant #H7)

In one interview a participant described how, in the PHC facility, they were initiating one person onto ART per day. She identified the value of having adherence treatment supporter from the onset, who would journey with the patient through ART and be a significant source of support:

"…a rough estimate I would say, because we are not so many and I try to speak to having a treatment support. I am trying to speak to all the logistics of having a treatment supporter because of all the failures. So if there is no treatment support we try to talk to the patient to get at least an RHM) or somebody (Participant #H3)

She further described how the PHC facility attempts to expedite ART initiation services, despite the need for a treatment supporter. This was especially valuable where the patient was both ready and empowered:

"…a patient can be diagnosed today, and the patient will say I want to start this ART and we will talk to the patient, and we will ask the patient to bring a treatment supporter, at least to show that you have disclosed, and the patient can come back the following day. They will come with the Treatment supporter they understand it and they feel like nurse I want it. We don't waste their time" (Participant H3)

This participant validated the need for a treatment supporter as a critical mechanism to ensure adherence once treatment was initiated. She further argued that treatment support was undermined by gossip:

"If I didn't even have anyone at home. There is another lady who is initiated well because she said that, 'I will ask my neighbour, because the children that I stay with are young. But at least my neighbour will be able to check on me every day, and remind me.' This lady then came with the neighbour. But if it were one of the patients who heard something from someone, they would not be comfortable to come with their neighbour right? Even with the treatment supporter. People would have so many

supporters. People would have supporters any day if there was no one hearing any gossip. How come about hypertension. They don't gossip about diabetes." (Participant #H3)

In the earlier-mentioned study conducted by Fatti et al. (2012:54) in Uganda, it was found that patients who were attached to a peer support health care worker had improved virological outcomes, the longer they were on treatment. The absence of treatment support would mean that ART initiation could not take place. This requirement could pose a barrier to prompt initiation because of fears of being gossiped about, as described above. Coupled with the need for a treatment supporter, was the need for patients to attend mandatory pre-ART counselling sessions before initiation of ART. A randomised control trial conducted by Nachega, Chaisson, Goliath, Efron, Chaudhary, Ram, Morroni, Schoeman, Knowlton and Maartens (2010:5) in Cape Town, explored the treatment outcomes of patients who were initiating ART. The trial arm received Directly Observed Therapy (DOTS) for ART. DOTS was provided by a patient-nominated treatment supporter. The control arm did not receive this support. These authors found that at six months, the DOT-ART arm had a greater CD4 cell count increase than the baseline (Nachega et al. 2010:5). The study further found that death rates were at 6.6% for the DOT-ART arm; much lower than the control group, where it was 15.3% (Nachega et al. 2010: 5).

This study reinforces the anecdotes from the study participants, on the critical role that treatment supporters play in providing targeted support. It also emphasises the positive impact of having a treatment supporter for pre-ART patients before ART initiation. However, contrary to Fatti et al.'s (2012) study findings, Nachega et al. (2010:5) found that the presence of a DOT-ART treatment supporter had no impact on the undetectable viral load at twelve or twenty-four months.

The following identified themes were sources of support.

4.3.3 THEME 3: SOURCES OF SUPPORT

This theme explores the role that support plays in influencing prompt or delayed initiation of ART among eligible pre-ART patients. The concept of support was

identified by participants as a constant connotation throughout the interviews. This shall be explored further from two categorical angles: individual patient support and NARTIS nurse support.

4.4.3.1 Individual patient support

According to the participants, the level of support a patient receives may positively influence their health seeking behaviour. Patient-level support can be further explored in the following category:

a) Patient resources

Participants described pre-ART patients who are eligible for ART as having challenges of poverty. One participant described how patients in the PHC facility's area did not have money to come to the PHC facility. When asked why patients had not attended their PHC clinic appointments, she said:

> *"Others say they had no money." (Participant #H2)*

Another participant supported this, saying:

> *"OK, some of them complain about money... they say they don't have money to come to the clinic." (Participant #H9)*

According to one participant, a patient's personal resources, such as their funds and access to transportation, may have a direct impact on the timing of ART initiation. This was explained as follows:

> *"Also the socio-economic status of the people. I don't know what can be done because some you find they really don't have the money. They don't have the money. To come to the clinic. Then you find that it delays" (Participant #H7)*

In a study conducted by the Ministry of Health (2011:31) in Swaziland to evaluate the linkage to care within HIV settings, one of the two key reasons why patients did not enrol into HIV services, was because they believed they had to wait hours for

assistance from a health care worker at a PHC facility, and also because the facility was too far and the cost incurred to travel there was too high for their personal financial resources. This study reinforces what is described above by the participants.

Another participant indicated that patients' frequent movements due to unstable residential addresses make their retention in the continuum of HIV care in facilities difficult. One nurse expressed this, saying:

> *"Some you find that they are nomadic. They move from one place to another they are in South Africa, Lavumisa. Some because they are now well. They feel there is no need to be serious in taking their treatment." (Participant #H7)*

Nomadic behaviours as described in the quote above may be as a result of patient experiences of stigma and discrimination. The impact of stigma and discrimination on patient movement is also described by another participant, who said:

> *"I have had patients who have wanted to initiate, but have not wanted to initiate at this clinic, because there is the community around. So if they see them going into that room...They feel that people will see them. So they go and initiate somewhere else, and refill somewhere else." (Participant #H3)*

Unlike nomadic patients, patients who are resourced with a stable home environment and who access service from the same PHC clinic facility may face fewer challenges with earlier ART initiation. The UNAIDS (2014) report on the reduction of HIV-related stigma and discrimination argues that stigma and discrimination cause people to fear seeking information about HIV, about health services that may reduce their risk of transmission to HIV, and even fear to adopt safer practises in case these practices imply that they may be HIV-positive (UNAIDS 2014:1). These adverse health seeking behaviours that result from patient experiences of stigma and discrimination discourage earlier enrolment of eligible pre-ART patients into ART. In the Malawi study conducted by McGuire et al. (2010:60), stigma was found to be the biggest reason that patients defaulted from pre-ART.

The next sub-category identified by the researcher was non-disclosure.

b) Non-disclosure

'Disclosure' can be defined as the sharing of a patient's HIV status with another person (Swaziland Ministry of Health National Comprehensive Package of Care for Adults and Adolescents 2010:3). Disclosure could include a family member, partner or health care worker, who could, in turn, become the patients treatment support (Swaziland Ministry of Health National Comprehensive Package of Care for Adults and Adolescents 2010:19). Disclosure only occurs when the patient's or the caregiver's consent has been obtained (Swaziland Ministry of Health Integrated HIV Management Guidelines 2015:28). Participants cited non-disclosure as a critical barrier to prompt initiation. One nurse identified non-disclosure as a significant challenge faced by patients:

> *"Most of them react fine. They accept their status. The issue is disclosure" (Participant #H3)*

This quote underscores the fact that it may just be easier to live secretly with HIV than it would be to secretly take ARVs. Taking ARVs, a lifelong treatment with potentially noticeable side effects, and demanding a lifetime commitment to treatment adherence, could be perceived as much harder to hide. Hence, patients may not have grave concerns about their HIV-positive status, but may choose to delay initiation to ART because of the challenges of disclosure.

Another nurse provoked the thought:

> *"Sometimes you find that they have not disclosed. Maybe at home it becomes a problem to explain where they are going when they leave the home." (Participant #H9)*

While another expressed the impact of disclosure within the working environment:

> *"The bosses don't understand, and others have not disclosed, so it's hard to explain to them" (Participant #H8)*

Another participant offered the following scenario:

"Like LLAPLA [Lifelong ART for pregnant and lactating women] . Do you know LLAPLA? Challenge, she is pregnant. I do HTC right then. She is still crying because she has just discovered her status. The next thing you tell her about ARVs. It's just too much. It's just too much. Other mothers who were in Pre-ART have no problem. Because she knows, and her husband knows. She tells herself that she will simply tell him that she is also like him. But for those who tested just now, it's hard [to disclose her status]. Even yourself you would find it hard, regardless of what the guidelines say. But they leave, and then they do come back." (Participant #H8)

A similar finding is observed in a study by Abaynew et al. (2011:4), which stated that non-disclosure was associated with late presentation to HIV care. This study describes how patients who did not disclose their HIV-positive status to their partner were more inhibited in seeking further HIV-related services and were more likely to present in the late stage of the illness to the health facilities compared to those who had disclosed (Abaynew et al. 2011:4). Further, McGuire et al. (2010:60) also found that 50% of patients who were lost to follow-up had not disclosed their HIV status to the family members they reside with.

Non-disclosure may limit workplace support, which was another observed sub-category.

c) Workplace support

Participants described poor workplace (employer) support as a significant barrier to early initiation of ART among eligible pre-ART patients. They expressed that some employers and employment conditions make frequent visits to the PHC facility difficult. One participant articulated this in the following statement:

"Yet there is also this issue of the employer not affording them ample time to go to the clinic. Even if you go back with a sick note, that you have been seen and attended, they will not even accept that…The employer … it difficult for them to ask for days to come to the clinic. And the majority of them are actually complaining. That is the reason why you find that with most clients who start at 8, we open at 7 o clock. You find them

coming early, so that by half past seven, or quarter to eight they are done and they go to work. I just don't know what we can do. It's not easy, it's really not easy." (Participant #H10)

Another participant described patients' working conditions as a possible reason they miss appointments, saying:

"Ok maybe sometimes its work problems. They don't receive the support at work." (Participants #H7)

This was supported by another participant, who said:

"Firstly it's where they work, they are not allowed. Either it's in the forest or in the kitchens. The bosses don't understand, and others have not disclosed, so it's hard to explain to them…Others work far, like in South Africa. So they can't come back on the date." (Participants #H8)

One participant felt that work-related commitments were the cause of ART initiation delays, saying:

"Normally we aim at initiating our clients within 2 weeks, we don't want to delay. If you find a client is initiated 2 or 3 months down the line, its normally them who want the delay because of work related commitments most of them. We call them they tell you eish, they can't release me at work." (Participants #H10)

In a study that explored employment discrimination and HIV stigma in Africa, Sprague, Simons and Sprague (2011:1) argue that there are high levels of employment discrimination based on HIV status. In Zambia and Kenya in particular, the study found that people living with HIV were faced with discrimination in hiring, loss of promotion and termination of employment because of their HIV status. The quotes shared by the participants, however, were more expressive of employers not wanting to allocate *time* and *support* to employees to seek health services, rather than it being because of their HIV status.

A participant proposed a recommendation emanating from observed challenges with patient employment demands by stating:

> *"Another thing I think, labour laws. So that when people need to come to the clinic, they allow them at the workplace. Because you find that many clients are held up by that. Others cannot leave work. They report that their bosses said no, so they remained at home." (Participant #H7)*

Where patients are engaged in informal employment, time spent waiting for services at the PHC facility may result in direct deductions from their salary. This means that the decision to attend services at the PHC facility can often be a financial one, rather than a health one. The TB-HIV co-infection study conducted in Zimbabwe by Mavhu et al. (2010:576) contend that in weak functioning health facilities, the cost incurred by the patient for seeking health services may not correspond to the quality of services rendered. According to the authors, participants in their study preferred to use the little money they had to get food for their children, rather than for seeking health services (Mavhu et al. 2010:576).

The second category identified under sources of support was NARTIS nurse support.

4.3.3.2 Limited NARTIS nurse support

This category describes the limitations in various types of support of NARTIS nurses that were identified by participants during the semi-structured interviews. The sub-category that was identified under this category was resource shortages.

a) Resource shortages

Staffing support was seen by participants to affect the NARTIS nurses' ability to adequately provide support to their patients. NARTIS nurses who were based in PHC facilities with less staffing experienced more workload burden within the workplace. This was an encumbrance to the level of support and care the nurse could provide to the patients.

Throughout the semi-structured interviews, the issue of resources is apparent. Participants make reference to resources that they need to improve their working conditions. Resources that were identified by the participants included PIMA machines, mini-labs, additional staffing and transportation. One of the participants stressed:

> *"We also need a mini-lab. So that the results can come back quickly... because sometimes you have to look at the chemistry, how the liver, how is the kidney. Before we can start." (Participant #H7)*

In a study by Pfeiffer, Montoya, Baptista, Karagianisa, Pugas, Micek, Johnson, Sherr, Gimbel, Baird, Lambdin and Gloyd (2010:6) on the integration of HIV/AIDS services into Africa's primary health care, shortages in the workforce are argued to be the single greatest impediment to the effective scale-up of HIV services. Often when PHC facilities face staff shortages, selected service delivery responsibilities are shifted to lower level cadres. Although this is coupled with the provision of the relevant training and building of capacity, it can lead to overburdening of staff and potential compromises in quality of care (Pfeiffer et al. 2010:7). Supported by this study, some participants requested additional staffing as the ingredient that would improve their working conditions. A participant stated:

> *"We need 3 more NARTIS nurses trained. Especially because if one is gone, the others are burdened." (Participant #H2)*

Staff shortages meant that nurses had to adapt their scopes of work to meet the patient demands, as articulated by a participant, who said:

> *"We no longer have [staffing for home visits]. The RHMs were complaining about that… saying that nurses don't visit them. But we can't. Also before, we used to have motorbikes for home visits, now there is nothing. When [nurse name] came, he said that he would be the Community Nurse, but also him, he is seeing patients. He will go [to work in the community] and leave them [the patients] with who?" (Participants #H8*

Another participant described how, even though they may have an adequate number of staff, not all of them are in the PHC facility providing services at the same time:

> *"Yes but you see today we are 2? One is at a workshop, we are never a complete number. It's not common that all of us are here" (Participant #H7)*

Participants also described how their PHC facility could not conduct follow-up of patients in their communities because of staff shortages:

> *"Even the Community. We need someone who could be in the community and encourage them to come. There are those who need someone in the community to encourage them." (Participant #H4)*

This is echoed in a study conducted by Celletti, Wright, Palen, Frehywot, Markus, Greenberg, Teixeira de Aguiar, Campos, Buch and Samb (2010:46), who argue that human resource shortages in health care are significant bottlenecks. This study explored community health worker cadres in HIV care services as a solution to staffing shortages. The study advocates for the strengthening of human resources for health as critical for universal coverage of HIV (Celletti et al. 2010:46).

Participants felt that a stand-alone ART unit that exclusively provided ART services by a full-time ART nurse would significantly reduce the workload burden. A participant stated:

> *"There is also such a burden of clients. They workload is just high, we can't initiate people. It needs to be quiet. We need 3 more NARTIS nurses trained. Especially because if one is gone, the others are burdened. We need an hour to initiate per patient. NARTIS should be stand alone. A separate clinic, with its own nurse. Then this nurse can focus on this and not be running to ANC [Antenatal Care]. Then you would even have time to crack jokes and to talk. Now it's just a give and take." (Participant #H2)*

Being overloaded with nursing responsibilities was also seen to compromise the efficiency of services. This was clear in one facility, where the participant expressed the inefficiency of processes which had resulted from staff shortages:

> *"If we were well staffed. If we knew that me I am here. I am responsible for child welfare and leave family planning. On the ART side, there would be a nurse that is responsible only for ART. That would be so much better. And its makes the work suit us. Because now nje, a women who comes to me, she comes for family planning. She has a child who is sick. This child needs a refill or NVP and CTX. The mother herself is also refilling. It requires that if she has come on a Tuesday, the day to take bloods, I have to buzz [nurse name] to bring me her file from that room, with her number. Then at the end of the day they bring the file in an envelope. So that it leaves here and goes straight back. After whatever minutes, I have to stand up and go to the phleb for bloods. So we need someone who can just focus on ART." (Participant #H8)*

Throughout the semi-structured interviews, participants were quick to identify resources that they would need to enable a perception of improved working conditions. Because nurses are generally aware of what "resource luxuries" other PHC facilities have, these shortages become a source of demotivation, demoralisation and burden. Participants who lacked on-site access to resources such as PIMA machines or other laboratory testing devices expressed frustration at the negative impact this limited support had on their ability to provide services to their patients, including the prompt initiation of ART for eligible pre-ART patients. One participant expressed considerable frustration with the poverty of resources within his working environment, saying:

> *"…I would be very happy to have a PIMA, because then we could take bloods daily. Also a Gene Expert. And more personnel. We need more people to test people for HIV, and a phlebotomist to take bloods. To be onsite. Because the sample transportation comes at 9am. Because of problems of transport, many people are not here by then. To take bloods. So it means that they have to return on another day." (Participant #H11)*

4.4 FIELD NOTES: OBSERVED ENABLERS OF THE SWAZILAND HEALTH SYSTEM

The researcher recorded field notes, such as observations and reflections, in a notebook.

The field notes that were taken by the researcher were of observations made when visiting the health facilities to conduct the interviews. These notes highlighted things that were not necessarily captured during the semi-structured interviews, but these were recorded by the researcher as interesting, thought provoking and relevant to the research topic.

During the PHC facility visits to conduct the semi-structured interviews, the researcher took field notes of observations around the free service provision, and the PHC facility tools. These shall be described below.

4.4.1 Free services

It was noted by the researcher in the field notes that most facilities offer free services. This meant that patients did not have to source funds for the consultation at the PHC facility as a prerequisite to receiving services. Consultation fees, therefore, posed no barrier to health services and created an enabling environment to access health care. This is key in terms of the initiation of ART amongst pre-ART patients, who would be able to access free services and need not worry about the consultation fees that may be imposed for ongoing refill visits. Further, this is a crucial enabler that the Swaziland Ministry of Health has implemented for service uptake. It is especially important as recent studies have found that those receiving ART in PHC facilities that provide it free of charge have significantly lower mortality than patients from clinics where a fee is charged (Lahuerta et al. 2013:370).

Other observations recorded by the researcher was around the availability of registers in the PHC facility.

4.4.2 Availability of registers

In all the PHC facilities the researcher noted the presence of patient follow-up registers such as the facility appointment register and the call log register. These tools assist in contacting eligible pre-ART patients, and enable patient tracing intervention.

Chronic care files to document patient services were noted as an enabler for early initiation of ART. Registers, such as the Appointment Registers, were used to track and follow-up on eligible pre-ART patients who had missed appointments. Patients who had tested positive for HIV, and were awaiting CD4 cell count results (in order to determine eligibility to start ART treatment) and were lost to care, could be tracked using this tool. The call log was used to monitor cell phone airtime usage and replenishment.

4.5 CONCLUSION

In this chapter, a description of the themes that the researcher identified during the semi-structured interviews with participants was presented. These themes were systematic enablers of prompt ART initiation, barriers to prompt ART initiation, use of agency, and sources of support. These themes were further segregated according to categories and sub-categories, which were discussed in this chapter, and reference has been made to studies that were conducted around similar thematic areas.

In this chapter, the data that was collected from the semi-structured interviews has been presented and interpreted. Themes, categories and sub-categories derived from the data was discussed, and literature control to these findings were demonstrated. In the following chapter, the research recommendations and limitations will be discussed.

CHAPTER 5
CONCLUSIONS, RECOMMENDATIONS AND LIMITATIONS

5.1 INTRODUCTION

The aim of this research was to enhance the understanding of factors that influence non-initiation of ART amongst pre-ART eligible patients and to increase the prompt initiation of ART for eligible pre-ART patients in rural PHC facilities in Swaziland. This research was conducted with the aim of addressing the following objectives:

- To explore and describe factors associated with non-initiation of ART among eligible pre-ART patients in rural PHC clinics in Swaziland.

- To make recommendations for health care workers to enhance early initiation of ART amongst eligible pre-ART patients for PHC facilities in Swaziland.

There are limited studies that focus on pre-ART patients and the timing of treatment initiation in Swaziland. This research gave insight into some of the critical factors that delay the initiation of eligible pre-ART patients onto ART. The participants provided a contextual landscape of the current processes for ART initiation amongst eligible pre-ART patients in their rural PHC facilities. They shared their insights on the factors that positively or negatively influence ART initiation. The participants also shared their views on what would be required for prompt treatment initiation. These contributions informed the recommendations that will be described in this chapter.

5.2 CONCLUSIONS OF FINDINGS

The objective of this research was to explore the contributors and influencing factors that ultimately lead to delays in ART initiation amongst ART-eligible patients. This objective was explored through drawing from a purposively sampled selection of NARTIS nurses, who were working in PHC facilities in Swaziland. The PHC facilities ranged from government facilities, NGO facilities, and mission facilities. The majority of participants were female (82%). Duration of employment within the PHC facility to

which they were employed ranged from one year to fourteen years, bringing the average to seven years. They reported initiating anything from one to thirty patients on ART per month, bringing the average to fifteen patients a month. Most (27%) were initiating eleven to fifteen patients on ART each month.

