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SCHOOL OF PUBLIC HEALTH

COLLEGE OF HEALTH SCIENCES

UNIVERSITY OF GHANA

ASSESSING RETENTION OF WOMEN ENROLLED IN PREVENTION OF MOTHER-
TO-CHILD TRANSMISSION OF HIV PROGRAMME AT THE
HO MUNICIPAL HOSPITAL

BY

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THIS DISSERTATION IS SUBMITTED TO THE UNIVERSITY OF GHANA, LEGON
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MASTER OF PUBLIC HEALTH DEGREE.

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DECLARATION

I, Isaac Folitse declare that this dissertation is my original work produced from research undertaken under supervision. All sources that I used have been duly acknowledged by means of complete references. This work has not been presented elsewhere for the award of any degree.

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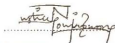
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Date

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(Supervisor)



Signature

11 - OCT - 2017

Date

This is dedicated to all persons living with HIV and AIDS especially to children born to HIV-positive mothers.

I have enjoyed good health throughout the period of my education and I believe that God's mercy is keeping me alive and glory be unto his name.

I acknowledge the supervisory role of Dr. Justice Nonvignon of the department of Health Policy Planning and Management who devoted his time to guide me step by step in developing this dissertation. I would also like to thank Dr. Genevieve Aryeetey for her support and advice.

I am grateful to Mr. John Hini who supported me financially in completing the programme. To my family and friends especially Eunice Adwubi, Delia, Cosmos Elikplim, Mary Kafui and Kezia Mensah, I'll remain indebted to you for bringing the best out of me; Thank you.

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Background: Prevention of mother-to-child transmission of HIV (PMTCT) is delivered in stages (or cascades) and high level of retention at each cascade step by mother and later by mother-infant pairs is required to eliminate maternal transmission of HIV which occurs through pregnancy, childbirth and breastfeeding. Reasons for low rates of retention in Ghana are not well understood though HIV sentinel sites situated across the country serve as good resource for collecting data for generating such knowledge. The aims of this study were to determine retention rates at each stage of the PMTCT cascade and explore patient and provider-level factors affecting retention at the Ho Municipal Hospital.

Methods: Retrospective data was collected from folders and electronic records of 69 women who were enrolled into PMTCT from January 2014 to December 2015. Data was entered into a PMTCT Cascade Analysis Tool and retention rates at different stages of the cascade was calculated. In-depth interviews were conducted for twelve mothers and seven carefully selected frontline PMTCT care providers. Patient-level and provider-level factors were manually extracted and coded from transcribed recorded conversation.

Findings/Results: Twelve-month postpartum retention was 66.7%. The highest drop-off along the cascade was found at the 'first at-risk child visit' for which 20 out of 52 babies were not brought for early infant diagnosis (EID). Provider-level factors identified as determinants for retention included counselling support, assurance of anonymity, clinic location and supportive and understanding team. Patient-level factors that emerged were desired quality life, social support and acceptance, stigma and partner influences.

Conclusion: Retention in PMTCT at the Ho Municipal Hospital was lower compared to reviewed

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literature from other resource constraint locations. Good counselling support, assurance of confidentiality, desired treatment outcome and privacy of clinic location are some of the reasons shown to affect retention at this site

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LIST OF ABBREVIATIONS

3TC	Lamivudine
ABC	Abacavir
ACTG 076	AIDS Clinical Trials Group (protocol 076)
AIDS	Acquired Immunodeficiency Syndrome
ANC	Antenatal care
ART	Antiretroviral Therapy
ARV	Antiretroviral
ATV/r	Atazanavir (ritonavir boosted)
AZT (or ZDV)	Zidovudine
BCC	Behaviour Change Communication
C/S	Caesarean Section
cART	Combination Antiretroviral therapy
CD4+	Cluster of Differentiation 4, a T-helper cell
CDC	Centers for Disease Control and Prevention
CD-ROM	Compact-Disk Read-only Memory
CHPS	Community-based Health Planning Services
DBS	Dried Blood Spot
DHIMS-2	District Health Information and Management System version 2
DNA	Deoxyribonucleic acid
DOT	Directly Observed Therapy, short course
DRV/r	Darunavir (ritonavir boosted)

DTG	Dolutegravir
EFV	Efavirenz
EID	Early Infant Diagnosis
FTC	Emtricitabine
GAC	Ghana AIDS Commission
GHS	Ghana Health Service
GRID	Gay-Related Immune Deficiency
GSS	Ghana Statistical Service
HAART	Highly Active Antiretroviral Therapy
HEU	HIV-exposed but uninfected
HIV	Human immunodeficiency Virus
HIVNET-012	A Phase IIB Trial to Determine the Efficacy of Oral Zidovudine and the Efficacy of Oral Nevirapine for the Prevention of Vertical Transmission of HIV-1 Infection in Pregnant Ugandan Women and Their Neonates
HP	Healthcare Provider
HTS	HIV Counselling and Testing Services
IAAT	Interagency Task Team on the Prevention and Treatment of HIV Infection in Pregnant Women, Mothers and Children (UNAIDS, UNICEF, UNFPA, WHO)
ICF-I	International Classification of Functioning, Disability and Health, Infant version
ICRW	International Center for Research on Women
IMB	Information-Motivation-Behavioural skills (a health seeking model)
INSPIRE	INtegrating and Scaling-up PMTCT through Implementation REsearch (INSPIRE) initiative

INSTI	Integrase Strand Transfer Inhibitors
LPV/r	Lopinavir (ritonavir boosted)
LTFU	Lost to follow-up
MCHC	Maternal and Child healthcare
MDGs	Millennium Development Goals
MOH	Ministry of Health
MTCT	Mother-to-child transmission of HIV
NACP	National AIDS/STI Control Programme
NDPC	National Development Planning Commission
NNRTI	Non-nucleoside Reverse Transcriptase Inhibitors
NRTI	Nucleoside Reverse Transcriptase Inhibitors
NtRTI	Nucleotide Reverse Transcriptase Inhibitors
NVP	Nevirapine
OVC	Orphaned and Vulnerable Children
PCAT	PMTCT Cascade Analysis Tool
PCR	Polymerase-chain reaction
PLWHIV	Persons Living with HIV
PLWHIVA	Persons Living with HIV and AIDS
PMTCT	Prevention of mother-to-child transmission of HIV
RAL	Raltegravir
RIC	Retention-in-Care
RNA	Ribonucleic acid

SAIA	Systems Analysis and Improvement Approach/Intervention
SD	Standard Deviation
SDGs	Sustainable Development Goals
SSA	Sub-Saharan Africa
STI	Sexually Transmitted Infections
SVD	Spontaneous Vaginal Delivery
TBA	Traditional Birth Attendants
TDF	Tenofovir
UN	United Nations
UNAIDS	Joint United Nations Programmes on HIV and AIDS (includes UNICEF, UNDP, UNFPA, UNDCP, ILO, UNESCO, WHO, WORLD BANK)
UNDP	United Nations Development
UNHCR	United Nations High Commission for Refugees
UNICEF	United Nations Children's Fund
US	United States of America
USAID	United States Agency for International Development
WHO	World Health Organization

The following are the working definitions employed throughout the study period:

- Adherence:** Adherence refers to compliance to programme recommendations including drug treatment schedules, dosage, as well as presence on schedule visits and applying recommended advice.
- Attrition:** Attrition refers to a situation where beneficiaries are no more seen in PMTCT due to either death or lost to follow-up (LTFU)
- Discrimination:** It is the shunning of HIV-infected mother from social interactions. It also means treating her unfairly because of her HIV status
- Drop-offs:** Refers to all individuals who do not report for scheduled visit regardless of the duration of absenteeism
- Early infant diagnosis:** Infants born to women living with HIV receiving a virological test for HIV within two months of birth
- Loss to Follow-up:** An individual is lost to follow-up if s/he misses schedule visits successively up to about three follow-up periods. For example for monthly follow-up that will be three months since last visit.
- Retention in care:** Individuals living with HIV known to be on treatment and who are present at the clinic on a schedule date and/or any programme-recommended period. It is measured at a specific programme time.
- Stigma:** Perceived disgrace or unfit for social acceptance due to HIV-status
- Vertical transmission:** Transmission of HIV infection from mother to child.

1.0 INTRODUCTION

1.1 Background

Globally, an estimated 50% of the over 37 million persons living with HIV (PLWHIV) are women. Almost 1.4 million of these women, 90% of whom reside in sub-Saharan Africa (SSA) give birth annually (Nachega et al., 2016; UNAIDS, 2016a). One hundred and sixty thousand children born in 2016 were infected with HIV, three new infections in every ten minutes (UNAIDS, 2017). In the absence of interventions, accumulated rates of mother-to-child HIV transmission (MTCT) range from 15% to 45% of all pregnancies among infected women. This accounts for more than 90% of all HIV infections in children less than 15 years old. However, maternal transmission of HIV can be reduced to less than 5% in breastfeeding mothers and 2% in non-breastfeeding populations through evidence-based strategies (UNAIDS, 2011b). Retention of more than 90% at each step of the PMTCT step (or cascade) is required to achieve good results (Ambia & Mandala, 2016).

The 2016 estimate of HIV prevalence in Ghana was 1.6% with 290,000 people estimated to be living with the infection. Fifty-three per cent (53%) of this number is made up of women while more than 11% are children below 15 years old. Currently, 90,000 Ghanaians are on antiretroviral therapy (ART), the unmet needs rising above 60% and low paediatric ART coverage of approximately 30%. The national HIV prevalence among women reporting for antenatal clinic for the first time was 2.4% in 2016 increasing from 1.8% in 2015. (NACP & GHS, 2016). The rate of mother-to-child transmission of HIV in Ghana in 2016 was 12% far above the national programme target of 5% (NACP & GHS, 2017).

Risk reduction interventions include HIV testing and counselling services (HTS), antiretroviral treatment (ART), avoiding unintended pregnancies, elective caesarean section, when indicated and where safe and feasible, safer delivery practices, antiretroviral (ARV) prophylaxis for HIV-exposed infant as well as infant-feeding counselling and support for safer feeding practices (GAC & GHS, 2014). These interventions are included in the prevention of mother-to-child transmission of HIV (PMTCT) package which is delivered in a step-wise approach called 'cascades'. The World Health Organization (WHO) provides leadership through research and publication of periodic guidelines for adaptation and further adoption by member countries.

The new PMTCT guidelines recommend lifelong ART in women enrolled into PMTCT regardless of CD4+ cell count or clinical staging. The new policy is referred to as the PMTCT Option B+ which is a scale up of the previous strategies, Options A and B (WHO, 2013b). The new approach promised increased chances of survival and reduced risk of mother-to-child transmission of HIV (MTCT) at lower costs to health systems and patients (Ishikawa et al., 2014). It also simplifies PMTCT services by reducing the need for assessing eligibility through CD4+ cell monitoring and switching between different regimens that were associated with the earlier options and which are challenging to health systems of lower and middle income countries (Adler, Riley, Bandazi, & Davis, 2013).

Retention in care (RIC) and compliance to antiretroviral therapy (ART) have been identified as key factors influencing the impact of the programme. Previous studies showed that facility-, provider-, patient- and community-related factors are associated with uptake and retention in PMTCT services by eligible women and their babies (Ambia & Mandala, 2016; Anígilájé, Ageda, & Nweke, 2016; Geldsetzer et al., 2016; Hodgson et al., 2014; Kohler et al., 2014; Mekuria, Prins, Yalaw, Sprangers, & Nieuwkerk, 2015).

1.2 Problem statement

Though the HIV and AIDS epidemic has received substantial political attention and commitment of resources in efforts to scale up access to ART and other support services, high rates of attrition is affecting retention in continuum of care, resulting in increased risk of mother-to-child transmission (MTCT) (Kak, Chitsike, Luo, & Rollins, 2010; WHO, 2006). Identified barriers include male partner involvement, socio-economic factors, religion and culture, stigma and discrimination as well as some facility-level factors, such as acceptance, privacy, counselling and availability of logistics (Anigilájé et al., 2016).

The effectiveness of the PMTCT intervention aimed at achieving elimination of perinatal HIV transmission requires that HIV-positive women and breastfeeding mothers with their children successfully go through a number of steps referred to as the PMTCT cascade which includes HIV testing and counselling services (HTS) at first antenatal visit, provision of ART, prophylactic treatment for babies born to these women, infant HIV testing and provision of antiretroviral drugs (ARVs) for babies infected (Ambia & Mandala, 2016). To achieve successful reduction in MTCT, a retention of 90% or more is required at each step of the cascade (UNAIDS, 2014b). However, drop-offs occur at all stages of the cascade. A large study in SSA showed that 70% of HIV positive women actually received ART, 64% of babies born were tested at 6 weeks and 55% of these babies receive their final diagnosis at 18 months (Kim et al., 2015; Wettstein et al., 2012).

Limited data on retention of mothers in PMTCT exist in Ghana and predictors of retention or factors associated with loss to follow-up within the programme have been generalized with experiences from sister sub-Saharan African countries. Knowledge of retention at the Ho Municipal Hospital has not been generated in the past and limited information is available on the

Data on retention from other resource-limited regions employed quantitative methodologies requiring expert statistical analysis of predetermined responses. Little work has been done to understand the real life experiences of the affected women. Employing qualitative data collection approach is useful to better understand what works or not from the perspectives of the beneficiaries. For example, how treatment has affected uptake and retention in care and how PMTCT has contributed in shaping their perception about lifelong ART and raising HIV-exposed but uninfected (HEU) children.

This study assessed PMTCT cascade flow using simple adaptable cascade analysis tool to measure level of retention. The study also used in-depth interviews to collect data needed to understand the reasons behind retention in PMTCT from both patient and provider perspectives.

1.3 Objectives of the study

1.3.1 General Objectives

The general objective of the study was to assess retention of pregnant women in PMTCT and associated factors at the Ho Municipal Hospital.

1.3.2 Specific Objectives

The specific objectives were:

1. To determine the rates of retention at all stages of PMTCT from 1st January 2014 to 31st December 2015
2. To explore provider-level factors associated with retention in PMTCT
3. To explore patient (client/patient)-related factors associated with retention,

1.4 Research Questions

1. What proportion of women was retained at each PMTCT cascade step between January 2014 and December 2015 inclusive, at the Ho Municipal Hospital?
2. What are the provider-level factors associated with retention in PMTCT?
3. What are the patient-level factors associated with retention?
4. What are the implications of provider and patient level factors for successful implementation of PMTCT at the Ho Municipal Hospital?

1.5 Justification of the Study

Following successful implementation of prevention of mother to child transmission of HIV in many African countries, concerns begin to rise with respect to compliance and retention in continuum of HIV care among women enrolled (Mitiku, Arefayne, Mesfin, & Gizaw, 2016). Retention in care measurement are varied and complex; measurement tools requiring adaptation to fit local contexts. PMTCT cascade analysis is no exception.

Ghana has recorded improvement in mortality statistics among people living with HIV and AIDS (PLWHIVA) from about 30,000 in 2003 to 15,000 in 2016. Orphaned and vulnerable children were estimated to be 170,000 in 2003 and 124,779 in 2014 (Ghana AIDS Commission, 2014; NACP & GHS, 2016; UNAIDS, WHO, & UNICEF, 2004). Though there is hope that concerted efforts can result in better outcomes for PLWHIVA especially women and children, Ghana made little progress in providing access to antiretroviral drugs to expectant mothers as captured in the final Millennium Development Goals (MDGs) report for Ghana (UNDP & NDPC, 2015). There is also limited documentation on patient-level experiences of intervention programmes. Concerns of patients are unnoticed by caregivers, while programme managers miss these opportunities to

This study used facility-adapted tools in accessing PMTCT cascade flow, explore and document experiences of women in PMTCT, as well as seek the view of care givers on implementation challenges and successes. The findings will provide evidence on how PMTCT has affected women enrolled at the Ho Municipal Hospital and the challenges they face in raising HIV exposed children. Their concerns will inform healthcare workers on the best way to adapt service delivery in order to improve retention in order to reduce childhood infection through pregnancy, delivery and breastfeeding. Policy makers will need to replicate this study on a larger scale for decisions to be taken on improving components that will ensure greater impact.

1.6 Conceptual Framework

The conceptual framework in Figure 1 depicts factors that have been shown in available literature to be associated with retention in PMTCT care as described below:

The framework is in three broad categories: the first one, comprising of provider- and patient-level factors shows variables that can be tempered with in order to achieve desired outcomes in the other two categories. The second category represents clinical characteristics of the patient. These are CD4+ cell count and viral load, two vital determinants of clinical symptoms of patients. The higher the CD4+ cells per millilitre of blood, the lower the viral load and vice versa. These two laboratory investigations are required in order to access the progress of treatment (NACP & GHS, 2016). The third category is the outcome category comprising of retention in care and status of exposed infant. The reasons for desiring optimum responsiveness of healthcare provision is to enhance positive client attitude which will ultimately culminate into reduced viral suppression, increased CD4+ cell count, reduced clinical symptoms and finally retention in care so as to prevent the HIV-exposed

baby from being infected.

The availability of trained and skilled provider supported by the requisite logistical inputs in the provision of supportive counselling to clients, thereby alleviating their fears of increased morbidity and death has been demonstrated in a study done in an urban setting in Kenya. The study found out that in addition to supportive counselling, admiration from nurses and doctors in a client-friendly environment has direct effect on patients who found hope to fulfil their lifelong desires to be mothers and to raise uninfected children. The same study also demonstrated the effects stigma, family and community support have on uptake of services in a hospital setting. Same can be said of cultural hindrances (Murithi, Masho, & Vanderbilt, 2015). A systematic review of 34 interventions to improve PMTCT service delivery and promote retention showed that training of healthcare workers, availability of home-based care (after-clinic support services), integration of PMTCT services (comprehensive care) and enhanced referral are significantly associated with increased male partner involvement, patient's compliance, improved symptoms and reduced vertical transmission of HIV (Ambia & Mandala, 2016).

Two separate studies conducted in Addis Ababa and Myanmar on retention and risk factors for attrition demonstrated statistically significant relationships between the following clinical characteristics and retention in continuum of care: severe immune deficiencies at enrolment, being bed-ridden or ambulatory, low CD4 count, being anaemic, low body mass index, having high WHO clinical staging and being on tuberculosis treatment (Mekuria et al., 2015; Thida et al., 2014).

Severe immune deficiency is a direct result of reduced CD4 cell count due to increased viral load, which follows the natural course of HIV infection without any intervention or due to non-

compliance or treatment failure. Worsened disease condition, undesirable symptoms as well as side effects of medicines have also been shown to affect adherence due to antiretroviral treatment. Physical, emotional and economic stress, postpartum depression and ART dosing frequency (pill burden) have also been found to be barriers to adherence to treatment in a systematic review and meta-analysis of 51 studies involving 20,153 HIV-infected expectant mothers (Nachega et al., 2012; Dionne-Odom et al., 2016; Geldsetzer et al., 2016; Gourlay et al., 2015; Mekuria et al., 2015; Mitiku et al., 2016; Tenthani et al., 2014; Woelk et al., 2016).

Finally, early initiation of ART, breastfeeding and safe practices during pregnancy and post-delivery are good indicators for reduced MTCT of HIV and improved growth and survival of children (Altan et al., 2016).

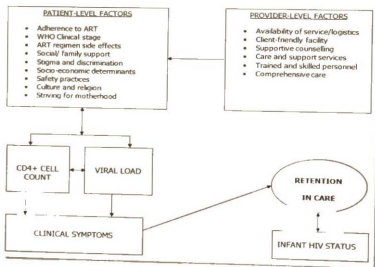


Figure 1 Factors associated with retention in PMTCT: Conceptual model

2.0 LITERATURE REVIEW

2.1 Introduction

The body of knowledge available as published literature and policy documents have been reviewed under this chapter. There are ten sections describing the burden of HIV and AIDS, what the virus is and how it replicates in a host cell. Therapeutic efforts to arrest the growth of the virus, global response to the epidemic and evidence of successes have been presented. The Ghana ART and PMTCT guidelines are introduced. Available literature on retention in different parts of the world, retention definition and its measurement and factors enhancing and/or impeding efforts to improve retention have been discussed here. Knowledge gaps discovered are outlined and the basis of this study firmly laid.

2.2 Burden of HIV and AIDS

Globally, as at December 2016, 36.7 million people are living with HIV and AIDS, 69.5% of them reside in sub Saharan Africa (SSA). About 18 million women above 15 years are HIV-positive globally. Children below age 15 living with the virus stood at an estimated figure of 2.1 million in 2016. Nineteen million people are living with HIV in Eastern and Southern Africa whilst 6.3 million live in West and Central Africa. About 35 million people died of AIDS-related causes globally since the beginning of the epidemic. One million died in 2016, 42.2% occurring in Eastern and Southern Africa and 30% in West and Central Africa. Global antiretroviral coverage was 19.5 million (13.9 million in SSA) in 2016 (UNAIDS, 2017). Though ART improves survival of PLWHIV, the coverage is still low in resource limited regions. In 2016 for example, almost half of all pregnant women living with HIV in West and Central Africa did not receive ART to prevent

mother-to-child transmission of HIV and only about 22% of children infected are accessing ART (UNAIDS, 2017).

The first case of AIDS to be reported in Ghana was in the year 1986. Since then, the incidence have been increasing. By 2003, 76,139 total number of cases have been documented with high female to male ratio. The prevalence of infection is highest among the reproductive age group (NACP, MOH, & GHS, 2005). The 2015 HIV prevalence in Ghana is 1.8%, a 0.2% increase from the 2014 figure. This has reduced further to 1.6% in 2016 (GAC, 2016b). As at the end of 2014, 197 ART sites and 2,152 PMTCT and HTS sites have been established by the Ghana Health Service (GHS) (NACP, GHS, & MOH, 2016). Out of the 2.3 million children living with HIV worldwide in 2014, 21,223 live in Ghana with 30% ART coverage (NACP & GHS, 2016). Childhood mortality due to HIV/AIDS in Ghana was recorded in 2014 as 1,295. Maternal orphans due to AIDS in 2014 was 61,198, a situation that calls for effective prevention activities in reproductive age group and increased maternal ART coverage and retention (Ghana AIDS Commission, 2014).

