

# University of the Western Cape

Faculty of Community and Health Sciences

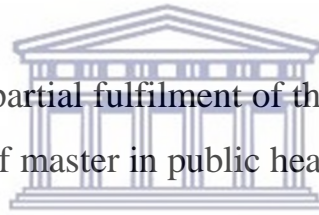
Acceptability of a Home-Based Antiretroviral Therapy Delivery Model among  
HIV patients in Lusaka District.

By

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A mini-thesis submitted in partial fulfilment of the requirements for the  
degree of master in public health



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## **Key Words**

Acceptability

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Community Models of ART

Community HIV Care Providers

Home based delivery of ART

People Living with HIV/AIDS

Lusaka

Zambia



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## ACRONYMS AND ABBREVIATIONS

<b>ART:</b>	Anti-retroviral Therapy
<b>FGDs:</b>	Focus Group Discussions
<b>HBM:</b>	Home Based Model
<b>HIV:</b>	Human Immunodeficiency Virus
<b>HTC:</b>	HIV Testing and Counselling
<b>IDI:</b>	In-depth Interview
<b>MOH:</b>	Ministry of Health
<b>PLWH:</b>	People Living with HIV
<b>PMTCT:</b>	Prevention of Mother to Child Transmission
<b>SSA:</b>	Sub-Saharan Africa
<b>UNAIDS:</b>	Joint United Nations Programme on HIV/AIDS
<b>USAID:</b>	United States Agency for International Development
<b>VCT:</b>	Voluntary Counselling and Testing
<b>WHO:</b>	World Health Organization



## **ABSTRACT**

**Background:** The Zambian anti-retroviral therapy (ART) program has successfully enrolled over 770, 000 people living with HIV (PLWH), out of a population of 1.2 million PLWH. This tremendous success has overburdened the clinic system resulting in many challenges for both patients and healthcare staff. To promote ART initiation, adherence, and retention and at the same time relieve pressure on the health system, a home-based ART delivery model (HBM) was piloted in two urban communities of Lusaka. This study explored levels of acceptability of the model and factors influencing this among PLWH living in the two communities. Acceptability was defined as degree of fit between the patient's expectations and circumstances and the home-based delivery model of ART, taking into consideration all the contextual elements surrounding the patient.

**Methodology:** A qualitative study of HBM acceptability was nested within a cluster-randomized trial comparing outcomes in patients receiving HBM intervention compared to the standard of care in two communities in Lusaka, Zambia. Using an exploratory qualitative study design and a purposive sampling technique, qualitative data were collected using observations of HBM delivery (n=12), in-depth interviews with PLWH (n=15) and Focus Group Discussions with a cadre of community health workers called community HIV care providers (CHiPs) administering the HBM (n=2). Data were managed and coded using Atlas.ti 7 and analysed thematically.

**Results:** Overall, the HBM was found to be a good fit with the lives and expectations of PLWH and therefore highly acceptable to them. This acceptability was influenced by a combination of cross cutting clinic based, program design and socio-economic factors that have been categorized into push and pull factors. Push factors were those related to the challenges that PLWH faced when accessing ART from the clinic and included congestion, long waiting times, confidentiality breaches and stigma arising from attending a dedicated clinic. These factors resulted in considerable direct and indirect livelihood opportunity costs. The HBM as an alternative had a number of 'pull factors'. PLWH described services offered through the model as convenient, confidential, trusted, personalized, less stigmatizing, comprehensive, client centred, responsive, and respectful. Disclosure of client's HIV status to people they lived with was found to be critical for the acceptability of the model.

**Conclusions and recommendations:** The HBM is highly acceptable and this acceptability is influenced by a combination of crosscutting push and pull factors. Key to the HBM's acceptability was its delivery design that was responsive to individual patient needs and the steps CHiPs took to minimize the ever-present threat of disclosure and stigma. Future adoption and scaling up of HBM should recognize the importance of these design features.



## DECLARATION

I declare that this thesis entitled “acceptability of a Home-Based Antiretroviral Therapy Delivery Model among HIV patients in Lusaka District” is my own work and it has not been submitted for any degree or examination in any other University and that all the references I have used or quoted have been acknowledged.

**Full Name:** Chiti Bwalya

**Signed:** 

**Date:** 31<sup>th</sup> September 2018.



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## **DEDICATIONS**

To my late dad, Felix Changomo Bwalya! You were the foundation for Greatness. We miss you, RIP dad.



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## CHAPTER ONE - INTRODUCTION

### 1.1 Background information

Zambia, like many other African countries, has made significant progress in scaling up antiretroviral therapy (ART) services. This scale up started in 2005 when the Zambian government announced a policy shift that brought about provision of free ART in public health facilities (Chankova, 2006). This has resulted in more people accessing ART over the years such that by 2016, 770,000 people out of a population of 1.2 million living with HIV PLWH were on ART (NAC, 2014; MOH, 2016). The policy shift to option B+ (treating all HIV positive pregnant women) and the adoption of the WHO 2016 “test and treat” guidelines (treating all HIV positive people regardless of CD4 count) have further increased numbers of PLWH on ART to a coverage of almost 85% of PLWH who know their status (WHO, 2015; ZAMPHIA, 2017).

In spite of these successes, the ART treatment program in Zambia still faces many challenges. From the supply point of view, the 2005 policy announcement increased the demand for ART services resulting in overcrowding and overburdening of clinics and thus increasing the workload and burnout for the few existing health care workers (HCWs) (Chankova, 2006; Association of Chartered Certified & Accountants-ACCA, 2013). This shortage of HCWs is significant: there is a deficit of over 70% doctors, nurses and clinical officers and inequality in both the distribution and skill mix is severely affecting ART service delivery (MOH, 2006; Morris et al., 2009; ACCA, 2013). The main causes of staff shortages have been lack of funding, capacity to train staff and the loss of staff through ‘brain drain’ (ACCA, 2013). Inadequate clinic space, lack of efficient patient record and laboratory systems are other problems confronting urban clinics (Musheke et al., 2012).

Apart from staffing problems and inefficient service delivery systems, because of poor health mapping, the distribution of clinics in many settings is inequitable leading to, in some cases, people walking longer distances to access health services with significant transport costs (ACCA, 2013; Mukumbang et al., 2017). On the demand side, access to ART services is challenging for PLWH. Musheke et al. (2012) observed that for some PLWH, frequent trips to the clinic and long waiting times present enormous opportunity costs.

This is especially the case for those without secure employment, forcing them to choose between going to the clinic for treatment and sustaining their livelihoods.



Mukumbang et al. (2017) further report that overcrowding and inadequate confidential working space at ART clinics are also common problems for many clinics in Zambia. This has compromised privacy and confidentiality for PLWH. In addition, inadequate clinic space for the many patients waiting to receive ART services has also contributed to access challenges for PLWH (ibid).

At the beginning of the scale up in 2005, many ART clinics were built as stand-alone facilities separate from other non-HIV services provided through the main clinic building. This separate layout of ART clinics has resulted in stigma against PLWH as they are easily identified as those with living with HIV (Bond et al., 2016). Some PLWH, especially those newly diagnosed therefore find it difficult to access ART, as they fear being seen at the ART clinic and having their HIV status involuntarily disclosed to other community members

Zambia is not a special case when it comes to ART service delivery challenges. In many ART programs across sub-Saharan African (SSA), researchers have described similar challenges. In Uganda for example, Tuller et al. (2010) report that long distance to the clinic is a serious access obstacle to ART services. In a systematic review of task-shifting for HIV treatment and care in Africa, Callaghan., et al. (2010) and Lambdin et al. (2011) found that the scale up of ART has been done without comparable increases in personnel to accommodate the large number of new patients. The resulting effect has been poor service delivery and access challenges for PLWH. In addition, this has also severely hampered the rollout of ART services. Alamo et al. (2013) reports that high patient loads at health facilities has resulted in long clinic appointments, long waiting times, poor staff attitudes and decreased quality of patient-provider interaction and patient satisfaction with HIV care. This, in turn, discourages health care seeking for those not yet on ART and leads to frustration and poor retention for those already on ART (Callaghan et al., 2010). To improve service delivery, task shifting of basic health services to community health workers has been suggested as a means of offering high quality cost effective health care in settings with high shortage of qualified health workers (Callaghan et al., 2010).

UNAIDS (2018) reports that of the estimated 1.2 million PLWH in Zambia, only 67% know their positive HIV status which means that approximately 400,000 people who are HIV positive will be in need of ART services in the near future. Expansion of the ART clinic program to increase coverage to cater for this extra number of people will further adversely compromise service delivery and present additional access problems for the existing and new patient load and negatively affect retention.

In order to continue expanding the number of PLWH on ART whilst retaining people in care and achieving high levels of treatment adherence within the Zambian ART programs, novel and innovative models, such as community-based delivery of ART are needed (WHO, 2014).

In the light of this, Zambart, a Zambian research organization, piloted a home-based delivery model of ART (hereafter referred to as HBM) among stable HIV patients in two Lusaka urban communities. The HBM study was a cluster-randomized non-inferiority trial comparing virological and clinical outcomes of patients participating in the HBM to those accessing treatment through the clinic (Limbanda et al., 2018). This study was nested within a larger community randomized trial, HPTN071 (Population effect of Antiretroviral therapy-PopART) evaluating the impact of household-based universal test and treat intervention (UTT), on HIV incidence in 12 Zambian and 9 South African communities (Hayes et al., 2014; Cori et al., 2014).

In Zambia, the 12 PopART communities were first randomized into three study arms (arm A, B and C). In arm A, four communities received the full PopART intervention package which included home-based voluntary HIV testing, and counselling offered to all residents as well as linkage to early treatment for all individuals testing HIV positives. In arm B, another group of four communities received the full door-to-door delivered PopART intervention package with ART being provided according to national guidelines. The last four communities were allocated to arm C as controls (Hayes et al., 2014). The PopART intervention package was delivered door to door by group of lay counsellors known community HIV care providers (CHiPs) (ibid).

The HBM as an intervention was only implemented in two PopART communities out of the 12. It involved the same CHiPs delivering the main PopART intervention visiting HIV patients' homes once every three months (twice a year) to provide adherence support, symptom screening, and dispense pre-packed ARVS. The PLWH accessing ART through the HBM were only required to visit the clinic twice in a year for routine clinical review and laboratory monitoring as well as have quick access ART (Limbanda et al., 2018)

For any health program to succeed, it needs to be not only available and affordable, but also acceptable to its users. This mini-thesis used the HBM sub-study to examine the acceptability of this model of delivering ART in Lusaka urban communities.

Yakob and Ncama (2016) have defined acceptability as the degree to which the services delivered by the health organization satisfy the individual's expectations, personal preferences and wishes.

Clark and Coffee (2011:3) have further defined acceptability as the “relationship of clients' expectations about personal and practice characteristics of providers to the actual characteristics of existing providers, as well as to provider attitudes about acceptable personal characteristics of clients”. In this study, acceptability of health services is defined as the “degree of fit” between the patient's expectations and circumstances and the home-based delivery model of ART, taking into consideration all the contextual elements surrounding the patient.

## **1.2 Problem Statement**

The HBM of ART has brought health service delivery closer to the patient and his or her surrounding micro-social environment, resulting in new interactions between the patient, this environment and a health intervention. Masquillier et al. (2016) have argued that this micro-social context inevitably affects the acceptability of community support initiatives. Yet interventions often ignore the social context in which they are implemented (Campbell et al., 2007; Glass & McAtee, 2006). In addition, experiences of accessing health services at local community clinics may positively or negatively influence how PLWH respond to community based intervention. There is a need to develop an understanding of how the pre-existing home and social dynamics surrounding PLWH and clinic based factors influence acceptability and uptake of HIV/AIDS programs especially community based ones. The HBM may increase access to care by removing geographical barriers but may also have negative impacts on household dynamics and social relations of the patient. For instance, it may influence voluntary or involuntary disclosure of patient's HIV status and impact on their experiences of stigma. Further, implementation of such novel interventions will only be a success when careful, deliberate and purposive actions are taken to ensure effective alignment and integration of the new programme with the clinic and community system. Proctor et al (2011), using the concept of penetration and sustainability, have argued that implementation of novel services should be in a manner that ensures practices are developed with such “intervention fit” within existing health systems.

### **1.3 Rationale**

Community models of ART such as the home-based delivery model of ART have been suggested as ways of expanding the ART program with assurance of improved service delivery and treatment outcomes for PLWH (WHO, 2014). This model is, however, a very new initiative that has never been implemented in urban areas of Lusaka before. There is need to fully understand how the model and the patient's social environment will interact and how this will influence acceptability of the model. A good understanding of how acceptable this model is and factors influencing its acceptability will inform the future design, scale up, integration and implementation of the model in other clinics in Zambia. The main study in which this study is nested was established in dialogue with the ministry of health and its implementing partners. Data from this study will therefore be additional evidence that the ministry of health can use for future design, integration and scale up of the HBM in Zambia.

### **1.4 Structure of the thesis**

This thesis is divided into five chapters. The remaining chapters are structured as follows: Chapter 2 presents a review of the literature on factors influencing acceptability of home and community-based HIV services. The third chapter describes the research methodology of the study. Chapter 4 presents the findings of the study. Chapter 5 follows, with discussion and interpretation of results. Lastly, chapter 6 presents the conclusion of the study and recommendations based on the findings of the study.

## CHAPTER 2 - LITERATURE REVIEW

### 2.1 Introduction

This chapter introduces the concept of community models of ART by giving a background to the need for these models and how effective they have been in other settings where they have been implemented. Subsequently, literature on factors influencing acceptability of home-based HIV services such as home-based HIV testing is presented.

### 2.2 Decentralized models of HIV care

In 2013, the World Health Organisation (WHO) (2014) recommended models of decentralised HIV treatment, with ART initiation done at the clinic and options of maintenance at community level. Community models of ART as means of providing care have proven to be effective in a number of settings, empowering patients on ART and communities to take responsibility for their own treatment (Rasschaert et al., 2014). These models have not been a one size fits all approach but context specific and called different names. For example, Medicine Sans Frontiers (MSF) piloted 'adherence clubs' in Khayelitsha, South Africa where stable patients received pre-packed antiretroviral (ARVs) and adherence counselling in groups of 20 people; while in Tete Province of Mozambique, community members gathered in groups of six and took turns in travelling to distant clinics to collect refills for the group (UNAIDS & MSF, 2015). UNAIDS and MSF (2015), further piloted 'community managed distribution points' in Kinshasa, Democratic Republic of Congo (DRC) where people would access care and support closer to their homes. In a 'home based delivery model' of ART in Tororo, Uganda, community health workers conducted home visits to all participants for drug delivery and monitoring (Apondi et al., 2007).

Community-based programmes have been effective in addressing the often cited health system challenges to ART scale-up in many poor countries, which include lack of comprehensive care, patient empowerment, defaulter tracing and the crippling shortage of staff (Wouters et al., 2012). Community based models have also been effective in reducing facility workload and time taken when accessing care in Kenya and in DRC (UNAIDS & MSF, 2015; Khabala et al., 2015). The models have also improved retention in care in Khayelitsha, South Africa and in Kenya (ibid). In Uganda, the home based ART delivery was ideal in rural settings that had

a shortage of clinical staff, and patients for whom transport costs and lost work-time provided obstacles to treatment initiation and adherence (Korenromp & Viisainen, 2009).

### **2.3 Acceptability of home-based delivery of HIV care**

There is little literature specifically addressing the acceptability of home-based delivered ART in Sub-Saharan Africa (SSA). A number of studies have, however investigated the acceptability of other community based interventions such as door-to-door delivery of HIV finger-prick testing and HIV self-testing (Mutale et al., 2010; Sekandi et al., 2011; Naik et al., 2012; Choko et al., 2015; Knight et al., 2015; WHO, 2016; Pérez et al., 2016; Ayles et al., 2017). In general, these studies reported that home-based HIV testing is acceptable when a number of factors are taken into consideration. These factors can be broadly be categorised into household, community social-economic, intervention design and health facility factors.

#### **2.3.1 Household/family factors**

Wouters et al. (2014) noted that in South Africa, provision of community peer ART adherence support led to positive immunological outcomes in “functional” families as compared to patients coming from “dysfunctional” families. Functional families were supportive of each other, innovative in dealing with problems and encouraged disclosure. In dysfunctional families on the other hand, family support was very limited and at times, not there at all. Despite support for the idea of HIV positive peers providing home visits, participants in the program expressed fear of involuntary disclosure of their HIV status to immediate family members (Ibid). Van Rooyen et al. (2016) also found that weak family support led to poor HIV testing, linkage to care, and adherence to treatment in South Africa.

Entrenched gender inequalities, poverty and unemployment were also found to influence uptake of home-based family HIV testing (ibid). Household gender dynamics disadvantage women in many areas including decision around health seeking behaviour (DiCarlo et al., 2014). In Uganda and Malawi, gender inequalities within a home were found to negatively influence uptake of home based HIV testing services by women, where men often played a dominant role in the decision making processes related to couple and family health issues (Sekandi et al., 2011; Kranzer et al., 2008). If a man was not agreeable or not present during a home visit, the whole family, including his wife, could not access HIV testing services.



In other settings, home-based testing has been acceptable for women because if the husband is present, it provides an opportunity for the couple to test together. In Lesotho, home-based testing for couples was acceptable because it provided women the opportunity to disclose their status to their partners (Mantell et al., 2014).

It was also seen as a strategy that encouraged family support as during the test family members present easily understood and supported the affected member (ibid). Moreover, in Malawi, home based HIV self-testing made testing together for couples logistically easier than facility-based services (Kumwenda et al., 2014). Similarly, in Nyanza Province, Kenya, home based testing was accepted because it provided opportunities for repeated testing and disclosure for couples and family members (Negin et al., 2009). Household composition and the HIV status of other individuals within a household have also shown to influence acceptability. Having an adult in the household who is living positively or previously accepted testing influenced adolescents in Zambia to accept an offer of a home based testing (Shanaube et al., 2017). Finally, losing a partner to HIV or discordance due to HIV within a home also acted as motivation for men to test in Uganda (Siu et al., 2014).

### **2.3.2 Livelihood factors**

Livelihood activities are cardinal for the survival of a household. Heads of households have obligations to make sure that they provide for their families and searching for work often entails having to be mobile. Mobility linked to livelihood activities often makes it difficult for people to access home-based HIV testing services. In Zambia, the provision of home-based counselling and testing by a large community based randomised trial proved to be challenging especially for men. This was so because adultmen were out for work or business during the day when this service was being offered (Bond et al., 2016; Shanaube et al., 2017; Hayes et al., 2017). On the other hand, Musheke et al. (2012) found that taking time off from economic activities to access treatment for many patients presents enormous opportunity costs and is a threat on their sources of income. Similarly, in rural Uganda, men missed out the opportunity for testing at home as they were not home due to mobility linked to livelihood options (Camlin et al., 2016). During certain seasons, informal sector labour opportunities for men often required extended absences from rural households. Working and finding time to go the facility proved problematic and at the organisation and scheduling of testing services, particularly in the public health centres, was a major obstacle (Siu et al., 2014).

Affordability of transport costs to and from the clinic is a problem for many patients. In many communities, clinics are far away from people's homes. In Tanzania, Nigeria and Uganda, Ware et al. (2009) found that ART patients had to raise transport money for clinic appointments through loans, piecework, selling of possessions and handouts from friends and families. Home-based delivery is convenient and deals with these challenges directly.

In Uganda, community members found it difficult to find time to leave their homes and were very positive about the home-based HIV testing service because it reduced travel distance and time spent at the clinic (Wolff et al., 2005).

### **2.3.3 Social factors**

Receiving a visit from a Community Health Worker is often a marker of HIV in neighbourhoods (Masquillier et al., 2016). This is especially problematic in informal housing settlements, where houses are built close to each other, and at times different families may share one building, compromising confidentiality. In a systematic review and meta-analysis on community-based approaches to testing across SSA, Suthar et al., (2013) noted that people rejected community based testing including door-to-door because they feared stigma and involuntary disclosure of their status. Successful HIV programs have had to first deal with high levels of background community stigma. For example, Yakob & Ncama (2016) showed how in Ethiopia, the reduction in stigma and discrimination of PLWH and the increased role of family members and the community in HIV care encouraged access and acceptability of HIV services.

