# EXPERIENCES OF EARLY ANTIRETROVIRAL THERAPY (ART) INITIATION AMONG PEOPLE LIVING WITH HIV IN LIVINGSTONE DISTRICT IN ZAMBIA

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**A mini-thesis submitted in partial fulfillment of the requirements for the degree of Masters in Public Health at the School of Public Health, University of the Western Cape, South Africa**

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**May 2018**

## KEY WORDS

HIV/AIDS
Antiretroviral therapy
People Living with HIV (PLHIV)
Early initiation of ART
Experiences
Health facility
Livingstone
Zambia

## ABBREVIATIONS

AIDS - Acquired Immunodeficiency Syndrome
ANC – Antenatal Care
ART - Antiretroviral Therapy
ARV - Anti-Retroviral
HCW – Health are Workers
HIV - Human Immunodeficiency Virus
HPTN - HIV Prevention Trials Network
PLHIV – People Living with HIV
PMTCT – Prevention of Mother to Child Transmission
PopART - Population Effects of Antiretroviral Therapy to Reduce HIV Transmission
RA – Research Assistant
SSA – Sub Sahara Africa
TasP – Treatment as Prevention
UNAIDS – United Nations Program on HIV/AIDS
UNZABREC – University of Zambia Bio-medical Research Ethics Committee
UTT – Universal test and Treat
VMMC – Voluntary Medical Male Circumcision
WHO – World Health Organization

## Definitions of key term

1. Early initiation of ART (also referred to as immediate ART) - ART initiation in all adults living with HIV, regardless of WHO clinical stage and at any CD4 cell count. For the purpose of this study, early initiation of ART was defined as initiation of ART at CD4 ≥500 cells/mm$^3$.

## ABSTRACT

### Background

Recent HIV treatment guidelines recommend offering antiretroviral treatment (ART) to all People Living with HIV (PLHIV) regardless of CD4 count. Given this new approach, insights on current experiences of PLHIV initiating early treatment (CD4 ≥500 cells/mm$^3$) are critical.

### Methods

In July 2017, in-depth interviews were conducted with fourteen purposively selected PLHIV initiated on ART early (6 men, 8 women, aged 20-49 years) in one health facility as part of a combination prevention community randomized trial (HPTN071 (PopART)). Additionally, three health care workers (HCWs) at the same facility were interviewed. Interviews were transcribed, managed using ATLAS.ti and analysed thematically.

### Results

Being healthy (*'feeling fine'*) and health deterioration (*'getting sick'*) were key health concerns among PLHIV prior to ART initiation. PLHIV often referred living with HIV as 'being sick' and experiencing poor health when already infected with HIV as 'very sick' and this perception about sickness and wellness partly determined the need and value placed on accessing HIV services. Motivations for starting treatment included needing to maintain or regain health, encouragement from HCWs, relatives and friends and believing in the effectiveness of ART to improve health. Prevention of HIV transmission to others was not cited to influence uptake. The majority of PLHIV reported stringent adherence to ART; even a half-hour delay in taking treatment was sometimes defined by participants as 'non-adherence'. Initial reminders for taking ART (setting alarm, placing pills where visible) fell away as daily medication became routine. However, daily uptake of treatment had its own psychosocial and economic consequences which PLHIV had to navigate. With few exceptions, when taking the first line regimen, most PLHIV experienced both temporal (hallucinations, vomiting) and long-term (dizziness and irregular heartbeat) side-effects attributed to ART, which although not considered life threatening, could undermine ART adherence. HIV status disclosure was both limited and selective (mainly to spouses, close relatives, friends and co-workers) and deemed as promoting adherence to treatment and access to HIV services. HIV/AIDS stigma persisted even among relatively healthy PLHIV due to links with 'promiscuity', hampering disclosure and access to HIV services. Competing demands on participants' time, especially livelihood activities, also disrupted accessing services. Good relationships between HCWs and PLHIV promoted access to services.

**Conclusion**

These findings suggest that taking ART among early initiators was motivated by personal health and not by preventing onward transmission. Whilst stringent ART adherence was seen as maintaining health, adherence could be impeded by side-effects, limited disclosure and stigma. PLHIV needed support from close family and desired easier access to ART. The successful roll-out and implementation of early initiation of ART should consider these dynamics in multiple contexts.

## DECLARATION

I, Melvin Simuyaba, declare that “*Experiences of early antiretroviral therapy (ART) initiation among people living with HIV in Livingstone district in Zambia,”* is my own work, that it has not been submitted before for any degree or examination at any other university, and that all sources I have used or quoted have been acknowledged.

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## ACKNOWLEDGEMENTS

Firstly I would like to express my sincere gratitude to my supervisor, Dr. Thubelihle Mathole and co-supervisor Dr. Virginia Bond for the continued support and guidance throughout the research process. Special thanks to the health staff that assisted in the data collection process. I would not have done it without you.

Sincere thanks to Florence Moyo for assisting with data collection. A big thank you to Zambart for allowing me to undertake this study, according me time to study whilst working and above all for the financial support throughout the program. I am forever indebted.

A heartfelt thank you to all the study participants. Thank you for participating in the study and taking time to share your experiences. I have learnt a lot from you.

I wish to thank my friend Moombe Hamoobola for accommodating me during the time I was collecting data. May God richly bless you.

Lastly, I would like to thank my family for the support and encouragement throughout my studies. To my wife (Tonia) and son (Milimo), thank you for your encouragement, support and above all, according me time to study. I dedicate this work to both of you.To my parents, sisters, cousins, uncles and aunties and grand parents, thanks for the support and encouragement.

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# CHAPTER ONE: DESCRIPTION OF THE STUDY

## 1.1 Background of the study problem

The HIV/AIDS epidemic is one of the world's biggest health problems (Vella *et al.*, 2012). Globally, approximately 36.7 million were living with HIV/AIDS in 2016 and an estimated 1.8 million new HIV infections were recorded in the same year (UNAIDS, 2017). The scale and impact of the epidemic has been worse in developing countries compared to developed countries. In 2016, Sub-Saharan Africa (SSA) had about 25.5 million People Living With HIV (PLHIV), which accounts for about 70 percent (%) of all PLHIV worldwide (UNAIDS, 2017).

Within SSA, the Eastern and Southern African region is home to about 19.4 million PLHIV, accounting for over half (52.8 %) of the world's population living with HIV (UNAIDS, 2017). Southern Africa experiences the most severe HIV epidemic in the world (UNAIDS, 2010). New HIV infections and overall HIV prevalence rates remain exceptionally high in southern Africa (UNAIDS, 2014b). At an estimated prevalence rate of 29.5%, Swaziland had the highest HIV prevalence rate in the world in 2009, UNAIDS (2010) while South Africa's adult HIV prevalence rate in 2016 was at 19.1% (South African National AIDS Council, 2017). South Africa equally had the largest HIV treatment program in the world with 3.4 million PLHIV on ART in 2015 (UNAIDS, 2016a).

Zambia is among the countries with the highest burden of HIV in SSA (Zambian National AIDS Council and Ministry of Health, 2017). In 2015, Zambia had approximately 1,200,000 PLHIV (UNAIDS, 2016b). According to the 2013 - 2014 Zambia Demographic and Health Survey, the estimated adult HIV prevalence rate in Zambia was 13% (15% among women and 11% among men) (Central Statistical Office, Ministry of Health and ICF International, 2014). The epidemic has had negative social and economic effects on the nation. It has been the major cause of illness and death in the most productive age group (Zambian National AIDS Council and Ministry of Health, 2013). This has consequently burdened the health system and deprived the country of its human resources required to foster development (Zambian National AIDS Council and Ministry of Health, 2013). Households have been faced with inadequate income due to loss of household heads and orphaned children and the elderly left to fend for themselves (UNDP, 2007).

Despite several efforts, scientists are still grappling with finding a cure for HIV/AIDS. Towards the end of the 20th century, antiretroviral (ARV) drugs, the lifesaving (lifetime) HIV treatment, were introduced, Vella et al. (2012) and since then have contributed significantly to the progressive turn of HIV infection from a fatal condition into a chronic manageable disease (Palmisano and Vella 2011). Initially the drugs were only available in small quantities and to fewer individuals, especially in developing countries, until early in the 21st century when the idea of a public health approach was developed, hence scaling-up the provision of ARVs (WHO, 2002). Access to antiretroviral therapy (ART) among PLHIV in Eastern and Southern Africa increased from about 24% in 2010 to 54% in 2015, making the total number of PLHIV on ART reach 10.3 million in the region (UNAIDS, 2016a). Subsequently, the region recorded a sharp decrease in HIV/AIDS related deaths, from about 1.1 million in 2004 to about 420,000 in 2016 (UNAIDS, 2017). In Zambia, efforts to increase access to ART were evident through the Government's declaration of the entire ART service package free in the public sector in 2005 (WHO, 2005). By the end of 2016, over 800,000 PLHIV were receiving ART in Zambia (Zambian National AIDS Council and Ministry of Health, 2017).

Over time, the World Health Organization (WHO) backed by scientific evidence, has been shifting the treatment guidelines moving towards early initiation of ART. In 2002, the WHO scaled up ART access in resource limited settings to reduce mortality and morbidity and improve the quality of life among PLHIV through recommending initiation of ART to PLHIV with a CD4 cell count of 200 cells/mm$^3$ and below (WHO, 2002). Eight years later, the WHO revised the treatment eligibility criteria in developing countries, recommending ART initiation at CD4 cell count of 350 cells/µL and below (UNAIDS, 2013).

Most countries in the region used these guidelines until the end of 2012 when they were further adjusted. In 2013, WHO recommended that national HIV programs provide ART to all PLHIV with a CD4 count of 500 cells/mm$^3$ or less, giving priority to those with advanced HIV disease (WHO, 2013). The current WHO guidelines focus on initiating ART among PLHIV at any CD4 cell count (WHO, 2016). These shifts have largely been influenced by evidence that early treatment initiation has both clinical and HIV prevention benefits to improve survival and reduce the incidence of HIV infection at community level (WHO, 2013). Supported by the Joint United Nations Program on HIV/AIDS (UNAIDS) ambitious 90-90-90 targets to reduce HIV/AIDS by 2020, it has become even more eminent that all PLHIV need to be initiated on ART regardless of CD4 cell count (UNAIDS, 2014a).

The HIV prevention benefits of ART have been evolving since the first program of Prevention of Mother-to-Child Transmission (PMTCT) was conceptualized (WHO, 2016).  The use of

ARVs prevents vertical transmission of HIV from mother to child either during pregnancy, labour, delivery or breastfeeding (WHO, 2006). The first guidelines for PMTCT were published in 2004 (WHO, 2016). However, they initially recommended short courses or single doses for the mother and infant after birth before the widespread roll out of lifelong ART to all pregnant and breastfeeding women living with HIV who were eligible for treatment was implemented (WHO, 2016). This shows a similar trend with how treatment guidelines have been changing towards earlier initiation of ART in the general population.

The scale-up of ART in most developing countries including Zambia has been rapid, thereby posing challenges to the health system (Hanefeld, 2010). These challenges are partly because the roll-out of ART in most developing countries has been influenced and heavily funded by global health initiatives yet the recipient countries have limited resources to improve their health systems (Hanefeld, 2010). Bigna et al. (2016) asserted that the implementation of the WHO (2016) treatment guidelines in low income countries would pose challenges due to their weak health systems. In Zambia, the challenges of HIV service provision have been documented overtime, mainly characterized by limited resources and challenging service provision environments, including; health staff work overload (limited human resources), long patient waiting time, overcrowding, limited space for service provision and intermittent supply of drugs and laboratory requirements (Simuyaba et al. 2017; Mukumbang et al. 2017; Topp et al. 2015; Hanefeld 2010).

## 1.2 The HPTN 071 (PopART) study

To measure the population based impact on HIV transmission of providing early and universal ART, often referred to as the Universal Test and Treat (UTT) approach, a large HIV prevention trial was carried out in 21 communities in Zambia (12) and South Africa (9) from 2014-17 (Hayes *et al.,* 2014). The Population Effects of Antiretroviral Therapy to Reduce HIV Transmission (PopART), an HIV Prevention Trials Network study (HPTN 071) was a three-arm, cluster randomized trial (Hayes *et al.*, 2014). The purpose of the study is to determine the impact of a combination HIV prevention intervention package on population-level HIV incidence in Zambia and South Africa (Hayes *et al.*, 2014). In Zambia, the PopART study was approved by the University of Zambia Biomedical Research Ethics Committee (UNZABREC Ref: 011-11-12).

The combination HIV prevention package that was offered in the PopART study included: offering three annual household Voluntary HIV Testing and Counselling (VCT) to all residents through a cadre of community HIV care providers, linking individuals diagnosed with HIV to local health facilities for HIV management, encouraging Voluntary Medical Male Circumcision (VMMC) for HIV uninfected men, promotion and provision of condoms, Tuberculosis and Sexually Transmitted Infections (STIs) screening and referral for care, referral of all pregnant women for antenatal care (ANC) where PMTCT services were provided to those living with HIV and offering immediate ART to those diagnosed with HIV (Hayes *et al.*, 2014). The impact of the package on HIV incidence in the study communities will be measured through a three-year population cohort study among randomly selected adults in all study communities (Hayes *et al.*, 2014).

The impact of immediate ART initiation to PLHIV was initially intended to be measured through the three treatment arms (Hayes *et al.*, 2014). Arm A study communities were receiving the full combination prevention package described above, Arm B study communities were provided with the full combination prevention package except ART initiation was based on local treatment guidelines, and the control arm (Arm C) was receiving standard of care services (Hayes *et al.*, 2014). However, due to the recent changes in the treatment guidelines recommending ART initiation to all PLHIV at any CD4 count, WHO (2016) and the subsequent adoption of these guidelines by the Zambian government, Ministry of Health (2016), the study protocol was revised. Therefore, in April 2016 all study arms started offering immediate ART to all individuals diagnosed with HIV irrespective of their CD4 cell count (HPTN 071 protocol, 2015).

## 1.3 Focus of the study

Given this backdrop, it is imperative to explore how the continued change in treatment guidelines towards earlier initiation of ART has been experienced among PLHIV. Few studies have been conducted to understand the experiences of PLHIV that have been initiated onto ART early. Because the PopART study has been offering immediate treatment to PLHIV in all arm A communities since 2014, it provided an opportunity to investigate the subject. Therefore, this qualitative study explored the experiences of early initiation of ART among a small number of PLHIV in one Zambian health facility in the PopART study.

## 1.4 Problem Statement

The shift in the WHO's guidelines towards early initiation of ART overtime has ultimately changed the focus of interventions hence increasing the number of PLHIV on ART. Although this has reduced mortality due to HIV and made some contribution to falling HIV prevalence globally, little has been done to understand the implications of early initiation of ART among PLHIV at community level. In the early years of the epidemic, PLHIV were initiated onto ART when they had a compromised immune system with a lower CD4 cell count. Therefore, it is important to understand the individual responses, experiences and factors that influence the uptake and motivation to stay on ART among PLHIV initiated onto ART early when they are healthier. Nested within the PopART study, this research sought to understand the experiences of PLHIV initiated on immediate ART since 2014 when the PopART study intervention begun.

## 1.5 Purpose of the study

This study provided early insights on the current experiences of PLHIV initiated on ART early in one Zambian health facility in the PopART study. These insights are critical for resource constrained settings like Zambia because UTT is a relatively new approach whose success is dependent on individual and communal responses. Therefore, the experiences of PLHIV initiated on ART early provide understanding on the factors influencing early uptake of ART, motivations for staying on ART and the practicability of community wide uptake of ART (including access to HIV services) among PLHIV offered ART regardless of their CD4 count. The recommendations of the study could inform the early implementation of UTT in Zambia.

# CHAPTER TWO: LITERATURE REVIEW

## 2.1 Introduction

Early initiation of ART among PLHIV is a relatively new concept and few studies aimed at exploring the experiences of PLHIV initiated onto ART early have been conducted. Therefore, most of the literature reviewed in this chapter is based on the experiences of PLHIV that have been initiated onto ART using the WHO guidelines that required initiating ART at a CD4 count of either 350 or 500 cells/mm$^3$ and below.

## 2.2 HIV/AIDS and ART

Although ARVs do not cure HIV/AIDS (WHO, 2002), there is evidence that they are an effective and lifesaving measure for PLHIV, enabling them to enhance their wellbeing, prolong life and regain health to carry out social and economic activities (Bond *et al.*, 2016). ARVs supresses the viral load in PLHIV to undetectable levels thereby making a considerable contribution towards reduced HIV incidence and opportunistic infections, Cambiano et al. (2011, in Kaye et al. 2013). The apparent HIV threat has reduced due to increased evidence that ART prevents onward transmission of the virus, Kennedy et al. (2007, in Wamoyi et al. 2011). In 2011, the HPTN 052 study showed that an HIV infected individual can significantly reduce sexual transmission of HIV to an uninfected partner by being on ART (Cohen et al. 2011). Since then, scientific evidence shows that early initiation of ART among PLHIV is more beneficial than delayed treatment (WHO, 2016).

## 2.3 The Trajectory of living with HIV

Given the evidence of the benefits of starting ART earlier, the global public health focus in HIV interventions has shifted towards early initiation of ART (WHO, 2016). Consequently, more PLHIV are being initiated on ART than before across the globe (UNAIDS, 2016a). However, starting HIV treatment is not a one off decision for many PLHIV. They often have to undergo a series of complex events that Gilbert & Walker (2009) called the trajectory of living with HIV. The full trajectory of living with HIV starts from the point of testing, deciding whom to disclose to, the decision to start treatment and the experiences around taking treatment (Gilbert and Walker, 2009).

## 2.4 Linking PLHIV into care

Despite the increased availability of ART which is offered for free in most government health facilities in SSA (Musheke, Bond and Merten, 2013), several studies have previously shown that linking newly diagnosed PLHIV into care is often sub-optimal (Mugglin et al. 2012; Rosen & Fox 2011; Horter et al. 2017). More recent universal test and treat studies in southern Africa have also shown similar trends. The HPTN 071 study in South Africa and Zambia, Hayes et al. (2017), the ANRS 12249 treatment-as-prevention (TasP) trial in rural South Africa, Plazy et al. (2016) and the HIV and Tuberculosis care project in Swaziland Parker et al. (2015) have all shown a gap in linking individuals diagnosed HIV positive into care, let alone starting treatment.

The fact that individuals newly diagnosed with HIV take long to access HIV services shows that there are several social, economic and contextual factors that affect the decision to access HIV services and start treatment, Andersen et al. (2000 in Holtzman et al. 2015). Therefore, the initial individual perceptions of HIV and ART prior to HIV diagnosis or soon after diagnosis are useful for understanding the lived experiences of PLHIV in the community, including their motivation to start ART and experiences with treatment (Mbonye *et al.*, 2013).

### 2.4.1 Factors influencing uptake of ART

Several social and environmental factors influencing uptake of ART have been identified by many scholars. Horter et al. (2017) identified acceptance of one's HIV status to be one of the factors that promotes access to HIV services and uptake of treatment. Individuals diagnosed with HIV who at least know a family member who is living with HIV are more likely to engage in HIV care compared to those who do not know any family member living with HIV (Plazy *et al.*, 2016). Disclosure of one's HIV status promotes uptake of HIV services (including treatment) and reduces the risk of transmission (Maeri *et al.*, 2016). Some PLHIV do not take up treatment until their health starts deteriorating, therefore feeling ill influences uptake of HIV treatment (Holtzman *et al.*, 2015).  In the ANRS 12249 TasP trial in rural KwaZulu-Natal in South Africa, PLHIV who lived closer to the health facility offering HIV services were more likely to link to care compared to those who lived further away, showing that distance to the clinic has economic and logistic barriers for PLHIV to access ART (Plazy *et al.*, 2016).

### 2.4.2 Factors influencing non-uptake of ART

Musheke et al. (2013) identified fear of taking medication for a lifetime, misconceptions about ART, side effects of the drugs, disruption of lifestyle due to taking ART, feeling healthy, livelihood insecurity, poor HIV service delivery and concerns about future availability of ART as some of the factors that inhibit uptake of HIV treatment in urban Zambia. Particularly pertinent to the test and treat era, individuals who do not feel unwell or experience any symptoms of illness are less likely to accept an HIV positive diagnosis which in turn influences uptake of treatment (Horter *et al.*, 2017). Additionally, PLHIV who do not disclose their status are less likely to start treatment and receive support when taking treatment (Gari *et al.*, 2014).

## 2.5 Experiences of PLHIV on ART

Living with HIV and being on ART has different meanings for individuals. Bravo et al. (2010) asserted that PLHIV experience diverse and complex psychosocial problems which have not been studied extensively. Gilbert & Walker (2009) termed the diverse experiences that PLHIV on ART undergo as 'social complexities' which include how PLHIV conceptualize their illness and experience the full trajectory of living with HIV. Because early initiation of ART is a relatively new concept which emphasizes ART as prevention, it may change how people perceive HIV testing, prevention and transmission as well as their behaviours towards uptake of HIV testing and ART (Orne-Gliemann *et al.*, 2015).The acceptability of ART among non-symptomatic HIV positive individuals, their adherence to ART, disclosure of HIV status, stigma and marginalization, quality of life, sexual behaviours and other factors affecting PLHIV may change (Orne-Gliemann *et al.*, 2015).

### 2.5.1 Perceptions and experiences with treatment

Pierret (2007) asserted that, although ARVs enhance wellbeing, they change the nature and experience of the illness. A study conducted in South Africa showed that PLHIV see ARVs as their life-line and a means by which they survive yet they also represent dependence and fear, for without them illness would prevail (Gilbert and Walker, 2009). Despite showing gratitude towards ARVs, PLHIV experienced challenges with the quantity and side effects of the drugs and the fact that they are a lifetime commitment without curing the virus (Gilbert and Walker, 2009). Other studies conducted in Zambia found that although ART positively impacted on the health of PLHIV, it was still perceived as harmful, worsening one's condition and causing bodily harm that could lead to death in unexplained circumstances (Musheke et al. 2013; Schumaker & Bond 2008).

A study conducted in Canada among youths living with HIV and on ART showed that they experienced difficulties with taking treatment (Veinot *et al.*, 2006). Taking drugs everyday ignited a depressing thought that reminded PLHIV of their illness, Beer et al. (2009, in Musheke et al. 2013; Veinot et al. 2006). Some PLHIV express reluctance to commit to a lifetime treatment that requires them to change their social lifestyles such as alcohol consumption (Musheke, Bond and Merten, 2013). The nature of the prescription of ART, which has to be taken at a specific time and often not in the presence of people who are not aware of a PLHIV's condition, disrupts social routines (Veinot *et al.*, 2006).

A focussed inquiry on the perceptions of early initiation of ART based on the participant's knowledge and experiences with HIV and ART in 21 Zambian and South African communities conducted in 2012/13 showed that, starting ART early was perceived to be more beneficial than delayed initiation of ART (Bond *et al.*, 2016).

### 2.5.2 Adherence to ART

Adherence to ART is critical for reducing HIV transmission as a public health benefit and achieving individual clinical benefits, thus, improving the health of PLHIV through viral suppression and avoidance of HIV resistance (Cohen *et al.*, 2011). In order to realise these benefits, greater than 95% adherence level to HIV treatment is required (Letta *et al.*, 2015). There are many known factors that promote and inhibit ART adherence.

#### *2.5.2.1 Factors associated with full ART adherence*

Gilbert & Walker (2009) identified disclosure, support from partners, employers and families and use of technology such as mobile phones to remind PLHIV routinely as facilitators of ART adherence. Similarly, adopting reminder strategies such as alarms, calendars, pillboxes and placing medication where it is visible improves ART adherence among PLHIV (Holtzman *et al.*, 2015). HIV status disclosure to family members, friends and neighbours enables PLHIV to keep clinic appointments and adhere to treatment (Holtzman et al. 2015; Letta et al. 2015). Disclosing to such networks provides support through moral encouragement and support in terms of reminders (both to take ART and make clinic visits) and assistance to access healthcare, for instance, accompanying them or offering transport (Holtzman *et al.*, 2015). Merten et al. (2010) pointed out that motivation for ART adherence improved with a positive identity and social role, including having a family and children to care for.

A study conducted in rural Zambia, found that, full ART adherence was associated with being 'female', and having a spouse who were also receiving ART (Sasaki *et al.*, 2012). Considering the pill burden on PLHIV who have to take the drugs on a daily basis, a medication regimen that requires PLHIV to take fewer pills that were also small in size and had minor side effects proved to improve adherence to ART (Nachega et al. 2014; Letta et al. 2015; Holtzman et al. 2015). A systematic review study of articles focussing on resource limited countries showed that community support initiatives including ART delivery models provide adequate psychosocial adherence support to PLHIV hence improving adherence to treatment (Wouters *et al.*, 2012).

#### *2.5.2.2 Hindrances of ART adherence*

PLHIV are often less likely to adhere to treatment when they feel better (Gilbert and Walker, 2009). Lack of partner support or inability to disclose one's HIV status compromises adherence to treatment (Merten *et al.*, 2010). Reasons for poor adherence in a study conducted in Zambia to assess the influence of demographic characteristics and social surrounding on adherence to ART during the initial months of treatment identified long distance to health facilities, food insufficiency, being busy, depression and forgetfulness (Sasaki *et al.*, 2012). Letta et al. (2015) also reiterated forgetfulness, being away from home (mobility) and being busy as some of the reasons for skipping doses of ART.

Fear of HIV/AIDS stigma and discrimination is one of the factors that hinders adherence to treatment (Audu, Morgan and Rutter, 2014). The fear of being stigmatized due to taking ART among PLHIV can be attributed to the risk of involuntary disclosure when taking ART in the presence of individuals whom they have not disclosed their HIV status to, especially in household settings that do not provide adequate privacy (Holtzman *et al.*, 2015). Consistence with taking ART is sometimes hampered by the volume and number of pills that PLHIV have to take (Holtzman *et al.*, 2015). ART regimens which require PLHIV to take pills that are bigger in size, of higher quantities and cause severe side effects impede adherence to treatment (Nachega et al. 2014; Letta et al. 2015; Holtzman et al. 2015). Other contributing factors to non-adherence of ART include: alcohol use, use of traditional alternatives to ART, being male, lack of social support, poor HIV service provision and depression (Heestermans *et al.*, 2016).

### 2.5.3 Disclosure

Qualitative research data from three research projects in France during a ten year period (1990 – 2000) showed that PLHIV grappled with knowing whom, when and how to disclose their HIV diagnosis (Pierret, 2007). The social processes beyond an individual's control influence decisions to either disclose or not disclose one's status and even when disclosing intentionally for good reasons, disclosing one's status may result into being stigmatized or rejected (Merten *et al.*, 2010). In their studies, Aransiola et al. (2014) and Lyimo et al. (2014) found that only a few PLHIV did not disclose their HIV status to anyone at all, while the majority mostly disclosed to family members and close friends whom they consider trustworthy to conceal the information.

Among the reasons given for not disclosing one's HIV status, Horter et al. (2017) identified failure to accept an HIV positive diagnosis, anticipated HIV/AIDS stigma and fear of being misjudged. Similarly, Pierret (2007) attributed non-disclosure of one's HIV status to fear of being pitied, rejected or misunderstood. Echoing how rejection and being misunderstood occurs for PLHIV, Aransiola et al. (2014) stated that, although various efforts have been made to change people's perceptions towards HIV/AIDS, individuals living with HIV continue to be perceived as victims of promiscuity and naughtiness and sometimes considered not worthy caring for. Non-disclosure of HIV status inhibits openness about individual and health problems (Nixon *et al.*, 2017).

Disclosure of one's HIV status facilitates the process of acceptance which aids social support and linkage to care (Horter et al. 2017; Nixon et al. 2017). Maeri et al. (2016) argued that non-disclosure of one's HIV status is a major obstacle to uptake of HIV services while disclosure (although sometimes results in rejection) promotes uptake of HIV services and reduces the risk of transmission. Disclosure of HIV/AIDS status also promotes adherence to ART (Letta et al. 2015; Holtzman et al. 2015; Gilbert & Walker 2009).

### 2.5.4 HIV/AIDS Stigma

#### *2.5.4.1 The role of ART on HIV/AIDS stigma*

The widespread availability of ART and its accessibility worldwide was seen as an opportunity to reduce HIV/AIDS stigma (Castro & Farmer 2005; Mbonye et al. 2013; Chan, Tsai, et al. 2015). However, this has not been the case. Setlhare et al. (2014) asserted that HIV/AIDS stigma has persisted despite improvements in the quality of life of PLHIV resulting from ART. Similarly, Chan, Weiser, et al. (2015) found that although ART was widely available and improving the health of PLHIV, there was an increase in HIV/AIDS stigma among PLHIV being initiated on ART and anticipated stigma continued in the general population. Some studies have shown that the role of ART on HIV/AIDS stigma is two-pronged. On one hand it is seen as reducing stigma while on the other ART is seen as contributing towards stigma. In one Zambian study, being on ART promoted acceptance due to health improvements and productivity of PLHIV whilst contributing towards stigma through associations with judgements about acquiring HIV, sickness and death and perceived unproductivity of PLHIV (Nixon *et al.*, 2017). Other studies make the same point (Maughan-Brown 2010; Horter et al. 2017).