The Ghana Demographic and Health Survey had reported higher fertility rates among rural women than urban dwellers and also in women with less than secondary school education than those who had at least secondary school education. The risk of HIV infection is however higher among more educated women than those with little or no education. According to economic status, women in the very low and very high economic class has lower prevalence of HIV compared to those in the middle class. However, rural women and women with less education and or belong the lower socio-economic class suffer more abuses and are more likely to engage in risky sexual practices with their husbands due to inability to negotiate for safer sex practices (GSS, GHS & ICF-I, 2015). A critical review of literature from Nigeria and Malawi demonstrated that socio-economic and socio-cultural factors affect successful implementation of HIV transmission reduction

interventions such as the PMTCT (Okoli & Lansdown, 2014).

2.3 The HIV virus

Human immunodeficiency virus (HIV) is the name given to the virus implicated in AIDS (Acquired immunodeficiency Syndrome). The name was formalized by The International Committee on the Taxonomy of Viruses in May 1986 (CDC, 2011). Previously, the US National Cancer Institute described HTLV-III (Human T-Lymphotropic Virus Type III), a retrovirus as the cause of AIDS.

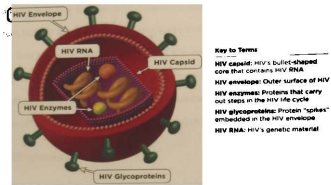
The first case definition for AIDS was:

“a disease at least moderately predictive of a defect in cell-mediated immunity, occurring in a person with no known cause for diminished resistance to that disease” (CDC, 2011).

The above definition is in recognition of the clinical presentation of advanced disease at the time which comprises of lowered immunity, increased opportunistic infections and higher risk of Kaposi's sarcoma, a rare and an aggressive type of cancer. In January 1985, the case definition was modified to describe infection with HIV (CDC, 2011). The definition is now more refined in response to advances in laboratory technologies, and the effort to separate infection with HIV and complications of advanced stage of infection, an effort to limit stigma and discrimination and demystify the disease (CDC, 2014).

Figure 2. Simplified structure and composition of the HIV virus.

Source: (AIDSinfo, 2016)



2.3.1 Life cycle of HIV

The virus attacks a particular cell in the body of infected persons called the T-helper cell (also called the CD4 cell) which is a white blood cell responsible for defending the body against infections. The virus attaches itself to receptors on the cell surface by use of the HIV glycoproteins (see Figure 2 above) through a process of **binding**. Secondly, it fuses itself with the host cell surface membrane and releases the viral capsid into the cytoplasm of the CD4 cell. This process is called **fusion**. Inside the capsid of the virus is a viral RNA which is converted into a viral DNA by the help of viral enzymes after they are released into the cell. This third process is called **reverse transcription**. The viral DNA can then cross into the nucleus of the CD4 cell and integrate itself into the DNA of the CD4 cell with the help of the **integrase** enzyme. As the DNA of the CD4 cell replicates, a process every cell goes through to make more proteins for its survival, more copies of the **integrated viral DNA** are made. This fifth process of **replication**, uses the cell's own mechanism to produce all the components (proteins) of the virus: viral enzymes, RNA and capsid.

These components move out of the nucleus and are **assembled** at the surface of the cell. A protease enzyme helps in putting together pieces of proteins needed to form a complete infectious virus which then buds off the cell membrane using the host cell's glycoproteins to form viral envelope through a final process of **budding**. The virus is then matured and ready to infect nearby healthy cells. Meanwhile, the infected CD4 cell will get exhausted after several rounds of **binding-fusion-transcription-integration-replication-assembly-binding** and then dies off. [See Figure 3 for illustration of HIV life cycle and sites of drug action] (AIDSinfo, 2016; AVERT, 2017).

2.4 HIV infection in women

Women have been shown to be at higher risk of contracting HIV compared to men. The physiological organization of their reproductive system has been identified as the cause. The vaginal anatomy provides a greater surface area for viral activity and infection (Tebit, Ndembu, Weinberg, & Quiñones-Mateu, 2012).

It has also be found out that children below the age of 15years are mostly (over 90% of the time) infected through pregnancy, delivery and breastfeeding. Reducing mother-to-child transmission (MTCT) will yield a 90% fold reduction in childhood infection which is associated with significant mortality. The worsened childhood disease is as a result of the unmet ART needs in this group. The best cost effective way of dealing with this is to halt the infection from being transmitted to children in the first place (Stanzi, Elaine, Roux, Abrams, Nguyen, & Myer, 2016).

Since the first case of HIV was recorded in Ghana in 1986 till about 2002, about 90% of all infections were recorded for people in their reproductive ages, with young women being the majority (MOH, 2002). In 2014, the Ghana AIDS Commission reported prevalence of HIV among men between 15-49 years to be 1.1 whilst for women in the same age group is 2.8 (GAC, 2016a).

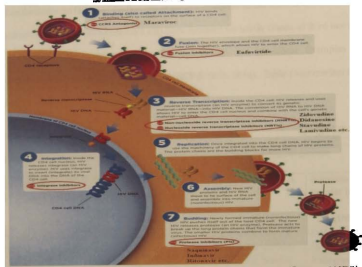
2.5 Antiretroviral therapy

Antiretroviral therapy is the drug treatment for HIV and AIDS. It slows the progress of the infection, thereby reducing development into more advanced clinical stages of AIDS, suppressed immunity and opportunistic infections. The main aim of ART is to improve quality of life and reduce the rate of hospitalization among persons living with the infection as well as reducing mortality (Joint Formulary Committee, 2016).

The medicines are in many classes and perform different pharmacological functions. However, for effective treatment, two or more drugs must be combined in one patient. This treatment strategy is referred to as combination antiretroviral therapy (cART). It is also called highly active antiretroviral therapy (HAART) (NACP & GHS, 2016).

Review of recent evidence by the technical working group of the World Health Organization maintains the use of combination antiretroviral therapy (cART) comprising of two drugs from the nucleoside reverse transcriptase inhibitor group and one drug from the non-nucleoside reverse transcriptase inhibitor group as the first line choice of medicines for treatment of HIV infection (WHO, 2013a).

The aim of combination ART is to attack the virus at multiple stages of its life cycle so as to prevent mutation of the virus and subsequent resistance to the medicines which can occur when single dose regimen is used. Figure 3 shows the life cycle of HIV and the site of action of the various types of antiretroviral medications.



Source: (AIDSinfo, 2016)

Figure 3 HIV life cycle and antiretroviral therapy designed to stop HIV at each stage.

Examples of the nucleoside reverse transcriptase inhibitors in use in Ghana are Lamivudine (3TC), Zidovudine (AZT/ZDV), Abacavir (ABC) and Emtricitabine (FTC). Tenofovir is a Nucleotide reverse transcriptase inhibitor which can be used when AZT or ABC are contraindicated in a patient. The non-nucleoside reverse transcriptase inhibitor in current use are Efavirenz (EFV) and Nevirapine, NVP (NACP & GHS, 2016).

In the treatment of HIV-type 2, the non-nucleoside reverse transcriptase inhibitors are not used. They are replaced by the Protease inhibitors. Examples of protease inhibitors are Lopinavir (LPV/r), Atazanavir (ATV/r), and Darunavir (DRV/r). All these three are boosted with a low dose protease inhibitor known as Ritonavir. The protease inhibitors are also considered as second line

options for treatment failure of the first line regimens. Integrase strand transfer inhibitors are group of antiretroviral medicines which have also been accepted for use in Ghana as third line regimen for managing treatment failure to the first and second line medicines. Examples include Dolutegravir (DTG) and Raltegravir (RAL) (NACP & GHS, 2016). Table 1 summarizes the ART guidelines in Ghana.

Table 1 Antiretroviral therapy in Ghana

Recommended antiretroviral drugs in Ghana in their pharmacological groups			
Nucleoside reverse transcriptase inhibitors (NRTI)	Non-nucleotide reverse transcriptase inhibitors (NNRTI)	Protease inhibitors (PI)	Integrase strand transfer inhibitors (INSTI)
Zidovudine (AZT or ZDV)	Nevirapine (NVP)	Ritonavir boosted Lopinavir (LPV/r)	Dolutegravir (DTG)
Lamivudine (3TC)	Efavirenz (EFV)	Ritonavir boosted Atazanavir (ATV/r)	Raltegravir (RAL)
Abacavir (ABC)		Ritonavir boosted Darunavir (DRV/r)	
Emtricitabine (FTC)			
Tenofovir (TDF) is the only Nucleotide reverse transcriptase inhibitor (NtRTI) in use in Ghana			
First Line ART regimen			
Preferred regimen	Dosage	Caution	Comments
Tenofovir + Lamivudine (or Emtricitabine) + Efavirenz	Once daily dosage at night	Not to be taken with oily meals. Be taken 3 hours after meals. Caution with Tenofovir use in renal dysfunction	Monitor renal function including urinalysis
Alternative regimen			
Tenofovir + Lamivudine (or Emtricitabine)	Tenofovir + Lamivudine taken daily after meals	Nevirapine is contraindicated in liver dysfunction and hypersensitivity. Use	Stop Nevirapine if client develops rashes or jaundice and call for advice

+ Nevirapine	Nevirapine taken twice daily after meals	with caution	or refer for further management
Second alternative			
Zidovudine + Lamivudine (or Emtricitabine) + Nevirapine	Fixed combination to be taken twice daily after meals	Zidovudine is contraindicated in severe anaemia	AZT should be changed to TDF if Hb falls below 25% of baseline value. Also use TDF if Hb is less than 8g/dl
Second Line ART regimen			
First alternative regimen		Comments	
Zidovudine + Lamivudine (or Emtricitabine) + Lopinavir/r (or Atazanavir/r)		Zidovudine is to be used if client used Tenofovir-based first-line regimen in the past. Also if Lopinavir/r was used for HIV-2 in the past, use Atazanavir/r	
Second alternative regimen			
Tenofovir + Lamivudine (or Emtricitabine) + Lopinavir/r (or Atazanavir/r)		Tenofovir is to be used if Zidovudine-based first line regimen used in the past. Consider Abacavir if client has used both Tenofovir and Zidovudine	
Third Line ART regimen			
First alternative regimen		Comments	
Darunavir/r + Dolutegravir (or Raltegravir) ± 1 or 2 NRTI		Darunavir must be taken with food. Dolutegravir and Raltegravir can be taken with or without food	
Second alternative regimen			
DRV/r + 2 NRTIs ± NNRTI		For patients that have used protease inhibitors in the past, Darunavir should be given twice daily.	

Source: NACP, 2016

Further information can be found in the NACP's 2016 ART guidelines for further regimen combinations in children, adolescents, dual HIV-1 and HIV-2 or only HIV-2 infections and in patients who are co-infected with Hepatitis B (NACP & GHS, 2016).

2.6 Prevention of mother to child transmission of HIV

The first attempt at recommending treatment for preventing MTCT was by the US Public Health Service in December 1985. Subsequently in 1998, and in recognition of available evidence, the Interagency Task Team on the Prevention and Treatment of HIV Infection in Pregnant Women, Mothers and Children (IAAT), was established which supported pilot intervention to test PMTCT in resource limited settings and subsequent scale up activities through non-governmental international collaborations and local commitment efforts (IAAT, 2016).

2.6.1 Clinical studies

Review of clinical studies in the past two decades reveal some ground-breaking researches notably the ACTG 076, conducted in 1994 which demonstrated that administration of Zidovudine to mother and baby reduced HIV transmission by 67.5% (Connor et al., 1994). The use of Nevirapine in a single-dose regimen at the onset of labour was shown in 1999 by the HIVNET-012 study conducted in Uganda to also reduce the risk of MTCT, a finding with the potential for implementing PMTCT on a wider scale in resource limited settings (Jackson et al., 2003). The safety of short course Zidovudine for preventing MTCT was investigated in a randomized trial in Cote d'Ivoire and showed estimated risk in placebo and treatment group of HIV-1 transmission at 24.9% and 15.7% respectively (Wiktor et al., 1999). Combined use of single-dose Nevirapine and standard dose Zidovudine prenatally and during labour and delivery was demonstrated to further reduce the risk of MTCT to less than 10% in another study conducted in Thailand (Lallemant et

al., 2004). More recently in 2008 and 2010, new studies focusing on more extended use of antiretroviral medicines in mother and/or infant to cover pregnancy and postnatal periods showed 50% decrease in HIV transmission during breastfeeding (Connor et al., 1994; Kumwenda et al., 2008; Shapiro et al., 2010).

2.6.3 Global response

Combination of the above interventions to expand PMTCT scope and further reduce transmission of HIV through pregnancy and postpartum to less than 5% was made possible through the leadership of the World Health Organization (WHO) by publishing periodic PMTCT guidelines (Adler R. et al., 2013).

The pioneer guidelines developed by the WHO to prevent mother-to-child transmission of HIV is preventive in approach, referred to as the Option A guidelines. This approach requires prophylactic ART for mother during delivery and breastfeeding and prophylaxis for baby for 3-6weeks. Improvements in data and evidence had informed the scale up of option A to Option B that requires immediate comprehensive ART cover for infected pregnant women until they cease breastfeeding and prophylactic ART for baby from birth till six weeks and Co-Trimoxazole till cessation of breastfeeding. Option B recommends lifelong ART for only women with significant immunosuppression as measured by the CD4+ cell count or WHO clinical staging (WHO, 2013a).

The most recent recommendation is lifelong antiretroviral therapy (ART) in women enrolled into PMTCT regardless of CD4+ cell count or clinical staging in the 2013 guidelines. The new guideline, referred to as the PMTCT Option B+ (WHO, 2013b) which is a scale up of Options A and B is meant to simplify and harness the benefits demonstrated in several clinical trials and other supporting studies (Adler et al., 2013). The new approach promised increased chances of survival

and reduced risk of mother-to-child transmission of HIV (MTCT) at a reduced cost to health systems and patients (Ishikawa et al., 2014). It also simplifies PMTCT services by reducing the need for assessing eligibility through CD4+ cell monitoring and switching between different regimens that were associated with the earlier options and which pose great challenges to health systems of lower and middle income countries. In addition, the scale up requires integrating PMTCT services with maternal antenatal care so as to improve access and uptake of these services (Adler et al., 2013; WHO, 2010).

The Joint United Nations Programme on HIV and AIDS (UNAIDS) has in 2010 developed the global plan towards eliminating new HIV infections among children by 2015 and keeping their mothers alive in 22 priority countries which contribute more than 90% to all new infections in children worldwide. New infections in children at the time was recorded at 370,000 and an estimated 42,000 to 60,000 pregnant women died because of HIV (UNAIDS, 2011a). The target was to achieve 90% reduction in vertical transmission of HIV in these low and middle income countries. However, at the end of 2014, 48% reduction was recorded as against the 90% target though that was an improvement from the earlier period by some 400% (UNAIDS, 2014a).

In the midst of the challenges, however, increased access to comprehensive HIV and pregnancy care in resource-limited countries, though faced with appreciable barriers, has resulted in marked reduction in perinatal transmission of the infection from more than 570,000 in 2003 to about 110,000 in 2015 within the 21 Global Plan priority countries in sub-Saharan Africa (UNAIDS, 2014a, 2016b). The new global target is to achieve zero percent transmission rate in keeping with the objectives of the Sustainable Development Goals (SDGs) and the global strategy to elimination HIV by 2030 (UNAIDS, 2011a, 2011b, 2016c).

2.6.4 Ghana's efforts to reduce maternal transmission of HIV

Ghana's first guidelines on PMTCT was published in 2002 with the aim of providing comprehensive healthcare to people living with HIV and AIDS. Among the different populations groups viz, heterosexual, homosexual, transgender and others, heterosexual transmission of HIV remains the highest mode of infection today. The 2000 sentinel surveillance report estimated the rate of mother-to-child transmission of HIV to be 15% (MOH, 2002). The same report in 2016 reports that the 2014 figure for the same parameter was 15.97 (GAC, 2016a).

Ghana has rolled out the Option B+ PMTCT strategy in July 2015 in order to improve survival of women and reduce perinatal transmission. It is worth noting that incidence of HIV among first registrants in antenatal clinics in Ghana was 2.4% in 2016, an increase from 1.6% recorded in the previous year. Mother-to-child transmission rate was recorded at 12% in 2016 which is still below the 5% target envisaged. Retention in PMTCT care postpartum has been mentioned as the main factor hampering progress towards the achievement of that goal (NACP & GHS, 2016, 2017).

2.6.5 Delivering PMTCT in the clinical setting

Ghana's health system, just like any other is made up of different cadres of professionals who are involved in rendering care to patients. In the delivery of PMTCT service, the client is picked through testing and counselling at the antenatal clinic (ANC) and referred to ART clinic for continuation of ART care while she still receives antenatal care at the ANC. Laboratory investigations are done by medical laboratory scientists who are also responsible for taking blood samples on schedule clinic days. Medicines are dispensed by pharmacists or other trained pharmacy staff.

The above process is simplified in many cases in order to improve upon service delivery and reduce

fatigue of patients in moving from one unit to another. There are recommendations to integrate PMTCT services within maternal and child healthcare services. A systematic review to assess retention in these integrated services in resource constrained regions showed low retention rates (Adler, et al., 2013; Tudor et al., 2013).

2.7 Retention in HIV care

Retention in care (RIC) is required to achieve successful suppression of HIV, provided adherence to ART is improved. The benefits are increased survival and improved quality of life. Retention is very crucial in PMTCT. Whilst about 70% compliance to treatment is required in general ART to achieve sufficient viral suppression, approximately 90% retention is required at each step of the PMTCT cascade to effectively reduce transmission of HIV to exposed babies (Ambia & Mandala, 2016). A systematic review of 44 studies in SSA however, revealed that of 94% pregnant women tested for HIV, 70% of HIV-positive mothers initiated ART, 64% of HIV-exposed babies were tested for HIV at six weeks and only 55.0% of this number had their final diagnoses communicated to their mothers or care givers at 18 months (Wettstein et al., 2012).

Retention in care is critical for the success of organized medical care and has been used in implementation research and programme surveillance (Assefa et al., 2012). The concept had been explored by different authors using different approaches. Assefa et al., (2012), defined Retention operationally as 'patients who are not registered as dead or lost to follow-up (LTFU) for any reason'. They authored a paper that sought to develop simplified tools for measuring retention in care. Their definition described the number of patients who are alive and on treatment. The term retention in care can be used in any organized system where patients must be followed up for continuity of care (Assefa et al., 2012).

Lost to follow-up (LTFU) is defined as 'patients who miss scheduled visits to the clinic within three months after the last visit'(Assefa et al., 2012). Retention in care can be divided into subsets in order to bring some clarity and answer the concerns of the INSPIRE team who conducted a study on behalf of the WHO and concluded that there is difficulty in standardizing the definition of RIC (Rollins et al., 2014). '*Current retention*' describes retention rate during a specific period among clients who were on treatment sometime during the period. '*Cohort retention*' is the retention determined at the end of a specific period among a cohort of patients ever started on treatment and followed longitudinally overtime (Assefa et al., 2012). '*Cumulative retention*' and '*Probability of retention*' were also used in the study above to mean, respectively, the total cohort retention by the end of the follow-up period among patients ever started on ART and the probability that a patient would be retained in care after a certain time period on treatment (Assefa et al., 2012).

Some of the concerns raised by the INSPIRE team is that, definition of retention in PMTCT is particularly challenging due to the fact that retention as a concept has, embedded in it, the idea of continuity and access to services when needed. There is the assumption that patients who are retained in care are compliant and that they receive the care at all stages of therapy. They also identified that some studies that measures retention define full retention in care as the attendance to clinic of mother-baby pairs at 12 months postpartum and ignores what happens in-between (Rollins et al., 2014). A longitudinal cluster randomized trial study in SSA employed a five-step, facility-level systems analysis and improvement intervention (SAIA) that addressed the above challenges (Sherr et al., 2014).

2.8 Retention in care measurement and tools

Measuring retention in care is critical to evaluate programme efficiency. A very important issue of implementation research is that the outcome should be relevant to programme managers and care givers. However, the measurement tools currently employed in calculating retention such as the Kaplan Meier (the most common) requires advanced software and statistical skills to do the survival analysis and calculate the hazard ratios. The methodology is relatively complex for facility-based care givers (Assefa et al., 2012). In addition, an analysis of six different tools for measuring RIC reveals that there is little harmony between them (Mugavero et al., 2013). The difference in retention rates calculated by the above tools is due to the difference in the definition of retention adopted by the authors.

A simplified tool for measuring current retention and cohort retention have been assessed by a group of researchers from Addis Ababa and Belgium. The authors, in a bid to address the above challenges, create subsets of retention and calculated retention rates along the cascade of care (Assefa et al., 2012).

Another tool that addressed the challenges with measuring retention in care is the PMTCT cascade analysis tool (PCAT) described under section 3.11.3. It was developed, tried and adapted for use in resource-limited settings (Gloyd et al., 2014; Sherr et al., 2014; Gimbel et al., 2014). Inherent in this PCAT is the ability to inform facility care givers and programme managers, the areas that interventions should be concentrated in order to achieve maximum outcome (Gimbel et al., 2014). The tool is also able to calculate retention at stages of the programme deemed to be most crucial for successful clinical outcomes of exposed babies.

2.9 Retention in care in sub-Saharan Africa

A systematic review of 34 peer-reviewed studies was aimed at identifying interventions to improve PMTCT service delivery and promote retention in Africa. Twenty-one of these studies aimed to improve ART initiation after HTS, eight was aimed at improving retention in the programme, nineteen to improve uptake of early infant diagnoses (EID) and two, to improve early initiation of infant ART. The studies reviewed were conducted in South Africa, Kenya, Mozambique, Malawi, Democratic Republic of Congo, Swaziland, Tanzania, Rwanda and Ethiopia. One study from the USA was also included. The review investigated interventions such as male partner involvement, peer mentoring, conditional cash transfer, community health workers, training of midwives, integration of PMTCT in routine maternal and child healthcare, mobile phone-based interventions and enhanced referral. It was concluded that mobile phone reminders increase uptake of early infant diagnoses (EID) of HIV, male partner involvements result in reduced infant infection, while the effects of other interventions on improving effectiveness of PMTCT were not clear. The review recommended further studies and stronger evidence on long term effects of interventions to improve retention throughout the PMTCT steps (Ambia & Mandala, 2016).

The subject of RIC in sub-Saharan Africa has been explored to some extent in General ART care but little is done in PMTCT care especially in West Africa.

Another study in Kenya aimed at exploring factors enhancing utilization of and adherence to PMTCT services identified disclosure, male partner involvement and stigma as the major hindrances to uptake of and retention in care. The mixed method study revealed that access to quality care within a functioning health system, coupled with health education alone does not improve the effectiveness of PMTCT; but rather harnessing the positive effects of these facility

and provider-related factors in the context of the patient and her immediate social environment (Murithi et al., 2015). This study improved the outcomes of a Nigerian study that sought to suggest that knowledge of PMTCT, community sensitization, availability and access to services are required for uptake of these services (Arulogun, Adewole, Olayinka-Alli, & Adesina, 2007).