In traversing this area through semi-structured interviews with NARITS nurse participants, the researcher identified themes, categories and sub-categories that classified the emerging views and perceptions of participants on the research objectives. The conclusions that were reached were based on the following research questions:

- What are the factors that might contribute to non-initiation of ART amongst eligible pre-ART patients at rural PHC clinics in Swaziland?

- What recommendations can be made for health care workers to improve the initiation practices of ART for eligible pre-ART patients at rural PHC clinics in Swaziland?

Both the factors that might contribute to non-initiation of ART amongst ART-eligible HIV-positive patients and the recommendations for improved ART initiation practises, will be addressed below.

5.2.1 Research question 1: What are the factors that might contribute to non-initiation of ART amongst eligible pre-ART patients at rural PHC clinics in Swaziland?

Primarily this research has found that there are both enablers and barriers to prompt ART initiation. The enablers referred to existing advantageous health system structures that can facilitate punctual initiation of ART amongst eligible pre-ART patients. This included both PHC and community level factors, encompassing service availability, MDT approach, health education, patient factors, and community-based outreach support.

The barriers involved existing health service provision processes that functioned as perpetual hindrances to prompt ART initiation. This included both the interdependence of the health system factors and patient-centred factors, encompassing weaknesses in laboratory processes, the compulsory prerequisite pre-ART counselling sessions, the need for a treatment supporter, patient readiness, and health status.

The enablers involved health system factors and community factors. Barriers included the interdependence of health systems, and patient-centred factors. All of these factors contributed to some degree to the patient ART initiation timing and process.

5.3 RECOMMENDATIONS

The recommendations that were derived from the data from this research were based on the second research question.

5.3.1 Research question 2: What recommendations can be made to improve the timing of ART initiation amongst eligible pre-ART patients at rural PHC clinics in Swaziland?

After conducting semi-structured interviews with the participants and exploring and describing factors associated with non-initiation of ART amongst eligible pre-ART patients for PHC facilities in Swaziland, definite recommendations emerged. NARTIS nurse participants in the sample generally found that although tremendous efforts have been made by the Swaziland Ministry of Health to promptly initiate eligible pre-ART patients on ART, levels of enrolment into ART are not as high as they could be. Through their feedback, a review of current literature, and the researcher's observations, the following recommendations were proposed in order to address this perpetual interlude.

5.3.2 Recommendations to improve practice

The following recommendations emerged from the research through the data from the semi-structured interviews.

5.3.2.1 Continued HIV scale-up

As long as patients in the pre-ART phase are predisposed to increased levels of mortality and mobility, prompt treatment initiation will always be critical. Delays in ART initiation seems to continue, as reflected by the study findings, despite all the interventions that the Swaziland Ministry of Health has implemented. It is, therefore, recommended that the Ministry of Health, partners and stakeholders continue efforts to aggressively scale-up HIV services, and create demand for increased uptake of HIV services, as a catalyst for prompt ART initiation. This is especially necessary in light of the newly released Integrated Management Guidelines, which increases ART eligibility to a CD4 cell count of 500mm3 (Swaziland Ministry of Health Integrated HIV Management Guidelines 2015:18). It is also critical in view of the new guidelines stipulation that all children under the age of five years are to be initiated on ART treatment, regardless of their CD4 cell count (Swaziland Ministry of Health Integrated HIV Management Guidelines 2015:19). Both these new regulations will result in the enlargement of the volume of pre-ART patients needing ART services. In the face of limitations in absorptive infrastructure capacity and staff shortages eluded to in the semi-structured interviews, this may only add a burden to already overwhelmed health care workers providing critical services within rural communities. As such, health facilities need to have the absorptive capacity to accommodate these anticipated high patient volumes. Lahuerta et al. (2013:367) echoes this recommendation in her study, emphasising the absorptive capacity of the health care system to meet the overwhelming demand for treatment through scale-up and decentralisation. This was also recommended by the participants, who felt that they needed the support of adequate training and capacity building of the PHC facility staff.

Currently, health care workers such as nurses, expert clients and community workers are using forums such as daily health talk's and one-to-one counselling sessions to promote service uptake for ART. It is further recommended that health care workers can use empowered clients to encourage service uptake within their families and communities; prompting others to begin treatment as early as possible, and avoid unnecessary and disadvantageous delays.

5.3.2.2 Standalone ART services

During the semi-structured interviews, participants often eluded to the challenges they face with staff shortages within the PHC facility. They felt that this compromised their ability to provide quality comprehensive ART services and may delay ART initiation of pre-ART patients who are eligible for ART. Some patients felt that the ART services took a lengthy amount of time, often to the detriment of other services. The processes for patients who were being initiated on ART took a considerable amount of time and just added to their burden of work. This is further compounded by the fact that in some PHC facilities nursing numbers were often reduced by colleagues being on leave or being away on workshops and training. This birthed the recommendation that ART become a standalone service. This notion was encouraged by a participant who advocated for standalone ART units, supported with adequate staffing to meet the demands of patients enrolling into pre-ART care or ART treatment. It is recommended that nurse staffing numbers per PHC facility be reviewed, and that systems of rotational short-term nursing placements be implemented to fill the gaps in ART service delivery when colleagues are attending training or are on leave. It is further recommended that non-monetary incentives such as compensation time for weekends worked, extra credits earned with the Swaziland Nursing Council for overtime hours worked, and supportive supervision from partners and stakeholders, for example, should be provided to nurses to alleviate low levels of morale and overburdened feelings.

5.3.2.3 Stronger engagement of Treatment Supporters

A Treatment Supporter is an immediate source of support to patients commencing ART. Treatment Supporters offer targeted social support, which positively influences behaviour change and psychological well-being (Nachega et al. 2010:7). Participants discussed the need for patients to return to the PHC facility with a Treatment Supporter as a prerequisite for ART initiation. It is recommended that *active* Treatment Supporter engagement at the PHC health facility begins at the point of testing positive for HIV. A Treatment Supporter's role would be more of a personal adherence supporter, intimately and uniquely supporting the patient's journey from testing for HIV, and cascading through to enrolment into pre-ART, initiation onto ART, all the way to the

attainment of viral suppression. This would include, for example, accompanying patients on pre-ART PHC facility visits, providing support and encouragement to the patient when outside of the PHC facility, identifying unique challenges the patient might face with treatment initiation, and being the entity that provides relevant feedback to the PHC facility about the patient's health progress. Treatment Supporters could further address patient-centred barriers to treatment initiation. The significant impact of patient attachment to a Treatment Supporter is further reinforced by the Swaziland National ART Programme Evaluation *SNAP-E* of 2012, which found that a patient's engagement with a Treatment Supporter had a positive correlation to retention in ART care (SNAP-E 2012:32).

5.3.2.4 Community Expert Clients as agents of community-based outreach support

The National Expert Client (EC) Programme was initiated in Swaziland in October 2007 (SNAP 2008:1). An EC is an individual who is living with HIV, who is on ARVs and is also adhering well to treatment. The objective of the programme was to complement the role of health care providers and play an important function in improving adherence and overall quality of services (SNAP 2008:1). One of the fundamental responsibilities of ECs is to model positive, healthy living and to address fears around HIV testing and ART initiation by demonstrating how to live happily and productively with HIV. The EC Programme was aimed to facilitate increases in enrolment into HIV care and treatment of all adult and paediatric patients, and also to decrease the number of adult and paediatric patients who discontinue treatment or are lost to follow-up in the National ART and PMTCT Programmes (SNAP 2008:1).

Some of the NARTIS nurse participants in the sample felt that the presence of a Community Expert Client (CEC) in their facility could be a significant enabler for getting eligible pre-ART patients quickly initiated on ART. CECs are expressly tasked with the follow-up of pre-ART patients who do not return to the PHC facility on the appointed dates. They work predominantly in the communities, providing household level adherence and psychosocial support services to defaulting patients, with the aim to return them to HIV care delivered at the PHC facilities. PHC facilities with CECs are more equipped to provide community level adherence support, to follow-up patients

quickly, and to facilitate that the patient barriers to returning to the PHC facility are swiftly addressed, so that enrolment into and initiation of ART treatment can begin. The participants' recommendations are echoed in an observational multi-cohort South African study by Fatti et al. (2012:56) of 66 953 patients enrolling into ART, comparing outcomes for those receiving Community Based Adherence Support (CBAS) of 19 668 to a control group of 47 285. This study found that retention after five years for CBAS patients was 79.1% and for non-CBAS patients was 73.6%, and that loss to follow-up rates were 13.2% for CBAS patients compared to 17.7% for non-CBAS patients (Fatti et al. 2012:53). These authors (Fatti et al. 2012:56) also argued that patients who were receiving CBAS had improved outcomes.

5.3.2.5 Laboratory systems strengthening: PIMA machines and mini labs

Many of the participants highlighted challenges of not having a PIMA POC device on-site. As a result, blood samples would be collected by the National Sample Transportation vehicles and taken to a central, larger, more equipped laboratory. They strongly recommended having PIMA machines in all PHC facilities in the country, bringing laboratory services closer to the community. Participants felt that a PIMA machine would alleviate many time delays and enable them to better support the patients in terms of earlier enrolment into ART treatment. Similar sentiments were resonated in a study by Mtapuri-Zinyowera et al. (2010:5) hat evaluated the PIMA POC CD4 analyser in VCT PHC clinics in Zimbabwe. These authors found that having a PIMA device on-site improved access to screening services for HIV, and ensuring HIV care and treatment services: by shortening turnaround time for results, and reducing multiple PHC clinic visits often mandated by the test process and return time to the PHC facility (Mtapuri-Zinyowera et al. 2010:5). The PIMA POC device may strengthen patient follow-up, reduce levels of patient loss to follow-up, facilitate treatment prioritisation for patients with determined low CD4 cell counts, facilitate earlier enrolment into ART, and produce improved patient outcomes (Mtapuri-Zinyowera et al. 2010:6).

Some participants highlighted that a PIMA POC machine was not the only diagnostic testing device needed to determine whether or not a patient could be started on treatment. They emphasised that there was also a need for blood tests such as Liver

Function Tests (LFT) and Full Blood Count (FBCs). Thus, they recommended having mini-labs on-site, inclusive of reagents. Having mini-labs on-site would remedy PHC facility challenges of over-reliance on the NST vehicle, which only operated under the mandate of stringent schedules and limited PHC facility coverage. This would require policy level budgetary commitments to always have adequate supplies of reagents in the mini-labs, and to equip the PHC facilities with the on-site laboratory resources they need to enrol eligible pre-ART patients on ART as early as possible.

5.3.2.6 Laboratory systems strengthening: the national sample transportation system

Throughout the semi-structured interviews, participants made reference to the challenge of the National Sample Transportation (NST) system. It was highlighted by participants that the NST were frequently confronted with difficulties of them not being able to arrive at the PHC facility at the scheduled time. Because many participants were wholly reliant on this vehicle for laboratory services, these challenges would often result in patients not being initiated on time. Analogous challenges are cited by Justman et al. (2009:32), who explored laboratory systems and infrastructure development for HIV scale-up. The authors highlight that challenges in national transportation systems often include resource limitations for courier services, cold chain prerequisites, delays and interruptions in transportation, adequate space for storing samples, and poor tracking systems (Justman et al. 2009:32).

It is recommended that a budgetary commitment is made to strengthen the NST, at policy level. This includes a financial commitment to provide routine maintenance of NST vehicles and laboratory equipment, communication support (to inform facilities as early as possible of changes in sample collection and delivery status), and the development of on-going tracking systems. Justman et al. (2009:32) further recommend solar powered refrigerators for facilities to store lab samples as an innovation that proved successful in Nigeria; and also having standard laboratory inventory systems (Justman et al. 2009:32). These authors' (Justman et al. 2009:32) most critical recommendation to strengthen laboratory services, however, was that central, more equipped laboratories should be synergised with facility based Point of Care systems. Laboratories would conduct the more complex laboratory diagnostics

and PHC facilities would conduct more frequent, basic laboratory tests; both complementing each other and essentially resulting in less requirements for NST to ferry both complex and basic sample results to each and every PHC facility in the region. Another recommendation was made around PHC facility processes.

5.3.2.7 PHC facility processes

Many of the PHC facilities reported operating from Monday to Friday. A recommendation would be that PHC facilities adapt their operating times (e.g. hours, days) to accommodate those patients who are restricted by working day hours, with an aim to increase service uptake. This is further recommended by Lahuerta et al. (2013:370), who highlighted that limited PHC facility days and hours could hinder enrolment, retention and appointment adherence for some patients. If PHC facilities were to open on weekends, for example, they might better support people who face inflexible working conditions and cannot spend too much time in the PHC facility.

Another critical recommendation is to initiate ART on the date of diagnosis.

5.3.2.8 ART initiation on determination of HIV-positive diagnosis

Some of the research participants cited the multiple compulsory pre-ART counselling sessions, a prerequisite for ART initiation, as a major challenge to the treatment initiation processes. The Swaziland Integrated HIV Management Guidelines (2015) encourage that ART-eligible patients “should be initiated as soon as possible, preferably on the same day of the HIV-positive diagnosis, while adherence counselling is ongoing” (Swaziland Ministry of Health Integrated HIV Management Guidelines 2015:69). It is recommended that as the country implements these guidelines, the focus should be shifted *away* from providing multiple pre-ART counselling sessions, and more to a single high-quality counselling session to be given on the ART initiation visit. This would be adopting the current local practice of ART initiation for pregnant women through Life Long ART for Pregnant and Lactating Women (LLAPLA), discordant couples, and for children under five years of age. It necessitates the provision of reliable counselling services, addressing all the unique counselling needs

of patients, and a strong patient understanding of why they should enrol in ART, especially if they are feeling well.

5.3.3 Recommendations to enhance policy and programme development

Some of the recommendations emerging from the data-informed policy design and programme development. These recommendations would then steer implementation to ensure that it is targeted, relevant and effective.

5.3.3.1 Patient centred approached to HIV service uptake and treatment initiation

It is a further recommendation that in adopting this aforementioned robust approach, efforts should also be aimed to address the indifference and the desensitisation to HIV that often leads to delays in ART initiation. This is also resounded in a study conducted in Kenya by Karau et al. (2014:67) that looked at the responsiveness to HIV education and VCT services amongst Kenyan rural women. These authors describe how after almost thirty years of aggressive campaigning against HIV through the media and the Kenyan government, their HIV testing numbers remained low.

Overcoming patient-centred barriers to ART initiation such as indifference, desensitisation and fear, could be facilitated by the development of forums such as routine facility-based support groups and peer support systems. These forums provide patients a safe and confidential opportunity to share their honest reservations around testing for HIV, or around being initiated on ART. These forums could give health workers the insight they need to develop targeted, relevant, impactful and supportive patient-centred interventions. These strategies could be incorporated into messaging tools, job aids, and printed information, such as educational and communication materials. They could also be addressed during one-to-one counselling sessions in pre-ART, unearthing reasons as to why patients may still resist enrolling into ART services despite having been exposed to ART information and counselling. Patient experiences with issues of disclosure, stigma, discrimination, support and socio-economic background, for example, are unique. So providing general, blanket

interventions may have limited effectivity. The recommendation of patient-centred strategies and packages addresses this.

This research highlighted the cavity in local, recent research pertaining to non-initiation of ART while in pre-ART care. The recommendation for locally derived evidence-based findings that can further inform programming and implementation emerged from the data. This will be described below.

5.3.4 Expansive local research

During the literature review and control, the researcher identified a scarcity of previous research conducted in Swaziland that looked at the timing of treatment initiation in pre-ART patients. This gap in literature highlighted that more research needs to be conducted in this particular area. Although the National ART Programme Evaluation *SNAP-E* (2012) followed a retrospective cohort from 2004 to 2010 to determine treatment outcomes for HIV-positive adults (SNAP-E 2012:1), there remains a need for more recent, locally conducted research. This can inform the most recent interventions, and evaluate their effectiveness in getting patients on treatment earlier. In a randomised control trial conducted in Haiti by Lahuerta et al. (2013:365), it was found that mortality rates can remain high even after ART initiation, especially where ART initiation occurred when CD4 cell counts were very low. This study cited a four-fold higher risk among those for whom ART initiation was delayed until after CD4 cell counts dropped below 200 cells/mm3, compared with those who started with CD4 counts between 200-350 cells/mm3 (Lahuerta et al. 2013:365).

In addition to research, another recommendation emerging from the data was the need for more supportive labour laws that enabled earlier initiation to ART amongst eligible pre-ART patients.

5.3.4.1 Supportive labour laws that enable health-friendly working conditions

Currently in Swaziland, patients attending PHC facilities during the week are given a sick note to present to the employer when they resume work duties. However, due to weak labour laws, employers are not bound by law to retain employees simply

because sick notes have been produced. Further, as some workers are paid on a daily rate, absence from work causes direct deductions from their monthly income. Because of these factors, some PHC facilities in the study were modifying their hours or days of operations: some were expediting health services for their employed patients, hence, the recommendation that surfaced during this research was for PHC multidisciplinary teams to create linkages with organisations and institutions that champion employer wellness, and advocate for employer health rights. Ideally, as a country, there is a need to enforce more supportive labour laws that pose no threat to employment status because of health status or commitments.

5.4 LIMITATIONS

The researcher identified some limitations while conducting this research. These are discussed below.

5.4.1 Negative health worker attitudes

Negative health worker attitude has often been cited as having impediments on patient care. Although this did not emerge in this data, it could be a possible limitation as participants could not always be honest about the impact of their attitude towards patient behaviour, especially if it was negative. Nurses' negative attitude towards patients may affect their level of adherence to PHC facility appointments and may have a bearing on their health seeking behaviour. This includes behaviours around ART Initiation.

5.4.2 Generalisability

A limitation of this study is that findings cannot be generalised. This is pertinent to most qualitative studies. However, because this study was contextual, it has provided a comprehensive description of the research setting, the data collection methods and the detailed data analysis, for the benefit of other researchers who may be conducting similar studies in the future.

It is also the researcher's hope that the study findings can be beneficial to provide support to ART patients seeking services at PHC facilities. In terms of the use of the study findings, the researcher hopes that these findings will positively impact future policy and planning to enhance ART initiation.

5.5 CONCLUSION

Through this research, the researcher aimed to highlight the factors associated with the non-initiation of ART amongst eligible pre-ART-eligible patients. This researcher did this through purposively sampling NARTIS nurses in one of the regions of Swaziland. These NARTIS nurses were fully informed of the research and invited to become participants. Participants provided informed consent for enrolment into the research. The researcher used semi-structured interviews as a tool to gather data around this research question. Thematic analysis of the data was done using Tesch's eight steps of open coding for qualitative studies, and the findings were discussed with a literature control in Chapter 4.

This research also aimed at making recommendations for health workers to enhance early initiation of ART among eligible pre-ART patients at PHC facilities in Swaziland. The twelve recommendations that emerged from the data have been proposed in light of recent and relevant literature. Some of these recommendations include continued HIV scale-up, strong engagement of treatment supporters, community expert clients, positive sexuality dialogue, laboratory systems strengthening, patient-centred approaches to HIV services uptake and treatment initiation, supportive labour laws, and research.

In an ideal world, there would be no lags between pre-ART eligibility and ART initiation and all patients who needed lifelong ART would be timeously initiated on it. As a country, Swaziland has made great strides in endeavouring to enable this, but there is still much that can be done to improve and strengthen the current processes. Prompt ART initiation for all will require commitments from patients themselves, from the health care workers, and strongly demonstrated political and financial commitments from the government of Swaziland to make this possible. The researcher hopes that

this study will shed more light on how Swaziland can reach this ideal standard. As Tata Mandela once said, *everything seems impossible until it is done.*

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ANNEXURE A

LETTER TO HHOHHO REGIONAL MATRON, SWAZILAND

P.O. Box 1459
Mbabane
Swaziland, H100

Hhohho Regional Matron
Ministry of Health
P.O. Box 5
Mbabane

7th January 2015

Dear Matron Lillian Simelane,

Re: Request to conduct my Masters degree research in Primary Health Facilities in the Hhohho Region, Swaziland.