In a study conducted in Northern Tanzania, participants perceived PLHIV who are on ART to be spreading the virus once they had regained strength and became sexually active  because they could not be physically identified as living with HIV, Roura et al. (2008) cited in (Maughan-Brown, 2010). In this regard, Chan, Weiser, et al. (2015) and Chan, Tsai, et al. (2015) acknowledged that widespread availability of ART alone is inadequate to reduce HIV/AIDS stigma.

### *2.5.4.2 HIV/AIDS stigma in settings and how it is experienced*

A study conducted in Botswana showed that, HIV/AIDS stigma causes psychological, emotional and psychiatric problems due to its influence on the relationships between PLHIV and their friends and spouses (Setlhare, Wright and Couper, 2014). Another study carried out in Nigeria among PLHIV in care, revealed that coping with HIV/AIDS and utilization of healthcare institutions was hampered by negative reactions from the community towards PLHIV (Mbonu, Van Den Borne and De Vries, 2011). Individuals living with HIV often fear being seen accessing services in the health facilities as that would mean they are involuntarily disclosing their HIV status and would eventually start being stigmatized (Horter *et al.*, 2017). For some PLHIV, skipping clinic appointments, using health facilities outside their communities, wearing obscure clothing among others are the measures taken to conceal their status and dodge others (Holtzman *et al.*, 2015). The study conducted by Gilbert & Walker (2009) revealed that there is need for a safe space where PLHIV would not have to hide their condition or medication and received support to enhance continued treatment adherence.

### **2.5.5 Side effects of HIV treatment**

Although ART has dramatically improved clinical outcomes and decreased mortality, some antiviral agents have side effects that limit their long-term application (HPTN 052 Protocol, 2003). The evaluations of the effect on the timing of ART initiation on clinical and microbiologic results comparing the costs, benefits and risks of ART overtime have been controversial (Cohen *et al.*, 2011). In the HPTN 052 study, more adverse events including adverse events resulting from ART were noted in the therapy group (initiated on ART early) compared to the control group (delayed initiation of ART) (Cohen *et al.*, 2011). This could imply that the risk of developing side effects increases for PLHIV initiated on ART earlier because they would have to stay on ART longer. However, Renju et al. (2017) argued that the benefits of taking ART including suppressing the virus are more than the risks of developing side effects.

Most PLHIV on treatment have reported some side effects due to taking ART and these side effects are among the reasons for poor adherence to ART (Koole *et al.*, 2016). Healthy PLHIV without any symptoms of sickness and feeling fine when initiated on ART are less likely to endure side effects resulting from ART hence they may discontinue taking ART and accessing HIV services when they experience side effects (Renju *et al.*, 2017). Pierret (2007) asserted that, the medication has undesirable, and in some cases serious side effects such as tiredness or diarrhoea. Merten et al. (2010) affirmed that side effects may be difficult to endure for a patient. Side effects experienced by PLHIV due to taking ART can either be severe or mild, and usually include dizziness, headaches, pain, fatigue, loss of energy, depression (Renju et al. 2017; Koole et al. 2016).

A study conducted in Canada showed how some youths experienced drug side effects – “I was given a medication and I wasn’t told that it would shift the body fat in my body, and I was mortified when I saw these really repulsive changes…” (Veinot et al. 2006:264). A study conducted in Zambia also revealed that side effects resulting from taking ART deterred PLHIV from starting treatment due to observable body changes they had seen from those who had already started taking treatment which also attracted HIV/AIDS stigma (Musheke, Bond and Merten, 2013). PLHIV explained how ART induced permanent body changes, citing breast enlargement, build-up of abdominal fat and muscle wasting, referring to these changes in body shapes as ‘structure-less’ or ‘deformation’ (Musheke, Bond and Merten, 2013).

### 2.5.6 Sexual desires and behaviours of PLHIV

Although ART restores normalcy for PLHIV, they sometimes struggle to continue living a normal sexual life and being in meaningful relationships especially if one had been identified as living with HIV due to illness or symptoms of HIV (Mbonye *et al.*, 2013). Pierret (2007) explained that, after infection, PLHIV had reservations about sexual relationships with particular conscience that sex had to be safe and the fear of spreading the virus to others was ever present. Similarly, studies conducted in Uganda described the changing sexual desires of PLHIV initiated on ART as diminished at the initial start of medication (Wamoyi et al. 2011; Mbonye et al. 2013). The reasons given for not indulging in sex despite reporting improved health since starting ART included; not having recovered fully, loss of interest in sex, Health Care Worker’s (HCW) advice of not engaging in sex, fear of superinfection, fear that the virus would regain strength and that they no longer considered sex as an important part of their lives among others (Wamoyi *et al.*, 2011).

However, as PLHIV regain strength, many reported increased desire for sex with difficulties in practicing safe sex or finding sexual partners (Wamoyi et al. 2011; Mbonye et al. 2013). Some PLHIV purposely seek sexual partners who are also living with HIV to either avoid stigma or being judged by other community members about their sex lives or avoid suspicion of vindictively infecting those perceived to be uninfected (Mbonye *et al.*, 2013). Others conceal their HIV status to their uninfected partners because of fear of jeopardising their relationships (Mbonye *et al.*, 2013). Newer HIV prevention approaches such as TasP have also ignited a blaming attitude towards PLHIV who are perceived to be responsible for reducing the spread of HIV (Bond *et al.*, 2016).

## 2.6 Gaps in the literature

The success of ART is highly dependent on PLHIV's experiences and ability to make decisions about treatment including starting and adhering to treatment (Do, 2011). The implementation of an HIV prevention approach like early initiation of ART should be tailored towards specific contexts and its acceptability needs to be researched further (Vernooij et al. 2016; Young & McDaid 2014). However, few studies have been conducted in developing countries to explore acceptability of ART as prevention of HIV transmission among users and their experiences with taking ARVs (Young and McDaid, 2014). Therefore, exploring the experiences of PLHIV initiated onto ART earlier will provide insights on its implications to PLHIV.

## 2.7 Summary of the literature review

ART does not cure HIV/AIDS but has been scientifically proven to be effective in improving the health of PLHIV. The HIV testing, linkage to care and ART journey for PLHIV is complex and requires navigating through socio-economic, psychological and contextual factors. The trajectory of living with HIV begins from HIV testing, deciding whom to disclose to, starting treatment and experiences around taking treatment (including but not limited to, side effects of ART, adherence to ART, HIV/AIDS stigma and accessing HIV services). These aspects of the trajectory of living with HIV are related, and one aspect often influences the other. The advent of early initiation of ART has shifted the focus of ART interventions from individual clinical benefits to community prevention benefits to reduce onward transmission of HIV to sexual partners. This may change the experience of PLHIV since they now have to be initiated on ART when they are still healthy. Exploring the experiences of PLHIV initiated on ART early adds knowledge to the field of HIV since few studies have been conducted in developing countries (particularly SSA) to understand the acceptability of TasP among users and their experiences with taking treatment.

## CHAPTER THREE: METHODOLGY

### 3.1 Introduction

The preceding chapters described the study and summarized some of the literature on the experiences of PLHIV who are on ART. This chapter describes the study methodology. It highlights the study aim and objectives, its design and describes the research setting. Further, it provides details of the study population, sample and sampling procedures that were used for the study. Lastly, the data collection and analysis processes, measures taken to maintain quality of the study and ethical considerations are also presented.

### 3.2 Study aim and objectives

The aim of this study was to explore the experiences of early ART initiation among PLHIV accessing ART services at a government health facility in Zambia.

The three main objectives were:

**3.2.1** To explore the motivating factors for early ART uptake among PLHIV accessing ART services at a government health facility in Zambia.

**3.2.2** To explore the individual experiences of taking ART among PLHIV initiated on ART early at a government health facility in Zambia.

**3.2.3** To describe the experiences of living with HIV in the community among PLHIV initiated on ART early at a government health facility in Zambia.

### 3.3 Study Design

This was an exploratory qualitative study design (Baum, 1995). This design was deemed suitable because it enabled the researchers to explore and derive a deep understanding of the perceptions, experiences, behaviors and social meaning of immediate initiation of ART among PLHIV initiating ART early in their socio-cultural context (Pope and Mays, 1995). Data were collected in textual form using open-ended questions which are exploratory in nature (Mack *et al.*, 2005). This allowed individual participants to provide unanticipated responses which enabled in-depth understanding and interpretation of their experiences with early ART initiation (Baum, 1995).

## 3.4 Study setting

The study was conducted at the main government health facility offering HIV services in one of the PopART study communities in Zambia. In 2016, the health facility's catchment area had a population of about 28,700 with about 2,297 accessing HIV services (ART clinic in-charge, 2016, personal communication, 31 August). The main HIV services provided at the facility include VCT, VMMC, PMTCT, ART and STI screening. With few exceptions, the clients accessing HIV services at the facility are mainly from within the research community. The PopART study, HPTN 071 protocol (2015) and the Ministry of Health's decision to pilot universal treatment, PEPFAR (2017) provided the impetus and opportunity to select the research community and facility where the researcher had been conducting research as part of the PopART study team since 2013. The research community is a large peri-urban community mainly characterised by low income households. The main ethnic groups living in the research community are Tonga and Lozi speaking people.

## 3.5 Study population and sampling

### 3.5.1 Description of the study population

The study population comprised of PLHIV and HCWs. The PLHIV group included PLHIV who were initiated on ART early either through the PopART study or through PMTCT interventions at the health facility and were still accessing HIV services at the research facility. These included both men and women over the age of 18 years who had started treatment at least one year prior to 17th July 2017 when data collection started. These participants were chosen because they could provide their personal experiences with early ART initiation.

The HCWs were the study key informants and they comprised of both professional and lay HIV healthcare providers at the research facility. HCWs (men and women) who at least had two years' work experience with providing HIV services at the research facility were considered for participation in the study. They were chosen as study key informants because of their familiarity with some of the experiences and attitudes of PLHIV who were initiated on ART early since they interacted with them when providing services.

### 3.5.2 Study sample and sampling procedure

Purposive sampling, Robson (2011) was used to select study participants. Participants who had been initiated on ART early were deliberately selected so as to explore their personal experiences with early ART initiation (Ritchie and Lewis, 2003). A heterogeneous sample, Robson (2011) of PLHIV, both men and women and of varying age groups who had been initiated on ART early at least a year prior to data collection were selected to participate in the study. A period of one year was chosen for one to be eligible to participate in the study because it was considered a sufficient period for PLHIV to have had adequate information to share about their experiences with early initiation of ART. Fourteen PLHIV were purposively selected based on gender, age and period since they were initiated onto ART.

Three key HCW representatives, two clinical staff and one Community Lay Worker (CLW) were selected to participate in the study. Only HCWs who had worked at the facility for at least two years were eligible to participate in the study. Two years was considered to be a sufficient period for HCWs to have been conversant with the experiences of PLHIV.

Although the initially proposed study sample for PLHIV participants was seventeen, the researchers only interviewed fourteen. This was because it was difficult to identify potential study participants and some participants refused to take part in the study. Though additional data would have been collected by interviewing more participants, the data gathered was sufficient to provide insights on the experiences of PLHIV initiated on ART early.

## 3.6 Data Collection

### 3.6.1 Data collection method

Data were collected through in-depth interviews, Ritchie & Lewis (2003) in the study participant's preferred language (Tonga, Lozi or English). In-depth interviews were used because they enabled the researcher to ask detailed questions which were useful for learning individual perspectives and prompted participants to share their personal experiences regarding early initiation of ART (Mack *et al.*, 2005). Additionally, individual interviews were deemed to be appropriate for data collection because the research topic was sensitive hence required the protection of individual participant's identity and HIV status which could easily be identified in a group discussion (Ritchie and Lewis, 2003).

### 3.6.2 Recruitment of study participants

The researcher with the help of a trained Research Assistant (RA) collected the data between 17th and 28th July 2017. Prior to data collection, the study was introduced to all key HCWs at the ART clinic department. This facilitated the development of an effective recruitment strategy for PLHIV study participants since the eligibility criteria for enrolment was also explained to the HCWs. The HCWs at the ART clinic played an instrumental role in identifying the potential PLHIV study participants using the clinic records (ART register and electronic smart care system). On each day of the data collection period, when the facility got less busy or the HCWs had attended to all the clients for that particular day, a HCW helped the researchers generate a list of potential study participants who had their routine clinic appointment on the subsequent day. The list was generated using the electronic smart care system. The generated list was stored in a lockable drawer in the data room at the health facility and retrived on the actual day of data collection. The RA would then compare the names on the generated list with those on the actual attendance register for PLHIV on a particular day.

The names of the potential PLHIV participants that were appearing on both lists were forwarded to a HCW at the registry or the one responsible for triage depending on how busy either of the service delivery points were on a particular day. The HCW would individually inform the potential study participants about the study in privacy within the service delivery point. The potential participants who agreed to participate in the study were referred (with the help of a HCW) to the researcher (in the PopART office located within the ART clinic building) who provided further explainations about the study and asked them to be interviewed. After each interview, participants were helped by the HCWs to access services to compensate any delays. Using this recruitment strategy, seventeen PLHIV participants were approached. Of the seventeen, fourteen were successfully enrolled and participated in the study, two participated but during the interview it was discovered that they were not eligible (error of clinic records used to identify them) hence the exclusion of their data in this study and one declined to participate. All the interviews with PLHIV participants were conducted in the PopART study office for privacy.

The study key informants were identified through the ART clinic in-charge who recommended potential study participants based on their knowledge and experience with providing HIV services at the health facility. The HCWs who were recommended by the ART in-charge to participate in the study were approached individually by the researcher, had the study explained to them and asked to participate in an interview at their convenient time and place of privacy within the facility. Out of four HCWs that were approached to participate in the study, three participated, one declined. Of the three that were interviewed, two were clinical staff and one was a CLW working as a registry clerk. Interviews with HCWs were equally conducted in privacy, two in the PopART study office and the other in the HCW’s office.

### 3.6.3 The interview processes

Interviews with PLHIV explored their motivation for early ART uptake, experiences with taking ARVs (adherence to treatment and side effects of the drugs) and their narratives of living with HIV in the community including, experiences of stigma and disclosure (see appendix IV for the interview guide). The researcher did not ask the questions in the interview guide in a chronological order but asked participants an initial open question and the subsequent questions depended on the responses given by the participants and often made additional probes (Ritchie and Lewis, 2003). All interviews began with the question, “to start with, we would like to hear from you how you tested for HIV and was diagnosed HIV positive?” This allowed for a smooth flow of the conversation enabling participants to give as much detail as they wished regarding the research topic, starting from how they were diagnosed with HIV, started treatment, their experiences with taking treatment and living with HIV (Robson 2011).

The HCWs shared useful information regarding their experiences with providing early ART to PLHIV and their observed attitudes, behaviours and perceptions of those initiated on ART early (see appendix V for the interview guide). Because qualitative research is flexible, Baum (1995), after the first interview with a HCW, the interview guide was slightly adapted in order to allow a logical flow of the interviews with the other two HCWs (see appendix VI for the adjusted interview guide with changes underlined and highlighted). The HCWs were also asked some follow up questions regarding what the PLHIV participants had said. Therefore, the interviews with HCWs were conducted towards the end of the data collection period.

All interviews except one (participant declined to be audio recorded) were audio recorded once participant’s consent was granted. Detailed notes were written for the interview that was not audio recorded. Additionally, for all the interviews, notes were also taken by the RA to note both the participant’s verbal and non-verbal cues and reflect on the interview process (Mack *et al.*, 2005). At the end of each day of data collection or interview the researcher and the RA debriefed and made comprehensive summaries of the interview notes in order to maintain their quality, reflect on the interview(s) and identify emerging issues for further follow up (Pope, Ziebland and Mays, 2000).

## 3.7 Data analysis

The interview recordings were verbatim transcribed and identifiable names of places and individuals were replaced with pseudonyms. All the interview recordings, notes and transcripts were clearly labelled and stored on a password protected computer and backed up on an external hard drive to avoid loss of data. Hard copies of the data were stored in a lockable drawer. The transcripts and interview notes were loaded in Atlas ti, a computer software package designed for analysing qualitative data which enables complex organization and retrieval of data (Pope, Ziebland and Mays, 2000).

Thematic analysis was used in this study (Robson, 2011). This involved exploring the textual data inductively to identify emerging codes and themes which were used to understand what the data means (Robson, 2011). The researcher started familiarizing himself with the data during data collection and whilst transcribing the interviews (Robson, 2011). However, after transcribing the data, the transcripts were read several times again by the researcher to immerse himself in the collected data and allow further familiarization with the data (Robson, 2011). In so doing, the researcher searched for meaning and patterns in the data whilst keeping memos of any reflective captions (Robson, 2011).

Thereafter, segments of the transcripts with particular meanings were identified and each assigned with a code (Robson, 2011). A coding framework was developed where each of the codes was defined so as not to lose meaning during the analysis process. The data was then coded with the aid of Atlas ti. Data assigned to the different codes were grouped into potential themes (Robson, 2011). Using Atlas ti. the themes were made by grouping the codes making up one theme into a family. The themes were further reviewed and comparisons made within and across them to understand what the data means (Robson, 2011). The interpretation process for the data collected helped unveil experiences of PLHIV initiated on ART early using the thematic networks in the data (Robson, 2011). Some of the codes in the data were used as quotations to illustrate interpretation.

## 3.8 Rigour

### 3.8.1 Data triangulation

In this study, data was triangulated to obtain multiple perspectives of the experiences of PLHIV initiated on ART early (Ritchie and Lewis, 2003). Thus, information was gathered from both PLHIV who had been initiated on ART early and HCWs at the facility. Gathering information from these two sources enabled comparing and substantiating the narratives of PLHIV with those of the HCWs (Creswell and Miller, 2000).

### 3.8.2 Member checking

During the interviews, the researchers had to ensure that the participant's responses were clear and that they had understood what the participants implied to avoid data misinterpretation. Although Robson (2011) defines member checking as returning either literally or through correspondence to respondents and presenting to them interpretations you have made, in this study the researchers would reaffirm what participants had said during the interviews.

### 3.8.3 Reflexivity

Ritchie & Lewis (2003) stated that researchers have to identify and make known their assumptions, prejudices and views about the study as a validity technique used in qualitative research. This then would allow readers to understand the researcher's viewpoint and the extent to which he suspended  his personal views from the study (Ritchie and Lewis, 2003). In order to keep track of this, a diary of the researcher's reflections on personal thoughts, feelings, ideas and challenges was maintained throughout the study period. This enabled the researcher to identify personal influences and carry out self-monitoring on the extent to which these views and expectations affected the study. These reflexive notes have been used in the discussion of the study findings.

#### *3.8.3.1 The researchers' background*

The researcher and the RA who collected the data were familiar with the research setting. The researcher had been periodically conducting fieldwork in the research community, including the health facility, for about four years prior to conducting this study while the RA had been working in the research community for about two years.

#### *3.8.3.2 The reserchers preconceptions*

Prior to conducting the study, the researcher anticipated that PLHIV who are initiated on ART with CD4 cell count above 500 cells/mm$^3$ had recently been diagnosed with HIV and had not experienced ill health. The researcher also assumed that adherence to treatment among PLHIV who are initiated on ART early could be problematic and worried that PLHIV who were initiated on ART early would be hesitant to participate in a study because of fear of being stigmatized and involuntary disclosure of their HIV status at the health facility.

### 3.8.4 Training the research assistant

The RA that assisted the researcher to collect data for the study was a trained social science research assistant. During the data collection period, she was further oriented on the study, ethical guidelines and the data collection techniques that were used.

### 3.8.5 Audio recording interviews and verbatim transcriptions

In order to ensure correct interpretation of data, interviews were audio recorded (with the participant's consent). Additionally, the audio recordings were verbatim transcribed. For the participant who declined to have the interview audio recorded, detailed notes were taken during the interview and expanded on the same day to avoid misinterpretation.

## 3.9 Ethics Considerations

### 3.9.1 Ethical approvals from relevant ethics boards

Ethical approvals for this research were obtained from the University of the Western Cape's Senate Research Committee (reference number: BM/17/1/8) and the University of Zambia Biomedical Research Ethics Committee (UNZABREC Ref: 011-11-12). The study approval letters have been attached as appendices VII and VIII respectively. Permission to conduct the study in Zambia was granted by the Zambian National Health Research Authority (Appendix IX) and the respective provincial and district medical officers. The manager at the health facility also allowed the researchers to collect data from the facility.

### 3.9.2 Protecting the identity of the study participants during recruitment

The potential PLHIV study participants were identified and privately approached by HCWs providing HIV services. Once approached by the HCWs, the potential study participants had to initially verbally consent to participate in the study before being referred to the PopART office located within the ART clinic building where the researcher explained the study to them in detail and privacy. The referral of potential study participants by HCWs to the PopART office where the researcher was positioned was not obvious because different clients accessing HIV services at the facility are referred to different points by HCWs. During the referral process, the HCWs, the researcher and RA coordinated effectively to ensure that potential study participants do not meet each other or queue up before meeting the researcher. Through this recruitment process, the identity and HIV status of the potential study participants was not identifiable hence their protection.

The HCW participants were identified using the ART clinic in-charge who recommended potential study participants based on our eligibility criteria. The identified potential HCW study participants were individually approached in privacy and asked to participate in the study at their convenient time and place of privacy within the facility. All the potential study participants when approached were informed that participating in the study was voluntary.

### 3.9.3 Informed consent process

The researcher adequately informed the potential study participants about the purpose of the study including the possible risks and benefits for participating in the study and reasons for audio recording the interviews. Information sheets (appendices I and II) detailing all the information described above were provided to each of the participants in their preferred language among the three that are widely used in the research community (Tonga, Lozi and English). If unable to read, the participant information sheet was explained to the participants in a language that they understood. This enabled them to make an informed decision on whether to participate in the research or not. Only participants who understood and agreed to participate in the study were enrolled by giving written consent on two copies of the consent forms (appendix III). Participants who were unable to write had to thumb print on the consent form in the presence of their preferred witness who also on their behalf wrote their names on the consent form.

The research participants also had to indicate on the consent form whether they agreed to be audio recorded or not. One copy of the signed consent form was given to the participant and the other was kept by the researcher in a lockable drawer. Participants were also informed and given autonomy to withdraw from participating in the study at any point without any penalty. Additionally, there was an option for a professional counsellor at the facility to help participants who experienced some discomfort, psychological or emotional stress as a result of participating in the study.

However, despite the researcher thoroughly explaining the information sheet and PLHIV consenting to participate in the interview, at the end of the interviews, three of the participants expressed a lack of understanding of why they were participating in the interviews. For instance, one of the participants asked, *"...now the things I have said here…or what I have signed here, now where are you taking it?"* For the other two participants, one asked if the researchers would include her name on the recording while the other asked if she could consult the individuals whose contact details were provided on the information sheet when she experiences health problems like a drop in CD4 cell count. In response to this the researcher had to re-explain the information sheet with particular focus on the questions that the participants had asked. These included explaining the purpose of the research, reassuring participants of confidentiality and the relevance of the contact details provided on the information sheet.

Another ethical issue that the researcher encountered during data collection was emotional stress that one of the participants experienced during the interview. This participant broke down and started crying as she was sharing her experiences. In response to this the researcher, gave the participant time to calm down without interference and offered to link her to a professional counsellor within the health facility. However, she declined to be referred to a professional counsellor saying, she usually cries when she remembers about her ex-husband whom she blamed for infecting her with HIV and also when she thinks about her children's welfare and future. When further asked if the interview should come to a close because of her emotional distress, she argued that it should continue as she was fine. Therefore, the researcher proceeded with the interview. However, after the interview the researcher informed the participant of his intent to inform a professional counsellor to provide emotional support and counselling for the participant. In this regard, a HCW was informed to facilitate emotional support and counselling for this participant through a trained counsellor at the facility. When a follow-up was made, the professional counsellor confirmed counselling the participant.

### 3.9.4 Protecting the information gathered from the participants

All the information gathered during the study was kept on a password protected computer and external hard drive. Hard copies of data were kept in a lockable drawer. The participant consent forms were each stored in an envelope and delinked from the interview recordings or notes. Both the hard copies and soft copies were only labelled by a unique participant identity code. This ensured confidentiality of information shared during the interview and also protected the participant's identity. Participants were assured of confidentiality on information shared and that when the research outcomes are written up, the participant's identities or any identifiable places will not be revealed. However, the researchers informed the study participants of the obligation to break confidentiality if serious health or welfare problems that could cause potential harm to the participant or others were identified during the research. The scenario of the participant who experienced emotional distress given above shows how shared confidentiality was managed during the research.

# CHAPTER FOUR: FINDINGS

## 4.1 Introduction

This chapter presents a brief summary of the study participant's profile and the four main themes and their related sub-themes emerging from the data, which include: PLHIV's health status prior to ART initiation, motivation for early uptake of ART, experiences with taking ART and experiences of living with HIV in the community.

## 4.2 Description of the study participants

The PLHIV participants were eight women and six men between the ages of 20 and 49 years initiated on ART between 25th July 2012 and 9th August 2016. The key informants included two professional HCWs (a 33 years old man who was a clinical officer and a 64 years old woman who was a clinical nurse) and one CLW, a 30 years old woman working as a registry clerk. These HCWs had been working at the health facility for three, four and six years respectively.

## 4.3 Profile of the study participants

### 4.3.1 Summary of PLHIV participants

More women (eight) than men (six) participated in the study. Most participants were middle aged (26 – 35 years), had been married before and had children. Only three participants had never been married and two had no children. Each of the participants had been on ART for at least one year. Additional details of the participants are provided in appendix X.

Table 1: *PLHIV participant details*

| ***Participant identification (ID) code** | **Date of interview** | **Age (Years)** | **Gender** | **Marital status** | **No. of children** | **Date started ART** | **CD4 count @ ART initiation** |
|---|---|---|---|---|---|---|---|
| P1_M_49_656 | 19/07/2017 | 49 | Man | Married | Six | 07/08/2013<br>( 4 Years) | 656 |
| P2_M_30_679 | 19/07/2017 | 30 | Man | Single | None | 09/08/2016<br>(1 Year) | 679 |
| P3_W_34_585 | 19/07/2017 | 34 | Woman | Married | Three | 10/02/2015<br>(2 Years) | 585 |
| P4_W_35_721 | 20/07/2017 | 35 | Woman | Married | Two | 08/07/2013<br>(4 years) | 721 |
| P5_M_32_559 | 20/07/2017 | 32 | Man | Married | Two | 19/11/2013<br>(3 years) | 559 |

| | | | | | | | |
|---|---|---|---|---|---|---|---|
| P6_M_44_661 | 20/07/2017 | 44 | Man | Divorced | Two | 10/05/2013 (4 years) | 661 |
| P7_W_29_523 | 24/07/2017 | 29 | Woman | Divorced | Two | 10/05/2014 (3 years) | 523 |
| P8_W_35_589 | 25/07/2017 | 35 | Woman | Divorced | Three | 08/06/2015 (2 years) | 589 |
| P9_M_44_797 | 25/07/2017 | 44 | Man | Widowed | Two | 10/12/2014 (2 years) | 797 |
| P10_W_20_554 | 26/07/2017 | 20 | Woman | Single | One | 29/01/2015 (2 years) | 554 |
| P11_M_36_559 | 26/07/2017 | 36 | Man | Single | None | 20/08/2015 (2 years) | 559 |
| P12_W_26_543 | 26/07/2017 | 26 | Woman | Divorcee | Two | 17/03/2015 (2 years) | 543 |
| P13_W_37_768 | 27/07/2017 | 37 | Woman | Married | Four | 30/04/2014 (3 years) | 768 |
| P14_W_35_534 | 27/07/2017 | 35 | Woman | Married | Three | 25/05/2012 (5 years) | 534 |

*Participant ID code: Participant number (P#) _Sex (Woman/Man) _Age_CD4 at ART initiation.

### 4.3.2 Summary of key informants

There were three key informants, one man and two women. Two were married and one was a divorcee. They had all been proving HIV services at the health facility for at least three years. The roles of the key informants at the health facility are provided in appendix XI.

Table 2: *Key Informant participant details*

| *Participant ID code | Date of interview | Age (Years) | Gender | Marital status | Period offering HIV services at facility | Department / Position |
|---|---|---|---|---|---|---|
| KI1_W_30_6 | 25/07/2017 | 30 | Woman | Married | Since 2011 (6 years) | Registry clerk |
| KI2_W_64_4 | 26/07/2017 | 64 | Woman | Divorcee | Since November 2013 (4 years) | Clinical nurse |
| KI3_M_33_4 | 27/07/2017 | 33 | Man | Married | 2013 – early 2017 (3 years) | Clinical officer |

*Participant ID code: Key Informant number (KI#) _Sex (Woman/Man) _Age_ Period of HIV service provision at health facility.