A retrospective cohort study involving 346 pregnant and breastfeeding mothers conducted in Ethiopia found a cumulative proportion of LTFU at 6, 12 and 24 months as 11.9%, 15.7% and 22.6% respectively. The rate was higher among younger women, those missing baseline CD4 test and those initiating ART on the day of diagnosis as well at women attending large hospitals as compared to those attending clinics located within the communities (Mitiku et al., 2016).

2.10 Experiences of women in PMTCT and programme challenges.

Though progress has been made in providing access to care and treatment of pregnant women infected with HIV, uptake remains low.

The health seeking behaviour of women in PMTCT is explained in an Information-Motivation-Behavioural (IMB) skills model by Smith et al (2012). The authors postulated that patients in chronic medical care requiring continuous follow-up clinical visits must be equipped with the right information, they must be well motivated and also possess the desired behavioural skills in order to remain in care (Smith, Fisher, Cunningham & Amico, 2012). This brings to the fore the interplay between patient and facility level factors tailored towards equipping the client with the right information that will produce the needed motivation to acquire required skills needed in self-management of chronic medical issues.

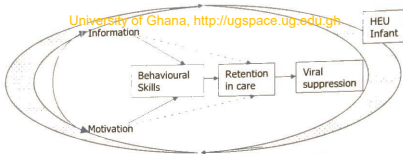


Figure 4 Information-Motivation-Behavioural skills model of retention in HIV care
(Adapted from Smith et al, 2012)

A systematic review and meta-analysis of 51 studies out of 72 original articles involving 20,153 HIV-infected pregnant women conducted to investigate ART adherence during and after pregnancy in low, middle and high income countries found out that only about 73.5% of pregnant women achieve optimal ART adherence. Pooled proportion of adequate adherence was higher during pregnancy than after. Barriers reported for nonadherence include physical, economic and emotional stress, postpartum depression, alcohol and drug use and ART pill burden. Reviewers recommend further research to investigate geographically-specific barriers and interventions to address them as an urgent need (Nachega et al., 2012).

The Ghana AIDS Commission has also admitted that lack of logistics was responsible for low programme coverage in 2014 as compared to previous years (Ghana AIDS Commission, 2014). Logistics constraints include unavailability of testing kits, reagents, PCR inputs, among others. Supply chain challenges have also been identified. Other health systems factors identified in a study conducted in Kumasi in Ghana are inadequate counselling, perceptions of privacy and confidentiality, waiting time, poor relationship with healthcare staff and fear of being positive (Kwapong, Boateng, Agyei-Baffour, & Addy, 2014).

A study in South Africa explored the feasibility of mobile health services and community directly observed therapies (DOT) as intervention to improve adherence to ART. The study found out that majority of women would want to be contacted on schedule reminders, motivational and medication updates. A greater percentage also can identify a person to be nominated as a community DOT supporter. However, concerns regarding supporter time availability and risk of unintended status disclosures, coupled with security of text messages were expressed (Nachega et al., 2016).

Barriers to uptake of PMTCT in a Nigerian study identified, 'forgetfulness' and 'falling asleep' as the reason for poor adherence to ART. 'Financial constraints' hampered attendance to clinic and 'delivering at home' was the reason for not initiating infant prophylactic Nevirapine (NVP) or Zidovudine (AZT). Lack of male partner support, preference for traditional birth attendants, unawareness of status, stigma and discrimination have also been identified as barriers to service uptake (Anigilájé et al., 2016). A study done in Kenya, Lusaka and Zambia also found women expressing similar concerns as barriers to compliance to PMTCT (Murithi et al, 2015; Auvinen, Kylmä, Välimäki, Bweupe & Suominen, 2013). Supportive counselling, striving for motherhood, assurance of confidentiality, affirmation and admiration were identified as factors facilitating uptake of care (Murithi et al., 2015). Women are also unable to insist on safer sex practices though they are aware of the negative consequences as reported in a study done in Botswana and Zambia (Gupta, ICRW & USA, 2000).

2.11 Summary and Conclusion

There is increasing interest in the subject of retention in HIV care and recently in PMTCT by programme managers and development partners in all 21 priority countries in Africa. There is

general recognition of the vulnerabilities of women and children because their fundamental human rights are widely abused in resource-limited regions; a clear violation of the UN Declaration of Fundamental Human Rights (UN General Assembly 1948). Access to PMTCT services is therefore a fundamental right of women and their unborn children. No child, with no fault of his/hers should be infected with HIV and concerted efforts must be expended towards virtual elimination of MTCT.

The complexities of steps required to be complied with in PMTCT coupled with lifelong drug therapy in a seemingly healthy young person are recognized challenges in this case. Of all SSA studies discussed, little was seen in West Africa. There is also few qualitative studies capturing the experiences of these women enrolled into the programme along the steps. Factors that affect retention need to be explored, especially in West Africa so as to inform policy decisions and improve service delivery. Ghana began enrolling the Option B+ policy in July 2015 but continues to record high rates of perinatal HIV transmission. The 2016 sentinel survey reported high HIV prevalence in the Volta Region of Ghana and reduced success in PMTCT intervention. There is however, limited understanding of the reasons associated with these findings (NACP, GHS & MOH, 2016).

This work aimed at using user-friendly and less complex methodologies to display the flow of women along the PMTCT cascade as well as explore the reasons for attrition among women enrolled. This will serve as a proxy in understanding the high rates of mother-to-child HIV transmission.

3.0 METHODOLOGY

3.1 Introduction

This chapter presents the approaches adopted to determine the level of retention at the study site and also to explore factors that are likely to affect retention rates. Retrospective analysis of secondary data was done to calculate retention while qualitative data collected using in-depth interviews was analysed using manual code extraction and interpretation. This chapter also covers a description of study design, location, inclusion and exclusion criteria employed in recruiting study population, sample size determination, sampling approach, ethical issues, data collection methods and tools. How data was analysed has also been presented in this chapter.

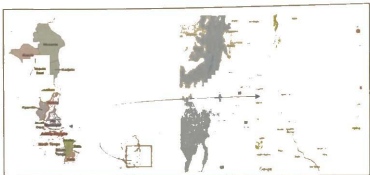
3.2 Study design

The study was a descriptive cross-sectional and explorative study incorporating both quantitative and qualitative study designs. The design generally employed descriptive analysis of retrospective data and qualitative methodologies.

3.3 Study location

The Ho Municipality is located in the Volta Region of Ghana (refer to map in Figure 5). According to the 2010 Population and Housing Census, the municipality made up about 8.4% of the nation's population with a sex ratio of 89.7. The General fertility rate of the municipality is 74.4 births per 100 women aged 15 to 49 years (Ghana Statistical Service, 2014). The 2014 status report of the Ghana AIDS Commission put the number of pregnant women screened for HIV in the region at 47,901 with 3% rate of infection among those tested. The number of babies screened after PMTCT

stood at 110 as at 2014 with 3% failure rate (Ghana AIDS Commission, 2014). The municipality has a high urban population of 62% served with one regional hospital, one district hospital, few privately owned clinics and a number of health centres and CHPS zones/compounds.



Source: ghanadistricts.com

Figure 5 Map showing Ho Municipality within the Volta Region of Ghana

The Ho Municipal Hospital is a 140 in-patient bed capacity primary healthcare Ghana Health Service facility within a catchment with population of 1147 and 4% pregnancy rate. The total antenatal attendance registered for the period under study is 3,101. Out of this number, the hospital detected a total of 34 HIV positive cases. However, the hospital also serves as a PMTCT referral centre for a number of maternal and child health clinics within the municipality. The Antiretroviral Treatment Clinic of the hospital registered 69 pregnant women in PMTCT care between January 2014 and January 2016 (Ho Municipal Health Directorate, 2017; Ho Municipal Hospital, 2017).

3.4 Study population

The primary study population was pregnant women reporting for ANC and who were offered HIV testing and counselling services (HTS) between January 2014 and December 2015.

A second study population was PMTCT providers at the facility. These are the professionals actively involved in offering ANC, HTS, ART, prophylaxis and other maternity services specially tailored towards reducing transmission of HIV from pregnant women to their babies. The providers were selected to give detail information on their experience with the programme and also to triangulate information received from mothers enrolled in care and who have consented and gone through the qualitative interview. Enrolment of PMTCT staff was done by convenience and availability. They were required to provide in-depth knowledge about PMTCT successes, challenges and limitations that are peculiar to the study location.

Inclusion criteria

1. All pregnant women who initiated antenatal care visit at the study location prior to diagnosis are eligible.
2. All newly diagnosed of HIV-positive pregnant women from January 1st 2014 to December 31st 2015.
3. All HIV-positive pregnant women who are successfully undergone PMTCT within the period
4. Study participants for qualitative data must be reachable by phone or home visit
5. Healthcare providers to be enrolled in qualitative study must be trained and knowledgeable in PMTCT and must be providing service at the study location before January 1, 2014.

Exclusion criteria

1. HIV-negative pregnant women
2. Women enrolled in PMTCT before 1st January 2014 and after 31st December 2015
3. Healthcare providers rendering PMTCT after 1st January 2014
4. Healthcare providers not involved in ART

3.5 Study variables

The following variables have been shown in available literature to be associated with the research objectives. They were explored to find out how far each of them relate to the situation at the study location. Refer to the table below:

Table 2: Table of variables and measurement

Variable Name	Measurement
Provider-Level factors:	
Age of care giver	age at last birthday
Sex of care giver	Male, female
Type of counsellor	Peer counsellor, nurse, doctor, pharmacist, other
Number of years in PMTCT Service	More than 5 years, 2-5 years, below 2 years
Counselling	Informed, not informed, motivated, not motivated
Privacy	High level, Moderate level, low level, no privacy
Technical expertise	Trained, not trained, experienced
Logistics availability	Excellent (>90%) Very good (70-90%), Good (40-60%), poor availability (<40%)
Cascade flow flexibility	Simple, adaptable, complex, rigid
After-clinic support	Phone call, SMS, home visit. [very often, not often, not at all]
Maternal care	Excellent, Very good, good, poor, very poor
Acceptance	Accepted, not accepted, rejected, insulted
Assurance	Assured, not assured, encouraged, discouraged, motivated, not motivated

Patient-level factors

Age of patient	Age at last birthday
Marital status	Married, not married, widowed, not widowed, cohabiting, other
Educational status	Tertiary, senior high, junior high, primary, no education
Occupation	Teacher, nurse, banker, trader, farmer, other
WHO clinical stage before ART	Stage I, Stage II, stage III, stage IV
ART experience	Before pregnancy, after pregnancy
Adherence to ART	Always take my medicine (misses ≤ 2 doses per month), forget to take medicines most of the time (>7 days in a month), forget to take medicines a few times (3-7days in a month)
PMTCT literacy	Very good, good, poor
ART regimen	TDF/3TC/EFV, TDF/3TC/NVP, AZT/3TC/EFV, AZT/3TC/NVP, other
Mode of delivery	Clinic with PMTCT support, clinic without PMTCT support, home, SVD, C/S, by doctor, midwife, student, TBA, other.
Time of infant prophylaxis	Immediately after birth, $>1-2$ weeks after delivery, >2 weeks
Infant feeding choice	Exclusive breastfeeding for 6months, breastfed for 6-1 year, no breastfeeding (specify feeding option),
HIV status disclosure	Disclosed (Husband, mother, sibling, friend) no disclosure,
Male partner support	Good support, little support, not support, not informed, left due to status
Family support	Good, little, rejected, not aware of my status,
Culture and religion	Against PMTCT, support PMTCT, no effect
Stigma	Ashamed, not ashamed, motivated, dejected
Discrimination	High discrimination, less discrimination, no discrimination, no one knows about my status
PMTCT supporter relations	Available, not available, helpful, not helpful

3.6 Sample size determination

3.6.1 Quantitative sample size

Sample size formula for determination of proportion, (for example, proportion of retention) is given (based on Leslie Kish formula, 1965) by:

$$N = \frac{z^2 p (1-p)}{d^2}, \text{ where:}$$

N = sample size

z = z value for 95% confidence interval = 1.96

p = estimated proportion = prevalence of pregnant women with HIV at first ANC = 2.4% (NACP, 2016)

d = maximum error allowed = 5% = 0.05

Therefore,

$$N = \frac{(1.96)^2 * (0.024) * (1-0.024)}{(0.05)^2} = 36$$

Meaning that a minimum of 36 HIV positive pregnant women taken from the population of all HIV positive pregnant women at any of the PMTCT sites countrywide will be enough to describe proportion of retention. This is because a national average of 2.4% was used. This figure is higher than a proportion of 1.0% calculated from the study area. The sample size calculation has therefore been stretched beyond the limits imposed by the study location.

Total number of women registered in PMTCT care within the study period = 69

Total number of women sampled for retention calculation = 69

Total sampling approach was however adopted in reviewing background data found to be complete

and relevant for answering the research questions. This was done because the study population is a specialized group of pregnant women who were enrolled into a specialized programme for the period under study. Majority of studies reviewed used similar approach. The quantitative data analysed in this study did not require response from patients, but rather a retrospective records review. The complete data available was therefore conveniently assembled for analysis.

3.6.2 Qualitative sample size

The total sample of patients satisfying the inclusion criteria was sampled for in-depth interviews. Women enrolled in PMTCT from January 2014 to December 2016 were offered the opportunity to enrol. Qualitative data was collected from participants until saturation point was reached. A total of 12 respondents took part in in-depth interviews.

The total number of caregivers available at the facility were recruited and asked to partake in the study. Effort was made to include all the diverse professional groups involved with rendering one service or the other in the discussions. Seven healthcare providers including one each from antenatal clinic, labour ward, laboratory, two from ART and Pharmacy were selected for qualitative data collection.

3.7 Sampling method/approach

3.7.1 Quantitative sampling approach:

A non-probability (convenience) sampling method was used for the collection of sample data. Data of clients who satisfy the inclusion criteria were retrieved.

A report of clients who were newly registered in PMTCT from 1st January 2014 to 31st December 2015 clients was requested from the ART data manager. The date of initiating antiretroviral therapy for each patient was also retrieved from the ART database. The pregnancy status of each

patient prior to initiating PMTCT was confirmed and the list updated in order to select only clients who satisfy the inclusion criteria.

3.7.2 Qualitative sampling approach:

A convenience purposive sampling approach was adopted to select respondents for in-depth interviews.

Qualitative sample was selected after review of background data. During the review, characteristics of patients that depict good understanding of the programme was taken note of. Example of these desirable characteristics are clients who have never missed a scheduled visit, those who have successfully completed PMTCT in the past and those whose clinical records showed improved outcome after ART. Patients whose background data suggested that they had challenges with the programme were also identified. Some of the characteristics that depict challenged patients are those who default multiple times during the period, those whose clinical symptoms suggested advanced disease, those with high viral load or low CD4 cell count, divorced women, those who were living in discordant relationships, patients with incomplete background data and any patient who have gone through the programme but the baby tested positive. A list of 40 patients were compiled by use of identity numbers previously generated from the ART database and are unique for each patient. This list was given to the data manager to identify them and make phone calls to schedule date for administering informed consent and in-depth interview of consented participants. A total of 21 meetings were scheduled.

The above approach was adopted in order to explore balanced view of diverse patient groups.

Healthcare providers directly involved in rendering PMTCT services were conveniently sampled. Where the head of department is not directly involved, the designated staff was asked to enrol.

Figure 6 shows the sampling approach adopted in recruiting patients whose data were to be reviewed as well as decide on who to recruit for in-depth interviews:

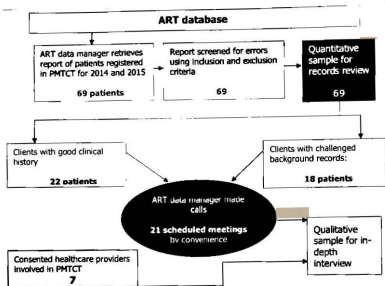


Figure 6 Schematic diagram of sampling approach

Source: Developed by Author, 2017

3.8 Data collection method/approach

3.8.1 Quantitative data collection method

A request for monthly antenatal returns was made to the nurse in charge of the ANC unit. The total number of pregnant women reporting for ANC between January 2014 and December 2015 was retrieved from the ANC records. The number of pregnant women offered HIV testing and counselling services (HTS) as well as number testing positive for HIV was also captured.

The total number of pregnant women referred to ART and registered in PMTC was later picked

from the ART clinic. Researcher introduced himself to unit heads and schedule meeting days that were convenient for them in order to access the required information. Reports given were reviewed and information needed retrieved and captured using a Microsoft® Excel computer application. The excel sheet is password protected. Copies of monthly returns and patient information were not made. A request for catchment data was sent to the Ho Municipal Health Directorate and data on catchment population and pregnancy rate were retrieved. Municipal ART Coordinator was also contacted and further clarification on available data assessed was sought from him.

Review of demographic and other clinical characteristics was also done using a data extraction tool to capture retrospective PMTCT records of all 69 patients. Data manager provided access to the PMTCT folders from which required data was gathered. Variables retrieved from folders include age, marital status, religion, occupation, level of education, dependants less than 18 years, age of pregnancy at registration, WHO clinical stage of patient, ART regimen used, expected date of delivery and follow-up dates. The last visit date of client was also recorded. Whether or not patient is alive, transferred out, loss to follow-up or defaulted was also captured with the help of data manager.

Labour and delivery records were retrieved from the labour with the help of the midwife in charge. Delivery record book for the period under review was provided. Clients on PMTCT who delivered at the facility were marked with a symbol making it easy for investigator to identify and cross-check with the list from ART. At this point, names of clients were used to pick data and recorded against their codes but the names were not captured on data extraction tool. Date of labour, age of pregnancy at the time of delivery, mode of delivery and baby's birth weight were recorded.

Records capturing the provision of prophylactic Zidovudine or Nevirapine for babies were

retrieved from the pharmacy department. Babies were bearing their mother's names at the time, making it possible for cross-checking against each patient and recording it as such.

Dried blood spot for early infant diagnosis, test results and DNA PCR test after 18 months was retrieved from the records at the ART. At the ART both mother and baby's names were written against the test results.

3.8.2 Qualitative data collection method

Meeting time and place was agreed between researcher and participants. This was done with support from facility caregiver. Though arrangements were made to use a sister facility as the preferred place for in-depth interview for patients, only two consented to the use of that facility. Ten of the patients preferred to be interviewed at the study site. Informed consent was read and interpreted to clients. Oral consent was given and recorded before interviews began. No participant offered to be interviewed at home. One respondent consented with the condition that less than 30 minutes be spent in interactions. Two recruits declined to participate. A total of 12 interviews were conducted out of a total of 40 eligible clients. Face-to-face interviews were conducted for each participant which lasted on average for about 35 minutes (minimum 20 minutes; maximum 56 minutes). The interviewer was seated while the patient was made to seat across and facing him with a table in-between. Participants were allowed to adjust their seating posture to ensure maximum comfort.

All healthcare providers responsible for PMTCT were offered the chance to partake in the study. One midwife working at the ANC, midwife in charge of labour ward, facility ART coordinator, one laboratory technician and member of the ART team, ART pharmacist, Pharmacy staff involved in PMTCT and ART data manager consented and enrolled into the study.

3.8.3 Data collection technique

Quantitative data was picked from secondary record. Variables such as patients' HIV status, marital status, age, clinic attendance, ART regimen, labour and breastfeeding information as well as babies test outcomes were collected using a data extraction tool described in section 3.9.1.1.

Qualitatively, data was collected by face-to-face in-depth interviews in a hospital setting. There was a tape-recording of all discussions with patients consent. Interviewer guides were used to guide discussions. Some short notes were also taken during the interviews in order to track important themes emerging. Basic information such as age, occupation, place of residence, husbands HIV status and disclosure information was received from client.

Frontline care givers, who were recruited into the study were made to seat with principal investigator for a face-to-face in-depth interviews. Tape recording and note taking was done as well. Interviewer guide used ensured that all relevant questions were asked and issues addressed.

3.8.4 Interview with patients:

The Volta Regional Hospital ART clinic was considered to be used for in-depth interview with patients. Permission was sought from facility authorities. The distance from the two hospitals is about 2.6km (eight minutes' drive; 31 minutes' walk). However, only two participants considered this arrangement convenient for them. An alternative arrangement was made and an office at the pharmacy department was used to interview three respondents. A separate office meant for use by the dietician was also prepared and used for the remaining seven interviews based on the preference of the participants.

During the interviews investigator periodically repeats what respondent had already mentioned in order to receive confirmation of emerging themes.

3.8.5 Interview with healthcare provider

Care givers were interviewed at the Ho Municipal Hospital. Date and time of interview was agreed with participants in order not to interfere significantly with their work schedule but also taking into consideration the data collection time plan. Participants were allowed to interrupt the interviews and attend to pressing work demands. Under this circumstance, the recording was paused and resumed whenever convenient.

3.9 Data collection tools

Information required for analysis was collected using tools described below:

3.9.1 Quantitative data collection tools

3.9.1.1 Data extraction tool

The data extraction tool is a modified fill-in form that was designed with predetermined fields to be completed with the help of ART data managers and staff at ANC clinic. Care was taken to include as many variables as can be possibly extracted from existing data. The data extraction tool is attached to this document in appendix I. This tool was pre-tested at the Sogakofe District Hospital and modified based on recommendations from ART data managers.

3.9.1.2 PMTCT-CAT

The PMTCT cascade analysis tool (PCAT) is a Microsoft Excel-based service monitoring tool designed by Sherr *et al* and tested in a system analysis and improvement (SAIA) trial (a cluster randomized trial) to optimize PMTCT. The study was carried out in three SSA countries using national representative samples. The findings, improvements and adaptations for use in SSA settings was published in Implementation Science. The tool was further tested by Gimbel *et al* in five clinics in Mozambique and discussed further with 27 local frontline managers. The final

version of the PCAT is simpler than the previous one and can be used by frontline healthcare providers to assess and improve on service delivery (Sherr et al., 2014).

PCAT requires data that is already available from routine service delivery to calculate the number as well as the proportion of women and children flowing through specified steps of the PMTCT cascade. It begins from the first ANC visit through HTS to ART, follow up CD4 cell count, Viral load determination, ART prophylaxis for baby and subsequent PCR testing and enrolment into regular ART of eligible children. The tool is able to provide information on the percentage retention and proportion of drop offs along the PMTCT cascade. It also has, inherent in it, a design that indicates which step, if improved will result in the highest efficiency gains (Gimbel et al., 2014). A copy of PCAT is presented in appendix 2.