Gender and cultural norms also constrain health-seeking behaviour especially among men who associate health seeking including HIV testing as a 'woman's thing' (Camlin et al., 2016). Literature has shown that most men consider themselves strong and seeking healthcare as a sign of weakness. In Uganda, healthcare seeking in general was often viewed as 'counter-normative' for men (an activity for women and children); and clinics were seen by men as 'female spaces' (Camlin et al., 2016). In Zambia, men looked at going to the clinic as a duty for women as they are the ones in charge of looking after children including the sick in a home (Simpson, 2009). Similarly, in Lesotho, "Men reported few opportunities for regular contact with health facilities or HIV testing sites, and commonly received information about HIV from television, radio, or friends" (DiCarlo et al., 2014. p 9).

Women may have more opportunities for contact with health services and HIV prevention, and may test for HIV during antenatal care, participants in Lesotho reported that men



commonly perceive HIV testing to be something that women do. (ibid). Consequently, HIV itself has come to be seen as a disease that women bring into the relationship and are responsible for managing (DiCarlo et al., 2014). Men therefore saw home-based testing as preferable to clinic-based testing because could avoid stigma linked to being seen at an HIV testing site (ibid). High levels of alcohol and substance abuse also have an influence on the delivery of home-based HIV services.

In Zambia, home-based HIV testing provided under a community randomized trial called PopART had challenges in reaching men who were often not at home, and who tended to gravitate towards the social environment of bars, drinking alcohol from mid-morning onwards (Bond et al., 2016).

Finally, rumours, myths and misconceptions (Simwinga et al., 2016) around blood and home-based finger-print testing may make it difficult for households to accept home-based testing. Blood based finger prick testing in Zambia and South Africa was associated with Satanism and it took sustained engagement between implementers of the intervention and community members for acceptability to be achieved (Simwinga et al., 2016).

#### **2.3.4. Health care factors**

In Uganda, where there has been a large demand for home-based HIV testing, Sekandi et al. (2011) concluded that this was because the home based provision of services was addressing the barriers associated with facility-based HIV testing which included stigma, discrimination, and lack of confidentiality. This was also reported by Yakob and Ncama (2016) in Wolaita, Ethiopia who found that HIV stigma reduced acceptability of clinic-based HIV services and in contrast, made home-based HIV services more acceptable. In addition, in South Africa, home-based HIV counselling and testing helped people to avoid long queues, lost results and poor treatment by staff (Knight et al., 2015). The study also found that home-based HIV testing was preferred to testing at the clinic because interactions between clients and counsellors were described as personal, offering privacy as well as confidentiality and clients were given opportunities to ask questions and have discussions with providers.

Health care workers and the way they interact with their patient's influences uptake of clinic-based testing services. Many patients have perceived or even experienced ill treatment at the clinic. Testing at the clinic also carried the greatest 'fear of being seen', exacerbated by congestion.

In South Africa, lack of trust of clinic staff, breaches of confidentiality as well as forced testing at the facilities were found as factors influencing acceptability of home based self-testing (Pérez et al., 2016).

Similarly, in another study in South Africa, Mambanga et al. (2016) found that men were not keen to test as they perceived lay counsellors to be unprofessional and where uncomfortable being tested by women counsellors.

A systematic review of factors enabling and deterring uptake of HIV testing in SSA also found that perceived health workers' inability to maintain confidentiality as one of the factors deterring uptake of HIV testing (Musheke et al., 2013). In Ghana, lack of information, negative perceptions of privacy and confidentiality, waiting time, poor relationships with health staff and fear of being positive was found to negatively influence uptake of clinic based testing (Kwapong et al., 2014). The structure of the clinic where HIV services have been separated from other services makes it difficult for some people to access HIV services. Stigma resulting from the fear of being seen and then being "gossiped about" makes people anticipate stigma related to HIV testing spaces at the clinic (Bond et al., 2016). In addition, the design and layout of clinic premises in some settings is unwelcoming for people from certain gender groups. For instance, men in Uganda defined clinics to be "inhospitable" or "unwelcoming" because of the absence of safe parking lots for their bicycles or motorcycles and citing it as a hindrance to making facility visits (Siu et al., 2014).

### ***2.3.5 Intervention design factors***

The design, implementation and delivery of a community-based HIV programme has been shown to influence uptake and acceptability. In addition, exposure to and local community history with HIV programs influences the acceptability of community-based HIV programs. In Sisonke District in KwaZulu-Natal (KZN), home-based HIV testing was highly accepted partly because of the extensive mobilisation strategies used to introduce the project to local leaders and communities. Moreover, high quality training which ensured that counsellors were confident when offering their services, and community members' trust in the counsellors' skills and the ability to uphold confidentiality enhanced acceptability (Naik et al., 2012).

In Zambia, high uptake and acceptability of home based HIV self-testing among adolescents was reported to be partly influenced by HIV sensitization programs conducted by other non-governmental organizations prior to the home based intervention (Shanaube et al., 2017; Bond

et al., 2016). This high exposure and rich history of community-based HIV testing in these communities meant that the home-based testing programme was not treated as a ‘strange programme’ despite its novelty in terms of testing for HIV without using blood.

Moreover, the intervention design of repeated annual home visits by lay counsellors in Zambia ensured that those that rejected an initial offer of home-based testing eventually often accepted it (Shanaube et al., 2017).

The use of lay workers that are residents of recipient communities to deliver home-based testing has also shown to influence acceptability. In South Africa, Wademan & Reynolds (2016) found that the use of resident lay counsellors that had knowledge of the community and were well known by community members encouraged uptake of door-to-door HIV services. At the same time, this physical and social closeness to their clients posed a problem for community members, who were concerned about the confidentiality of their HIV status.

Home delivery of HIV testing services have been shown to be labour intensive and good quality of care may be hard to maintain. In Uganda, Wolff et al., (2005) found that HIV counsellors complained that delivering results at home also meant a lot more time, energy and fuel money to reach scattered rural residences, and frustration when participants were not found at their homes. In Tanzania, counsellors providing door to door testing also had challenges as they had to walk long distances resulting in constant burn out and some withdrawing from work (Negin et al., 2009).

## **2.4 Summary**

In summary, the literature has shown that patients live in complex social environments and a variety of factors can positively or negatively influence the acceptability of home-based HIV services. These include home, social, clinic based, intervention design and livelihood factors. Most of the available literature is on home-based rural HIV testing services.

However, little is known about the use of the home delivery model as a means of delivery of ART in an urban setting. In addition, there is very little research exploring acceptability using qualitative research methods.

## CHAPTER 3 – RESEARCH METHODOLOGY

### 3.1 Introduction

This chapter describes the methodology used in the study. It outlines the study design, study population, sampling procedures, data collection, data analysis, rigour, ethical considerations and limitations of the study methods.

### 3.2 Aim and objectives

This study explored levels of, and the influences on, acceptability of the home-based delivery model of ART among HIV patients in Lusaka district.

### 3.3 Specific Objectives

The study objectives are as follows.

- To explore levels of acceptability of the home-based delivery model of ART among PLWH HIV patients in Lusaka district.
- To explore health care based and intervention factors influencing acceptability of a home-based delivery model of ART among PLWH in Lusaka district.
- To explore household and social factors influencing acceptability of a home-based delivery model of ART among PLWH in Lusaka district.
- To explore livelihood factors influencing acceptability home-based delivery model of ART among PLWH in Lusaka district.

### 3.4 Study design

This study was an exploratory qualitative study design (Baum, 1995). Since the aim of the study was to explore levels of acceptability of the HBM and factors influencing it, qualitative methods were appropriate because of their ability to collect data on health, which is embedded in the social, political and economic factors that influence health and disease among individuals (Baum, 2005; Pope & Mays, 2000).

### 3.5 Research setting

This study was nested within the home-based delivery model intervention implemented in two townships of Lusaka (Limbanda et al., 2018). These two communities are predominantly low-income, high-density urban residential settings located about 10km from the city centre in Lusaka. Each community has an estimated population of more than 120,000 people (Hayes et al., 2014).

These communities are comprised of multilingual ethnic groups with Nyanja being the most commonly spoken language. Socio-economic status and housing structures are mixed but predominantly residents are poor. The majority of the residents are either in the informal sector of the economy and unemployed or in low-paid jobs in the public and private sectors (Bond, et al., 2016)

Health services in each community are provided by one government clinic that provides both in-and out-patient health services. These health facilities were designed for a smaller population and do not have the capacity for the current catchment population therefore creating access challenges, although both are being expanded and rebuilt to improve service delivery (Musheke et al, 2012). Community one, based on the census conducted prior to the PopART study in 2013 has a total 14,282 households and a population of 100,391 of which 50,196 are 18+ and a prevalence of HIV standing at 12.6% . Community two has a total 13,368 households and a population of 100,011 which 50,006 are 18+. The prevalence of HIV stands at 11.3% (PopART intervention and Population cohort data, 2017). Hayes et al. (2014) also reports that in the two communities, roughly about 13% to 38% of HIV positive individuals are on ART. The two clinics do not have sufficient number of health staff and are supplemented by lay counsellors. For the purposes of the HBM sub-study, each community was divided into 104 zones. Those PLWH living in households that fell within the zones randomized into the intervention arm of the model were asked to take part in the home-based ART delivery model intervention study (Limbanda et al., 2018).

### **3.6 Study Population**

The primary population for this study was comprised of all PLWH, both men and women, aged between 18 and 49 years of age accessing ART through HBM. The second study population was comprised of CHiPs responsible for delivering treatment to PLWH in their own homes.

### **3.7 Sampling procedure**

Purposive sampling as explained by Robson (2013) was used to recruit PLWH. All clients that were receiving care through model are listed in a 'home-based register' and together with the help of the CHiPs, participants were purposefully chosen from the different zones, age and gender groups to have representation across the range of program recipients. Once a participant was chosen, I together with the CHiP worker called the participant and asked for

permission to conduct a household visit. When the participant had agreed, the CHiP worker and I visited the household, provided information on the study and recruited the participant. I also recruited participants during the home-based delivery observations, while others were recruited during their clinic appointment visits.

These procedures worked very well because the CHiPs were known and trusted by the clients in the communities. Once I was introduced, clients readily participated in the study. All CHiPs directly involved in implementing the HBM interventions (n=16) were also selected purposively and invited to participate in focus group discussions (FGDs). Through the supervisor and the nurse in charge of coordinating the intervention, CHiPs interested in participating were informed of the date when the discussions would take place.

### **3.8 Sample size**

This study had two samples. The first sample was 27 PLWH from the two communities accessing care through the HBM. The second sample was that of 16 CHiPs (n= 8 CHiPs per group discussion) drawn from the population of CHiPs delivering treatment through HBM in the 19 intervention zones in each site.

### **3.9 Data collection**

Three methods of data collection, in-depth interviews (IDIs), FGDs and observations were used in this study.



#### ***3.9.1 Observation of home-based delivery of care.***

Observations of the home delivery of care to PLWH by the CHiPs were carried out eight months after the start of the intervention using an observation guide (see appendix 15). Twelve household visits, involving 10 CHiPs, were observed. Observations provided insights into the delivery of care as well the household and community dynamics. Observations were conducted between October 2017 and December 2017.

Before going into the community, I would ask the nurse in charge of coordinating the HBM to assign me a pair of CHiPs to accompany me into the community. I would then meet with the CHiPs to explain the purpose of the observations. This was done in order for CHiPs to understand that the observation was not a monitoring visit to check how well they performed but rather a research activity whose aim was to explore experiences of PLWH with the model.



I visited the 12 households together with CHiPs. During these visits, I observed what they did and how the client being visited responded. Whilst observing, I took a few notes in a diary, which I later on expanded. These included taking note of the home, social environment and the economic status of the house being visited and the sex and approximate age of the client. I also took note of the number of children the client had, livelihood activities taking place at home, type of house the client lived in and its location in the community.

I also observed the process of delivering care. This included noting the time the CHiP worker arrived at the house, the quality of counselling provided and my impression of the client's response to the service provided. I also paid attention to the steps taken by the CHiPs to make the model more acceptable to clients.

### 3.9.2 In-depth interviews (IDIs) with PLWH.

Observations were followed by audio recorded IDIs (n=15) with PLWH either in Nyanja, or English, and were conducted by the investigator. Interviews were used as a method of gathering information because they provided access to the meaning that people attribute to their experiences and social words (Legard et al., 2003). Interviews using questions from an interview guide started with questions on experiences with accessing of ART services at the facility (see appendix 14). This was then followed with a question on why PLWH accepted the model and how well the model fitted in their lives. Interviews then ended with participants plotting their overall opinion of the HBM on a simple visual scale with different facial expressions (emoji's) corresponding to degrees of satisfaction from not all satisfied to extremely satisfied (see figure 3.1 below).

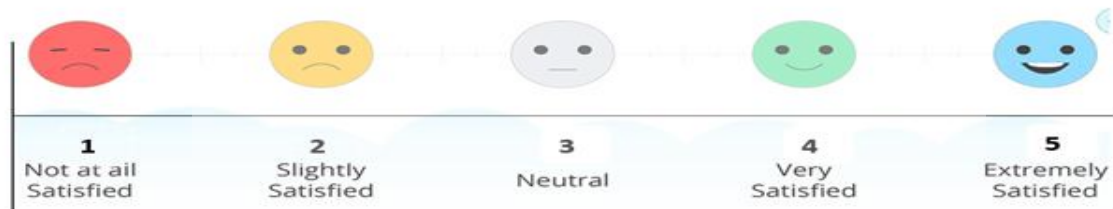


Figure 3.1 visual analogue scale (VAS)

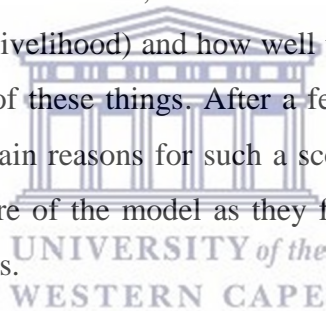
Probes were used to solicit reasons and explanations as to why participants chose a certain level on the scale, and the factors that made them score higher or lower on the scale. Using

this visual scale worked well for most of our participants but was challenging for those participants that were illiterate and needed additional explanations.

### ***3.9.3 FGDs with Community HIV Care Providers (CHiPs)***

One audio-recorded FGD (n=8) was conducted in each of the two communities was held with CHiPs. These followed the same line of questioning as for clients. Discussions started with questions from a group discussion guide, which were around PLWH's experiences with accessing ART services from the facility (see appendix 13). This was then followed with questions on what the CHiPs felt were the reasons why PLWH accepted the model and how well the model fitted in their lives. The last part of the discussion involved CHiPs plotting their overall opinion of the HBM on the visual scale.

The use of a Visual Analogue Scale (VAS) with CHiPs worked very well as they were able to understand the questions and found plotting on the scale easy. Each CHiP was given a copy of the scale and asked to think around their work, their client's experiences with accessing ART (including their social context and livelihood) and how well this model fitted into their clients lives taking into consideration all of these things. After a few minutes, each CHiP was then asked to share their score and explain reasons for such a score. During the discussion, some CHiPs did not contribute their score of the model as they felt what they wanted to say had already been said by their colleagues.



### **3.10 Data Management and Storage**

After collecting the data, I transcribed the audio recordings verbatim from the interviews and FGDs, as I was familiar with the local “slang” and accents used by participants. During the transcription process, the translation of the content from local languages into English was also done. To avoid loss of meaning during transcription and translation process, an external research assistant was engaged to check transcripts while listening to the audio recording. The transcription process took approximately two months and was started in December 2017 and ended in January 2018.

Notes taken during and after the observation labelled with a code representing each participant then added to Atlas.ti in readiness for the coding and analysis phase.

Data for the study was managed and stored at ZAMBART house located at the University of Zambia, School of Medicine, Ridgeway Campus in Lusaka, Zambia. The data collected in this study was stored on a password-protected computer and backed up on an external hard drive



on which the documents were password protected. Hard copies of the data were also stored in a lockable drawer. Only the researcher knew the computer password and access to the lockable drawer was also be restricted as keys for the drawer were kept safely away. After finalizing the transcription and writing up of observations, all data transcripts were loaded into Atlas.ti 7, a qualitative data analysis software that was used to help with the management and analysis of the data. All the data collected for this research study will be destroyed after a period of five years.

### 3.11 Data analysis

Using the Thematic Coding Analysis (TCA) approach, all parts of the data transcripts and notes from observations were loaded in Atlas.ti 7 were read several times and open coded to inductively identify possible codes (Pope and Mays, 2000; Nowell et al., 2017)). Similar codes emerging from the data were then merged and a final codebook, which was a list of all codes related to the levels of acceptability and factors influencing acceptability, was developed. Each code in the codebook was then given a definition. This definition was to facilitate consistent coding of all transcripts. After this, all codes in Atlas.ti were then re-named and redefined following those coded in the codebook. The coding process was started in February 2018 and took about a month to finish. Figure 3.1, provides a sample, which shows the coding process in Atlas.ti 7.

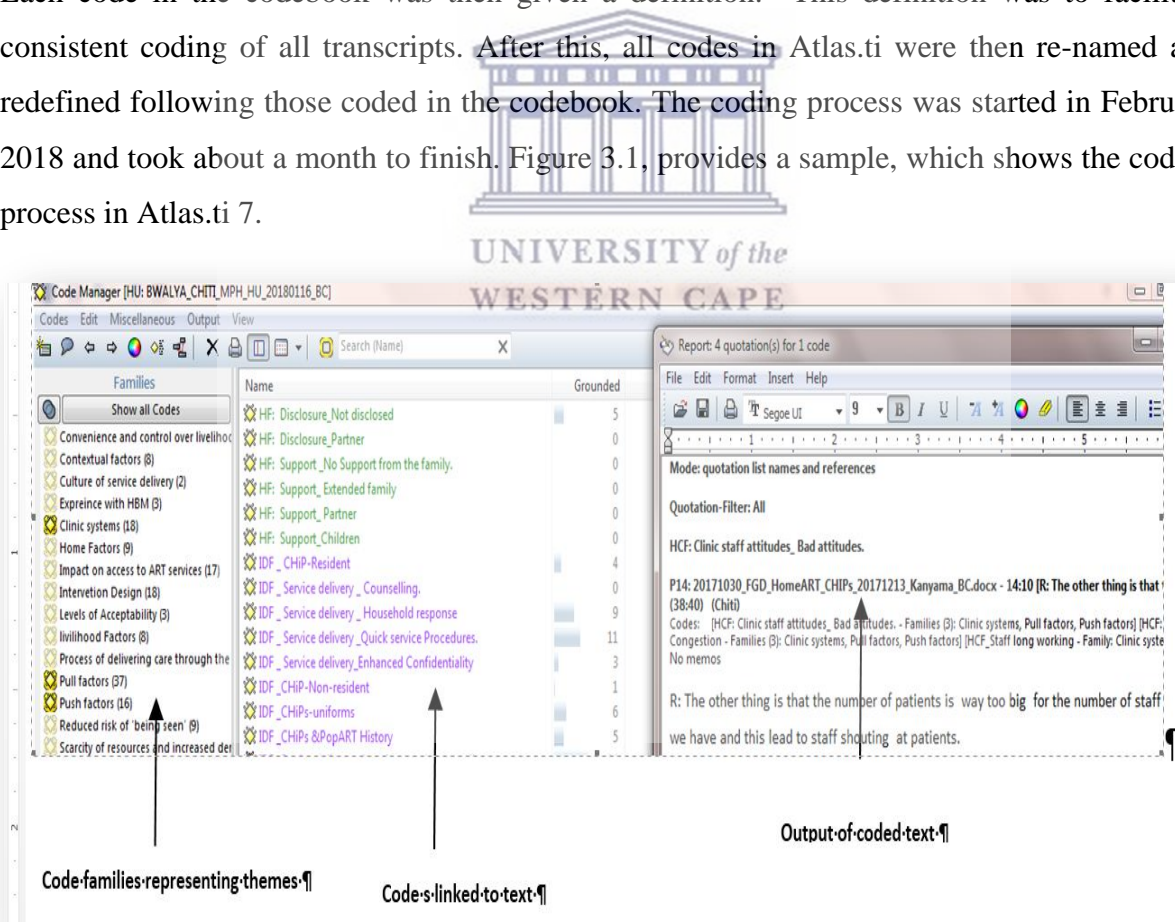


Figure 3.1: Coding process of transcripts using Atlas.ti 7

After the coding process, was completed, all codes with the same label were grouped together in a family, which represents a theme. Using Atlas ti7, code outputs [codes linked to quotations from transcripts and summed up in a theme- see figure 3.2] were created representing recurrent themes related to the factors influencing the acceptability of the HBM were elicited for further explanation and served as basis for further analysis and interpretation (Robson, 2013).