## 4.4 Experiences of early ART initiation among PLHIV

### 4.4.1 PLHIV's health status prior to ART initiation

This theme describes the health condition of PLHIV when they were commencing ART. It includes descriptions of the health of PLHIV from the time they were diagnosed with HIV until when they started treatment. Feeling down and hopeless, and feeling normal and 'fit' were key health experiences of PLHIV at the time they were starting treatment. Feeling down and hopeless was attributed to the poor and deteriorating health that PLHIV experienced before commencing treatment which brought feelings of despair on whether they would survive or regain good health. On the other hand, feeling normal and 'fit' was a description of health used by PLHIV who had not experienced any ailments before starting treatment.

#### *4.4.1.1 Feeling down and hopeless*

Although all PLHIV were initiated on ART with CD4 cell counts above 500 cells/mm$^3$, some participants experienced poor health with episodic illnesses prior to ART initiation. Health deterioration prompted some participants to test for HIV and consequently start treatment. Previous treatment guidelines that required PLHIV to be initiated on ART at CD4 cell counts of either 350 or 500 cells/mm$^3$ were blamed for poor health outcomes among some PLHIV because they could not start treatment immediately. Health deterioration was mainly described by changes in physical appearance (weight loss) and getting sick (headache, diarrhoea, stomach pain and feeling dizzy and cold). Knowledge of an HIV positive status and the resulting poor health outcomes diminished hope for survival and recovery. Before starting treatment, P3_W_34_585 expereinced episodic illnesses and lost weight as shown in the excerpt below.

> *I got very sick such that there was nothing good* [loss of hope]... *I used to walk and I also used to do some work, now just the way I used to feel in my body, I would feel cold, a headache, stomach pain…You keep losing weight but you are eating* (P3_W_34_585).

Delays to start treatment caused by previous HIV treatment guidelines that inhibited PLHIV to start treatment early were blamed for poor health outcomes among some PLHIV. After testing HIV positive, PLHIV had to wait for their CD4 cell count to drop before they could be initiated on ART. The quote below shows how one participant felt that his health deteriorated whilst waiting to be initiated on ART.

> *…after testing positive… I was told no I could not be on, be on ART… that was the rule by then… November I realized I think I had gone down* [health deteriorating]*…So, to me I would say, probably by then if I was given my medication at, the time that I was found with the virus, ehhh my CD4 count would have...wouldn't have gone down* (P6_M_44_661).

One HCW relayed that PLHIV initiated on ART regardless of CD4 cell count still exhibit some symptoms of illness and sometimes experience poor health due to compromised immune system. However, the HCW explained that those with high CD4 cell counts have a quicker capacity to recover than those with lower ones.

> *My understanding is that as long as somebody is HIV positive… the immune system has been lowered…But that one who has got a high CD4…the recovery time will be shorter than the one who has got a very low CD4* (KI2_W_64_4).

#### *4.4.1.2 Feeling normal and 'fit'*

Conversely, some PLHIV did not experience any health defects when they were diagnosed with HIV or started taking ART. Feeling normal and fit included narrations of living with the virus and not being aware of it until testing HIV positive due to lack of sickness or any identifiable health changes on the body. Wellbeing was expressed both in terms of physical appearance and the absence of illness. Body weight was often mentioned as a good indicator of health. Maintaining or gaining weight often associated with good health while weight loss was associated with poor health.

Expressing normalcy in terms of physical wellbeing and lack of illness at ART initiation, one woman who was diagnosed HIV positive through ANC explained that she had not noticed anything that would make her suspect that she was infected with HIV.

> *I did not see any change which would make me sick or what…I did not experience anything like getting sick and the like…Everything was just normal* (P4_W_35_721).

Three of eight women who were living with HIV were diagnosed with HIV during pregnancy. They were not aware of their infection until ANC at the health facility provided an opportunity to test. The excerpt below shows how being unaware of HIV infection when actually living with the virus was puzzling for PLHIV.

> *I did not know that I was infected with HIV, because I do not know the day that HIV got into my body…I just used to walk around without knowing…When I came for antenatal that is when I knew that I was infected* (P10_W_20_554).

### 4.4.2. Motivation for early uptake of ART

There were six main reasons that PLHIV mentioned to have motivated them to start treatment early. For some PLHIV, a single factor was enough to influence them to start treatment while others had multiple factors that contributed towards making a decision to start ART. For instance, a HIV positive test result was enough to make some PLHIV to start taking ART. Other reasons that were mentioned by participants included needing to maintain good health, knowing someone who was already on ART, feeling ill, HCW's advice to start treatment and ART being seen as the only alternative once diagnosed with HIV.

#### *4.4.2.1 Being diagnosed with HIV*

In this study, the period of ART initiation from diagnosis varied among PLHIV because starting ART is voluntary and depends on an individual's willingness to commit to lifelong treatment. However, being diagnosed with HIV is the single factor that made all the participants to start thinking about taking ART. Although some PLHIV were not explicit about this, when asked what made him to agree to start treatment early, P2_M_30_679 explained that his reason for starting ART early was a HIV positive test result.

> *I looked at how the test results were…because they found that, I had the infection…that is how I started, that is what made me to start* (P2_M_30_679).

#### *4.4.2.2 Needing to maintain good health*

Maintaining good health was a key motivation for starting treatment early because it was seen as helping PLHIV avoid poor health that would be difficult to recover from. Prolonged sickness was feared to create a burden on relatives particularly if bedridden. Health deterioration resulting from non-uptake or delayed uptake of ART was feared to promote HIV/AIDS stigma due to visible symptoms of HIV/AIDS related illnesses that would develop. The fear of death was also imminent among PLHIV. In order to prolong life and be able to take care of the family, good health was required and starting ART early enabled this.

Having HIV was often referred to as 'being sick' and experiencing poor health when one was already infected with HIV was termed as being 'very sick'. Starting ART was seen as the only way to avoid getting very sick. The excerpt below shows how some participants feared that if they take longer to start ART, their health would deteriorate and if their health deteriorates, it would take longer to regain their normal health status due to weakened immune system with the possibility of death.

> *I think that starting treatment whilst there is still time before you get sick is good…if you wait until you are sick…it will be a bit difficult to get your body back to its normal because you get very sick…sometimes you can even lose your life…at least you start treatment early, so that you preserve your life* (P12_W_26_543).

Maintaining good health through early uptake of ART was also seen as necessary among PLHIV to avoid being a burden to family members when too sick and incapacitated to do anything on their own. This was also partly influenced by participant's previous experiences of PLHIV that became very sick due to HIV.

> *Even so that you do not distress your parents…not that kind of thing where they start taking care of you when you are sick, they start moving you from one position to the other on the bed. Those days are gone…unless you don't know that here what is happening to me is this…* (P12_W_26-543).

Others felt that early uptake of ART without any health ailments would help maintain good health hence inhibiting HIV/AIDS related stigma because the HIV/AIDS symptoms would not show. Delaying to start treatment could lead to visible HIV/AIDS symptoms that would make a PLHIV identifiable to others and risks both self and enacted stigma. The excerpt below is a narration from one PLHIV showing how someone she knew in the community delayed starting treatment and visibly appeared to be living with HIV.

> *…when you are found with this disease….You are not supposed to wait for a long time without taking medication…so her, it's like she discovered she was positive then she waited…so it started showing to people that she was sick* [infected]*…Even when she accepted, people had already known that this person is sick* (P7_W_29-523).

One study key informant also reaffirmed that the need to maintain good health is a motivating factor for PLHIV to start treatment early. He explained that since the new HIV treatment guidelines stipulate that they no longer have to wait for the CD4 count to drop before initiating PLHIV on ART, they are rarely affected by opportunistic infections and do not get bedridden.

> *…since we are not even waiting for the CD4, we just start them as soon as they are just*

> *tested. You find that they don't get ahh, they don't have all those opportunistic infections…those days we used to find that most people used to be bedridden, some used to even go into the HIV* [AIDS] *itself…*(KI3_M_33_3).

### *4.4.2.3 Knowing someone on ART*

Having a partner, close relative, friend or co-worker who has been taking ART also influenced the decision of some participants to start treatment early. The encouragement and support received from those who were already taking ART was a source of hope and played a major role in motivating PLHIV to start treatment early.

> *Because the person I was going out with was also on the medication. So that is what made to ahh, even me let me just start taking the drugs* (P2_M_30_679).

> *…my friends are the ones who strengthened me to start because I was afraid at first…they told me that just start, even us here where you are seeing us we are taking the drugs. When it is 20:00 hours, I see them taking the drugs. So I said to myself, even that one is taking the drugs, let me also just start* (P3_W_34_585).

### *4.4.2.4 Feeling ill*

Feeling ill precipitated early initiation of ART for PLHIV whose health started deteriorating both post and prior to HIV testing. For some PLHIV, when asked if they would have started treatment if they had not been sick, their response was that they would still have waited to get sick prior to starting treatment. When feeling sick, starting treatment as soon as possible was regarded as helpful to regain health and live on. A few of those that had fallen sick before starting treatment appreciated the fact that nowadays PLHIV are being initiated on ART while they were still healthy rather than waiting for them to get sick. One PLHIV who started treatment because he had been feeling ill said:

> *I came to the clinic soon after testing in the community because my health was deteriorating….I started taking treatment with the view that I wanted my health to be fine and prolong my life…* (P9_M_44_797).

### *4.4.2.5 HCW's advice*

The advice and HIV/AIDS counselling that HCWs gave to PLHIV influenced them to start ART early. PLHIV narrated how HCWs explained the importance of starting treatment early (whilst energetic) as well as the dangers associated with delaying to start treatment (being bedridden, suppressed immune system and death). Being informed by HCWs that their CD4 cell count had dropped also persuaded participants to start treatment early.

> *I was told at the clinic, that delaying to start treatment is dangerous. Because when you are found HIV positive while you still have energy to walk, it is good that you start treatment unlike starting treatment when you are bedridden…That is very dangerous, some die, they do not get healed because they delayed. You find that now, the soldiers* [white blood cells] *in the body are finished. It is just the virus which is there.* (P3_W_34_585).

P14_W_35_534 tested HIV positive about five years prior to ART initiation and had been monitoring her CD4 cell count. When asked how she made the decision to finally start treatment even though she was feeling fine, she said:

> *They* [HCWs], *they advised me to say, your CD4 count has gone down its better you start the medication…* (P14_W_35_534).

HCWs also mentioned that they gave advice to PLHIV to start treatment early even when they were feeling healthy.

> *…you make them understand why they should be taking those drugs. You explain to them. I think the most important is, when they understand, they are motivated because they…know it's their life they are protecting…* (KI1_W_30_6).

### *4.4.2.6 ART as the only alternative*

Some participants saw ART as the only option they had once diagnosed with HIV hence opting to start treatment early. Thoughts about their future, hope for long life yet faced with the reality of living with HIV which is irreversible left them with only the option to start ART.  The quotes below illustrate this point as said by two participants.

> *I just thought of my life, because here were I am, am still young and am pregnant. So if I do not continue to take the drugs, even if I refuse today, I am already sick* [infected]. *So that is how I took the drugs so that I can have a long life* (P10_W_20_554).

> *When I came here, they asked me. After they asked me. I told them that I am going to, first let me think about it…but I decided on my own that I should just accept…even if I stay* [live without taking ART], *I have it* [HIV], *it will not come out* (P7_W_29_523).

### 4.4.3 Experiences with taking ART

Each participant explained their unique experience with taking ART. Although these experiences were different, three main experiences emerged: taking the drugs, adherence to ART and side effects due to taking ART. Descriptions of taking the drugs were about the time that PLHIV took their drugs (including the convenience of taking them at a particular time or location) and their perceptions about the effectiveness and strength of the drugs. All PLHIV mentioned that their preferred time to take the drugs was 20:00 hours (8 PM). The drugs were thought to be effective in improving health and very strong. The strength of the drugs was feared to adversely affect PLHIV if they took them on an empty stomach hence the need to eat prior to taking the drugs. Taking treatment also affected the social life of PLHIV because the drugs had to be taken in privacy and were often said to disrupt social routines like taking alcohol.

The majority of PLHIV expressed strict adherence to treatment with only a few mentioning that they sometimes delayed to take the drugs at a specified time (20:00 hours). However, a few still struggled with treatment adherence. Adherence to ART was shaped by factors influencing and hindering adherence to treatment. Factors identified to influence adherence to ART included; observing time and particular routines such as eating before taking the drugs, setting reminders, family support, the fear of getting sick and death, placing the pills where they are visible, being responsible to take the drugs, pill size and encouragement from friends and family. Conversely, adherence to treatment was hindered by; alcohol use/abuse, mobility, specific instructions from HCWs about taking treatment, exhaustion with taking ART, being busy, side effects of the drugs and feeling healthy.

Taking ART for PLHIV resulted in temporal side effects when starting treatment as well as long-term side effects. However, some participants never experienced any side effects from the time they started taking the drugs. The severity of these side effects sometimes affected adherence to treatment. None of the PLHIV raised concerns about the possibility of future side effects resulting from being on ART for a long time since they started treatment early. Although this was raised by HCWs, the fact that research is carried out prior to recommending ART for PLHIV undermined the fears of future side effects.

#### *4.4.3.1 Taking the drugs*

All PLHIV mentioned 20:00 hours as their preferred time to take the drugs. This decision was usually made during ART initiation when HCWs asked them to choose a particular time in a day when they would be free to take their drugs. The time to take treatment had to be tactfully chosen because taking the drugs was feared to interrupt social relationships since they had to be taken in privacy. PLHIV that experienced poor health prior to ART initiation appreciated the effectiveness of the drugs in improving health. The drugs were also said to be very strong. This raised concerns about food security in PLHIV's households because they felt that the drugs were too strong to be taken without food.

#### 4.4.3.1.1 The best time to take the drugs

When asked what time they take the drugs, all the PLHIV participants mentioned that their preferred and agreed time (with HCWs) to take the drugs was 20:00 hours in the evenings.

> *I take the drugs at 20:00 hours every day and it is easy to take the drugs at that time* (P9_M_44_797).

#### 4.4.3.1.2 Social life and taking treatment

Taking treatment was said to disrupt social life as participants mentioned that they had to take the drugs in privacy, often needing to avoid nearby individuals whom they had not disclosed their HIV status to when taking the drugs. Some participants mentioned that they had coped with taking the drugs in the presence of others without disclosing to them by simply picking the pill from the pocket and pretending to hold their mouth whilst releasing the tablet in the mouth and later taking some water. Others said they just excuse themselves from the individual(s) they are with and take the drugs elsewhere in privacy. When asked how she manages to take her drugs in the presence of her boyfriend since she had not disclosed her status to him, P10_W_20_554 said:

> *I take the drugs in advance at home…like my boyfriend, he comes home at night. Then if we go in the afternoon, he returns me home at night. So I find time to take the drugs* (P10_W_20_554).

#### 4.4.3.1.3 The effectiveness and strength of the drugs

The effectiveness of the drugs in improving and restoring the health of PLHIV was widely mentioned by those who initially fell sick before starting treatment. Equally, the strength of the drugs did not go unnoticed as PLHIV described how the first doses of treatment made them develop side effects (dizziness, rash on the body, nausea and hallucinations) and later felt an improvement in their health status within a short period of taking the drugs. Among the notable health changes were weight gain and disappearance of intermittent illnesses (sores on the body, tiredness, dizziness and weakness).

> *When they gave me the drugs for two weeks, just one pill which I took at 20:00 hours, I felt my body lightened…I felt dizzy on the face…after three days, I started feeling my body changing. After two weeks ahhh, I had changed… By the end of the month even on the scale my weight improved, because I was weighing about 40 KGs…I started weighing about 50… just like that I was changing…* (P3_W_34_585).

#### 4.4.3.1.4 The role of food amid taking strong drugs

ART was considered to be a strong drug by many PLHIV and taking the drugs without food was feared to threaten life and worsen the side effects resulting from talking the medication. One participant lamented how expensive food and other necessities had been in the recent past and lobbied that the Government or NGOs should make initiatives to provide food supplements for PLHIV like they used to in the early years of the epidemic. P7_W_29_523 explained how she always had to eat even when she had lost appetite so that she would endure the strength of the drugs in the body and their immediate side effects.

> *…when I take the drugs I would feel like I am drunk, I would feel dizzy…but what was helping me a lot is that I was eating. I was not losing appetite…when I am about to lose appetite, I would still force myself. I knew that the medication is strong. It can kill me if I am…not eating food. So I was forcing myself to eat anything* (P7_W_29_523).

### *4.4.3.2 Adherence to ART*

PLHIV were open about their experiences with adherence to treatment. Most of them said they had never skipped a dose since they started ART. However, some participants mentioned that they would sometimes delay to take the treatment by a few minutes or hours. A few participants said they struggled with treatment adherence. Echoing these sentiments, one HCW when asked about adherence to treatment among PLHIV initiated on ART early said:

> *Most of them do, they do adhere. We ask them, have you missed any drugs, no. Most of them do adhere. There are only a few who would miss or just stop taking or get the drugs and pack them at home…* (KI1_W_30_6).

#### 4.4.3.2.1 Complete adherence to treatment

Though phenomenal, never having skipped a single dose of ART was mentioned by most

PLHIV regardless of period they had been on ART. They mentioned how it had become a part of them (getting used) to take the drugs on a daily basis and how something inherent would remind them to take the drugs. However, it was sometimes confusing for PLHIV to remember whether they had actually taken their dose for a particular day and they would sometimes end up taking their daily dosage twice. P14_W_35_534 had been on ART for about five years and said she had never skipped a single dose.

> *I've never forgotten to take the medicine. From the time I started I have never…It has just become something like which is in me…I've gotten used to it. If I have not taken, something will keep on ringing into me to say, you haven't done something* (P14_W_35_534).

#### 4.4.3.2.2 Intermittent adherence to ART

Not all PLHIV were consistent with taking the drugs on a daily basis or at a specified time. Skipping a dose and delaying taking a dose was mentioned by some PLHIV. This irregular uptake of treatment was usually not intentional and the PLHIV who had such experiences narrated that they continued taking the treatment on their subsequent dose (for those who missed on a certain day or days) or took the dosage later on in the day (for those who had delayed to take the medication at 20:00 hours). The common reasons that were mentioned for this irregular uptake of treatment were; forgetting the medicine at home when going for work on night duty or travelling out of town, being busy at work, delaying to return home or being in the presence of others.

> *…I do not forget. Sometimes I delay by a few minutes or seconds or even hours…sometimes maybe you delay for a short while because you were a bit far…because I take the drugs at 20:00 hours, sometimes I will delay to take the drugs by maybe one hour and in the end when I get home I take the drugs* (P5_M_32_559).

#### 4.4.3.2.3 Poor adherence to ART

Inconsistence with taking drugs either for short or prolonged periods of time was identified among a few PLHIV. This trend was sometimes caused by conditions that PLHIV could not comprehend. For instance one woman said whenever she took the drugs after she became pregnant her heart would beat faster until HCWs advised her to take the drugs after every other day to attenuate this. Only one participant mentioned that she had not taken her drugs for a period of one month when she had travelled away from home for a funeral and never carried her drugs.

> *I have missed for many days… last month I went for a funeral, I forgot my medication…I went last last month…on 23…so I came back to Livingstone on 20…so all these days I have not taken any medication…I was supposed to come and collect my drugs on 26 last month* (P10_W_20_554).

#### *4.4.3.3 Factors influencing adherence to treatment*

The factors that were identified to influence adherence to treatment among the study participants included: adequate preparation ahead of taking the drugs; ease of access to the drugs; various reminders used when it is time to take the drugs; family support; fear of death and poor health outcomes resulting from non-adherence to treatment; taking on the responsibility of treatment; the size of the pills and encouragement from social networks.

##### 4.4.3.3.1 Preparing in advance to take the drugs and ease of access to the drugs

Prior to taking the drugs, participants mentioned some preparatory routine activities they had to carry out. Having to eat before or soon after taking the drugs and routinely checking on time to ensure that the dosage was taken at the right time were mentioned by most participants. PLHIV who frequently travel to places further from their households during the day often mentioned that when it is almost 20:00 hours, they had to find their way home so that they can be there in time to take their drugs. Those that needed to travel far from their homes and knew that they would not return on the same day or before it is time to take the drugs would carry the drugs with them so that they take them wherever they would be when it is time to take the drugs.

###### *4.4.3.3.1.1 Taking meals before or soon after taking ART*

Eating was considered an important aspect prior to taking ART or soon after taking it. For some participants, it was a routine practice to ensure that they have their meals 30 minutes prior to taking ART while others ensured that the food was ready by 20:00 hours so that they could eat soon after taking the medication. The quotes below show how routinely having to eat before or after taking the drugs was followed by some participants.

> *…what I do, when it is like 19:30 hours I should have already eaten…Then I will just wait a few minutes, I take that medication and drink it* (P7_W_29_523).

> *…I take it* [ART] *at 20:00 hours before I eat. When I am done taking the pill, that is when I would eat, by then it would have already been 20:00 hours* (P13_W_37_768).

#### *4.4.3.3.1.2 Checking on time to ensure treatment is taken at the right time*

Having to look at the watch to check if it is already time to take the drugs was mentioned by many participants. Some participants would not have a personal watch hence would ask what time it is from other family members, neighbors or nearby passersby.

> *…sometimes I do not have a phone, I do not have a watch but if I am with someone nearby, then I will ask, what time is it?…I will not tell them why I am asking for the time but on my own I will know that I have to do this thing* [take the medication] (P1_M_49_656).

#### *4.4.3.3.1.3 Needing to carry the drugs*

PLHIV that needed to travel further from their households for long periods mentioned that they had to factor in packing their drugs in their luggage taking into consideration how long they would be away. In cases where their travel plans coincided with their routine clinic visits, some participants mentioned that they had to either cancel their plan or collect the drugs in advance from the clinic to ensure that they have enough drugs for the period they would be away. One participant narrated how he carries his drugs with him and when it is time to take his dosage, he goes to a nearby household and asks for a glass of water so that he can take his medication. The excerpt below shows how PLHIV who carry their drugs with them adhere to treatment.

> *… I do not miss taking treatment from the time I started…I have never. I am strict on that one, even if I go somewhere I make sure they are in the bag* (P4_W_35_721).

#### *4.4.3.3.1.4 Needing to return home early to take ART*

In fear of skipping their dosage, the need to return home early regardless of what they were doing preoccupied some PLHIV. Most participants mentioned that they were in a habit of returning home before it is 20:00 hours so that they could take the drugs on time. P5_M_32_559 mentioned that for him to take the drugs on time, he has to get home in time and usually starts planning for this when the sun sets.

> *Eeehh, we are even used nowadays, ahh even wherever you are, when the sun just sets, that's all, because you now know that it will soon be time to take the drugs…* (P5_M_32_559).

### 4.4.3.3.2 Reminders to take treatment

The use of reminders to take treatment was commonly mentioned by PLHIV, particularly when starting treatment. Once they got used to taking the drugs, it became part of their daily routine hence not needing any reminder. The two main reminders for taking treatment were: setting an alarm and remembering the fact that one was living with HIV. However, some PLHIV said they did not need any reminder to take their drugs as that was inherent (probably after being on ART for some time). The excerpts below show both how PLHIV expressed using an alarm to remind them to take treatment and later stopping and not needing any reminder at all.

When asked if she ever sets an alarm to remind her to take her medication, P12_W_26_543 said:

> *No, I used to do that when I just started taking the drugs. Now I am used* (P12_W_26_543).

On the other hand, when asked what helped her remember to always take her medication since she said she had never skipped a single dose, P4_W_35_721 said:

> *It is just in my mind. When I just look at the time I even know that I have to take the medication…It is like am addicted, when it is just 20:00 hours, I will just have a feeling like my mind is telling me that there is something which I didn't do…then you find that I even go and take the medication* (P4_W_35_721).

### 4.4.3.3.3 Family support

For some PLHIV, their families supported them by reminding them to take their drugs or taking the drugs to them when they had forgotten to carry them when going for work and working on night shift. For couples that were both living with HIV and on treatment, they reminded each other to take the drugs. Some participants mentioned that even though they were not living with their spouses, when it was time to take the drugs they still reminded each other via phone. A participant who said her children helped remind her to take the drugs said:

> *…Even the children even if it is not yet time, they will ask, Mummy have you taken the drugs, it is 20:00 hours. Or sometimes when I see that it is 20:00 hours I will tell the children to bring the drugs so that I take them* (P13_W_37_768).

4.4.3.3.4 Fear of death and poor health outcomes resulting from non-adherence to ART

The thought of close friends and other people who had died due to non-adherence of treatment influenced some PLHIV to adhere to treatment. Seeing friends die due to poor adherence to ART induces fear that one would also die if they did not adhere to treatment. Others feared that the drugs would not respond very well if they did not adhere to treatment which would further threaten their health. The quotations below illustrate what PLHIV said influenced them to adhere to treatment.

> *…Because of that same painful death of my friend, when I saw my friend dying, I just have to do it… because I have seen a lot of ahhh friends…They've died because of neglecting ummh putting aside the drugs* (P11_M_36_559).

> *…If I do not take the medication, I will go backwards…sometimes the medication will stop working properly because I am not following what I was told at the hospital…I am not supposed to skip taking that medication* (P7_W_29_523).

4.4.3.3.5 Taking on the responsibility of treatment

Some PLHIV felt that it was their responsibility to make sure they adhere to treatment because they were living with HIV. They mentioned that taking the drugs was for their own wellbeing hence needed to be committed. However, commitment to take the drugs was also dependent on personal will and acceptance of their HIV status. One of the PLHIV said:

> *…am used, it's a thing which I've taken it like, ummhh, it's one of my responsibility to do so… I've taken it to be like ahhhh the way I eat nshima…I eat nshima to be ummhh to feed my body and then to have energy…so I have to take the drugs…to protect my body from the disease* (P11_M_36_559).

Deliberating on what facilitates adherence to treatment among PLHIV, one study key informant mentioned acceptance of one's HIV status.

> *Acceptance…when somebody accepts then everything goes well* (KI2_W_64_4).

4.4.3.3.6 The size of the pills

Adhering to treatment was considered easy by some participants because the pills were small and easy to swallow. In this regard, taking the drugs did not induce choking or vomiting.

> *It is not hard because the kind of pill, it does not choke you on the throat, once you just*

> *take it then it goes straight…passed the throat* (P10_W_20_554).

4.4.3.3.7 Encouragement from social networks

Bearing the burden of taking treatment alone was not easy for some PLHIV. In times of adversity and at a point of almost giving up and losing hope, social networks provided encouragement to PLHIV which influenced them to continue taking the drugs and adhering to treatment. PLHIV who had been on ART for longer periods encouraged those who had disclosed to them and seemed to be struggling with adjusting to taking treatment. P5_M_32_559 was almost losing hope when he got sick but because he had a neighbour who had been on ART for close to five years and was encouraging him to take treatment, he persisted with taking treatment.

> *There is this, our neighbor, because even him he started a long time ago…so he used to encourage me…"These things help a lot…right now it is almost five years since I started treatment". Now I imagined, I just started taking the treatment, what more by the time I will be five years on treatment…I said, let me just be strong…what more my neighbor is still fit* (P5_M_32_559).

### 4.4.3.4 Factors hindering adherence to treatment

The factors hindering adherence to treatment as described by participants were: alcohol use, travelling away from home, HCW's stern instructions to take treatment at a specified time without delay, treatment fatigue, being busy, feeling healthy and side effects due to taking ART.

4.4.3.4.1 Alcohol use

The use of alcohol when on treatment was perceived to undermine the effectiveness of ART. Some participants explained how they perceived alcohol made PLHIV skip taking treatment while others mentioned that due to alcohol use they had actually skipped taking treatment. To avoid forgetting to take the drugs after taking alcohol, one participant mentioned that she would sometimes take the drugs in advance before going to take alcohol.

> *….Like when I go to drink alcohol, I forget, when I get back, I am drunk, I sleep and I even forget. I don't drink the medication. Sometimes if I remember, before I start off, I take the medication in advance then I go and drink beer…But if I want, sometimes I wait until it is 20, I take the drugs then I go* (P10_W_20_554).

#### 4.4.3.4.2 Travelling away from home

Travelling away from home posed a challenge for some PLHIV to adhere to treatment because they would have either forgotten to carry their drugs with them or their drugs finished while they were away from home. Seeking HIV services away from home seemed to be feared as it would lead to involuntary disclosure.

> *Last month I went for a funeral, I forgot my medication….I went last, last month on 23…I came back to Livingstone on 20…so all these days I have not taken any medication….I was supposed to come and collect my drugs on 26 last month* (P10_W_20_554).

A HCW who had observed a similar trend among PLHIV accessing services at the health facility who travel away from their homes attributed their poor adherence to non-disclosure of their HIV status.