3.9.2 Qualitative data collection tools

The following tools were used to collect qualitative data:

3.9.2.1 Note taking

Written note was taken by researcher using notebooks, notepads, highlighters, pencils, rulers and pens. Transcription of information recorded was done verbatim using same tools but different notebook. The two notes were compared, coded, categories created and themes extracted. The note taking was necessary and complementary to the audio recording.

3.9.2.2 Audio recording

A digital audio recording device was used in collecting digital data. Prior consent was sought from study participants. Both interviews with care givers and patients were recorded. Recording was needed to capture the details of information gathered during the interviews. Audio recording was done together with note taking, though limited notes were taken due to the face-to-face nature of

the interactions. Recording was copied and password-scripted on a CD rom and deleted from digital recorder. CD Rom was locked away in locker and kept safely in a secured place. This will be discarded after study findings are published or after two years if unable to publish.

3.9.2.3 Interviewer guides:

The interview guides are set of tools that were used in the collection of qualitative data. It was used as a guide to help keep track of issues to be discussed with patients and service providers. For the purpose of clarity and to reduce confusion, two sets of interviewer guides were adapted for use for each category of participants mentioned above. A purposive sampling technique was used to select individuals who were in a good position to give accurate information about the topic. Copies of the interviewer guide are attached to this document in appendix 3, 4 and 5.

3.10 Quality control

Data extraction tool was pretested at the Sogakofe District Hospital after a consent was sought from facility managers as well as National AIDS Control Programme. Consent from antenatal and ART managers was also sought. The data extraction tool was used to collect available data on patients at the primary study location for analysis.

In order to improve the quality of data collected, different approaches (described below) have been adopted and fused within each stage of the design: Similar information available at various units were assessed at all those units. For example, delivery information was picked from both patient's folders as well as delivery books available at the labour ward. Antenatal clinic attendance was computed from monthly report and triangulated with annual reports and also with information available at the health information department of the hospital.

Translation was made for some participants who could not speak English. Local language used was Ewe. The local language recordings were transcribed verbatim and translated at the department of languages, University of Ghana School of Languages. Back-translation was done by an independent person to ensure that information gathered was accurate. Where disagreements exist, both parties discussed and came to a conclusion.

3.11 Analysis of data

3.11.1 Quantitative analysis of secondary data

Data from retrospective record review are presented in the results section of this report in frequency tables and graphs with the help of Microsoft® Excel and Stata 14. Information on patient flow through the service cascade was entered into the PCAT (described in section 3.9.1.2) for calculation of retention level and proportion of drop offs across the cascade.

3.11.2 Qualitative data analysis of primary data

Qualitative data collected was transcribed verbatim from audio recording into a notebook. Interviews conducted in the local language were translated into English. Local language expressions that qualify to be used for theme extraction were discussed with a third party for uniformity and preservation of respondent information. Patients' responses were coded P1 to P12, such that P1 implies patient respondent one. This applied to all twelve respondents. Health provider responses were coded in like manner (HP 1 to HP 7).

The final data was coded and grouped into themes using similarities and differences in identified barriers and enablers from both patient and care-giver point of view.

Final interpretation of information gathered was done manually by researcher and presented in the analysis section.

3.12 Ethical issues

Ethical clearance was sought from the Ghana Health Service Ethics Review Committee. Data sharing agreement was signed between student and the National AIDS/STI Control Programme (NACP) and permission to use ART database was received from same authority.

Permission to conduct the study was sought from hospital authorities before commencement of the study.

Department-specific requests were made and the relevant forms filled where deemed necessary. For example, before access was granted to use patients folders, a data request form was filled and signed by hospital administrator. This also made it possible for the investigator to receive information from the DHIMS-2 on hospital background information and other relevant details from the Health Information department of the hospital.

3.12.1 Consent

All participants (both patients and providers) who participated in this study gave both oral and written consent. Facility managers provided written consent on their own behalf and also a formal permission to use data of their clients. Complete information on the study was provided. Patients who cannot read or understand English language had it read and explained to them in the local languages of their choice. *Ewe* was the only local language used during the study. Participants were informed that the conversation will be tape-recorded. One participant who gave limited time for discussions was not denied the compensation allocated. Consent forms can be found at Appendices 6, 7 and 8.

3.12.2 Compensation

Compensation was provided in the form transportation from place of residence to the discussion site. An amount of GH 20 (equivalent of about 5 USD) was given to each patient' respondent. Healthcare providers were given recharge cards as compensation for their time. Rejection of interview site and alternative site recommended by the participants was considered and agreed on by both parties. Healthcare givers at the ART were involved in arranging an alternative site for the study.

3.12.3 Confidentiality, privacy and anonymity

Participants were assured of confidentiality of all information gathered. Data retrieved from ART database did not contain patient name but coded by use of alphanumeric characters. Other tools used to gather information where patients names appear were packaged and kept at the ART clinic. There was agreement between the principal investigator and caregivers for information to be kept intact until that time that the researcher is done with final presentation of report and successful publication in scientific journal. Where investigator delays for more than 3 years, the caregivers have the discretion to safely dispose of data.

Data entered with codes and identity numbers into computerized softwares was password-protected. Duplication of data was also avoided.

3.12.4 Data storage, security and handling

Information was recorded on portable voice recorders, copied completely onto a password-protected storage device. Hard-copy recording materials and interviewer guides were safely deposited in a locked cupboard. These will be kept until final publication of the work in a peer-reviewed journal.

3.12.5 Conflict of interest

The researcher declares hereby that there is no conflict of interest in the designing, sampling methods, collection of data, findings and analysis of data. Funding of the research work and final report was borne by the principal investigator.

A data sharing agreement was signed with the National AIDS Control Programme. Due acknowledgement will be given in all publications that will emanate from this research work.

3.12.6 Potential risks/benefits

The methodology makes it possible for facility managers to see at a glance the flow of women and their babies along the programme cascades. They will be informed on the steps that will yield greater benefit if interventions are targeted there, keeping other steps as they were. The possibility to own the data analysis tool is also very likely because it is easy to use and developed purposely for frontline managers.

The patients will however need to travel from their places of residence to be interviewed. Apart from risks associated with road transport, the study did not involve any procedure on client. The working time of both consented patient and healthcare provider will be disrupted.

3.12.7 Research funding information

The research was fully funded by the principal investigator. There was no additional funding from any institution or individual.

5.0 PRESENTATION OF THE STUDY FINDINGS/RESULTS

4.1 Introduction

This chapter presents the major findings that emanated from the analysis and interpretation of raw data collected for the study. It is divided into three broad sections. The first part presents demographic, clinical and treatment history as well as labour, delivery and infant baby follow-up records that were reviewed. The second section presents results of retention calculation done by analysing secondary follow-up records. The final section of this chapter displays the qualitative analysis of in-depth interviews and presents results.

Summaries of key findings from both quantitative and qualitative data are also presented.

4.2 Background characteristics of respondents

Characteristics of patients whose data were reviewed have been summarized in Tables 3 and 4 below. Data on 69 patients were reviewed and retention characteristics described. The mean age of sample was 30 years. About 73.0% had some basic education and only four of them had tertiary education. Three of the sample were in formal employment while almost 70.0% were involved in different kinds of skilled employment; either trading, farming, tailoring or hairdressing. More than 92.0% were Christians and 52 out of the 69 of them were either married or cohabiting. Data on delivery and subsequent follow-up has also been presented. Availability of baby for dry blood sample to be taken after six weeks of Zidovudine syrup has been shown.

Follow-up care of baby up to at least six weeks after breastfeeding (usually this is 12 months plus six weeks) was also retrieved from retrospective data. Data for clients who have completed all

three tests: first after six weeks Zidovudine or Nevirapine, second test after breastfeeding and third test at 18 months of life produced four positive cases, two of which were detected at the first testing and the remaining two at 18 months follow-up. Majority of the women delivered at the hospital and average birth weight of babies born was 2.74kg. Zidovudine was the predominant antiretroviral medication given as prophylaxis to babies immediately after birth. Records of dried blood spot for early infant diagnosis were sparse. Mothers did not bring their babies for testing on time and those who brought their babies for sample to be taken did not receive their results on time. Refer to Tables 3 and 4:

Table 3 Patients socio-demographic, clinical and treatment characteristics

Patient Characteristic		Value*
Age-years^a, mean (SD)	30	(5.96)
Educational status^a		
No formal education or not recorded	6	(9.52%)
Basic (Primary and JHS or JSS or Middle school)	46	(73.01%)
Secondary	7	(11.11%)
Tertiary	4	(6.35%)
Religion^a		
Christian	58	(92.06%)
Muslim	3	(4.76%)
Other, no religion or not recorded	2	(3.18%)
Marital status^a		
Never married or not recorded	9	(14.28%)
Married or cohabiting	52	(82.54%)
Divorced or separated	1	(1.59%)
Widowed	1	(1.59%)
Residential location^a		
Urban	22	(34.92)
Rural	41	(65.08)
Occupation^a		
Unemployed, student, pupil, apprenticeship, not recorded	16	(25.40%)
Working/informal e.g. trader, farmer, seamstress, etc.	44	(69.84%)
Working/formal e.g. banker, teacher, lawyer, nurse, etc.	3	(4.76%)
WHO clinical stage^a		
Stage I	55	(87.30%)
Stage II	8	(12.70%)
ARV regimen given^b		
TDF/3TC/EFV	56	(88.89%)
TDF/3TC/NVP	1	(1.59%)
AZT/3TC/EFV	5	(7.94%)
AZT/3TC/NVP	1	(1.59)
Age of pregnancy at the beginning of PMTCT (weeks), mean, (SD)	20	(7.55)
Retention status at 12 months postpartum		
Active in care	37	(58.73%)
Transferred out	5	(7.94%)
Default and Lost to follow-up	19	(30.15%)
Death	2	(3.17%)

Key

* values are n (%) unless indicated otherwise

^a at enrolment in PMTCT^b at the time of data collection

NVP Nevirapine;

AZT Zidovudine;

JSS

Junior Secondary School;

JHS

Junior High School;

SVD

Spontaneous Vaginal Delivery

EFV

Efavirenz;

TDF

Tenofovir;

Table 4 Labour, delivery and baby follow-up record

Patient characteristic		Value*
Gestation period at delivery^b (weeks), mean, (SD)	36	(1.71)
Mode of Delivery^b		
SVD, home	10	(15.87%)
SVD, hospital	37	(58.73%)
Hospital, caesarean section	3	(4.76%)
Not determined (record not found)	13	(20.63%)
Birth weight^b, kg		
Above 3.0	11	(17.46%)
Between 2-3	33	(52.38%)
Below 2.0	3	(4.76%)
Not recorded	16	(25.40%)
Prophylaxis for baby at birth		
AZT	50	(79.37%)
NVP	2	(3.17%)
Not given or no record found	11	(17.46%)
DBS taken at 6-12 weeks		
Yes	32	(50.79%)
No	20	(31.75%)
Undetermined	11	(17.46%)
DBS taken at 12 months + 6 weeks		
Yes	15	(23.81%)
No	30	(47.62%)
Undetermined	18	(28.57%)
Outcome of baby follow-up tests^b:		
DNA-PCR results (DBS taken after 6 weeks zidovudine):		
Positive	2	(3.17%)
Negative	31	(49.21%)
Not done/not ready	30	(47.62%)
DNA-PCR test results (DBS taken from 6 weeks after cessation of breastfeeding):		
Positive	0	0
Negative	10	(15.87%)
Not done/not ready	53	(84.13%)
Antibody test results (sample taken when baby is 18 months old):		
Positive	2	(3.17%)
Negative	18	(28.57%)
Not done/not ready	43	(68.25%)

Key

* values are n (%) unless indicated otherwise

^a at enrolment in PMTCT^b at the time of data collection

AZT Zidovudine

SVD spontaneous vaginal delivery

PCR Polymerase chain reaction

DBS Dried blood spot

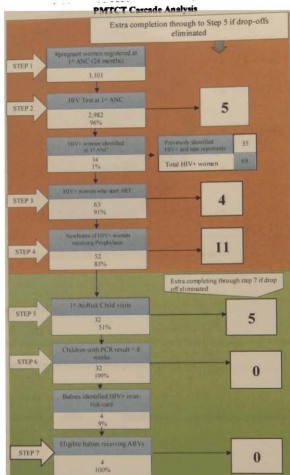
NVP Nevirapine

Source: Field data May-June 2017

4.3 Retention in PMTCT

Figure 7 displays the proportion of women retained in PMTCT care during the prenatal period and the proportion of woman-baby pairs retained postpartum till all tests for the babies have been done and infected babies registered in care and offered antiretroviral treatment. The figure was drawn from the cascade analysis tool. The tool has, inherent in it, the ability to depict the potential gains per step that will be achieved if that particular step is improved to a hundred per cent while holding the interventions at the other steps untouched.

The seven-step cascade is divided into two broader categories: (1) the prenatal period, made up of the first-four steps and the postpartum period which makes up the remaining three (adapted from Sherr et al., 2014). Refer to Figure 7 below. For example, the retention of woman-baby pairs at Step 4, where the infants are given prophylactic antiretroviral (Zidovudine or Nevirapine) was 83%. Improving retention to 100% at this step keeping all other interventions at the other steps constant will yield a gain of up to 11 mother-baby pairs in care as shown. In addition, five more babies will be present for DBS if the fifth step is improved to 100% keeping every other steps as they were. At the end of antibody testing for babies, four children were identified HIV positive and were all registered and taking antiretroviral medicines. Below is the extract from the PMTCT cascade analysis tool:



KEY

The above figure depicts the number of women and/or woman-baby pairs lost along the PMTCT cascade and the potential gain per step if that step is improved keeping all other interventions constant.
 ANC → Maternity (Orange background), Postpartum (Green background)

Figure 7 PMTCT Cascade analysis

Source: Field data May-June 2017

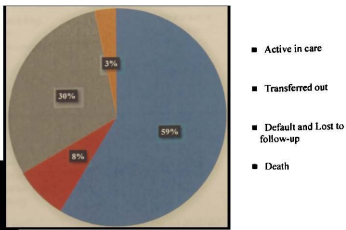


Figure 8 Retention of women in PMTCT at 12 month postpartum

Source: Field data May-June 2017

4.4 Qualitative results

Qualitative data was collected by means of in-depth interviews of 12 eligible and consented clients.

Background data of respondents has been presented in Table 5:

Table 5: Background information on Patient respondents to IDI

ID	Age Marital status Educational background Occupation	ART experience	Disclosure Status	Husband and Baby details
P1	38 Married No formal education Farmer	Old ART but new to HAART	Disclosed to husband, mother, siblings and husband's siblings	Husband is positive and on treatment. Baby is 2 years old, and completed the third test. Baby is uninfected

P2	22 Cohabiting JSS Not working	New to ART	Disclosed to an uncle Partner's family got to know by accident.	Partner is negative. (3 HTS sessions). Does not use condom during sex. Baby is 1 year 3 months old. Previous test is negative
P3	39 years separated Primary school Trader	Old ART but new to HAART	Disclosed to husband and mother	Husband is HIV positive but not on treatment. No longer sexually active. Husband provides baby's needs. Baby is 18 months old, yet to do the third test previous ones are negative.
P4	30 years Married Tertiary Teacher (basic school)	Old to ART but new to HAART	Disclosed to husband only	Husband is HIV-2 positive and on treatment but does not take medication on time. Baby is 8 months old and has completed the first test. the first result is negative
P5	36 years Married JSS Trader	New to ART	Did not disclosed to anybody. Husband's name was picked from folder as treatment supporter	Husband does not staying with us. Does not know husband's status. Baby is two years old and negative. Will do the last test today.
P6	36years. Married Trader Uneducated	5years experience in ART.	Not disclosed to husband or any family member	Husband is perceived talkative. Baby is 22 months old. Last test is yet to be done. Child is in school. Husband status in unknown.
P7	34years Married Uneducated unemployed	New to ART	Disclosed status to husband alone.	Husband refused to test. Baby is 11 months old, the first test is negative.
P8	30years old	ART experienced	Disclosed to husband only	Husband's status in unknown Baby is uninfected.
P9	26years old Married Trader JSS	ART experienced.	Disclosed status to husband	Husband's status unknown. Has 2 previous uninfected children through PMTCT. Current child is 15 months now. Yet to do antibody test

P10	20-years old Cohabiting Unemployed JSS	New to ART	Status known to husband and husband's family	Husband is negative but supportive. Baby is 11 months old. Has done the first test which is negative.
P11	33years old Trader, farmer No formal education Married, Christian	ART experienced since 2002	Status known to husband	Husband is positive and on treatment. Husband was positive first. Lost one child to HIV in 2002. Now have two uninfected children through PMTCT. The second child is doing her last test today.
P12	32 years old Married Seamstress JSS, Christian	New to ART through PMTCT	Disclosed status to husband and his brother	Husband is positive and on treatment in another facility. Husband is not compliant to treatment. Women is able to refuse sex in the absence of condom use. Baby is 20 months old and uninfected.

Key: P1-P12: Patient respondent 1– Patient respondent 12

Source: Field data May-June 2017

Another in-depth interview was conducted for seven recruited and consented healthcare workers.

The background information on this group of people is presented below:

Table 6 Background information on frontline healthcare givers recruited

ID	Age Sex	Department Profession	No of years in ART care
HP1	46 Female	Antenatal care clinic Midwife	2 years in the current facility
HP2	48 Female	Labour ward-in-charge Midwife	5 years
HP3	53 Female	ART clinic Midwife	7 years

HP4	51 Male	Laboratory Medical laboratory scientist	9 years
HP5	28 years Male	Medicine counter assistant Pharmacy	4 years
HP6	36 years Male	ART Clinic Biostatistician	5 years
HP7	35 years Male	Pharmacy Pharmacist	4 years

Key: HP1-HP7: Healthcare provider respondent 1 – Healthcare provider respondent 2

Source: Field data May-June 2017

Emerging themes from data collected are structured under the main objectives of the study. Nine key themes emerged out of the nineteen in-depth interviews conducted. Five themes reflected provider-level factors associated with retention including counselling support, assurance of anonymity, clinic location, supportive and understanding team and acceptable treatment outcome. The other four themes are patient-related and they are desired good quality life, social support and acceptance, stigma and partner influences.

4.4.2 Facility-level factors associated with retention in PMTCT

The themes were identified as facility-related includes counselling support, assurance of anonymity, clinic location, supportive and understanding care team and acceptable treatment outcome.

4.4.2.1 Counselling support

Counselling is the most mentioned factor by respondents as the key indicator of adherence to treatment in the presence of side effects and increased pill burden. Both peer counsellor's role in counselling and facility care provider counselling are captured under the same theme. The second

respondent expressed opinions relating to how counselling helped them to comply with treatment.

This quote captures patients' views:

In the past when I come here, I cry a lot. I had no hope. I thought I will die ... But there was a woman who used to counsel us here. She was the one who helped me to stop thinking. She is so caring and talks to us well. Her encouragement helped be to stop crying ... I began taking the medicine and with the continuous advice they give us, I realized that even if you have the disease, there is hope for life. (P2)

Many other respondents expressed similar sentiments. Counselling support was themed from a number of categories including the various roles played by peer counsellors and availability and delivery of counselling services by ART care team.

4.4.2.2 Assurance of anonymity:

Most patients would prefer not to disclose their status to any other person. Most clients who expressed this kind of attitude are in the higher and middle socio-economic class of the community. They are mostly health workers and some high profile public servants. They believe that remaining unknown by members of society and work colleagues will preserve their self-image and pride. The availability of ART services at the comfort of this group of people is the only means by which they are ready to accept care. This represents the opinions of health workers on the issue of anonymity:

We have people who are businessmen and workers who will not want to step here; especially if the person is a health worker, so you have to find a means by which this person can collect his/her medicines, if the person comes here and people are here, the person will go back; unless you are alone. (HP3)

Though the above is the case for general ART client behaviour, it is worth mentioning because, this class of people are missing in PMTCT services. All the background data reviewed contained limited information on middle-class working population such as health workers, teachers, bankers, public servants among others.

The provision of standard maternity services during labour and delivery also ensures that patient's privacy and anonymity is maintained. This is so because, both HIV-positive and HIV-negative clients are delivered in the same ward using similar standard of care. The labour ward-in-charge described it thus:

We have a symbol that shows every staff that will have access to patient's antenatal card the status of the expectant mother in labour. The staff will know that this person is a positive client, we do not give any special care to ART clients we treat them all equally. We only ensure that those that are no more having drugs, they get it before they go home and we make sure that the baby too is booked for the six weeks review after delivery...Everything about delivery is same for all women. You will not know who is positive or who is not.

(HP2)

Providers expressed worry about the situation of trying to hide the status of clients from the immediate family. According to them, non-disclosure to immediate family is increasing the risk of infecting other members of the family.

...that is what I have said that the secret that we are keeping is rather killing us because sometimes you see relatives doing things that they are not supposed to do but your mouth will be heavy to say it. You see, now we are trying our best to use this delivery mat so that after delivery we just discard the blood and all those things. But there are some who are

poor. First delivery things we rinse them with our own detergents; but what happens when they go home? When you start educating them that if you go home, do this, do that, then they start suspecting things, so sometimes we find it difficult. Some relatives do not even wait for us to disinfect the mats, before you realize, they have taken it out (HP2)

Providers recommended that more education be given to the general public in order to destigmatize the disease so that patients can live freely and the family members too will be protected.