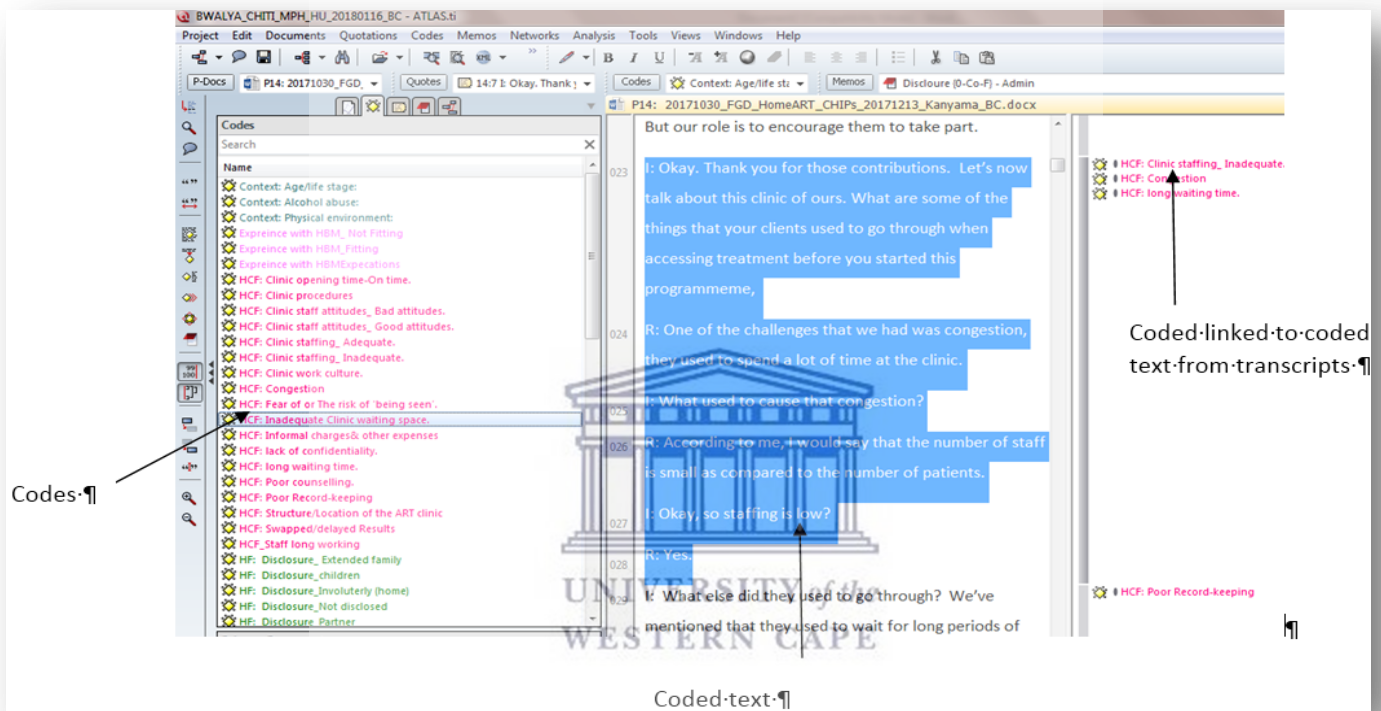


Figure 3.2: Examples of moving from codes to themes

### 3.12 Limitations of the methods

Study participants were interviewed nine months into the intervention with some only being visited once while others were visiting the clinic for the first time hence limiting their experiences with the model. An ideal situation would have been interviewing and observing participants after a longer period to explore experiences. This would have given us much more information on participant’s experiences with the model and how these would have changed over time. The other limitation was the use of Chinyanja local language during the interviews. I am not very fluent with Nyanja although my understanding of the language is good. This was however, not so much of a problem.

Participants understand English and another local language called Bemba which I am fluent in hence I could mix the three languages to make my questions much clearer. In addition, the use of the VAS was a bit problematic for some participants, which may have resulted in them giving us wrong answers. Lastly, some information may have been lost during the translation process. This may have been due to the background noise especially during the FGD, which was conducted when it was raining. I went through the recording and transcripts several times in attempt to have the right words as said by participants.

### **3.13 Rigour**

To enhance study rigour, five strategies were adopted. To achieve dependability, triangulation as a strategy was used and it entails “a validity procedure where researchers search for convergence among multiple and different sources of information” (Creswell & Miller, 2000). The rationale is that different sources of information will increase validity by a corroborating different description of the phenomena under investigation. For this study, I triangulated data sources across methods and participants as data was collected using FGDs with CHIPs, IDIs with PLWH and observations of ART delivery in PLWH’s homes.

Reflexivity was the second strategy. A diary of my thoughts, feelings, ideas and challenges were maintained throughout the research. The reflexive notes were then used during the discussion of the study findings. Thirdly, peer debriefing and support was used. Creswell & Miller (2000) argue that this is where research data is reviewed by an expert in the field. This strategy ensures that ideas and advice from other researchers increases the validity of one’s study. For our study, I worked closely with my supervisor and co-supervisor.

Fourthly, the provision of clear documentation of all research activities and documentation ensured auditability (Creswell & Miller, 2000; Robison 2013). For this study, I also kept records of written field notes, preliminary schedules, verbatim transcriptions and recordings for review by others. Finally, thick descriptions of the study setting, participants, and the themes have also been provided. I have also provided a detailed description of the data collection methods to allow others to assess how transferable the research findings are (Rudolf, Elfriede & Ghauri, 2008).

### **3.14 Ethical Consideration**

The University of the Western Cape’s Biomedical Research Ethics Committee approved this study in November 2016 (see appendix 8). Ethical approval was also sought and granted from University of Zambia Biomedical Research Ethics Committee (see appendix 9).

In addition to this, permission was also sought from the Zambian National Health Research Authority (see appendix 10), the Ministry of Health (MOH) provincial office (see appendix 11) and the Lusaka District Health Offices to enable me to conduct the study in the two communities (see appendix 12). Moreover, permission was sought from Zambart head office to enable me have full access to the required information and records on the HBM intervention.

After ethical approval, to ensure that autonomy and respect for the dignity of persons is observed, voluntary informed consent using information sheet and consent forms (see appendix 1,3,5 and appendix 2,4,6) was sought from all participants. Participants were given explanations of the nature and purpose of the research, expected benefits to the participants and society, and any foreseeable risks of participating in the research. Participants were also informed that they had the right to withdraw from the research at any stage if they felt any emotional discomfort. Moreover, they were not to answer any questions that they found uncomfortable to ensure that no harm either as a direct or indirect consequence of the research was experienced (Wassenaar, 2007). This consenting process was conducted with no difficulties because all our participants have at one time consented through the main PopART study as well as the main community model's intervention. When we requested that they sign the consent forms, all of them did so with no hesitation. During the home visits of clients, the researcher and CHiP worker made sure they were not wearing identifiable uniforms or clothing.

To ensure privacy and confidentiality, interviews and FGDs were held in a neutral location (mostly within the homes for IDIs and at clinic for FGDs) that was chosen by the respondents themselves. Pseudonyms were used in all transcribed transcripts and the data collected was saved on a password-protected computer. Furthermore, the identity of the two communities where the study was implemented has also been protected. The principle of justice will also be observed. To uphold this principle, research findings will be shared with study participants. Mack (2005) has argued that all those who take on the burden of research participation should share the benefits of the knowledge gained.

### **3.15 Summary**

This chapter gave a detailed description of the methodology used in the study. It has described the methods used to identify participants that were observed during the home delivery, those that were interviewed as well as those that participated in the group discussions.

The chapter has also described how ethical principles were taken into consideration during the data collection, management and analysis process and the measures put in place to ensure that the whole process was rigorous enough to paint a true picture of participant's views. The next chapter explains the findings on how acceptable the HBM was and factors influencing this acceptability among PLWH.



## CHAPTER 4 – FINDINGS

### 4.1 Introduction

In this chapter, findings from observations, interviews and group discussions from the two sites are presented. The chapter begins with a description of the socio-demographic profile of participants. Thereafter, it describes the process of delivering care through the HBM and levels of acceptability of the model to both PLWH and CHiPs. It concludes with a presentation of the themes emerging from the analysis of factors influencing acceptability, categorized into “push” and “pull” factors.

### 4.2 Socio-demographic profile of participants

A total of 43 participants (as shown in table 4.1) participated in this study and these were more or less evenly distributed across the two communities studied and by respondent type i.e. PLWH interviewed at the facility, PLWH observed and interviewed at home and service providers who were the CHiPs.

*Table 4.1 Number and characteristics of participants that participated in the study.*

Site	Community 1		Community 2		
	Men	Women	Men	Women	
PLWH interviewed	2	6	3	4	15
PLWH home visited	1	5	2	4	12
CHiPs FGD	4	4	4	4	16
<b>Total</b>	<b>7</b>	<b>15</b>	<b>9</b>	<b>12</b>	<b>43</b>
Grand total per site	<b>22</b>		<b>21</b>		

#### 4.2.1 Socio-demographic profile of PLWH

There was an evenly distributed number of participants from the age groups of 25 years and above (table 4.2). Most participants were married or were living with partners and had been on treatment for more than 5 years.



Table 4.2 Characteristics of PLWH that participated in the study.

Characteristics	Number
	Total N=27
<b>Sex</b>	
Women	19
Men	8
<b>Age</b>	
18 to 24	2
25 to 34	8
35 to 44	6
>=45	11
<b>Marital status</b>	
Married/ living with a partner	11
Single	1
Widowed	6
In a relationship	9
<b>Length on treatment</b>	
<5 years	11
5 to 10 years	9
+10 years	7
<b>Sources of livelihood</b>	
Formal employment	5
Informal employment	20
Not working/dependent	2

In terms of employment and livelihood options, a small number of PLWH were formally employed, they were either working in super markets, commercial farms or security companies as guards. Others worked as mechanics and house cleaners in the nearby high-income residential area. The majority, however, worked in the informal sector running small businesses at markets within and outside the community, with working hours from morning until evening. In addition, some operated small businesses from home selling alcohol, second hand clothes, vegetables and groceries. A few owned houses that were rented out to other families. Two respondents depended on their families for support.

#### 4.2.2 Socio-demographic profile of CHiPs.

All of the CHiPs had previously worked as counsellors for the PopART study, the majority for more than two years. Their previous roles of delivering home-based HIV counselling and testing had resulted in established relationships with households.

Table 4.3: Characteristics of CHiPs that participated in FGDs.

Characteristics	N (total =16)
Sex	
Male	8
Female	8
Length work as CHiPs	
1-2 years	4
3-4 years	7
>4 years	5

#### 4.3 Process of delivering care through the model

The process of delivering home based care was guided by a routine procedure, stipulated in the home delivery standard operating procedures (SOPs) as drawn up in the study protocol (Community ART protocol, 2017:21). According to the SOPs, after registration of clients from the health facility [where the explanation of the program and consenting was done], a date for the first visit is set. Thereafter, the first and subsequent home visits are carried out following a sequence of steps shown in fig 4.4.

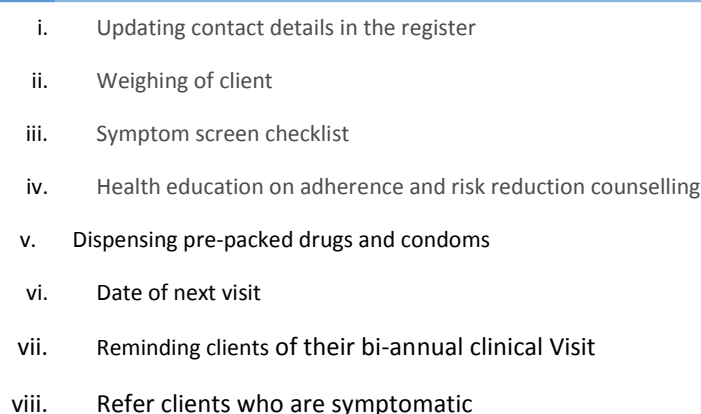
- 
- i. Updating contact details in the register
  - ii. Weighing of client
  - iii. Symptom screen checklist
  - iv. Health education on adherence and risk reduction counselling
  - v. Dispensing pre-packed drugs and condoms
  - vi. Date of next visit
  - vii. Reminding clients of their bi-annual clinical Visit
  - viii. Refer clients who are symptomatic

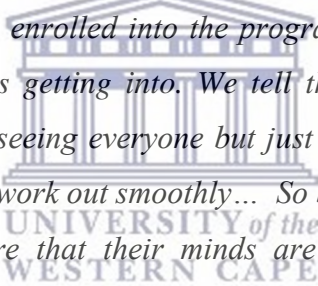
Figure 4.4 SOP on the procedure of delivering care (Source: Community ART protocol)



The SOPs further stipulate that, if a participant is not found at home during the home visit, s/he is supposed to be called or anyone present at home is to be given the message to ask the participant to get to the clinic to collect his or her drugs.

This is then recorded in the register as a missed visit and the pre-packed drugs will be returned to the clinic. However, if a participant is contacted and agrees to a home visit within seven days of the missed visit, CHiPs would then reschedule the visit.

This process of delivering care was for the most part followed by the CHiPs, although not always as exactly as stipulated in the SOPs, depending on the type of client visited and their specific situation. FGDs with CHiPs, observations of delivery and interviews with PLWH revealed that the first stage of delivering care was recruitment, where participants were screened and those considered “stable” were recruited. The next stage was the consenting process where the program was explained to clients, their details updated in the client register, and a detailed explanation of what will be happening during the home visit was provided. As one CHiP explained:



*“... Those people that we enrolled into the programme; we told them what they were themselves getting into. We tell them when we bring your drugs, ‘we won’t be seeing everyone but just you, so you have to be free’ so that things can work out smoothly... So before they enter the programme, we make sure that their minds are prepared” (CHiPs FGD, Community 1).*

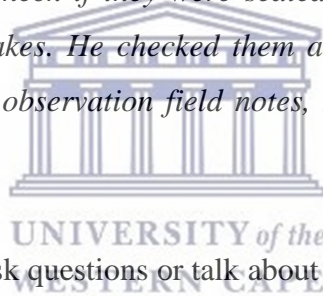
Once a client had agreed and consented, they were notified of the date for the first visit. A few days before this date, the CHiPs would call the clients to remind them of the visit. On the actual day of the appointment, the clients were called again and if the clients were home, CHiPs would schedule the time for the visit before starting off from the clinic. When CHiPs arrived at client’s house, they were at all times warmly received by their clients, who in most instances invited CHiPs to talk to them inside their homes.

*‘When we reached the house after a 15 minutes’ walk,[this was a first visit] we knocked on the door, she came out and to me she seemed like a person who knew the CHiPs personally as her facial expression was set alight. She was happy to receive us and told us to come in’ (Home-delivery observation field notes, 20171201, community 2).*

Once inside the house, CHiPs would greet the clients and engage in small talk to create a relaxed and conducive environment for the visit.

Thereafter, they would start talking about the home delivery of care following a routine set of screening questions, eliciting feedback from the client and imparting information. In certain homes, depending on the situation, CHiPs would cover the topics in the SOPs, but not necessarily follow the stipulated sequence of how the topics should be delivered. However, dispensing of drugs and scheduling of the next visit would always be the last items as observed during one home delivery observation.

*'After the CHiP was done with talking about the client's health and their treatment, they now moved to giving the drugs to the client. The drugs were carried in a special bag with a tag that has the client's name. The CHiPs took out the three bottles, which were given to the client. He was told to check if they were sealed and if they were the correct drugs that he takes. He checked them and he said everything was ok (Home-delivery observation field notes, 20180105, community 2)*



The client was then given time to ask questions or talk about challenges if any, to which the CHiPs provided answers and guidance. Giving enough time and listening were emphasized in the FGDs with CHiPs. As one reflected:

*“So, if I have an appointment, I have enough time to give to my clients to ask all the questions, bearing in mind that I am a counsellor who should have big ears and a small mouth. So, I need to give my clients enough time to talk more. Maybe they have challenges they're facing and they can't ask here at the clinic, but maybe they can ask me as a counsellor visiting them”(CHiPs FGD, community 2)*

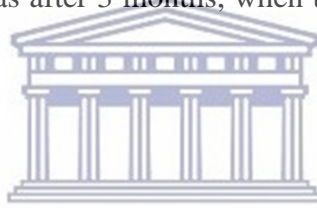
Once all questions and concerns were attended to, the next stage was dispensing drugs to the client. Before any drugs were given out, the client was asked to present the bottles with the old stock of drugs. This was to make sure that the correct drugs were dispensed by comparing the new stock to the labels on the bottle of the old stock. Clients were also asked

to check and make sure that the bottles for the drugs were sealed, as observed in this household.

*‘After the CHiP was done with talking about the client’s health and their treatment, they now moved to giving the drugs to the client. The drugs are carried in a special bag that has the client’s name. The CHiPs then took out the three bottles, which were given to the client. He was then told to check if they were sealed and if they were the correct drugs that he drinks. He checked them and he said everything was ok’ (Home-delivery observation filed notes, 20171021, Community 2).*

After the confirmation, drugs were dispensed. In the last stage of the process clients signed for the drugs as proof that, they had received them. The CHiPs also reminded the clients of the next appointment date which was after 3 months, when the client was required to go to the clinic.

#### 4.4 Levels of acceptability



Acceptability in this study was taken to mean the “degree of fit” between the patient’s expectations and the home-based delivery model of ART, taking into consideration all the circumstances surrounding the patient. Figure 1 represents the numbers of PLWH and CHiPs and their views on how they experienced the model using the VAS.

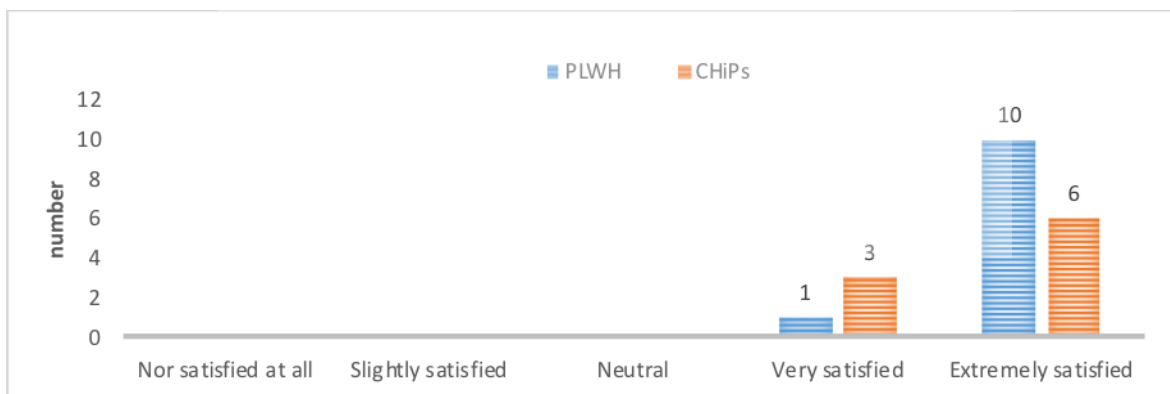


Figure 4.5 levels of acceptability of the HBM to PLWH and CHiPs.

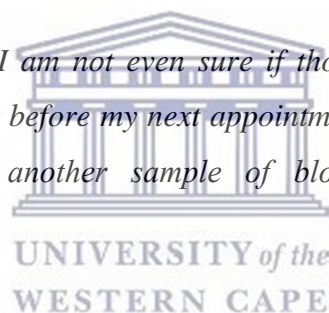
According to figure 1, the majority of PLWH [10/11]<sup>1</sup> gave the model a score of 5 out of 5, indicating that they were extremely satisfied with the way the model had fitted in their lives. This satisfaction is reflected in the following quote from one participant.

*“Well, I am very happy with this programme and everything that happens in it. It has reduced the problems I used to face when I used to go to the clinic, making us stand in queues, leaving the clinic late; it has reduced all of that.” (IDI, woman, community 2).*

One participant rated the model 4 out of 5 indicating that he still faced problems with follow-up procedures at the facility.

*“Because challenges are still there. For example, when I came during the last visit, they took blood samples from me using a wrong file number.*

*You see, meaning that I am not even sure if those results will be mine. It also means that before my next appointment date, I have to come here and give another sample of blood”, (IDI, man, community 2).*



Two thirds of CHIPs [6/9]<sup>2</sup> rated the model as extremely satisfying, because their clients were able to take control of their lives. They would get quick access to their drugs and this enabled them have enough time to get back to work on time and be productive. As one CHiP reflected:

*“Clients are able to plan for their day compared to the clinic visits they used to have; it used to kill the whole day, hence killing their business. But for today, they are able to say ok, in an hours’ time, I will get my drugs and go back to my business” (CHiP, FGD, community 1).*

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<sup>1</sup> During in-depth interviews WITH PLWH, four participants did not grade the model because the interviews ended before they could be asked this question.