> *If somebody didn't disclose to the partner or to relatives that is how some people have got poor adherence…We have seen some clients… leave Livingstone going to Western province…we always tell them that wherever you go, you can access the treatment. They say ahhh, ba sister I go there and again I start asking my relatives. Already there is some form of stigma* (KI2_W_64_4).

#### 4.4.3.4.3 Stern instructions to take treatment at a specified time without delay

During the process of ART initiation, HCWs give strict instructions to PLHIV to take their drugs at the agreed time without delay. For this reason, some PLHIV felt that if they had delayed to take their dosage on a particular day, it was better to entirely skip that particular day's dosage. One participant mentioned that if he delayed to get home from work, he would skip taking the drugs based on the HCWs' advice.

> *There are times when I go somewhere, maybe I go to work somewhere and I return home late at say around 22 – 23 hours, I will not take the drugs for that day. At the clinic I was told that I should only take the drugs the following day if I do not manage to take them at the right time* (P9_M_44_797).

#### 4.4.3.4.4 Treatment fatigue

While some PLHIV who have been taking treatment for a long time expressed how it had become a routine for them to always take the drugs, others seemed to have been getting fed up of the routine. The experiences shared by some PLHIV showed that they were getting tired of taking treatment and cared less to take measures to adhere to treatment. For instance, a young woman who had only been on treatment for about two years narrated how she always used to carry the drugs with her in a special bottle whenever she is going somewhere but was now getting reluctant to continue this practice. A HCW also gave an example of a client who stopped taking treatment after two years of being on ART due to treatment fatigue. The client travelled to Botswana where she stopped taking treatment and when her CD4 count started dropping she panicked and came back to Zambia to start treatment.

> *What she said about the reason why she stopped taking treatment like, she was like, ahhh nooo, I felt like I was getting tired in terms of taking drugs not knowing that I was actually killing myself* (KI3_M_33_4).

#### 4.4.3.4.5 Feeling healthy

When feeling healthy, it was difficult for some participants to adhere to treatment. This was common among PLHIV when they were just starting treatment and still feeling fine. However, one HCW explained how both adherence and non-adherence to treatment was influenced by the health status of PLHIV. Some PLHIV would stop adhering to treatment when they see that their CD4 cell count had gone up and they had become healthy. Once they had stopped adhering to treatment, their health would again deteriorate and they would again start adhering to treatment. Expressing how feeling healthy at ART initiation influenced non-adherence to treatment, one participant said:

> *…I was one kind of a person who never even ahhh, took things so seriously. I would just take them seriously when they get serious, the disease itself when it gets serious…so that's when I would get serious start taking the drugs according to the way they are supposed…* (P11_M_36_559).

Other factors affecting adherence to treatment were being busy, forgetfulness, lack of privacy to take the drugs and side effects due to taking the drugs. Being busy was attributed to being preoccupied especially when at work such that one delays or forgets to take the dosage for that day. Some PLHIV also mentioned that they sometimes forgot to take their drugs or carry them when they were either going for work or travelling away from home for a longer period of time. Not being able to take the drugs in privacy hindered adherence to treatment because PLHIV do not always disclose their HIV status to everyone around them. Equally, when the side effects due to taking ART created discomfort among PLHIV, treatment adherence was threatened.

### *4.4.3.5 Side effects due to taking ART*

PLHIV described their experiences with side effects resulting from taking ART. These experiences have been categorised into three, namely, temporal side effects experienced when starting treatment, long-term side effects and never experienced any side effects. The fourth category focused on PLHIV's perceptions about the future impact of the drugs on their body.

#### 4.4.3.5.1 Temporal side effects when starting ART

Most PLHIV had experienced some side effects due to taking treatment in the initial months after ART initiation. However, these side effects were temporal and only lasted for a short while. These temporal side effects were mostly attributed to the body adjusting to the introduction of the drugs. However, these temporal side effects did not deter any PLHIV from continuing with treatment. HCWs attributed the persistence with taking treatment to their adherence counselling during which PLHIV were informed about the likelihood of experiencing certain side effects when they just start taking the drugs. Among the common side effects mentioned were; dizziness, diarrhea, skin rashes, nausea, vomiting, abdominal pains, hallucinations and loss of appetite.

> *…I used to feel dizzy… if you just take the drugs, then there is nowhere else you can go…when I sleep in the house, even if it is just one corner, I would see them as two corners…I said, this drug is strong. But in the end I got used to it…It just stopped, it was just at the beginning that is why I was feeling like that…After that…I started getting diarrhea…Sometimes they would make you to have bad dreams but eventually they all stopped…even the appetite increased and I got more strength…these days there is nothing* (P5_M_32_559).

HCWs confirmed these assertions and clarified that they usually explain the possibility of experiencing temporal side effects to PLHIV during ART initiation. One HCW when asked about the experiences with side effects among PLHIV initiated on ART early said:

> *…before a client is initiated, we always counsel them…we always tell them to say there are side effects…somebody will have a rash on the body…some they will develop diarrhea, nausea, dizziness…and they will experience some bad dreams…But that one will pass and it is not everybody* (KI2_W_64_4).

#### 4.4.3.5.2 Long term side effects due to ART

A few participants experienced side effects even after they had been taking treatment for some time. For some PLHIV, conditions such as pregnancy and the type of work they did led to the side effects they experienced after being on ART for a while. The side effects that were mentioned to have either persisted, resumed or occurred for the first time after being on treatment for some time were; changes in body structure, a back ache and feeling dizzy and irregular heart beat whenever ART was taken. However, none of these side effects were thought to be life threatening. HCWs attested to this fact by elaborating that they had not seen any client that had developed severe side effects since they started offering early ART initiation to PLHIV. They further mentioned that, since PLHIV are monitored throughout the period they are on treatment, detecting early signs and taking remedial measures was easy. One woman who had been on ART for about two years started experiencing side effects which also affected her adherence to treatment when she got pregnant.

> *…in the night, when I just take the medication, after one hour, ma, ma, ma…it is as if the heart wants to come out from its position, Pah! Pah!...You wake up and sit down, you bath and take a walk around, you do this, you sit on the bed until sleep comes…I will stay the whole night, until the pill melts in the body. That is when I will sleep…but if I do not take the drugs, ahhh, I will sleep peacefully* (P3_W_34_585).

The HCW who had observed long term side effects (changes in the body structure of men) due to taking treatment said:

> *They grow breasts, like men…I think it is after some time of taking the drugs…I don't know which drug is making them…for women I have not heard that complaint* (KI1_W_30_6).

#### 4.4.3.5.3 Never experienced side effects due to ART

Some PLHIV had not experienced any side effects from the time they had started taking ART. This was described by some PLHIV as, 'the drugs working well for them' while others perceived it as the advantage of starting treatment in good health. Describing how she was feeling when she started taking treatment, P4_W_35_721 said:

> *I did not see any change which would make me sick or what…maybe that is the advantage of starting treatment while the cells are ok. I did not experience anything like getting sick and the like…everything was just normal* (P4_W_35_721).

#### 4.4.3.5.4 Anticipated future side effects due to ART

None of the participants anticipated long term adverse side effects that would result from starting treatment early and having to take the drugs for a lifetime. However, the HCWs expressed some concerns but mentioned that their clients are monitored routinely to avoid any unforeseen complications and had not yet seen a client who experienced that ever since they started providing HIV services. After being on ART for two years, P12_W_26_543 was not worried about future side effects due to ART.

> *Ahh, there is nothing I have seen. Maybe when I start noticing changes* (P12_W_26_543).

When asked if HCW's had any worries about the long term effects of ART on the liver, kidney and other body part's functioning for PLHIV initiated on ART early, one HCW said:

> *Ahaahh, we can have a concern but what we know is that, I think these drugs that are taken…they go through tests…the concern is there but we have to monitor, clients are being monitored…that's why they do CD4 every six months. Somebody before he is initiated, the, the most important thing is the liver function…creatinine, we check* (KI2_W_64_4).

### 4.4.4 Experiences of living with HIV in the community

Living with HIV in the community has some social and psychological effect on PLHIV as experienced by the study participants. The key issues identified to have had an influence on life among PLHIV in the community were: HIV/AIDS stigma, disclosure of one's HIV status, seeking HIV services at the health facility, personal feelings about living with HIV and taking care of oneself to maintain or regain health.

#### *4.4.4.1 HIV/AIDS stigma*

Although a few PLHIV experienced HIV/AIDS stigma (referred to hereafter as stigma) enacted by some community members including neighbors, friends and family members, all the other study participants had never experienced stigma in the community. However, most PLHIV had heard of others being stigmatized due to their HIV status and still feared to be stigmatized if other community members learnt about their status. Internalized stigma was widely experienced despite not being realized by most PLHIV. A few participants mentioned that stigma was more pronounced in the past than it is now. HIV/AIDS was no longer considered to be a shameful infection by most participants and was often likened to any other diseases.

Starting treatment early was widely acknowledged to have helped PLHIV to conceal their HIV status hence avoiding stigma. Two other remedial actions identified to have contributed towards stigma reduction were acceptance of HIV status and the health facility's intervention not to use obvious identifiers such as clinic care cards and files specifically meant for PLHIV.

#### 4.4.4.1.1 Never experienced stigma in the community

Apart from two PLHIV, all the others that participated in the study had never experienced stigma regardless of their health status at ART initiation. Their descriptions of not being stigmatized were based on not noticing any stigmatizing attitudes towards them from anyone and also not hearing anyone talking ill of them because of their HIV status. When asked if she had ever experienced any form of discrimination because of her HIV status, P13_W_37_768 said:

> *For me there is no one…it has not happened because I visit many people, we eat, laugh together. There is nothing like, since this one is positive we stop laughing with him/her, no* (P13_W_37_768).

##### *4.4.4.1.1.1 Reasons for not being stigmatized in the community*

Physical appearance resulting from being healthy was a reason given by many for not being stigmatized. Some PLHIV narrated that even when they had disclosed their HIV status to some of their friends and relatives, they remained in disbelief because of looking healthy (no physical changes on their body either after regaining their health due to ART or maintaining good health by starting ART early). Conversely, some PLHIV attributed not experiencing stigma in the community to their limited disclosure network. P6_M_44_661 had not experienced any stigma and even though he tried to disclose his status, people often did not believe him because he had regained his health after starting treatment.

> *…I haven't noticed it yet. Though what I have realized is that people do not believe that what I say ehhh is the truth. Even among the relatives that I have told, some do feel…it's like it's a joke. I don't know whether it's because of the appearance…But to those that had seen me eehh previously when I was starting … those can still believe me because definitely my health was really down* (P6_M_44_661).

#### 4.4.4.1.2 Hearing stigmatizing comments about PLHIV in the community

The fact that most PLHIV did not experience any form of stigma did not imply that there was no stigma in the community. PLHIV narrated how they had heard of other PLHIV being stigmatized either through conversations they had overheard in the community, at the health facility or work places. One PLHIV narrated how a woman (not living with HIV) who was seated next to him on the queue at the health facility made a stigmatizing comment. She told him that she did not want to be mistaken for a PLHIV since all clients that were coming to the facility regardless of their HIV status were being given similar ‘smart care cards’ (health access cards linked to an electronic management programme). Another PLHIV who had not experienced stigma but had noticed some stigmatizing attitudes from people in the community said:

> *Some people, the way they talk, they do not understand what it is. Them what they think is for one to be HIV positive, they think someone has been a prostitute or something else…so mostly I tell them to say, it comes accidentally and it is just a condition…it’s just like any other disease like diabetes, heart disease…* (P14_W_35_534).

#### 4.4.4.1.3 Enacted stigma

The two PLHIV who experienced stigma were ill talked to by relatives, friends, neighbors including the spouse for one of them. One of them started treatment when she had fallen sick and would hear relatives, friends and neighbors talk about how she was finished without any hope for her recovery and that she would soon die. The other used to be ill-treated by her husband who would mock her about her HIV positive diagnosis and usually spoke badly about her in the open whenever he was drunk with the intent of disclosing her status to the neighbors. Yet he did not want to test for HIV himself.

> *…my husband, when I just started taking the drugs…he used to talk ill of me, he would say me I am not taking ARVs, this one is suffering from HIV, she is taking ARVs…he was saying that from outside because he does not keep any secret…* (P13_W_37_768).

#### 4.4.4.1.4 Internalized stigma

Living with HIV was not thought to be shameful by most PLHIV. Therefore most of them said they did not experience internalized stigma or at least did not share their experiences of internalized stigma. However, they thought other PLHIV in the community experienced internalized stigma. Internalized stigma was identified through PLHIV not wanting to be seen accessing HIV services, avoiding people they knew when accessing HIV services and seeking HIV services in health facilities considered private to avoid being seen accessing HIV services. HCWs also mentioned how some PLHIV wanted special treatment (offered services without queuing) so that they are not seen when accessing HIV services. Internalized stigma was also mentioned to sometimes lead to disengagement from care by some PLHIV. Talking about accessing HIV services at the health facility, one PLHIV said:

> *…people that you see, you meet here, those that I know, immediately they see you, maybe there could be some neighbors, you would find they want to, they want to start hiding even when they don't know what you've come here for…so already that is stigma…what do they want to hide?* (P6_M_44_661).

A HCW who had made a similar observation at the health facility said:

> *…you know ahhh like around this time…what I have observed is there is too much of self-stigma, not others stigmatizing like other people but self, somebody just stigmatizing him or herself…Like when…coming to the facility, you find this person will like just be thinking like ahh noo, those people maybe they are thinking about this…maybe about me. So they end up stigmatizing themselves and at some point you even end up wanting to stop* (KI3_M_33_4).

### 4.4.4.1.5 Anticipated stigma

Anticipated stigma occurred among PLHIV regardless of whether they had previously been stigmatized or not. PLHIV that anticipated stigma kept their status a secret from friends and sometimes close relatives. The negative perceptions that community members had about PLHIV led to heightened fears about anticipated stigma. One of the negative perceptions about PLHIV which was mentioned was that HIV infection was a result of 'promiscuity'. Knowledge about living with HIV among friends and relatives was also considered to potentially lead to isolation of PLHIV. Worrying about disclosing her HIV status to her friends, P10_W_20_554 said:

> *…I do not have a close friend…the ones I have, they come to me we laugh, they go to other girls they laugh so, I feel shy that if I tell one, she will go and tell the others, everyone will know that I am sick* [infected with HIV]. *So I cannot feel good if everyone knows that I am sick….because my friends I know them very well, they are heartless…The way I see it is that they might start laughing at you and looking down on you and you will not be close friends like that* (P10_W_20_554).

4.4.4.1.6 A reduction of stigma in the community

Comparing stigma in the past and the present in the community, both PLHIV and HCWs said it had reduced. PLHIV expressed that they were living normal lives just like those who were not infected. The reduction of stigma was attributed to increased knowledge among community members about the various forms of contracting HIV (a common source of stigma) and the increased prevalence of HIV infection in the community hence considered to be like any other common illnesses.

> *…that kind of thing has stopped. It used to happen a long time ago…because nowadays…a person who is positive and the one who is negative they are just the same…you will just be living the same way, maybe that thing of doing what, the razor blade that you have used your friend cannot use, yes that is still happening, not what used to happen a long time ago that maybe they look down on you, no that has stopped because these days people have known how HIV is contracted…*(P12_W_26_543).

4.4.4.1.7 Overcoming stigma in the community

In order to overcome stigma, both PLHIV and HCWs mentioned acceptance of one's HIV status to be important. Being open about your HIV status and not feeling shy about accessing HIV services were considered to be steps towards overcoming stigma. PLHIV talked of HIV infection being like any other disease and less dangerous than diseases like cancer yet people with the more dangerous diseases were open about them. Encouragement and advice from friends and HCWs was identified to play a critical role in overcoming stigma especially to those who had internalized stigma. HWCs mentioned that identifying PLHIV when accessing HIV services was getting more obscure because all clients (whether living with HIV or not) now had similar clinical care access cards.

Unlike his friends who sought transfers to access HIV services at more private health facilities due to fear of being seen accessing HIV services at the health facility, P6_M_44_661 explained how he was free to access services regardless of who saw him or found out about his HIV status.

> *I am well known within here…my house is just next to the clinic but I still come to, to the clinic…we've seen people with ummhh cancer, they open up…and meanwhile I, I believe ahh cancer is one of the deadly diseases as compared to HIV. What would make us not come into the open? Even if you were to come outside with this medication that…I*

> *accessed there, you came to meet outside, I was not going to feel bad…it is something that I have accepted* (P6_M_44_661).

#### *4.4.4.2 Disclosure of HIV status*

After being diagnosed with HIV, all PLHIV disclosed their status to some individuals in their social network although the period within which they disclosure varied. Disclosure was selective, often to partners, family members, friends, neighbours and co-workers whom they were close to and could trust to keep the information confidential. The process of disclosure was sometimes done casually, especially to friends and co-workers because it delivered the intended message without anyone making a fuss about it. However, disclosure sometimes occurred inadvertently because of health deterioration, coinciding clinic appointment dates and failure to conceal HIV status when visiting relatives.

Some PLHIV felt it was their obligation to inform others about their status so that they could get some form of support and encouragement. A few PLHIV disclosed to family members who were health providers with the view of getting additional guidance on how to take care of themselves and live positively. The motivation for disclosing to relatives and friends was to enable them know about their condition so that they could provide both emotional and physical support. Informing co-workers facilitated the process of seeking permission for routine clinic visits and awareness of their status in case of health problems affecting work. Disclosure was also seen as a way of relieving stress by offloading the burden of an HIV positive diagnosis through sharing with someone. Words of encouragement and remorseful feelings were often expressed by individuals whom the HIV status was disclosed to.

##### 4.4.4.2.1 Deciding whom to disclose HIV status

All PLHIV disclosed their HIV status to selected individuals considered trustworthy. Among the individuals disclosed to were: family members (including spouses, siblings, close and distant relatives and those living in close proximity as well as far away), close friends and neighbours and co-workers and supervisors at work.

> *…the first person I disclosed that was my wife…and then after telling my wife I told my younger brother….I have disclosed to so many, uummhh, I've disclosed to my sister…my two nieces* (P6_M_44_661).

##### 4.4.4.2.2 Process of disclosure

The process of HIV status disclosure was described by some participants. Some PLHIV felt obligated to disclose their HIV status to relatives. One participant narrated that the HCWs asked him to identify a close family member whom they could put as next of kin apart from his spouse. Once he had decided on whom his next of kin would be, he had to disclose to that individual so that he was also aware in case the HCWs decided to contact him. Disclosure to friends and co-workers was done casually so as to avoid being pitied. P6_M_44_661 narrated how he casually disclosed his HIV status to a co-worker.

> *…it was more like I was joking to say, tomorrow I will not be working, I have to go and access my medication. But what sort of medication? I said ahh no, these tablets that we take. So he developed interest and asked me, which medication I said am am on ART…He said ahh, you are on ART too? I said yes… I am also on ART…* (P6_M_44_661).

#### 4.4.4.2.3 Reactions to disclosure of HIV status by participants

Disclosure of HIV status was received in various ways. For some, it was followed by words of encouragement and others remorse. Those that received the information with sadness sympathized with PLHIV because of negative perceptions associated with HIV and the thought of other family members that had died due to HIV. Words of encouragement emphasized being healthy despite living with HIV, the normalcy of living with HIV, importance of treatment and adherence. After disclosing her HIV status, P13_W_37_768 received words of encouragement from her friends:

> *…everything will be fine, it is the things of this world, even us that is what we are waiting for. Don't you see that nowadays there are many people infected, it has become like it is malaria. You do not have to laugh at your friend* (P13_W_37_768).

#### 4.4.4.2.4 Involuntary disclosure

A few PLHIV mentioned that their status was unintentionally disclosed to others in the community. The main reasons attributed to involuntary disclosure of HIV status included physical symptoms of HIV infection resulting from health deterioration (weight loss) and being seen accessing HIV services at the health facility by onlookers and other people also accessing services. Other circumstances that led to involuntary disclosure were failure to keep confidential one's HIV status when visiting relatives due to either taking the drugs in the presence of others or taking precaution to prevent child infection such as exclusive breastfeeding or giving oral medication. Describing how she disclosed her HIV status to her aunty when she went to visit, P10_W_20_554 said:

> *Even my aunty, the young sister to my mother…I went to visit…even her she got to know about it…I told her because she saw the child, I was giving the child septrin* (P10_W_20_554).

### 4.4.4.2.5 Factors influencing disclosure of one's HIV status

Disclosure of one's HIV status was influenced by many factors. Irrespective of whom disclosed to, the need for some form of psychological or physical assistance was usually raised. Some PLHIV disclosed to co-workers and supervisors because they had to routinely ask for permission to go to the health facility to access services and inform them of their condition in case health problems affecting work arose. Others disclosed to relatives and friends who had experience with providing health services with the hope of getting help and advice about living with HIV. Disclosing to family members was considered important because they are the ones who would take care of PLHIV if they fell sick and could sometimes help with accessing HIV services at the health facility when busy and remind them to take treatment. Keeping an HIV positive diagnosis to oneself was thought to be an overwhelming burden by one PLHIV. Therefore, disclosure was seen as a way of easing the burden and receive support and encouragement. Additionally, HCWs felt that disclosure of one's HIV status especially to family members improved adherence to treatment. The excerpt below is a narration showing how one participant disclosed her status to her co-workers and supervisors so that they provide assistance with her routine clinic visits.

> *…I even told them my status. So that they are informed…when I realize that next week, I am coming here* [clinic], *I will inform the manager that next week on such a day, I will need to go to the clinic, hospital to get drugs* (P3_W_34_585).

### 4.4.4.2.6 Factors influencing non-disclosure of HIV status

The main reason given for non-disclosure of one's HIV status was fear of stigma. Lack of trust in some individuals inhibited disclosure because they were perceived to be more likely to disclose a PLHIV's status to other individuals in the community. This was exacerbated by not having a close friend (who could also be trusted). Close relatives if informed about an individual's HIV positive status were perceived to be more likely to conceal this information compared to friends. One participant mentioned lack of openness to talk about HIV in relationships as a factor that inhibits disclosure of HIV status. Some coping mechanisms used to keep one's HIV status concealed were: swapping working days with co-workers to keep the clinic appointment date without skipping work and taking ART in the absence of individuals unaware of an individual's HIV status.

When asked if she could disclose her HIV status to anyone else apart from her mother in the near future, P8_W_32_589 said:

> *Maybe a sister I can tell not any other person because they will embarrass me…what they will be doing is that wherever they go, they will be telling people, that one is taking drugs. Now your relative cannot be telling people…* (P8_W_32_589).

#### *4.4.4.3 Accessing HIV services at the health facility*

Accessing HIV services was a routine for all PLHIV. During the initial period of starting ART, all PLHIV were only given a short supply of ART (two weeks or a month). This meant that they had to initially visit the health facility frequently. Depending on how an individual responded to treatment, thus, impact of ART on health such as adverse side effects and the observed practices with adherence to treatment and observance of clinic appointments, PLHIV were later given a drug supply of up to three months. Although necessary, these routine clinic visits sometimes inconvenienced PLHIV since they had to endure long waiting time at the health facility at the expense of securing income. For some PLHIV, the routine clinic visits came at a cost because they needed to pay for transport from their homes to the health facility and return. PLHIV prefered going to the health facility to access HIV services very early in the morning to avoid long queues. Despite the challenges with routine clinic visits, some PLHIV prioritized accessing services and had adapted to the challenges. The HCW-client relationships at the health facility were said to be good.

##### 4.4.4.3.1 Frequency of accessing HIV services at the health facility

At ART initiation, clinic visits were more frequent as PLHIV were given a short term drug supply in order to assess their response to the medication. Once their ability to routinely access HIV services and adherence to treatment had been ascertained and no adverse side effects due to taking ART observed, they were then given drugs that would last them three months. Most PLHIV took pride in collecting a drug supply that lasted them three months because it reduced the frequency of clinic visits. Some PLHIV suggested that health providers should consider extending the three months limit on the supply of drugs that one can get to six months so that individuals responding well to treatment would only come to the health facility twice in a year. The quotation below is a description of the supply of ART given to one participant from the time he started treatment.

> *…I was given the first dosage ahh it was for two weeks…after 14 days I came…Then again, I got again for 14 days…Then from there I was given for a month…I went monthly like that, monthly, monthly...eventually I graduated to three months* (P11_M_36_559).

4.4.4.3.2 Making time to access HIV services

For most PLHIV, accessing HIV services was a priority. They always endeavored to spare time regardless of how busy they were. However, routine access of HIV services was often a challenge due to competing demands such as livelihood options. Many PLHIV narrated how they adjusted their work schedules by either finding someone to work on their behalf, swapping work shifts with other co-workers, seeking permission to report for work late or take time off work in order to make time to access HIV services. PLHIV that had not disclosed their HIV status at work struggled to negotiate time off work hence would seek permission for reasons other than accessing HIV services. Even when permission was granted, the delays at the health facility would sometimes make PLHIV unable to fulfil their obligation to report back for work at an agreed time putting their job at risk. Those in informal employment lamented about how time spent accessing HIV services deprived them of potential opportunities for being sub-contracted to do some work in the community. When creating time to access HIV services proved impossible due to other commitments, some PLHIV requested close family members to collect the drugs on their behalf. Considering how important accessing HIV services was for some participants, they had become accustomed to all the procedures without any complaints. The excerpts below demonstrate some of the points raised by participants.

Expressing how he always made time to go to access HIV services on his appointment dates, P1_M_49_656 said:

> *…even if am at work, am reporting in the morning, if my appointment date has reached, I will find a way. I will ask someone to work on my behalf then I will work during that person's shift* (P1_M_49_656).

Narrating challenges of how time consuming accessing HIV services at the health facility was and the risks it posed to employment especially when permission to be away from work was not explicitly sought on the basis of accessing HIV services due to non-disclosure at work, one PLHIV said:

> *I was supposed to be at work… but am here…and I said I was going to be back I think by 10 – 13 somewhere there but … I haven't managed …I haven't even given a reason as to why…I haven't been there… I might be understood today but tomorrow they might not understand me* (P6_M_44_661).

Describing how making time to access HIV services on the appointment date was not always possible due to other commitments and having to request a close relative to collect the drugs from the health facility on her behalf, P12_W_26_543 said:

> *On the date I was supposed to come here* [health facility], *at work they did not give me permission. I tried to ask but they did not give me…but I still had drugs…that is how I told my mother, my papers were at my mother's place, that is how she came to collect the drugs for me…*(P12_W_26_543).

#### 4.4.4.3.3 Challenges with accessing HIV services at the health facility

Accessing HIV services at the health facility was characterized by long queues and prolonged waiting time. Long waiting time was mainly attributed to slow service delivery, overcrowding and preferential treatment of some PLHIV. All the complaints about poor service provision made by PLHIV were about the delays at the registry caused by slow service delivery by HCWs. There were no complaints of the HCW-client relationships or exhibition of bad attitudes by HCWs when providing services. However, suggestions about increasing the health workforce in order to address slow delivery of HIV services were made by both PLHIV and HCWs.

Expressing concerns over HCWs from the registry and preferential treatment of some PLHIV, P14_W_35_534 said:

> *…mostly where we find challenges is those people from registry…with these others there are no problems…the pulling of files and the like. What those chaps does mostly, they have got friends they are staying with in the compound. So even if that person has come late, they'll first serve that person leaving the person who has come early. So that one am seeing it to be a challenge…I think those people from registry they need to be talked to seriously* (P14_W_35_534).

A PLHIV who complained about the procedures (undergoing registration, adherence counselling, laboratory tests, seeing a clinician and collecting drugs) at the health facility and slow service delivery contributing to long waiting time said:

> *The procedure here, ahhh! On the procedure that is where there is a problem. It is a bit slow…6 hours the person is already here…14:00 hours a person is still here at the clinic…so they need to improve on their work culture, at least they should be a bit faster* (P5_M_32_559).

In order to avoid the long queues and be attended to quicker, most PLHIV usually arrived at the health facility very early in the morning. Arriving early at the health facility implied leaving home very early in the morning when it was still dark. This posed a risk of being attacked by criminals as PLHIV walked to the health facility. One participant narrated that she once left home at about 04:11 AM and as she was walking to the health facility along the railway line, she was almost attacked and had to shout for help and run to a nearby household. Securing funds for transport also posed a challenge in accessing HIV services as PLHIV always had to ensure they solicit for transport money in order to avoid skipping a clinic appointment, or walk.

> *Transport is a challenge. Sometimes you will find that if I do not have money, I keep borrowing money to come here…if I don't have, mummy gives me, if I don't have, I ask from my friend…But I used to make sure that on such a date I have to find so much money* (P10_W_20_554).