My name is Nosipho Gwebu Storer. I graduated from the University of Cape Town (UCT) in 2003, where I was awarded a Bachelor of Social Science degree in Psychology. I subsequently completed my Honours degree in Psychology through the University of South Africa (UNISA). Currently I am enrolled in UNISA pursuing my Masters Degree in Public Health. I am currently employed as the Adherence, Psychosocial Support (APS) and Linkages Advisor for ICAP in Swaziland.

I am writing this letter to request to conduct my Master's research at 10 randomly selected Primary Health Facilities in the Hhohho Region. My research proposal is entitled ***"Factors contributing to non-initiation of ART amongst eligible Pre-ART patients in rural clinics in Swaziland."*** To conduct this research, I will use a semi- structured interview guide to be conducted amongst NARTIS trained nurses. Through this research, I will explore the reasons why patients who are eligible for ART by CD4 or by WHO Clinical Staging, are subsequently not initiated on ART.

I have recently been granted approval from the University of South Africa (UNISA), to conduct this study (please see Ethical Clearance Certificate enclosed). My research protocol, along with all the relevant supporting documents, will be submitted to the South African Clinical Review Board, the South African Ethical Review Board and the Swaziland Ethical Review Board for approval.

Thank you in advance for your consideration of my request. I look forward to hearing from you.

Sincerely,

Nosipho Gwebu Storer

Tel: 2404 5797
Cell: 7614 8279

Cc:	Sister Bonsile Mkwanazi,	Clinic Supervisor, Hhohho South
	Sister Dudu Dlamini,	Clinic Supervisor, Hhohho North
	Sister Gule,	Clinic Supervisor, Hhohho North under Nazarene Clinics

ANNEXURE B

LETTER OF PERMISSION FROM HHOHHO REGIONAL MATRON

Telegrams:
Telex:
Telephone: (+268 404 2431)
Fax: (+268 404 2092

MINISTRY OF HEALTH
P.O. BOX 5
MBABANE
SWAZILAND

THE KINGDOM OF SWAZILAND

P.O. Box 1459
Mbabane
Swaziland

7th January 2015

Dear Ms Nosipho Gwebu Storer

Re: Request to conduct your research at primary Health Facilities in the Hhohho region.

Thank you for the request you made to conduct your Masters research entitled "***Factors contributing to non-initiation of ART amongst eligible Pre-ART patients in rural clinics in Swaziland.'***

In light of the importance of this study, you are granted the permission focus your thesis on this specific clinic facility. We wish you all the best with your thesis submission to the relevant Ethics Committees and Review Boards for the approval of your study.

Warm regards,

LILLY SIMELANE
HHOHHO REGIONAL MATRON

ANNEXURE C

LETTER TO HHOHHO REGIONAL HEALTH ADMINISTRATOR

P.O. Box 1459
Mbabane
Swaziland, H100

Hhohho Regional Health Administrator
Ministry of Health
P.O. Box 5
Mbabane

7th January 2015

Dear Mr M. Khumalo,

Re: Request to conduct my Masters degree research in Primary Health Facilities in the Hhohho Region, Swaziland.

My name is Nosipho Gwebu Storer. I graduated from the University of Cape Town (UCT) in 2003, where I was awarded a Bachelor of Social Science degree in Psychology. I subsequently completed my Honours degree in Psychology through the University of South Africa (UNISA). Currently I am enrolled in UNISA pursuing my Masters Degree in Public Health. I am currently employed as the Adherence, Psychosocial Support (APS) and Linkages Advisor for ICAP in Swaziland.

I am writing this letter to request to conduct my Master's research at 10 randomly selected Primary Health Facilities in the Hhohho Region. My research proposal is entitled ***"Factors contributing to non-initiation of ART amongst eligible Pre-ART patients in rural clinics in Swaziland."*** To conduct this research, I will use a semi- structured interview guide to be conducted amongst NARTIS trained nurses. Through this research, I will explore the reasons why patients who are eligible for ART by CD4 or by WHO Clinical Staging, are subsequently not initiated on ART.

I have recently been granted approval from the University of South Africa (UNISA), to conduct this study (please see Ethical Clearance Certificate enclosed). My research protocol, along with all the relevant supporting documents, will be also submitted to the Swaziland Ethical Review Board for approval.

Thank you in advance for your consideration of my request. I look forward to hearing from you.

Sincerely,

Ms Nosipho Gwebu Storer

Advisor, Adherence Psychosocial Support and Linkages; ICAP in Swaziland.

UNISA Masters Student

Tel: +268 2404 5797
Cell: +268 7614 8279

Cc: Matron Lilly Simelane Hhohho Regional Matron

ANNEXURE D

LETTER OF PERMISSION FROM HHOHHO REGIONAL HEALTH ADMINISTRATOR

Telegrams:
Telex:
Telephone: (+268 404 2431)
Fax: (+268 404 2092

MINISTRY OF HEALTH
P.O. BOX 5
MBABANE
SWAZILAND

THE KINGDOM OF SWAZILAND

P.O. Box 1459
Mbabane
Swaziland

7th January 2015

Dear Ms Nosipho Gwebu Storer

Re: Request to conduct your research at primary Health Facilities in the Hhohho region.

Thank you for the request you made to conduct your Masters research entitled "***Factors contributing to non-initiation of ART amongst eligible Pre-ART patients in rural clinics in Swaziland'*** in the Hhohho region of Swaziland.

I would like to inform you that you are granted the permission focus your thesis on the 10 facilities you will randomly select in the Hhohho region. Kindly share your research findings with the Hhohho RHMT when you research is completed.

Sincerely,

P.O. BOX 8 MBABANE H100 12 JAN 2015

MKHOSI KHUMALO
HHOHHO REGIONAL HEALTH ADMINISTRATOR

ANNEXURE E

LETTER TO SWAZILAND ETHICS COMMITTEE

P.O. Box 1459
Mbabane
Swaziland, H100

Ministry of Health
P.O. Box 5
Mbabane
Swaziland, H100

9th January 2015

To the Research Officer,

Re: Submission of Research for review by the Swaziland Ethics Committee (SEC).

I hope this finds you well. Subsequent to our conversation earlier this week, the following refers;

I am writing this letter to request to request approval from the Swaziland Ethics Committee to conduct my Masters in Public Health research at 10 randomly selected Primary Health Facilities in the Hhohho Region. My research proposal is entitled ***"Factors contributing to non-initiation of ART amongst eligible Pre-ART patients in rural clinics in Swaziland."*** To conduct this research, I will use a semi- structured interview guide to be conducted amongst NARTIS trained nurses. Through this research, I will explore the reasons why patients who are eligible for ART by CD4 or by WHO Clinical Staging, are subsequently not initiated on ART.

This folder comprises of the research proposal, the SEC Application form, and also following documents:

- The approval certificate from the University of South Africa (UNISA), to conduct this study (please see Ethical Clearance Certificate enclosed).
- My signed UNISA declaration to comply with UNISA research Ethics
- Letter of Approval from Hhohho Regional Health Administrator
- Letter of Consent from Hhohho Regional Matron
- Informed Consent Form English
- Informed Consent Form Siswati
- Semi Structured interview guide for NARTIS nurse
- My Curriculum Vitae

Enclosed is also the FNB deposit slip for the application fee of SZL250.

Thank you for your consideration of my research proposal. I look forward to hearing from you.

Many thanks,

Nosipho Storer

ANNEXURE F

LETTER OF APPROVAL FROM SWAZILAND ETHICS COMMITTEE

Telegrams:
Telex:
Telephone: (+268 404 2431)
Fax: (+268 404 2092

MINISTRY OF HEALTH
P.O. BOX 5
MBABANE
SWAZILAND

THE KINGDOM OF SWAZILAND

FROM: The Chairman
Scientific and Ethics Committee
Ministry of Health
P. O. Box 5
Mbabane

TO: **Ms.Nosipho Storer**
Principal Investigator

DATE: 18th February 2015

REF: MH/599C/ FWA 000 15267/IRB 0000 9688

Factors Contributing to Non – Initiation of ART amongst Eligle, Pre – ART Patients in Rural clinics in Swaziland

The committee thanks you for your submission to the Swaziland Scientific and Ethics Committee, after the review the committee acknowledges that the study is very useful and will help assist in the uptake of ART but further requests that you address the following comments;

- There is a need to build in a pilot to validate the data collection tool. Even a small sample of healthcare workers, just to see if the tool collects the data that the researcher is intending to collect and whether the questions in their current format are acceptable to the participants.
- The researcher also needs to clearly define the inclusion and exclusion criteria for this study. Please make this addition to the methodology section of the protocol

Swaziland Scientific and Ethics Committee (SEC) 19 FEB 2015 P.O. Box 5 Mbabane H100 SWAZILAND

Yours Sincerely,

RUDOLPH T.D. MAZIYA
THE CHAIRMAN, SEC
cc: SEC members

ANNEXURE G

UNISA ETHICAL CLEARANCE CERTIFICATE

UNISA university of south africa

UNIVERSITY OF SOUTH AFRICA
Health Studies Higher Degrees Committee
College of Human Sciences
ETHICAL CLEARANCE CERTIFICATE

REC-012714-039

HSHDC/369/2014

Date:	10 December 2014	Student No:	3566-172-0
Project Title:	Factors contributing to non-initiation of ART amongst eligible Pre ART patients in a rural Clinic in Swaziland.		
Researcher:	Nosipho Nontsikelelo Gwebu Storer		
Degree:	Masters in Public Health	Code:	DIS4986
Supervisor:	Dr E Janse van Rensburg		
Qualification:	D Cur		
Joint Supervisor:	-		

DECISION OF COMMITTEE

Approved [√] **Conditionally Approved** [ ]

Prof L Roets
CHAIRPERSON: HEALTH STUDIES HIGHER DEGREES COMMITTEE

Prof MM Moleki
ACADEMIC CHAIRPERSON: DEPARTMENT OF HEALTH STUDIES

PLEASE QUOTE THE PROJECT NUMBER IN ALL ENQUIRES

ANNEXURE H

INFORMED CONSENT FORM - ENGLISH

Factors contributing to non-initiation of ART amongst eligible Pre ART patients in a rural Clinic in Swaziland

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Study title:

Factors contributing to non-initiation of ART amongst eligible Pre-ART patients in a rural clinic in Swaziland.

Principle Investigator:

Ms Nosipho Gwebu Storer

Institution:

University of South Africa (UNISA)

Potential participants:

Registered nurses who are NARTIS trained, and working in a rural primary health facility.

Preferred Language: *(tick)*

English ☐ siSwati ☐

Part I: STUDY INFORMATION SHEET

Introduction

My name is Nosipho Gwebu Storer. I am a student at UNISA, studying toward my Masters degree in Public Health (MPH). I would like to invite you to participate in this research study. This study aims to determine the reasons why patients who are eligible to be started on Antiretroviral Therapy (ART), end up not being initiated on ART. As I explain the study to you, please feel free to ask questions or seek clarity at

any time. After having explained this study to you, you are free to choose to become a study participant, or not to become a study participant. You are also invited to take time to reflect on whether you would like to become a participant in this study or not.

Purpose of the research

The purpose of the study is to try and identify why people who are in need of ART do not end up being initiated on ART. Knowing more about these factors will help to create deeper understanding of the challenges that people face with accessing life saving ART when they need it. It will also enable us as a country to develop strategies and solutions that are directly addressing these barriers.

Participant selection

Your name was purposively selected to participate in this study because you are a registered NARTIS nurse who is working in a primary health facility. We would to discuss with you your views on this. We hope that this information will help us to better understand some of the unique factors that cause the delay between ART eligibility and ART Initiation.

Voluntary Participation

Your participation in this study is purely voluntary. There are no financial gains or incentives that will be gained from your participation in this study. There are no negative consequences if you choose to not participate in the study. Further, you are free to withdraw from this study at any time.

What procedures does this study involve?

When consent is given, this study will involve conducting one to one interviews with participants to identify reasons for delayed ART initiation amongst eligible patients. During these interviews, participants will be encouraged to speak freely, and to ask as many questions as they desire. The interviews will have both close and open ended questions. The interviews will be held at the clinic.

To conduct this study, the researcher will use a semi- structured interview guide to interview NARTIS nurses who are stationed at primary health facilities in the Hhohho region.

Each interview will last no more than 30 minutes.

What are the risks involved?

This study does not involve any experimental or clinical trials. There is no medication that will be administered.

You may however, feel the following risks:

- There is a risk that you may feel uncomfortable talking about the challenges that patients in your community face with enrolling into HIV care.
- There is a risk that some of the questions in the interview may make you feel uncomfortable.

It is not my desire to make you feel uncomfortable at any time, so please be rest assured that you do not have to answer any question that you feel uncomfortable with. Further, please be ensured that all the information you share will be kept in the strictest confidence.

What are the benefits?

By participating in this study, you are giving us an opportunity to learn more about the reasons why people do not get care when they need to. The research question aims at gathering information that is based on evidence, and not on assumptions. This information can be used to develop targeted strategies, and hopefully prevent others from facing the same challenges. It can enable us to increase access of HIV care to our communities, our society and our entire country.

Confidentiality

All your information will be kept confidential. It will not be shared. Your identity will not be disclosed at any time. Instead, a Unique Study Identifier will be assigned to you to ensure anonymity. All the information you provide will documented and all interviews be recorded. When documented material is transported from the interview site to the central office, it will be locked away in a sealed envelope and only opened

by myself on arrival to the central office. Recorded tapes and documents will be locked away in a lockable cabinet and no one other than myself will have the key.

During the interview process, only I will be present.

Dissemination of Results

I plan to share the results of this study. Here, again your identity will not be disclosed. Instead a Unique Study Identifier will be used. The study may further be published and disseminated, or it may be shared in local and international conferences.

Refusal to participate or withdrawal from the study

Your participation in this study is entirely voluntary. You are free to withdraw at any time.

Who may I contact?

If you have questions, concerns or need clarity, please feel free to contact myself **Nosipho Gwebu Storer** at **24045797** or **7614 8279**. Further, if you feel that you have been harmed or disadvantaged as a result of your participation in this study, please contact the **Swaziland Ethics Committee** at **2404 3697**.

Part II: CERTIFICATE OF CONSENT:

I have read the study information, and it has also been read to me. I was given time to ask questions and seek clarity. My questions have been addressed in full, and I fully understand the study. I also understand that I may withdraw from it at any time.

I consent to participate in this study.

Unique Identifier of participant _____

Signature of consenting participant _____

Date: (DD/MM/YY)_____

***If the consenting person is <u>not literate</u>** (to be completed by a witness):*

I have witnessed that the study has been explained to the candidate participant in a language and in a manner they can understand. The candidate participant was also invited and encouraged to ask questions, and these were addressed to their satisfaction. The candidate participant has freely consented to being a participant in the study.

Name of witness _____

Signature of witness _____

Date: (DD/MM/YY)_____

Thumbprint of the participant

<u>Part III:</u> <u>CONSENT STATEMENT FROM RESEARCHER OBTAINING CONSENT</u>

I have read the information sheet for the study participant in a language they understand. They have also asked questions, and I have addressed these to the best of my ability. I have done my best to ensure that the candidate participant has fully understood the study, and the implications of their participants in the study.

Name of researcher _____

Signature of researcher _____

Date: (DD/MM/YY)_____

ANNEXURE I

INFORMED CONSENT FORM - SISWATI

Tintfo letibangela kutsi tigulane letivumelekile kutsi tingacala iART tingacaliswa njengalokubhekekile emitfolamphilo yakaNgwane lesetindzaweni letisemakhaya.

Sihloko selucwaningo:

Tintfo letibangela kutsi tigulane letivumelekile kutsi tingacala iART tingacaliswa lokulashwa ngalendlela njengalokubhekekile emitfolamphilo yakaNgwane lesetindzaweni letisemakhaya.

Umseshi lobuketa lolucwaningo:

Make Nosipho Gwebu Storer

Sikolwa:

University of South Africa(UNISA)

Bantfu lokuhloswe kutsi babe yincenye yalelucwaningo:

Bonesi labacecesiwe nge NARTIS labasebenta emitfolamphilo lesetindzaweni letisemakhaya.

Khetsa lulwimi lowungatsandza kulisebentisa: (maka)

Singisi □ SiSwati □

<u>Sigaba 1:Lwati Lolumayelana Nelucwaningo</u>

Singeniso

Libito lami ngingu Nosipho Gwebu Storer. Ngingumfundzi enyuvesi yase UNISA. Ngifundzela kutfola sitifiketi lekutsiwa peceleti yiMaster's degree in Public Health (MPH). Ngitsandza kukumema kutsi ufake sandla ekutseni lolucwaningo lube yimphumelelo. Lolucwaningo luhlose kutfola tinchazelo mayelana nekutsi tigulane lekufanele kutsi ngabe seticale kutfola kulashwa lekutsiwa yi Antiretroviral Therapy (ART) tigcine tingakacali lokulashwa ngalendlela. Tivele ukhululekile kutsi ubute

imibuto lewunayo ngalolucwaningo ngisakuchazela kute ucaciseleke kahle.Nasengikuchazele kabanti ngalolucwaningo, unelilungelo leliphelele lekutsi ungavuma kuba yincenye yalolucwaningo nobe cha. Ngicela kutsi ucabangisise kahle kutsi ufisile yini kuba yincenye yalolucwaningo nobe cha.

Injongo yalolucwaningo

Injongo yalolucwaningo kutfola timbangela tekutsi tigulane lekumele kutsi ngabe seticale kulashwa lokutsiwa yiART tigcine tingakacali kulashwa ngalendlela. Kutfola lwati ngaletincabekelwane letibangela loku kutawusiniketa lwati lolujulile ngetinkinga tigulane letibhekana nato uma sekumele kutsi ticale lokulashwa loku lokusita kakhulu ekutseni kugcine imphilo yalona logulako. Futsi, kutawusisita ekutseni silive lakaNgwane sitfole tindlelanetisombululo letikhona kuchaza kabanti ngaletingcinamaba letibhekene nalolucwaningo.

Kukhetfwa kuze ube yincenye yalolucwaningo

Ligama lakho lakhetfwa ngenhloso ngoba kwatiwa kutsi ulinesi lelabhalisa kaNARTIS lelisebentela emtfolamphilo loniketa lusito lwekucala. Singatsadza kuva imivo yakho ngalesihloko salolucwaningo. Siyetsemba kutsi lelwati lelutawutfolakala kulelucwaningo lutawusisita ekutseni sitfole letincabekelwane letibangela kutsi tigulane lekufanele kutsi ngabe seticale iART tigcine tingakayicali ngesikhatsi lesifanele.

Kuba yincenye yalolucwaningo ngentsandvo yakho

Kuba yincenye yalolucwaningo kutawuba ngenca yekutsi uyafuna wena. Kute imali nobe tipho letitawutfolakala ngenca yekutsi wena uvumile kutsi ube yincenye yalolucwaningo. Kute tincabekelwane letinganambitseki letingakuvelela ngenca yekutsi ungavumi kutsi ube yincenye yalolucwaningo. Futsi, unelilungelo lekutsi ungayekela kuba yincenye yalolucwaningo nobe kunini.

Yini Lokucuketfwe ngulolucwaningo?

Emvakwekutsi kuvunyelwane, lolucwaningo lutawudzinga kutsi kube nekhulumiswano lapho khona umseshi lowenta lolucwaningo utawube abuta lonalovume kubayincenye yalolucwaningo imibuto letsite kuze kutfolakale tizatfu letibangela kutsi lokulashwa lekutsiwa yiART kungacalwa ngesikhatsi lesifanele.

Bonkhe labayincenye yalolucwaningo bayakhutsatwa kutsi bakhululeke kutsi babute imibuto labafise kutsi batfole kuchazeleka kuyo nobe ngabe minengi kangakanani. Lemibuto letawubutwa ngumseshi lowenta lolucwaningo inemibuto lecondze ngco kanye nemibuto lengakacondzi. Letinkhulumiswano titawubanjelwa emtfolamphilo.

Ekwenteni lolucwaningo, umseshi utawusebentisa imibuto lehleliwe lekatawuyibuta emanesi eNARTIS labasemitfolamphilo yelusito lekucala letfolakala esifundzeni sakaHhohho.

Inkhulumiswano iyinye ngeke itsatse sikhatsi lesindlula emaminitsi lengemashumi lamatsatfu.

Yini bungoti lobungavela?
Lolucwaningo alufaki ekhatsi kulashwa lokutsite.Kute imitsi yekulapha letawukhishwa ngenca yalelucwaningo.