<sup>2</sup> In the FGDs, not every participant [9 out of the 16] contributed to the discussion, when asked how they and their clients experienced the model.

In contrast to the ratings by the clients themselves, one third of the CHiPs [3/9] rated their satisfaction as ‘very’ rather than ‘extremely’ satisfied, citing a number of challenges they faced when delivering care. These included clients giving them wrong phone numbers and addresses while others did not answer their phones when called. In addition, some clients wanted CHiPs to visit them with no uniforms, as they feared that their status would involuntarily be disclosed. Furthermore, at the clinic, pharmacists did not pre-pack the drugs on time especially when CHiPs had early deliveries.

#### 4.5 Factors influencing acceptability

Acceptability of the model was influenced by two categories of factors, labelled as ‘push’ and ‘pull’ factors. On one hand, push factors propelled PLWH into accepting the model and these included all the negative experiences that PLWH had with accessing ART services at the clinic. On the other hand, pull factors drew PLWH towards accepting the model and these included all the positive experiences with accessing ART through the model. This section of the report now presents these two categories.

##### 4.5.1 Push factors

The ART clinic system at inception was a symbol of efficiency especially when it was serving few patients in 2005. The Ministry of Health, together with help from its implementing partners, started offering free ART in government clinics. As the numbers of PLWH accessing ART started increased, the ART clinic system began to be congested, resulting in many challenges for patients.

Data collected from participants and through Observations of delivery revealed the following health service factors that pushed participants into accepting the HBM.

*Table 4.6 Push factors influencing acceptability.*

Main theme	Sub theme
Scarcity of resources coupled with increased demand	High patient load
	Inadequate staffing leading to staff burnout
	Inadequate space
Clinic systems	Disorganized record keeping
Work culture	Staff poor work ethic
	Informal payment system
Impact on experiences of accessing ART services.	Long waiting time
	Livelihood opportunity costs

#### **4.5.2 Scarcity of resources and increased demand**

This theme describes how a lack of resources at the facility and increased demand for ART services resulted in supply and demand challenges. Participants mentioned that the two clinics lacked human, material and financial resources necessary to satisfy demand for ART services. The two clinics were also said to be providing ART services to more clients than they were built for, and the space was completely inadequate. High patient load was therefore central to the problems that the facility faced which in turn negatively affected PLWH's experiences.

Congestion at the clinic was observed to be particularly prominent at the start of the day as the clinic opened. For all PLWH interviewed and those observed, overcrowding of the ART clinic was the major reason why they decided to accept the HBM. As one male participant reflected: *'The issue of having too many people at the clinic was a real problem that made the waiting worse.'* *'Congestion is a real and big problem at the clinic'*, added another female participant.

CHiPs also mentioned overcrowding at the clinic was the main reason that made people accept the home delivery of ART.

The waiting area was said to be very small, with only a few benches that could not accommodate all clients and most had to stand for a very long time while they waited to be attended to. The clinic in Community 1 had a shaded outdoor waiting area. However, this waiting area was very small, leaving most patients to stand in the sun:

*"There were a lot of us, we used to fill up almost all the rooms, and some were outside. You could get to the clinic at 07:00hrs but you would find that all the benches have been filled with people and so you're forced to stand, sometimes until 12:00hrs, that you even feel your heart starts to hurt."* (IDI, woman, Community 1)

It is this standing for a long time that especially made participants dislike their clinical appointment days. Moreover, the location of these waiting areas was a problem for some patients because they feared being seen by others while they were waiting at the separate ART clinic building.

*"I don't know whether I can say its stigma or not, they mention the location of the clinic. They say it is not fair that they are separated from the rest of the*



*clinic... I have 2 clients, for them they even said they have even stopped coming to the clinic. 'When going to get my drugs, the location of clinic makes everyone to see you immediately you enter and they will know that you have gone to get ARVs'. One is a commissioner in a big church so he feels shy coming to get drugs as his church members may see him. For him the best thing is integrating the clinic so that they get drugs with the rest of the people with other diseases". (FGD, CHiPs, community 1)*

CHiPs felt that this type of stigma for some patients was still a challenge. For others, being attended to by a staff member they know, or who comes from the same area as them, was a challenge. They would worry about such clinic staff knowing their HIV status and then gossiping about them.

*"Even before they reach the facility, they are already demoralising themselves. Telling themselves all sorts of things, 'how will people look at me, how will the clinicians look at me, all that'. For such people, they will even start off to come to the clinic but for them to just access treatment or stay on treatment, it's a big challenge because they have self-stigma." (FGD, CHiPs Community 2)*

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The majority of respondents felt the clinic had inadequate staff to cater for their service needs. In the past, a number of paid volunteers, such as support group members and peer educators, were on hand to supplement the facility staff. However, after a cut in funding, there has been a reduction in their numbers. Inadequate staffing together with the problem of heavy patient loads caused staff to become stressed.

*"They [clinic health care workers] work more than they are supposed to because there are a lot of clients", (CHiPs, FGD, and community 1).*

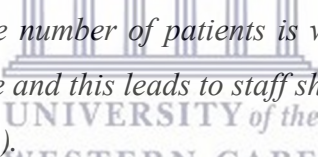
*"For me I think the problem was they [clinic staff] used to get tired, maybe they've work too much and they become stressed". (IDI, woman, Community 1)*

Staff stress and burnout were seen as the main cause of tension between staff and clients and the mistreatment clients were subjected to by clinic staff, including some lay counsellors. Being shouted at and the use of stigmatizing language was a commonly reported experience by the PLWHs as reported by CHiPs;

*“Others felt as if they were not treated with dignity and respect, which caused them to get frustrated. If someone calls you name and you do not respond, you will be shouted at, ‘eh, ‘we are calling you and you are not answering, did you not hear your name being called’. So, those clients started feeling frustrated. So when we came in [referring to CHiPs and the Model], they started saying that this was easy” (CHiPs, FGD, community 1).*

Many of the participants believed that most of the staff that worked at the facility were good and that the stressful work environment had turned them into rude people that shouted at their patients.

*“The other thing is that the number of patients is way too big for the number of staff that we have and this leads to staff shouting at patients” (CHiPs, FGD, community 1).*

The logo of the University of the Western Cape, featuring a classical building facade with columns and a pediment, with the text 'UNIVERSITY of the WESTERN CAPE' below it.

Staff burnout due to heavy patient loads compromised service delivery. CHiPs indicated that staff at the clinic did not have time to provide comprehensive counselling, as they wanted to attend to as many people as possible and finish off the long queues on time. ‘When you reach the counselling room, it’s always ‘next’ and the patient moves on to the next room after just a few minutes’ as one CHiP recounted. This resulted in patients not being given sufficient time to ask as many questions as they would want to. Even when it came to adherence counselling, patients were only asked one or two questions concerning their drugs.

#### **4.5.3 Clinic systems**

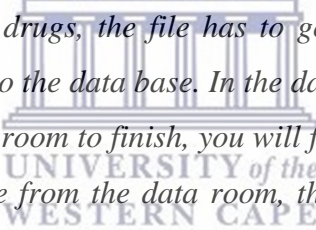
Observations, IDIs and FGDs with participants around service delivery revealed that contributing to their negative experiences when at the facility was a disorganized record keeping system that was unable to cope with the patient loads. What determined the time



when a client would be seen was the time his or her file was retrieved from the filing room. This then meant that at times, some PLWH would then be attended to very late in the afternoon despite being at the clinic very early. As this one participant reflected:

*“I used to start off from home at around 06:45, so that on the queue, my card can be on number one or so. Although, even when you are early and your card is number one, they will only pull the files they will find and those that are not found are pulled later and in most cases very late. So, if they don’t find your file even when you are number one, your file won’t be retrieved”. (IDI, woman, community 2)*

The problem of filing clerks taking long to find patient’s files and in some instances patient files going missing was a very common experience for participants. The cumbersome process of managing and capturing data from these patient files contributed to files being lost. As one CHiP narrated:



*“When someone collects the drugs, the file has to go to data so that the information can be entered into the data base. In the data room you will find heaps of files. So, for the data room to finish, you will find that it takes some time. And when the files come from the data room, they have to be sorted out so that this file goes to the big container, or the small container, So, you will find that there are too many... even the filing clerks will not even know where to start from when looking for that file for that particular client”*  
(CHiPs FGD, Community 2)

Apart from the long data capturing process, CHiPs reported that some filing clerks also made mistakes and misfiled patient’s files. PLWH indicated that when in such situations they were powerless and could only hope that their file would be found on time. As two women reflected:

*“Well, when going to get drugs, it used to be very bad. Every time when you reach the clinic, you find that your file has been lost. Sometimes, you can be there from morning, sometimes I used to leave the clinic around 16:00hrs. There is no file while you are just seated in a queue waiting and hoping to*

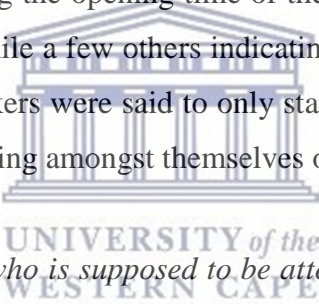
*be called. When you ask the staff, all they would tell you is to just sit and wait [participant sounding angry]” (IDI, Woman, Community 1)*

Once a patient file is not found, a temporary file was issued to the patient. However, this only happened later in the day when a patient had waited and was tired. After this, the patient could then access ART.

#### **4.5.4 Poor Work culture**

For many of the participants, challenges experienced at the health facility also emanated from how staff worked and behaved. Two major factors were pointed out as those that reflected the work culture at the ART facility: a negative staff work ethic and the practice of informal payments.

There were mixed views concerning the opening time of the clinic with many participants saying the clinic opened on time while a few others indicating it opened late. Nevertheless, when the clinic opened, health workers were said to only start work after attending to their personal needs like having tea, chatting amongst themselves or being on the phone.



*“You will find that the nurse who is supposed to be attending to you is on the phone while you are on the queue waiting.... This was a problem” (IDI, man, community 2)*

For PLWH, this was seen as especially insensitive as they may have arrived at the clinic as early as 05:30am. Even if participants arrived early and were the first ones in the queue, this did not mean that they would be the first ones to be seen.

*“When you get to the clinic and you give them the treatment cards... they [clinic staff] won't follow the queue and the order in which the cards were given to them. So even if you are number one on the queue, you may even be the person that gets the drugs last just when they are about to knock off” (IDI, woman, community 1)*

In order for patients to avoid long queues and receive drugs more quickly, an informal trade between patients and clinic staff, especially lay counsellors was established. Participants mentioned that for them to skip the queue and be attended to faster, they could pay staff from 10 kwachas (\$1) to 50 kwachas (\$10), with the amount to be paid at times being dependent on the economic status of the client. Once this was done, the staff would then find means for a patient to be attended to in the quickest manner possible. This trade also reportedly happened in other ways. For example, patients would get phone numbers of someone who works at the ART facility and when the time came for their refill, they would call in advance and within a short period receive their drugs.

*“For others, you just get a number for someone who works at the clinic and when the appointment date comes, before you start off to the clinic, you just call them, ‘my friend I am coming to the clinic’. Immediately you reach the clinic, they will just get your card and within an hour they will give you your drugs. You then leave him with a 30 kwacha or a 50 kwacha. So for those that don’t have money, they will stay at the clinic the whole day, even if they came at 08:00hrs, they will only leave after 16:00hrs” (CHiPs FGD, community 1).*



Another method was for clients to leave their patient cards with lay counsellors at the facility and the lay counsellors would then be paid to home deliver their drugs when their stocks of drugs ran out. One CHiP narrated how difficult it was for him to see some of his patient’s ART cards whenever he requested them during the home visits, until one of his patients revealed to him where their cards were and who had them. Another CHiP told the story of one of his patients who was happy with the free home delivery of ART by CHiPs through the HBM, as he no longer had to meet lay counsellors from the clinic somewhere in the community to pick up and pay for his drugs.

This informal trade was perceived to add to the waiting times for those patients that did not have money to pay the staff. Those that paid could come late and be seen before those that came early. This informal and hidden arrangement was considered to have become part of the organizational routines of the clinic.

*“If you wanted to be attended to quickly, just pay a K50. In addition, it has actually become a routine, because for those that pay, they will spend at*

*least an hour and then leave. But for those who don't, they are likely to spend the whole day there" (CHiPs FGD, community 2).*

This created tension between staff and clients who came on time and could not bribe clinic staff.

*"We don't know why they were shouting at us ... when we just ask them that we came a long time ago because they used to first want to attend to people that they know and jump us the people on the queue, the people that came early" (IDI, woman, community 1)*

CHiPs felt strongly that the only way to put an end to this trade was by increasing the number of staff at the facility as this would improve service delivery and enable people to access ART on time.

#### **4.5.5 Impact on access to ART services**

This theme describes the how the scarcity of resources leading to inadequate staffing and clinic space together with increased demand for ART services and a disorganized record keeping affected how PLWH experienced accessing ART from the two clinics. As already described, these factors resulted in very long waiting times, leading to denial of care in some instances as well as significant livelihood opportunity costs.

In the process of waiting, some clients indicated they would become tired and give up and go back home without accessing treatment. Others would leave because they had not eaten since leaving their homes early in the morning. One client narrated how difficult it was for her when hungry and the person seated next her was eating and she did not have any money to get herself some food. *'You don't even have a 1 ngwee to go outside and get yourself a snack, it was never good'*, she explained.

Long waiting times created many challenges for people that worked or ran businesses, as they had to choose between accessing health care and getting to their work. One male participant who worked as a security guard mentioned that it was very difficult for him to get time off from work to spend the whole day at the clinic. Another male participant recounted how he was almost fired by his employer who told him that by doing so, this would *"help him [the patient] with all the time he needed for his clinic visits"*. A third was

afraid that if he kept on asking for more leave days to enable him get to the clinic, he would get fired:

*“I was always asking for days off at the office and at times the clinic used to give me drugs for one month hence this meant that I had to keep on asking for more off days to come back to the clinic for my drugs. I feared they would fire me because of this”. (IDI, Man, community 1)*

For those in the informal sector, being at the clinic the whole day meant them losing income for that day. For others, being at the clinic all day meant that their lives came to a standstill, as they could not do anything else at home until they came back from the clinic. One participant narrated how her house was broken into by thieves when she was at the clinic while another mentioned how difficult it was to take her children to school in the morning and then find time to take them lunch especially on days she was supposed to be at the clinic.

#### 4.6. Pull Factors

Participants described their experiences with the home delivery model as the opposite of that of the clinic. Data collected from participants revealed a number pull factors ( see table 4.7) that came with the model and made their experience different and as such positively influenced acceptability. These factors are categorized into three key themes:



Table 4.7 Pull factors influencing acceptability.

Theme	Sub theme
Convenience	Reliable appointment system
	No livelihood opportunity costs.
Culture of delivery	New HIV initiative delivered by known and trusted counsellors.
	Personalized and comprehensive counselling.
Reduced experiences of stigma	Reduced risk of being seen.
	Disclosure cardinal for family support.
Impact on access of ART	No waiting time.
	Improved confidentiality and trust.
	Reduced contact with and preferential treatment at the clinic.

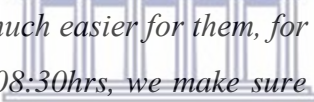
#### 4.6.1 Convenience and control over livelihood activities

The overriding advantage of HBM was its convenience and the control patients were able to retain over their livelihood activities.

The model made it possible for them not have to choose between the clinic and going to work. Drugs were also delivered at prearranged times through an appointment system, enabling PLWH to plan their work or business activities around this.

As indicated in earlier sections, the majority of the clients worked in the informal sector, with some individuals formally employed. Livelihood activities for some PLWH demanded that they leave home early in the morning and come back late in the day.

To ensure that there was no disruption in their clients' work, CHIPs always made sure that they contacted them before delivery and delivered drugs at an agreed and convenient time, leaving the client enough time to get to back to work. For those that were formally employed, CHIPs indicated they also tried to get to the community early in the morning (around 07:00) so that they could see their clients early enough and leave them enough time to get to work.



*“Those who go for work it’s much easier for them, for example, if someone is supposed to be at work at 08:30hrs, we make sure that we are there at 07:30hrs, we communicate with them, deliver the drugs so that they can leave for work after we are done” (CHIPs FGD, community 1).*

This practice, however, was constrained by delays by the facility pharmacists, who never pre-packed the drugs that were to be delivered to clients. For those in the informal sector, an appointment was made and at times, they would be followed up to their place of work such at the shop, the market or those selling on the street (see for example, Figure 4.8).





Fig: 4.8 Client trading from a makeshift stand by the roadside:

The practice of CHiPs making and re-confirming appointments with clients allowed them the mobility they required to continue livelihood activities. CHiPs said that once appointments were made, clients waited for them and only left when the CHiPs were done with the deliveries. CHiPs also mentioned that at times, it was the clients themselves that called them just to confirm the dates and time for the delivery so as to make sure that on that day, they were available. This confirmation was mostly done when a client had an appointment somewhere and wanted to make sure that CHiPs came right on time before the client left his or her house for the appointment or work.

*“For me, I have the phone number for Mr. E (a CHiP) and if I have any thought of leaving the house, I always have to call him. He also has my number and he calls whenever he wants to come and tell me that I am coming and I should find you, please don’t go anywhere” (IDI, Man, community 2)*

These strategies, scheduling appointments and being on time were key to protecting the livelihoods of clients.

*“Sometimes others appreciate us very much, when you deliver drugs. Say maybe you reach their home at 9:00 and they had promised their boss that*



*they will be at work by 10.00, a lot are managing to be on time, they always say they manage” (CHiPs FGD, community 2)*

#### **4.6.2 Culture of service delivery**

The theme addresses the way the model was delivered at household level. It describes how CHiPs and their established relationships resulting from their prior work within the households enabled them to deliver a novel model. In addition, the manner in which the service was delivered was described as personalized and comprehensive.

##### **4.6.2.1 New HIV initiative delivered by trusted counsellors**

The PopART study intervention and its implementation started in 2013 and by the time of data collection for this research in December 2017, CHiPs had been active for 5 years in the two study communities. Their prior work had involved door-to-door delivery of HIV services, which included HIV counselling and testing.

Working and making repeated visits to the same household meant that CHiPs were known, had built relationships and were trusted by the household members.

*“They are welcoming, because we’ve been with them and we have created that rapport from the beginning. So, they know us” (CHiPs FGD, community 2)*

*When asked how the program [HBM] was so far and why she had enrolled, the client said she did so because she knew the CHiPs, and from the interactions, I could tell that they knew each other. In addition, I noted that there was a history of visits between the clients and the CHiPs. (Home-delivery observation field notes, 20171020 Community 1).*

In all the observed homes visits by CHiPs, clients seemed very happy with the visit, greeting us with smiles. For those that were busy with household chores or had visitors, we observed them stopping everything they were doing to give the CHiPs all the attention they needed.

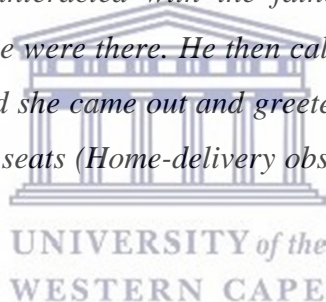
*When we arrived, the client was busy with some visitors that had come to see her, but when she saw us, she came out of the house so that she could attend*

*to us. She was happy to see us and she even brought two chairs for us to sit on (Home delivery field notes, 20170922, community 1).*

*We arrived at the household around 09.30.... What I saw was a very good relationship between the client and the CHiPs as they appeared to know each other... What I also saw was the fact that because the client knew the CHiP, she trusted her (Home delivery field notes, 20171123, Community 2).*

This relationship was not only between the CHiPs and their HBM clients, but also with the entire household. When CHiPs arrived at their client's households, they first talked to other household members and then they would ask about where their client was and then see the client alone from inside the house or other private space. In their discussions with other household members, respectful and friendly relationships were observed.

*When we arrived, we first interacted with the father who we felt was expecting us and knew why we were there. He then called the daughter, the client we had gone to see, and she came out and greeted us. She ushered us into the house and offered us seats (Home-delivery observations field notes, 20171020, community 1).*



*We arrived at the house around 09:00 and when we entered the gate, we found 3 women who were washing and these were the client's sisters and aunts. They seemed happy to receive us and they jokingly started having a conversation with the CHIP I was with. The CHIP then asked about the client and we were then told that he was inside the house waiting for us. (Home-delivery observation field notes, 20170922 communities 2)*

These types of interactions with other family members, however, were only possible if the client had disclosed and explained the purpose of the home visits.