### *4.4.4.4 Personal feeling about living with HIV*

This sub-theme focuses on PLHIV's convictions about living with HIV. It highlights how PLHIV felt about their diagnosis with HIV and having to live with it for a lifetime. In order to derive responses regarding personal feelings about living with HIV, PLHIV were usually asked the questions, *"…on your own, if you come to think of it, how do you feel about living with HIV? When you realized or whenever you think of the fact that you are living with HIV, how do you feel or what do you think about?"*

In response to these questions, some PLHIV said they initially had worrying thoughts about living with HIV. The thought of death due to HIV persisted among some PLHIV despite taking ART. The fact that ART does not cure HIV continued to raise concerns and worries among PLHIV. Some of the persistent worries that PLHIV had about their condition were fears about eventual health deterioration and bearing children infected with HIV (mostly for pregnant women). Most of these concerns were based on what PLHIV had seen from others both in the community and at the health facility who had either died or had poor health outcomes due to HIV. One PLHIV narrated how he was worried about securing the future of his children in case he died because ART did not cure HIV. However, as time passed by and PLHIV got used to living with their condition, these concerns gradually fell away and they continued living a normal life.

Although few, some PLHIV said they never had any worries about living with HIV from the time they were diagnosed HIV positive and sometimes even forgot that they were living with HIV. Acceptance of HIV status, the fact that ART was accessible for free and feeling normal to perform any kind of work just like any other individual not living with HIV were mentioned to be key to positive living. The aforementioned factors perpetuated expectations for long life and sometimes hope to be cured from HIV. The quotations below demonstrate what some of the PLHIV said.

Describing initial feelings of distress and worry about her health and that of her unborn child due to other people's conditions she had seen at the health facility when she had just been diagnosed with HIV and started taking ART, P10_W_20_554 said:

> *What used to bother me a lot, like when I was coming to the clinic, I used to see others their babies have been born HIV positive, the other woman got too sick she had HIV, so what I was thinking was that even me I am going to get sick like the way this woman is. Maybe when my child is born, he/she will also suffer like the child I saw at the clinic…Right now there is nothing I feel…I just live like someone who is not sick…* (P10_W_20_554).

Seeing others die due to HIV caused worry for one of the participants. It made her imagine that she was also going to die because she is living with HIV. As a result of these distressing thoughts, she would lose body weight even with a minor illness.

> *…when you see that someone has died, you also start thinking that, maybe even me I might be next on the death list. Even if you are working with your friends, you will find that you just get worried…Especially if it is at night…your friends are sleeping but you stay awake just thinking that so I am also going to die…when you just get sick, you lose weight because there are a lot of thoughts on your mind* (P3_W_34_585).

P11_M_36_559 said since he was already infected, it was not something to worry about and was hopeful of long life with the possibility of getting cured of HIV.

> *I don't have even time to think of that because I know that if there was a mistake, the mistake was done then, the only thing I should think of is to pray to God to say that no, may the lord please increase more days upon my life as I am taking these drugs…if possible a miracle should happen, if one can happen…because I have heard other people…the disease itself disappears…so yeah. It's possible* (P11_M_36_559).

#### 4.4.4.5 Precautions to maintain or regain good health when living with HIV

Although PLHIV had different health outcomes from the time they were diagnosed with HIV and throughout the period they had been taking ART, the need to maintain good health was dominant among them. This sub-theme describes some of the precautions that PLHIV took in order to regain or maintain good health. Some of the measures that PLHIV undertook to stay healthy included sticking to one sexual partner, practicing safe sex and adhering to treatment. Some also said they avoided stress resulting from worries about HIV infection, its future implications on their life and other socio-economic issues affecting them in the community. To determine their health, most PLHIV monitored their CD4 cell count results each time a test was conducted at the health facility. A drop in CD4 cell count was regarded as a sign of health deterioration. PLHIV who had maintained a high CD4 cell count or yielded a CD4 cell count result higher than the previous one considered themselves to be more healthy and responding well to treatment (sometimes comparing their CD4 cell count to that of people not living with HIV). However, a few PLHIV were not sure of their CD4 cell count results and did not know what indication the test results gave for their health.

Avoiding taking risky sexual practices such as unprotected sex and having multiple sexual partners were some of the practical measures known by many PLHIV to help maintain good health. Unprotected sex was feared to be a risk for re-infection and multiplication of the virus in the body. One PLHIV who irregularly took ART because she experienced side effects narrated how she would not sleep on the same bed with the husband on the day she skipped her dosage. She feared that the virus would be active in her body on the day she skipped treatment hence if they had sex with the husband, they would re-infect each other which increased their chances of developing ill health.

Taking ART and adhering to treatment regimens was considered to both improve and maintain good health. Therefore, uptake of treatment was also motivated by the need to maintain and regain health. Another widespread belief about maintaining good health was to avoid worrying about HIV infection or any other issues affecting an individual. Worrying too much about anything was said to be stressful and harmful to one's health. Both PLHIV and HCWs mentioned that having a troubled mind could even result in one's CD4 cell count dropping, an indication of health deterioration. One participant in an abusive relationship explained how she tried to keep herself happy by chatting with friends and laughing with her children when her husband goes for work in trying to avoid feeling sad. Eating good healthy food and seeking treatment for other illnesses at the health facility whenever feeling sick was said to have a positive impact on health and improved wellbeing.

Stressing on the importance of monitoring the CD4 cell count and how worrying about issues affecting her life could lead to a drop in her CD4 cell count, P3_W_34_585 said:

> *…it's important to come and get your CD4 checked so that you know how you are faring…Because they even encourage that, let's say it has gone down… they will tell you the reasons why, sometimes maybe they will tell you that there is something that is bothering you and you keep thinking about it* (P4_W_35_721).

One participant recommended taking a combination of these measures to maintain health. She mentioned the importance of adherence to treatment, having one sexual partner and using condoms for every sexual encounter whether on treatment or not.

> *Taking medication on time and looking after your body, not engaging in prostitution anyhow if I may say so…I heard that if a person is sleeping around and is on treatment, then the viruses will become many…even if the person is on treatment, that person has to use condoms anytime you want to have sex* (P12_W_26_543).

# CHAPTER FIVE: DISCUSSION

## 5.1 Introduction

This chapter gives an interpretation of the study findings. To facilitate this, a summary of the study aim and its key findings will be provided. The meaning of the findings will be substantiated and compared with previous research studies that have been conducted. Lastly, the study limitations will be highlighted.

## 5.2 Summary of study aim and key findings

This study aimed to explore the experiences of early ART initiation among PLHIV accessing ART services at a government health facility in Zambia. The inquiry focused on the motivating factors for early ART uptake, the individual experiences with taking ART and how the socio-economic and contextual factors interact with HIV management.

Findings reveal different experiences of PLHIV throughout the trajectory of living with HIV. Being healthy (feeling fine) and health deterioration (getting sick) were key health concerns among PLHIV prior to ART initiation. When feeling healthy, it was unusual to suspect HIV infection until diagnosed with HIV. However, experiencing poor health and an HIV positive diagnosis resulted in feelings of despair and impelled the need to maintain or regain health. PLHIV often referred living with HIV as 'being sick' and experiencing poor health when already infected with HIV as 'being very sick' and this perception about sickness and wellness partly determined the need and value placed on accessing HIV services. Motivations for starting treatment included needing to maintain or regain health, encouragement from HCWs, relatives and friends, and believing in the effectiveness of ART to improve health. Prevention of HIV transmission to others was not mentioned as influencing uptake.

The majority of PLHIV reported strict adherence to treatment; even a half hour delay in taking treatment was sometimes defined by participants as non-adherence. Initial reminders for taking ART such as setting an alarm, placing the pills where they are visible and remembering the fact that one was living with HIV fell away as daily medication became routine. However, daily uptake of treatment had its own psychosocial and economic consequences which PLHIV had to navigate. Several individual, communal, health and environmental factors were identified as barriers and facilitators of treatment adherence.

With few exceptions, most PLHIV experienced both temporal (hallucinations, vomiting, dizziness, diarrhoea, skin rashes, nausea, abdominal pains, and loss of appetite) and long-term (backache, feeling dizzy and irregular heartbeat) side effects due to taking ART. None of the side effects were considered life threatening but their severity could undermine adherence to treatment. Living with HIV in the community had several social and psychological consequences among PLHIV. HIV status disclosure was both selective and limited (mainly to close family members, friends and co-workers) and deemed as promoting adherence to treatment and access to HIV services. Stigma has persisted even among relatively healthy PLHIV due to links with ‘promiscuity’ and it hampered disclosure and access to HIV services. Competing demands on participants’ time especially livelihood activities also disrupted accessing services. PLHIV reported having good relationships with HCWs, a factor that promoted access to services.

## 5.3 PLHIV’s health status prior to ART initiation

The study showed that the health of some PLHIV had deteriorated prior to ART initiation despite that they all started treatment with a relatively high CD4 cell count (above 500 cells/mm$^3$). This was contrary to the researcher’s assumption that PLHIV initiated on ART with a relatively high CD4 cell count would not have any health ailments before being initiated on ART. This assumption was based on the established relationship between CD4 cell count and advancement of AIDS and other HIV related health conditions, MacArthur et al. (2005, in Mwesigire et al. 2015). Low CD4 cell count is associated with poor health and vice versa (Harding et al. 2014; Akinboro et al. 2014).

In support of these study findings, two other studies conducted within SSA, Mwesigire et al. (2015) and Igumbor et al. (2013) to determine the association between immunological markers (CD4 cell count and viral load) and health related quality of life among PLHIV found a weak association between the two variables. Subjective measures of quality of life such as happiness, and individual perceptions about general wellbeing (being able to access basic needs) which were influenced by socio-economic and psychological factors were also identified to influence the quality of life scores among PLHIV (Mwesigire et al. 2015; Igumbor et al. 2013). Therefore, the experiences of poor health outcomes among some PLHIV in this study may have been attributed to a common perception that if living with HIV and not on treatment, one’s health deteriorates rather than biomedical markers. This is particularly true of the experiences of four PLHIV who were diagnosed with HIV when ART initiation was dependent on CD4 cell count (WHO, 2013).

## 5.4 Motivation for early uptake of ART

Given that the study targeted PLHIV who were relatively healthy, it was worth exploring their motivations for starting treatment early since previous studies have shown that PLHIV were less likely start ART when feeling healthy (Gilbert & Walker 2009; Feldacker et al. 2012). In the early years of the epidemic when ART initiation was based on CD4 cell count thresholds WHO (2002); UNAIDS (2013) and WHO (2013), PLHIV usually started ART when they were feeling ill (Parkes-Ratanshi et al. 2010; Fox et al. 2010). In this study, half of the PLHIV's motivation for starting treatment were because they were feeling ill, hence this resonates with previous studies that were conducted in the early years of the epidemic. Similar to the findings of this study, previous studies have also shown that starting treatment has been influenced by HCW's advice and encouragement from other family members and friends (Kim et al. 2016; Parkes-Ratanshi et al. 2010).

Another decisive motivation for early uptake of ART among PLHIV in this study was the need to maintain good health. Critical to this motivating factor has been the widespread scale-up of ART provision for almost two decades now which increased its access to most PLHIV in eastern and southern Africa, UNAIDS (2016b) thereby providing evidence that it prolongs life, enables PLHIV with ill health to regain their strength and maintain good health (Bond *et al.*, 2016). A qualitative study aimed at identifying factors influencing linkage to HIV care for PLHIV within a test and start pilot study in Swaziland also showed that early uptake of ART was influenced by fear of being ill and the need to stay healthy (Horter *et al.*, 2017). A study conducted in Malawi also showed that the desire to maintain health was among the main reasons for starting and remaining on ART among pregnant and postnatal HIV infected women (Kim *et al.*, 2016).

In this study PLHIV often referred HIV infection as 'being sick' while experiencing poor health when already infected with HIV was termed as 'being very sick'. Therefore, it is not surprising that a key motivation for starting treatment was to maintain or regain health because PLHIV, once infected considered themselves as 'sick' or 'very sick' if suffering from opportunistic infections. Individual perceptions of sickness and wellness partly determine the need and value placed on accessing health services (including starting or not starting ART). In their study, Horter et al. (2017) showed how acceptance of an HIV positive diagnosis was challenging for PLHIV who were asymptomatic and delayed starting treatment because they considered themselves healthy. These findings are similar to those of the ANRS 12249 TasP trial in rural

South Africa which showed that although ART uptake was generally high, initiation was quicker (within one month) among PLHIV with poor health compared to those who were healthier (Boyer *et al.*, 2016).

Although previous studies have shown that ART reduces the risk of HIV transmission to one's sexual partner, Rodger et al. (2014) and Cohen et al. (2011), a factor that has to a large extent pushed the agenda of early initiation of ART WHO (2016), none of the PLHIV in this study mentioned this as their motivation for starting treatment. This shows that the concept of TasP has not yet been comprehended by most people in these communities and they are still mostly focussing on the individual health benefits of ART (Bond et al. 2016; The INSIGHT START Study Group 2015). Lack of awareness and acceptability of the use of ART for HIV prevention at community level has also been documented by other PopART study analyses and other research (Bond et al. 2016;Young & McDaid 2014). This suggests that key messages at individual and community level need to effectively promote the global agenda on the public health benefits of ART in preventing HIV transmission.

Despite not mentioning prevention of onward transmission of HIV to their sexual partners as the reason for starting treatment, PLHIV were aware of the role of viral load in the risk of transmission, referring to 'viral multiplication' and the risk of 're-infection' when engaging with multiple sexual partners. One participant mentioned how she would always avoid having sex with her husband (also living with HIV) by sleeping on a separate bed whenever she skipped her dosage so as to avoid re-infection. The study conducted by Wamoyi et al. (2011) had similar findings, where PLHIV worried that resuming sex after recovering from an HIV/AIDS related illness would enable the virus to regain strength hence risking 'superinfection'. Knowledge about the risk of HIV infection when having unprotected sex has been emphasised from the early years of the epidemic and key HIV prevention methods focussed on practicing safe sex (WHO, 2002).

## 5.5 Experiences with taking ART

### 5.5.1 Taking the drugs

ART is a lifetime commitment that requires PLHIV to take a daily dosage (Vella *et al.*, 2012). Taking the drugs at the same time on a daily basis had psychosocial and economic consequences on PLHIV. For instance, they had to remember to always carry the drugs when travelling and going for work (during night shifts) or ensure that they returned home before it was time to take the dosage. Returning home in time sometimes required secure and reliable transport at a fare. Food insecurity further threatened daily uptake of ART. PLHIV mentioned how social routines sometimes had to be forgone to ensure treatment adherence. Additionally, taking the drugs had to be done in privacy which was not always guaranteed. Daily adherence demands commitment and could sometimes be overwhelming. One participant narrated how on a particular day he took two doses instead of one because he could not remember whether he had already taken the day’s dosage or not. Many other studies have shown similar findings on how being on daily treatment for a lifetime can be a burden for PLHIV (Heestermans et al. 2016; Holtzman et al. 2015; Koole et al. 2016; Letta et al. 2015). It perpetuates stigma and consequently leads to non-adherence to treatment (Holtzman *et al.*, 2015) and sometimes loss to follow up (Mukumbang, Mwale and van Wyk, 2017).

### 5.5.2 Adherence to ART

All but two PLHIV reported high levels of ART adherence. Similar findings have been shown in two TasP trials, the ANRS 12249 in KwaZulu-Natal, South Africa, Iwuji et al. (2016) and the SEARCH trial in Kenya and Uganda, Petersen et al. (2016) which have provided bio-medical evidence of sustained viral suppression among PLHIV on ART, an indication of ART adherence. This suggests that, although there are challenges with linking some newly diagnosed HIV-positive individuals to care, Mugglin et al. (2012); Rosen & Fox (2011) and Horter et al. (2017), once on treatment, PLHIV are more likely to adhere. These findings are similar to the 2016 Zambia population-based HIV impact assessment which showed that about 89.3% of PLHIV between the ages of 15-59 who are on ART in Zambia were virally suppressed (Ministry of Health Zambia, 2017). The factors identified to have influenced adherence to treatment are similar to those mentioned in other studies (Gilbert & Walker 2009; Holtzman et al. 2015; Letta et al. 2015; Merten et al. 2010).

However, there were some factors that hindered adherence to treatment. For instance, some PLHIV showed signs of exhaustion with taking ART. This means that, in the long-term PLHIV might struggle to sustain treatment. Therefore, adherence support and encouragement from both the HCWs and relevant social networks should be on-going even for PLHIV who have been on ART for a long time, regardless of health status. The importance of social support in promoting adherence to treatment has been emphasized by many other studies (Heestermans et al. 2016; Holtzman et al. 2015; Letta et al. 2015). As in this study, many other studies have also highlighted alcohol use as influencing both uptake and adherence to treatment (Heestermans et al. 2016; Holtzman et al. 2015; Musheke et al. 2013).

### 5.5.3 Side effects due to taking ART

Taking the first line regimen, ten of fourteen PLHIV experienced temporal but minor side effects (stated above) in the initial months of ART initiation. Only two experienced some side effects even after being on ART for some time. Four PLHIV did not experience any side effects. However, none of the PLHIV that experienced side effects thought they were life threatening. Side effects due to taking ART have been identified to influence adherence to treatment (Koole *et al.*, 2016). In this regard, Renju et al. (2017) argued that PLHIV initiated on ART early were less likely to endure side effects when they experience them and would affect their adherence to ART. This is contrary to this study's findings which shows that adherence among PLHIV was exceptionally high despite experiencing some side effects. Only one pregnant woman had poor adherence to treatment after experiencing side effects and the latter could have been also related to pregnancy itself. A possible explanation for PLHIV in this study to have endured the side effects is the fact that HCWs informed them about the likelihood of experiencing temporal side effects during ART initiation.

Therefore, future studies should consider investigating the long-term side effects of ART among PLHIV initiated on treatment early. This is particularly important because the debate on the benefits and risks of the timing of ART initiation overtime has not yet been settled (Cohen *et al.*, 2011). While some scholars argue that the benefits of starting treatment early outweigh the risks, Renju et al. (2017) and The INSIGHT START Study Group (2015), the findings from the HPTN 052 and the WHO technical working group review showed otherwise (Cohen et al. 2011; WHO 2016).

## 5.6 HIV status disclosure and stigma

All PLHIV in this study had disclosed their HIV status to close relatives, friends and co-workers. However, deciding whom to disclose to and when to disclose was often selective, mostly dependent on the confidant's trustworthiness. This corresponds to the findings of other studies that have shown that PLHIV face difficulties deciding whom to disclose their HIV status to, Pierret (2007) and Bond (2010), and usually disclose to trustworthy family members and friends (Aransiola et al. 2014; Bond 2010; Lyimo et al. 2014). In the test and treat era, HIV status disclosure is important for social support which promotes adherence to treatment and access to HIV services (Horter et al. 2017; Heestermans et al. 2016). Since PLHIV initiated on ART early are relatively healthy and actively involved in economic activities, disclosure could aid support to accessing services at the clinic if the PLHIV is committed or cannot get permission from work on the clinic appointment date, a trend which was common among PLHIV in this study.

While disclosure is important for social support, sometimes it is also a source of rejection, (Maeri et al. 2016; Merten et al. 2010). The negative perceptions about HIV, fear of being pitied or stigmatized result in non-disclosure of HIV status (Horter et al. 2017; Mbonye et al. 2013; Aransiola et al. 2014). In this study, two PLHIV experienced enacted stigma while the majority had heard of other PLHIV in the community being stigmatized due to their HIV status. All participants hence experienced internalized stigma. Although starting treatment early was widely acknowledged to have helped avoid involuntary HIV status disclosure thereby reducing chances of being stigmatized, uncertainties of reactions from others if they learnt about the PLHIV's status limited disclosure. Disclosure was sometimes done casually to avoid undesirable reactions. The persistence of stigma overtime still poses a threat to both access of HIV services in health facilities and uptake of HIV treatment, factors which have an influence on achieving the UNAID's second and third 90-90-90 goals (UNAIDS, 2014a).

However, the study shows a wide recognition of a reduction in stigma over the years. Among PLHIV, HIV infection was considered to be like any other illness. Both HCWs and PLHIV explained how in recent times PLHIV were not being isolated compared to the earlier years of the epidemic and that they were now living healthy and productive lives like any other people in the community. This is similar to what other studies have shown (Mbonye et al. 2013; Chan, Tsai, et al. 2015). Additionally, the study also provides evidence that discussions about HIV are common within the community and in work places. This is a step closer towards breaking the silence on the reality of the impact of HIV in communities and accepting that it affects everyone. Therefore, stigma reduction activities need to be emphasized at household and community level in order to further reduce stigma.

### 5.7 Accessing HIV services

Despite being necessary, PLHIV's routine clinic appointments for health monitoring and drug collection sometimes disrupted their daily activities, especially when they were at odds with their livelihood demands. The long waiting time they have to endure at the health facility due to overcrowding and slow service delivery demotivated then whenever accessing HIV services. Mukumbang et al. (2017) and Musheke et al. (2013) identified similar challenges with accessing HIV services among PLHIV in Zambia. The rapid change in HIV treatment guidelines UNAIDS (2013);WHO (2013);WHO (2016) has been feared by HCWs to increase the number of PLHIV accessing services thereby overburdening the health system (Simuyaba *et al.*, 2017). Infrastructural development in health facilities has not corresponded with the increase in number of clients accessing HIV services overtime, thereby causing delays in service provision (Mukumbang et al. 2017; Simuyaba et al. 2017). Bigna et al. (2016) argued that, given the weak healthcare infrastructure in less developed countries, implementation of universal treatment on a large scale was likely to pose challenges for the health system.

Given that PLHIV initiated on ART early are relatively healthy and are actively engaged in socio-economic activities in their communities, the Zambian health system needs to adjust the HIV service provision hours in order to accommodate those who struggle to negotiate time-off their busy schedules to access HIV services as shown in this study. In addition, the challenges in accessing HIV services need to be addressed otherwise they remain a threat to accessing HIV services and uptake of ART. Musheke et al. (2013) also reiterated that health facility challenges such as overcrowding and prolonged time to access services was feared to increase the likelihood of PLHIV being seen accessing services (leading to involuntary disclosure) and interrupt livelihood activities and as such are a barrier to linkage to care and uptake of ART. Adopting different ART delivery models such as home delivery of ART that have proven to be effective in decongesting health facilities in SSA could improve HIV service delivery in high burden communities (Luque-Fernandez et al. 2013; Bemelmans et al. 2014; UNAIDS & Médecins Sans Frontières 2015).

## 5.8 Limitations of the study

The study was limited in that it relied on self-reported experiences of PLHIV who were initiated on ART early. These responses could have been influenced by having study participants who were recruited by HCWs providing HIV services at the facility. The responses could have also been influenced by conducting the interviews at the health facility. Additionally, PLHIV who are open about their HIV status are more likely to share positive experiences about HIV services, care and treatment. The findings of the study may also be limited because this study is being conducted among participants who were enrolled into care through the PopART trial which included additional interventions to facilitate access to HIV services. Had there been no interventions at the health facility and in the community, their experiences could have been different. Lastly, the research did not compare the experiences of PLHIV who had been initiated onto ART with lower CD4 cell counts with those of PLHIV initiated on ART early during the implementation of the PopART study. This could have provided further insights on the differences in experiences among these two groups of individuals.

# CHAPTER SIX: CONCLUSION AND RECOMMENDATIONS

This chapter presents the conclusion and recommendations applicable to the Zambian context based on the findings.

## 6.1 Conclusion

The study findings suggest that PLHIV who start treatment early are prone to experience ill health prior to ART initiation despite having a CD4 cell count greater than 500 cells/mm$^3$. This indicates that apart from immunological and biomedical markers, socio-economic and psychosocial factors also determine individual health outcomes among PLHIV. Early uptake of ART among PLHIV was motivated by the need to maintain or regain health, encouragement from HCWs, relatives and friends and believing in the effectiveness of ART in improving health. Prevention of HIV transmission to others was not cited to influence uptake. PLHIV reported stringent adherence to treatment with the view of ART helping them to either maintain or regain health. However, adherence to treatment could be undermined by side effects (temporal and long-term) due to taking ART and social consequences of living with HIV, including limited HIV status disclosure and stigma. Throughout their treatment journey, PLHIV needed continued support from social networks and HCWs to adhere to treatment and remain in care. The experiences of PLHIV with accessing HIV services in the health facilities was characterized by social, structural and institutional barriers which demotivated them and they desired easier access. The successful roll-out and implementation of early initiation of ART should consider these dynamics in multiple contexts.

## 6.2 Recommendations

Based on the study findings and related literature, the following seven recommendations have been made to improve service delivery and promote uptake of immediate ART among PLHIV in Zambia.

1. The findings and literature review show that HIV/AIDS stigma has persisted overtime and impedes uptake of HIV services and ART. Therefore, stigma reduction activities need to be emphasized at household, community and health facility levels to reduce stigma among PLHIV.

2. Given the success recorded so far in the fight against HIV, health messages should de-emphasise the notion that living with HIV is a sickness.

3. Although HIV status disclosure sometimes results in rejection and discrimination of PLHIV, it is an important step in the trajectory of living with HIV because it not only helps prevent onward transmission of HIV but also promotes access of HIV services, uptake of treatment and adherence to ART.

   - Therefore, HIV status disclosure among PLHIV must be encouraged in health facilities. This should include practical skills in negotiating HIV status disclosure and engagement of partners or any other relevant social networks. This is particularly important because the study shows how PLHIV struggled to disclose their HIV status (sometimes even to sexual partners).

   - Once PLHIV have disclosed, to promote continued uptake of treatment, adherence support and encouragement from both the HCWs and relevant social networks should be on-going even for PLHIV who have been on ART for a long time, regardless of health status.

   - Support from social networks is also important for the daily management of HIV among PLHIV. Taking ART daily was demanding and had psychosocial and economic consequences on PLHIV that had an influence on social routines and sometimes work.

4. Side effects due to taking ART have the potential to influence adherence to treatment. Given the unsettled debate in literature on the long-term side effects due to taking ART, further research is needed to ascertain this among PLHIV initiated on ART early.

5. Social-economic, structural and health system (including policies) barriers towards the effective delivery of HIV services among PLHIV need to be addressed in order to facilitate access to immediate ART for all PLHIV. This includes but is not limited to:

   - Implementing flexible HIV service provision hours or extending the hours (including afternoons and evenings) or days (including weekends) of providing HIV services in the health facilities so that PLHIV can access services in health facilities throughout the week.

   - Advocating and implementing flexible work place policies that permit PLHIV to access HIV services when needed and

- Reducing waiting time and overcrowding when PLHIV are accessing services in health facilities.

6. Innovative approaches of delivering ART such as adherence clubs and community delivery of ART for long-term and stable clients could help decongest health facilities and reduce the frequency of clinic visits for PLHIV. This would ultimately encourage PLHIV to access HIV services, take up treatment, reduce stigma and promote adherence to ART.

7. Given that the study showed that uptake of ART among PLHIV was not motivated by the TasP concept, health messages encouraging PLHIV to start treatment early should focus on promoting the public health benefits of ART use to prevent onward transmission of HIV to sexual partners. Increased awareness of viral load and its implication on sexual transmission of HIV among PLHIV could also increase awareness about the public health benefits of ART.

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## APPENDICES

### Appendix I: INFORMATION SHEET (Clients)

**Project Title:** Experiences of early antiretroviral therapy (ART) initiation among people living with HIV in Livingstone district in Zambia.

### What is this study about?

This is a research project being conducted by Melvin Simuyaba, a Master in Public Health student at the University of the Western Cape. You have been invited to participate in this research project because you are among the people accessing HIV services at a government health facility in Zambia and you were initiated on immediate Antiretroviral Therapy (ART), thus starting ART as soon as you are tested HIV positive. The purpose of this research project is to explore the experiences of early ART initiation among people living with HIV accessing ART services at a government health facility in Zambia.

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

You will be approached by a health care worker during one of your routine clinic visits. The health care worker will inform you about the study and ask you to participate in the research. If you are agreeable to participate in the research, you will be referred to a private space within the clinic building where you will meet the researcher. The researcher will further explain to you in detail about the study in a language that you understand and request you to participate in an interview. Through the interview, the researcher will seek to understand your experiences with taking antiretroviral drugs, experiences of living with HIV in the community and motivating factors for uptake of immediate ART. You will be required to give written consent for participating in the interview. The individual interviews will last not more than 40 minutes and will be audio recorded with your permission. The interview will be audio recorded to enable the researcher to adequately capture all your views and will serve as a reference point for clarification when making interpretations of what you said. Researchers use audio recordings to prepare word for word translations from audio to text to facilitate interpretations of participant’s views.

**Would my participation in this study be kept confidential?**

The researcher will undertake to protect your identity and the nature of your contribution. To protect your identity, all research participants (like you) will be identified through the clinic triage system and interviews will be conducted in privacy. Your name will not be included or mentioned on any data that is collected. Each research participant will be given a unique identification code which will only be known by the researcher. The unique identification code that you will be given will not be linked to any information that can be associated with you, your occupation or household, including the signed consent forms, interview notes or recordings. Information sought from you will only be linked through an identification key.