Kodvwa bungoti lobungabakhona nguloku lokulandzelako.

- Kungenteka kutsi ungajabuli ngekukhuluma ngetinkinga tigulane tasendzaweni yangakini letibhekana nato nakumele ticale kulashwa lokucondzene neligciwane leHIV
- Kunebungoti ekutseni leminye yalemibuto lebutwako kulelucwaningo ingahle ikuphatse kabi.

Akusiso sifiso sami kutsi ngikuphatse kabi nobe kutsi ngikushiye ungakajabuli. Ngako ke, unelilungelo lekutsi ungawuphendvuli umbuto longafuni kuwuphendvula. Ngitsandza nekukwatisa kutsi konkhe lositjelakona ngeke bese kuvetwa lapho kungafaneli khona.

Yini imiphumela lemihle yalolucwaningo?
Ngekusisita kulelucwaningo utawube usiniketa lwati kabanti ngatimbangela tekutsi tigulane tingatfoli lusito letilidzingile ngesikhatsi lesifanele nalapho setilidzinga khona. Lolucwaningo luhlose kutfola lwati ngetintfo letentekako hhayi lokungabe

kucabangwa kutsi mhlawumbe ngiko lokwentekako. Lelwati lolutawutfolwa lutawusita ekutseni kutfolakale tindlela tekulwa naletimbangela taletinkinga letikhona kuze kutsi letinye tigulane tingavelelwa ngulokufanako. Lelwati lutawusita kutsi sikhulise kunakekelwa lokunikwa lokumayelana neligciwane le HIV emimmangweni yaketfu nasetigodzini tetfu kanye naseveni lonkhana.

Konkhe lotokusho kutawuba yimfihlo

Kute lotawuba nemvume yekutsi ati kabanti ngetimphendvulo losikete tona. Ngeke kwatiwe ngulabanye bantfu. Kodvwa, utawuniketwa ligama lelinye kuze kuciniseke kutsi imininingwane yakho ingatiwa ngumuntfu lomunye. Yonkhe imininingwane loyinikako itawugcinwa futsiyonkhe inkhulumiswano itawutsebulwa.Khonkhe lokubhalwe phasi endzaweni lapho bekwentelwa khona lenkhulumiswano kutawuvalelwa emvilopheni kuze kuvulwe ngimi nakufika enhloko hhovisi. Kanjalo tinkhuluswano letigciniwe titawukhiyelwa ebhokisini lelitsite lelikhiywako. Ngimi kuphela lotawuba netikhiya talelo libhokisi.

Ngimi kuphela lotawube akhona kulenkhulumiswano.

Kukhululwa kwemiphumela

Ngihlose kutsi imiphumela yalolucwaningo ngiyivete esiveni njengemihalngano lekhona lapha kaNgwane nobe lesemaveni. Kanjalo futsi, imininingwane yakho ngeke ivetwe.

Uma ungafuni kubayincenye yalolucwaningo nobe nangabe sewufuna kuyekela

Ngengoba ngishito, kuba yincenye yalolucwaningo kusentsandvweni yakho. Uvumelekile kutsi ungayekela nobe kunini.

Ngubani longachumana Naye?

Nangabe unemibuto nobe kukhona lfise kukuvisisa kahle ungangishayela mine **Nosipho Gwebu Storer** enombolweni letsi **24045797** nobe letsi **76148279**. Futsi, nangabe uva kungatsi kukhona lapho uphatseke kabi khona ngenca yekutsi ube yincenye yalolucwaningo, ngicela khutsi ushayele l **Swaziland Ethics Committee** ku **20403697**

Sigaba 2:Sitifiketi Sesivumelwano

Sengiyifundzile imininingwane lekhuluma ngalolucwaningo futsi sebangifundzele. Nginiketiwe litfuba lekutsi ngibute imibito ngaphindze ngatfola tinchazelo kulobekungakacaci. Imibuto yami iphendvuleke ngalokuphelele. Phindze futsi ngiyayicondza injongo yelelucwaningo. Ngiyacondza ngalokuphelele kutsi nginelilungelo lekuyekela kutimbandzakanya nalolucwaningo nobe kunini lapho sengisafuni khona kuchubeka.

Ngiyavuma kubayincenye yalolucwaningo.

Lotowatiwa ngako lokuhlukile_____

Sayina lapha_____

Lusuku: (DD/MM/YY)_____

*Uma lona losavume kubayincenye yalolucwaningo angakwati kuvudza (kutawugcwalisa fakazi)

Ngingufakazi wekutsi lona losavume kubayincenye yalolucwaningo uchazelwe kabanti ngenjongo nangalokucuketfwe ngulolucwaningo ngelulwimi lalatiko futsi lalicondzako. Futsi lona lovume kuba yincenye yalolucwaningo utjeliwe kutsi unelilungelo lekutsi angabuta imibuto lafise kutfo inchazelo kiyo. Lemibuto lena iphendvulwe ngalelusetulu lucophelelo futsi naye utijabulele letimphendvulo latitfolile. Lona lovume kuba yincenye yalolucwaningo uvume ngentsandvo yakhe kuba yincenye yalolucwaningo.

Libito lalongufakazi_____

Sayina lapha_____

Lusuku: (DD/MM/YY)_____

Sitfupha salona lovume kubayincenye yalolucwaningo

Sigaba 3: **Sivumelwano Lesentiwa Ngulowenta Lolucwaningo**

Ngifundze loluhla lolucuketse lwati ngalolucwaningo ngelulwimi lalivako lona losavume kubayincenye yalolucwaningo. Imibuto layibutile ngiyiphendvule ngako konkhe lokusemandleni ami. Ngente konkhe lokusemandleni ami kucinisekisa kutsi lona losavume kubayincenye yalolucwaningo utfole lwati nekucondza lokuphelele ngalolucwaningo nangetincabekelwane letingabangelwa kutsi uyincenye yalolucwaningo.

Libito lalona lwenta lolucwaningo_____

Sayina lapha_____

Date: (DD/MM/YY) _____

ANNEXURE J

PLANNING OF THE RESEARCH

Phase 1 Obtain Ethical approval			
No	**Activity**	**Person Responsible**	**Resources**
1.1	**Activity:** Project Proposal		
1.1.1 1.1.2	**Sub Activities:** -Draft project proposal for approval -Obtain approval	Researcher	-Printing
Phase 2 Develop Scope of the Research			
No	**Activity**	**Person Responsible**	**Resources**
2.1	**Activity:** Developing critical guidance systems for the project		
2.1.1	**Tasks:** -Drafting of consent forms	Researcher	-Printing
Phase 3 Implement of the Research			
No	**Activity**	**Person Responsible**	**Resources**
3.1	**Activity:** Selection of sample		
3.1.1 3.1.2	**Tasks:** **-**Select participants from NARTIS facilties Obtain consent	Researcher	-Transportation costs
3.2	**Activity:** **Data**		
3.2.1 3.2.2.	**Tasks:** -Collection of data -Data entry	Researcher	-Lockable cabinet

3.2.3	-Data Cleaning-Analysis		
Phase 4 Close out and termination of the Research			
No	**Activity**	**Person Responsible**	**Resources**
4.1	**Activity:** Dissemination of Research report		
4.1.1	**Sub- Activity:** - Report writings of Research findings	Researcher	-1 laptop
4.1.1.2 4.1.1.3	**Tasks:** -Compile a comprehensive report -Report disseminate to all relevant entities	Researcher	

ANNEXURE K

SEMI-STRUCTURED INTERVIEW GUIDE - ENGLISH

NARTIS Nurse Interview			
Unique Identifier Study No			
Date: (DD/MM/YYYY)			
PART I: Clinic Characteristics and Services Information Form			
Clinic Name:		**Region**	
Clinic Chiefdom		**Clinic Inkhundla**	
Primary Health Care Clinic type:	*Type (circle):* Mission Military Company	*Type (circle):* *Public/ Private/ Mission* *Public/ Private/ Mission* *Public/ Private/ Mission*	
ART Initiating Site?	Y/N	**When did the site begin initiating**	**(DD/MM/YYY)** **Unsure** **Other:** **……** **……** **…….** **……** **……** **……** **……**
ART refilling site?	Y/N	How often are refills done:	**……** **…….** **……** **……** **……** **……**
Service Providers at the health facility	**Cadre**	**How many?**	
	Please tick ☐ Expert Client ☐ M2M ☐ Nurse ☐ Doctor ☐ Phlebotomist ☐ Pharmacist *Other:* …… …… …… …… …… ……	 1 2 3 4 5 1 2 3 4 5 1 2 3 4 5 1 2 3 4 5 1 2 3 4 5 *How many?*	
Equipment available at the health facility	***Equipment Frequency of use:……Person responsible for use: Maintenance:*** …… …… …… ……		

	…… …… *Key words: PIMA, cell phone*
Community based Services provided at the health facility	*Please tick* □ Outreach …… …… ……. □ HBC Outreach …… …… ……. □ RHMs …… …… ……. □ Support groups …… …… ……. □ Other …… …… …….
No of staff trained on HIV Care, Linkages and follow-up SOP	No of staff trained:…….. Dates they received trainings: …… …….. …… …….. ……
No of staff trained on National Referrals & Linkages National tool	No of staff trained:…….. Dates they received trainings: …… …….. …… …….. ……
Cell phone available on site for patient follow-up	Y/N
Airtime always available in the phone	Y/N Comment: …… . …… … …… … …… ….

Who provides airtime and maintains the phone	…… . …… … …… …
Who makes the calls to patients for patient follow-up?	…… …… … …… … …… ….
Who conducts the home visits, and how often?	…… …… … …… … …… ….

NARTIS Nurse interview	
PART II: Pre-ART Follow – Up Form	
How long have you been stationed at this facility?	Date: **(DD/MM/YYYY)**
How many patients do you initiate in a day?	…… ……
How many patients do you initiate in a month?	…… ……
How do most patients react after receiving an HIV-positive diagnosis?	…… …… …… ……
Who informs them of their HIV status?	…… …… ……
Who informs them that they need to begin ART?	…… …… ……
What factors determine ART eligibility amongst patients in this facility?	…… …… ……
What would you say is the amount of time between ART eligibility and ART initiation?	…… …… …… ……
Can you tell me some of the reasons for not attending last appointment?	*Please tick* ☐ Too sick to come to clinic ☐ No money for transport ☐ Does not want to continue treatment (ART, CTX)

	☐ Visitor in other facility (write name of facility) ☐ Did not remember appointment ☐ Has appointment on (*write date)* ☐ Was not given appointment by the facility staff ☐ Client has transferred to other ART centre (*name centre)* **Other:** Please specify: …… …… …… …… ……
What are the factors that influence when people will come for an HIV test in this community?	…… …… …… ……
At what point after diagnosis are patients informed that they are eligible to begin ART?	…… …… …… ……
What additional support would a patient need in order to promptly begin ART? care and treatment	…… …… …… ……

ANNEXURE L

SEMI-STRUCTURED INTERVIEW GUIDE - SISWATI

NARTIS Nurse Interview			
Unique Identifier Study No			
Date: (DD/MM/YYYY)			
PART I: Clinic Characteristics and Services Information Form			
Clinic Name Libito lwemtfolamphilo:		**Region Sigodzi**	
Clinic Chiefdom		**Clinic Inkhundla**	
Primary Health Care Clinic type: Luhlobo lwekliniki.	*Type (circle):* Mission Military Company	*Type (circle):* *Public/ Private/ Mission* *Public/ Private/ Mission* *Public/ Private/ Mission*	
ART Initiating Site? Lomtfolamphilo uyacalisana ART?	Y/N	**When did the site begin initiating Ucale nini lomtfolamphilo kucalisa ART?**	**(DD/MM/YYY)** **Unsure** **Other: ……** **……** **……** **……**
ART refilling site? Umtfolamphilo loniketa emaphilisi ekutsintsibalisa ligciwane (ART)	Y/N	How often are refills done: Evikini mangakhi emalanga lakuniketwa khona emaphilisi?	**……** **……** **……**
Service Providers at the health facility: Labaniketa lusito kulomtfolamphilo.	**Cadre**	**How many?**	
	Please tick ☐ Expert Client ☐ M2M ☐ Nurse ☐ Doctor ☐ Phlebotomist ☐ Pharmacist *Other Lokunye:* …… …… …… …… …… ……	1 2 3 4 5 1 2 3 4 5 1 2 3 4 5 1 2 3 4 5 1 2 3 4 5 *How many? Bangakhi?*	
Equipment available at the health facility: Emathulusi ekusebenta lakhona kulomtfolamphilo.	***Equipment Frequency of use:……Person responsible for use: Maintenance:*** …… …… …… …… …… *Key words: PIMA, cell phone*		

Community based Services provided at the health facility: Tinsita temmango letentiwa kulomtfolamphilo.	*Please tick* □ Outreach …… …… □ HBC Outreach …… …… □ RHMs …… …… □ Support groups …… …… □ Other …… ……
No of staff trained on HIV Care, Linkages and follow-up SOP Inombolo yetisebenti temphilo leticeceshwe/fundziswe nge HIV and follow-up SOP.	No of staff trained Inombolo lefundzisiwe:…….. Dates they received trainings Tinsuku labafundziswa ngato: …… …….. …… …….. ……
No of staff trained on National Referrals & Linkages National tool. Inombolo yetisebenti temphilo leticeceshwe/letifundziswe ngeNational Referrals & Linkages National Tool.	No of staff trained Inombolo lefundzisiwe:…….. Dates they received trainings Tinsuku labafundziswa ngato: …… …….. …… …….. ……
Cell phone available on site for patient follow-up Ukhona mahlalekhukhwini kulomtfolamphilo wekulandzelela tigulanee.	Y/N
Airtime always available in the phone I-air time ihlale ikhona kulolucingo?	Y/N Comment: …… …… …… ……
Who provides airtime and maintains the phone. Ngubani lotsenga i-air time aphindze anakekele kugcinwa kwalolucingo?	…… …… ……
Who makes the calls to patients for patient follow-up? Ngubani loshayela tigulane, kutilandzelelela?	…… …… …… ……
Who conducts the home visits, and how often? Ngubani lovakasha emakhaya? Ukwenta kangakhi?	…… …… …… ……

NARTIS Nurse interview	
PART II: Pre-ART Follow – Up Form	
How long have you been stationed at this facility? Sewusebente sikhatsi lesinganani kulomtfolamphilo?	Date: **(DD/MM/YYYY)**
How many patients do you initiate in a day? Baba bangakhi bantfu lobacalisa emaphilisi ngelilanga?	…… ……
How many patients do you initiate in a month? Baba bangakhi bantfu lobacalisa emaphilisi ngenyanga?	…… ……
How do most patients react after receiving an HIV-positive diagnosis? Linyenti lebantfu litsatsa kanjani uma litfola kutsi lineligciwane?	…… …… …… ……
Who informs them of their HIV status? Ngubani lobatisako ngesimo sabo sengati?	…… …… ……
Who informs them that they need to begin ART? Ngubani lobatisako kutsi sekumele bacale ART?	…… …… ……
What factors determine ART eligibility amongst patients in this facility? Ngutiphi tintfo letikhomba kulungela kwekucala ART kulabaneligciwane kulomtfolamphilo?	…… …… ……
What would you say is the amount of time between ART eligibility and ART initiation? Ungatsi sibanganani sikhatsi kusukela lapho umuntfu alungela kucala ART nalapho amucala khona?	…… …… …… ……
Can you tell me some of the reasons for not attending last appointment? Yini tizatfu letikwente kutsi ungeti emtfolamphilo kulelilanga lekugcina bekumele ubuye ngalo?	*Please tick* ☐ Too sick to come to clinic Bekagula kakhulu kutsi ungeta ekliniki. ☐ No money for transport Bekute imali yekugibela ☐ Does not want to continue treatment (ART, CTX) Akasafuni kuchubeka nekutfola tinsita ngekwemaphilisi (ART, CTX) ☐ Visitor in other facility (write name of facility) Sivakashi kulomunye umtfolamphilo.

	□ Did not remember appointment Wakhohlwa lilanga lekubuyela emtfolamphilo. □ Has appointment on (*write date) Lilanga lekubuyela emtfolamphilo ngu(….)* □ Was not given appointment by the facility staff Labasebenta emtfolamphilo abazange bamunike lilanga lekubuya □ Client has transferred to other ART centre (*name centre) Watfunyelwa kulomunye umtfolamphilo we ART e……* **Other:** Please specify: Lokunye: Sicela uchaze …… …… …… …… ……
What are the factors that influence when people will come for an HIV test in this community? Yini tintfo letiphocelela bantfu kutsi bete ngalesikhatsi labetangaso kutohlola ligciwane kulomango?	…… …… …… ……
At what point after diagnosis are patients informed that they are eligible to begin ART? Kubangunini lapho losatfolakale aneligciwane atiswa kutsi sekumele acale ART?	…… …… …… ……
What additional support would a patient need in order to promptly begin ART? care and treatment Nguluphi lusito lolwengetiwe lolungadzingwa nguloneligciwane kutsi acale ngekushesha kunakekelwa ka-ART?	…… …… …… ……

ANNEXURE M

TRANSCRIBED SEMI-STRUCTURED INTERVIEWS

Date:	**07.04. 15**
Clinic	
Interviewer	**Nosipho Gwebu- Storer**
Interviewee:	
Code:	**H1**

NARTIS Nurse Interview			
Unique Identifier Study No	**H1**		
Date: (DD/MM/YYYY)	**07.04.15**		
PART I: Clinic Characteristics and Services Information Form			
Clinic Name:		**Region**	Hhohho
Clinic Chiefdom		**Clinic Inkhundla**	
Primary Health Care Clinic type:	*Type (circle):* Mission Military Company	*Type (circle):* *Public/ Private/ Mission* *Public/ Private/ Mission* *Public/ Private/ Mission*	
ART Initiating Site?	Y/N	**When did the site begin initiating**	**(DD/MM/YYY)** **Unsure** **Other:** **……** **…….** **……** **……** **……** **……..……..** **……..** **……..**
ART refilling site?	Y/N	How often are refills done:	**……** **……** **DAILY** **……** **……..……..** **……..** **……..**
Service Providers at the health facility	**Cadre**	**How many?**	
	Please tick □ Expert Client □ M2M □ Nurse □ Doctor □ Phlebotomist □ Pharmacist *Other:* …… ……maid groundsman security	 1 2 3 4 5 1 2 3 4 5 1 2 3 4 5 1 2 3 4 5: come monthly 1 2 3 4 5 *How many?* *1* *1* *1*	

Equipment available at the health facility	***Equipment Frequency of use:……Person responsible for use: Maintenance:*** *Cellphone EC URC* *Key words: PIMA, cell phone*
Community based Services provided at the health facility	*Please tick* .Outreach …… ……HBC Outreach …… …… RHMs …… ……. Support groups ……..…… Other ……M2M trying to form a support group at the moment.
No of staff trained on National Referrals & Linkages National tool	No of staff trained:…2…….. Dates they received trainings: ……..…… Sometime in 2014
Cell phone available on site for patient follow-up	Y/N
Airtime always available in the phone	Y/N Comment: ……Always available……
Who provides airtime and maintains the phone	…URC…
Who makes the calls to patients for patient follow-up?	EC and nurses make the calls to patients.
Who conducts the home visits, and how often?	…… ……..... Home visits are currently not done.