4.4.2.3 Clinic location within the hospital

This theme describes the structural inconveniences that patients voiced out as a discomfort they experience anytime they attend clinic. This has been alluded to by the caregiver in charge of the unit as a challenge the facility is working hard to address. The ART block is located almost at the centre of the hospital surrounded immediately by the diabetic and hypertension clinic, the maternity ward, administration block and the general out-patient department (OPD). The block is also shared by the obstetric ultrasound scan unit of the hospital. There are two access routes to the block and only one is served with a translucent glass door. Though the ultrasound unit does not work on ART clinic days, a mother expressed the following concerns:

Something should be done about this place... You see the way this place is? Sometimes, some people seat on the corridor there and face this place...Sorry to say this but some of our peers are not taking good care of themselves and so when someone sees them among us, they will judge that may be this people are suffering from this sickness... when sis Cynthia was here, she locks the door so that people seating on the corridor will not be seeing us... so if they can get a place for us with in-built toilet facilities, it will be of help to us. Those who are having problem with walking too, they can manage. "(P3)

The nurse in charge of the clinic said

"Where we are, we are not happy. We are at the middle of the hospital. There are plans to move us to a better place. This whole place is for two things: the HIV clinic and the scanning. So on clinic days, the scanning is not done. We also do not paste HIV educational posters around this place for people to know what goes on here... So if you are not used to this place you will not know what clinic it is. (HP3)

The pharmacist responsible for ART at the facility also said the following:

Our place is a very challenged environment for those assessing care in general; not only those assessing PMTCT. The place is very small. It is not comfortable, it is not spacious, even patients folders are competing with those of us who render care at the clinic, so generally, the place is not comfortable at all. On heavy clinic days, patients do not even get spaces to seat, some have to stand for long hours. It actually affects the quality of care we give to patients at the clinic. (HP7)

4.4.2.4 Supportive and understanding team

Patients expressed satisfaction with the services rendered by all the different cadres of staff involved in rendering care. When asked whether care at the antenatal is different from what they receive from the ART clinic, majority of those interviewed expressed similar satisfaction with services at both places. They also mention availability of medicines as a good indicator of a supportive team. A number of the women also mentioned that they would have preferred that their ART clinic days are given to coincide with their antenatal visit days, so that they can receive both services at a single schedule visit. Providers also shared similar sentiments.

The ART have their own schedules and we also have our own schedule with HIV-positive clients. But in their visit days tally with ours, then they will come here and go there as well... For transportation wise, sometimes when you give them dates to come, some will say I don't have money. Money is their complaint. Like today, someone whom I asked to come in a week's time, she went and spent three weeks at home... Assuming I want to repeat her test at 34 weeks, then we would have missed that opportunity. (HP1)

Providers at the ART recommended that in order to improve the attendance of first referrals to the ART, the ANC nurses should personally accompany clients to the ART unit.

In their views, providers at ANC mentioned that the non-availability of the laboratory staff to take samples of clients on clinic days is affecting the take-up of some laboratory services by clients.

The following quote highlights such confessions:

...they are supposed to come and take the samples here but they always complain that they do not have enough staff. So, for most people, it is difficult for them to go and do the lab... that is the problem we have at the moment... Formerly, when we started, I was assigned two people to be taking the samples here. They came for three times and then they stopped coming. When I went there, their in-charge says they do not have enough staff (HP3)

However, patients expressed opinions relating to how the care of nurses at the ART helped them to cope with their status. They explained how the support and care they received from health providers gave them hope and reason to comply with treatment. These statements highlight such confessions:

...when it happened like that the boy who got me pregnant says he cannot be with me again,

he always picks quarrel with me and even beats me up sometimes. If not because of the hope of the nurses, I would not have been alive today... The medicine too, when I am taking it, I realized that it is good... When I do not take it, I see changes. (P2)

The facility manages the client at different service point depending on which cascade level the client is assessing service. The availability of supportive therefore is needed to enhance compliance. Another example is that the labour ward is supplied zidovudine syrup to be given to children at the point of delivery before the baby's six weeks supply is provided later on. The maternity ward in-charge, the medicine counter assistant involved in PMTCT, the ART nurse and the patients themselves mentioned the above arrangement.

4.4.2.5 Acceptable treatment outcome

Respondents mentioned that they are doing well on the treatment. They expressed how being on treatment has given them hope because they feel better now than they used to. Those who are raising their second and third uninfected children through PMTCT had high praises for the programme.

Before I began treatment, I fall sick a lot. I get running stomach, get dizzy and I am always weak. I did a lot of tests but they did not see anything but since I came here and they began teaching us that the medicine is good and that it will keep you from getting sick of other diseases, I was determined to take my medicines well. I do not fall sick frequently again. For about 3 years now, I do not come to hospital like I used to for any other sickness too... You yourself, when you are serious you will see that the form in which you were before coming, you will change a lot and people will not know that you are in any problem. (P9)

A different respondent also said:

I was encouraged and anytime I come and I am given medicine. I take it too... I do not fall sick again like before. I always feel strong within me... (P11)

The categories that were collapsed to create the above themes are presented in Table 7:

Table 7 Qualitative data coding (provider-level factors)

NO.	Categories	Themes
1	Peer counsellor roles	Counselling support
	Staffing strength to improve one-on-one counselling	
	Availability of supportive care	
2	Out-of-clinic day services	Assurance of anonymity
	House deliveries	
	Labour ward anonymity pros and cons	
3	Structural inconveniences	Clinic location
	Location of ART within the facility	
	Availability of services for both positive and negative clients within the same block	
	Inadequate waiting space	
4	ANC/ART collaborations	Supportive and understanding team
	ART/Pharmacy collaborations	
	Client-tailored care	
	Availability of logistics and inputs	
5	Feels better now	Acceptable treatment outcome
	Do not fall sick again	
	Have hope that I can live long	
	If you do not take medicines you do not want to live long	

Source: Interview data, May-June 2017

4.4.3 Patient-level factors identified in In-depth interviews with patients

As mentioned earlier, four key themes were derived from the interviews that are patient-related and have some impact on the retention of women in the intervention designed to prevent mother-to-child transmission of HIV. Details are described below:

4.4.3.1 Desired good quality life

Most respondents mentioned that they are discouraged to remain in care because of the hope that they will stay alive. Others also desire that they live well and be healthy so the disease will not show clearly on them. There is embedded in the above expressions, the desire to hide status from immediate family and friends. Child protective instincts of mothers made them ready to accept care in order to protect innocent unborn child from future suffering. The following are excerpts from some of the respondents:

...my life and the life of the child I want to bring into this world that the disease will not show clearly on us that is why I have to take good care of myself and take the medicines. I do not want to fall sick and be going on and off hospitals. I want to remain well and look healthy so that people will not know I have this problem. (P4)

Me too, I am scared that I will die. In addition to that, I do not want the disease to show glare on me. I will not look fine again... The baby's life too is important, though people asked me why I stopped breastfeeding early, I do not reply them because I know what is wrong with me and what to do to keep myself and my baby healthy, so I do not give them that hearing at all. (P7)

4.4.3.2 Social support and acceptance

Fear of family rejection and losing their support are expressed by a number of the women. One

also mentioned that disclosure of status will destroy her family image and status in society. Many others also think believe it is better to remain unknown by immediate family members so that they will not lose the respect and support they give her. These are some examples of what the women said:

No one knows about my sickness. My family does not know. I did not tell anybody and I do not want to....No.... if I do, they will spread me in town. They will even reject me. That is why I have not disclosed it to anybody. My husband to is a talkative so I do not want to let him know. (P6)

Some patients however gave a comforting side of the above concern and expressed confidence in the importance of disclosure of status.

I do not see that my case will be heard by anyone here. This is because, this people do not know where I come from. In addition, the one who gave birth to me is the one who brought me to clinic first so she is aware of my condition. Even if other people know about it, it will make no difference because they cannot confront me with it. My siblings as well as my husband's sibling are in the known. The reason I do not think it is good to hide it from them is that, I can fall sick at any time and at that point, especially if I am hospitalized, I will need their support to recover better. If they know now, then they know how to take care of me when that time comes. (P1)

The fear of losing family and social support was therefore expressed in both positive and negative terms.

4.4.3.3 Stigma

Stigma is well mentioned as a major reason for default by many women especially those of the higher socio-economic status. The second respondent, 22 years, whose partner is HIV negative (discordant cohabiting couple) described her lack of self-worth in the following words:

For me, I always say that where I am now, I am not good for anything. I say it every day. When I am talking with someone, I always say it. I also tell my man that I am not good for any good thing because of this disease. I have only one sexual partner and he is negative. I do not understand how I got this disease ...hmm. (P2)

When asked whether or not they could be a peer counsellor, patients responded they can do but only at places where they are not known.

For me, I will not be able to talk on radio to advice people because my people are gossips, they will ridicule me. I can however do it outside of where I come from, there nobody knows me. (P1)

4.4.3.4 Partner influences.

Partner influences include, support, rejection, lack of understanding, refusal to test and non-adherence for those on treatment. Some expressed dissatisfaction with discordant couples. The nurse in-charge also mention a few examples. These are their comments:

My husband does not take his medicines well. He is not compliant at all. But I do not know how to talk to him about it. He does not listen. I am however able to insist on condom use during sex. If he will not use it, then he will not get it. (P12)

We have problem with husbands rejecting their wives a lot. Some time ago, a lady came

here and was tested positive. She was asked to bring the husband who came, but he tested negative. After counselling, they left. The lady came back that the man said she should pack and go, so the lady left. (HP3)

...if my husband had been on treatment before refusing to use the condom, I would not have been worried. But he says that he will not use it. He should come for testing too, he is refusing that one too. (P7)

On a positive note a few of the women expressed support from their partners in refilling their prescription and helping them take medications on times though they themselves are not compliant. Here are some examples:

I am grateful to God that the father of the baby also knows about it, so I am lucky and I do not put those things on my mind again. I am relaxed about it, I asked him to come and do the test so that even if he will not come for medicines, anytime I come, I can pick his too for him. He, however is yet to do it; and this is our second child since I tested positive. But when I come and go home, he asks me about what we learned and I teach him everything (P9)

...sometimes, my husband brings the card to take medicines for me, I make sure I get transportation from my place to the station at least and then I walk to the hospital. I also will walk back to the station before taking the car home. (P8)

The following table shows how the themes were generated from the various categories coded from the interviews:

Table 8 Qualitative data coding (patient-level factors)

NO.	Categories	Themes
1	Fear of worsened disease	Desired good quality life
	Child protective instincts	
	Hope for motherhood	
2	Fear of losing friends	Social support and acceptance
	Preserve family image	
	Lack of disclosure	
	Negative peer behaviours	
	Family rejection	
3	Shame	Stigma
	Low self-worth	
	Fear of losing self-image, pride and respect	
4	Refusal to test	Partner influences
	Non-compliance to medication	
	Refusal to use condom	
	Discordant partner acceptability	

Source: Interview data, May-June 2017

TABLE 8 Qualitative data coding (patient-level factors)

NO.	Categories	Themes
1	Fear of worsened disease	Desired good quality life
	Child protective instincts	
	Hope for motherhood	
2	Fear of losing friends	Social support and acceptance
	Preserve family image	
	Lack of disclosure	
	Negative peer behaviours	
	Family rejection	
3	Shame	Stigma
	Low self-worth	
	Fear of losing self-image, pride and respect	
4	Refusal to test	Partner influences
	Non-compliance to medication	
	Refusal to use condom	
	Discordant partner acceptability	

Source: Interview data, May-June 2017

5.0 DISCUSSIONS

5.1 Introduction

The chapter discusses key findings from the results presented in the previous chapter. The discussion relates results to research objectives and prevailing literature. Variable emerging from the finding are also discussed with reference to the research questions.

5.2 Background characteristics of respondents

Review of demographic characteristics revealed that most of the women enrolled in the PMTCT programme are from the lower socio-economic status. From the background data reviewed, 73% of the enrollees have up to middle school or Junior High School education and four of them had tertiary education. The proportion of women in informal employment such as farming, trading or skilled labour was almost 70.0% as against 5.0% in the formal employment, two teachers and a banker. The question to ask is whether there is higher rate of reproduction among the lower socio-economic class than the upper class population, or whether or not there is higher rate of infection in the lower class as compared to the higher socio-economic class.

According to the 2014 Ghana Demographic and health survey, there is lower fertility rate among women who had at least secondary school education compared with those who had up to a middle school education. The same trend is seen for HIV infection among women from the two sides of the socio-economic strata (GSS, GHS, & ICF-I, 2015). Women with lower economic and social status have are less likely to insist on their rights especially to negotiate for safer sexual practices with their husbands. Most of them also depend on their husbands for their upkeep and transportation to the hospital. This phenomenon has negative impacts on the adherence to

programme recommendation such as condom use and honouring schedule visits if the male partner is not supportive. A critical literature review of 12 primary research articles from Malawi and Nigeria showed that socioeconomic and sociocultural factors are the biggest barriers to PMTCT success, as well as limited male partner involvement (Okoli & Lansdown, 2014). There is therefore the need to consider these factors in designing innovative solutions to improve success of PMTCT interventions.

5.3 Retention in PMTCT care

The assessment of the proportion of drop-offs along the PMTCT cascade is a proxy for the measurement of the level of retention in the continuum of care. The 12-month postpartum retention of women at the study location is lower compared with what was seen in sister sub-Saharan African countries and which has been discussed in the literature review. The losses observed along the cascade of care were also higher (section 2.9). The total retention of women at 12 months postpartum at the Ho Municipal Hospital was 66.7% including 8.0% transfers. The transferred patients were however not followed to measure their compliance to treatment schedule at the current sites. There were two deaths and 30% were lost to follow-up. The proportion of babies reporting for DBS at six weeks after completing prophylactic antiretroviral treatment was 51% and as high as 84% of records for antibody testing and result at 18 months of babies' life were not available at the time of data collection.

A systematic review of 44 studies in SSA reported 64% retention at six weeks postpartum and 55% retention for testing at 18 months. In addition, the review also found an average proportion of 94% of pregnant women testing for HIV whilst 70% of those who tested positive receive ART. At the Ho Municipal Hospital, 96% of pregnant women receive testing and counselling for HIV

while 91.3% of those found positive were enrolled into the PMTCT programme and had access to medications (Wettstein et al., 2012). Though there is improvement in testing at antenatal clinic at the study site with improved access to ARVs, there is a challenge in keeping the women in the continuum of care as shown in Figure 7 above. There is therefore lower rates of retention along continuum of care as well as retention at a 12 month postpartum at the study site compared with what was seen in other sister countries though retention in all these cases were below the expected 90% at all the cascade steps. As was pointed out earlier, retention of 90% and above is required in order to achieve the PMTCT success; which is to eliminate maternal transmission of HIV (UNAIDS, 2014b).

From the ensuing discussion, though there is cost-effective intervention to reduce mother-to-child transmission of HIV, health system factors and their interaction with patient's expectations and community determinants are affecting the outcome of the programme.

The reasons for the low retention rate as discussed below are quite similar to those observed in other studies. The patient-level factors that emerged from in-depth interviews included desired good quality life, social support and acceptance, stigma and male partner influences. Several categories have been merged into each of the themes above as shown in Table 6 above.

5.4 Patient-level factors

Patient-level factors will be discussed based on the information, motivation, and behavioural-skills (IMB) model of health behaviour situated to the demands of retention in care (refer to section 2.10).

The demands placed on patients by chronic medical care requires that they are equipped with the

right information, are well motivated and possess the correct behavioural skills in order to remain in care (Smith, Fisher, Cunningham, & Amico, 2012). The model is therefore situated within the above contexts and the discussions below will therefore be based on this theory.

Information is acquired through supportive counselling on HIV, the role of laboratory investigations in caring for the client, usefulness of medicines and their side effects, patients' rights to privacy, dignity in treatment, confidentiality as well as duration of treatment. Misinformation, ineffective communication and inaccurate facts can affect patients' understanding of treatment and subsequently their behaviour towards continuation of care. Motivation includes both personal and social motivation. Personally, the client will be able to prioritize HIV care over other competing interests, monitor results and focus on improved quality of life and longevity. Interpersonal motivation stems from involvement of significant others in supportive care at home. The absence of motivation from personal and interpersonal point of view can result in skipping schedule visits, avoiding clinics and non-adherence to treatment recommendations. Finally, the model is theorizing that patients in chronic care such as HIV care need the right behaviour skills such as systems navigation skills (ability to identify care and to enrol, etc.), functional (organizational and planning skills) which includes the ability to fit personal schedules into HIV appointment dates, arrange work schedules and maintain privacy, arrange for transportation, etc. The third behaviour skill required is activation skills where patient is able to harness available resources to improve on the positive outcomes of treatment while minimizing anxiety and fear, dealing with treatment failure, maintain resilience in prioritizing self-care among others.

The three variables: information, motivation and behaviour skills when harnessed together will improve retention in care and subsequently, viral suppression, increased CD4 count, improved health and better outcomes that is increased HIV-exposed but uninfected infants. The themes

generated from the in-depth interviews fall under either or multiples of the above as discussed below.

General reluctance on the part of the women to disclose status to other members of their families means that they are not well motivated socially or interpersonally. Some even hid their status from their partners. The result of the above behaviour is increased in unsafe sexual practices during pregnancy and reduction in male partner support in adhering to treatment schedules. When women miss treatment schedules, they are not available also for counselling and refill of their medicines. There will be reduced adherence, increased viral load and reduced likelihood of preventing mother-to-child transmission. Many of the women would prefer to remain unknown because of perceived discrimination and fear of losing support from family and being ostracized by society and shun by friends and loved ones. Similar concerns were raised in other studies in Malawi and Kenya (Kim et al., 2015; Murithi et al., 2015). The effects of stigma has also been demonstrated and refusal of male partners to test and receive treatment as well reported less compliance to treatment among respondents reveals gender imbalance on designing and implementation of PMTCT programme.

On the positive side however, almost all of the women interviewed expressed hope in living fulfilled lives and also to secure for their children improved quality of life. This was well expressed by the women and reported at the result section of this report. The desire to become a mother and the hope of raising HIV-negative babies is what keeps some of the women coming for treatment every time and improving their compliance to medication. They were however not able to negotiate safer sex practices with their husbands. A section of the women who had disclosed their status to their spouses also faced similar challenges. This is worth paying attention to because it brings to fore the issues of the security of the rights of women and children as stipulated in the United

Nations declaration on human rights (UN General Assembly, 1948). Women and children are disproportionately affected compared to men and boys who are less likely to suffer human rights abuses. Widespread disproportion of respect for fundamental human rights between males and females as well as between children and adults have been widely studied and reported. The UNAIDS 2016-2021 Strategy on the fast track to end AIDS has recognized gender equality and empowerment of women and girls as a major strategy in preventing HIV transmission, improvement of access to services, education and employment and paves the path for lives free of violence (UNAIDS, 2016c).

There is increased disassociation of male partners from HIV counselling and testing services. They mostly do not avail themselves for counselling and therefore are less informed about the relevance of their roles in improving the health of their pregnant wives and exposed children. Male partner support is one major determinant of retaining women in antenatal and HIV care. Almost all studies aimed at unearthing facilitators and barriers to retention in care mention male partner support as one of the major determinants (Ambia & Mandala, 2016; Anigilájé et al., 2016; Auvinen, Kylmä, Välimäki, Bweupe, & Suominen, 2013; Murithi et al., 2015; Okoli & Lansdown, 2014).

Interventions to improve relationships between discordant couples also do not seem to be working at the study site. It was reported by managers of the clinic that though the men agree to living in these discordant relationships, majority of them reject the women in the long run. The women in discordant relationships who are negative however accept the men better. Two out of the twelve respondents reported being infected by their husbands while in a discordant relationship. This supports earlier discussions suggesting that women are either unable or do not succeed in negotiating protection and are less likely to leave relationships they consider to be risky because of their social and economic vulnerabilities. From what had been reported in the results section, it

can be seen that women who access service at the Ho Municipal Hospital face similar challenges as their counterparts in Botswana and Zambia who would allow their husbands to engage in unsafe sex practices with them though they are aware of the negative consequences to their own health and that of the unborn babies (Gupta, ICRW, & USA, 2000).

Family support and societal acceptance is crucial for improved self-worth and positive attitude to life which culminated into increased quality of life. Some of the women fear losing the support of families and acceptance by peers and society at large and so would rather keep their HIV status a secret and not disclose it to their immediate families. The respondents mentioned that their families take good care of them and that they have not been discriminated against because their status are not known. The fear of losing family trust and bringing family image into disrepute is preventing many women from disclosing their status. It was demonstrated from the study that though people readily accept and associate with their friends when status is undisclosed they behave differently if told about the positive status of the same person they used to live with. This shows that discrimination against people living HIV and AIDS is still rampant in our communities. Though a caregiver raised the issue of demystifying HIV and removing the 'scare' associated with the diagnosis in a way that people can easily disclose their status so as to reduce the risk of infecting other family members during times of hospitalization; it may however be difficult for women to disclose their status to their close relatives just as they had voiced out during the in-depth interviews.

Other patient-related factors found in the literature reviewed were severe disease at enrolment, attending hospital as compared to attending clinics, starting ART on the date of diagnosis, missing CD4+ cell count. Receiving diagnosis prior to pregnancy is associated with better retention compared with HIV diagnosis during or after pregnancy (Dionne-Odom et al., 2016; Geldsetzer et

al., 2016; Gourlay et al., 2015; Mekuria et al., 2015; Mitiku et al., 2016; Tenthani et al., 2014; Woelk et al., 2016). The women enrolled in care at the study site were relatively healthy and ambulatory because they were registered from antenatal care. Treatment was also initiated immediately as required by the programme guidelines. 55 out of 63 women are classified at WHO stage I while none is beyond stage II showing that the women were stable on treatment.

5.5 Provider-level factors

Provider level factors identified from the study suggests that a well-motivated and compliant patient can be negatively influenced by unfavourable clinic and/or staff conditions such as a talkative staff, uncaring team, non-availability of logistics as well as poor clinic location that does not ensure adequate privacy. Supportive counselling had been demonstrated to be directly linked to the provision of the right information to clients which will in the long run help in building the required motivation for attitudinal change as described in the IMB model above.

Supportive counselling have been reported in few qualitative studies that exist in predicting provider-level determinants of retention in PMTCT (Murithi et al., 2015). In-depth interviews of both beneficiaries of the programme and programme managers showed that both patients and healthcare providers consider good counselling as a major contributing factor in improving retention rates. All the twelve patients interviewed mentioned that they were able to cope with the treatment regimen partly because of the education and assurance they received from the care givers.

However the location of the ART clinic is not convenient for a lot of the respondents. They mentioned the fact that the unit is being shared by another department and so their privacy is not assured. The healthcare providers alluded to their concern as a factor that is possible to affect

acceptance of care and hence retention in the programme.

Though several units offer PMTCT care at different point of care delivery, the respondents mentioned that they are happy because each cadre of staff handle them with care. Confirmation, affirmation and admiration has been reported in a Kenyan study as a factor women consider to be appropriate in keeping them in care (Muriithi et al., 2015).

Anonymity as mentioned by women in this study can be seen in two different ways: positive and negative which has implications for the mother adhering to counselling recommendations. While women dread being discriminated against and losing respect and admiration of their families if their status is known, there is increasing concern that at the time of delivery, close relatives are almost always involved in rendering intimate services, putting them at increased risk of infection. Anonymity is however provided both at the antenatal clinic and the labour ward which the women enjoyed so much as they mentioned in their own words. It is however clear from past studies that societies with little or no discrimination of PLWHIVA promote better survival and increased quality of life. There is also increased acceptance of service and support is available to improve retention in care. Several expert working groups convened by the Joint United Nations programme on HIV and AIDS recognized this and always recommend interventions to end discrimination against PLWHIVA. The UNAIDS "On the fast-track to an AIDS-free generation" is an example of such publication (UNAIDS, 2016b).