To ensure protection of your contribution, all the information gathered during the study (recordings, transcripts and interview notes) will be kept on a password protected computer and hard drive. Hard copies of data and consent forms will be kept in a lockable drawer. Only the researcher will have the computer password and the keys for the drawer will be stored safely away from the drawer. Access to the research data will be restricted until it is destroyed after five years. Although the interview will be audio recorded, with your permission, information will not be linked or traced back to you. When the discussion is fully written up, it will not bear actual names of informants or identifiable places. Only unique identification codes assigned to participants will be used on information that can be associated with you. If a report or article about this research project is written, full quotes from individual participants may be used, but your identity and information you share will be protected because the quotes will not be linked to named individuals.

In accordance with legal requirements and/or professional standards, the researcher will disclose to the appropriate individuals and/or authorities information that comes to his attention during the course of this research concerning serious health or welfare problems that could cause potential harm to you or others. In this event, the researcher will inform you that he has to break confidentiality to fulfil his legal responsibility to report to the designated authorities.

**What are the risks of this research?**

All human interactions and talking about self or others carry some amount of risks. There is a chance that some of the questions the researcher will ask you may cause discomfort or emotional stress to you. The researcher will nevertheless minimise such risks and act promptly to assist you if you experience any discomfort, psychological or otherwise during the process of your participation in this study. If you feel uncomfortable about any questions you are asked by the researcher, feel free not to answer them. Where necessary, an appropriate referral will be made to a suitable professional for further assistance or intervention.

**What are the benefits of this research?**

This research is not designed to help you personally, but the results may help the investigator learn more about the experiences of people living with HIV initiated on ART earlier. The researcher hopes that, in the future, other people might benefit from this study through improved understanding of the implications of early initiation of ART to people living with HIV in Zambia. This will help take into account the perspectives of people living with HIV when influencing immediate ART uptake. Additionally, the researcher hopes that the research will inform policy makers and other decision makers about the practicability of community wide uptake of immediate ART that will be useful for making recommendations for the pending national wide roll out of immediate ART initiation in Zambia.

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

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

**What if I have questions?**

This research is being conducted by Melvin Simuyaba, a student at the School of Public Health, Faculty of Community and Health Sciences at the University of the Western Cape, South Africa. My supervisor is Dr. Thubelihle Mathole of the School of Public Health, Faculty of Community and Health Sciences, University of the Western Cape, South Africa. If you have any questions about the research study itself, please contact Dr. Thubelihle Mathole of address: University of the Western Cape, School of Public Health, Private Bag X17, Belville 7535, South Africa; Telephone: +27 21 959 9384 and email: tmathole@uwc.ac.zm or myself at -

address: Zambart, University of Zambia, Ridgeway Campus, Nationalist road, P.O Box 50697, Lusaka, Zambia; Cell phone number: +260966930471 and email: msimuyaba@gmail.com.

Should you have any questions regarding this study and your rights as a research participant or if you wish to report any problems you have experienced related to the study, please contact:

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This research has been approved by the University of the Western Cape's Senate Research Committee (reference number: BM/17/1/8) and the University of Zambia Biomedical Research Ethics Committee (UNZABREC Ref: 011-11-12).

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**Appendix I:** **PAMPILI YA PATAHAZO (Batu baba anga kolo)**

**Taba ye musebezi wa patisiso:** Ze bafitile mwateni batu baba pila ni kakokwani ka HIV baho baba kalisiza kunuwa kabubebe mulyani wa ku kalafa ka kokwani ka HIV (ART) mwa sikiliti sa Livingstone mwa naha ya Zambia.

**Kana tuso ya tuto ye ki ifi?**

Musebezi wa patisiso ye iyezewa nibo Melvin Simuyaba, mwana sikolo sesi tuna sa Western Cape uituta 'Master mwa Public Health'. Mu kupiwa kuli munga kolo mwa musebezi wa patisiso ye ka kuli mina ni batu babangwi muhamuhela tuso kaza HIV kwa sipatela sa muso mwa naha ya Zambia mi hape ne ba mikalisize kunwa mulyani wa ku kalafa kakokwani ka HIV (ART) kabubebe, kutalusa kuli, mukalisize kunwa mulyani wa ART amufeza kutatubiwa kuli munani kakowani ka HIV. Tuso ya musebezi wa patisiso ye ki ku batisisa kuli luziba zomuziba ni ze ba fititile mwateni bao baba pila ni kakokwani ka HIV mi ba hamuhelaa mulyani wa ART kwa le kwa sipatela sa muso mwa naha ya Zambia.

**Kana baka ni kupa ku yeza ngi haiba na lumela kuunga kolo?**

Mu yo bonana ni ba beleki ba makete amutoya kwa sipatela kuyo pota sina kamita. Ba beleki ba makete bayo mi taluseza kaza tuto ni kumi kupa kuli munga kolo mwa patisiso. Haiba mwa lumela ku unga kolo mwateni mwa patisiso, ba yo miluma ku yo ya mwa sibaka se sina ni mukunda mwa sipatela kuli mu yo kopana niba batisisi. Ba batisis ba yo mi tolokela mwa bu ngata kaza tuto mwa mushobo o mu utwa mina mi ni kumikupa kuli munga kolo kwa ku ambolisana. Ka ku ambolisana, ba batisisi ba bata ku ziba ze mu ziba, mina amoho ni zo mufitile mwateni kaza kalafo ya kunwa mulyani wa ART,ze mufitile mwateni mi ni za bupilo bwa mina kakupila ni kakokwani ka HIV mwa sibaka mi hape ni ze zi kezize kuli mu kale kalafo ya kunwa ART kabubebe. Muswanela ku nyetela kappa ku ngola ku bonisa kuli mulumezi kunga kolo kwa ku ambolisana. Ku ambolisana kwa teni ko yo nga nako ye fita fa 40 minutes hape luka mikupa kuli mululumelise kuli lubeye manziwa amina kappa kuambilisana mwa rekoda. Luka rekoda ku ambolisana ku yezeza ba batisisi kuli banga kaufela maikuto ni mi naano ye mina mi hape, ku rekoda ku ka lutusa kuziba handehande zemutalusa ka mukwa wa ku nahanela fateni fa ku ambolisana. Ba batisisi ba belekisanga ma nzwi kappa ku ambolisana ko kubeyiwa mwa rekoda ku ngola kaufela zene zi ambozwi (lizwi ni lizwi la ngolewa mwa li ngolo) kutusa mukwa wa ku nahanela fateni fa ku ambolisana.

**Kana kuunga kolo kwa ka mwa patisisi ye kukaba ni kunutu?**

Ba batisisi baka seleleza kuli amusika mwa zibiwa mi hape zo muka bulele zifi ni zifi zi ka selelezwa ni kunutu. Ku sepisa ni ku yeza kuli amusika mwa zibiwa, kaufela baba unga kolo (inga mina cwalo) mu yo ketiwa ku fitala kwani ku ba ngolele ni ku pima bakuli mi hape ku ambolisana ku yoba mwa mukunda. Libizo lamina aiyo kubateni kappa kubehawa fa makande ayo ingiwa. Ufi ni ufi anga kolo mwa patisiso uka fiwa nombolo ye kazibiwa fela niba batisisi. Nombolo ye mo yo fiwa aiyo ama ka za patahazo kappa makande amina, musebezi wa mina kappa za lubasi wa mina, amoho ni lipampili za ku lumelisana, lingolo kappa zo lu ka rekoda. Patahazo ye ikazwa ku mina iyo ama mina fela ku fitela mwa nombolo.

Ku sepisa kunutu ya mina, kaufela patahazo lu kanga mwa tuto (ku rekoda, zo luyo ngola kuzwa mwa rekoda ni zo lu yo ngola lu ambolisana) zi yo bulukiwa ni ku seleliziwa ki nombolo mwa komputa. Lipampili za makande ni lipampili za ku lumelisana zi yo bulukiwa hande mu kukwaliwa. Konji fela ba batisis ki bona bayo ba ni nombolo ya kwa komputa ya ku kwa lulu hape keyi ya kwa drowa iyo bulukiwa hande kwaule ni drowa.Mukwa wa kubona linepo za patisiso uyo ba oushupila konji linepo za patisiso ziyo shiniwa akufita likweli ze kata lizoho. Neba kuli ku ambolisana ku ka rekodiwa amukalulumelisa, akuna patahazo ye yo ama mina. Ku ambolisana ko aku yo ngolwa, ze yo ngolwa azina kuyo bonisa ma bizo amina/ba halabi kappa sibaka. Konji fela ma nombolo ayo fiwa ba ba unga kolo ki yona ya yo boniswa ku ama mina. Haiba lipatisiso ha se natisizwe ku zwa mwa tuto li ta hatiswa mwa ma buka ya ba batisisi, kono ku sina mabizo a fiwa ku mutu ufi kappa ufi, kono makande amina ya yo behawa kusina ku ama batu kappa mina.

Ku latelela mu laho zo bulela hape/ kappa swanelo ya musebezi, ba batisisi ba swenela kubulelela batu hape/kappa ba muso kaza patahazo ye kona kufumaneha mwa nako ya patisiso ye ama kaza bupilo kappa makete kappa butata mwa muinelo o kona kutisa kozi kumina kappa babangwi. Aeba ki cwalo, mu batisisi uka mizibisa kuli uswanela ku kupwacha kunutu ka kuli a swanela ku biya ku baba bona za butata bo ku latelela mulaho.

### Kana kozi mwa patisiso ye ki ifi?

Kaufela ku kopana kwa batu ni ku kandeka za mina kappa ba bangwi kubanga ni kozi nyana. Mwendi lipuzo ze ba ka mibuza ba batisisi za kona ku mi utwisa bu mayi. Kono mu batisisi uka yeza kuli kozi ibe ye inyani kappa kuyi sufalisa ni ku hangufa ku mi tusa haiba mu twile bu mayi, kuliyangana mwa booko kappa mo mungwi mwa mukwa wa ku unga kabelo kappa kolo mwa tuto. Haiba mu utwa ku salukuluha kappa bumai kali baka ka li puzo ze ba buza ba batisisi, mu lukuhile ku sa lihallaba lipuzo. Aku tokwa, baka miluma ku yo hamuhala tuso ye swanela kappa ye batahala.

### Kana miselo ya patisiso ye ki ifi?

Patisiso ye aisika pangiwa kutusamina, kono linepo za kona kutusa ba batisisi ku ituta maikuto, ni bupilo wa batu ba ba pila ni ka kokwani ka HIV bani ba ba kalile kunwa mulyani wa ART kabubebe. Ba batisisi ba sepa kuli kwa pata ya mazazi, mwendi batu ba kona kufumana tuso/bu nde kappa miselo libaka ka tuto ye kufitela ka ku tisa zwelo pila ku ziba hande taluso ya ku kalisa kunwa mulyani wa ART kabubebe mwa batu baba pila ni ka kokwani ka HIV mwa naha ya Zambia. Se, si ka tusa ku utwa ni ku ziba minahano, maikoto ya batu ba ba pila ni kakowani ka HIV mi hape ni moba bonela ze susuweza kuli ba no kala kunwa mulyani wa ART kabubebe. Ku ekeza fateni, ba batisisi ba sepa kuli patisiso ika zibisa ba ba panga milao niba ba bangwi ba ba na ni mata aku bona fa milao kubona mwendi kuli ze za kona ku yezahala kwa sichaba se si tuna kunwa milyani ya ART kabubebe, kuli ba bona mwendi mulao usalibelela wa ku kalisa batu kunwa milyani ya ART kabubebe wa kona hala mwa naha kaufela ya Zambia.

### Kana ni swanela ku ba mwa patisiso ye, kana na kona ku siya kunga kolo ka nako ifi ni ifi?

Kunga kolo mwa patisiso ye ki ku itombola mina bangi. Mwa kona kuketa ku sanga kolo mwateni. Haiba mwa keta ku sanga kolo mwa patisiso ye, mane mwa kona kusiya kappa mu lukuluhile ku tuhela lipatisiso fa nako yo mulatela, kusina koto ku mina kappa ku latehelwa miselo yo mu swanela ku hamuhela.

### Kana haiba nina nilipuzo?

Patisiso ye iyeza nibo Melvin Simuyaba, mwana wa sikolo mwa sikolo sa Public Health, ko kwa Faculty ya Community ni Health Sciences kwa sikolo sa University kwa Western Cape, mwa naha ya South Africa. Baba bona ba kappa ba bateheli ba bona kibo Dr. Thubelihle Mathole ba kwa sikolo sa Public Health, Faculty ya Community ni Health Sciences, University ya kwa Western Cape, mwa naha ya South Africa. Haiba muna ni lipuzo ka za tuto ya patisiso ye, mwa kupiwa ku lume luwaile kubo Dr. Thubelihle Mathole ba kwa : University ya kwa Western Cape, sikolo sa Public Health, Private Bag X17, Belville 7535, South Africa; Telephone: +27 21 959 9384 and email: tmathole@uwc.ac.zm kappa na kwa : Zambart, University ya Zambia, Ridgeway Campus, Nationalist road, P.O Box 50697, Lusaka, Zambia; Cell phone number: +260966930471 and email: msimuyaba@gmail.com.

Amunani lipuzo ze ama tuto ni liswanelo za ama inga mina ba banga kolo mwa patisiso kappa haiba mwa bata ku biya kozi kappa butata bobu hezahalile mwa tuto ye, amu lumele kappa ku biya kubo:

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Patisiso ye ilumelisiwa kibo University ya Western Cape's Senate Research Committee (reference number BM/17/1/8) ni ka kwata kaka bona milawo yaku ezeza lipatisiso kakubizwa Biomedical Research Ethics Committee (UNZABREC Ref: 011-11-12) ka kwa University of Zambia.

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**Appendix I:** **IPEPA LYA MAKANI (Ibajana lugwasyo)**

**Izyina Lya Ciiyo:** Izyibonwa akaambo kakutalika kusilikwa sikalileke icakutalindila akati kabantu ibapona asikalileke mucitiliti ca Livingstone mucisi ca Zambia.

**Sena Mulimonzi wa ciyoo eeci?**

Ibeendelezya ciiyo eeci mbaba Melvin Simuyaba, balo ibaiya ciiyo cilanganya makani anseba abukale bwa banamaleya ica Public Health ookuya kucikolo cipata ica University of the Western Cape. Mwatambwa ikuti mutole lubazu mu ciiyo eeci akaambo kakuti mulibamwi alibaabo bantu ibatambula ilugwasyo lujatikizya makani aasikalileke acibbadela cisyoonto ica mfulumende mu cisi ca Zambia alimwi mwakatalika ikusilikwa sikalileke icakutalindila, eeci caamba ikutalika kusilikwa sikalileke cakufwambaana mbomwamanina buyo kupimwa akujanwa akazunda kasikalileke. Mulimo wa ciiyo eeci nkuvwuntauzya izyibona bantu ibapona akazunda ka sikalileke ibatalika ikusilikwa sikalileke ica kutalindila acibbadela cisyoonto ica mfulumende mu cisi ca Zambia.

**Sena ncinzi ncetikalombwe ikucita ikuti na ndazumina ikutola lubazu muciiyo?**

Ibabesyi banseba baya kulomba kwaambaula andinwe cimwi ciindi nomuswaya cibbadela mbobuli lyoonse. Ibabelesi banseba baya kumuzyibya imakani alimwi akumalomba kutola lubazu mu ciiyo. Ikuti naa mwazumina ikutola lubazu muciiyo, muyakutondezyegwa busena busesekene mumwena mucibbadela cisyoonto mwalo momutikajane ibavwuntauzyi. Ibavwuntauzyi bayakwiindilizya ikumupandulwida ikwakusinizya imakani aa ciiyo mumulaka ngomumvwa alimwi akumulomba kuti mutole lubazu mumubandi. Ikwiinda mumubandi, basikuvwuntauzya bayakukapaula iluzyibo lwamakani azyintu nzyomubona akaambo kakusilikwa sikalileke, izyintu nzyomubona mumunzi akaambo kakupona a sikalileke alimwi atwaambo itupa ikulombozya ikutalika kusilikwa sikalileke icakutalindila. Muyakuyandika ikuti mukape cizuminano kwiinda mukulemba kamutana kuba amubandi. Imubandi tuukaindi kumaminiti aasika ku makumi one na 40 alimwi imajwi ayakutolwa mumunchini ikuti na kamuzumizya. Imajwi ayakutolwa amuncini ikutegwa ibavwuntauzyi bakabwezye imajwi enu oonse ibuyandika alimwi ayakubelesyegwa mukuleezyegwa ikuti na kwayandika ikusyomezya ciindi cakwaalanganya. Ibavwuntauzyi babelesya imajwi aatolwa amincini kusandululula jwi a jwi ikuzwa mumubandi uutoledwe mumuncini ikutola mumalembe ikutegwa bagwasyigwe kubambulula twaambo twabasikutola lubazu.

**Sena ikutola lubazu kwangu mu cciyo eeci kuyakuyobolwa mumaseseke?**

Ibavwuntauzyi bayakuliimikizya ikukwabilila imazyina alimwi abube bwa twaambo twenu. Ikutegwa mutakazyibwi, boonse ibatola lubazu mu ciiyo (mbobuli ndinwe) bayakuzyibwa kwiinda mu mbeleko zyacibbadela cisyoonto alimwi imubandi uyakuba mumaseseke. Izyina lyenu talikayungizyigwi na kubandwa mumakani kufwumbwa, aati kabwezyegwe. Umwi a umwi uutola lubazu mumubandi uyakupegwa cizyibyo calo icitikazyibwe buyo a bavwuntauzyi. Cizyibyo ncomutikapegwe tacikayaami kumakani oonse aanga agama ndinwe, milimo yenu na nganda, ikuyungizya amapepa aacizuminano asainidwe, imabala amubandi na imajwi aatolwa amuncini. Imakani aatolwa kuzwa kulindinwe ayakumagama buyo kwiinda mumanambala ikuzyibya.

Ikutegwa kubonwe kuti kwaba maseseke, itwaambo ituya kubwezyegwa (majwi atolwa mumuncini, malembe aazwa kumajwi aatolwa mumuncini alimwi amalembe aajatikizya mubandi) tuyakuyobolwa mu kompyuta ikwabibilidwe alimwi amuncini wakuyobweda zintu uukwabibilidwe. Imapepa aatwaambo acizuminano ayakuyobolwa mu busena ibukiigwa. Mbabasikuvwuntauzya ibalo ibatinooli anguzu zyakujalula kompyuta alimwi imaki abusena buyobwedwa ayakuyobwedwa ikule abusena oobu. Inzila yakubona makani iyakukwabililwa mane akaakujaigwe kwainda myaka iili yosanwe. Anokuba kuti imajwi eenu ayakutolwa mumuncini, kamupede nguzu, imakani taakamugami na ikujolwa ikuti muzyibwe kuti ngeenu.

Ikulemba ikwa majwi eenu aatoledwe amuncini kwaakumaninina, imapepa aaya taakabi amazyina abasikutola lubazu na imasena aanga azyibwa. Pele buyo imanambala aakuzyibya basikutola lubazu ngaaya ikubelesyegwa kumakani aanga apa kuti mulizyibye. Ikuti na kwaba ikulemba izyitikajanwe mu ciiyo itwaambo twaamba basikutola lubazu inga twabelesyegwa mukumaninina, pele izyina lyenu amakani ngomuyakubandika abasikuvwuntauzya ayakukwabililwa akaambo kakuti itwaambo tatukagami ibantu kwiinda mukubaamba mazyina.

Ikucilila ibuyandika kumulawo alimwi/nape malailile abubelesyi, basikuvwuntauzya inga bayubununa twaambo kubantu ibayandika alimwi/nape ibeendelezyi imakani ngobajana ciindi ca ciiyo eeci aajatikizya ikuciswa kupati na imapenzi aabukale alangilwa ikuti inga aleta ntenda kuli bamwi. Kwaba boobu, basikuvwuntauzya bayakumuzyibya ikuti baya kujaya maseseke ikutegwa babeleke kweendelana amulawo ikuzyibya beendelezyi ibapedwe.

**Sena nintenda nzi izili mu ciiyo eeci?**

Ikujanana kwabantu koonse alimwi akwaambaula alilwenu nape ibambi kulaantenda anokuceya. Kulalangilwa ikuti imibuzyo imwi njobayakubuzya basikuvwuntauzya inga yamapa ikutalimvwa kabotu na ikumapa ikulimvwa bubi kumoyo. Basikuvwuntaizya nokuba, bayakusola kujola aansi ntenda mbobuli zyeezyi alimwi akufwambaana ikumagwasya ikuti na mwalimvwa bubi, kumoyo nape ubuli boonse ciindi nomutola lubazu mu ciiyo eeci. Ikuti na tamulimvwi kabotu akaambo kamibuzyo kufwumbwa, njobabuzya basikuvwuntauzya, amwaangulukwe ikutaivwiila. Kwayandika, ikuleezyegwa ikweelede kuyakuba ikuya kuli basibupampu ikuyungizya ikugwasilizya na kulugwasyo lucilila na bukwabilizyi.

**Sena mbubotu nzi ibwa ciiyo eeci?**

Eeci ciiyo tacibambidwe ikuti cimagwasye ikumagama lwenu, pele iziyakujanwa zilangilwa kuti inga zyagwasya basikuvwuntauzya ikuti bazyibe izyinji kumakani azyibona bantu bapona asikalileke balo ibatalika kusilikwa sikalileke icakutalindila. Basikuvwuntauzya balangila kuti, kumbele aamazuba, bamwi ibantu inga bajana bubotu kwiinda mukusumpula luzyibo ilujatikizya mbocaamba ikutalika kusilikwa sikalileke icakutalindila kubantu ibapona asikalileke mucisi ca Zambia. Eeci ciyakugwasya ikulanganya mizeezo yabantu ibapona aasikalileke iciindi nobatonkelezyegwa ikutalika kusilikwa icakutalindila. Kuzwa waawo basikuvwuntauzya balangila ikuti ciiyo ciyakugwasya basimubamba milawo abamwi beendezyi ikuti bazyibe ikuti na ikutalika kusilika sikalileke icakutalindila mu cooko coonse inga kwaba, calo iciyakugwasya mukupa nguzu zyakuyanda kwakutalika kusilika sikalileke icakutalindila mucisi coonse ca Zambia.

**Sena mane ndeelede ikuba mu ciiyo eeci alimwi sena inga ndaleka kufwumbwa ciindi?**

Ikutola lubazu ikwenu muciiyo eeci nkwakulyaaba. Mulakonzya ikutatola lubazu. Ikuti na mwazumina ikutola lubazu mu ciiyo eeci, mulakonzya ikuleka ikutola lubazu kufwumbwa ciindi. Ikuti na mwasala ikuleka kutola lubazu mu ciiyo eeci nape ikuti na mwaleka kutola lubazu kufwumbwa ciindi, takukabi impanisi na ikusweekelwa ibubotu bwalo mbomweeledwe.

**Ino kuti nkeli aamibuzyo?**

Ibeendelezya ciiyo eeci mbaba Melvin Simuyaba, balo ibaiya ciiyo cilanganya makani anseba abukale bwa banamaleya ica Public Health ookuya kucikolo cipata ica University of the Western Cape ku cisi ca cakumusanza ica South Africa. Ibazololi bangu mbaba Dr. Thubelihle Mathole ibaku cikolo cilanganya makani anseba abukale bwa banamaleya ica Public Health ookuya kucikolo cipata ica University of the Western Cape ku cisi ca cakumusanza ica South Africa. Ikuti na kamuli aamibuzyo ijatikizya ciiyo ilwancico, twamulomba mukwabane aba Dr. Thubelihle Mathole iba keala ilya: University of the Western Cape, School of Public Health, Private Bag X17, Belville 7535, South Africa; Luwaile: +27 21 959 9384 alimwi magwalo a email: tmathole@uwc.ac.zm nape ilwangu a keala lya : Zambart, University of Zambia, Ridgeway Campus, Nationalist road, P.O Box 50697, Lusaka, Zambia; luwaile : +260966930471 alimwi alugwalo lwa email: msimuyaba@gmail.com.

Ikuti na mulaamibuzyo iijatikizya ciiyo na inguzu zyenu mbuli ibantu ibatola lubazu muciiyo napa ikuti na muyanda ikutoongoka mapenzi kufwumbwa, ngomwabona aajatikizya ciiyo, twamulomba mukwabe ba:

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Eeci ciiyo cazumizyigwa aba kabunga kalanganya zyiiyo kucikolo cipati ica University of the Western Cape (reference number: BM/17/1/8) alimwi akabunga kalanganya zyiiyo kucikolo cipati ica University of Zambia kategwa University of Zambia Biomedical Research Ethics Committee (UNZABREC Ref: 011-11-12).

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## Appendix II: INFORMATION SHEET (Key informants)

**Project Title:** Experiences of early antiretroviral therapy (ART) initiation among people living with HIV in Livingstone district in Zambia.

### What is this study about?

This is a research project being conducted by Melvin Simuyaba, a Master in Public Health student at the University of the Western Cape. You have been invited to participate in this research project because you are a health care worker offering HIV services at a government health facility in Zambia. We are particularly interested with your experience in offering immediate Antiretroviral Therapy (ART), thus starting clients onto ART as soon as they test HIV positive. The purpose of this research project is to explore the experiences of early ART initiation among people living with HIV accessing ART services at a government health facility in Zambia.

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

You will be individually approached by the researcher who will explain the study to you in a language that you understand. The researcher will request you to participate in an interview at your convenient time and private space within the health facility. Through the interview, the researcher will seek to understand your experiences with providing immediate ART to people living with HIV and your observed attitudes, behaviours and perceptions towards immediate ART initiation among those initiated onto ART earlier. You will be required to give written consent for participating in the interview. The individual interviews will last not more than 40 minutes and will be audio recorded with your permission. The interview will be audio recorded to enable the researcher to adequately capture all your views and will serve as a reference point for clarification when making interpretations of what you said. Researchers use audio recordings to prepare word for word translations from audio to text to facilitate interpretations of participant’s views.

### Would my participation in this study be kept confidential?

The researcher will undertake to protect your identity and the nature of your contribution. To protect your identity, all research participants (like you) will be approached individually and interviews will be conducted in privacy. Your name will not be included or mentioned on any data that is collected. Each research participant will be given a unique identification code which will only be known by the researcher. The unique identification code that you will be given will not be linked to any information that can be associated with you, your occupation or household including the signed consent forms, interview notes or recordings. Information sought from you will only be linked through an identification key.

To ensure protection of your contribution, all the information gathered during the study (recordings, transcripts and interview notes) will be kept on a password protected computer and hard drive. Hard copies of data and consent forms will be kept in a lockable drawer. Only the researcher will have the computer password and keys for the drawer will be stored safely away from the drawer. Access to the research data will be restricted until it is destroyed after five years. Although the interview will be audio recorded, with your permission, information will not be linked or traced back to you. When the discussion is fully written up, it will not bear actual names of informants or identifiable places. Only unique identification codes assigned to participants will be used on information that can be associated with you. If a report or article about this research project is written, full quotes from individual participants may be used, but your identity and information you share will be protected because the quotes will not be linked to named individuals.

In accordance with legal requirements and/or professional standards, the researcher will disclose to the appropriate individuals and/or authorities information that comes to his attention during the course of this research concerning serious health or welfare problems that could cause potential harm to you or others. In this event, the researcher will inform you that he has to break confidentiality to fulfil his legal responsibility to report to the designated authorities.

**What are the risks of this research?**

All human interactions and talking about self or others carry some amount of risks. There is a chance that some of the questions the researcher will ask you may cause discomfort or emotional stress to you. The researcher will nevertheless minimise such risks and act promptly to assist you if you experience any discomfort, psychological or otherwise during the process of your participation in this study. If you feel uncomfortable about any questions you are asked by the researcher, feel free not to answer them. Where necessary, an appropriate referral will be made to a suitable professional for further assistance or intervention.

**What are the benefits of this research?**

This research is not designed to help you personally, but the results may help the investigator learn more about the experiences of people living with HIV initiated on ART earlier. The researcher hopes that, in the future, other people might benefit from this study through improved understanding of the implications of early initiation of ART to people living with HIV in Zambia. This will help take into account the perspectives of people living with HIV when influencing immediate ART uptake. Additionally, the researcher hopes that the research will inform policy makers and other decision makers about the practicability of community wide uptake of immediate ART that will be useful for making recommendations for the pending national wide roll out of immediate ART initiation in Zambia.

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

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

**What if I have questions?**

This research is being conducted by Melvin Simuyaba, a student at the School of Public Health, Faculty of Community and Health Sciences at the University of the Western Cape, South Africa. My supervisor is Dr. Thubelihle Mathole of the School of Public Health, Faculty of Community and Health Sciences, University of the Western Cape, South Africa. If you have any questions about the research study itself, please contact Dr. Thubelihle Mathole of address: University of the Western Cape, School of Public Health, Private Bag X17, Belville 7535, South Africa; Telephone: +27 21 959 9384 and email: tmathole@uwc.ac.zm or myself at -address: Zambart, University of Zambia, Ridgeway Campus, Nationalist road, P.O Box 50697, Lusaka, Zambia; Cell phone number: +260966930471 and email: msimuyaba@gmail.com.