NARTIS Nurse interview	
PART II: Pre-ART Follow – Up Form	
How long have you been stationed at this facility?	Date: **(DD/MM/YYYY)** **August 2013**
How many patients do you initiate in a day?	*1 or 2 initiated per day*
How many patients do you initiate in a month?	*We initiate maybe 15*
How do most patients react after receiving an HIV-positive diagnosis?	*Most of the patients babakahle. They react okay. There are only few who are shocked.*
Who informs them of their HIV status?	*The nurse.*
Who informs them that they need to begin ART?	*During the 1st counseling session, the eligibility criteria is explained. It is done by the EC.*
What factors determine ART eligibility amongst patients in this facility?	*CD4 and Clinical staging. All the pregnant women in this facility are initiated.*

What would you say if the amount of time between diagnosis and ART initiation?	*A patient would be initiated within 2months.*
Can you tell me some of the reasons for not attending last appointment?	*Please tick* □ Too sick to come to clinic □ No money for transport □ Does not want to continue treatment (ART, CTX) □ Visitor in other facility (write name of facility) □ Did not remember appointment □ Has appointment on (*write date)* □ Was not given appointment by the facility staff □ Client has transferred to other ART centre (*name centre)*
What are the factors that influence when people will come for an HIV test in this community?	**Other:** Please specify: *Some patients run away. Some just don't come. And don't tell you why. Other patients are travelling to Mbabane or Piggs Peak. Others say they have tested and are HIV negative.* *For CD4 we need LFTs. Sometimes the car to collect the bloods does not come.* *Sometimes there are no reagents at Piggs Peak, so CD4 cannot be done. Some people come after at test, and then return later for results. Some patients feel sick and come. Some have known their status from way back, then decide to come for a test one day.*
At what point after diagnosis are patients informed that they are eligible to begin ART?	*After 2 weeks. Return dates are given on Wednesdays, as this is the day when labs are done and results are brought to us. Then it takes another week for the results. Sometimes you can tell is the Clinical staging if low, then we will tell the results to them.*
What additional support would a patient need in order to promptly begin ART? care and treatment	*We need strengthened follow-up. The nurses are too busy. We also need a CEC to conduct the home visits.*

Date:	**07.04. 15**
Clinic	
Interviewer	**Nosipho Gwebu- Storer**
Interviewee:	
Code:	

NARTIS Nurse Interview			
Unique Identifier Study No	**H2**		
Date: (DD/MM/YYYY)	**07.04.15**		
PART I: Clinic Characteristics and Services Information Form			
Clinic Name:		**Region**	
Clinic Chiefdom		**Clinic Inkhundla**	
Primary Health Care Clinic type:	*Type (circle):* Mission Military Company Government	*Type (circle):* *Public/ Private/ Mission* *Public/ Private/ Mission* *Public/ Private/ Mission* *Public/ Private/ Mission*	
ART Initiating Site?	Y/N	**When did the site begin initiating**	**(DD/MM/YYY)** **Unsure** **Other: ……2012**
ART refilling site?	Y/N	How often are refills done:	**……** **…….** **DAILY**

Service Providers at the health facility	**Cadre**	**How many?**	
	Please tick □ Expert Client □ M2M □ Nurse □ Doctor □ Phlebotomist □ Pharmacist *Other:* …… ……cleaners	 1 2 3 4 5 1 2 3 4 5 1 2 3 4 5 1 2 3 4 5 1 2 3 4 5 *How many?* *1*	
Equipment available at the health facility	***Equipment Frequency of use:……Person responsible for use: Maintenance:*** *Cellphone Always Senior nurse URC* *Key words: PIMA, cell phone*		
Community based Services provided at the health facility	*Please tick* □.Outreach …… ……□ HBC Outreach …… …… □ RHMs ……this facility words with 10 of them……. □ Support groups ……..…… □ Other …		
No of staff trained on National Referrals & Linkages National tool	No of staff trained:…3 nurses…….. Dates they received trainings: ……..……2013/2014		
Cell phone available on site for patient follow-up	Y/N		
Airtime always available in the phone	Y/N Comment: ……Always available……		
Who provides airtime and maintains the phone	…URC…		
Who makes the calls to patients for patient follow-up?	…… …….....EC and assigned nurse, depending on their circulating system.		
Who conducts the home visits, and how often?	…… ……..... None are done now. When the EC was there, they were done.		

NARTIS Nurse interview	
PART II: Pre-ART Follow – Up Form	
How long have you been stationed at this facility?	Date: **(DD/MM/YYYY)** **2002**
How many patients do you initiate in a day?	*2 to 3 patients are initiated per day*

How many patients do you initiate in a month?	*We initiate about 12people per month.*
How do most patients react after receiving an HIV-positive diagnosis?	*Bayetfuka. But most welcome the diagnosis. People still feel that HIV is far from them. They feel it is not with me.*
Who informs them of their HIV status?	*The nurse.*
Who informs them that they need to begin ART?	*The nurse and the EC, but mostly the nurse.*
What factors determine ART eligibility amongst patients in this facility?	*CD4 and WHO staging.*
What would you say if the amount of time between diagnosis and ART initiation?	*Plus or minus 6 weeks.*
Can you tell me some of the reasons for not attending last appointment?	*Please tick* □ Too sick to come to clinic □ No money for transport □ Does not want to continue treatment (ART, CTX) □ Visitor in other facility (write name of facility) □ Did not remember appointment □ Has appointment on (*write date)* □ Was not given appointment by the facility staff □ Client has transferred to other ART centre (*name centre)* **Other:** Please specify: *Most patients say they were busy. Others say they had no money. Some arrive after the sample transportation have gone, they leave at 10am.*
What are the factors that influence when people will come for an HIV test in this community?	*There is no PIMA here. So CD4 is taken on Monday and Wednesday. They (the patients) suspect something themselves, and they just walk in. With some, they say ngivile bakhuluma, ngadecida.*
At what point after diagnosis are patients informed that they are eligible to begin ART?	*After the CD4 cell test. There are no reagents at the moment, so we are using clinical staging.*
What additional support would a patient need in order to promptly begin ART? care and treatment	*A PIMA machine. There is also such a burden of clients. They workload is just high, we cant initiate people. It needs to be quiet.* *We need 3 more NARTIS nurses trained. Especially because if one is gone, the others are burdened.* *We need an hour to initiate per patient.* *NARTIS should be stand alone. A separate clinic, with its own nurse. Then this nurse can focus on this ad not be running to bo ANC. Then you would even have time to crack jokes and to talk. Now its just a give and take.*

Date:	**07.04. 15**
Clinic	
Interviewer	**Nosipho Gwebu- Storer**
Interviewee:	
Code:	

NARTIS Nurse Interview	
Unique Identifier Study No	**H3**

Date: (DD/MM/YYYY)	**07.04.15**		
PART I: Clinic Characteristics and Services Information Form			
Clinic Name:		**Region**	
Clinic Chiefdom		**Clinic Inkhundla**	
Primary Health Care Clinic type:	*Type (circle):* Mission Military Company Government	*Type (circle):* *Public/ Private/ Mission* *Public/ Private/ Mission* *Public/ Private/ Mission* *Public/ Private/ Mission*	
ART Initiating Site?	Y/N	**When did the site begin initiating**	**(DD/MM/YYY)** **Unsure** **Other: ……2014**
ART refilling site?	Y/N	How often are refills done:	**……** **…….** **Everyday.** **When did you start refilling daily?** *Mid…Maybe we should go to the ART department so I Can tell you exactly?* **No the year is ok.** The year is ok? I think its last year that it become consistent. **Ok, then 2014?** Yes
Service Providers at the health facility	**Cadre**	**How many?**	
	Please tick □ Expert Client □ M2M □ Nurse □ Doctor □ Phlebotomist □ Pharmacist *Any Other cadre:* ……TB Screening officers Orderly	1 2 3 4 5 1 2 3 4 5 1 2 3 4 5 1 2 3 4 5 – *He is supposed to visit monthly, but its not a consistent thing.* 1 2 3 4 5 *How many?* *1* *2*	
Equipment available at the health facility	***Equipment Frequency of use:……Person responsible for use: Maintenance:*** *Cellphone Always Everybody URC* *Key words: PIMA, cell phone*		
Community based Services provided at the health facility	*Please tick* □.Outreach …… ……□ HBC Outreach …… □ **RHMs** : *We have RHMS, it's only just started, it's the first time I was giving out disposables from WHO. I have 6 RHM Leaders.*		

	□ **Support group**: No…. but it's not related to ART…….We have a group, a *Shukumo Gogo group. Which is the elderly. We meet. We talk about things, we even talk about PMTCT because it's them that hinder the whole things, and then we do a few exercises. Teach them about hygiene. Nje. But it's for gogos, it's for the elderly*. □ Other …
No of staff trained on National Referrals & Linkages National tool	No of staff trained: *Everybody because I think they same on site. Everybody knows how to use it.* ***How many are you in this facility?*** *As in the nurses, the trainers..* **So you have a cellphone. Is there always airtime kulelicingo?** Um….. yaaa…. {laughs} *We usually ask for it before it gets finished, before the month ends*. Ok on the referral tool, *it is there….but…ok we don't use it like every time because they don't receive the priority they are supposed to receive. It's the same as you have said the patient please go to Piggs Peak and you write on the prescription sheet what you have done. It's more or less the same thing. So sometimes we feel like its time consuming. Yabona nje lelilaynini. And busy filling out this whole thing, and yet lomuntfu bengamattendi with priority.* *And whether you have filled it in or not the referral thing that you are supposed to return is never returned back. So, leni?*
Cell phone available on site for patient follow-up	Y/N
Airtime always available in the phone	Y/N **So you have a cellphone. Is there always airtime kulelicingo?** Um….. yaaa…. {laughs} *We usually ask for it before it gets finished, before the month ends*. Ok on the referral tool, its there….
Who provides airtime and maintains the phone	…URC…
Who makes the calls to patients for patient follow-up?	…… …….....*All of us. Because the Cough Officers follow-up the sputum, the EC calls to follow up patients who haven't come for their appointments. The nurses also call to follow up patients...nje its everybody. The only people who don't use the phone it's the orderly's.*
Who conducts the home visits, and how often?	…… ……..... *We never have the time to. There is one that usually does home visits but ke ah….* **This there a Community Expert Client here?** *No*

NARTIS Nurse interview	
PART II: Pre-ART Follow – Up Form	
How long have you been stationed at this facility?	Date: **(DD/MM/YYYY)** *Since it opened it 2011 I was the opening one.*
How many patients do you initiate in a day?	*Ngatsi a rough estimate I would say 1, because we are not so many and I try to speak to having a treatment support. I am trying to speak to all the logistics of having a treatment supporter because of all the failures. So if there is no treatment Support we try to talk to the patient to get at least a*

	Mgcugcuteli or somebody. Who will… so….That makes it initiation rate yethu ingalingani mhlawumbe nalamanye ema facilities but I'm saying it works. In terms of retention. Ema problems lesibanawo endzaba yema patients are a bit big.
How many patients do you initiate in a month?	*30 is just too much. Ngiko ngitsi roughly…. ngoba kute point. Ku a person. But its less than 30 in a month. A lot of them are on ART already from PP.*
How do most patients react after receiving an HIV-positive diagnosis?	*Most of them react fine. They accept their status. I issue is disclosure.*
Who informs them of their HIV status?	*The nurses.*
Who informs them that they need to begin ART?	*The nurses. And the EC as wall because now we are saying that everybody should initiate, as long as they are willing.*
What factors determine ART eligibility amongst patients in this facility?	*Readiness. (laughs)*
What would you say if the amount of time between diagnosis and ART initiation?	*It depends on the patient. The reason why I say that I say that is a patient can be diagnosed today, and the patient will say I want to start this ART and we will talk to the patient, and we will ask the patient to bring a treatment supporter, at least to show that you have disclosed, and the patient can come back the following day. Ete na Treatment supporter ba understander eve ngatsi nurse I want it. Asimwasteli sikhatsi.* **So you are not taking bloods on a certain day?** *We do take. But we don't wait. We do take, like we only take tispecimen on a Wednesday. But naye le client iyeta mhlawumbeni asitisi iyeta Friday and then ibuye mhlamwumbe Monday. Ngeke sitsi sitawumela. We will initiate them. Wednesday they will come and get their specimen. The initiation will follow.* **So you initiate first as a priority? Kutawulandzela lokunye.** *Kutawulandzela lokunye because kuyafanana. The CD4 ayikho, kute emareagents. Kute ini ini. I mean really. The patients waits for a long itme now.*
Can you tell me some of the reasons for not attending last appointment?	*Please tick* □ Too sick to come to clinic □ No money for transport □ Does not want to continue treatment (ART, CTX) □ Visitor in other facility (write name of facility) □ Did not remember appointment □ Has appointment on (*write date)* □ Was not given appointment by the facility staff □ Client has transferred to other ART centre (*name centre)* **Other:** Please specify: *Ok most of them are disclosure. Usuku angakadisclosozi, lokunye Ihave had patients who have wanted to initiate, but have not wanted to initiate at this clinic, because kuna le community around. So uma abonakala angina lapha…. Bantfu batamboma. So ahambe ayo iniitate somewhere else, a refiller somewhere else and then uba I down referral. So nawubabuta ufelani. Batsi eish y ye nesi kunabanibani bamamkhuluma kutsi bambone kulelinye lilayini lela. Manje eish, mine I don't wnt them to see me in that line. They we say ok ye fana if you are not comfortable being in that line tell us, we will refill for you in the room that you are comfortable with. Uyabona? Then you see thatther4e is an issue with that particular room. But we at trying to continue to use that room, it really doesn't matter.*

What are the factors that influence when people will come for an HIV test in this community?	*I think that this community sees the importance of testing. A lot. Ema walk ins manengi. I used say to those who are support HTC or whatever, who would tell me not to tick the column for HTC because it was for PSI blah blah blah blah blah. I said to them, you know what I am not going to stop ticking that column because it's the only way I can see that patients are just coming in; It's got nothing to do with the nurse, it's got nothing to do with anything. The patients just… there are even 2 people sitting here today. No one coerced them to come. They ask bona kutsi where testing is done and they wait in the line; and its got nothing to so with the nurse. So we do have a lot of that. The critical thing is the way forward. Ok so you have now tested, then what???* *And another thing that is strange with this community. I don't know if it has anything to do with that you are asking currently or what, but the males, they are so head on with dealing with HIV and so on, They are the ones who come for testing and so on. But the females don't. So we are finding a lot of makes partners. We are finding a lot of issues where the female partner is HIV-positive, the male partner is negative but they have never come together so they don't know each others status. Any we don't know how to deal with it, and it's a problem. We have even gone to an extent of lying and saying we are not allowed to test individually, they have to come together. And the female partner refuses. The make comes for a re test, and we tell him then he is not allowed to come alone, and that he must bring his partner. Because we know the patients. We know that this one is this one's husband. Then the wife refuses, and we know why the wife is refusing. And they are some patients who say I don't mind getting this one's HIV once they have disclosed to each other. They say they don't see a problem.* *One patient got pregnant. She is HIV-positive this female. She became pregnant this female. When she came for testing at 6 weeks, he said ''ok, please test me too'' (the male). He know her status. When asked how did you guys become pregnant? He said nurse me I dont mind even if I contract HIV. It would even make me very happy if we were to take tablets together with her. And then, we are thankful to the couple that at least now there is a child, we tell them "now you must please use a condom."" He says "eish we use it, but it would be good nurse if we could all take the treatment?"* *There is another guy as well who says "I grew up not using condom, and I won't start now just because someone has HIV. This person I brought this person all the way from SA, and now I am going to use a condom just because she has HIV?" Kantsi what kind of people get HIV?* *A challenge we have is with alcoholism. They drink. Quite a bit. this community. They have this misperception that… "" Ye nesi we started a long time ago collecting these tablets. We were collecting them from PP. On they day I go to collect their medication I wont drink. I will drink when I come back. But you are a problem because you know us. You stay with us in this very community. You see us, you know us as drinkers.* *A*
At what point after diagnosis are patients informed that they are eligible to begin ART?	*From diagnosis. We tell you: if you really want the treatment you can start the treatment because HIV affects all parts of the body. Even in parts you will not see. So if you want to start, you can start.*
What additional support would a patient need in order to promptly begin ART? care and treatment	*I'm not sure because you cannot say you will integrate it with all the rooms because still they will take the treatment. When they leave this room they would be frustrated. And still It would be promoting stigma and hiding. So I don't see it. Because I even went to the chiefdom to teach on adherence and so on because of they drink. And even at the chiefdom the men argued that*

HIV is contracted by those who feel like contracting it. So they undertstand all that, so I'm not sure what is missing. I don't know, I don't know. There is nothing missing because even at chiefdom level they know the whole story, and they continue with their choices.

Disclosure. Yaaaaa. Someone who gossips about another person and speak negatively about HIV. If there was a law against that! That would help us because really really there is no reason for anyone to have any issues except for the fact that "" I heard so and so talking badly about so and so..." that is where the issue starts.

If I didn't even have anyone at home. There is another lady who is initiated well because she said that, "I will ask my neighbor, because the children that I stay with are young. But at least my neighbor will be able to check on me everyday, and remind me." This lady then came with the neighbor. But if it were one of the patients who heard something from someone, they would not be comfortable to come with their neighbor right? Even with the treatment supporter. Peoples would have so many supporters. Peoples would have supporters any day if there was no one hearing any gossip. How come about hypertension. They don't gossip about diabetes.

Also another thing that would be in place. Patients are very scared of sexual issues. The gogos nje from Shukumo support group, when you talk to them about sexual issues they say "hhayi man Mkhjumane!" "Ye wena You are playing with us." They are still forbidden nje to talk about those kind of topics. Even though they say to me " ahh vele this one is crazy" but at least they get to hear. So issues around sex are not easy. And nurses, they also don't about sex easily. I have noted, Its not all nurses are comfortable with sex. If a patient comes and say " eish nurse one of my girlfriends…" "how many girlfriends do you have??!!!" You know or whatever. Don't stigmatize me. Promote me to use condom rather. You understand? So these nurses themselves they are still not, what can I say? These sexual issues should be nice: guys you should have sex. But just have nice sex with a condom. Yes, let it be something good. Because if it sex is something good, I won't feel ashamed that I contracted HIV. How I contracted HIV will not matter. " You had sex!!!"

Date:	**07.04. 15**
Clinic	
Interviewer	**Nosipho Gwebu- Storer**
Interviewee:	
Code:	

NARTIS Nurse Interview			
Unique Identifier Study No	**H4**		
Date: (DD/MM/YYYY)	**07.04.15**		
PART I: Clinic Characteristics and Services Information Form			
Clinic Name:		**Region**	
Clinic Chiefdom		**Clinic Inkhundla**	
Primary Health Care Clinic type:	*Type (circle):* Mission Military Company Government	*Type (circle):* *Public/ Private/ Mission* *Public/ Private/ Mission* *Public/ Private/ Mission* *Public/ Private/ Mission*	
ART Initiating Site?	Y/N	**When did the site begin initiating?**	**(DD/MM/YYY)** **Unsure**

			Other: ……We started in February 2014
ART refilling site?	Y/N	How often are refills done:	**…… …… every day, except on not on weekends**
Service Providers at the health facility	**Cadre**	**How many?**	
	Please tick □ Expert Client □ M2M □ Nurse □ Doctor □ Phlebotomist □ Pharmacist *Other:* …… ……orderly	1 2 3 4 5 1 2 3 4 5 1 2 3 4 5 1 2 3 4 5 1 2 3 4 5 *How many?* *1*	
Equipment available at the health facility	***Equipment Frequency of use:……Person responsible for use: Maintenance:*** *Cellphone Always Expert Client URC* *Key words: PIMA, cell phone*		
Community based Services provided at the health facility	*Please tick* □.Outreach …… ……□ HBC Outreach …… …… □ RHMs ……4……. □ Support groups …no longer having any support groups…… □ Other …		
No of staff trained on National Referrals & Linkages National tool	No of staff trained:…1 EC and 1 nurses…….. Dates they received trainings: ……..……2014		
Cell phone available on site for patient follow-up	Y/N		
Airtime always available in the phone	Y/N They always ask for it before it finishes. It has never finished on us this year.		
Who provides airtime and maintains the phone	…URC…		
Who makes the calls to patients for patient follow-up?	…… …….....EC and sometimes the nurses.		
Who conducts the home visits, and how often?	…… ……..... We don't have any		

NARTIS Nurse interview	
PART II: Pre-ART Follow – Up Form	
How long have you been stationed at this facility?	Date: **(DD/MM/YYYY)** 9 years.
How many patients do you initiate in a day?	*Yiii (laughs) we only have a few people in this area that are initiated. We would have to count and say "roughly." Can I please count in the register? (counts the registers)*
How many patients do you initiate in a month?	*Less than 7 per month.*
How do most patients react after receiving an HIV-positive diagnosis?	*Here there are a few people who get shocked, but most of them are easily able to accept circumstances. They just tell themselves that there are things in life that just happen.* *Oh they accept? Yes they do.*
Who informs them of their HIV status?	*The nurse.*
Who informs them that they need to begin ART?	*The nurse.*
What factors determine ART eligibility amongst patients in this facility?	*CD4 and WHO staging.*
What would you say if the amount of time between diagnosis and ART initiation?	*(Laughs) When will you start treatment…. By the way, you test. You test, you take CD4 some the same day, then return on Monday or on a Wednesday. You can take a CD4 and baselines when it's not the right day. So I would say 2 to 3 weeks.* *You take it on Monday or Wednesday? Wednesday. But now its LAPLLA now, we just give people on the same day.*
Can you tell me some of the reasons for not attending last appointment?	*Please tick* □ Too sick to come to clinic □ No money for transport □ Does not want to continue treatment (ART, CTX) □ Visitor in other facility (write name of facility) □ Did not remember appointment □ Has appointment on (*write date)* □ Was not given appointment by the facility staff □ Client has transferred to other ART centre (*name centre)* **Other:** Please specify: *Others say they were too busy. Others say they stay far. But there is no transport here. The bus leaves in the morning at 7am. And then again at 4pm, so it's hard.*
What are the factors that influence when people will come for an HIV test in this community?	*There are those who just walk in. They are many. Recently there was an event by CHAI, and others who have come to teach in the communities. Others are assisted by their friends.*
At what point after diagnosis are patients informed that they are eligible to begin ART?	*When we test the patient and take CD4 we tell the patient that it is possible that you need to start ARV. If we have to wait ke for the CD4, that is what will tell us what to tell the patient.*
What additional support would a patient need in order to promptly begin ART? care and treatment	*I wish we had a PIMA, but a PIMA also comes with a person who can work with the PIMA.*

Even the Community. We need some someone who could be in the community and encourage them to come. There are those who need someone in the community to encourage them.