#### **4.6.2.2 Personalized and comprehensive counselling**

The counselling offered by CHiPs was said to be personalized and comprehensive. When asked about their view on the quality of counselling, most PLWH echoed the observations. Compared to

the clinic, PLWH said CHiPs provided enough time for them to ask all questions and would answer clients back politely and nicely. Participants [PLWH) said this allowed them to be free with them and ask about anything. As one participant reflected;

*“They are very open, when they come; you are free to tell them any problem you are facing. We have made them to be more like family members. They are friendly too much, even when she comes with a new partner, they are good too.” (IDI, Woman, community 1)*

Compared to the facility staff, many PLWH indicated that the CHiPs treated them with dignity and respect, and never shouted at them: *“We work together, their attitude towards us is also good; they talk to us nicely and they teach so many things”* one woman said. *“When he comes home, he is a person who shows us happiness, He is a person that brings happiness”*, added another male participant. It was observed during the deliveries that most clients were free and not scared of the CHiPs. No tension was observed between the CHiPs and their clients. The impressions gained during the observations were that the clients were happy with the quality of service provided.

*I noticed that the counselling was done very well... The client was given enough time to digest and was also asked if she there was anything that was been discussed that she did not understand. She was also asked to ask if she had any questions. (Home-delivery observations field notes, 20171003, community 2)*

This counselling was not just about adherence to ART but included other areas of treatment. CHiPs did not only focus on ART adherence but included talks on reproductive health, family planning, education on TB (as well symptomatic TB screening), nutrition and referral of clients to the clinic if they had any health problem that required referral. CHiPs also took time to teach clients on things they did not know or had forgotten about. For instance, in one household, the client was asked if she knew how to use a condom and she said “No”. CHiPs then took their time explaining and demonstrating how a condom is used. This kind of counselling in a tension free environment created by CHiPs which was also away from the clinic was appreciated by many PLWH.

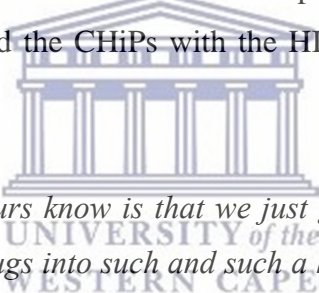
#### **4. 6.3 Reduced experiences of stigma**

This theme describes the experiences of PLWH with the model, and how its design and the way the CHiPs conducted the home visits reduced experiences of stigma. However, disclosure of HIV status was cardinal for family support and significantly mediated the experiences of stigma.

#### ***4.6.3.1 Reduced risk of ‘being seen’***

The HBM was said to reduce the stigma previously experienced at the clinic. Accessing ART from dedicated local clinic was interwoven with fears about ‘being seen’ and being recognised as a person who has HIV. This ‘fear of being seen’ by family, friends, neighbours and community members, and thereby “feeling shy to access ART” at the local health facility was commonly raised by CHiPs and some PLWH.

Establishing the HBM on the back of a door-to-door HIV testing programme and using the same people (CHiPs) was mentioned by the majority of PLWH as one major factor that minimised stigma during the home visits. This was especially so for those that had not yet disclosed their status to either their family or neighbours. The existence of the prior programme helped veil the delivery of ARVs as everyone identified the CHiPs with the HIV testing programme and not with the ART delivery programme.



*“The only thing that neighbours know is that we just go there to test, they don’t know that we deliver drugs into such and such a home. When they just see us, they just think, ‘oh, these are the people that just test’, such that they even call you so that you can test them too.” (CHiPs FGD, community 1).*

*‘My neighbours do not know the reason why they visit me but what they do know is that they move door to door in each and every household checking on people.’ (IDI, woman, community 2).*

Despite the home delivery reducing the ‘risks of being seen’, some clients still feared involuntary disclosure of their status hence they sometimes asked CHiPs to either call before coming home or visit the client with no uniforms or to be met away from home. As one CHiP reflected;

*“To be honest with you, some people are not 100% comfortable. Why I am saying so is that, there are some people that still have fear such that*

*immediately they see you, then it means people will know that a person who deals with HIV has come. I think that's why we have some people that would love to be met from the roadside so that you can give them the drugs.*

*Some don't want to see you in a t-shirt [PopART uniform] when you visit their home. For example, from our area, there was a time we needed to see this family, they were not comfortable with the t-shirts, so we had to change and go in with our civilian t-shirts", (CHiPs FGD, Community 1).*

According to the CHiPs, those clients that had disclosed their status did not mind other people seeing them receiving ART. However, during the home delivery observations, all apart from one received their drugs from inside the house and this suggested some fear of being seen. When CHiPs were asked about this, however, they indicated it was more an indicator of the respectful nature of their relationship.

#### **4.6.3.2 Disclosure and family support**

Close social relationships within a household were found to be cardinal for the acceptance of the model and helped clients to overcome stigma, especially the fear of being seen and involuntary disclosure.

When clients disclosed to their family the reasons why they were being visited, they received a lot of support from their family members and were free to receive the CHiPs.

*"When a client has disclosed, it's easy for us to see him, it's easy for such a client to see us from anywhere in the house and they don't fear other family members knowing about the status. They also receive support" (CHiPs, FGD, and community1).*

Both IDIs with PLWH and FGDs with CHiPs revealed that disclosure of HIV status within homes was very common, although disclosure networks tended to be limited to partners, elderly children, siblings and biological parents. Additionally, disclosure patterns also differed across age groups, with younger men and women having more challenges disclosing. In some homes, disclosure was also limited to the spouse and not the children. One CHiP narrated how a child was chased from inside the home during a home visit. Participants did not disclose to their children because of young age, and fear of them thinking their parents would die soon if they were to know.

Interviews with PLWH revealed that disclosure networks remained limited to immediate household members and did not extend to neighbours and other surrounding households. Participants said they did not disclose to their neighbours, as they feared “being gossiped” about.

Disclosure facilitated freedom of communication. Even when the client was not home, it made it possible for the CHiPs to leave a message so that clients could be told to come to the clinic for the drugs or have the visit rescheduled. In other instances, when CHiPs visited homes and did not find the client, their relatives, be it their wives or children, would ask them to leave the drugs. However, the drugs were never left and the CHiPs insisted on seeing the client.

*“Last week I had a delivery, the client, the father was not home yet but he told us when we called, he said he was home. When we reached home, we asked the children where their father was and the child responded saying ‘he is not home but we were told the reason why you have come, you can give us the drugs’ that was the child talking, you can give us the drugs”*  
(CHiPs FGD, Community 2)

After disclosing, PLWH said they received support from their families; *“they have been encouraging me saying, since you have started, there is no stopping”*, said one woman. *“When my husband finds me asleep, he wakes me up to ask whether I’ve taken my medicine or if I’m not feeling well, they he would my medicine for me to take ”*, added another participant. CHiPs echoed this;

*“Like in my zone, one of my clients is being supported by his mother. He is a drunkard but every time he is supposed to take his drugs, the mother takes the drugs to him and reminds him that he is supposed to take them.”* (CHiPs FGD, Community 1)

Accessing ART through the HBM was challenging for those that did not disclose to anyone. Such clients had to find ways of avoiding involuntary disclosure and by doing so; they made the home visits challenging to conduct. One pair of CHiPs narrated how a woman refused to see them from inside the house because she had visitors. In addition, when she was given drugs, she hid them in a plastic. Others were worried about their family finding out about their status because of the home visits. They asked CHiPs to always call

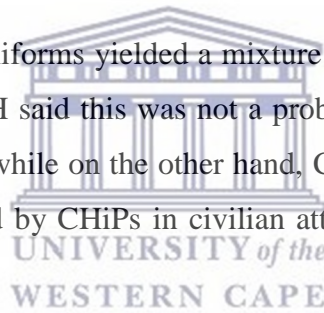


before the visit so that drugs were brought when no one was around at home apart from the client.

Others wanted CHiPs to lie about their visits and say they came to conduct an HIV test. As one CHiP narrated:

*“When you reach home and they don’t want their partners to know that you’ve brought drugs, you will just see them call you on the side and say, ‘oh Auntie, please come and test for me the child you did not manage to test last time’. This was done so that the partner would only think that we were there to just test the child when in fact we delivered drugs. When we ask them why they have not disclosed to their husbands, they say they don’t want their husbands to know. Ok, ‘what about the way we now bring you drugs, won’t he find out?’ ‘no, that’s why I call you so that you can come when he is not around’ (CHiPs FGD, Community 1).*

Discussions around CHiPs wearing uniforms yielded a mixture of responses from PLWH and CHiPs. On the one hand, some PLWH said this was not a problem as they were comfortable with the visits by CHiPs in uniforms while on the other hand, CHiPs mentioned that they had some clients that wanted to be visited by CHiPs in civilian attire to avert any suspicion. As one CHiP reflected;



*“So, we have a delivery for her next month and she told us [the client] when you come home, you should not put on your uniforms” (CHiPs FGD, Community 2)*

Some clients requested to be met from somewhere in the community and not in their homes. Others indicated they were afraid of the main Pop ART intervention coming to end as this meant an end for door-to-door HIV testing, hence making the door-to-door delivery of ART much more visible.

The social context, especially the way housing units in the communities have been built, was another factor that influenced acceptability. Many of our participants [HBM Clients] lived in houses that were open with no fences or hedges and if people were around, they could easily see who ever visited. Others lived in homes that were walled in but within the yards were other houses, hence making them more visible and easier for people to see who has come to



visit. Participants were specifically asked if others have come to know about their HIV status because of the repeated visits. Many of them said no. However, there was one case of social harms that was reported by CHiPs, where a client who did not wish to disclose her status to her family ended up having her status disclosed because of the home visits. When the family members came to know about it, they started stigmatizing her. As one CHiP narrated:

*“Not everyone else in the household knew that she was on medication until we started delivering drugs. When we delivered the drugs, that is when people started suspecting and then they started stigmatising that person. So, for her, it become more like a challenge and she started thinking that, ‘if I did not enrol into this programme, it would have been my secret but the fact that I enrolled into the programme, it’s more like I disclosed my status to my family members” (CHiPs FGD, Community 1).*

#### **4.6.4 Impact on access of ART**

This theme describes how by its design and the way the model was implemented together with the history of work by CHiPs impacted on access to ART. As already described, these resulting experiences included faster and quick access to ARVs, trusted and confidential service and reduced contact with clinic.

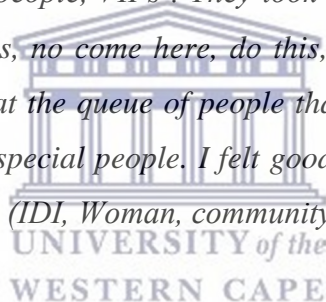
One of the major complaints that came with accessing ART from the clinic was long waiting time. Observations of delivery showed that the HBM did not keep PLWH waiting for a very long time. On average, it took CHiPs about 30 minutes to finish everything especially if the client did not have any health problems. As CHiPs and one woman reflected on their experience with model;

*“Then sometimes I think it depends on the client. You will find your client waiting for you and they will tell you, I just wanted to get my drugs and rush off to somewhere. Then you as a counsellor will start begging for some more time asking. ‘I will just ask you to quickly write here, answer a few questions, do you have a fever, headache etc., so, it depends on the client. But like my friends have said, it takes on average 30 minutes”. (CHiPs, FGD, community1).*

*“Not like it was when I come here [at the clinic], I would be standing on a queue wasting a lot of time when I have a lot of things to do at home. However, with this program, they come and within a short time, they will counsel me, talk to me about when to take my drugs and within a short time, they give me my drugs and they go. I then remain at home with a lot of time to do other things, may be go for work. This program gives me freedom” (IDI, woman, community 2)*

During the clinic visits, HBM clients had their clinic files kept separately from the rest of the patients and when they visited the clinic, they were fast tracked as one woman reflected.

*“Last time at the clinic, I felt very good. We were treated like were staff, very important people. I was laughing with the people I was with as we were getting drugs in groups of fours. ‘We look like we are military; we are special people, VIPs’. They took us from one point to the other, pulled our files, no come here, do this, I said to myself ha, this is good. We looked at the queue of people that were on it waiting and thought us we were special people. I felt good and hoped that this program should not end” (IDI, Woman, community 1)*



This meant that even when they [HBM clients] were at the facility for their clinic visits and re-fills, there was no waiting time. The delivery of ART through the model was considered confidential and CHiPs were considered trustworthy and as upholding confidentiality. Delivering drugs in-doors facilitated confidentiality. In addition, no one in the community apart from the client was thought to know that CHiPs brought ARVs. *“Confidentiality is what they like as drugs are delivered in their homes in secrecy and no one can suspect anything”*, one CHiP said. Participants also liked the way in which the CHiPs conducted the visits, as this did not breach confidentiality. CHiPs made sure that when talking to clients, no one was around to listen to the conversation.

*“When they come and they find you with other people, they will not just start talking about HIV, no. They will wait until you invite them inside the house and that’s when they will start talking” (IDI, woman, community 1)*

When CHiPs visited households where clients did not disclose their status, they always would do whatever it took to avoid involuntary disclosure. For instance, at one household, it was observed that they lied that they came to test a child they missed in the last visit and because of this; no one suspected that they had brought ARVs for the client. This is reflected in the field notes below;

*When we arrived, we found the client seated outside with her neighbours, her daughter and her grandchildren, one of the CHiPs came up with a strategy to separate the client from the neighbours, and she informed the client that she needed to test the children for HIV. She could not tell the client that they were there to deliver the drugs as the client had not disclosed. (CHiPs home delivery observation field notes, community 2,).*

Once they had the client in a confidential space, then they would start talking about the home delivery of ART. The model also reduced frequent clinic visits, which resulted in reduced costs especially for those clients that lived very far and had to pay a bus fare to get to the clinic. Coming to the clinic frequently also attracted other expenses such as buying snacks while waiting and at times paying health staff to access drugs. In addition, through the model, participants said there were given drugs for 3 months and this meant that they only had to visit the clinic twice a year.

#### **4.6.5. Summary**

In summary, the HBM was highly acceptable among PLWH. This acceptability was influenced by a combination of crosscutting clinic based; program design and social-economic factors that have been categorized into push and pull factors. Push factors were those challenges especially at the clinic that made access to ART services challenging. Pull factors on the other hand was the HBM which for PLWH was alternative that allowed them to avoid the many clinic challenges as it made access to ART easier. PLHW described services offered through the model as convenient, confidential, trusted, personalized, less stigmatizing, comprehensive, client centred, responsive, and respectful. Disclosure of client's HIV status within a home was found to be cardinal for the acceptability of the model as those that disclosed faced minimal problems with stigma while those that did not disclose had difficulties with home visits.

## CHAPTER 5 – DISCUSSION

### 5.1 Introduction

The study explored levels of, and the influences on, acceptability of the HBM among PLWH in Lusaka district. Acceptability in this study was defined as the “degree of fit” between the patient’s expectations and the HBM, taking into consideration all the circumstances surrounding PLWH. In order to fully understand acceptability and factors influencing it, clinic based, intervention design, and social-economic contextual factors were explored. The study found that HBM was a good fit with the lives and expectations of PLWH and therefore highly acceptable to them. This acceptability was influenced by a combination of crosscutting clinic based; program design and socio-economic factors that have been categorized into push and pull factors.

Push factors were those related to challenges that PLWH faced when accessing ART from the clinic and included congestion, long waiting times, confidentiality breaches and stigma arising from attending a dedicated clinic. These factors resulted in considerable direct and indirect livelihood opportunity costs. The underlying driver for the push factors came out of the rapid expansion in demand for HIV services.

The HBM as an alternative had a number of ‘pull factors’, allowing PLWH to avoid many clinic-based challenges. PLWH described services offered through the model as convenient, confidential, trusted, personalized, less stigmatizing, comprehensive, client centred, responsive, and respectful. The model was not only convenient but also reduced opportunity and other costs attached to accessing ART while protecting PLWH from involuntary disclosure and stigma. Despite all advantages that came with the model, disclosure was found to be cardinal for the acceptability of the model. PLWH that had disclosed their status to people they lived with faced minimal problems with stigma while those that did not disclose had difficulties with home visits.

The following section examines these factors with reference to literature on home based delivered HIV services. It then considers the sustainability of HBM of care in urban communities and makes recommendations for future scale up and implementation.

## 5. 2 Acceptability of home-based ART delivery and factors influencing this

Having too many people accessing ART at a clinic with limited resources negatively affected PLWH's experiences of care. Congestion together with inadequate space was found to be the main underlying push factor for the HBM at both clinics.

To avoid these challenges, PLWH were forced to come to the clinic early while others chose to pay some clinic staff. These access challenges are similar to findings in other settings, (Kruse et al., 2007; Musheke et al., 2012; Musheke et al., 2013; Ndou et al., 2013; Mukumbang et al., 2017) and dissuade PLWH from accessing HIV services and staying on ART. Studies in many parts of SSA have shown high acceptability of home based delivered HIV services because this mode of delivery enables people to avoid the many clinic based service delivery problems (Sekandi et al., 2011; Musheke et al., 2013; Mantell et al., 2014; Kwapong et al., 2014; Knight et al., 2015).

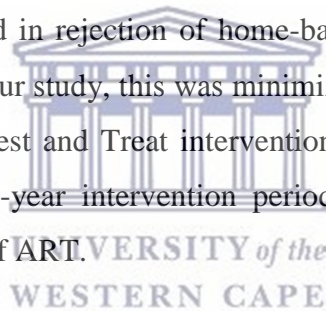
Research has also shown that in many settings around sub-Saharan Africa, poor attitudes of clinic staff discourages people from accessing clinic-based HIV services (Varga et al., 2008; Bogart et al., 2014). In a study conducted in Malawi, staff burnout was associated with suboptimal patient care practices such as shouting at patients (Kim et al., 2018). Similarly, this study showed that PLWH experienced ill-treatment at the clinic especially when they complained about the waiting time and when they felt clinic staff were attending to people they knew.

This research had key findings on stigma. PLWH were scared of clinic staff they knew and what they would say if they saw them at the clinic reflecting internalised stigma. PLWH also had fears about being seen accessing drugs, which reflects anticipated stigma. Both internalised and anticipated stigma were said to be common and negatively affected access to ART. These findings are similar to what others (Musheke et al., 2013; Dos Santos et al., 2014; Olowobi et al., 2015) found on the impact of stigma on access to ART and other HIV services. In our research, the 'fear of being seen' was particularly common amongst those recently initiated on ART and PLWH that come from higher social positions. HIV services are not integrated with other non-HIV services and this, together with the layout design of the clinic amplified a fear of being seen. In a study conducted in eight Zambian communities, Bond et al. (2016) mapped the layout and design of the clinic to find out which areas of the clinic were uncomfortable for PLWH. The ART clinic together with other spaces in the clinic that are associated with HIV were found to be places where PLWH felt uncomfortable. In addition, the



physical infrastructure, coloured patient's files and other clinic factors combined were found to make PLWH conspicuous when visiting the clinic hence increasing the fear of being seen. In contrast to these experiences, the HBM and the CHiPs implementing it took deliberate care to ensure that PLWH did not experience any involuntary disclosure and resulting stigma.

CHiPs in their work also made sure that they did not breach confidentiality and that they protected the participant's status at all costs. Drugs were delivered in a space that was confidential, and in most cases, inside the house. Studies in many other settings around home based delivered HIV services such as HIV self-testing found that privacy and confidentiality that came with this mode of delivery positively influenced acceptability (Choko et al., 2011; Makusha et al., 2015; Kurth et al., 2016; Pérez et al., 2016; Indravudh et al., 2017). Other studies have also found that home delivery of HIV services is highly acceptable because it is considered more confidential and there is less experienced stigma (Wolf et al., 2005; Sekandi et al., 2011; Sabapathy et al., 2012; Yakob et al., 2016). In addition, it has also been shown that home visits from a community lay worker are often a marker of HIV in a neighbourhood and this has in some cases resulted in rejection of home-based HIV services. (Suthar et al., 2013; Masquillier et al., 2016). In our study, this was minimized by the fact that the HBM was nested within a larger Universal Test and Treat intervention where door-to-door delivery of HTC was established over a four-year intervention period. This larger HTC intervention effectively concealed the delivery of ART.



There is need for more stigma reduction activities at the clinic to minimise the impact of both internalised and externalised stigma especially for those PLWH not accessing ART through the HBM model. Bond et al. (2016) has argued that this can effectively be done through addressing and reducing congestion through changes to physical infrastructure, patient flow, use of community models of ART and ensuring that HIV identifiers are either removed or less obvious and providing more integrated services.