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Should you have any questions regarding this study and your rights as a research participant or if you wish to report any problems you have experienced related to the study, please contact:

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This research has been approved by the University of the Western Cape's Senate Research Committee (reference number: BM/17/1/8) and the University of Zambia Biomedical Research Ethics Committee (UNZABREC Ref: 011-11-12).

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**Appendix II:** **PAMPILI YA PATAHAZO (Ba beleki ba makete)**

**Taba ye musebezi wa patisiso:** Ze bafitile mwateni batu baba pila ni kakokwani ka HIV baho baba kalisiza kunuwa kabubebe mulyani wa ku kalafa ka kokwani ka HIV (ART) mwa sikiliti sa Livingstone mwa naha ya Zambia.

**Kana tuso ya tuto ye ki ifi?**

Musebezi wa patisiso ye iyezewa nibo Melvin Simuyaba, mwana sikolo sesi tuna sa Western Cape uituta 'Master mwa Public Health'. Mu kupiwa kuli munga kolo mwa musebezi wa patisiso ye ka kuli mina mu ba beleki ba makete baba swala musebezi wa za HIV fa sipatela sa muso mwa naha ya Zambia. Lubata ahulu mane ku ziba zo muziba ni zo mu fita mwateni amuswala musebezi wa ku kalisa batu kabubebe kunwa mulyani wa kalafo ya HIV (ART) amufumana kuli anani kakowani ka HIV, kutalusa kuli, mukalisa batu kunwa mulyani wa ART kabubebe (amufeza kuba tatuba) fa sipatela. Tuso ya musebezi wa patisiso ye ki ku batisisa kuli luziba zomuziba ni ze ba fititile mwateni bao baba pila ni kakokwani ka HIV mi ba hamuhelaa mulyani wa ART kwa le kwa sipatela sa muso mwa naha ya Zambia.

**Kana baka ni kupa ku yeza ngi haiba na lumela kuunga kolo?**

Mu batisisi uyo mitela mina banosi ku mi tolokela/taluseza kaza tuto mwa mushobo omu utwisisa mina. Mu batisisi ukami kupa kuli munga kolo mwa patisiso fa nako ye izi hande ku mina ni sibaka se sina ni mukunda mona mo mwa sipatela. Ka ku ambolisana, bu batisisi ba bata ku ziba ze mu ziba, mina amoho ni zo mufitile mwateni mwa musebeza mwa mina amu swala/yeza musebezi wa ku kalisa batu baba pila ni kakowani ka HIV kunwa mulyani mwa ku kalafa HIVkabubebe mi hape ni minahano,likezo,mikwa ni ze babulelanga ze ama ku kalisa kunwa mulyani wa ART kabubebe. Muswanela ku nyetela kappa ku ngola ku bonisa kuli mulumezi kunga kolo ku ambolisana. Ku ambolisana kwa teni ko yo inga nako ye fita fa 40 minutes hape luka mikupa kuli mulululumelise kuli lubeye manziwa amina kappa kuambilisana mwa rekoda. Luka rekoda ku ambolisana ku yezeza ba batisisi kuli banga kaufela maikuto ni mi naano ye mina mi hape, ku rekoda ku ka lutusa kuziba handehande zemutalusa ka mukwa wa ku nahanela fateni fa ku ambolisana. Ba batisisi ba belekisanga ma nzwi kappa ku ambolisana ko kubeyiwa mwa rekoda ku ngola kaufela zene zi ambozwi (lizwi ni lizwi la ngolewa mwa li ngolo) kutusa mukwa wa ku nahanela fateni fa ku ambolisana.

**Kana kuunga kolo kwa ka mwa patisisi ye kukaba ni kunutu?**

Ba batisisi baka seleleza kuli amusika mwa zibiwa mi hape zo muka bulele zifi ni zifi zi ka selelezwa ni kunutu. Ku sepisa ni ku yeza kuli amusika mwa zibiwa, kaufela baba unga kolo (inga mina cwalo) mu yo ketiwa ku fitala kwani ku ba ngolele ni ku pima bakuli mi hape ku ambolisana ku yoba mwa mukunda. Libizo lamina aiyo kubateni kappa kubehawa fa makande ayo ingiwa. Ufi ni ufi anga kolo mwa patisiso uka fiwa nombolo ye kazibiwa fela niba batisisi. Nombolo ye mo yo fiwa aiyo ama ka za patahazo kappa makande amina, musebezi wa mina kappa za lubasi wa mina, amoho ni lipampili za ku lumelisana, lingolo kappa zo lu ka rekoda. Patahazo ye ikazwa ku mina iyo ama mina fela ku fitela mwa nombolo.

Ku sepisa kunutu ya mina, kaufela patahazo lu kanga mwa tuto (ku rekoda, zo luyo ngola kuzwa mwa rekoda ni zo lu yo ngola lu ambolisana) zi yo bulukiwa ni ku seleliziwa ki nombolo mwa komputa. Lipampili za makande ni lipampili za ku lumelisana zi yo bulukiwa hande mu kukwaliwa. Konji fela ba batisis ki bona bayo ba ni nombolo ya kwa komputa ya ku kwa lulu hape keyi ya kwa drowa iyo bulukiwa hande kwaule ni drowa.Mukwa wa kubona linepo za patisiso uyo ba oushupila konji linepo za patisiso ziyo shiniwa akufita likweli ze kata lizoho. Neba kuli ku ambolisana ku ka rekodiwa amukalulumelisa, akuna patahazo ye yo ama mina. Ku ambolisana ko aku yo ngolwa, ze yo ngolwa azina kuyo bonisa ma bizo amina/ba halabi kappa sibaka. Konji fela ma nombolo ayo fiwa ba ba unga kolo ki yona ya yo boniswa ku ama mina. Haiba lipatisiso ha se natisizwe ku zwa mwa tuto li ta hatiswa mwa ma buka ya ba batisisi, kono ku sina mabizo a fiwa ku mutu ufi kappa ufi, kono makande amina ya yo behawa kusina ku ama batu kappa mina.

Ku latelela mu laho zo bulela hape/ kappa swanelo ya musebezi, ba batisisi ba swenela kubulelela batu hape/kappa ba muso kaza patahazo ye kona kufumaneha mwa nako ya patisiso ye ama kaza bupilo kappa makete kappa butata mwa muinelo o kona kutisa kozi kumina kappa babangwi. Aeba ki cwalo, mu batisisi uka mizibisa kuli uswanela ku kupwacha kunutu ka kuli a swanela ku biya ku baba bona za butata bo ku latelela mulaho.

**Kana kozi mwa patisiso ye ki ifi?**

Kaufela ku kopana kwa batu ni ku kandeka za mina kappa ba bangwi kubanga ni kozi nyana. Mwendi lipuzo ze ba ka mibuza ba batisisi za kona ku mi utwisa bu mayi. Kono mu batisisi uka yeza kuli kozi ibe ye inyani kappa kuyi sufalisa ni ku hangufa ku mi tusa haiba mu twile bu mayi, kuliyangana mwa booko kappa mo mungwi mwa mukwa wa ku unga kabelo kappa kolo mwa tuto. Haiba mu utwa ku salukuluha kappa bumai kali baka ka li puzo ze ba buza ba batisisi, mu lukuhile ku sa lihallaba lipuzo. Aku tokwa, baka miluma ku yo hamuhala tuso ye swanela kappa ye batahala.

**Kana miselo ya patisiso ye ki ifi?**

Patisiso ye aisika pangiwa kutusamina, kono linepo za kona kutusa ba batisisi ku ituta maikuto, ni bupilo wa batu ba ba pila ni ka kokwani ka HIV bani ba ba kalile kunwa mulyani wa ART kabubebe. Ba batisisi ba sepa kuli kwa pata ya mazazi, mwendi batu ba kona kufumana tuso/bunde kappa miselo libaka ka tuto ye kufitela ka ku tisa zwelo pila ku ziba hande taluso ya ku kalisa kunwa mulyani wa ART kabubebe mwa batu baba pila ni ka kokwani ka HIV mwa naha ya Zambia. Si ka tusa ku utwa ni ku ziba minaano, maikoto ya batu ba ba pila ni kakowani ka HIV mi hape ni moba bonela ze susuweza kuli ba no kala kunwa mulyani wa ART kabubebe. Ku ekeza fateni, ba batisisi ba sepa kuli patisiso ika zibisa ba ba panga milao niba ba bangwi ba ba na ni mata aku bona fa milao kubona mwendi kuli ze za kona ku yezahala kwa sichaba se si tuna kunwa milyani ya ART kabubebe, kuli ba bona mwendi mulao usalibelela wa ku kalisa batu kunwa milyani ya ART kabubebe wa kona hala mwa naha kaufela ya Zambia.

**Kana ni swanela ku ba mwa patisiso ye, kana na kona ku siya kunga kolo ka nako ifi ni ifi?**

Kunga kolo mwa patisiso ye ki ku itombola mina bangi. Mwa kona kuketa ku sanga kolo mwateni. Haiba mwa keta ku sanga kolo mwa patisiso ye, mane mwa kona kusiya kappa mu lukuluhile ku tuhela lipatisiso fa nako yo mulatela, kusina koto ku mina kappa ku latehelwa miselo yo mu swanela ku hamuhela.

**Kana haiba nina nilipuzo?**

Patisiso ye iyeza nibo Melvin Simuyaba, mwana wa sikolo mwa sikolo sa Public Health, ko kwa Faculty ya Community ni Health Sciences kwa sikolo sa University kwa Western Cape, mwa naha ya South Africa. Baba bona ba kappa ba bateheli ba bona kibo Dr. Thubelihle Mathole ba kwa sikolo sa Public Health, Faculty ya Community ni Health Sciences, University ya kwa Western Cape, mwa naha ya South Africa. Haiba muna ni lipuzo ka za tuto ya patisiso ye, mwa kupiwa ku lume luwaile kubo Dr. Thubelihle Mathole ba kwa : University ya kwa Western Cape, sikolo sa Public Health, Private Bag X17, Belville 7535, South Africa; Telephone: +27 21 959 9384 and email: tmathole@uwc.ac.zm kappa na kwa : Zambart, University ya Zambia, Ridgeway Campus, Nationalist road, P.O Box 50697, Lusaka, Zambia; Cell phone number: +260966930471 and email: msimuyaba@gmail.com.

Amunani lipuzo ze ama tuto ni liswanelo za ama inga mina ba banga kolo mwa patisiso kappa haiba mwa bata ku biya kozi kappa butata bobu hezahalile mwa tuto ye, amu lumele kappa ku biya kubo:

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Patisiso ye ilumelisiwa kibo University ya Western Cape's Senate Research Committee (reference number BM/17/1/8) ni ka kwata kaka bona milawo yaku ezeza lipatisiso kakubizwa Biomedical Research Ethics Committee (UNZABREC Ref: 011-11-12) ka kwa University of Zambia.

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## Appendix II: IPEPA LYA MAKANI (Basyaa bupampu)

**Izyina Lya Ciiyo:** Izyibonwa akaambo kakutalika kusilikwa sikalileke icakutalindila akati kabantu ibapona asikalileke mucitiliti ca Livingstone mucisi ca Zambia.

**Sena Mulimonzi wa ciyoo eeci?**

Ibeendelezya ciiyo eeci mbaba Melvin Simuyaba, balo ibaiya ciiyo cilanganya makani anseba abukale bwa banamaleya ica Public Health ookuya kucikolo cipati ica University of the Western Cape. Mwatambwa ikuti mutole lubazu muciiyo eeci nkaambo kakuti mulibabelesyi ibanseba iipa lugwasyo ilujatikizya sikalileke kucibbadela cisyoonto ica mfulumende mucisi ca Zambia. Tuyandisya kapati ikuzyiba nzyomubona mumilimo yakutalisya bantu ikusilikwa sikalileke icakutalindila, eeci caamba ikutalisya cakufwambaana kusilika sikalileke akati kabantu ibaboola kucibbadela mbobamanizya buyo kupimwa akujanwa akazunda ka sikalileke. Mulimo wa ciiyo eeci nkuvwuntauzya izyibona bantu ibapona akazunda ka sikalileke ibatalika ikusilikwa sikalileke ica kutalindila acibbadela cisyoonto ica mfulumende mucisi ca Zambia.

**Sena ncinzi ncetiikalombwe ikucita ukuti na ndazumina ikutola lubazu muciiyo?**

Muyakugamwa ilwenu a basikuvwuntauzya balo ibaya ikumapandulwida makani ajatikizya ciiyo mumulaka ngomumvwa. Ibavwuntauzyi baya kumulomba ikuti mutole lubazu mumubandi muciindi alimwi abusena busetekene ibwamucibbadela. Kwiinda mumubandi, basikuvwuntauzya baya kukapaula ikuba aaluzyibo anzyomubona akaambo kakubeleka milimo iyakutalisya bantu ibapona asikalileke ikusilikwa sikalileke icakutalindila alimwi ibube mbomubona, micito alimwi amizeezo iigama ikutalika kusilikwa sikalileke icakutalindila akati ka bantu ibatalisyigwa icakufwambaana. Muyakuyandika ikuti mukape cizuminano kwiinda mukulemba kamutana kuba amubandi. Imubandi tuukaindi kumaminiti aasika ku makumi one na 40 alimwi imajwi ayakutolwa mumunchini ikuti na kamuzumizya. Imajwi ayakutolwa amuncini ikutegwa ibavwuntaizyi bakabwezye imajwi enu oonse ibuyandika alimwi ayakubelesyegwa mukuleezyegwa ikuti na kwayandika ikusyomezya ciindi cakwaalanganya. Ibavwuntauzyi babelesya imajwi aatolwa amincini kusandulula jwi a jwi ikuzwa mumubandi uutoledwe mumuncini ikutola mumalembe ikutegwa bagwasyigwe kubambulula twaambo twabasikutola lubazu.

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**Sena ikutola lubazu kwangu mu cciyo eeci kuyakuyobolwa mumaseseke?**

Ibavwuntauzyi bayakuliimikizya ikukwabilila imazyina alimwi abube bwa twaambo twenu. Ikutegwa mutakazyibwi, boonse ibatola lubazu mu ciiyo (mbobuli ndinwe) bayakugamwa a basikuvwuntauzya mulicabo akubandika mubuseseke. Izyina lyenu talikayungizyigwi na kubandwa mumakani kufwumbwa, aati kabwezyegwe. Umwi a umwi uutola lubazu mumubandi uyakupegwa cizyibyo calo icitikazyibwe buyo a bavwuntauzyi. Cizyibyo ncomutikapegwe tacikayaami kumakani oonse aanga agama ndinwe, milimo yenu na nganda, ikuyungizya amapepa aacizuminano asainidwe, imabala amubandi na imajwi aatolwa amuncini. Imakani aatolwa kuzwa kulindinwe ayakumagama buyo kwiinda mumanambala ikuzyibya.

Ikutegwa kubonwe kuti kwaba maseseke, itwaambo ituya kubwezyegwa (majwi atolwa mumuncini, malembe aazwa kumajwi aatolwa mumuncini alimwi amalembe aajatikizya mubandi) tuyakuyobolwa mu kompyuta ikwabibilidwe alimwi amuncini wakuyobweda zintu uukwabibilidwe. Imapepa aatwaambo acizuminano ayakuyobolwa mu busena ibukiigwa. Mbababasikuvwuntauzya ibalo ibatinooli anguzu zyakujalula kompyuta alimwi imaki abusena buyobwedwa ayakuyobwedwa ikule abusena oobu. Inzila yakubona makani iyakukwabililwa mane akaakujaigwe kwainda myaka iili yosanwe. Anokuba kuti imajwi eenu ayakutolwa mumuncini, kamupede nguzu, imakani taakamugami na ikujolwa ikuti muzyibwe kuti ngeenu.

Ikulemba ikwa majwi eenu aatoledwe amuncini kwaakumaninina, imapepa aaya taakabi amazyina abasikutola lubazu na imasena aanga azyibwa. Pele buyo imanambala aakuzyibya basikutola lubazu ngaaya ikubelesyegwa kumakani aanga apa kuti mulizyibye. Ikuti na kwaba ikulemba izyitikajanwe mu ciiyo itwaambo twaamba basikutola lubazu inga twabelesyegwa mukumaninina, pele izyina lyenu amakani ngomuyakubandika abasikuvwuntauzya ayakukwabililwa akaambo kakuti itwaambo tatukagami ibantu kwiinda mukubaamba mazyina.

Ikucilila ibuyandika kumulawo alimwi/nape malailile abubelesyi, basikuvwuntauzya inga bayubununa twaambo kubantu ibayandika alimwi/nape ibeendelezyi imakani ngobajana ciindi ca ciiyo eeci aajatikizya ikuciswa kupati na imapenzi aabukale alangilwa ikuti inga aleta ntenda kuli bamwi. Kwaba boobu, basikuvwuntauzya bayakumuzyibya ikuti baya kujaya maseseke ikutegwa babeleke kweendelana amulawo ikuzyibya beendelezyi ibapedwe.

**Sena nintenda nzi izili mu ciiyo eeci?**

Ikujanana kwabantu koonse alimwi akwaambaula alilwenu nape ibambi kulaantenda anokuceya. Kulalangilwa ikuti imibuzyo imwi njobayakubuzya basikuvwuntauzya inga yamapa ikutalimvwa kabotu na ikumapa ikulimvwa bubi kumoyo. Basikuvwuntaizya nokuba, bayakusola kujola aansi ntenda mbobuli zyeezyi alimwi akufwambaana ikumagwasya ikuti na mwalimvwa bubi, kumoyo nape ubuli boonse ciindi nomutola lubazu mu ciiyo eeci. Ikuti na tamulimvwi kabotu akaambo kamibuzyo kufwumbwa, njobabuzya basikuvwuntauzya, amwaangulukwe ikutaivwiila. Kwayandika, ikuleezyegwa ikweelede kuyakuba ikuya kuli basibupampu ikuyungizya ikugwasilizya na kulugwasyo lucilila na bukwabilizyi.

**Sena mbubotu nzi ibwa ciiyo eeci?**

Eeci ciiyo tacibambidwe ikuti cimagwasye ikumagama lwenu, pele iziyakujanwa zilangilwa kuti inga zyagwasya basikuvwuntauzya ikuti bazyibe izyinji kumakani azyibona bantu bapona asikalileke balo ibatalika kusilikwa sikalileke icakutalindila. Basikuvwuntauzya balangila kuti, kumbele aamazuba, bamwi ibantu inga bajana bubotu kwiinda mukusumpula luzyibo ilujatikizya mbocaamba ikutalika kusilikwa sikalileke icakutalindila kubantu ibapona asikalileke mucisi ca Zambia. Eeci ciyakugwasya ikulanganya mizeezo yabantu ibapona aasikalileke iciindi nobatonkelezyegwa ikutalika kusilikwa icakutalindila. Kuzwa waawo basikuvwuntauzya balangila ikuti ciiyo ciyakugwasya basimubamba milawo abamwi beendezyi ikuti bazyibe ikuti na ikutalika kusilika sikalileke icakutalindila mu cooko coonse inga kwaba, calo icayakugwasya mukupa nguzu zyakuyanda kwakutalika kusilika sikalileke icakutalindila mucisi coonse ca Zambia.

**Sena mane ndeelede ikuba mu ciiyo eeci alimwi sena inga ndaleka kufwumbwa ciindi?**

Ikutola lubazu ikwenu muciiyo eeci nkwakulyaaba. Mulakonzya ikutatola lubazu. Ikuti na mwazumina ikutola lubazu mu ciiyo eeci, mulakonzya ikuleka ikutola lubazu kufwumbwa ciindi. Ikuti na mwasala ikuleka kutola lubazu mu ciiyo eeci nape ikuti na mwaleka kutola lubazu kufwumbwa ciindi, takukabi impanisi na ikusweekelwa ibubotu bwalo mbomweeledwe.

**Ino kuti nkeli aamibuzyo?**

Ibeendelezya ciiyo eeci mbaba Melvin Simuyaba, balo ibaiya ciiyo cilanganya makani anseba abukale bwa banamaleya ica Public Health ookuya kucikolo cipata ica University of the Western Cape ku cisi ca cakumusanza ica South Africa. Ibazololi bangu mbaba Dr. Thubelihle Mathole ibaku cikolo cilanganya makani anseba abukale bwa banamaleya ica Public Health ookuya kucikolo cipata ica University of the Western Cape ku cisi ca cakumusanza ica South Africa. Ikuti na kamuli aamibuzyo ijatikizya ciiyo ilwancico, twamulomba mukwabane aba Dr. Thubelihle Mathole iba keala ilya: University of the Western Cape, School of Public Health, Private Bag X17, Belville 7535, South Africa; Luwaile: +27 21 959 9384 alimwi magwalo a email: tmathole@uwc.ac.zm nape ilwangu a keala lya : Zambart, University of Zambia, Ridgeway Campus, Nationalist road, P.O Box 50697, Lusaka, Zambia; luwaile : +260966930471 alimwi alugwalo lwa email: msimuyaba@gmail.com.

Ikuti na mulaamibuzyo iijatikizya ciiyo na inguzu zyenu mbuli ibantu ibatola lubazu muciiyo napa ikuti na muyanda ikutoongoka mapenzi kufwumbwa, ngomwabona aajatikizya ciiyo, twamulomba mukwabe ba:

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

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

The Chairperson
Biomedical Research Ethics Committee
University of Zambia, Ridgeway Campus
P.O Box 50110
Lusaka, Zambia.
unzarec@zamtel.zm
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Eeci ciiyo cazumizyigwa aba kabunga kalanganya zyiiyo kucikolo cipati ica University of the Western Cape (reference number: BM/17/1/8) alimwi akabunga kalanganya zyiiyo kucikolo cipati ica University of Zambia kategwa University of Zambia Biomedical Research Ethics Committee (UNZABREC Ref: 011-11-12).

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## Appendix III: CONSENT FORM

**Title of Research Project:** Experiences of early antiretroviral therapy (ART) initiation among people living with HIV in Livingstone district in Zambia.

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

Please indicate by ticking (√) appropriately below whether you agree or not to be audio recorded during the interview.

___ I agree to be audio recorded during my participation in this study.

___ I do not agree to be audio recorded during my participation in this study.

**Participant's name: …………………………………………………………………………..**

**Participant's signature/thumb print: ……………………………………………………..**

**Consent Date: ………………………………………………………………………………**

**Researcher Conducting Informed Consent: ………………………………………………..**

**Signature of Researcher: ………………………………………………………………….**

**Date: ………………………………………………………………………………………..**

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**Appendix III:** **PAMPALI YA KULUMELISANA**

**Taba ye musebezi wa patisiso:** Ze bafitile mwateni batu baba pila ni kakokwani ka HIV baho baba kalisiza kunuwa kabubebe mulyani wa ku kalafa ka kokwani ka HIV (ART) mwa silikiti sa Livingstone mwa naha ya Zambia.

Tuto ye bani talusize mwa mushobo oni utwa na. Lipuzo zaka ka za tuto bali halabila kaka tala. Ni utwisise ze inzi mwateni ku unga kolo mi ni lukuhilwa ni ku itombola kuli na lumela ku unga kolo. Ni utwiise kuli siswaniso saka asiyo zibiwa kumangi ni mangi kappa ufi ni ufi. Ni utwisise kuli na kona ku tuhela kunga kolo mwa tuto ye nako ifi kappa ifi kusina kufa libaka mi hape kusina kusaba/bohi bwa koto kappa kulatehalwa miselo.

Mwa kupwa kuli mu chonga (√) fo ku swanela fa fasi fa mwendi mwa lumela kappa amulumeli kuli lu rekoda alu ambolisana.

___ Na lumela kuli muni rekoda aninga kolo mwa patisiso ye.

___ Ani lumeli ku kuli muni rekoda aninga kolo mwa patisiso ye.

**Libizo la ba inga kolo (Ling'oliwe): ……………………………………………….**

**Kunyetela kuba ba inga kolo: ……………………………………………………**

**Lizazi la kunyatela: ……………………………………………………………**

**Libizo la bo mubatisis (Ling'oliwe): …………………………………………………**

**Bo mubatisisi ba nyatele: ………………………………………………………..**

**Lizazi: ……………………………………………………………………………..**

**Appendix III:** **IPEPA LYA CIZUMINANO**

**Izyina Lya Ciiyo:** Izyibonwa akaambo kakutalika kusilikwa sikalileke icakutalindila akati kabantu ibapona asikalileke mucitiliti ca Livingstone mucisi ca Zambia.

Eeci ciiyo capandululwa mumulaka ngwendimvwa. Mibuzyo iijatikizya ciiyo yavwiilwa. Ndateelela iciyakutola busena netola lubazu muciiyo alimwi ndazumina ikutola lubazu mukuyanda kwangu alimwi akulyaaba ilwangu. Ndilizyi ikuti izyina lyangu talukayubununwi kumuntu uuli oonse. Ndilizyi ikuti inga ndazwa mu ciiyo kufwumbwa ciindi kakunyina ikupa kaambo alimwi kakunyina bukandi ibwazyibi izyinga zyacitika nape ikusweekelwa kwabubotu.

Twamulomba amutondezye kwiinda mukukwalula (√) ibuyandika aansi ikuti na mwazumina nape ikutolwa jwi amuncini ciindi camubandi.

___ Ndazumina ikutolwa jwi ciindi netola lubazu mu ciiyo eeci.

___ Ndakaka ikutolwa jwi ciindi netola lubazu mu ciiyo eeci.

**Izyina lya sikutola lubazu: ……………………………………………………….**

**Kusaina kwa sikutola lubazu: ………………………………………………...**

**Buzuba: ………………………………………………………………………...**

**Izyina lya sikubuzya: ………………………………………………………**

**Sikubuzya asayine: ………………………………………………………...**

**Buzuba bwasunu: …………………………………………………………….**

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## Appendix IV: In-depth interview guide with clients accessing HIV services.

**Purpose:** *This guide is to be used by the researcher to carry out in-depth interviews with clients accessing HIV services and were initiated on immediate Antiretroviral Therapy (ART) at a government health facility that is part of the PopART study in Zambia. The form should be used to guide the discussion with the aim of understanding the experiences of people living with HIV initiated on ART earlier.*

**Materials:**

2 copies of this interview guide, notebook, pens, Recorder, AAA size batteries, information sheets and consent forms, A4 envelopes.

**Form of data recording:** *(1) Audio-recording of interview. (2) Notes of key points into a note book during the discussion.*

**Researcher should also note:**

- **Recruitment strategy:** How did you meet the participant?
- **Interaction with participant/s:** How was the attitude of participant? Were there any issues that the participant was uncomfortable with?
- **Questions asked by participant/s:** Were there any questions asked before or after the interview?

**Venue:** Private spaces within health facility.

**Time:** Explain that this interview will take no longer than 40 minutes.

**Collect participant details**

Make sure you also collect the following information from the participant and keep records on a separate sheet.

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**E-mail:** soph-comm@uwc.ac.za

**Participant details:**

Client's unique code: ____________________________

Date: ______________

Time interview starts: __________________Time interview ends: ________________

Place interview conducted: _____________________________

Age [in years]: _____________ Period participant has been on ART: ______________

Sex [circle one]: FEMALE MALE

**Introduction**

This research study is about how people living with HIV accessing HIV services at a government health facility that is part of the PopART study in Zambia experience immediate initiation of Antiretroviral Therapy (ART), thus, early initiation of ART regardless of CD4 count.

1. Could you please tell me about your own experience since learning you were HIV-positive? Probe about disclosure, experiences of stigma and own perceptions of living with HIV.

2. Could you please share your experience with me about how you decided to start taking Antiretroviral Therapy (ART)? Probe about motivations for uptake of ART earlier.

3. Could you also share with me what your experience has been with taking antiretroviral (ARV) drugs? Probe about adherence to treatment and side effects.

4. What has been your experience with accessing HIV services at the clinic? Probe about frequency of coming to the clinic amid other commitments, queues, experiences with health staff.

5. Is there anything else you would like to discuss with me?

We have come to the end of the interview. I would like to thank you for your time and sharing this information with me. The information collected in this interview is strictly for research purpose only and will be kept confidential.

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## Appendix V: In-depth interview guide with health staff offering HIV services at a government health facility.

**Purpose:** *This guide is to be used by the researcher to carry out in-depth interviews with health staff offering HIV services and immediate Antiretroviral Therapy (ART) initiation at a government health facility that is part of the PopART study in Zambia. The form should be used to guide the discussion with the aim of understanding the experiences of people living with HIV initiated on ART earlier.*

**Materials:**

2 copies of this interview guide, notebook, pens, Recorder, AAA size batteries, information sheets and consent forms, A4 envelopes.