Date:	**07.04. 15**
Clinic	
Interviewer	**Nosipho Gwebu- Storer**
Interviewee:	
Code:	

NARTIS Nurse Interview			
Unique Identifier Study No	**H5**		
Date: (DD/MM/YYYY)	**07.04.15**		
PART I: Clinic Characteristics and Services Information Form			
Clinic Name:		**Region**	
Clinic Chiefdom		**Clinic Inkhundla**	
Primary Health Care Clinic type:	*Type (circle):* Mission Military Company Government	*Type (circle):* *Public/ Private/ Mission* *Public/ Private/ Mission* *Public/ Private/ Mission* *Public/ Private/ Mission*	
ART Initiating Site?	Y/N	**When did the site begin initiating?**	**(DD/MM/YYY)** **Unsure** **Other: ……We started in 2012, before even I arrived**
ART refilling site?	Y/N	How often are refills done:	**…… …… daily**
Service Providers at the health facility	**Cadre**	**How many?**	
	Please tick □ Expert Client □ M2M □ Nurse □ Doctor □ Phlebotomist □ Pharmacist *Other:* …… ……ICAP RA Groundsmen Hygienist	 1 2 3 4 5- *we had 2, now we have one. We have the one who is in side, not the one who outside.* 1 2 3 4 5 –*we do, we have 1 who is inside and also we have Community Mentor Mothers, 4 of them. So we are 5.* 1 2 3 4 5 we are 4. 1 2 3 4 5- we don't have 1 2 3 4 5 1 2 3 4 5 *How many?* *1* *1* *1*	
Equipment available at the health facility	***Equipment Frequency of use:……Person responsible for use: Maintenance:*** *PIMA. The nurse services it, it's under Link 4 Health. The PIMA is under CHAI.* *A cellphone is also there, under ICAP. And also one for the clinic that is under Nazarene. So we have got 2. One is for the facility because there is no landline. It replaces the landline. And then the one for ICAP we are using for our clients.*		

	So where does the phone stay? It stays in the facility. Everyday we open it at 8am, and then it remains that side (points to ART room) in case they want to call. But this one for the facility we are calling cases that are linked to the facility. ***Ok, so which person does the phone reside with?*** *With the nurses, because they are the ones who call, with the help for the EC from ICAP. Otherwise it stays with the nurse.* *Key words: PIMA, cell phone*
Community based Services provided at the health facility	*Please tick* .Outreach: *Not really. Ok, it's mostly the M2M and the Expert Client. But if it does happen that lets say we have enough staff, when it does happen, sometimes the nurse will go and see the clients who cannot come here, so she can go and see them.* HBC Outreach …… RHMs *They are not many. OK most of them are not active. OK we don't have the figure. But they are able to communicate with the community EC. Us we usually talk to the Community EC because they are the ones who know who is residing where. With the help of World Vision. But in cases we that allow we do go, after we have identified the clients because they live in the community we know them.* Support groups: *We have one for kids, and one for PMTCT, pregnant women who are breastfeeding. They are both active.* *One for kids, one for breastfeeding?* *No the PMYTCT one is mixed with the pregnant and breastfeeding one. For those who are 2 years from pregnant. They are active these ones. They meet monthly. We are just about to start the 3rd one for families.* *That one is in the pipeline? Yes. A family support group.* Other …
No of staff trained on National Referrals & Linkages National tool	No of staff trained:…*the 4 nurses* Dates they received trainings: *Last year*
Cell phone available on site for patient follow-up	Y/N
Airtime always available in the phone	Y/N *Ok with the ICAP phone, they informed us that when there is E50 remaining, we have to call. But sometimes lets say you call and they are not in the office and you have so many clients to call. So you find you call and you didn't find them in the office, or you find someone who will say wait a little they are not in the office yet you want to call. So you find that it finishes like that.* So who buys the airtime for the RFM phone? *It's bought from the office at RFM.*
Who provides airtime and maintains the phone	…RFM Office …
Who makes the calls to patients for patient follow-up?	…… …….....*It's the focal person for ART, but usually it's the nurse who is in the ART department for that week. So if for example today there are patients who have not come, after 2 to 3 days she calls them.*

	But there is a focal person who needs to ensure that there is still airtime in the phone, that the phone is still ok and that the services are still ok.
Who conducts the home visits, and how often?	…… ……..... *With home visits those who are active with them it's the community Mentor Mothers. And the CEC we used to have used to do them. When we see there is a need, then maybe someone form the facility can go. Maybe those few hours, then they come back.*

NARTIS Nurse interview	
PART II: Pre-ART Follow – Up Form	
How long have you been stationed at this facility?	Date: **(DD/MM/YYYY)** 2013 January
How many patients do you initiate in a day?	*In the ART department? Initiations. Eish the complications is that now there is LAPLLA. Its depends. I can say that It fluctuates because now nje we were delayed by bloods. Because there was a time 2 to 3 months….Now nje CD4 is not being done. As much as we do them with the PIMA, we cannot do follow-ups. Then labs also paused as well. Now Dvokolwalko is not doing them. Moneni is not doing them. So they are only being done at Mkhuzweni. And at Mkhuzweni fro them to be done we have to have them to Dvokolkwako, then Dvokolwako will take theirs and their babies (facilities) to Mkhuzeni. Mkhuzweni also has their own babies. So there is now a queue. So now we have a maximum per day of not more than 10, which is Mondays and Wednesday, only those 2 days.* *So that sis the samples? Yes, we now only take those who need to initiate, we have stagnated with follow-ups. Then with LAPLLA, isn't it LAPLLA doesn't wait for results, we were just initiating. Otherwise we initiate. Sometimes you find we initiate 5 a day. Sometimes we can't initiate because you find the CD4 is fluctuating and the bloods.* *But LAPLLA everyone is initiated? Everyone is initiated.* *So you say 5, are you meaning LAPLLA or not really? Ok when we first started they were more. So because now mostly they are already initiated, people who we are now seeing for bo PMTCT they are refilling. It's only the first ANC because they have children who are breastfeeding, and all of them are on ART already. So it's just the new ANC now, the initial cases to avoid them seroconverting, otherwise most are on ART.*
How many patients do you initiate in a month?	*Would say plus or minus what nje? It wasn't that high. When we started LAPLLA in December January, we had much. I would say plus or minus 20. Per month.*
How do most patients react after receiving an HIV-positive diagnosis?	*People have now accepted. Most of them because when you talk of initiation or if being on ART or adherence, most will say "anything that will make me be right." They are ready now. They have the readiness I think. It's rare to find someone who is very hard. They are now right. Even for LAPLLA nje.*
Who informs them of their HIV status?	*The nurse who does the pre-counseling*
Who informs them that they need to begin ART?	*The nurse as well. The same nurse.*
What factors determine ART eligibility amongst patients in this facility?	*CD4 and staging. And also LAPLLA.*
What would you say is the amount of time between diagnosis and ART initiation?	*Ok you know what we do now. We try to enable that clients don't queue for long. So let's say they came. It depends on which department they came to. Let's say they came for counseling. They will go to the nurse counselor, who*

counsels him and everything. Then they will go to lab. So what happens when they get to the lab, will depend on the queue that side and the day; what day is it. But if they have go to HTC, HTC doesn't take as much time as others. So they squeeze them in to see if they are reactive. They run the PIMA. While they PIMA is running, they will enroll and counsel the patient. By the time the CD4 result comes, they are in on going counseling. It takes about 20 minutes. So by that time they have done the physical exam, and have been counseled, by the time they come, because she has to determine their if she needs to prepare him for ART or continue him for Cotrim. So when the patient come he is in-between so it's simple. You just check the CD4. If it's below 350, you just counsel the patient towards ART. If it's the day to take bloods you can give him the third adherence, but if its not, you counsel them and give them the first adherence and ask that they come back the following day or if its a Wednesday or Monday, they come on either of those 2 days. When they return they are initiated. So we assign a day to avoid them coming many times. When the 2nd day they return, it's the day they will initiate. Usually you find that its 2 visits before we initiate. We try. And also the fact that we do it all in the same place, and the nurse does everything. Otherwise the waiting time is not long. Its just that days are not the same, like today we are 2. We have had to compromise a little.

So that is 2 visits within a week? Or 2 visits in 2 weeks? Let's say the patient come on a Monday, that's the results go, on a Monday. we would do 1st adherence and enroll, and tell him to return on a Thursday because the labs would have arrived on the Wednesday. So when they come on Thursday, the labs will be here. We check the labs and we do 2nd adherence and then initiate. So it can be on the next visit.

So if I came on a Wednesday, on the day you take bloods? Would I be initiated same day? No it won't because we would have to wait for labs. That sample would go. Let me make an example of Monday. On Monday the samples would go, same time. But Thursday we will be sure that that sample would have returned. We don't say Wednesday because we don't know when the car will arrive. We will say Thursday. If he comes early, he will no line and find all his things arrived.

Can you tell me some of the reasons for not attending last appointment?

Please tick
- ☐ Too sick to come to clinic
- ☐ No money for transport
- ☐ Does not want to continue treatment (ART, CTX)
- ☐ Visitor in other facility (write name of facility)
- ☐ Did not remember appointment
- ☐ Has appointment on (*write date)*
- ☐ Was not given appointment by the facility staff
- ☐ Client has transferred to other ART centre (*name centre)*

Other: Please specify:
Ok we actually ask them where they stay, and if they will be able to take public transport to come. This is what made us synchronize our visits. So that if theey have come for something else they can do everything here. So the first few month, they will come after 2 weeks, Then monthly monthly. If you are adhering well. After some few months, you will come after 2 months. So more than anything we emphasize the advantages of ART, and tell them that if you adhere, you will have fewer visits. We also tell them that. There is no payment as well.

There are some that don't come. At the end of the day we check the appointment register, because when we appoint them we write what they are appointed for at this facility. We start with the ART initiations.

	Some say its transport one. Some, when you talk about the labs, they opt to go to Dvokolwako themselves. You find that they would rather goto Dvokolewakho on a Tuesday than come to Bhalkenae on a Wednesday because their results are given same day. They would rather take them, wait for them, and then return with them. Most of them prefer to go to Mkhuzweni. Tke them and wait for them. Then the day they need to return they come with them. Then they are initiated. We do tell them that they can continue with Mkhuzweni if they wish. We write a lab request form for them, and they take it to Mkhuzweni. *So do you find that some patients who get results from Mkhuzweni same day for example, decide to just continue with Mkhuzweni? Or do most of them come back?*
What are the factors that influence when people will come for an HIV test in this community?	*They come back. They go there, do their bloods, and then come back. They come for HTC. I think its friends and health education. Another thing that influences is the community M2M, because they go into people's homes. So when they go in the homestead they don't only look at the babies, but they also counselling. Also, in the community meetings, they go to educate them.*
At what point after diagnosis are patients informed that they are eligible to begin ART?	*When you have done your test, and you are receiving post-test counseling. We start with the post test, and we look at the readiness of the clients. We see how far is the readiness. We look at the readiness of the client and we ask them before if they are ready. They we can see if the client themselves are ready to start.*
What additional support would a patient need in order to promptly begin ART? care and treatment	*Machine to do the LFTs on site. Facility based. If we had those. Only that.*

Date:	**21.04. 15**
Clinic	
Interviewer	**Nosipho Gwebu- Storer**
Interviewee:	
Code:	

NARTIS Nurse Interview			
Unique Identifier Study No	**H6**		
Date: (DD/MM/YYYY)	**21.04.15**		
PART I: Clinic Characteristics and Services Information Form			
Clinic Name:		**Region**	Hhohho
Clinic Chiefdom		**Clinic Inkhundla**	Mbabane West
Primary Health Care Clinic type:	*Type (circle):* Mission Military Company Government NGO	*Type (circle):* *Public/ Private/ Mission* *Public/ Private/ Mission* *Public/ Private/ Mission* *Public/ Private/ Mission* *Public/ Private/ Mission*	
ART Initiating Site?	Y/N	**When did the site begin initiating?**	**(DD/MM/YYY)** **Sometime in April. I had been initiating previously but I needed to have the consent. But I needed to attend the initiation workshop before I could continue. You mean April this year?**

			This side? Oh you mean this side. No it was 2012.
ART refilling site?	Y/N	How often are refills done:	**Every day. I mean everyday.**
Service Providers at the health facility	**Cadre**	**How many?**	
	Please tick □ Expert Client □ M2M □ Nurse □ Doctor □ Phlebotomist □ Pharmacist *Other:* …… ……Cough Officer TB/HIV Adherence Officer Data Capturer Accounts Clerk	 1 2 3 4 5- 1 2 3 4 5 – 1 2 3 4 5 1 2 3 4 5- we have a visiting doctor every week. 1 2 3 4 5 1 2 3 4 5 *How many?* *1* *1* *1* *1*	
Equipment available at the health facility	***Equipment Frequency of use:……Person responsible for use: Maintenance:*** *Yes we have a cell phone.* *How often is it used? Its used almost every day.* *And who is responsible for the cell phone? The head nurse.* *And who is responsible for the maintenance of the cell phone? URC* *Key words: PIMA, cell phone*		
Community based Services provided at the health facility	*Please tick* □.Outreach: of late no. Except for follow-up of patients. □ HBC Outreach …… □ RHMs: Otherwise we have 34, but only 25 are active. □ Support groups: □ Other …		
No of staff trained on National Referrals & Linkages National tool	No of staff trained: *The national linkages tool? The national referral form? Yes.* *Oh yes. The 5 nurses were trained.* Dates they received trainings: We were trained at…. I'm trying to think of the name. When coming from Ezulwini it's on the right. *Royal Villas!* *When was that? It was maybe 2 years ago now.*		
Cell phone available on site for patient follow-up	Y/N		
Airtime always available in the phone	Y/N		
Who provides airtime and maintains the phone	It's URC		
Who makes the calls to patients for patient follow-up?	It's the Community.. the community Expert Client. The Community….. because we have 2 of them. And the Expert client in the community, and one is the facility expert client.		
Who conducts the home visits, and how often?	We don't actually do them. But we do send an ambulance for those clients if need be.		

	You hava n ambulance here on site? Yes.

NARTIS Nurse interview	
PART II: Pre-ART Follow – Up Form	
How long have you been stationed at this facility?	Date: **(DD/MM/YYYY)** I have been working here since …..almost 2 years now….. Yeah 2013.
How many patients do you initiate in a day?	*It depends because we initiate patients as they come. We don't make patients come on a special day to initiate. We initiate every day.*
How many patients do you initiate in a month?	*Around an average of 21 per month.* *12 per month? Yes.* *What about daily then? Sometimes I would say we initiate 2 to 3.*
How do most patients react after receiving an HIV-positive diagnosis?	*In my experience I have never come across patient who are overwhelmed. They seem to all accept.*
Who informs them of their HIV status?	*The nurse.*
Who informs them that they need to begin ART?	*It's the nurse who is responsible for pre-ART.*
What factors determine ART eligibility amongst patients in this facility?	*Hhmmm it's the… no….. it is…. The WHO stages and the CD4 count of…..it had been yes 350, but we have been initiating patients from the government hospital. Now it's at 500.*
What would you say is the amount of time between diagnosis and ART initiation?	*It depends on the individual patient. Some of them, it takes about 3 days. I mean as soon as the CD4 count result comes. This is if it is not by WHO staging..*
Can you tell me some of the reasons for not attending last appointment?	*Please tick* □ Too sick to come to clinic □ No money for transport □ Does not want to continue treatment (ART, CTX) □ Visitor in other facility (write name of facility) □ Did not remember appointment □ Has appointment on (*write date)* □ Was not given appointment by the facility staff □ Client has transferred to other ART centre (*name centre)* **Other:** Please specify:. Most of them say they are…. They were at work. *OK, any other reasons?* Hhmm some of them…. there are few that will say would turn up and say they were not ready. Patients do come, is interested, but would like to know {their HIV status} but are not able to do it because reagents are out of order. So they come when they are really sick. Sometimes a patient will come, and you would find that the patient would like to know more about the CD 4 count.
What are the factors that influence when people will come for an HIV test in this community?	*I think most patients who have tested somewhere, who already know this status. Im most cases its patients who have tested before, its patients who…..or maybe their partners already know. People who have tested before and there is a change in their lives. They have started falling sick.*
At what point after diagnosis are patients informed that they are eligible to begin ART?	*As soon as they get their CD 4 count.*
What additional support would a patient need in order to promptly begin ART? care and treatment	*If only our facility had a PIMA. Then patients would be started on time. We would be starting more patients on ART than we do now. At the moment, I don't see…*

Date:	**22.04. 15**
Clinic	
Interviewer	**Nosipho Gwebu- Storer**
Interviewee:	
Code:	

NARTIS Nurse Interview			
Unique Identifier Study No	**H7**		
Date: (DD/MM/YYYY)	**22.04.15**		
PART I: Clinic Characteristics and Services Information Form			
Clinic Name:		**Region**	
Clinic Chiefdom		**Clinic Inkhundla**	
Primary Health Care Clinic type:	*Type (circle):* Mission Military Company Government NGO	*Type (circle):* *Public/ Private/ Mission* *Public/ Private/ Mission* *Public/ Private/ Mission* *Public/ Private/ Mission- it's a government clinic. The clinic was donated by a mission, but it's under government.* *Public/ Private/ Mission*	
ART Initiating Site?	Y/N	**When did the site begin initiating?**	**(DD/MM/YYY)** **2012**
ART refilling site?	Y/N	How often are refills done:	**Every day.**
Service Providers at the health facility	**Cadre**	**How many?**	
	Please tick □ Expert Client □ M2M □ Nurse □ Doctor □ Phlebotomist □ Pharmacist *Other:* ……HTC Counsellor Cough Officer Receptionist Orderly	1 2 3 4 5- There are two. One for TB and one for ART. 1 2 3 4 5 1 2 3 4 5 1 2 3 4 5- we don't have, but we do have doctors visits. Oh how often? Every week. 1 2 3 4 5 1 2 3 4 5 *How many?* *1* *1* *1* *1*	
Equipment available at the health facility	***Equipment Frequency of use:……Person responsible for use: Maintenance:*** *Cell phone. We have one cell phone and then a landline.* *How often is it used? Almost on daily basis.* *And who keep the cell phone? The Expert Client.* *What about maintenance? I think its URC.* *We have a PIMA. It's used every day.* *Who is responsible for the PIMA? It's me. Because I am the only one currently trained. We were two, but the other nurse was transferred to another clinic.* *Who maintains the PIMA? People from CHAI.*		

	Key words: PIMA, cell phone
Community based Services provided at the health facility	*Please tick* .Outreach: *Yes we have follow-up patients on ART and TB. Who does the follow up? The Expert Client. I also do them on my motorbike.* HBC Outreach. *Yes, I am responsible. When they have not come back, I go and check them.* RHMs: We have about 20. Support groups: We don't have. Other …
No of staff trained on National Referrals & Linkages National tool	No of staff trained: *I think we were all trained because I attended a workshop I think we were 2 and then we came back and shared all the information. Oh ok, so how many are you in this facility who were trained? I think all the 4 nurses. Because they are the ones who refer to other facilities.* When were they trained*: I think 2014.*
Cell phone available on site for patient follow-up	Y/N
Airtime always available in the phone	Y/N
Who provides airtime and maintains the phone	It's URC
Who makes the calls to patients for patient follow-up?	It's the Expert Client and the nurse.
Who conducts the home visits, and how often?	Expert client and the community nurse.