It is also obvious that the introduction of the model, alongside an ongoing intervention that the community had already accepted and was delivered by CHiPs who were familiar and trusted, contributed to this acceptability. As a matter of fact, repeated home visits by CHiPs during the delivery of door-to-door HTC solidified the relationship between CHiP and households (Shanaube et al., 2017), and this therefore contributed to the acceptability. In addition, covert home delivery strategies by CHiPs (e.g., lying about their reasons for visiting and taking off their uniforms) avoided anticipated and experienced stigma but did not challenge self-stigma. In fact, this mode of delivery can inadvertently increase internalized stigma and leave stigma

unchallenged. Some PLWH mentioned that stigma at the beginning of their journey on ART was a problem for them but because they braved it through accessing ART at the clinic, they were able to stand and fight it and eventually it was no longer a problem.

This may not be the case with PLWH receiving ART through the model because by accessing ART at the clinic, individuals have to face stigma and deal with it while those receiving ART home don't have to face stigma and deal with it. Some expressed discomfort with future home visits after the end of the main door-to-door delivered PopART intervention. This argument is in line with Rodrigues-Garcia's (2013) who argued that community-based interventions can have adverse consequences such as exacerbating experienced level of stigma, leading to withdrawal from community-based programs.

Flexibility in the design of the model was another factor positively influencing acceptability. This attribute allowed CHiPs to be flexible around patient individualized needs and made it possible for CHiPs to make changes to how they delivered care in situation that demanded a change hence re-enforcing acceptability. For instance, getting into the community early, following up of clients to their place of work, exchange of phone numbers between CHiPs and clients and the use of an appointment system. In addition, making and re-confirming of appointments, drug delivery at pre-arranged times, and being on time also ensured that that the model was a good fit with daily routines of clients. There is need to acknowledge that it was not just the delivery of drugs on time and the convenience which were important but the need to be responsive to things that mattered the most to PLWH. This included how CHiPs treated their clients and how they upheld confidentiality. This culture of delivery was cardinal for the acceptability and success of the model.

PLWH lived in a social environment surrounded by family members within the household and neighbours outside the household. Central to this social environment was disclosure. At household and social level, there were two types of clients, those that disclosed and those that did not. Similar to what a study found in South Africa (Ndou et al., 2013), in this study, there was selective disclosure which was mostly limited to people within the household. Maman (2014) also found a similar pattern of disclosure as PLWH only disclosed to those they perceived would offer them support. Disclosure was a therefore a pull factor in itself and was cardinal to the beneficiary's positive experiences with the model while non-disclosure was a push factor that potentially reduced acceptability of the model. However, with one exception, the model did not bring about involuntary disclosures for most of the participants that had not disclosed.



There is a high possibility of increased involuntary disclosure and experienced stigma if the HBM is implemented on its own without being concealed in a larger test and treat intervention.

Home based delivery of ART is therefore suited for PLWH that have been on treatment long enough and disclosed their status to their families. Observation around delivery also revealed that all but one PLWH observed received their drugs from inside the house and did not want to be attended to outside. This also suggests that PLWH feared being seen by their neighbours and the resulting involuntary disclosure and this might be the reason why most of them did not disclose their HIV status to people living outside their homes.

Mobility due to livelihood in many sub-Saharan African settings has been cited as an access barrier to home based and clinic based HIV services (Bond et al., 2016; Camlin et al., 2016; Hayes et al., 2017; Shanaube et al., 2017; Bond et al., 2018; Hoddinott et al., 2018). Our study however found that mobility due to livelihood was not a barrier for home delivered ART as long as the client was contacted by phone and an appointment was made. Our study found that the use of a phone call appointment system was another key factor in the acceptability of the model. This culture of delivery proved to work for clients despite a few PLWH not being found at home or having their phones switched off. This experience can also be attributed to the fact that most of the HBM clients were stable patients that have been on ART for a long time have seen, and lived through the benefits of ART, managing to more successfully balance different needs in their lives. Additionally, the use of cell phones worked very well in this study, contributed to acceptability and should be encouraged in follow up activities and delivery of HIV and other home-based services.

Clinic visits threatened livelihoods for many clients through the loss of income and potentially contributed to job insecurity. The model reduced expenditure of accessing ART especially transport and lunch costs. There was also a sufficient supply of drugs from CHiPs and PLWH did not have to travel to the clinic frequently for refills. Several other studies (Wools-Kaloustian et al. 2009; Selke et al., 2010; Bemelmans et al., 2014) have shown that home based HIV and community based services have been highly acceptable because of convenience and reduction in the number clinic visits and costs attached to access of ART. Moreover, congestion, long waiting time and stigma forced PLWH to pay clinic staff especially lay counsellors in order to have quick access to ART or have their drugs delivered to them somewhere in the community. The model therefore was a pull factor as it removed this additional cost and the covert negotiations and discomforts associated with it.

### **5.3 Prospects for integration, scale up and sustainability of the HBM**

The successful scale up of the HBM and its sustainability depends on how well the model is integrated into the clinic structure and broader primary health care system.

The process of integration and scale-up will only be effective if there is support at different levels of the health system (service, program and policy level). Integration is about the assimilation of health interventions or operational programs into each critical component of the health system in order to maximize and improve service delivery (Atun et al., 2010).

The first stage of integration and scale up of the HBM should be health system preparedness, which will involve getting information on the existing structures of the clinics, assessing where the model will fit, and areas where it may experience challenges. As pointed out by Topp et al. (2018, p. 299) “lack of information on the impact of integration as well as the necessary pre-conditions for achieving it including assessment of the health systems within which integration must occur, continue to hamper the ability of policy makers and programme implementers to prospectively assess how feasible or worthwhile integration may be”. Having information on the pre-conditions for integration and preparing the health system for this process will therefore be important for this scale up and integration of the model. This should start with an assessment of the physical space at the clinic. In an assessment of knowledge, perception and willingness of health care workers to deliver integrated mental health services in primary health care setting in Ethiopia, Abera et al. (2014) found that the availability of appropriate physical space was a potential enabler of effective integration. In Malawi, Chan et al. (2010) also identified the importance of space for storage of medicines as an enabler of the process of decentralizing HIV care from hospitals to Primary Health Care facilities. There should also be enough space as well for community health care workers delivering the drugs to enable them meet, plan and write daily delivery reports.

Apart from clinic space, having adequate qualified staff at the clinic is also important. In most cases, the integrated program comes as an additional workload for the existing staffing levels. As a result, service delivery inefficiencies for the whole system are more evident. In Uganda, lack of qualified staff acted as a barrier to the provision of integrated TB and HIV in primary health care facilities (Nansera, 2010). Before the HBM is integrated, a good coordinating and supervision structure for lay counsellors should also be established.

Drug supply is another important area for effective integration. There should be sufficient supply of drugs to avoid stock outs, which will then interfere with the home delivery dates. This HBM intervention was nested within the main PopART intervention, which had made sure that there were no interruptions in the supply of drugs. If integrated, measures by the Ministry of Health and the clinic should be put in place to ensure that there is adequate supply of drugs and no rationing of drugs for PLWH accessing ART through the model.

Rationing of drugs will mean frequent home visits for lay counsellors and it will defeat the whole purpose of the model because by its design, there should only be two home and two clinic visits per year for each client. In an outcome assessment of decentralization of ART provision in Malawi, Chan et al (2010), found and argued that expanded access to drugs and relevant laboratory services should always be strengthened for effective decentralization.

In the same manner, that community trust for health services promotes acceptability, decision making on design and implementation of integrated services requires engaging the community on these processes (Topp et al., 2018). The engagement of the community should be used to help with decisions on how best the clinic can encourage uptake of the new service, fight stigma and avoid involuntary disclosure. Each clinic in Zambia has a health committee of resident community members and volunteers that represent the community in matters of health at clinic level. This committee should be used in the engagement process to determine how best the model can be implemented at both household and clinic level. This committee can also support the implementation of the model as some of its members also work as volunteers at the clinic. In Malawi, engaging village health committees in the planning and managing of decentralized community services was found to be critical for the initiation and sustainability of these services (Nsona et al., 2012). Health committees where involved from the start, they took responsibility and helped with the management of the integrated program and conducted activities like monitoring drug storage boxes (ibid). In the context of the HBM, care should be taken when engaging the community. There should not be any mass sensitization to all community members about a new program of lay counsellors going door to door delivering ART. Letting every community member know about the new service will bring about involuntary disclosure and low uptake of the new service. Engagement should only be extended to those influential members of the community and to all clients that will be receiving ART through the model

## 5.4 Conclusion

The study explored levels of, and the influences on, acceptability of the HBM among PLWH in Lusaka district. Acceptability in this study was defined as the “degree of fit” between the patient’s expectations and the HBM, taking into consideration all the circumstances surrounding PLWH. In order to fully understand acceptability and factors influencing it, clinic based, intervention design, and social-economic contextual factors were explored.

The study found that HBM was a good fit with the lives and expectations of PLWH and therefore highly acceptable to them. This acceptability was influenced by a combination of crosscutting clinic based; program design and social-economic factors that have been categorized into push and pull factors. Push factors were those related to challenges that PLWH faced when accessing ART from the clinic and included congestion, long waiting times, confidentiality breaches and stigma arising from attending a dedicated clinic. These factors resulted in considerable direct and indirect livelihood opportunity costs. The underlying reason for the push factors came out of the rapid expansion in demand for HIV services. The HBM as an alternative had a number of pull factors, allowing PLWH to avoid many clinic-based challenges. PLWH described services offered through the model as convenient, confidential, trusted, personalized, less stigmatizing, comprehensive, client centred, responsive, and respectful. The model was not only convenient but also reduced opportunity and other costs attached to accessing ART while protecting PLWH from involuntary disclosure and stigma.

Despite all advantages that came with the model, disclosure was found to be cardinal for the acceptability of the model. PLWH that had disclosed their status to people they lived with faced minimal problems with stigma while those that did not disclose had difficulties with home visits. The HBM is highly acceptable and this acceptability is influenced by a combination of crosscutting push and pull factors. Key to the HBM’s acceptability was its flexible delivery design around individual patient needs and the steps CHiPs took to minimize the ever-present threat of disclosure and stigma. Future adoption and scaling up of HBM should recognize the importance of these design features and the role that CHW play in the delivery of this service.

## 6.0 Recommendations

In the quest to implement the test-and-treat strategy within the Zambian ART programme which has already been overstretched by many PLWH accessing ART services, innovative community models of ART such as the HBM are needed to improve access to ART and the overall function of this programme. Community models will reduce the patient loads and enable clinicians to focus on cases that are more serious.

Improved access to ART will in turn improves adherence and treatment outcomes for PLWH. Based on findings from this research, it is clear that home delivery of ART is highly acceptable. Scale up and integration of this model is therefore highly recommended. This process should, however, take into consideration the following:

### 6.1 Design of the model

- ***Flexibility:***

The design of the model should be flexible to allow lay counsellors to respond to needs arising from the households. For example, mobility of clients. Flexibility in the model will allow mobile clients to have access to the drugs as lay counsellors can hold on to the drugs and deliver to them later after leaving a message with their families who will in turn pass on the message from CHWs informing them of the missed visit and that they get in touch with clinic or CHW to get their drugs

- ***Mobile phone appointment system:***

The use of mobile phones should be incorporated into the design of the model because mobility, as mentioned above, is a big threat for any home-based delivered HIV services. When appointments have been made, PLWH are usually willing to wait for the lay counsellors. Phone numbers for lay counsellors should be shared with clients just in case they need to re-confirm their appointment dates or get additional support on their treatment.

- ***Non-use of uniforms by lay workers***

To avoid involuntary disclosure for those clients that have not yet disclosed, use of uniforms by lay workers should be discouraged. Disclosure, however limited, should heavily be encouraged for such individuals to facilitate their access to HIV services.

- ***Dispensing of correct drugs***

To ensure that correct drugs are dispensed all the time, a confirmation of drugs before CHW leave the household should be done. This can be done by comparing the new stock of drugs dispensed to the bottle of old stock that client was given when they visited the clinic.

- ***Monitoring and evaluation***

Monitoring and evaluation of community-based HIV intervention such the HBM should be done taking into consideration as well as unintended social consequences such as stigma, which might threaten success, long term management of the program and treatment for PLWH. Moreover, this monitoring and evaluation plan should include SOPs and data collection tools to be used by all staff involved in the deliveries

## **6.2 Clinic based factors**

Clients receiving drugs through the model will still be required to visit the clinic twice a year for their clinical appointments. A few changes to services delivery at the clinic should be made to ensure a reduction in the impact of the push factors. To improve access experiences, we can recommend the following:

- ***Integration of health services***

HIV services should be integrated with other non-HIV services to reduce stigma. This will mean that all services at the clinic should be provided from one service delivery point and there should be no separation.

- ***Engagement of PLWH/volunteers in HIV service provision***

To improve service delivery, more volunteers should be engaged to help with service delivery at the clinic and help lay counsellors conducting the home deliveries. One source of volunteers can be PLWH that receive services through model as they can be asked to contribute at least a few hours to the cause. In addition, PLWH can also be engaged to help with filing of patient's files after a more simplified filing system has been developed. An efficient filling system will reduce waiting time.



- ***Engagement with Healthcare Providers***

Apart from having adequate clinic staff, there is need to identify health care workers that are willing to implement the model as some health care workers may interpret integration of the model into the main clinic system as additional workload. Benefits of the model such as reduced patient loads and improved access and adherence for their patients should be explained and emphasized to improve cooperation and participation.

### **6.3 Social and Home-based factors**

- ***Model suitable for stable patients***

The HBM is not recommended for newly diagnosed patients that are not stable and have not disclosed their HIV status. Only those that have been on treatment for a long time, have accepted their HIV status, have disclosed to their families, and are comfortable with the home visits should be encouraged to be part of the programme.

#### ***Disclosure***

Those that have not disclosed should be encouraged to disclose to at least one or two people at home to provide them with the support they need. For those that are not yet ready to disclose, they need to liaise with lay counsellors on the best and safest way they can be visited. For example, the non-use of uniforms or making phone calls asking when it is safe to have the drugs delivered worked well for some clients. Even for such individuals, disclosure should be encouraged after some time.

- ***stigma reduction activities***

At community level, there is need for extensive stigma reduction activities in the communities to reduce on the impact of stigma on access to HIV services. .



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## Appendices

### Appendix 1: participant information sheet for PLWH



#### UNIVERSITY OF THE WESTERN CAPE

Private Bag X 17, Bellville 7535, South Africa

Tel: +27 21-959 2809 Fax: 27 21-959 2872

E-mail: [soph-comm@uwc.ac.za](mailto:soph-comm@uwc.ac.za)

#### INFORMATION SHEET (PLWH)

**Project Title:** Acceptability of the Home-Based Antiretroviral Therapy Delivery Model among HIV patients in Lusaka district.

#### **What is this study about?**

My names are Chiti Bwalya, a student at the University of the Western Cape. I am inviting you to participate in this research project because you are a household member receiving ART care through the Home-based ART model being delivered in your community by ZAMBART through Community HIV Care Providers. The purpose of this research project is to explore levels of acceptability of the Home-based ART model as well as explore factors that influence this acceptability among HIV patients in Lusaka district.

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

You will be asked to answer questions that will take about approximately 45 minutes of your time. The questions will be on the following issues: You will be given a scale (diagramme) printed on plain paper where you will be asked to plot your opinion of how acceptable the Home-based ART model of care has been to you. We will also ask you about how the model has been working out for you in relation to your home and community networks as well as your livelihood activities. This interview will take place at a venue you will chose and is comfortable with.

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

Confidentiality means I as the researcher will protect your identity and take steps to make sure that all the information you provide is separated from your identity (name, address, phone number or any audio recording) as a person so that someone reading a report based on the information you will give will not be able know your identity. Every effort will be made to protect your confidential information. For example, none of the information you give will be kept in the same place as your name or other personal identifiers. Your name and any other information that may identify you or your household will be kept confidential. Although we will record the interviews with your permission, information from the interview will not be linked or traced back to you. Data collected using the audio recorder will be downloaded to password protected secure computer, which only I the researcher has access to.

When this interview is fully transcribed (written up), the recordings will be destroyed and transcripts will be checked and cleaned to remove any identifiers. Any written report or publication of this study will not mention your name or identify you personally. However, in accordance with legal requirements and/or professional standards, we will disclose to the appropriate individuals and/or authority information that comes to our attention concerning



child abuse or neglect or potential harm to you or others. In this event, we will inform you that we have to break confidentiality to fulfil our 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 our questions may cause discomfort or emotional stress. If so, you are not obligated to answer them. We will nevertheless minimise such risks and act promptly to assist you if you experience any discomfort, psychological or otherwise during the process of your participation in this study. Where necessary, an appropriate referral will be made to a suitable professional for further assistance or intervention.

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

There are no direct benefits associated with participation in this study, but there may be indirect benefits for your community in the future. The results from this study will help the investigator learn more about how acceptable the Home-based ART delivery is and factors that influence this acceptability. We hope that, in the future, other people might benefit from this study through improved understanding of the delivery of ART in within people's homes. The information gained from this study may help organizations to design future intervention and programs that will help improve ART service delivery. This study will also benefit for policy-makers and intervention implementers to understand the impact of this model on service delivery as well as access to HIV services and this information will be used to help improve service delivery at the clinic.

**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 such as access to health to which you otherwise qualify.

**What if I have questions?**

This research is being conducted by Mr Chiti Bwalya, at student at the School of Public Health at the University of the Western Cape. If you have any questions about the research study itself, please contact Chiti Bwalya at: ZAMBART Project PO Box 50697, Ridgeway Campus, and School of Medicine Lusaka. Telephone: +260 211 254710. 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:

**Chairperson,**

Bio-medical Research Ethics Committee,  
School of Medicine, Ridgeway Campus,  
University of Zambia,  
P.O. Box 50110,  
Lusaka, Zambia.  
Telephone: 260 211 256067

Prof Helen Schneider  
School of Public Health  
Head of Department  
University of the Western Cape  
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Bellville 7535

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Prof José Frantz  
Dean of the Faculty of Community and Health Sciences  
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Private Bag X17  
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This research has been approved by the University of the Western Cape's Senate Research Committee. (REFERENCE NUMBER: *to be inserted on receipt thereof from SR*)



**Appendix: 2 Consent form for PLWH**



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**Tel: +27 21-959 2809 Fax: 27 21-959 2872**  
**E-mail: [soph-comm@uwc.ac.za](mailto:soph-comm@uwc.ac.za)**

**CONSENT FORM (PLWH)**

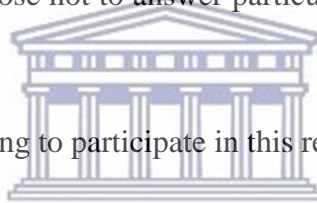
**Project Title: Acceptability of the Home-Based Antiretroviral Therapy Delivery Model among HIV patients in Lusaka district.**

**VOLUNTARY CONSENT**

I have read (or the study has been explained to me) the information about this research as contained in the Participant Information Sheet. I have had the opportunity to ask questions about it and any questions I have asked have been answered to my satisfaction.

**I agree/disagree to be quoted anonymously in this study.**

I now consent voluntarily to be a participant in this study and understand that I have the right to withdraw at any time, and to choose not to answer particular questions that are asked in the course of the interviews.



Signature below says that I am willing to participate in this research:

**Participant's name(Printed):** .....  
**UNIVERSITY of the WESTERN CAPE**

**Participant's signature/thumb print** .....**Consent Date:** .....

**Witness's name (Printed):**.....**Date:**.....

**Witness's Signature:**.....

**Researcher Conducting Informed Consent (Printed)**.....

**Signature of Researcher:** .....**Date:** .....

I agree to be audiotaped during my participation in this study.

I do not agree to be audiotaped during my participation in this study.