Women also miss scheduled visits because of family and societal expectations. A conversation between principal investigator and programme manager reveal that patients from the higher socio-economic class default more. They miss schedule visits due to fear of losing societal respect if their status is known. The patient is not socially motivated and so is unable to remain in care as

theorized by Smith et al (2012). Further investigation is required to understand the role of socio-economic status in testing and counselling as well as subsequent adherence.

In summary, higher rates of drop-offs were seen at HIV testing and counselling as well as newborns receiving prophylaxis and first at risk child visit. The highest gains to make from the PMTCT will result from paying more attention to these steps while keeping current interventions at the other stages constant. In addition, supportive counselling, comfortable clinic space, partner involvement and a caring clinical staff are needed to retain women in continuum of care.

5.6 Strengths and limitations of the study:

The study has contributed to the understanding of the reasons behind high rates of attrition among women enrolled in PMTCT care at a primary level of healthcare facility in a low middle income country. The other major strength of the methodologies used is that it employed a simple adaptive tool in describing the level of retention along the PMTCT cascade. This makes understanding of the research findings easy for everyone including the frontline healthcare providers without requiring the assistance of biostatisticians.

As a set-back, the study site was selected based on convenience and sampling technique used in arriving at the total sample used for the descriptive analysis was a non-probability or convenience method. The unavailability of some relevant information from facility records has also reduced the strength of the findings.

Participants for in-depth interviews were purposively selected from patients who are already retained in care. Tracing women lost to care and sampling their views will give a different perspective to the finding of the study. Qualitative study in itself is an inductive process. The

reasons for retention as have been extracted from all the interviews are highly summarized from several categorization of responses from patients and care givers. It is possible to derive more themes from the primary data. These reasons for retention are also socially constructed and reflects the views of only women who receive care at the Ho Municipal Hospital leaving little room for generalization to the general PMTCT population. Though care have been taken to reduce error and improve the rigor of the methodology, qualitative research is an intuitive process and personal biases are embedded in its analysis.

5.7 Summary and Conclusion

The chapter discussed the findings in the light of available literature and theories. Strengths and limitations have been presented. This is helpful to guide future researchers to design a more robust and rigorous methodology.

6.0 CONCLUSIONS AND RECOMMENDATIONS

This chapter provides a summary of the finding and the major inferences drawn from research findings and analysis. The chapter presents the reasons behind the calculated figures from records as well as the qualitative variables discovered from interacting with study participants. Hence a basis is laid for recommendations that the author postulates are key issues needed to be addressed in order to improve retention rates at the Ho Municipal Hospital

6.1 Conclusions

The level of retention in PMTCT at the Ho Municipal Hospital were 96% at *testing and counselling* and 91.3% of those who tested positive were *started on ART*. Out of all the women registered in care that had successfully delivered live babies, 82.5% of the *newborns received ART prophylaxis*, while 50.8% of mother-baby pairs reported for *first at-risk child visits*. Results for *DNA-PCR test at 6 weeks* was available for 30 (50.8%) babies. Four babies were identified HIV-positive at the end of testing at 18 months. Thirty-seven (37) women comprising 58.7% of those who were tested positive at ANC remained in care at the study site while five (7.9%) of them were transferred out. Assuming 100% retention for all those who were transferred out, total retention at 12 months postpartum was 66.7%. All babies who tested positive had been enrolled in care and all of them have been put on treatment. Some of the women delivered at home but brought babies for prophylaxis. However, many of these women also miss testing at six weeks after breastfeeding and 18 months of the babies' life.

Provider level factors associated with retention in care included supportive counselling, assurance of anonymity, clinic location within the hospital, supportive and understanding team and

acceptable treatment outcome.

Patient-level factors identified included desired good quality life, social support and acceptance, stigma and partner influences.

The study findings showed that effectiveness of interventions to improve uptake and retention in PMTCT does not depend only on the availability and accessibility of a functional and healthcare system but also on good interaction between healthcare providers and patients in a client-friendly environment that ensures desired patient confidentiality and privacy. It can also be inferred that contextual factors are very important in understanding the factors enabling and/or inhibiting the success of intervention programmes. Though there is a clinic dedicated to the provision of PMTCT at the study site, patients raised concerns about the fact that the unit is been shared by other service providers which is an infringement on their privacy. If this is the case, then separation of the Ultrasound Scan unit from the ART should improve patient comfortability with service delivery as far as their privacy is concerned.

Many HIV-positive mothers are well educated on their disease condition and well informed about what to do to prevent transmission of infection to their babies but same cannot be said of their male partners. This raises the issue of gender imbalances which create so many missed opportunities for the women to apply acquired knowledge and mobilize needed support to benefit from available services. Male partner issues at the study site are not different from those from other sister African countries. Provision of home-based care involving the male partners may be an issue worth considering.

Healthcare provider characteristics such as provision of counselling and smooth flow of work from one level of service provision to the other without compromising the integrity and confidentiality

of the patient is a very important concern to patients.

Retention rates at the Ho municipal hospital is below optimum and this will result in increased maternal transmission of HIV. The factors discussed above should be employed to improve the interest of patients and retain them in care.

6.2 Recommendations

The above study is an explorative study that was had been successful in bringing up issues for further reviews and investigation.

1. Further studies should be done to uncover more factors associated with less than 90% retention in care.
2. Future studies should consider not only review of background data but also structured interviews and be conducted during clinic days when patients self-report to the facility. This will undoubtedly take more than eight months to achieve but is sure to achieve better results. Home visits should also be done to receive the views of defaulting clients and those loss to follow-up.
3. Managers of PMTCT programme should receive periodic feedback from clients especially during counselling sessions in order to understand their difficulties and attempt to address them.
4. Healthcare provider should consider integrating their services within the ART in order to render comprehensive care to patients at each visit date.
5. Facility managers should consider expanding the ART unit and separating it from all any other service point in order to improve patient confidentiality and privacy.
6. There should be increased sensitization of the general public on radio and television about

the success rates of PMTCT and the role of all member of the family in helping reduce maternal transmission of HIV.

7. Effects of stigma and discrimination should also be reduced by destigmatizing HIV through periodic educational campaigns.
8. Sufficient multi-disciplinary health workforce trained in delivering ART should be ensured at all sentinel sites to promote efficient delivery of service.
9. Timely provision of logistics and capital should also be ensured.
10. Data management should also be improved at the facility to improve follow-up data collection and determination of retention rates.

- Adler R., M., Riley L., P., Bandazi, S., & Davis K., M. (2013). How Option B+ is shifting the PMTCT paradigm. *African Journal of Midwifery & Women's Health*, 7(1), 7–13. Retrieved from <http://search.ebscohost.com/login.aspx?direct=true&db=cin20&AN=2011892078&site=ehost-live>
- AIDSinfo. (2016). The HIV Life Cycle | Understanding HIV/AIDS. Retrieved July 7, 2017, from <https://aidsinfo.nih.gov/understanding-hiv-aids/fact-sheets/19/73/the-hiv-life-cycle/>
- Altan, A. M. D., Taafu, F., Fopa, F., Buonomo, E., Marazzi, M. C., Nielsen-Saines, K., ... Palombi, L. (2016). An assessment of option b implementation for the prevention of mother to child transmission in dschang, cameroon: Results from the dream (drug resource enhancement against aids and malnutrition) cohort. *Pan African Medical Journal*, 23, 1–10. <https://doi.org/10.11604/pamj.2016.23.72.7958>
- Ambia, J., & Mandala, J. (2016). A systematic review of interventions to improve prevention of mother-to-child HIV transmission service delivery and promote retention. *J.Int.AIDS Soc.*, 19(1), 20309–20309-. <https://doi.org/10.7448/IAS.19.1.20309>
- Anígílájé, E. A., Ageda, B. R., & Nweke, N. O. (2016). Barriers to uptake of prevention of mother-to-child transmission of HIV services among mothers of vertically infected HIV-seropositive infants in Makurdi, Nigeria. *Patient Preference and Adherence*, 10, 57–72. <https://doi.org/10.2147/PPA.S87228>
- Arulogun, O. S., Adewole, I. F., Olayinka-Alli, L., & Adesina, A. O. (2007). Community gate keepers' awareness and perception of prevention of mother-to-child transmission of HIV services in Ibadan, Nigeria. *African Journal of Reproductive Health*. <https://doi.org/10.2307/30032489>
- Assefa, Y., Worku, A., Wouters, E., Koole, O., Haile Mariam, D., & van Damme, W. (2012). Simplified tools for measuring retention in care in antiretroviral treatment program in Ethiopia: Cohort and current retention in care. *PLoS ONE*, 7(6), 1–8. <https://doi.org/10.1371/journal.pone.0038555>
- Auvinen, J., Kylmä, J., Välimäki, M., Bweupe, M., & Suominen, T. (2013). Barriers and Resources to PMTCT of HIV: Luba-Kasai Men's Perspective in Lusaka, Zambia. *Journal of the Association of Nurses in AIDS Care*, 24(6), 554–568. <https://doi.org/10.1016/j.jana.2013.05.002>
- AVERT. (2017). How HIV infects the body and the lifecycle of HIV. Retrieved July 17, 2017, from <https://www.avert.org/about-hiv-aids/how-infects-body>
- CDC. (2011). A Timeline of HIV/AIDS. Retrieved November 12, 2016, from <https://www.aids.gov/hiv-aids-basics/hiv-aids-101/aids-timeline/>

- CDC. (2014). Revised Surveillance Case Definition for HIV Infection - United States, 2014. Retrieved November 8, 2016, from <https://www.cdc.gov/mmwr/preview/mmwrhtml/rr6303a1.htm>
- Connor, E., Sperling, R., Gelber, R., Kiselev, P., Scott, G., O'Sullivan, M., ... Pediatric AIDS Clinical Trials Group Protocol 076 Study Group. (1994). Reduction of maternal-infant transmission of human immunodeficiency virus type 1 with zidovudine treatment. *The New England Journal of Medicine*, 331(18), 1173-1180. <https://doi.org/10.1056/NEJM199411033311801>
- Dionne-Odom, J., Welty, T. K., Westfall, A. O., Chi, B. H., Ekouevi, D. K., Kasaro, M., ... Tita, A. T. N. (2016). Factors associated with PMTCT cascade completion in four african countries. *AIDS Research and Treatment*, 2016(Article ID 243936), 1-9. <https://doi.org/10.1155/2016/2403936>
- GAC. (2016a). National HIV and AIDS Strategic Plan. Accra, Ghana: Ghana AIDS Commission. Retrieved from [http://www.ghanaiids.gov.gh/gac1/pubs/EXPRESSION OF INTEREST SUB PROJECT.pdf](http://www.ghanaiids.gov.gh/gac1/pubs/EXPRESSION%20OF%20INTEREST%20SUBJECT%20PROJECT.pdf)
- GAC. (2016b). Summary of the 2016 HIV Sentinel Survey report. Retrieved July 27, 2017, from http://www.ghanaiids.gov.gh/gac1/aids_info.php
- Geldsetzer, P., Yapa, H. M. N., Vaikath, M., Ogbuaji, O., Fox, M. P., Essajee, S. M., ... Bärnighausen, T. (2016). Review article A systematic review of interventions to improve postpartum retention of women in PMTCT and ART care. *Journal of the International AIDS Society*. <https://doi.org/10.7448/IAS.19.1.20679>
- Ghana AIDS Commission. (2014). 2014 status report. *Ghana Aids Commission* (Vol. 1). <https://doi.org/10.1017/CBO9781107415324.004>
- Ghanadistricts.com. retrieved from https://en.wikipedia.org/wiki/Ho_Municipal
- Ghana Health Service. (2014). *PMTCT Handbook for Healthcare Providers in Ghana*. Accra, Ghana: GHS. Retrieved from Hard copy book
- Ghana Statistical Service. (2014). *District Analytical Report, Ho Municipality*. Retrieved from [http://www.statsghana.gov.gh/docfiles/2010_District_Report/Volta/HO MUNICIPAL.pdf](http://www.statsghana.gov.gh/docfiles/2010_District_Report/Volta/HO_MUNICIPAL.pdf)
- Gimbel, S., Voss, J., Mercer, M. A., Zierler, B., Gloyd, S., Coutinho, M. de J., ... Sherr, K. (2014). The prevention of mother-to-child transmission of HIV cascade analysis tool: supporting health managers to improve facility-level service delivery. *BMC Research Notes*, 7, 743. <https://doi.org/10.1186/1756-0500-7-743>
- Gloyd, S. S., Robinson, J., Dalí, S. A., Granato, S. A., Bartlein, R., Kouyaté, S., ... Koné, A. (2014). *Pmtct Cascade Analysis in Côte D ' Ivoire : Results From a National*, (May).
- Gourlay, A., Wringe, A., Todd, J., Cawley, C., Michael, D., Macheмба, R., ... Zaba, B. (2015). Factors associated with uptake of services to prevent mother-to-child transmission of HIV in

GSS, GHS, & ICF-L. (2015). *Demographic and health survey*. Accra, Ghana.

Gupta, G. R., ICRW, & USA. (2000). Approaches for Empowering Women in the HIV/AIDS Pandemic: a gender perspective. Retrieved July 18, 2017, from <http://www.un.org/womenwatch/daw/csw/hivaids/Gupta.html>

Ho Municipal Health Directorate. (2017). *Hospitals cathment population data*. Ho, Ghana.

Ho Municipal Hospital. (2017). *Monthly antenatal returns*. Ho.

Hodgson, I., Plummer, M. L., Konopka, S. N., Colvin, C. J., Jonas, E., Albertini, J., ... Fogg, K. P. (2014). A systematic review of individual and contextual factors affecting ART initiation, adherence, and retention for HIV-infected pregnant and postpartum women. *PLoS ONE*, 9(11). <https://doi.org/10.1371/journal.pone.0111421>

IAAT. (2016). Background & History. Retrieved November 8, 2016, from <http://emctct-iatt.org/background-history/>

Ishikawa, N., Shimbo, T., Miyano, S., Sikazwe, L., Mwangi, A., Ghidinelli, M. N., & Syakantu, G. (2014). Health Outcomes and Cost Impact of the New WHO 2013 Guidelines on Prevention of Mother-to-Child Transmission of HIV in Zambia. *PLoS ONE*, 9(3). <https://doi.org/10.1371/journal.pone.0090991>

Jackson, J. B., Musoke, P., Fleming, T., Guay, L. A., Bagenda, D., Allen, M., ... Mmiro, F. (2003). Intrapartum and neonatal single-dose nevirapine compared with zidovudine for prevention of mother-to-child transmission of HIV-1 in Kampala, Uganda: 18-Month follow-up of the HIVNET 012 randomised trial. *Lancet*, 362(9387), 859–868. [https://doi.org/10.1016/S0140-6736\(03\)14341-3](https://doi.org/10.1016/S0140-6736(03)14341-3)

Joint Formulary Committee. (2016). *British National Formulary. Bnf 70* (70th ed.). London: BMJ Group; Pharmaceutical Press.

Kak, L., Chitsike, I., Luo, C., & Rollins, N. (2010). Prevention of mother-to-child transmission of HIV / AIDS programmes. *Opportunities for Africa's Newborns*, 113–126. Retrieved from <http://www.who.int/pmnch/media/publications/oanfullreport.pdf>

Kim, M. H., Ahmed, S., Hosseini, M. C., Giordano, T. P., Chiao, E. Y., Yu, X., ... Abrams, E. J. (2015). Implementation and operational research: the impact of option B+ on the antenatal PMTCT cascade in Lilongwe, Malawi. *Journal of Acquired Immune Deficiency Syndromes (1999)*, 68(5). <https://doi.org/10.1097/QAI.0000000000000517>

Kish L. (1969). Survey Sampling. *Journal of the Royal Statistical Society. Series A (General)*, 132(2)pp.272. <http://www.jstor.org/stable/2343791>.doi10.2307/2343791

Kohler, P., PhD, M. P. H., Ondenge, K., Mills, L., MD, Ms., Okanda, J., ... MD, P. (2014). Shame,

Guilt and Stress: Community Perceptions of Barriers to Engaging in Prevention of Mother to Child Transmission (PMTCT) Programs in Western Kenya. *AIDS Patient Care STDS*, 28(12), 643–651. <https://doi.org/10.1089/apc.2014.0171>

- Kumwenda, N. I., Hoover, D. R., Mofenson, L. M., Thigpen, M. C., Kafulafula, G., Li, Q., ... Taha, T. E. (2008). Extended Antiretroviral Prophylaxis to Reduce Breast-Milk HIV-1 Transmission. *New England Journal of Medicine*, 359(2), 119–129. <https://doi.org/10.1056/NEJMoa0801941>
- Kwapong, G. D., Boateng, D., Agyei-Baffour, P., & Addy, E. A. (2014). Health service barriers to HIV testing and counseling among pregnant women attending Antenatal Clinic: a cross-sectional study. *BMC Health Services Research*, 14, 267. <https://doi.org/http://dx.doi.org/10.1186/1472-6963-14-267>
- Lallemant, M., Jourdain, G., Le Coeur, S., Mary, J. Y., Ngo-Giang-Huong, N., Koetsawang, S., ... Perinatal HIV Prevention Trial (Thailand) Investigators. (2004). Single-dose perinatal nevirapine plus standard zidovudine to prevent mother-to-child transmission of HIV-1 in Thailand. *The New England Journal of Medicine*, 351(3), 217–28. <https://doi.org/10.1056/NEJMoa033500>
- Mekuria, L. A., Prins, J. M., Yalew, A. W., Sprangers, M. A. G., & Nieuwkerk, P. T. (2015). Retention in HIV care and predictors of attrition from care among HIV-infected adults receiving combination anti-retroviral therapy in Addis Ababa. *PLoS One*, 10(6), e0130649. <https://doi.org/10.1371/journal.pone.0130649>
- Mitiku, I., Arefayne, M., Mesfin, Y., & Gizaw, M. (2016). Factors associated with loss to follow-up among women in Option B+ PMTCT programme in northeast Ethiopia: A retrospective cohort study. *Journal of the International AIDS Society*, 19(1), 1–9. <https://doi.org/10.7448/IAS.19.1.20662>
- MOH. (2002). Guidelines for Antiretroviral Therapy in Ghana. Accra: MOH. Retrieved from <http://apps.who.int/medicinedocs/documents/s16437e/s16437e.pdf>
- Mugavero, M. J., Westfall, A. O., Zinski, A., Drainoni, M., Gardner, L. I., Keruly, J. C., ... Wilson, T. E. (2013). Measuring Retention in HIV Care: The Elusive Gold Standard. *PLoS One*, 8(5), 574–580. <https://doi.org/10.1097/QAL.0b013e318273762f.Measuring>
- Murithi, L. K. aruta, Masho, S. W., & Vanderbilt, A. A. (2015). Factors enhancing utilization of and adherence to prevention of mother-to-child transmission (PMTCT) service in an urban setting in Kenya. *AIDS and Behavior*, 19(4), 645–654. <https://doi.org/10.1007/s10461-014-0939-0>
- Nachega, J. B., Skinner, D., Jennings, L., Magidson, J. F., Altice, F. L., Burke, J. G., ... Theron, G. B. (2016). Acceptability and feasibility of mHealth and community-based directly observed antiretroviral therapy to prevent mother-to-child HIV transmission in South African pregnant women under Option B+: An exploratory study. *Patient Preference and Adherence*, 10, 683–690. <https://doi.org/10.2147/PPA.S100002>

- Nachege, J. B., Uthman, O. A., Anderson, J., Peltzer, K., Wampold, S., Cotton, M. F., ... Mofenson, L. M. (2012). Adherence to antiretroviral therapy during and after pregnancy in low-income, middle-income, and high-income countries. *Aids*, *26*(16), 2039–2052. <https://doi.org/10.1097/QAD.0b013e328359590f>
- NACP, & GHS. (2016). *Guidelines for Antiretroviral therapy in Ghana*. Accra: Ministry of Health.
- NACP, & GHS. (2017). IMAI PMTCT Training Slides. In NACP (Ed.) (p. 26). Ho, Ghana: National AIDS/SIT Control Programme.
- NACP, GHS, & MOH. (2016). *HIV Sentinel Survey Report*. Accra,.
- NACP, MOH, & GHS. (2005). *Guidelines for Antiretroviral therapy in Ghana*. Accra, Ghana.
- Okoli, J. C., & Lansdown, G. E. (2014). Barriers to successful implementation of prevention-of-mother-to-child-transmission (PMTCT) of HIV programmes in Malawi and Nigeria: A critical literature review study. *Pan African Medical Journal*, *19*, 1–6. <https://doi.org/10.11604/pamj.2014.19.154.4225>
- Rollins, N. C., Becquet, R., Orne-Gliemann, J., Phiri, S., Hayashi, C., Baller, A., & Shaffer, N. (2014). Defining and Analyzing Retention-in-Care Among Pregnant and Breastfeeding HIV-Infected Women: Unpacking the Data to Interpret and Improve PMTCT Outcomes. *J Acquir Immune Defic Syndr*, *67*(Suppl 2), 150–156. <https://doi.org/10.1097/QAI.0000000000000355>.
- Shapiro, R. L., Hughes, M. D., Ogwu, A., Kitch, D., Lockman, S., Moffat, C., ... Essex, M. (2010). Antiretroviral Regimens in Pregnancy and Breast-Feeding in Botswana. *New England Journal of Medicine*, *362*(24), 2282–2294. <https://doi.org/10.1056/NEJMoa0907736>
- Sherr, K., Gimbel, S., Rustagi, A., Nduati, R., Cuembelo, F., Farquhar, C., ... Gloyd, S. (2014). Systems analysis and improvement to optimize pMTCT (SAIA): a cluster randomized trial. *Implementation Science : IS*, *9*(1), 55. <https://doi.org/10.1186/1748-5908-9-55>
- Smith, L. R., Fisher, J. D., Cunningham, C. O., & Amico, K. R. (2012). Understanding the behavioral determinants of retention in HIV care: a qualitative evaluation of a situated information, motivation, behavioral skills model of care initiation and maintenance. *AIDS Patient Care and STDs*, *26*(6), 344–55. <https://doi.org/10.1089/apc.2011.0388>
- Stanzi M. le Roux, Elaine J. Abrams, K. N. and L. M., Le Roux, S. M., Abrams, E. J., Nguyen, K., & Myer, L. (2016). Clinical outcomes of HIV-exposed, HIV-uninfected children in sub-Saharan Africa. *Tropical Medicine and International Health*, *21*(7). <https://doi.org/10.1111/tmi.12716>
- Tebit, D. M., Ndembi, N., Weinberg, A., & Quiñones-Mateu, M. E. (2012). Mucosal transmission of human immunodeficiency virus. *Current HIV Research*, *10*(1), 3–8. <https://doi.org/10.2174/157016212799304689>