NARTIS Nurse interview	
PART II: Pre-ART Follow – Up Form	
How long have you been stationed at this facility?	Date: **(DD/MM/YYYY)** I came in 2012 so now it's 3 years.
How many patients do you initiate in a day?	*3*
How many patients do you initiate in a month?	*10. Plus or minus 10.*
How do most patients react after receiving an HIV-positive diagnosis?	*Most of the people… they…they receive it well because they come here when they are sick so they just accept the situation. They come here because they know they are sick. Yes, they just accept.*
Who informs them of their HIV status?	*The HTC Counselor, but if they are patients who needs a referral, they come to the nurse.*
Who informs them that they need to begin ART?	*It's the nurse.*
What factors determine ART eligibility amongst patients in this facility?	*Ok we use the CD4 count and the WHO staging*
What would you say is the amount of time between diagnosis and ART initiation?	*AAhhhh I think if you were just diagnosed today and you are eligible we start the same week. Maybe on Monday, you find that on Thursday we are starting. We don't wait. If somebody is ready… because we are initiating every day.*

Can you tell me some of the reasons for not attending last appointment?	*Please tick* □ Too sick to come to clinic □ No money for transport □ Does not want to continue treatment (ART, CTX) □ Visitor in other facility (write name of facility) □ Did not remember appointment □ Has appointment on (*write date)* □ Was not given appointment by the facility staff □ Client has transferred to other ART centre (*name centre)* **Other:** Please specify: *Ok maybe sometimes its work problems. They don't receive the support at work. Some they are taking alcohol. You find that they are not serious in taking the treatment. Some you find that they are nomadic. They move from one place to another they are in South Africa, Lavumisa. Some because they are now well. They feel there is no need to be serious in taking their treatment.*
What are the factors that influence when people will come for an HIV test in this community?	*Ok sometimes it's the health education we are providing in the clinic. Some people they have come here for… just they are sick, but after hearing the health education they are forced to take, they are encouraged for HTC. Sometimes they are sick. Somebody is sick, now they want to test. Another thing is that seeing other people taking the ART, and they say "Eh let me go and test, people are living."*
At what point after diagnosis are patients informed that they are eligible to begin ART?	*We can tell you same day because we have a PIMA. When they test, and I take blood and put it in the PIMA. It then tells me that the CD4 is low, they need to be started on treatment.*
What additional support would a patient need in order to promptly begin ART? care and treatment	*Ok, one. They must increase the staff. Staff. You are 5? Yes but you see today we are 2? One is at a workshop, we are never a complete number. It's not common that all of us are here. Another thing is that they should increase the turn around to get results. Even though we take the CD4, when there is none, we use government hospital again. It takes a long looong time.* *We also need a mini-lab. So that the results can come back quickly.* *So a minilab can help even though there is a PIMA? Yes because sometimes you have to look at the chemistry, how is the liver how is the kidney. Before we can start.* *Also the socio economic status of the people. I don't know what can be done because some you find they really don't have the money. They don't have the money. To come to the clinic. Then you find that it delays.* *Another think I think.. labour laws. So that when people need to some to the clinic, they allow them at the workplace. Because you find that many clients are held up by that. Others cannot leave work. They report that their bosses said no, so they remained at home.*

Date:	**15.5.15**
Clinic	
Interviewer	**Nosipho Gwebu- Storer**
Interviewee:	
Code:	

NARTIS Nurse Interview			
Unique Identifier Study No	**H8**		
Date: (DD/MM/YYYY)	**15.5.15**		
PART I: Clinic Characteristics and Services Information Form			
Clinic Name:		**Region**	
Clinic Chiefdom		**Clinic Inkhundla**	
Primary Health Care Clinic type:	*Type (circle):* Mission Military Company Government	*Type (circle):* *Public/ Private/ Mission* *Public/ Private/ Mission* *Public/ Private/ Mission* *Public/ Private/ Mission*	

	NGO	*Public/ Private/ Mission*	
ART Initiating Site?	Y/N	**When did the site begin initiating?**	**(DD/MM/YYY) 2012**
ART refilling site?	Y/N	How often are refills done:	**Every day.**
Service Providers at the health facility	**Cadre**	**How many?**	
	Please tick □ Expert Client □ M2M □ Nurse □ Doctor □ Phlebotomist □ Pharmacist *Other:* Orderly Counsellor	1 2 3 4 5- One of them of the Community (CEC). 1 2 3 4 5 1 2 3 4 5 There are 2 staff nurses, and one nursing assistant. 1 2 3 4 5- 1 2 3 4 5 1 2 3 4 5 *How many?* *1* *1*	
Equipment available at the health facility	***Equipment Frequency of use:……Person responsible for use: Maintenance:*** *We have a landline. It uses electricity, so when there the electricity goes it also goes. We also have a cell phone.* ***How often is it used?*** *Whenever it is needed, it is used.* ***Where is the phone kept?*** *The phone is kept at the reception.* ***So anyone can use it anytime?*** *Ok, whoever uses it needs to report on who they were calling. But we nurses we use it, and it is also used by the ECs when they are doing follow-ups.* ***What about a PIMA?*** *We have one. Its usually CHAI who we call when it stops function.* *Key words: PIMA, cell phone*		
Community based Services provided at the health facility	*Please tick* □.Outreach: □ HBC Outreach. □ RHMs: *We don't really have outreach activities, but we do have RHMs. Our CEC did used to do them, but with problems related to funding, we no longer have her. There was no more money for transport. Yes, used to. Ok, what will I say…as you know I have just come to this new big position, but we had some challenges. Those kind of challenges with RHMs. Here and there…I only had a meeting with them this week Monday. They asked that they come back home. Nje… I don't know… But we had problems. The fact that the men from WV and ICAP will report that they are pulling away so we need to have a way to work with them. They are aware that the RHMs are linked here. I asked the men to leave and we remain and talk about it with them. It was the RHM Leads. I told them that we do not know each other in the first place. So these men cannot tell us that they will go and sort it out at top level. Issues around planning to link RHMs and this clinic. We have problems at this level. Some of them I know, some of them you know. I told them that many of them believed that RHMs were chased from Sigangeni Clinic, but I explained that I am not the one who chased them. The one who chased them left this clinic. I never witnessed you stealing, I also heard. So please come back and we start on a clean slate. Let's start again and work together. Because the linkage points you to this direction. I also told them that I had heard that they often meet at the Inkhundla center. And deliver*		

	reports, but I don't even know it. The report has information of people who are dying in their homes. But I don't know it. If I am asked, what am I going to say? Because there is nothing that I know about that…So the leads came on Monday and they talked. I felt so bad, but I apologised. You know when you apologise for something you do not know… but ya… I apologised. I think they will return. □ Support groups: □ Other …
No of staff trained on National Referrals & Linkages National tool	No of staff trained: *Im not sure. I remember that Nurse Thwala and myself were trained. Where you trained here or did someone come to this facility to train? No we went somewhere to train. But the tool is here. I went and came back with it. Also H went and came back with it.* When were they trained*: last year.*
Cell phone available on site for patient follow-up	Y/N
Airtime always available in the phone	Y/N
Who provides airtime and maintains the phone	*It's URC. The problem is often with us, when we don't ask for it on time, but otherwise they do give it to us.*
Who makes the calls to patients for patient follow-up?	*It varies…because the EC, because they were the one doing the home visits…GU… she is the one who would often call. But on this end, for the positive DBS, or mothers who are Positive, we call. If there is another one with a complicated case that needs consultation with the doctor, we call.*
Who conducts the home visits, and how often?	*We no longer have them. The RHMs were complaining about that… saying that nurses don't visit them. But we can't. Also before, we used to have motorbikes for home visits, now there is nothing. When Hlatshayo came, he said that he would be the Community Nurse, but naye he is seeing patients. He will go and leave them with who?*

NARTIS Nurse interview	
PART II: Pre-ART Follow – Up Form	
How long have you been stationed at this facility?	Date: **(DD/MM/YYYY)** June will be my 3rd year.
How many patients do you initiate in a day?	*Eish, I know how. It's often seasonal I don't know how. Sometimes they are many, there times there are none. Now nje, the ones I can talk well about are the ones I see when I am stationed here (at the ART room). You see now I have a challenge. It's a long time since we have seen a child who will test at 6 weeks and be HIV negative. And at 6 months they test negative. But now, I think we have 3 or 4 who have tested HIV-positive. It makes us not to understand what is happening. This morning another. At 6 weeks the child was HIV negative. We initiate children. I don't think we initiate more than 2 per day. Maybe it's because one is tired or what. But it's really hard to initiate more than 2 a day. It because one minute you are here, I'm burdened, I'm alone. You understand? I need to do it this side, and not be rushed; I must not tell myself that I am rushing back to the other room. You need to give yourself time and be sure that everything that they were supposed to learn they learned, and that they came with a treatment supporter. So there is no where you can rush to. Then it requires that you come back to another room. You have talked so much that side, the treatment supporter has asked all their questions, and the patient themselves have also asked all their questions. On some days you feel so tired. You feel like after a single initiation, you just go and sleep. Because you feel that you go back and forth to ensure that this patient is ready. If then she is not, you feel that you did it justice, they will come again on another day. At least 2. Also we*

How many patients do you initiate in a month?	*book a patient, we need to ask when they can be initiated. Because Tuesdays and Thursday we take bloods, they can't be booked on these days. So Monday, Wednesday and Friday, those are the better days.* *It varies, but we don't initiate more than 5 in a month. Maximum.*
How do most patients react after receiving an HIV-positive diagnosis?	*Others I can say, have known for a long time. The one who only discovered now... It's a challenge. Like LAPLLA. Do you know LAPLLA? Challenge, she is pregnant. I do HTC right then. She is still crying because she has just discovered her status. The next think you tell her about ARVs. It's just too much. It's just too much. Other mothers who were in Pre-ART have no problem. Because she knows, and her husband knows. She tells herself that she will simply tell him that she is also like him. But for those who tested just now, it's hard. Even yourself you would find it hard, regardless of what the guidelines say. But they leave, and then they do come back.*
Who informs them of their HIV status?	*The nurse discloses. And the counselor discloses, but those who are testing positive she does not tell them. Only the negative ones.*
Who informs them that they need to begin ART?	*Ok isn't it when you are in Pre-test, they are educated by the EC that if the CD4 is above this, or below that… you see. So when they come back its easier. Those testing CD4 all take bloods on the PIMA. Even if they don't know what its for. They will be told to wait for their result. So when they come to the ART room they already have their CD4. So you will disclose what the CD4 says and what it means. They have already given them information in the Pre-test. They will be able to understand their CD4 status, and it will even be obvious to them.*
What factors determine ART eligibility amongst patients in this facility?	*CD4. And the staging, We know that it needs to be done, but we have never had to really use it. So it's mainly the CD4.*
What would you say is the amount of time between diagnosis and ART initiation?	*Ok they have 3 classes. It depends on the person because they are not the same. The first class is what we call day 1. They are together. It's the day they learn about their status. They are shocked, and there isn't much you can say to them alone. SO you ask them when they can come back so that one can continue talking with them about the way forward in terms of beginning ART. We can't push them. We ask when they can return, as in the following week Wednesday or Thursday. The patients then tells you which day can suit them. They do come back on the date they said, rather than you giving them the return day. We also ask them that between Monday, Wednesday or Thursday, which date would you prefer? So we can give them attention, rather than them coming on a Tuesday and then we cannot give them attention. They come back, they go to class, led by the EC. The Second class, they have come back, and they learn some time. Thursday class, we initiate them on ART.* ***So the classes are within 2 weeks?*** *Well there are those who say I will come back tomorrow, and then again the next day. But we feel that we want them to be at peace and rest. Because others have known their status for a long time, but are shocked by the CD4. They its like their will be some kind of magic because of the ARVs. But 3 weeks does not finish before we have initiated them. If they come Monday and Wednesday…. Friday if they have a treatment supporter, then we will start them.*
Can you tell me some of the reasons for not attending last appointment?	*Please tick* □ Too sick to come to clinic □ No money for transport □ Does not want to continue treatment (ART, CTX) □ Visitor in other facility (write name of facility) □ Did not remember appointment □ Has appointment on (*write date)* □ Was not given appointment by the facility staff □ Client has transferred to other ART centre (*name centre)*

	Other: Please specify: *Firstly it's where they work, they are not allowed. Either it's in the forest or in the kitchens. The bosses don't understand, and others have not disclosed, so it's hard to explain to them. Also I think us ourselves, when we count the tablets, we find that there were so many tablets. So the patient does not come back on their date because there are so many tablets left. Others work far, like in South Africa. So they can't come back on the date.*
What are the factors that influence when people will come for an HIV test in this community?	*They do come. Other say that they saw a sick relative who died, and they were suspicious of themselves, but had been too afraid to test all this time. Others reside in company camps. Men. Then they are able to encourage each other to go and test. Also supporters end up supporting each other. When you ask the patient who they will come back with, they say they will come with the one they stay within the same room. So they return with their roommate, all to find that the roommate is on ART. So they end up both being on treatment, supporting one another. They are able to really support each other.*
At what point after diagnosis are patients informed that they are eligible to begin ART?	*When they come with the result. Then when you talk to them about their CD4. When you probe what they were taught about CD4, and when is the indication to start ART, you then show then their CD4 and that they are below 350, they can see that they need to start.*
What additional support would a patient need in order to promptly begin ART? care and treatment	*If we were well staffed. If we knew that me I am here. I am responsible for child welfare and leave family planning. On the ART side, there would be a nurse that is responsible only for ART. That would be so much better. And its makes the work suit us. Because now nje, a women who comes to me, she comes for family planning. She has a child who is sick. This child needs a refill or NVP and CTX. The mother herself is also refilling. It requires that if she has come on a Tuesday, the day to take bloods, I have to buzz Maseko to bring me her file from that room, with her number. Then at the end of the day they bring the file in an envelop. SO that it leaves here and goes straight back. After whatever minutes, I have to stand up and go to the phelb for bloods. So we need someone who can just focaus on ART.*

Date:	**15.5.15**
Clinic	
Interviewer	**Nosipho Gwebu- Storer**
Interviewee:	
Code:	

NARTIS Nurse Interview			
Unique Identifier Study No	**H9**		
Date: (DD/MM/YYYY)	**15.5.15**		
PART I: Clinic Characteristics and Services Information Form			
Clinic Name:		**Region**	
Clinic Chiefdom		**Clinic Inkhundla**	
Primary Health Care Clinic type:	*Type (circle):* Mission Military Company Government NGO	*Type (circle):* *Public/ Private/ Mission* *Public/ Private/ Mission* *Public/ Private/ Mission* *Public/ Private/ Mission* *Public/ Private/ Mission*	
ART Initiating Site?	Y/N	**When did the site begin initiating?**	**(DD/MM/YYYY)** **2012**
ART refilling site?	Y/N	How often are refills done:	**Every day.**
	Cadre	**How many?**	

Service Providers at the health facility	*Please tick* □ Expert Client □ M2M □ Nurse □ Doctor □ Phlebotomist □ Pharmacist *Other:* Cough Officer	1 2 3 4 5- we have 2 ECs that are local, then there is also have 1 community. 1 2 3 4 5 6 – we have 2 local, and 4 community 1 2 3 4 5 - Four staff nurses, and one nursing assistant. 1 2 3 4 5- Ok they visit us once a month. 1 2 3 4 5 1 2 3 4 5 – we have 1 Assistant Pharmacist. *How many?* *1*
Equipment available at the health facility	***Equipment Frequency of use:……Person responsible for use: Maintenance:*** *We have some cell phones. We have 2. We ask for support from WV and also from ICAP. Also from M2M, they have their own phone.* ***So there are 3 phones in this facility?*** *Yes. When is responsible for the cell phones? The M2M phone stays with the M2M, the EC phones, the ICAP one stays with them; and the WV phone is kept by the Community EC.* ***Who finds the airtime?*** *The ICAP phone is funded by ICAP. The WV one for the CEC is WV and the M2M one is funded by M2M.* *We also have a PIMA, but I'm not sure who funds it.* ***Who uses it?*** *Its used by all the phlebotomists and the nurses who are trained.* *Key words: PIMA, cell phone*	
Community based Services provided at the health facility	*Please tick* □.Outreach: The CEC do go out. Also the M2M. □ HBC Outreach. □ RHMs: *We have RHMs. We have a calendar of them.* □ Support groups: □ Other …	
No of staff trained on National Referrals & Linkages National tool	No of staff trained: *Ok, the ECs. I think the senior nurse was also trained.* When were they trained*: I think 2013 to 2014. Somewhere around there.*	
Cell phone available on site for patient follow-up	Y/N	
Airtime always available in the phone	Y/N	
Who provides airtime and maintains the phone	*It's the partners. Yes the partners.*	
Who makes the calls to patients for patient follow-up?	*The ECs. OK also the nurse does do calls, but only when we call the doctor when they are problems maybe with the clients. But we don't call the clients for follow-up. That is usually done by the ECs.*	
Who conducts the home visits, and how often?	*Twice a week I think. It depends on how often the person needs to be followed. But usually it's twice a week.*	

NARTIS Nurse interview	
PART II: Pre-ART Follow – Up Form	
How long have you been stationed at this facility?	Date: **(DD/MM/YYYY)** 2009.
How many patients do you initiate in a day?	*Ummm, the average is 7.*
How many patients do you initiate in a month?	*About 30.*

How do most patients react after receiving an HIV-positive diagnosis?	*Aaaahh, it depends on the individuals. Others are ready, they know. They don't have a problem. They are very few who you find they take it badly.*
Who informs them of their HIV status?	*The nurse. Only the nurses are allowed to disclose.*
Who informs them that they need to begin ART?	*It's the nurse again.*
What factors determine ART eligibility amongst patients in this facility?	*Ok we look at the client, to see how are they. We also look at CD4 count. Then also their willingness, because they may can eligible but not willing.*
What would you say is the amount of time between diagnosis and ART initiation?	*It's about 2 to 3 months.*
Can you tell me some of the reasons for not attending last appointment?	*Please tick* □ Too sick to come to clinic □ No money for transport □ Does not want to continue treatment (ART, CTX) □ Visitor in other facility (write name of facility) □ Did not remember appointment □ Has appointment on (*write date)* □ Was not given appointment by the facility staff □ Client has transferred to other ART centre (*name centre)* **Other:** Please specify: *OK, some of them complain about money. Others were too sick to come. Some say they were working.* ***What do they say about money?*** *They say they don't have money to come to the clinic. Sometimes you find that they have not disclosed. Maybe at home it becomes a problem to explain where they are going when they leave the home.*
What are the factors that influence when people will come for an HIV test in this community?	*Yes they are there. What influences this? Others maybe had heard that there are testing services at this clinic. Or others we may have told that they needed to test, but they were not ready. Then when they are ready, they come to the facility.*
At what point after diagnosis are patients informed that they are eligible to begin ART?	*At the very same time because we have PIMA. We can take their CD4 count.*
What additional support would a patient need in order to promptly begin ART? care and treatment	*A machine for taking LFTs because we are sometimes held up because we have to take samples to Mbabane. I think that if we had that it would help.*

Date:	**23.5.15**
Clinic	
Interviewer	**Nosipho Gwebu- Storer**
Interviewee:	
Code:	

NARTIS Nurse Interview			
Unique Identifier Study No	**H10**		
Date: (DD/MM/YYYY)	**23.5.15**		
PART I: Clinic Characteristics and Services Information Form			
Clinic Name:		**Region**	
Clinic Chiefdom		**Clinic Inkhundla**	
Primary Health Care Clinic type:	*Type (circle):* Mission Military Company Government NGO	*Type (circle):* *Public/ Private/ Mission* *Public/ Private/ Mission* *Public/ Private/ Mission* *Public/ Private/ Mission* *Public/ Private/ Mission*	