**What if I have questions?**

This research is being conducted by Mr Chiti Bwalya, at student at the School of Public Health at the University of the Western Cape. If you have any questions about the research study itself, please contact Chiti Bwalya at: ZAMBART Project PO Box 50697, Ridgeway Campus, and School of Medicine Lusaka. Telephone: +260 211 254710. 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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### Appendix 3: information's sheet for PLWH (Chinyanja language)



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#### **Participant information sheet ( PLWH) translated into Chinyanja**

**Pepala ya uthrnga na otengako mbali – Akaswili okambisana nao**

**Mutu wa kufufuza:** – *Kufufudza malo onse, ndi zokhudza momwe kapokeledwe ka njira yo pasila mankhwala ya kalombo ka-HIV (ART)mu manyumba, kwa iwo okhuzidwa ndi kalombo ka-HIV mu m'zinda wa Lusaka.*

#### **Kodi uku kufufudza n'kotani?**

Uku ndi kufufudza kucitiwa ndi bambo Chiti Bwalya m'phunzi wapa sukulu lalikulu la University la kumadzulo kwa m'zinda wa Cape, m'dziko la South Africa. Ndikuitanani/ndi kufunsani kuti mutengeko mbali mukufufudza uku cifukwa ndinu amodzi mwa okhala munyumba ino ndiponso mulandira thandizo la mankhwala a kalombo ka-HIV (ART) kuphyolela muka bungwe kothandidzira mu manyumba, ncito yomwe ili kutsogoleledwa ndi aza ncito za cisamaliro mu malo yanu, kucokera ku bungwe lochedwa ZAMBART. Lingo lake la uku kufufudza ndi kufuna kufufudza momwe njira yo thandidzira ndi kupatsira mankhwala ya kalombo ka-HIV mu ma nyumba kwa wo khuzidwa ndi kalombo ka-HIV, kuphatikizapo kuona ona zina zomwe zikhudzana ndi kalandilidwe ka iyi ncito pakati ka iwo omwe akhuzidwa ndi kalombo ka-HIV, mu m'zinda wa Lusaka,

#### **Kodi ndiza funsiwa kucita ciyani ngati nabvomera kutengamo mbali?**

Muza funsiwa kuyankha mafunso ang'ono, omwe aza tenga nthawi pafupi-fupi mpindi makhumi anai ndi zisanu (45).Mafunso ya za khudza izi: Muza pasidwa pepala pomwe muzaona sikelo/mupimo pomwe muza funsidwa kulemba ganidzo lanu momwe ncito yo thandidzira mu ma nyumba ku khudzana ndi kupatsira mankhwala ya kalombo ka-HIV ilandilidwa, ndi momwe zaku khalilani inu.Tiza kunfunsaninso momwe njira iyi ya kusebenzerani mu mugwirizano pa nyumba ndi mu malo yanu ndiponso pa zocitika mu umoyo wanu. Uku kukambisana kuza tengera mbali mu malo yomwe muza sankha komwe muza zimvera omatsuka.

#### **Kodi kutengamo mbali kwanga kuza sungiwa mu cisinsi?**

Cinsinsi citanthauza kuti ofufudzawo aza tetedza kudziwika kwanu ndipo aza sathira njira zo ona kuti mau omwe mwapasila asankhulidwa/patulidwa ku zo dziwika zanu (dzina, keyala, nambala ya lamy mwina mau onse ojambulidwa). Niza cita izi kucita kuti wina owerenga nkhani yomwe muza ndi patsira, saza kwanilitsa kudziwa kuti ndinu. Tiza yesa ndi mphamvu zones kutetedza cisinsi pa mau omwe muzati patsira. Mwacisanzo, kulibe mau omwe a onesta zo dziwisa za inu omwe aza sungidwa mu malo amodzi ndi momwe mau ya dzina lanu kapena zina zo ziwisa inu ziza sungidwa. Dzina lanu kapena zina zo ziwitsa inu kapena a munyumba mwanu, ziza sungidwa mwa cisinsi. Nga khale tiza jambula kukambisana ndi inu potilola, kukambisana uku sikuza konkewa kukusakilani.

Mau osankhanisidwa mumakina ojambula mau, aza singidwa pa makina ya komputa, yotetezedwa ndipo ndi iwo okha opezeka mu kufufudza uku omwe angathe kutsegula makinawo. Pomwe mawu ojambulidwa awa aza lembedwa pa mapepala, aya mawu ojambulidwa aza fafanisidwa ndipo zolembedwazo ziza fufudziwa kuona kuti kulibe

zodziwisa inu.. Zolemba zili zonse pa kufufudza uku, sikuza khala ku tomola dzina lanu kapena kudziwisa za inu. Komabe, kunkana ndi zofunikira za lamulo la m'dziko ndi ka gwilidwe ka ncito, tiza ulusa koyenera ku bantu kapena ancito oloedwa, mau omwe timgathe ku kumana nawo okhudza zo zunza ana acicepele, kapena kusa sunga bwino bana mwina kukhala kuti inu kapena a banja lanu ali mu ciophyedzo. Zikathero, tiza kudziwitsani kuti tiza pwanja cisinsi kuti tifikilize mbali yathu pakusata malamulo ya m'dziko, mu ka sebenzedwe kathu, ndipo tiza fikiza mau kumalo yo yenera.

### **Kodi kuli ziophyedzo mu kutengamo mbali mukufufudza uku?**

Ku kudzana konse kwa bantu ndi ku kambisana pa za umuntu kuma khala ndi ziophyedzo zazi ng'ono. Komabe, tiza yesesa kucepesa izi ziophyedzo ndi kucita mwacangu kuthandizira ngati kwapedzeka kuti kwacitika zina zosa kukhazikisani bwino, mwina muma ganidzo kapena pa nthawi yomwe mutengamo mbali muku fufudza uku. Ngati nikofunikira, tiza kutumidzani kwa othandizira ena akatswiri, kuti muka pedze thandizo lokwana.

### **Ndi phindu lanji pa ku tengamo mbali mu kufufudza uku?**

Uku kufufudza sikuna khazikidwe kuthandzira inu panokha, koma zotulukamo ziza thandizira ofufudza kuphunzirirapo momwe njira yo thandidzira mu manyumba, kupereka mankhwala ya ART, yalandiridwa ndi kuona zina zomwe zizetsa kuti njira iyi ilandiridwe motere. Tikhulupirira kuti, mtsogolomu, bena bantu azatha kupezamo phindu mu zotulukamo mukufufudza uku kuphyolera muku tukula njira zopelekelamo thandidzo la mankhwala ya ma ARVs muma nyumba ya bantu. Mau osonkhanisidwa mukufufudza uku mwina niku thandidzira bungwe kuikako njira za tsopano, m'tsogolomu, zomwe ziza tukura kasebenzedwe kokhudzana ndi kapelekedwe ka zincito zokhudza ART. Ici ciza thandidzirako o panga mfundo ndi o gwira zincito, kumvetsetsa momwe iyi njira ikhudzira kapelekedwe ka ncito ndi kapezedwe ka zincito zo khudzana ndi HIV.

### **Kodi nikofunikira kuti nitengemo mbali ndipo kodi ningathe kusiya nthawi ili yonse?**

Kutengako mbali kwanu mukufufudza uku n'kozifunira. Mungathe kusankha kusa tengako mbali. Ngati mwasankha kutengako mbali mukufufudza uku, munga siye pa nthawi ili yonse. Ngati mwasankha kusa tengako mbali ndi kapena ngati mwasiyira panjira, simu za landira cilango cili conse kapena kuphonya za phindu zomwe munaganizira kulandira.

### **Manje ngati ndili ni mafunso?**

Uku kufufudza kucitidwa ndi bamboo Chiti Bwalya m'phunzi wapa sukulu lalikulu pa za Thanzi la munyinji, la University la ku madzulo kwa m'zinda wa Cape, m'dziko la South Africa. Ngati mui ndi mafunso pa kufufudza uku, conde kambisanani nawo bamboo Chiti Bwalya, opedzeka ku ZAMBART Project P.O. Box 50697, Ridgeway Campus, School of Medicine Lusaka. Telephone: +260 211 254710.

Ngati kuliko yena mafunso pakufufudza uku ndi

**Wofufuza wamukulu /wothandiza wofufuza (Madzina, Kumene Apezeka ndi ma nambala a malamya):**

**Chiti Bwalya,**

Project, P.O. Box 50897,

Ridgeway Campus, school of medicine,

Lusaka.

Lamya: +260 211 254710.



**Akhumuphando,**  
Bio-medical Research Ethics;  
Akusukulu yapamwamba ya  
University of Zambia.  
Lamya: +260 211 256067.

**A Director,**  
Directorate of research and graduate studies aka ku University of Zambia.  
Lamya: +260 211 290258.

Prof Helen Schneider  
School of Public Health  
Head of Department  
University of the Western Cape  
Private Bag X17  
Bellville 7535  
[soph-comm@uwc.ac.za](mailto: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](mailto:chs-deansoffice@uwc.ac.za)



This research has been approved by the University of the Western Cape's Senate Research Committee. (REFERENCE NUMBER: *to be inserted on receipt thereof from SR*)

UNIVERSITY of the  
WESTERN CAPE

**Appendix 4: Consent Form For PLWH (Chinyanja Language)**



**UNIVERSITY OF THE WESTERN CAPE**  
**Private Bag X 17, Bellville 7535, South Africa**  
**Tel: +27 21-959 2809 Fax: 27 21-959 2872**  
**E-mail: [soph-comm@uwc.ac.za](mailto:soph-comm@uwc.ac.za)**

**Consent form (PLWH)**

**Pepala ya uthrnga na otengako mbali – Akaswili okambisana nao**

**Mutu wa kufufuza: – *Kufufudza malo onse, ndi zokhudza momwe kapokeledwe ka njira yo pasila mankhwala ya kalombo ka-HIV (ART)mu manyumba, kwa iwo okhuzidwa ndi kalombo ka-HIV mu m'zinda wa Lusaka.***

Kufufudza uku kwa fotokozedwa kwa ine mu cilankhulo comwe namvetsetsa. Mafunso yanga pa kufufudza uku ayankhidwa. Namvera comwe cifunikira pakutengamo mbali kwanga ndipo na bvomera kutengamo mbali mosa kakamizidwa, mozi sankhila ndekha. Namvera kuti zodziwisa ine siziza ulusidwa kwa wina ali yense. Namvera kuti ningathe kusiya/kucokamo muku fufudza uku nthawi ili yonse, kosa pasa mulandu ndipo osada nkhwawa kuti mwina n'kulandira cilango kapena kuphonya za phindu.

Kusindikiza kwanga pansipa kunena kuti ndine omasuka kutengako mbali mu kufufuza uku.

**Dzina la otengako Mbali (lembani):** .....

**Chisindikizo cha otengako mbali:** ..... **Tsiku:**.....

**Dzina la mboni(Lembani)**..... **Tsiku**.....

**Kusindikiza kwa mboni(Lembani)**.....

**Dzina la ofufuza:**..... **Tsiku:**.....

**Chisindikizo cha ofufuza:** ..... **Tsiku:** .....

Nda bvomera kujambulidwa mau pa makina potengamo mbali mukufufudza uku..

Si ndi bvomera kujambulidwa mau pa makina potengamo mbali mukufufudza uku.

Wofufuza wamukulu /wothandiza wofufuza (Madzina, Kumene Apezeka ndi ma nambala a malamya):

Chiti Bwalya,

Project, P.O. Box 50897,  
Ridgeway Campus, school of medicine,  
Lusaka.  
Lamya: +260 211 254710.

Akhumuphando,  
Bio-medical Research Ethics;  
Akusukulu yapamwamba ya  
University of Zambia.  
Lamya: +260 211 256067.

A Director,  
Directorate of research and graduate studies aka ku University of Zambia.  
Lamya: +260 211 290258.

Prof Helen Schneider  
School of Public Health  
Head of Department  
University of the Western Cape  
Private Bag X17  
Bellville 7535  
[soph-comm@uwc.ac.za](mailto: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](mailto:chs-deansoffice@uwc.ac.za)



## Appendix 5: information sheet Community HIV Care Providers (CHiPS)



### UNIVERSITY OF THE WESTERN CAPE

Private Bag X 17, Bellville 7535, South Africa

Tel: +27 21-959 2809 Fax: 27 21-959 2872

E-mail: [soph-comm@uwc.ac.za](mailto:soph-comm@uwc.ac.za)

### INFORMATION SHEET FOR COMMUNITY HIV CARE PROVIDERS (CHiPS)

**Project Title:** An exploration of the acceptability of the Home-Based Antiretroviral Therapy Delivery Model among HIV patients in Lusaka district.

#### **What is this study about?**

My names are Chiti Bwalya, a student at the University of the Western Cape. I am inviting you to participate in this research project because you are a Community HIV Care Provider delivering care through the Home-based ART model being delivered in this community by ZAMBART. The purpose of this research project is to explore levels of acceptability of the Home-based ART model as well as explore factors that influence this acceptability among HIV patients in Lusaka district.

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

You will be put in a group together with other Community HIV Care Providers delivering care through the Home-based ART model where you will be asked to answer questions. This discussion will take about approximately 1 hour and 30 minutes of your time. The questions will be on the following issues: You will be given a scale (diagram) printed on plain paper where you will be asked to plot your opinion of how acceptable the Home-based ART model of care has been to your clients. We will also ask you about how the model has been working out for your clients in relation to their home and community networks and their livelihood activities. This discussion will take place at a venue you as group will choose and is are comfortable with.

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

Confidentiality means I as the researcher will protect your identity and take steps to make sure that all the information you provide is separated from your identity (name, address, phone number or any audio recording) as a person so that someone reading a report based on the information you will give will not be able know your identity. Every effort will be made to protect your confidential information.

For example, none of the information you give will be kept in the same place as your name or other personal identifiers.

Your name and any other information that may identify you or your household will be kept confidential. Although we will record the discussion with your permission, information from the discussion will not be linked or traced back to you. Data collected using the audio recorder will be downloaded to password protected secure computers which only I the researcher has access to. When this discussion is fully transcribed (written up), the recordings will be destroyed and transcripts will be checked and cleaned to remove any identifiers. Any written report or publication of this study will not mention your name or identify you personally. However, in accordance with legal requirements and/or professional standards, we will disclose to the appropriate individuals and/or authority information that comes to our attention concerning child abuse or neglect or potential harm to you or others. In this event, we will

inform you that we have to break confidentiality to fulfil our 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. We will nevertheless minimise such risks and act promptly to assist you if you experience any discomfort, psychological or otherwise during the process of your participation in this study. There is a chance that some of our questions may cause discomfort or emotional stress. If so, you are not obligated to answer them. Where necessary, an appropriate referral will be made to a suitable professional for further assistance or intervention. In addition, to ensure that all that will be disused is not disclosed outside the group, all participants will be required to sign a confidentiality binding form.

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

There are no direct benefits associated with participation in these individual interviews, but there may be indirect benefits for your community in the future.

The results from this study will help the investigator learn more about how acceptable the Home-based model ART is and factors that influence this acceptability. We hope that, in the future, other people might benefit from this study through improved understanding of the delivery of ART in within people’s homes. The information gained from this study may help organizations to design future intervention and programs that will help improve ART service delivery. This study will also benefit for policy-makers and intervention implementers to understand the impact of this model on service delivery as well as access to HIV services and this information will be used to help improve service delivery at the clinic.

**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.

UNIVERSITY OF THE WESTERN CAPE

**What if I have questions?**

This research is being conducted by Mr Chiti Bwalya, at student at the School of Public Health at the University of the Western Cape. If you have any questions about the research study itself, please contact Chiti Bwalya at: ZAMBART Project PO Box 50697, Ridgeway Campus, and School of Medicine Lusaka. Telephone: +260 211 254710.

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:

**Chairperson,**  
Bio-medical Research Ethics Committee,  
School of Medicine, Ridgeway Campus,  
University of Zambia,  
P.O. Box 50110,  
Lusaka, Zambia.  
Telephone: 260 211 256067

Prof Helen Schneider  
School of Public Health  
Head of Department  
University of the Western Cape  
Private Bag X17

Bellville 7535  
[soph-comm@uwc.ac.za](mailto: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](mailto:chs-deansoffice@uwc.ac.za)

This research has been approved by the University of the Western Cape's Senate Research Committee. (REFERENCE NUMBER: *to be inserted on receipt thereof from SR*)





**Appendix 6: Consent Form Community HIV Care Providers (CHiPs)**



**UNIVERSITY OF THE WESTERN CAPE**

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

**CONSENT FORM (CHiPs)**

**Project title**

An exploration of the acceptability of the Home-Based Antiretroviral Therapy Delivery Model among HIV patients in Lusaka district.

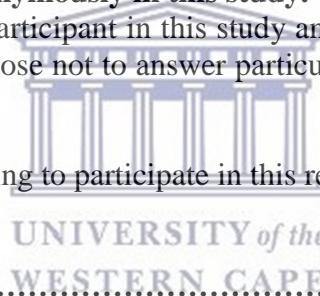
**VOLUNTARY CONSENT**

I have read (or the study has been explained to me) the information about this research as contained in the Participant Information Sheet. I have had the opportunity to ask questions about it and any questions I have asked have been answered to my satisfaction.

**I agree/disagree to be quoted anonymously in this study.**

I now consent voluntarily to be a participant in this study and understand that I have the right to withdraw at any time, and to choose not to answer particular questions that are asked in the course of the interviews.

Signature below says that I am willing to participate in this research:



**Participant's name (Printed):** .....WESTERN CAPE.....

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

**Consent Date:** .....

**Witness's name (Printed):**.....**Date:**.....

**Witness's signature:**.....

**Researcher Conducting Informed Consent Name (Printed)**.....

**Signature of Researcher:** .....**Date:** .....

I agree to be audiotaped during my participation in this study.

I do not agree to be audiotaped during my participation in this study.

**What if I have questions?**

This research is being conducted by Mr Chiti Bwalya, at student at the School of Public Health at the University of the Western Cape. If you have any questions about the research

study itself, please contact Chiti Bwalya at: ZAMBART Project PO Box 50697, Ridgeway Campus, and School of Medicine Lusaka. Telephone: +260 211 254710. 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:

**Chairperson,**

Bio-medical Research Ethics Committee,  
School of Medicine, Ridgeway Campus,  
University of Zambia,  
P.O. Box 50110,  
Lusaka, Zambia.

Telephone: 260 211 256067

Prof Helen Schneider

School of Public Health

Head of Department

University of the Western Cape

Private Bag X17

Bellville 7535

[soph-comm@uwc.ac.za](mailto: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](mailto:chs-deansoffice@uwc.ac.za)



UNIVERSITY *of the*  
WESTERN CAPE

**Appendix 7: Focus group confidentiality binding form for CHiPs**



**UNIVERSITY OF THE WESTERN CAPE**

**Private Bag X 17, Bellville 7535, South Africa**

**Tel: +27 21-959 2809 Fax: 27 21-959 2872**

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

**FOCUS GROUP CONFIDENTIALITY BINDING FORM**

**Title of Research Project:**

An exploration of the acceptability of the Home-Based Antiretroviral Therapy Delivery Model among HIV patients in Lusaka district.

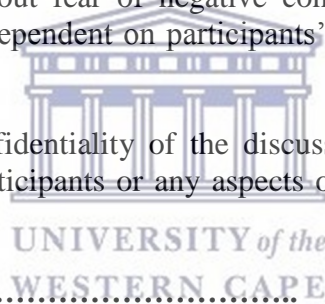
The study has been described to me in language that I understand. My questions about the study have been answered. I understand what my participation will involve and I agree to participate of my own choice and free will. I understand that my identity will not be disclosed to anyone by the researchers. 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. I understand that confidentiality is dependent on participants' in the Focus Group maintaining confidentiality.

I hereby agree to uphold the confidentiality of the discussions in the focus group by not disclosing the identity of other participants or any aspects of their contributions to members outside of the group.

**Participant's name.....**

**Participant's signature.....**

**Date.....**



## **Appendix 8: University of the Western Cape Ethics Approval Letter:**



OFFICE OF THE DIRECTOR: RESEARCH  
RESEARCH AND INNOVATION DIVISION

Private Bag X17, Bellville 7535  
South Africa  
T: +27 21 959 2988/2948  
F: +27 21 959 3170  
E: [research-ethics@uwc.ac.za](mailto:research-ethics@uwc.ac.za)  
[www.uwc.ac.za](http://www.uwc.ac.za)

06 December 2016

Mr C Bwalya  
School of Public Health  
Faculty of Community and Health Sciences

**Ethics Reference Number:** BM/16/5/27

**Project Title:** An exploration of the acceptability of the home-based antiretroviral therapy delivery model among HIV patients in Lusaka District.

**Approval Period:** 24 November 2016 – 24 November 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.

UNIVERSITY of the  
WESTERN CAPE

A handwritten signature in blue ink that reads 'Josias'.

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

*PROVISIONAL REC NUMBER -130416-050*

## Appendix 9: University Of Zambia Biomedical Ethics Committee Approval Letter



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

26<sup>th</sup> May, 2017.

Your Ref: 015-04-17.

Mr. Chiti Bwalya,  
ZAMBART,  
University of Zambia,  
Ridgeway Campus,  
P.O Box 50697,  
Lusaka.

Dear Mr. Bwalya,

**RE: RESUBMITTED RESEARCH PROPOSAL: "AN EXPLORATION OF THE ACCEPTABILITY OF THE HOME BASED ANTIRETROVIRAL THERAPY DELIVERY MODEL AMONG HIV PATIENTS IN LUSAKA DISTRICT" (REF. No. 015-04-17)**

The above-mentioned research proposal was presented to the Biomedical Research Ethics Committee on 22<sup>nd</sup> 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: 26<sup>th</sup> May, 2017.