**Form of data recording:** *(1) Audio-recording of interview. (2) Notes of key points into a note book during the discussion.*

**Researcher should also note:**

- **Recruitment strategy:** How did you meet the participant?
- **Interaction with participant/s:** How was the attitude of participant? Were there any issues that the participant was uncomfortable with?
- **Questions asked by participant/s:** Were there any questions asked before or after the interview?

**Venue:** Private spaces within health centre, allow participant to identify the private space.

**Time:** Explain that this interview will take no longer than 40 minutes.

**Collect participant details**

Make sure you also collect the following information from the participant and keep records on a separate sheet.

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**E-mail:** soph-comm@uwc.ac.za

**Participant details:**

Client's unique code: ____________________________

Date: ______________

Time interview starts: __________________Time interview ends: ________________

Place interview conducted: _____________________________

Age [in years]: _____________ Period participant has been working at the clinic: _________

Sex [circle one]: FEMALE MALE

## Introduction

This research study is about how people living with HIV accessing HIV services at a government health facility that is part of the PopART study in Zambia experience immediate initiation of Antiretroviral Therapy (ART), thus, early initiation of ART regardless of CD4 count. We would like you to share your experiences with offering immediate ART to clients and your observations about the clients' experiences during your interactions with them.

1. Could you please tell me what you think of immediate initiation of ART, thus, early initiation of ART regardless of a client's CD4 count to people living with HIV accessing HIV services at this health facility?

2. I would like you to share with me what your experience has been with offering immediate ART, thus, early initiation of ART regardless of CD4 count to people living with HIV accessing HIV services at this health facility. Probe about the response from clients initiated on ART earlier and their acceptability of earlier initiation of ART.

3. As a health staff providing HIV services at this health facility and from your own observations during your interactions with people living with HIV who have been initiated on ART earlier, could you tell me what you think your clients experience as a result of early initiation of ART? Probe about their attitudes, behaviours and perceptions towards early initiation of ART (adherence to treatment, side effects of the drugs and experiences of stigma).

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## Appendix VI: In-depth interview guide with health staff offering HIV services at a government health facility.

**Purpose:** *This guide is to be used by the researcher to carry out in-depth interviews with health staff offering HIV services and immediate Antiretroviral Therapy (ART) initiation at a government health facility that is part of the PopART study in Zambia. The form should be used to guide the discussion with the aim of understanding the experiences of people living with HIV initiated on ART earlier.*

**Materials:**

2 copies of this interview guide, notebook, pens, Recorder, AAA size batteries, information sheets and consent forms, A4 envelopes.

**Form of data recording:** *(1) Audio-recording of interview. (2) Notes of key points into a note book during the discussion.*

**Researcher should also note:**

- **Recruitment strategy:** How did you meet the participant?
- **Interaction with participant/s:** How was the attitude of participant? Were there any issues that the participant was uncomfortable with?
- **Questions asked by participant/s:** Were there any questions asked before or after the interview?

**Venue:** Private spaces within health centre, allow participant to identify the private space.

**Time:** Explain that this interview will take no longer than 40 minutes.

**Collect participant details**

Make sure you also collect the following information from the participant and keep records on a separate sheet.

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**E-mail:** soph-comm@uwc.ac.za

**Participant details:**

Client's unique code: ______________________________

Date: _______________

Time interview starts: ___________________Time interview ends: _________________

Place interview conducted: _______________________________

Age [in years]: ______________ Period participant has been working at the clinic: _________

Sex [circle one]: FEMALE MALE

**Introduction**

This research study is about how people living with HIV accessing HIV services at a government health facility that is part of the PopART study in Zambia experience immediate initiation of Antiretroviral Therapy (ART), thus, early initiation of ART regardless of CD4 count. We would like you to share your experiences with offering immediate ART to clients and your observations about the clients' experiences during your interactions with them.

1. Could you please tell me what you understand by early initiation of ART or immediate initiation of ART?

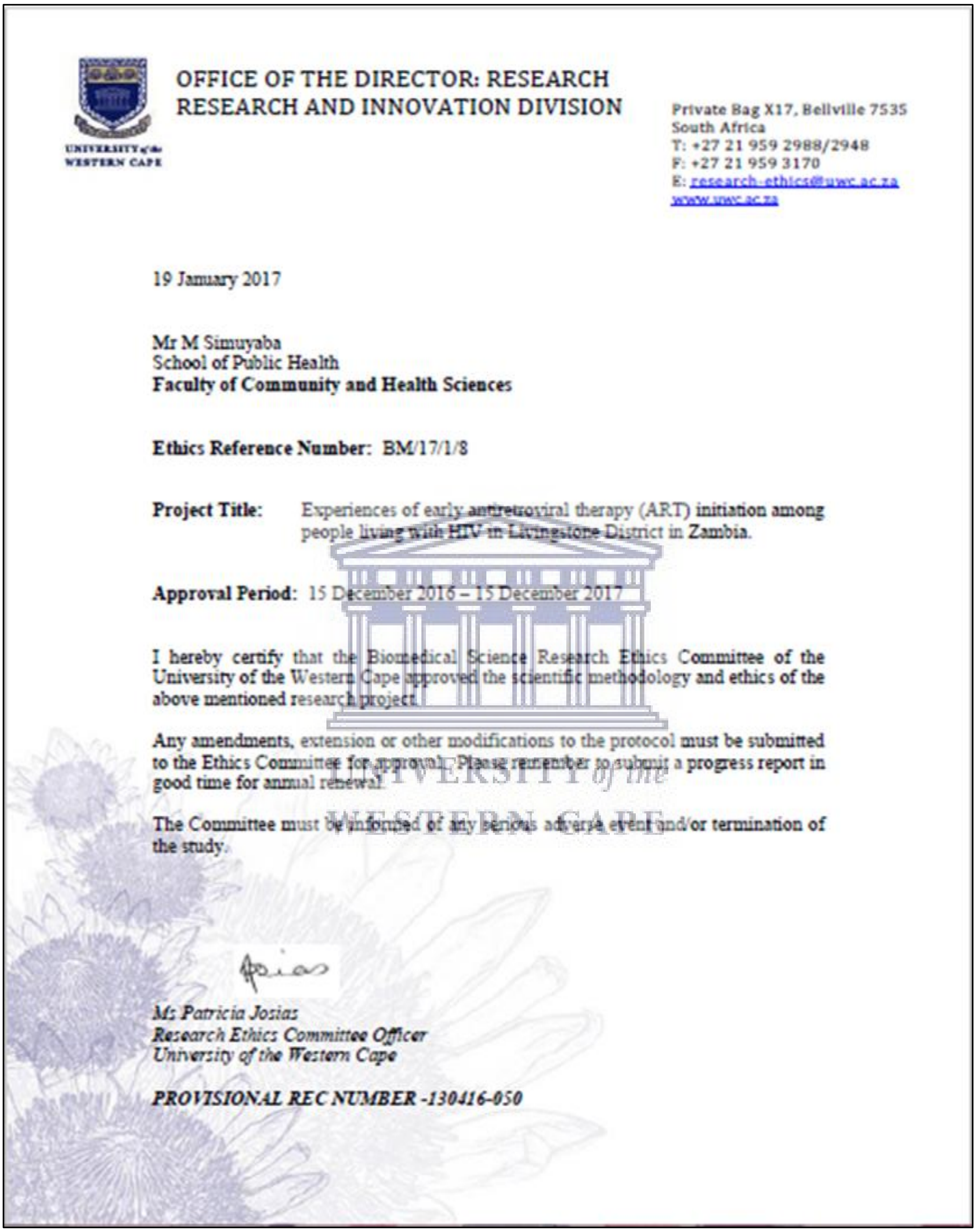
2. Could you please tell me what you think of immediate initiation of ART, thus, early initiation of ART regardless of a client's CD4 count to people living with HIV accessing HIV services at this health facility?

3. I would like you to share with me what your experience has been with offering immediate ART, thus, early initiation of ART regardless of CD4 count to people living with HIV accessing HIV services at this health facility. Probe about the response from clients initiated on ART earlier and their acceptability of earlier initiation of ART. Is it easy to initiate a newly diagnosed client on ART early? Are there a lot of PLHIV who have been initiated on ART at this health facility? Do PLHIV initiated on ART experience any HIV symptoms?

4. Is providing HIV services to PLHIV who are initiated on ART with low CD4 cell count different from providing the same services to PLHIV who have been initiated on ART with a high CD4 cell count?

5. As a health staff providing HIV services at this health facility and from your own observations during your interactions with people living with HIV who have been initiated on ART earlier, could you tell me what you think your clients experience as a result of early initiation of ART? Probe about their attitudes, behaviours and perceptions towards early initiation of ART (adherence to treatment – what is it that makes them to adhere or not to adhere to treatment, side effects of the drugs and experiences of stigma).

## Appendix VII: Approval letter - University of the Western Cape's Senate Research Committee.



UNIVERSITY of the WESTERN CAPE

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19 January 2017

Mr M Simuyaba
School of Public Health
**Faculty of Community and Health Sciences**

**Ethics Reference Number:** BM/17/1/8

**Project Title:** Experiences of early antiretroviral therapy (ART) initiation among people living with HIV in Livingstone District in Zambia.

**Approval Period:** 15 December 2016 – 15 December 2017

I hereby certify that the Biomedical Science Research Ethics Committee of the University of the Western Cape approved the scientific methodology and ethics of the above mentioned research project.

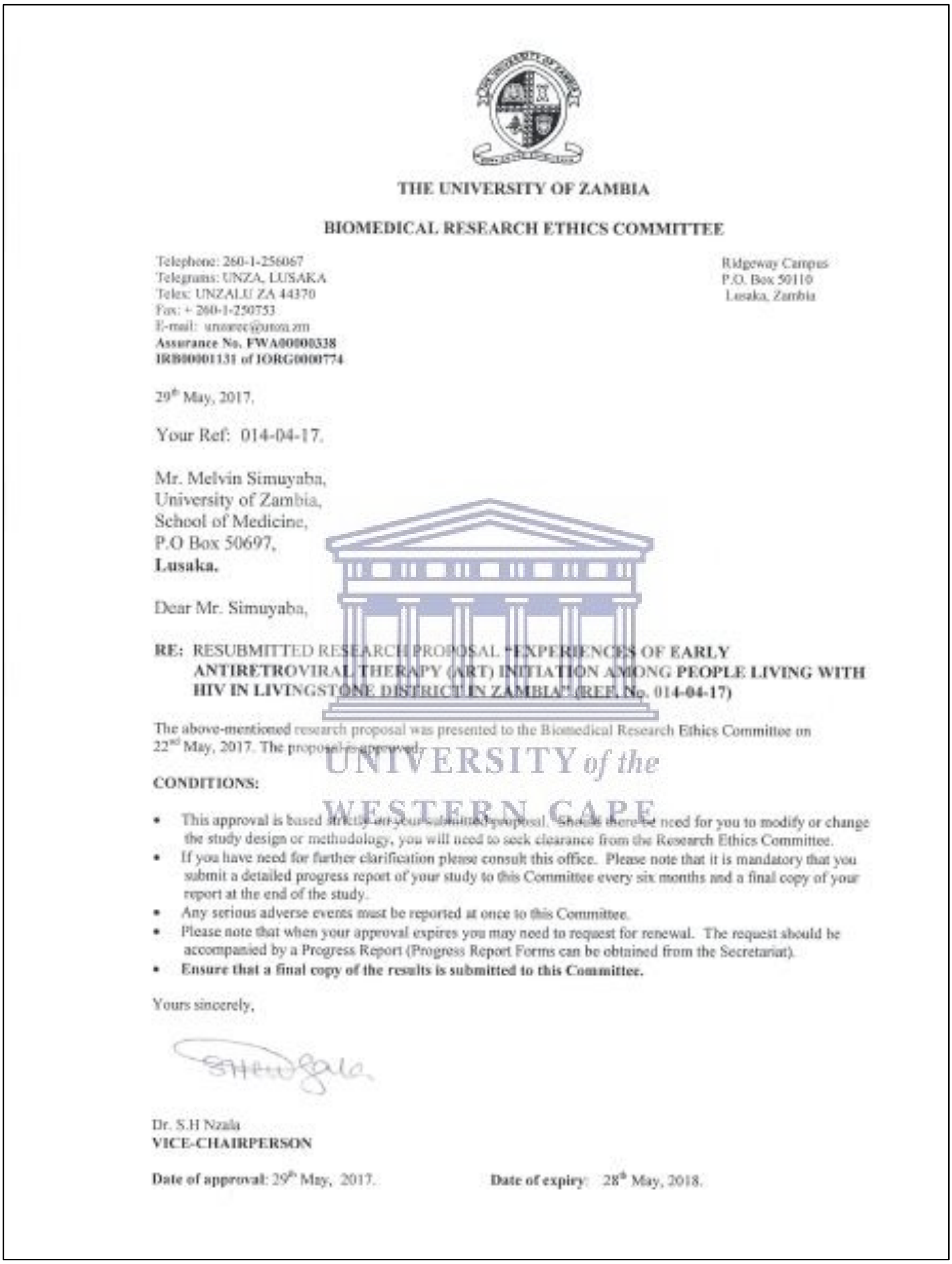
Any amendments, extension or other modifications to the protocol must be submitted to the Ethics Committee for approval. Please remember to submit a progress report in good time for annual renewal.

The Committee must be informed of any serious adverse event and/or termination of the study.

*Ms Patricia Josias*
*Research Ethics Committee Officer*
*University of the Western Cape*

***PROVISIONAL REC NUMBER -130416-050***

## Appendix VIII: Approval letter - University of Zambia Biomedical Research Ethics Committee.



THE UNIVERSITY OF ZAMBIA

BIOMEDICAL RESEARCH ETHICS COMMITTEE

Telephone: 260-1-256067
Telegrams: UNZA, LUSAKA
Telex: UNZALU ZA 44370
Fax: + 260-1-250753
E-mail: unzarec@unza.zm
**Assurance No. FWA00000338**
**IRB00001131 of IORG0000774**

Ridgeway Campus
P.O. Box 50110
Lusaka, Zambia

29th May, 2017.

Your Ref: 014-04-17.

Mr. Melvin Simuyaba,
University of Zambia,
School of Medicine,
P.O Box 50697,
**Lusaka.**

Dear Mr. Simuyaba,

**RE:** RESUBMITTED RESEARCH PROPOSAL **"EXPERIENCES OF EARLY ANTIRETROVIRAL THERAPY (ART) INITIATION AMONG PEOPLE LIVING WITH HIV IN LIVINGSTONE DISTRICT IN ZAMBIA" (REF. No. 014-04-17)**

The above-mentioned research proposal was presented to the Biomedical Research Ethics Committee on 22nd May, 2017. The proposal is approved.

**CONDITIONS:**

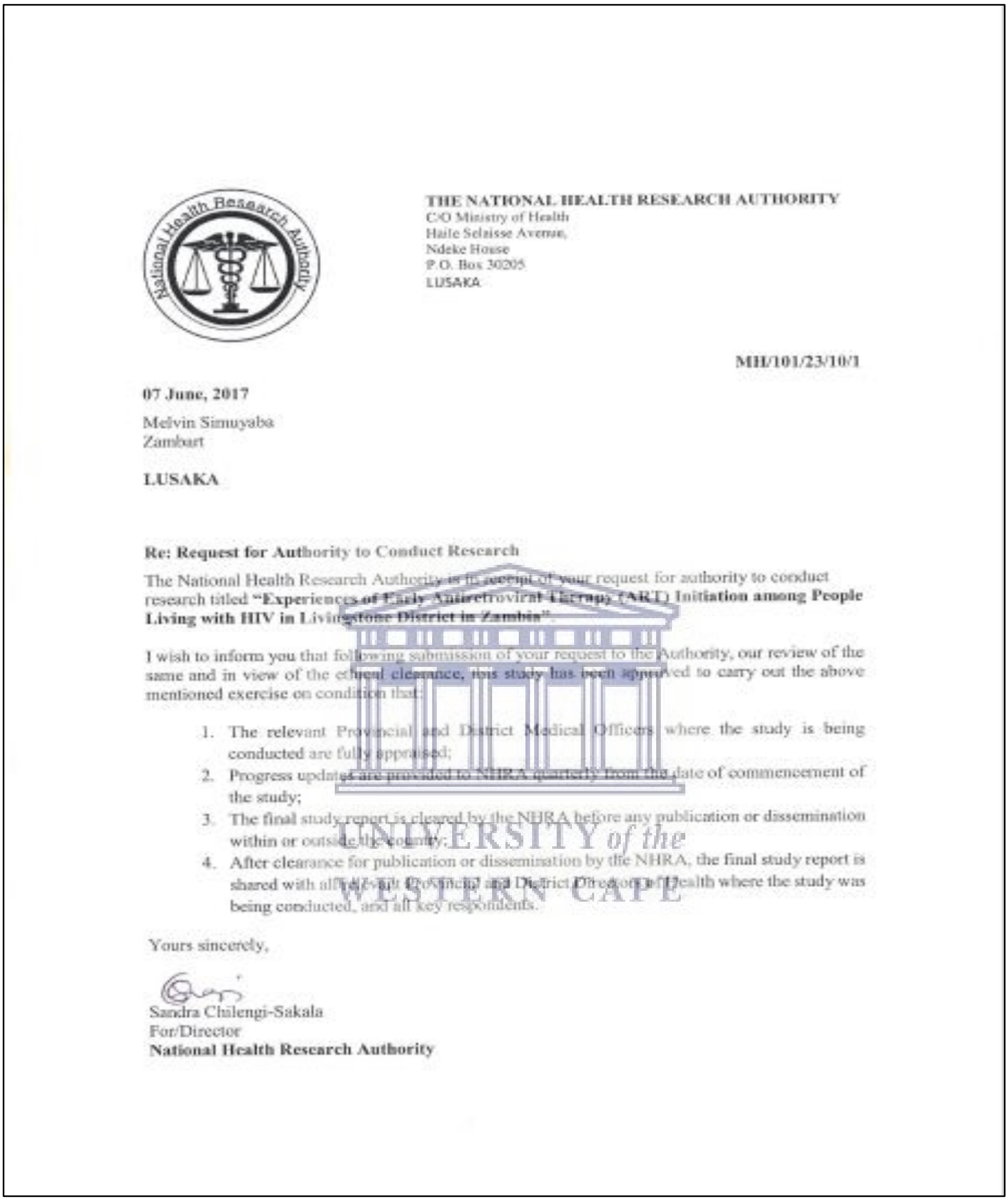
- This approval is based strictly on your submitted proposal. Should there be need for you to modify or change the study design or methodology, you will need to seek clearance from the Research Ethics Committee.
- If you have need for further clarification please consult this office. Please note that it is mandatory that you submit a detailed progress report of your study to this Committee every six months and a final copy of your report at the end of the study.
- Any serious adverse events must be reported at once to this Committee.
- Please note that when your approval expires you may need to request for renewal. The request should be accompanied by a Progress Report (Progress Report Forms can be obtained from the Secretariat).
- **Ensure that a final copy of the results is submitted to this Committee.**

Yours sincerely,

Dr. S.H Nzala
**VICE-CHAIRPERSON**

**Date of approval:** 29th May, 2017. **Date of expiry:** 28th May, 2018.

## Appendix IX: National Health Research Authority's permission to conduction research



**THE NATIONAL HEALTH RESEARCH AUTHORITY**
C/O Ministry of Health
Haile Selaisse Avenue,
Ndeke House
P.O. Box 30205
LUSAKA

**MH/101/23/10/1**

**07 June, 2017**

Melvin Simuyaba
Zambart

**LUSAKA**

**Re: Request for Authority to Conduct Research**

The National Health Research Authority is in receipt of your request for authority to conduct research titled **"Experiences of Early Antiretroviral Therapy (ART) Initiation among People Living with HIV in Livingstone District in Zambia"**.

I wish to inform you that following submission of your request to the Authority, our review of the same and in view of the ethical clearance, this study has been approved to carry out the above mentioned exercise on condition that:

1. The relevant Provincial and District Medical Officers where the study is being conducted are fully appraised;
2. Progress updates are provided to NHRA quarterly from the date of commencement of the study;
3. The final study report is cleared by the NHRA before any publication or dissemination within or outside the country;
4. After clearance for publication or dissemination by the NHRA, the final study report is shared with all relevant Provincial and District Directors of Health where the study was being conducted, and all key respondents.

Yours sincerely,

Sandra Chilengi-Sakala
For/Director
**National Health Research Authority**

## Appendix X: Summary of PLHIV study participant's profiles

| Participant ID. | Household location and members | Marital status & HIV status of spouse | HIV testing history | Starting ART | Occupation |
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| P1_M_49_656 | Lives within the research community (About 5 – 10 minutes' walk from the health facility).<br>Lives with his wife and children. | Married, spouse also living with HIV and on ART. | Tested HIV+ in 2013 at the research health facility. Wife persuaded him to test when she was diagnosed HIV+. | Started ART a month after testing HIV+. | - General worker at a local lodge |
| P2_M_30_679 | Lives with the mother and sister within the research community. Distance from household to clinic is about 5 – 10 minutes' walk. | Single & no intentions of getting married.<br>Was previously cohabiting with his ex-girlfriend.<br>Ex-girlfriend had not disclosed her HIV status to him until she got sick | -Tested HIV+ on 9th August 2016 through Household Counselling and Testing (HTC) provided under the PopART study. | -Referred to the research clinic and started ART on the same day he was diagnosis HIV+. | - Debt collector – individuals hire him to collect debts on their behalf and gets commission based on the collected debt. |
| P3_W_34_585 | Lives close to the research clinic (about 20 – 30 minutes' walk from her household).<br>Household located outside the boarders of community 'X'. | First husband died in 2013 and got married again in 2016.<br>First husband died when he stopped taking ART. Current husband also on ART. | - Diagnosed with HIV in 2004. | Started taking treatment in 2015 after her health started deteriorating. | - Currently unemployed.<br>- Stopped working as a security officer in 2014 due to sickness. |
| P4_W_35_721 | Lives within the research community (about 15 – 20 minutes' | She is married and her husband is also living with HIV and also on ART. | - Diagnosed with HIV in 2011 when she was pregnant. | Never started ART immediately, took a single dose for PMTCT. | - Business woman, owns a salon and barbershop at her household. |

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|  | walk from the research clinic).<br>Lives with her two children. | Husband lives in South Africa (working as a tour guide there). | - Tested from the research health facility when accessing antenatal care services. | Started treatment in 2013 after learning about early initiation of ART. |  |
| P5_M_32_559 | Lives within the research community (about 15 – 20 minutes' walk from the research clinic).<br>Lives with the wife and children. | Married, and the wife is also living with HIV and on ART. | - Tested HIV positive in July 2013 through HCT provided by PopART.<br>- Had poor health at the time of testing. | Started treatment about four months after being diagnosed with HIV. | - Carpenter (self-employed) – community members contract him to do some carpentry work. |
| P6_M_44_661 | Lives within the research community, a few meters from the health facility.<br>Lives with his second born son. Daughter is in boarding school although lives with the mother. | Divorcee.<br>Differed with the wife because she refused to test for HIV and suspicion that she had been concealing her HIV status. | - Tested HIV positive through HCT offered by the PopART study. | Although willing, did not start ART immediately after diagnosis.<br>Waited for CD4 count to drop due to national guidelines then.<br>Felt like health was deteriorating due to waiting for CD4 count to drop.<br>Started ART in May 2013. | - Works as a chef at a renowned hotel in Livingstone. |
| P7_W_29_523 | Lives in the research community.<br>Lives alone in her house. | Divorced with the husband who is also living with HIV<br>Husband had a girlfriend who was also on ART & used to spend nights at her place leaving the | - Tested HIV+ on 9th May 2014 at the research clinic.<br>- Went for an HIV test due to ill health. | Started treatment on 10th May 2014 – the day after she tested HIV+. | - She works as a cleaner in a shop located in Livingstone town center. |

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| | Children are staying with the mother in another province. | wife and children hence the divorce.<br>Ex-husband has since remarried. | - Did not get surprised by the diagnosis because of her ex-husband's affair with a woman living with HIV. | | |
| P8_W_35_589 | Lives far from the research clinic (about 40 minutes' walk) but within the boundaries of community 'X'.<br>Lives with her three children. | Divorced due to marital problems with the husband.<br>Not sure whether the ex-husband is living with HIV since they are no longer together. | - Tested HIV+ in 2013 at a health facility located near the research clinic.<br>- Referred to the research clinic for HIV services.<br>Initially kept the referral slip at home. | After two years (in 2015), experienced health problems, went to the research clinic, was re-tested to confirm HIV status<br>Started ART a month after re-testing | - Unemployed, mostly relying on neighbors and relatives to meet her needs and those of her children. |
| P9_M_44_797 | Lives about 10 minutes' walk from the research clinic within community X.<br>Lives with the sisters.<br>The children live with relatives in separate towns. | Wife died but at the time of her death they had divorced due to her infidelity. | - Was diagnosed with HIV in 2015 through HCT provided in PopART.<br>- Was referred to the research clinic after HIV diagnosis. | Went to the research clinic soon after being referred.<br>Was re-tested and commenced on ART the same day he went to the health facility. | - Used to work for the military.<br>- Now works as a brick layer – relying on winning building contracts from individuals. |

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| P10_W_20_554 | Previously used to live with the mother in a rural area.<br>Relocated to her sister's place due to complication of relationship with father to the child.<br>Lives with the sister outside community X (about 50-60 minutes' walk or 10 minutes' drive). | Not married – was dating a married man & got pregnant.<br>Father to the child tested HIV-.<br>Currently has a boyfriend but status not disclosed because boyfriend not open to discussion about HIV. | - Diagnosed with HIV on 29th January 2015 during pregnancy.<br>- Was tested through antenatal care services at the research clinic. | Started ART on the same day that she was diagnosed with HIV. | - Business woman, owns a stand selling cosmetics products in one of the main markets near her home. |
| P11_M_36_559 | Lives within the research community, a few minutes away from the research clinic. | Single. | - Tested HIV positive in 2005 when he was in junior high school.<br>- Did not seek HIV services until 2012 when he came to the research clinic. | Despite coming to the clinic in 2012, gave up before starting ART due to long procedures.<br>Only started treatment in 2015 after developing poor health. | - Theology student |
| P12_W_26_543 | Lives in a rural area located about 15 kilometers from community X.<br>Relocated from community X to a rural area to live with parents after marriage dissolution. | Divorcee<br>- Husband refused to ever test for HIV. | - Had been testing for HIV (every after three months) since 2014 due to lack of trust for the husband until diagnosed with HIV. | Started treatment on 17th March 2015 when she was still married.<br>Lives far from community 'X' hence always have to set some money aside for transport. | - Business woman, buys clothes for resale. |

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| | | | - Mainly used to test through HCT and the research clinic. | | |
| P13_W_37_768 | Previously used to live in community ‘X’.<br>Relocated to another community (about 50-60 minutes’ walk from the research clinic. | Married.<br>Husband never tested and does not support her with taking ART or accessing HIV services. | - Diagnosed HIV+ during her fourth pregnancy in 2011 when accessing antenatal services.<br>- Was on Septrine for a while and was given a single dose for PMTCT. | Started treatment in 2014 after learning about early initiation of ART.<br>Fond of accessing HIV services at the research clinic although it is far from her home.<br>Sometimes walks to access HIV services. | - Unemployed hence relies on the husband to provide household needs. |
| P14_W_35_534 | Lives outside Livingstone town.<br>Lives at a school where she teaches but husband lives near community ‘X’.<br>Visits the husband every weekend and during school holidays. | Married.<br>Husband has been on ART since 2007. | - Was diagnosed HIV positive in 2007 at a health facility near the research clinic.<br>- Was then referred to the research clinic for HIV services. | Had her CD4 count routinely monitored at the research clinic until May 2012 when HCWs recommended ART.<br>Had taken single doses of ARVs for PMTCT during all her three pregnancies between 2007 and 2012.<br>Travels when it is her appointment date at the health facility. | - Teacher |

## Appendix XI: Summary of the roles of the study key informants in HIV service delivery at the health facility

| **Participant ID.** | **Key roles in HIV service delivery** |
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| KI1_W_30_6 | - Works as a registry clerk at the research clinic.<br>- Main roles include:<br>• Opening files for newly enrolled clients and entering their details in their respective files.<br>• Retrieving client's files when they come for their subsequent clinic visits so as to assess the types of services they have come to access at the clinic and for clinicians to refer to.<br>• Controlling client flow in the health facility (with the help of other lay health workers). |
| KI2_W_64_4 | - Retired professional HCW (clinical nurse).<br>- Had been re-engaged by a local non-governmental organization that is assisting the Zambian Ministry of Health in providing HIV services at the research clinic.<br>- Main roles include:<br>• Adherence counselling for PLHIV<br>• Assisting with clinical aspects of clients accessing services at the health facility. |
| KI3_M_33_4 | - Clinical officer by profession.<br>- Main role involves assessing clinical aspects and treatment for PLHIV accessing services at the research health facility. |