ART Initiating Site?	Y/N	**When did the site begin initiating?**	**(DD/MM/YYYY)** **3rd October 2013**
ART refilling site?	Y/N	How often are refills done:	**Every day, Monday to Friday.**
Service Providers at the health facility	**Cadre**	**How many?**	
	Please tick □ Expert Client □ M2M □ Nurse □ Doctor □ Phlebotomist □ Pharmacist *Other:* Lay counsellor Receptionist Grounds man Drivers	1 2 3 4 5- not now. Currently we do not, we used to. 1 2 3 4 5 6 – 1 2 3 4 5 6 7- 1 2 3 4 5- 1 2 3 4 5 1 2 3 4 5 – *How many?* *1* *1* *2* *2* *This clinic is not like other clinics, because we even have an administration departments, where there is an administrator, with a captain as this is a mission clinic. Then we have as assistant and a secretary, an accountant.. [laughs] its overstaffed really. We have a project officer, because currently we are running a project with NORAD. And we also have an M&E officer, still under the NORAD project. And we also have a social department. For the OVCs. We give bursaries to OVC. And we have 2 outreach clinics as well. One in Mbuluzi, we go there Monday to Wednesday. And we also have another one at Dlangeni. Dlangeni we only go there on Thursday only.*	
Equipment available at the health facility	***Equipment Frequency of use:……Person responsible for use: Maintenance:*** *Unfortunately we don't have a PIMA and we actually love to have that. Because I would like to believe that we do qualify to be regarded or considered as a high volume site. We have been challenged with CD4, where suppose the machine is down at our Mother Facility, it's quite a challenge. So if we could have a PIMA machine we would really really appreciate.* *We have a cell phone sponsored by URC, for patient follow- up. The phone is kept at the Pharmacy. Who is responsible for calling patients? It used to be the EC in those days, when we had one. But now we are using the Lay Counsellor. In most instances its her who does that. But any other nurse….. like currently she is away she is writing exams…. any other nurse….if there us a need, she can call. Then the M2M, that one they have got their own.* *Key words: PIMA, cell phone*		

Community based Services provided at the health facility	*Please tick* .Outreach: *We have seen a lot of activities being done by Salvation Army in the community. We actually go out into the community to check our patients. Because as Salvation Army we are servicing in this community, we are also servicing Fonteyn community as well as Sidwashini community. And we normally go out there to consult with our patients.* HBC Outreach. We also have a Home Based care program. We have nurse counsellors, who are involved in that program. If ever there is a client who lives within the community, who is bedridden.. Just to day nje they will be leaving anytime to… I've forgotten he place… they will be leaving to see another client who is bedridden. That client falls within our jurisdiction so one of our nurse counsellors will go. RHMs: *There was a training for RHMs the whole week. We started on the 13th April until the 26th April, it was on Miekes Mount. What were you training them on? Oooooh on every health related issue, that is health related. We use the RHMS in their community in which they serve, they take care of those clients who are home based. Home based clients. They also keep record of all the chronic clients.* Support groups: Other …
No of staff trained on National Referrals & Linkages National tool	No of staff trained: 1, I remember only 1 Do you remember when they were trained? It should be 2012.
Cell phone available on site for patient follow-up	Y/N
Airtime always available in the phone	Y/N Aritime is always avaiable
Who provides airtime and maintains the phone	URC
Who makes the calls to patients for patient follow-up?	*The Lay counsellor does the call.*
Who conducts the home visits, and how often?	*The 2 nurse counsellors in the facility are the ones who are responsible for home visits. Oh, and how often do they do them? It's just that we are quite busy, since we have started refilling and initiating, you can imagine… At times even if they want to go, they can't. But then its only when the client is critical, like today, the administrator had to come and discuss with the senior sister that can the nurse counsellors go. Otherwise, they are supposed to be going out on a weekly basis to see their clients.*

NARTIS Nurse interview	
PART II: Pre-ART Follow – Up Form	
How long have you been stationed at this facility?	Date: **(DD/MM/YYYY)** I've been here since 2012, 13th April.
How many patients do you initiate in a day?	*It depends…. Ok ok it depends. The maximum of…. I would say plus or minus 6 per day. But there is a time when I used to initiate maybe 10 or so. Like being the only NARTIS trained nurse… at this facility…. There was a challenge that I had to go and take my annual leave. I had to go for the whole 21 days… so for that period there were no initiations, and all the pending patients were waiting for me. So when I came back it was hectic. It was hectic! I would initiate 9, 10, 9, 10. We started off initiating once a week on Thursday, but now we are initiating on a daily basis, because we want to cater for the LAPLLA clients.*
How many patients do you initiate in a month?	*It depends, the figures always fluctuate. The months are not the same. I wish we could just count and give an average. But the months are not the same. They are not the same. There are plus or minus 20. Just recently, in April I*

	initiated 17 general clients. It varies. It also depends on the number of clients who are eligible in that period.
How do most patients react after receiving an HIV-positive diagnosis?	*The ones I have seen… The majority, they have learned to live with this thing. They have just learnty to accept the condition as any other chronic condition. Its only a few clients, there are very few instances when they would have problems. When they start grieving, but the majority. You know why is that? What I have noted: when somebody comes to test, they would have already counseled themselves. Do you know…And I have always thought that is the reason why once the result is positive, they are able to cope. Somehow their coping mechanism, it's not that bad. They easily accept. Though because yes it would come as a surprise. But the reason why somebody has some to test is… there is something they have picked. Something has actually promoted them for testing. And when they come they are expecting anything. Of course a positive result will obviously shock them, but the coping mechanism its there. I think since I have started testing I have only had 2 encounters. Dealing with pregnant women. And the other one recently needed to be started on LAPLLA, because she was pregnant. She couldn't just take it. She said no. I said to her let you just go home, when you are don't grieving, you will come back and we talk more.*
Who informs them of their HIV status?	*The Lay Counselor, she tells the client. When the client tests positive she tells them. And also the nurse counselors. So anyone who dies the test is the one to disclose? Yes.*
Who informs them that they need to begin ART?	*In our HTC department, they have a specific department. They have nurse counselors. And they have a lay counselor. So for subsequent visits the person coming for HTC they can be seen by anyone. Upon testing they are going to be in Pre-ART. We draw chemistry and the blood work, and then when they are given a review date to come back for the result. And maybe the CD4 is down. Then the lay counselor will straight away prepare the client for initiation. And will inform her or him that your CD4 has gone way too low. You need to start on ARVs. The same applies when If they are seen by the nurse. Same story. You tell them your CD4 is gone down, according to the guidelines its below… currently we are using the 350… as long as their CD4 is below 350, or they have been staged and they are stage 3 or stage 4, they are told that we have to start on ARVs. And counseling again is needed. Maximum of 2 sessions….Maximum of 3. And one the third day, we initiate.*
What factors determine ART eligibility amongst patients in this facility?	It's the CD4, and the WHO staging. The WHO clinical staging.
What would you say is the amount of time between diagnosis and ART initiation?	Normally we aim at initiating our clients within 2 weeks, we don't want to delay. If you find a client is initiated 2 or 3 months down the line, its normally them who want the delay because of work related commitments most of them. We call them they tell you eish, they can't release me at work. Or some of them they are just not yet ready to start ARVs. And some its provider initiated you have seen your client is sick. Because maybe you have seen your client is sick, they have fever, diarrhoea, they have herpes zoster. When you initiated the test as the health care provider. They do test, only to be shocked that they are positive. And when you start talking about ART initiation, they say they are just not ready.
Can you tell me some of the reasons for not attending last appointment?	*Please tick* □ Too sick to come to clinic □ No money for transport □ Does not want to continue treatment (ART, CTX) □ Visitor in other facility (write name of facility) □ Did not remember appointment □ Has appointment on (*write date)* □ Was not given appointment by the facility staff □ Client has transferred to other ART centre (*name centre)* **Other:** Please specify:

	Work related. The employer obviously. They make it difficult for them to ask for days to come to the clinic. And the majority of them are actually complaining. That is the reason why you find that with most clients who start at 8, we open at 7 o clock. You find them coming early, so that by half past seven, or quarter to eight they are done and they go to work. I just don't know what we can do. It's not easy, it's really not easy. In some instances you find that some of our clients are working on the other side of the border, but they are very few. *And then you even have those, you call them and it's the wrong number. Somebody answers that phone, they tell you it's a wrong number. They tell you that they don't even know that person.*
What are the factors that influence when people will come for an HIV test in this community?	*They are simply empowered. They have the information. They know the benefits of testing and knowing your HIV status. Ok yesterday I was testing another client. I was asking about her last sexual exposure, unprotected. She said it was 4 years ago. Then I just asked her 'and you are not in a relationship currently?' She said no. Then I asked why test? She told me she was listening to a program on the radio about this other lady who had not slept with anyone for four years, and then when she went for testing, she was tested positive. So I wanted to make sure I was safe.*
At what point after diagnosis are patients informed that they are eligible to begin ART?	*If the CD4 is low, we call them. To say come to the clinic for a clinical review. We don't disclose over the phone about whatever we need them for. We just ask them to come to the clinic as soon as possible, and that it is important. A PIMA.*
What additional support would a patient need in order to promptly begin ART? care and treatment	*Obviously more staff…. because we don't want them to queue for long long hours. We have noted that majority of clients that we see here are the working class, so when they queue for long hours its just so stressful to them, yet there is also this issue of the employer not affording them ample time to go to the clinic. Even if you go back with a sick note, that you have been seen and attended, they will not even accept that.*

Date:	**23.5.15**
Clinic	
Interviewer	**Nosipho Gwebu- Storer**
Interviewee:	
Code:	**H11**

NARTIS Nurse Interview			
Unique Identifier Study No			
Date: (DD/MM/YYYY)	**23.5.15**		
PART I: Clinic Characteristics and Services Information Form			
Clinic Name:		**Region**	
Clinic Chiefdom		**Clinic Inkhundla**	
Primary Health Care Clinic type:	*Type (circle):* Mission Military Company Government NGO	*Type (circle):* *Public/ Private/ Mission* *Public/ Private/ Mission* *Public/ Private/ Mission* *Public/ Private/ Mission* *Public/ Private/ Mission*	
ART Initiating Site?	Y/N	**When did the site begin initiating?**	**(DD/MM/YYYY)** **October 2013**
ART refilling site?	Y/N	How often are refills done:	**Every day of the week.**
	Cadre	**How many?**	

Service Providers at the health facility	*Please tick* □ Expert Client □ M2M □ Nurse □ Doctor □ Phlebotomist □ Pharmacist *Other:* Orderly Night watchmen Health assistant	 1 2 3 4 5- not now. Currently we do not, we used to. 1 2 3 4 5 6 – 1 2 3 4 5 6 7- plus 1 Nurse Assistant. 1 2 3 4 5- 1 2 3 4 5 1 2 3 4 5 – *How many?* *2* *1* *1*
Equipment available at the health facility	***Equipment Frequency of use:……Person responsible for use: Maintenance:*** *We have 2 cell phones. One is specifically for ART clients, and the Pre-ART. And then the other one is for Mothers to Mothers. For calling clients.* *Key words: PIMA, cell phone*	
Community based Services provided at the health facility	*Please tick* □.Outreach: □ HBC Outreach. □ RHMs: We have RHMs. We have probably 100. We use them specifically for tracing clients. ART clients and Pre-ART clients. And for dissemination of information. □ Support groups: We have a support group for M2M here at this clinic. Every 2 weeks. It for those who are breastfeeding. □ Other …	
No of staff trained on National Referrals & Linkages National tool	No of staff trained: I would say all of us. 3 When I recall, it was 2013	
Cell phone available on site for patient follow-up	Y/N	
Airtime always available in the phone	Y/N Airime is always there	
Who provides airtime and maintains the phone	Its from URC	
Who makes the calls to patients for patient follow-up?	*It the Expert Client*	
Who conducts the home visits, and how often?	*We don't have.*	

NARTIS Nurse interview	
PART II: Pre-ART Follow – Up Form	
How long have you been stationed at this facility?	Date: **(DD/MM/YYYY)** 8 years.
How many patients do you initiate in a day?	*Per day? It's hard to say per day. But I would say 1 client per fortnight.*
How many patients do you initiate in a month?	*In a month, it's about 2 or 3 clients per week.*
How do most patients react after receiving an HIV-positive diagnosis?	*Ok few show shock. Others come when they are already ready.*

Who informs them of their HIV status?	*They are informed by the nurse, who has tested them.*
Who informs them that they need to begin ART?	*Its the nurse who tests them. And the Expert Client as well because when the sample transportation car arrives with the bloods, they are the ones who receive the labs results. They then tell the patient that they need to start ART.*
What factors determine ART eligibility amongst patients in this facility?	WHO staging. And CD4.
What would you say is the amount of time between diagnosis and ART initiation?	It depends on when the results come back. If the results come back today, then then client is called today. And told to come to the clinic. I would say, even the following day or let's just say 3 to 5 days.
Can you tell me some of the reasons for not attending last appointment?	*Please tick* □ Too sick to come to clinic □ No money for transport □ Does not want to continue treatment (ART, CTX) □ Visitor in other facility (write name of facility) □ Did not remember appointment □ Has appointment on (*write date)* □ Was not given appointment by the facility staff □ Client has transferred to other ART centre (*name centre)* **Other:** Please specify: *Others take advantage of their buffer stock. They know they have other pills. They tell themselves that they still have pills.* *Also issues of transport. There is a shortage of transport. Others of them, even though its not that common, but they cannot read. Its their level of education and literacy.*
What are the factors that influence when people will come for an HIV test in this community?	*There are also some comorbidities. Such as diabetes. If their date for their other illness is not the same as the other refill date, they will pick a date that is workable for them. Then you find they miss their set appointment date, Some tell me that they had exposure in that particular month. Others have been treated for and STI. They come for treatment, but they don't want to test on that day. Then they return for and HIV test when they are ready.*
At what point after diagnosis are patients informed that they are eligible to begin ART?	*When the Expert Client and Nurse see them in pre-ART.*
What additional support would a patient need in order to promptly begin ART? care and treatment	*I would say I would be very happy to have a PIMA, because then we could take bloods daily. Also a Gene Expert. And more personnel. We need more people to test people for HIV, and a phlebotomist to take bloods. To be onsite. Because the sample transportation comes at 9am. Because of problems of transport, many people are not here by then. To take bloods. So it means that they have to return on another day.*

ANNEXURE N

TABLE 1: TABULATED ASSIGNMENT OF UNIQUE IDENTIFIERS

Series	Visit date	Unique Identifier No.
1	07.04.15	2015/H1
2	07.04.15	2015/H2
3	07.04.15	2015/H3
4	07.04.15	2015/H4
5	07.04.15	2015/H5
6	21.04.15	2015/H6
7	22.04.15	2015/H7
8	15.05.15	2015/H8
9	15.05.15	2015/H9
10	23.05.15	2015/H10
11	23.05.15	2015/H11

ANNEXURE O

TESCH'S OPEN CODING

- Get a sense of the whole by reading and re-reading the transcripts.

- Explore the underlying meaning of the transcripts, through asking the question, *"what is this all about?"*

- Explore this process for several more transcripts, listing the emerging topics and themes that emerged through each interview, and that cut across the interviews. The process of identifying emerging themes and developing a category scheme begins here. This thematic analysis ascribes meaning across a dataset that assisted to provide an answer to the phenomenon being explored.

- List the topics, and making continuous reference to the transcribed interviews, identify the segments where these topics emerged.

- Code them as categories and subcategories. Coded themes were indexed and filed. This reductionist approach will assist to convert the data into smaller, more manageable units that can be retrieved and reviewed by the researcher (Polit & Beck 2012:558).

- Finalise all the coding, organising the categories and sub-categories.

- Review and analyse the data within in each category.

- During analysis of the data within each category, there are opportunities to re-code the existing data

ANNEXURE P

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Adults and adolescents	Children
Clinical Stage 1	
Asymptomatic Persistent generalized lymphadenopathy	Asymptomatic Persistent generalized lymphadenopathy
Clinical Stage 2	
Moderate unexplained weight loss (<10% of presumed or measured body weight) Recurrent respiratory tract infections (sinusitis, tonsillitis, otitis media, pharyngitis) Herpes zosterAngular cheilitis Recurrent oral ulceration Papular pruritic eruption Fungal nail infections Seborrhoeic dermatitis	Unexplained persistent hepatosplenomegaly Recurrent or chronic upper respiratory tract infections (otitis media, otorrhoea, sinusitis, tonsillitis) Herpes zoster Lineal gingival erythema Recurrent oral ulceration Papular pruritic eruption Fungal nail infections Extensive wart virus infection Extensive molluscum contagiosum Unexplained persistent parotid enlargement
Clinical Stage 3	
3Unexplained severe weight loss (>10% of presumed or measured body weight) Unexplained chronic diarrhoea for longer than 1 month Unexplained persistent fever (intermittent or constant for longer than 1 month) Persistent oral candidiasis Oral hairy leukoplakia Pulmonary tuberculosis Severe bacterial infections (such as pneumonia, empyema, pyomyositis, bone or joint infection, meningitis, bacteraemia) Acute necrotizing ulcerative stomatitis, gingivitis or periodontitis Unexplained anaemia (<8 g/dl), neutropaenia (<0.5 x 109/l) and/or chronic thrombocytopaenia (<50 x 109/l)b	Unexplained moderate malnutrition not adequately responding to standard therapy Unexplained persistent diarrhoea (14 days or more) Unexplained persistent fever (above 37.5°C, intermittent or constant, for longer than one 1 month) Persistent oral candidiasis (after first 6 weeks of life) Oral hairy leukoplakiaLymph node tuberculosis Pulmonary tuberculosis Severe recurrent bacterial pneumonia Acute necrotizing ulcerative gingivitis or periodontitisUnexplained anaemia (<8 g/dl), neutropaenia (<0.5 x 109/l) or chronic thrombocytopaenia (<50 x 109/l) Symptomatic lymphoid interstitial pneumonitis Chronic HIV-associated lung disease, including bronchiectasis

Clinical Stage 4	
HIV wasting syndrome Pneumocystis (jirovecii) pneumonia Recurrent severe bacterial pneumonia Chronic herpes simplex infection (orolabial, genital or anorectal of more than 1 month's duration or visceral at any site) Oesophageal candidiasis (or candidiasis of trachea, bronchi or lungs) Extrapulmonary tuberculosis Kaposi sarcoma Cytomegalovirus infection (retinitis or infection of other organs) Central nervous system toxoplasmosisHIV encephalopathy Extrapulmonary cryptococcosis, including meningitis Disseminated nontuberculous mycobacterial infection Progressive multifocal leukoencephalopathy Chronic cryptosporidiosis Chronic isosporiasis Disseminated mycosis (extrapulmonary histoplasmosis, coccidioidomycosis) Lymphoma (cerebral or B-cell non-Hodgkin) Symptomatic HIV-associated nephropathy or cardiomyopathy Recurrent septicaemia (including nontyphoidal Salmonella) Invasive cervical carcinomaAtypical disseminated leishmaniasis	Unexplained severe wasting, stunting or severe malnutrition not responding to standard therapy Pneumocystis (jirovecii) pneumonia Recurrent severe bacterial infections (such as empyema, pyomyositis, bone or joint infection, meningitis, but excluding pneumonia) Chronic herpes simplex infection (orolabial or cutaneous of more than 1 month's duration or visceral at any site) Oesophageal candidiasis (or candidiasis of trachea, bronchi or lungs) Extrapulmonary tuberculosis Kaposi sarcoma Cytomegalovirus infection (retinitis or infection of other organs with onset at age more than 1 month) Central nervous system toxoplasmosis (after the neonatal period)HIV encephalopathy Extrapulmonary cryptococcosis, including meningitis Disseminated nontuberculous mycobacterial infection Progressive multifocal leukoencephalopathy Chronic cryptosporidiosis (with diarrhoea) Chronic isosporiasis Disseminated endemic mycosis (extrapulmonary histoplasmosis, coccidioidomycosis, penicilliosis) Cerebral or B-cell non-Hodgkin lymphoma HIV-associated nephropathy or cardiomyopathy

In the development of this table, adolescents were defined as 15 years or older. For those aged less than 15 years, the clinical staging for children should be used.

For children younger than 5 years, moderate malnutrition is defined as weight-for-height <–2 z-score or mid-upper arm circumference ≥115 mm to <125 mm.

Some additional specific conditions can be included in regional classifications, such as penicilliosis in Asia, HIV-associated rectovaginal fistula in southern Africa and reactivation of trypanosomiasis in Latin America.

For children younger than 5 years of age, severe wasting is defined as weight-for-height <–3 z-score; stunting is defined as length-for-age/height-for-age <–2 z-score; and severe acute malnutrition is either weight for height <–3 z-score or mid upperarm circumference <115 mm or the presence of oedema.