Date of expiry: 25<sup>th</sup> May, 2018.

**Appendix 10: National Health Research Authority Approval Letter**



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

MH/101/23/10/1

07 June, 2017

Chiti Bwalya  
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 **“An Exploration of the Acceptability of the Home Based Antiretroviral Therapy Delivery Model among HIV Patients in Lusaka District”**.

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 11: Ministry of Health, Provincial Office authorization Letter**



**Appendix 12: Ministry of Health, District Office authorizations Letter**

P. O. Box 50827  
Lusaka  
Tel: +260-211-235554  
Fax: +260-211- 236429



In reply please quote:

No:.....

REPUBLIC OF ZAMBIA

**MINISTRY OF HEALTH  
LUSAKA DISTRICT HEALTH OFFICE**

15<sup>th</sup> June 2017

The Principal Investigator  
Zambart  
P. O. Box 50697  
LUSAKA

Dear Sir/Madam

**RE: AUTHORITY TO CONDUCT RESEARCH IN LUSAKA DISTRICT**

We are in receipt of your letter over the above subject.

This serves to inform you that permission has been granted by Lusaka District Health Office for Zambart to conduct research on "An exploration of the acceptability of the home based Antiretroviral Therapy delivery model among HIV patients in Chipata and Kanyama 1<sup>st</sup> Level Hospitals, Lusaka District."

Kindly ensure that your findings are shared with the health facility and District Health Office and that the normal operations of the facility are not disturbed.

By copy of this letter, the Medical Superintendents for Chipata and Kanyama are herewith informed to facilitate accordingly.

Yours faithfully,

Dr. C. Mbwili-Muleya  
**PRINCIPAL CLINICAL CARE OFFICER  
FOR/DISTRICT HEALTH DIRECTOR**

C.C: Medical Superintendent: Chipata 1<sup>st</sup> Level Hospital  
C.C: Medical Superintendent: Kanyama 1<sup>st</sup> Level Hospital

## Appendix 13: Focus Group Discussion Guide Community HIV Care Providers

### Instructions and information for the investigator:

#### **Purpose:**

This document is to be used as a guide for the researcher discussing acceptability of the home delivery model among PLWH in Chipata and Kanyama. The discussion is to be held with community HIV care providers in the two communities.

#### **Materials:**

Two copies of this guide, Facilitator Notebook, Pens, Pens, Pencils, digital recorder, AAA size batteries, Information sheets, Consent forms and A4 envelopes. Printed copies of the analogue scale.

#### **Researcher should also note:**

- Interaction with participant/s: attitude of participant/s? Were there any issues that participants were uncomfortable with?
- Questions asked by participant/s: were there any questions asked before or after the discussion?
- Additional notes: anything that stood out during the discussion?

**Participants:** 8 – 12 participants

#### **PARTICIPANT CHARACTERISTICS**

As you wait for participants to arrive, the facilitator should go around the circle, and, for each participant, record the following: **Participant number, Age, Sex, and Marital Status, church, and length of residence in site.**



#### **Introduction**

Ask: Which language participants are most comfortable using:

#### **ADMINISTER INFORMATION SHEET AND INFORMED CONSENT FORMS**

**Record the time the activity starts**

## **TOPIC AREA ONE: ROLE OF PARTICIPANTS IN THE HBM**

### **1. How would you describe your role/job in the home delivery model of ART.**

Probe:

- What are your duties and responsibilities? Is your job different from what you expected?

## **TOPIC AREA 2: HEALTH CARE BASED FACTORS:**

### **2. I would like us to now talk about some the things that your clients used to go through when accessing treatment from the clinic. Could you share with me what some of the experience that you clients have after testing for HIV?**

Probe:

- Ask about what happens when clients start accessing treatment and from where?

### **3. What do you think about the services at the clinic where your clients used to receive their treatment before the home based model?**

Probes about these challenges.

- What about congestion, long waiting hours,
- Availability of staff
- Healthcare staff attitudes towards patients
- Facility stigma
- Clinic opening and closing time

### **4. What do you think made your clients decide to be receiving their treatment through the home based delivery of drugs?**

Probe:

- What role did their experience at the clinic play in their decision?

### **5. Can share with me some of your client's experiences with the home delivery of drugs at the start?**

Probe:

- What expectations do they normally have?

### **6. What has been their experience now with the home based delivery of ART?**

Probes

- What is it that they like/don't like about the service
- Do they face any challenges?

### **7. Has the home based delivery of drugs helped to overcome all the health facility problems your clients were facing the time they were accessing treatment from the clinic.**

Probe:

- If not, why do you say so, if yes why have you said so?

### **TOPIC AREA 3: HOME BASED AND SOCIAL FACTORS**

**8. I would like us now to talk about what happens in your patient's homes and their neighbourhood in relation to the visits you do when delivering their drugs. Can you narrate to me what happens when you reach your client's homes?**

Probe:

- How do you reach the house?
- Do your clients disclose to anyone about the reasons why you visit them?
- If yes, to whom do they disclose?
- What has been the result of this disclosure?
- What do their partners, families or community members think of you visiting the clients?
- If a client has not disclosed, do they worry about someone from their household or community finding out about their status because of the home visits?
- If yes, how has that affected how they receive their treatment from you?
- Has anyone come to know about your client's HIV status because the visits?
- If a client has disclosed to their family, what do they experience?
- Are families supportive or not supportive?
- What kind of support do they give to the client?
- Are clients happy/not happy with the support?

**9. Do your clients have any have challenges with these visits at home?**

Probe

- what happens when you visit and you don't find your client at home?
- Is alcohol or drugs abuse a problem for your visits?
- 

### **TOPIC AREA 4: INTERVENTION FACTORS**

**10. Now I would like to talk about you as the people delivering this services. I know that you visit multiple households on each day. How do people respond when you knock on their doors?**

Probes:

- What has been your experience delivering drugs in people's homes?
- Are they mostly welcoming, hostile, friendly, curious, disinterested?
- What has been the most interesting thing that you have experienced?
- What has been the most challenging thing that you have gone through?
- If you live/don't live in this community, how does that affect your job?
- What is your opinion on scaling up this services to other communities?
- Do people react differently if you are familiar to them or if you are a stranger?
- Do your clients in households have any reservations because you are (a younger/older man/woman)? Do you feel that some of your clients react differently because of this?
- Who are the most difficult people to provide care to? Why do you think this is?

**11. We know that you visit your clients every after 3 months, are they comfortable with these repetitive visits?**

Probe

- Do they look forward to being visited?
- What is it that you wear when you visit them?
- What do clients say about what you wear when visiting them

- Do clients prefer counsellors that are known in the community or those not known?
- Are there things that they have requested that you do before or when you visit?
- Describe to me how you treat your clients when you visit them?
- How do clients react to the way you treat them?
- Do you give them enough time to discuss /talk about their treatment experience?
- What kind things do they talk to you about?
- Do you help sort out all their treatment related challenges?
- 

#### **TOPIC AREA 5: LIVELIHOOD FACTORS**

**12. I would like us now to talk about economic activities that your clients are involved. This are activities that bring food on their table and I would like to know how they manage these activities and at the same time find time to access their treatment. What are the sources of income for your client's family/households?**

Probe

- What type of work are they involved in either formal or informal job?
- How many hours do they work?
- How far are their job or business from their home?
- Do their jobs or business keep them away from home all the time?
- How where they managing to find time off from work/business and go to the clinic for the treatment?
- What challenges where they facing and how did they overcome them
- What is it that has changed today now that you delivering treatment in their homes?
- How do they manage to see you when on the day of the visits they are supposed to be at work or business?
- Are their jobs or business interfering with your work?
- Have you visited client only to find him/her not at home?
- If no, can you narrate to me how it happens?
- If yes, can you explain to me what makes that happen and what you do next in such a situation?
- What challenges do your face because your clients have to be work or business and at the same time treatment from you?

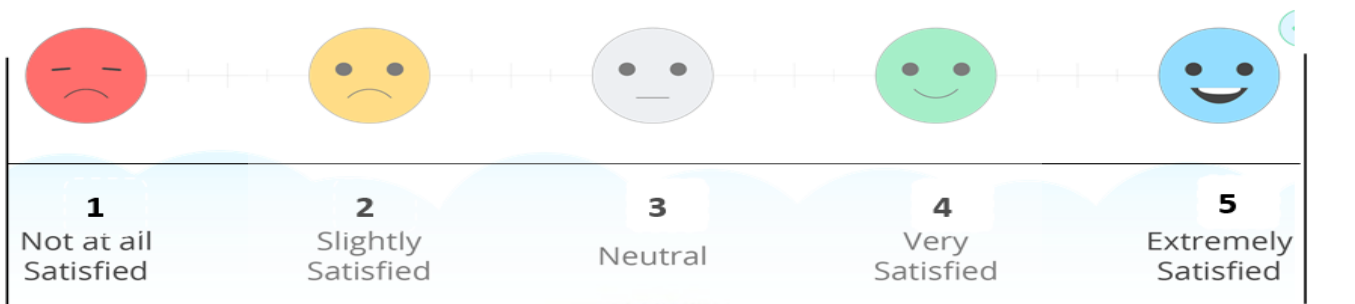


**TOPIC AREA 6: LEVELS OF ACCEPTABILITY**

**13. We have been talking about your client’s experiences with the home-based ART delivery model and how this model has been working out for them taking into consideration their home, neighbours, the clinic as well as their economic activities.**

**I want to find out from you, taking into consideration all we have talked about, what is your overall opinion of the home delivery of ARVs? Using the diagram below, if you were to plot your opinion on how this service is fitting in your client’s lives as well as it meeting their expectation and wishes, where would you put it?**

**Probes:**



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- Why have you placed at the level of you have chosen?
- What is it that you experienced that has made you place it there?
- what is it that can make you lower your or raise your score

Thank you again for your time. We greatly appreciate your participation in this discussion. Do you have any final thoughts before we turn off the audio recorder and call this discussion to a close?

## Appendix 14: interview guide for PLWH

### INTERVIEW GUIDE FOR PLWH

#### **Participant details:**

Date activity is conducted: .....

Code for the Participant:.....

Age [in years].....

Sex [circle one]:      female          male

Community:.....

Community Zone:.....

#### **Introduction**

Ask: Which language participants are most comfortable using?

**ADMINISTER INFORMATION SHEET AND INFORMED CONSENT FORMS**

**Record the time activity starts**

#### **Introduction of the participant**

1. Kindly tell me about yourself
2. How long have you lived in this community?
3. What do you like and not like about this community?

#### **Health care based factors**

4. Could you share with me what your experience has been with health care since you tested for HIV?

Probe about when participant started accessing treatment and where?

5. What do you and peers (friend on treatment) think about the services you were receiving the time you were collecting your drugs from the clinic?

Probes

- What about congestion, long waiting hours,
- Availability of staff
- Healthcare staff attitudes towards patients
- Facility stigma
- Clinic opening and closing time

6. Can share with me your experiences with the home delivery of drugs at the start?

Probe:

- What expectations did you have?

7. What made you decide to be receive your treatment through the home based delivery of drugs?

Probe:

- What role did your experience at the clinic play in your decision?

9. What has been your experience now with the home based delivery of ART?

Probes

- What is it that you like/don't like about the service
- Do you face any challenges?

10. Has the home based delivery of drugs helped to overcome all the health facility problems you're where facing the time you were accessing treatment from the clinic.

Probe:

- If not, why do you say so, if yes why have you said so

#### **Home based and social factors**

11. Have you disclosed to anyone about the reasons why you are being visited?

Probe:

- If yes, to whom have you disclosed?
- What does your partner, family or the community members think of you being visited?

12. Do you worry about someone from your household or community finding out your status because of the home visits?

Probes

- Has anyone come to know about your HIV status because the visits from the counsellor?
- How has this affected how you receive your drugs

13. If you have disclosed to your family, what has been your experience?

- Are they supportive or not supportive?
- What kind of support do they give you?
- Are you happy/not happy with the support?

14. Do you have any challenges with these visits at home?

Probe

- When you are not around, what happens when the counsellor comes to visit you.

#### **Intervention factors**

15. We know that the counsellor visits you every after 3 months, Are you comfortable with these visits?

Probe

- Do you look forward to being visited?
- Are there things that you would love the counsellor to do before or when they visit you?

16. What is your opinion on the quality of work that the counsellors do when they visit you?

Probe

- Counsellor's attitudes towards you
- Are you given all the attention you need?
- Do they give you enough time to discuss /talk about your treatment experience?
- Do they help you sort out all your treatment related challenges?

#### **Livelihood factors**

17. Tell me about the source of income for your family/household?

Probe

- What type of work either formal or informal job?
- How many hours do you work?
- How far is your job or business from your home?
- Does your job or business keep you away from home all the time?

18. Tell me about your work/business and how you or friends were managing to get time off work to go to the clinic for your drugs.

Probe

- What challenges were you facing and how did you overcome them

19. How do you or friends manage to see the counsellor when they come to visit you and at the same time attend to your business or go for work?

Probe:

- Has the counsellor ever come to see you and not found you at home because you were out for work or business
- What challenges do you face because of your work and access to home based delivery of treatment?

### Levels of acceptability

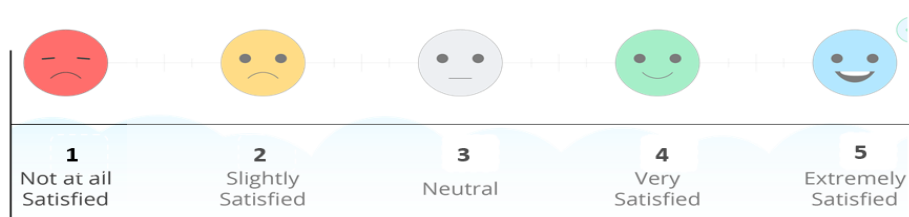
20. We have been talking about your experiences with the home based ART delivery model and how this model has been working out for you taking into consideration your home, your neighbours, your clinic as well as how you been managing the home visits and your business or job. I want to find out from you, taking into consideration all we have talked about, what is your overall opinion of the home delivery of ARVs? Using the diagram below, if you were to plot your opinion, where would you put it?

Probes:

- Why have you placed at the level of you have chosen?
- What is it that you experienced that has made you place it there?
- what is it that can make you lower your or raise your score?

Thank you again for your time. We greatly appreciate your participation in this discussion. Do you have any final thoughts before we turn off the audio recorder and call this discussion to a close?

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## Appendix 15: Home based ART delivery Observation guide

### Home based ART delivery Observation guide

Date of the activity.....  
 Community.....  
 Zone.....  
 Household number .....  
 Visit number.....

#### Instructions

- i. This documents should be used to give guidance during the home based ART delivery observation. The observations however should not be limited only to the listed probes as all the interactions between the client and the provider should be noted and written.

	<u>Home, social and economic context of the household.</u>	<u>Notes</u>
<b><u>1</u></b>	<b>Describe the home, social environment as well as the economic status of the house being visited.</b> please take note of the number of children, any livelihood activities, type of house and its location in the community, describe who the patient is by sex and approximate age etc,	
<b><u>2</u></b>	<b>Factors influencing acceptability</b>	
<b><u>2.1</u></b>	<b>Describe the client’s reaction to the visit and service being provided by the CHiP worker?</b> e.g. how does the patents respond when the CHiP worker? knocks on the door, is the client interested, not interested, busy, Not happy, very happy, not at home, etc)	
<b><u>2.2</u></b>	<b>Describe the process of delivering care at the being household.</b> What time did the ChiP worker arrive the house, Is the chip worker late or on time, observe the quality of counselling, <ol style="list-style-type: none"> <li>i. very good attitude and friendly, explained things clearly, provides time for clients to answer questions no tension between the client and the CHiP Worker etc</li> <li>ii. is the ChiP worker not friendly, didn’t communicate clearly; made demands on the client; departed household without explaining everything Cleary,</li> </ol>	

	<p>iii. What was your impression of the patients experience with the quality of service provided (happy, not happy describe and give reasons why you think so</p>	
<b><u>2.3</u></b>	<p><b>How do the participants use this opportunity to speak about their experience of the with the home visit,</b> are they taking the chance to complain? do they have any challenges, do they worry about CHiPs visiting them again, what other things do they talk about during the visit? Did the patient have any concerns or talk about any challenges related to the service</p>	
<b><u>2.4</u></b>	<p>What challenges did the ChiP worker have at this household?</p>	
<b><u>2.5</u></b>	<p>What questions did the patients ask and how did the Community HIV care provider respond?</p>	
	<p>OTHER – interesting observations related acceptability of the home based model</p>	

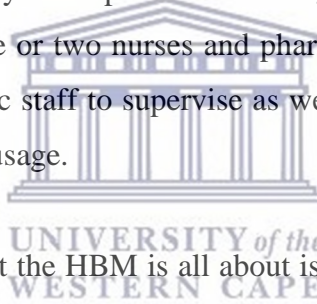


**Appendix 16: Recommendation for the Zambian Ministry of Health.**



## Design of the model

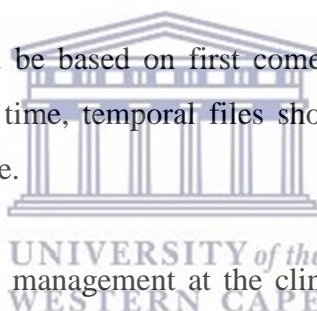
- To ensure continued access for mobile trusted individuals not found at home, drugs for such individuals should be left home and a message for them to pass through the clinic to sign for the drugs.
- The model should be flexible enough enable lay workers to liaise with clients on when and where the drugs can safely be delivered.
- At the clinic, pharmacist pre-packing drugs for home deliveries should be done a day before the actual day of the delivery to avoid delays especially in case where lay counsellors want to deliver drugs early in the morning to capture those clients that go for work.
- The HBM can effectively be implemented through lay counsellors who can work with volunteers with one or two nurses and pharmacists. There is however a need to engage qualified clinic staff to supervise as well as help with the pre-packaging and monitoring of drug usage.
- Training of staff on what the HBM is all about is another cardinal area that should be implemented more than once: there should be routine training of both old and new staff. In Zambia, transfer of government staff is very common and this can cripple service delivery especially if the person coordinating the HBM is transferred to another clinic. To avoid this, a team of dedicated staff should be trained and engaged in coordinating and supervising of the delivery of the HBM to ensure continuity of institutional memory for the HBM as the other team members will remain and continue coordinating the work should there be any transfer of staff.
- At national policy level, the ministry of health should provide clear guidance and support to clinic staff for the newly integrated HBM services. A non- $\rightarrow$  bureaucratic policy environment that fosters devolution of decision-making power should be established. This will enable integration of the model to be implemented at local clinic levels in a manner that is responsive to the clinic and social environment of



PLWH. In addition, there should be clear instructions on different roles that clinicians taking part in this model should be playing.

### *Clinic based factors*

- The clinic should also be made much more comfortable: the waiting area for PLWH should be expanded and more seats provided. A simple wall or blinds should be erected around the waiting area so as to protect those waiting from on lookers walking into the clinic. This has worked in other clinics that have erected a wall around the waiting area and PLWH have appreciated this as they no longer fear been seen at the clinic.
- The use of coloured patient files should be discouraged as this makes PLWH more visible and makes the fear of being seen more prominent.
- Service delivery should be based on first come basis and for those whose files have not been found on time, temporal files should be created there and then to reduce on the waiting time.
- A stricter SOP on drug management at the clinic should also be developed. No unauthorised staff should be allowed into the ART pharmacy. This will reduce on drugs falling into wrong hands of clinic staff who in return engage themselves in the illegal trade with clients.
- No member of staff should be allowed to collect drugs on behalf of a client.
- Clinic staff should be encouraged to start work on time and the use of phones and social media during working hours should be prohibited. Tea time should be before working hours and if possible, staff should to take turns for these breaks so that they do not all go for tea and cripple service delivery.



### *Social and Home-based factors*

- The HBM is not recommended for newly diagnosed patients that are not stable and have not disclosed their HIV status. Only those that have been on treatment for a long time, have accepted their HIV status, have disclosed to their families, and are comfortable with the home visits should be encouraged to be part of the programme.
- Those that have not disclosed should be encouraged to disclose to at least one or two people at home to provide them with the support they need. For those that are not yet ready to disclose, they need to liaise with lay counsellors on the best and safest way they can be visited. For example, the non-use of uniforms or making phone calls asking when it is safe to have the drugs delivered worked well for some clients. Even for such individuals, disclosure should be encouraged after some time.