- Tenthani, L., Haas, A. D., Tweya, H., Jahn, A., van Oosterhout, J. J., Chimbowandira, F., ... Ministry of Health in Malawi and IeDEA Southern Africa. (2014). Retention in care under universal antiretroviral therapy for HIV-infected pregnant and breastfeeding women ('Option B+') in Malawi. *AIDS (London, England)*, 28(4). <https://doi.org/10.1097/QAD.0000000000000143>
- Thida, A., Tun, S. T. T., Zaw, S. K. K., Lover, A. A., Cavailler, P., Chunn, J., ... Clevenbergh, P. (2014). Retention and risk factors for attrition in a large public health ART program in myanmar: A retrospective cohort analysis. *PLoS ONE*, 9(9). <https://doi.org/10.1371/journal.pone.0108615>
- Tudor Car, L., Brusamento, S., Elmoniry, H., van Velthoven, M. H. M. T., Pape, U. J., Welch, V., ... Atun, R. (2013). The Uptake of Integrated Perinatal Prevention of Mother-to-Child HIV Transmission Programs in Low- and Middle-Income Countries: A Systematic Review. *PLoS ONE*, 8(3). <https://doi.org/10.1371/journal.pone.0056550>
- UN General Assembly. Universal Declaration of Human Rights, United Nations 217 A (III) (1948). UN: United Nations. Retrieved from <http://www.ohchr.org/EN/UDHR/Pages/UDHRMaterials.aspx>
- UNAIDS. (2009). *Strategic Guidance for Evaluating HIV Prevention Programmes*. Retrieved from https://www.google.com.gh/url?sa=L&rc=j&q=&esc=s&source=web&cd=2&cad=rja&uac=t=8&ved=0ahUKewi11PrqtOTUAhUGKFAKHWMiCsqFggIMAE&url=http%3A%2F%2Fwww.unaids.org%2Fsites%2Fdefault%2Ffiles%2Fmedia_asset%2F2017-Global-AIDS-Monitoring_en.pdf&usq=AFQjCNEb4AxH0EM
- UNAIDS. (2011a). *Countdown to zero: Global plan towards the elimination of new HIV infections among children by 2015 and keeping their mothers alive, 2011-2015. Joint United Nations Programme on HIV and AIDS*. Geneva, Switzerland. [https://doi.org/10.1016/S1471-0846\(07\)70033-1](https://doi.org/10.1016/S1471-0846(07)70033-1)
- UNAIDS. (2011b). *Towards the Elimination of Mother-to-Child Transmission of HIV: Report of a WHO Technical Consultation*. Geneva, Switzerland. https://doi.org/978_92_4_150191_0
- UNAIDS. (2014a). *2014 Progress report on the global plan towards the elimination of new HIV infections among children by 2015 and keeping their mothers alive (Vol. 371)*. Geneva 27 - Switzerland. <https://doi.org/3C2502/1/E>
- UNAIDS. (2014b). *The GAP report: summary*. Geneva, Switzerland. Retrieved from http://www.unaids.org/sites/default/files/media_asset/09_ChildrenandpregnantwomenlivingwithHIV.pdf
- UNAIDS. (2016a). *Global AIDS Update*. Geneva, Switzerland. Retrieved from <http://www.who.int/hiv/pub/arv/global-aids-update-2016-pub/en/>
- UNAIDS. (2016b). *On the Fast-Track To an AIDS-Free Generation*. Geneva 27 -Switzerland. Retrieved from http://emctc-iat.org/wp-content/uploads/2016/06/GlobalPlan2016_en.pdf

- UNAIDS. (2016c). On the Fast-Track to end AIDS. *Joint United Nations Programme on HIV and AIDS*. Geneva, Switzerland: UNAIDS. Retrieved from http://www.unaids.org/sites/default/files/media_asset/20151027_UNAIDS_PCB37_15_18_EN_rev1.pdf
- UNAIDS. (2017). Fact sheet - Latest statistics on the status of the AIDS epidemic | UNAIDS. Retrieved July 17, 2017, from <http://www.unaids.org/en/resources/fact-sheet>
- UNAIDS, WHO, & UNICEF. (2004). *Epidemiology Fact sheet on HIV/AIDS and sexually transmitted infections. Ghana Update*. Accra, Ghana. Retrieved from http://data.unaids.org/publications/fact-sheets01/ghana_en.pdf
- UNDP, & NDPC. (2015). *2015 Ghana Millennium Development Goals Report | UNDP in Ghana*. Accra, Ghana. Retrieved from <http://www.gh.undp.org/content/ghana/en/home/library/poverty/2015-ghana-millennium-development-goals-report.html>
- Wettstein, C., Mugglin, C., Egger, M., Blaser, N., Vizcaya, L. S., Estill, J., ... Keiser, O. (2012). Missed opportunities to prevent mother-to-child-transmission: systematic review and meta-analysis. *AIDS (London, England)*, 26(18), 2361–73. <https://doi.org/10.1097/QAD.0b013e328359ab0c>
- WHO. (2006). *Opportunities for Africa's Newborns: Practical data, policy and programmatic support for newborn care in Africa. The Partnership: for maternal, newborn and child health*. Geneva, Switzerland. [https://doi.org/10.1016/S0140-6736\(86\)91254-7](https://doi.org/10.1016/S0140-6736(86)91254-7)
- WHO. (2010). PMTCT strategic vision 2010–2015: preventing mother-to-child transmission of HIV to reach the UNGASS and Millennium Development Goals. *World Health Organization*, 1–40.
- WHO. (2013a). *Consolidated guidelines on the use of antiretroviral drugs for treating and preventing HIV infection: recommendations for a public health approach*. *World Health Organization*. Geneva, Switzerland. https://doi.org/978_92_4_150572_7
- WHO. (2013b). The WHO consolidated guidelines on the use of antiretroviral drugs for treating and preventing HIV infection; recommendations for public health approach - Implications for the African region, (September), 2–6.
- Wiktor, S. Z., Ekpini, E., Karon, J. M., Nkengasong, J., Maurice, C., Severin, S. T., ... Greenberg, A. E. (1999). Short-course oral zidovudine for prevention of mother-to-child transmission of HIV-1 in Abidjan, Côte d'Ivoire: a randomised trial. *Lancet (London, England)*, 353(9155), 781–5. [https://doi.org/10.1016/S0140-6736\(98\)10412-9](https://doi.org/10.1016/S0140-6736(98)10412-9)
- Woelk, G. B., Ndatimana, D., Behan, S., Mukaminega, M., Nyirabahizi, E., Hoffman, H. J., ... Ryan Phelps, B. (2016). Retention of mothers and infants in the prevention of mother-to-child transmission of HIV programme is associated with individual and facility-level factors in Rwanda. *Journal of the International AIDS Society*, 19(Suppl 4), 5–16. <https://doi.org/10.7448/IAS.19.5.20837>

Data Extraction Tool

DATA EXTRACTION TOOL (RETROSPECTIVE RECORDS REVIEW)

PROJECT NAME: MPH DISSERTATION-PMTCT RETENTION ANALYSIS

NAME OF RESEARCHER: ISAAC FOLTSE (UGSPH-MPH/10599087)

ETHICAL CLERANCE INSTITUTION AND NUMBER: GHANA HEALTH SERVICE/GHS-ERC: 157/02/17

NAME OF STUDY SITE (REGION): HO MUNICIPAL HOSPITAL (VOLTA)

RECORDS/ DATABASES TO BE REVIEWED: ANC REGISTER/MONTHLY REPORT
 ART DATABASE
 PATIENT FOLDER
 DELIVERY RECORDS

CLIENT DEMOGRAPHIC CHARACTERISTICS

AGE [] RESIDENTIAL LOCATION: [urban] or [rural]

HOME ADDRESS: []

MARITAL STATUS: []

RELIGION/DENOMINATION: []

ALIVE [A] OR DEAD? [D] []

OCCUPATION: []

HIGHEST LEVEL OF EDUCATION: []

NUMBER OF DEPENDANTS BELOW 18YRS: []

ANTENATAL CARE

DATE OF FIRST ANC VISIT: ___/___/___

AGE OF PREGNANCY AT FIRST ANC: [] weeks

DATE OF FIRST HIV TESTING AND COUNSELLING (HTS): ___/___/___

DATE OF REFERRAL TO ART CLINIC: ___/___/___

LABOUR, DELIVERY AND AZT (OR NVP) PROPHYLAXIS AT BIRTH

DELIVERY DATE: ___/___/___

TIME OF DELIVERY: ___:___ PLACE OF DELIVERY []

AGE OF PREGNANCY AT DELIVERY [] weeks

MODE OF DELIVERY: SVD []; CAESAREAN SECTION []; other (specify) []

WEIGHT OF BABY AT BIRTH [] kg

ART PROPHYLAXIS AT BIRTH: P&T []
DATE AND TIME OF ART PROPHYLAXIS []/ []/ [] AND []: [] (early, not early, too late)

FEEDING OPTION: []

EXCLUSIVE? YES [] or NO []

DURATION OF BREASTFEEDING (if breastfed) []

BABY WAS GIVEN **SEPTRIN SYRUP** DURING BREASTFEEDING? NO [] or YES []

PROPHYLAXIS [] or YES []

BABY ALIVE (A) OR DEAD (D) [] AGE AT DEATH (if dead) []

DURATION OF BREASTFEEDING (if breastfed) []

ART CLINIC FOLLOW-UP CARE (BABY+MOTHER)

BABY COMPLETED 6 WEEKS AZT OR NVP? NO [0] or YES [1];

BABY TESTED AFTER 6 WEEKS ZIDOVUDINE SYRUP (EID): NO [] ; YES []

	0-6MONTH	12M+6WKS	18+ MONTHS
RESULT OF BABY TESTS [P=positive; N=negative; ND=not done]	[]	[]	[]
OUTCOME OF EXPOSED BABY:	INFECTED [];	NOT INFECTED []	

HIV+ BABY ENROLLED INTO ART? [0] or [1]; HAART? [0] or [1]; HAART REGIMEN []/ []/ []

DATE REGISTERED IN ART CARE: []/ []/ []

DATE OF INITIATING MOTHER ON HAART []/ []/ []

PMTCT START DATE: []/ []/ []

AGE OF PREGN AT START OF PMTCT: [] weeks

BASELINE LABS, YES [1], NO [0]: FBC []; CD4 []; VL []; LFT []; RFT []

WHO CLINICAL STAGING (mother) []

TYPE OF CARE: PPO [] TREATM []

RETAINED IN CARE: YES [] NO []

DATE OF LAST VISIT (if not retained): []/ []/ []

SCHEDULE DATES AND RE-FILL OF ART:

DATES	HAART	VOLUME OF RE-FILL
1/1/2010	_____	[1] TABS
1/1/2010	_____	[2] TABS
1/1/2010	_____	[3] TABS
1/1/2010	_____	[4] TABS
1/1/2010	_____	[5] TABS
1/1/2010	_____	[6] TABS
1/1/2010	_____	[7] TABS
1/1/2010	_____	[8] TABS
1/1/2010	_____	[9] TABS
1/1/2010	_____	[10] TABS
1/1/2010	_____	[11] TABS
1/1/2010	_____	[12] TABS
1/1/2010	_____	[13] TABS
1/1/2010	_____	[14] TABS
1/1/2010	_____	[15] TABS
1/1/2010	_____	[16] TABS
1/1/2010	_____	[17] TABS
1/1/2010	_____	[18] TABS
1/1/2010	_____	[19] TABS
1/1/2010	_____	[20] TABS
1/1/2010	_____	[21] TABS
1/1/2010	_____	[22] TABS
1/1/2010	_____	[23] TABS
1/1/2010	_____	[24] TABS
1/1/2010	_____	[25] TABS
1/1/2010	_____	[26] TABS
1/1/2010	_____	[27] TABS
1/1/2010	_____	[28] TABS
1/1/2010	_____	[29] TABS
1/1/2010	_____	[30] TABS
1/1/2010	_____	[31] TABS
1/1/2010	_____	[32] TABS
1/1/2010	_____	[33] TABS
1/1/2010	_____	[34] TABS
1/1/2010	_____	[35] TABS
1/1/2010	_____	[36] TABS
1/1/2010	_____	[37] TABS
1/1/2010	_____	[38] TABS
1/1/2010	_____	[39] TABS
1/1/2010	_____	[40] TABS
1/1/2010	_____	[41] TABS
1/1/2010	_____	[42] TABS
1/1/2010	_____	[43] TABS
1/1/2010	_____	[44] TABS
1/1/2010	_____	[45] TABS
1/1/2010	_____	[46] TABS
1/1/2010	_____	[47] TABS
1/1/2010	_____	[48] TABS
1/1/2010	_____	[49] TABS
1/1/2010	_____	[50] TABS

APPENDIX 3

Interview Guide for In-depth interview with patients

PROJECT NAME	MPH DISSERTATION – FACTORS ASSOCIATED WITH RETENTION IN PMTCT CARE
RESEARCHER:	ISAAC FOLTSE, UGSPH/MPH
RESEARCH ASSISTANT ART COUNSELLOR
METHODOLOGY	NARRATIVE
STUDY POPULATION	PMTCT BENEFICIARIES
LOCATION OF INTERVIEW	ART CONSULTING ROOM, VOLTA REGIONAL HOSPITAL
DURATION OF INTERVIEW	40-60 MINUTES

DISCUSSION TOPICS

Participants will be called on phone and schedule meeting arranged with their usual care-givers. During the meeting, the purpose of the research is explained to them and they are given the chance to enroll or decline. Transportation to and from their places of residence and lunch will be provided to everybody including those who will decline to partake in the study.

The proposed place of the interview will be the Volta Regional Hospital ART consulting room. Permission from authorities will be sought for the purpose. Suitability of the location will be discussed with participants and they are allowed to suggest locations.

Interview will be done by the researcher together with a PMTCT trained female counsellor, who will be trained in qualitative enquiries by the student researcher.

Topics to be discussed will include the following in-exhaustive list. Participants are allowed time to express themselves and notes are taken alongside. Audio recording will be done with participant consent.

The meeting will begin by congratulating the participants on enrolling into the PMTCT. A query session to confirm demographic characteristics will be held. A PMTCT literacy guide will also be discussed to score participants on three scales, high PMTCT literacy (7/10 or more), low PMTCT (<4/10) literacy and moderate PMTCT literacy (4-6 on 10 score scale).

Interview will go on as long as possible with as many eligible participants as have consented till emerging themes begin to repeat themselves (saturation point is reached)

DISCUSSION GUIDE:

Icebreaker question:

1. You have been identified as one of the few mothers who are really concerned about your unborn child. Do you find the PMTCT programme very useful?

Maternal care:

2. It has been found out from research that some facilities do not treat HIV positive mothers with the best of care. How will you describe the kind of care you receive from the facility before and after you were tested and counseled?
3. Will you describe the care you received as 'special' or 'as usual-similar care at ANC'?

Assurance of privacy:

4. Do you feel reluctant to come to clinic here for fear that other people may hear about your status from care givers?
5. Do you like the environment where you normally report for PMTCT care? Does the environment make you feel that other people are looking at you or know about your status?
6. Have you been assured that receiving care at this unit is strictly between you and the caregiver and that your status and information will not be shared with anyone else? If not, do you think this information is necessary? **(probe further for general perceptions)**

Counselling support:

7. How do you get to know about PMTCT?
8. The health facility care givers are supposed to give you adequate information about the programme and what to expect. What are some of the things you remember from the discussion? Do you have difficulties practicing any of them **(probe further on each item)**
9. How will you describe your understanding before and after HTS **(probe for clarity)**

After-clinic support:

10. Will you have preferred that the nurse, doctor call you at home to remind you of your medicines?
11. What other services are rendered in this facility after you have gone home that makes you want to come back? If none, will you recommend some services to be rendered to you from the hospital when you are at home?

Cascade flow and flexibility:

(PI to draw a cascade flow chart that represent service delivery steps at the hospital)

12. Do you come to only ANC and you are given all that you need or you have to walk to another unit? Briefly describe what normally happens when you come for scheduled visit. [the information provided will be transposed by confirmation from frontline caregivers]

ARV shortage/regimen switch/stability:

13. Do you always get your medicines when you come for re-fill? How often do you have to leave without your medicines? Has your combination ever changed?

ART adherence:

14. Can you rate yourself on a 10-score scale how often you forget to take your medicines? Let's try it. There is no penalty for this. Let us know if you have challenges taking your medicines so that we can help you. Do you understand?

Safety practices:

15. What feeding practice is best suited for you. Were you counselled to make a choice?
16. What are some of the difficulties you face feeding your child?
17. Can you tell us more about raising a child like yours, especially adhering to safe breastfeeding practices? Can you please share some with us?
18. Do you think it is important for pregnant women who are living with HIV to insist on condom use during sexual intercourse? Have you been informed about the risk of unsafe sex and the benefits of condom use? Please feel free to share your experience with us. It will help us help other women.

Male partner disclosure and support:

19. In the home, you may have challenges with your husband. This is very common. Can you share some of the experiences you had or been having with your husband?
20. Have you disclosed your status to your husband? How did you do it and what was his reaction?
21. Has his attitude changed since the day of disclosure? Does he support your coming to clinic and practicing all that you have learnt from counsellors? [probe further to understand relationship between patient and partner as a result of HIV status disclosure]

Status disclosure to other members of family and/or close confidants:

22. Have you ever told any other person apart from your husband about the infection? Who are they and what was their reactions? How do they treat you now?

Stigma and discrimination:

23. Many of your friends are afraid to tell people about their status. They have not even told their mothers about it. This is because of fear of being rejected. Do you feel the same?

How does that feeling affect the way you attend clinic.

24. Some other people think that this infection make them less important than un-infected women. Do you agree with them?
25. Have you ever have any experience where you have been mocked or looked down upon or removed from a group because someone knows your status and made it known to other people? Can you please share what happened? How does the experience affect your compliance to schedule visits and ART adherence
26. Do you fail to come to clinic or take your medicines because you think people will ask questions about why you visit the hospital very often or take medicines all the time? Can you please share with us how you were able to manage all these thoughts?

Family support and understanding:

27. Do you have any problem with your parents or in-laws in coming to clinic every month, taking medicines, breastfeeding or complying with other recommendations?
28. If your immediate family is not aware of your status, how were you able to stop breastfeeding after the recommended period expires. How were you able to take your medicines on time and remember to come to clinic all the time? [probe further for family challenges]

Peer influencers:

29. Do you know someone in the community who also went through the same programme? If yes will you confide in her? If not do you think knowledge and relationship with such a person will help in living with your condition, attending clinic and raising uninfected child?

Culture and religion:

30. Do you have any challenges from the society in complying with the recommendations? Some of your peers confirm that their relatives wanted them to deliver at home with TBAs. Some too cannot take medicines because of spiritual reasons-pastors tell them they are healed; traditional healers give them herbs that they claim will cure them, etc. Did you face some of these challenges? Please share some of your experiences with us.

OTHER EMERGING THEMES:

31. What advise will do you have for pregnant women reporting for ANC and offered HTS?
32. Please tell us any other thing you would like us to know. You can add some of the things we did not discussed, especially things that you would otherwise not tell anyone. This information will help us help other people [review new information].

THANK YOU VERY MUCH. WE APPRECIATE YOUR COOPERATION.

APPENDIX 4

Translated Interview Guide for In-depth interview with patients (English-Ewe)

PROJECT NAME	MPH DISSERTATION – FACTORS ASSOCIATED WITH RETENTION IN PMTCT CARE
RESEARCHER:	ISAAC FOLITSE, UGSPH/MPH
RESEARCH ASSISTANT ART COUNSELLOR
METHODOLOGY	NARRATIVE
STUDY POPULATION	PMTCT BENEFICIARIES
LOCATION OF INTERVIEW	ART CONSULTING ROOM, VOLTA REGIONAL HOSPITAL
DURATION OF INTERVIEW	40-60 MINUTES

DISCUSSION TOPICS

Participants will be called on phone and schedule meeting arranged with their usual care-givers. During the meeting, the purpose of the research is explained to them and they are given the chance to enroll or decline. Transportation to and from their places of residence and lunch will be provided to everybody including those who will decline to partake in the study.

The proposed place of the interview will be the Volta Regional Hospital ART consulting room. Permission from authorities will be sought for the purpose. Suitability of the location will be discussed with participants and they are allowed to suggest locations.

Interview will be done by the researcher together with a PMTCT trained female counsellor, who will be trained in qualitative enquiries by the student researcher.

Topics to be discussed will include the following in-exhaustive list. Participants are allowed time to express themselves and notes are taken alongside. Audio recording will be done with participant consent.

The meeting will begin by congratulating the participants on enrolling into the PMTCT. A query session to confirm demographic characteristics will be held. A PMTCT literacy guide will also be discussed to score participants on three scales, high PMTCT literacy (7/10 or more), low PMTCT (<4/10) literacy and moderate PMTCT literacy (4-6 on 10 score scale).

Interview will go on as long as possible with as many eligible participants as have consented till emerging themes begin to repeat themselves (saturation point is reached)

Safety practices:

15. Devi nuɖuɖu kae soa nawo wu? Alo ɖe ɖevi nuɖuɖu kae nebu be enyo wu. Ɖe wofia wò nufiafia tao ɖevi nuɖufu nɔti be nate nɔ awɔ titia si nebu be enyo wu na wò nɔta maha? Ate nɔ awɔ titia nyuie ta maha? [mention each practice one by one: exclusive breastfeeding, general feeding, safer sex practices, condom use, personal hygiene, etc]
16. Kuxi kawoe tena ɖe dziwo le nuɖuɖu nana ɖevi la me?
17. Meɖekuku gblɔ nuwiwo me neto na le ɖevia dzi kpakpo me; Vevieto le nonana fe ɖoɖowo dzi wowa me. Meɖekuku madi be na mā wo nutefekpakpo kpɔ miawo ha.
18. Ɖe nebu be ele vievie na nyɔnu funɔ siwo nɔ dolelea le be woazi wosrɔwo dzi be woaza condom le gbɔɔɔ me?
- Ɖe nexɔ nufifia alo woxɔ nuwo tso gbɔɔɔ fe nuwɔna siwo menyo o la nɔta? Meɖekuku gblɔ fia mi wo nuxɔmenya tso condom zaza fe vievienyeye nɔ.
- Ɖe netea nɔ wɔna ɖe aɖaɖa siawo dzia? Nuka woe nye wo kuxi le ɖoɖo sia me?
- Nyà siwo nagblɔ nani la akpe ɖe nyɔnu bubuwo nɔ. Medi be nagblɔ nyatefea nani.

Male partner disclosure and support:

19. Le afeme la, kpɔtsɔtsɔ geɖe wo atenu ava le wo kple srɔwo dome, vivieto le dalele sia kple enu kuxiwo. Nyà si bo le miatɔwo dome le dukɔ bubuwo me. Ate nɔ ama wo nutefekpakpo kpɔ mi tso alesi srɔwo xɔ wo dalele fe nyaa?
20. Egbɔ wo dalelea na srɔwoa? Alekee newɔe, eye alekee woxɔe?
21. Ɖe efe noname trɔ ɖe nɔwò tso yeyi si negblɔe nɔ kple fifia?
- Ɖe wokpe na ɖe nuwò le wo dɔyɔfe vava mea? Ekpe na ɖe nɔwò be natenu awɔ ɖe ɖoɖo siwo kata wofia wò to nuxɔme mea? [probe further to understand relationship between patient and partner as a result of HIV status disclosure]

Status disclosure to other members of family and/or close confidants:

22. i) amebubua ɖe taɔ 'wu srɔwo nyà nu le wo dalele nɔta? Ameka woe wonye nawò eye aleke nye wofe nuwɔna esi negblɔe nawo? Alekee wo wɔna nawo fifia?

Stigma and discrimination:

23. Nɔwiwo geɖe wo siwo le ɖoɖo sia te medina be yewoagblɔ yewo fe dalelea na ame aɖeke o. Ame gedewo mena wo nɔwo kura ha nya o. Susu si ta wowɔ siae nye be

wobu be woagble yewo ɔ̄ ne wonyā.

De nusia ka wohaa? Meɔ̄ɔ̄kuku gbl̄ wo nutefekpokpo nami.

24. Amebubuwo bui be HIV ɔ̄lele kutsetsea wɔ̄wo ame gbl̄sewo wu amesiwo ɔ̄u ɔ̄lelea mele o. Aleke nekpo tso nya sia ɔ̄u.

25. De amewo koa wo alo ɔ̄ua fewu le ɔ̄uwoa? Nutefekpokpo kae le asiwo le amewo fe fewuɔ̄ɔ̄fɔ̄ amɛɔ̄u me? De woɔ̄ewo le hāme kpo ɔ̄e wɔ̄ ɔ̄lelea ta alo ame aɔ̄e si neuu eme na eye wokakae na amebubuwo maha? Gbl̄ nuwiwo ɔ̄zo la name.

Aleke nuwɔ̄na sia gble nu le nuwoe? Vivietɔ̄ aleke wo tɔ̄tɔ̄ wɔ̄fe ɔ̄yɔ̄fe vava alo atsike nono ɔ̄e ɔ̄ɔ̄ɔ̄ ɔ̄u?

26. De nebu amewo fe fudeame kple fewuɔ̄ɔ̄ɔ̄ ta eye ne da le ɔ̄yɔ̄fe vava dzi kple susu sia be woa bia be nuka tae nele ɔ̄yɔ̄fe vam yesixia alo edziedzi? De susu siawo tɔ̄a tame nawo maha?

Meɔ̄e kuku gbl̄ wɔ̄ nutefekpokpo nami. Aleke newɔ̄ hafi to esiawo kata me [**you don't have to ask this if not applicable to patient**].

Family support and understanding:

27. De kuxi aɔ̄e le wɔ̄ kple dziwolawo alo arɔ̄wo fe fometɔ̄wo dome tso wɔ̄ ɔ̄yɔ̄fe vava dzinu sia dzinu, atike nono yesiaɔ̄i, nonana vidzi alo wɔ̄wɔ̄ ɔ̄e ɔ̄ɔ̄ɔ̄awo kata dzi abe alesi wofia wo la ene ɔ̄ua? [**this question should be broken down and asked in short brief sentences**]

28. Ewu wɔ̄ ɔ̄lelea me na wo fometɔ̄ viviewoa? Ne melee me nenema o ɔ̄e, aleke newɔ̄ hafi wɔ̄ɔ̄e nonana fe aɔ̄aɔ̄u ɔ̄ɔ̄ɔ̄wo kata dzi? Aleke hā newɔ̄ have dzudzo nonana le ɔ̄eyiɔ̄i si woɔ̄ nawɔ̄ ladzi? De netea ɔ̄u noa atikewo kata le ɔ̄eyiɔ̄i dzi? Aleke neteaɔ̄u noa wɔ̄ atikewo ɔ̄e ɔ̄eyiɔ̄i dzi kple alesi neva na ɔ̄yɔ̄fe ɔ̄e ɔ̄ɔ̄ɔ̄ nu yesiaɔ̄i? [**probe further for family challenges**]

Peer influencers:

29. De nenyā ame aɔ̄e le miafe dume alo tokɔ̄ me si ha le ɔ̄ɔ̄ɔ̄ sia tea? Ne ele eme nenema ɔ̄ee, midze si mianɔ̄e woa? De mietea ɔ̄u uua miaɔ̄kui me na mia newo maha?

Ne enye be menya ame aɔ̄eke nenema o ɔ̄e, ɔ̄ee nebui be aanyo be yeakpo kpekpe

APPENDIX 5

Interview Guide for In-Depth Interview: Healthcare worker

PROJECT NAME	MPH DISSERTATION – FACTORS ASSOCIATED WITH RETENTION IN PMTCT CARE
RESEARCHER:	ISAAC FOLITSE, UGSPH/MPH
RESEARCH ASSISTANT	ART COUNSELLOR (recording and note taking)
METHODOLOGY	NARRATIVE
STUDY POPULATION	PMTCT CARE GIVER
LOCATION OF INTERVIEW	ART CONSULTING ROOM, HO MUNICIPAL HOSPITAL
DURATION OF INTERVIEW	20-30 MINUTES

DISCUSSION TOPICS

The complexity of this group of people is acknowledged. The challenge that may arise with regards to competing routine work schedule and possibility of leave from work and off-duties is also considered. Efforts will be taken to contact the facility managers and the study participants well before the data collection date. Each person will be allowed to fix their own schedule and place of meeting (in case the suggested location is not favourable).

The aim of this session is to confirm some challenges expressed by patients with respect to facility-level barriers to service uptake. They will also be required to comment on some logistic and human resource challenges they face in rendering the service. Participants will include, doctors, nurses, pharmacists, biomedical scientist, peer counsellors and any other person involved in care for the HIV-positive mother.

A flow chart of PMTCT flow, beginning from ANC will be drawn with the help of this group. PCAT will also be discussed with them to consider the possibility of local adoption.

DISCUSSION GUIDE:

ICEBREAKER QUESTION:

1. Your facility is one of the few sites identified and supported to render PMTCT programme. What has been your personal view about the policy?

Maternal care:

2. Do you prioritize the care you give at this unit, or do you give standard care that is

received at the ANC?

3. What will you say is different from the care given to women undergoing PMTCT and those who are not?
4. There have been recommendations about the method of delivery and prevention measures during labour and delivery. What measures do you implement here? Are these measures different from what is given to all women as part of standard maternity care?

PMTCT cascade flow and flexibility:

[PI to sketch a cascade flow chart with the help of caregivers]

5. Can you please take us through the steps involved in registering a client for PMTCT?
6. Kindly help me draw a flow chart of the flow of services from HTS to registration in ART care.

Accessibility and structural privacy:

7. Is the clinic very easy to locate by patients? [PI to walk around and experience ease of access before beginning interview]
8. How does the location of the clinic (from other service points) ensure that patient privacy and confidentiality is enhanced?
9. How will you rate the use of service here? Can you please help me fill this form at the end of the interview? [PCAT adaptation for use]

Counselling support:

10. Do you have a standard checklist for counselling? Is it easy to follow? How long since you have been trained have you been using it? [Probe further to discover more on counselling barriers. Probe knowledge on infant feeding, condom use, other items]
11. Can you confirm that you do not always have everything you need to render this care? Can you share some experiences with us [probe further to confirm response and gather further evidence]
12. Do you agree with people who suggest that retention in care is the responsibility of care givers? Please give us your suggestions?
13. Who is directly involved in counselling? [Doctors], [nurses], [peer counsellors], [other]. Do you think the training counsellors receive is adequate to help the clients? Please give your views. [probe to understand perceptions about the qualification of counsellors]
14. Do you ever have the incidence of client expression dissatisfaction about counselling

service rendered by a member of the counselling team or preferring one counsellor over the other? What in your view constitute good counselling support?

Logistics:

15. Challenges with ANC, HTS, and PMTCT logistics have been well documented. What are some of the bottlenecks you face with regard to that?
16. Do you receive your supplies from regional or district medical stores or you procure them from the open market?
17. How often do you run out of medicines and testing kits as well lab reagents and other logistics? Please help me fill this form:

LOGISTICS INPUTS	AVERAGE AVAILABILITY	PERCENTAGE
HIV Oral Quick Kit		
Kit for HIV confirmatory test		
DNA-PCR Test Kit		
CD4-Count Machine		
CD4-Count Reagents		
Viral load machine		
Viral load reagents		
Adult ARV regimen: TDF/3TC/EPV		
Paediatric prophylactic regimen: AZT or NVP		

After-clinic support services:

18. Do you call your patients at home to remind them of schedule visits and/or medications? How effective do you think this approach is?
19. Will you prefer sms texting to phone call? Please help us understand your recommendation.
20. Do you think the Ghana AIDS Commission should provide resources for following up on patients by phone, sms, home visit, etc.

OTHER EMERGING THEMES:

21. What do you think should be done to retain patients in care?
22. Please tell us every other thing. Including what you think works for people who are successful in the programme and those who are not.

WE ARE VERY GRATEFUL FOR YOUR HELP. THANK YOU.

APPENDIX 6

Consent form: Hospital Authorities

Introduction: My name is Isaac Folitse, a student of the University Of Ghana School Of Public Health. I would like to seek your approval and permission to conduct an academic study in your facility (details below). This study is part of the requirements for the award of Master of Public Health degree.

Project Topic: Assessing Retention of women in PMTCT

Objectives of the Study: Successful uptake and retention in prevention of mother to child transmission of HIV programmes is a prerequisite for achieving a sustainable low prevalence of HIV infection. It has been shown that there are identifiable and modifiable barriers affecting retention (and loss to follow-up) of pregnant women enrolled or the loss of their babies after delivery. Identification of systems barriers and patient factors will inform local strategies in order to improve upon service delivery and quality of life of children. The facility will not be negatively implicated in any way.

Study Methods: I will be collecting information on the number of women registered for ANC, HTS, PMTCT, ART. I will also collect information on ART prophylaxis for HIV-exposed babies and early infant diagnosis. I would require ART data, ANC records, patient folder and maternity record for this work. Patient anonymity will be ensured. I will be conducting interviews for women who went through the programme and currently enrolled onto the regular ART. I will also conduct interviews for frontline care givers in the ART and ANC units. I would like to use **electronic recording device to gather information for analysis**. This exercise is for academic purposes only and information gathered will be well protected until analysis is completed when it will be safely and completely destroyed.

Study participants: PMTCT women will be asked to enrol in the study voluntarily. I would like to ask for your assistance to recruit care givers at the ANC and ART into the study to provide information needed. I will not coerce anybody to partake in the study. The anonymity and confidentiality will be ensured. Compensations will be provided for participants

Other activities: I would like to engage the participants in in-depth interviews at the Volta

Regional Hospital. This location is chosen on the basis of availability of larger ART space as well as ensure clients feel free to express their concerns to a third party for academic purposes only. Transportation fares will be refunded for participants and lunch packs or money for lunch will be provided. Trained counsellor will be recruited from a sister facility to help me with data collection.

Benefits of the Study: The methodology makes it possible for facility managers to see at a glance the flow of women and their babies along the programme cascades. You will be informed on the steps that will yield greater benefit if interventions are targeted there, keeping other steps as it is. The possibility to own the data analysis tool is also very likely.

Potential risks/interruptions due to the study: The patients would have to travel from their places of residence to the study site. Apart from road transport risks, the study do not involve any procedure on client. Their working time may also be disrupted. I will be engaging some staff of your facility during working hours. There is the potential of reducing active working time during the study period. But your staff is free to excuse researcher and attend to work-related issues.

Confidentiality: I assure the authorities of the hospital of utmost security of all information gathered. The information of patient gathered from hospital record as well as from interviews will be treated with the highest level of confidentiality.

Consent Declaration:

I, (name and position in the facility):

would like to introduce the above researcher to your unit. Kindly give him the necessary support with his work. I have read the details of his activities and have considered all the implications and benefits of study.

.....
Signature
..... (Researcher)
(024-890-6259; ifolitse@st.ug.edu.gh)

.....
Date

**In case of any concern you can contact the Ethics Administrator, Ms Hannah Frimpong,
GHS/ERC on: 0243235225 / 0507041223**

APPENDIX 7

Consent form: Patients

Introduction: My name is Isaac Folitse, a student of the University Of Ghana School Of Public Health. I had sought permission from the medical director of the hospital and would like you seek your assistance in completing my study on schedule. You can at any point during the study discontinue participation. However, I would be glad if you can help me till the end.

Project Topic: Assessing Retention of women in PMTCT

Objectives of the Study: Your participation in the programme involving the use of medicines from this unit to prevent infecting the baby means that you are a beneficiary of a sponsored programme. It is expected that some things are put in place to help you benefit from it fully. However, scientists have realized that other women from other countries face some challenges making it difficult for them to complete the process. If you help me, we would be able to throw more light on what is happening in our area here that help the programme and those things that are drawing women backwards from achieving success in the programme. Your name will not be mentioned and your voice recording will be discarded after I have finished the analysis and will not be shared with anyone without coming back to ask you for permission.

Study Methods: I will be asking you several questions and will require that you tell me genuinely what you experienced. This is necessary in order to tell the true story. The hospital will not know who said what. **I will be making an audio recording of all our discussions to help me remember what we discussed here so that I can analyse it later.** I will not allow any other person to have access to your voice recording and it will be destroyed after I have finished writing everything out on paper. **Your name will not be written against the transcribed information.** I have also asked a nurse from regional hospital to help me so that you can feel free to tell her anything you feel you cannot tell me personally.

Study participants: all other women who were pregnant and were given treatment to prevent infection to the baby are also part of this research. I will not force any of you to partake in the study. The anonymity and confidentiality will be ensured. You can stop the discussion anytime in-between if you feel you cannot continue with it. Your decision to leave will not affect you when

you come back to this hospital or any other hospital for service. But I will be happy if you can help us to the end.

Benefits of the Study: the work we are doing will help the hospital taking care of you know how the programme is helping you and your baby. It will also show the problems facing you and your other colleagues though they will not be able to tell who provide which information.

Potential risks/interruptions due to the study: The study will take some of your working time. I have made provision for your transportation, though I agree that the care you take to his place is a risk. Apart from that I have taken my time to reduce other risks involved with protection of your identity to absolute zero.

Confidentiality: The information I will gather from you are strictly confidential. I will not discuss your personal information with the hospital authority. I will however inform them about the final findings which is a collective experience of all of you. This will only be done if they are interested in sharing the final information. I also will only agree to share the information with them if they agree to use it to improve service delivery.

Consent Declaration:

I have read (or was read and explained to me) the details of this research work and I agree to take part in it. I also understand that I can withdraw at any time in-between. I grant the researcher my permission to record interviews with the condition that information will be protected until analysis when it will be safely destroyed.

.....
Signature

.....
Date

..... (Researcher)

(24-890-6259; ifofitse@ug.edu.gh)

In case of any concern you can contact the Ethics Administrator, Ms Hannah Frimpong,

GHS/ERC on: 0243235225 / 0507041223

APPENDIX 8

Consent form: Frontline healthcare providers

Introduction: My name is Isaac Folitse, a student of the University Of Ghana School Of Public Health. I had sought permission from the medical director of the hospital and would like you seek your assistance in completing my study on schedule. You can at any point during the study discontinue participation. However, I would be glad if you can help me till the end.

Project Topic: Assessing Retention of women in PMTCT

Objectives of the Study: Your work with women enrolled into this programme requires that high rate of retention is ensured so as to be successful. Many other studies have shown that some barriers can be modified to improve outcome. It is my aim to help the facility to unearth barriers and enablers of retention in care so that your efforts and sacrifice culminates into good outcome.

Study Methods: I will be collecting information on the number of women registered for ANC, HTS, PMTCT, ART. I will also collect information on ART prophylaxis for HIV-exposed babies and early infant diagnosis. I would require ART data, ANC records, patient folder and maternity record for this work. Patient anonymity will be ensured. I will be needing your help in collecting the above information and would also like you to partake in a 20 minutes interview. I will be making an audio recording of all our discussions to help me remember what we discussed here so I can analyse it later. I will not allow any other person to have access to your voice recording and it will be destroyed after I have finished writing everything out on paper. Your name will not be written against the transcribed information. Information received from you is confidential and shall be protected.

Study participants: PMTCT women will be asked to enrol in the study voluntarily. I would like. I will not coerce anybody to partake in the study. The anonymity and confidentiality will be ensured. You are at liberty, at any point, during the interviews, to excuse the researcher and attend to other work-related issues.

Benefits of the Study: The methodology makes it possible for facility managers to see at a glance the flow of women and their babies along the programme cascades. You will be informed on the steps that will yield greater benefit if interventions are targeted there, keeping other steps as it is.

The possibility to own the data analysis tool is also very likely.

Potential risks/interruptions due to the study: The study will take some of your working time. Permission have been sought from the medical director so that you can spend some time with me. The methodology however have no inherent harm to participants.

Confidentiality: The information I will retrieve from record are confidential and will be treated as such. The information you will provide during the interviews will also be protected. Destruction of recorded information will be done after analysis of data.

Consent Declaration:

I have read the details of this research work and agree to take part in it. I also understand that I can withdraw at any time in-between. I grant the researcher my permission to record interviews with the condition that information will be protected until analysis when it will be safely destroyed.

.....
Signature

.....
Date

..... (Researcher)

(024-890-6259; ifo@itsec@st.ug.edu.gh)

**In case of any concern you can contact the Ethics Administrator, Ms Hannah Frimpong,
GHS/ERC on: 0243235225 / 0507041223**

APPENDIX 9 Approval letters

A. Ethical Clearance from Ghana Health Service

In case of reply the number and date of this Letter should be quoted.



GHANA HEALTH SERVICE ETHICS REVIEW COMMITTEE
 Research & Development Division
 Ghana Health Service
 P. O. Box MB 190
 Accra
 Tel: +233-302-681109
 Fax + 233-302-683424
 Email: ghserc@gmail.com

MyRef: GHS/RDD/ERC/Admin/APP/147C
 Your Ref. No.

Isaac Folitae
 University of Ghana
 School of Public Health
 Legon, Accra

The Ghana Health Service Ethics Review Committee has reviewed and given approval for the implementation of your Study Protocol.

GHS-ERC Number	GHS-ERC: 157/02/17
Project Title	Assessing Retention of Women Enrolled in PMTCT at the Ho Municipal Hospital
Approval Date	10 th May, 2017
Expiry Date	9 th May, 2018
GHS-ERC Decision	Approved

This approval requires the following from the Principal Investigator

- Submission of yearly progress report of the study to the Ethics Review Committee(ERC)
- Renewal of ethical approval if the study lasts for more than 12 months,
- Reporting of all serious adverse events related to this study to the ERC within three days verbally and seven days in writing.
- Submission of a final report **after completion** of the study
- Informing ERC if study cannot be implemented or is discontinued and reasons why
- Informing the ERC and your sponsor (where applicable) before any publication of the research findings.

Please note that any modification of the study without ERC approval of the amendment is invalid.

The ERC may observe or cause to be observed procedures and records of the study during and after implementation.

Kindly quote the protocol identification number in all future correspondence in relation to this approved protocol

SIGNED.....
 DR. CYNTHIA BANNERMAN
 (GHS-ERC CHAIRPERSON)

Cc: The Director, Research & Development Division, Ghana Health Service, Accra

B. Data Sharing Agreement with National AIDS/STI Control Programme

NATIONAL AIDS/STI CONTROL PROGRAMME
(NACP)

In case of reply the
number and date of this
letter should be quoted.

My Ref: nacp/gen/vo ...

Your Ref. No. ...



P. O. Box KB 547
Korle-Bu, Accra
Tel (233-302) 67 84 57 - 9
Fax (233-302) 66 26 91
Email: info@nacp.org.gh

24th May, 2017

**RE: SUPPORT OF DATA SHARING AGREEMENT;
MR. ISAAC FOLITSE**

We wish to state that the National AIDS/STI Control Programme (NACP) has signed a data sharing contract with Mr Isaac Folitse of the School of Public Health, University of Ghana, Legon, to enable him acquire data for his research activities using HIV data at the Ho Municipal Hospital. He will need similar information from the District Hospital in Sogakope to be used for pre-test.

In line with the above, please be informed that the NACP has agreed to allow Mr Isaac Folitse the right of limited access to the datasets for the research activities using HIV data at the Ho Municipal Hospital and the Sogakope District Hospital.

He may therefore go ahead with the said research taking into consideration the conditions in the agreement.

We count on your cooperation.

DR. STEPHEN AYISI ADDO
PROGRAMME MANAGER

THE MEDICAL SUPERINTENDENT
HO MUNICIPAL HOSPITAL
HO, VOLTA REGION

THE MEDICAL SUPERINTENDENT
SOGAKOPE DISTRICT HOSPITAL
SOGAKOPE, VOLTA REGION

✓cc: Mr. Isaac Folitse
Dept. of Health Policy, Planning & Management
School of Public Health
University of Ghana
Legon

C. **Permission to conduct research at the Ho Municipal Hospital**

In case of reply the number
and the date of this
letter should be quoted

My Ref No: HHH/G-373/Vol.11

Your Ref. No.



HO MUNICIPAL HOSPITAL
GHANA HEALTH SERVICE
P. O. BOX 49
HO, V/IL
Ghana, West Africa
Tel: (03620) 28205/6/8
Mobile No. 0200003033/055575657
Fax: 03620 - 28119
Email: homunicipal140@gmail.com

12 January 2017

OUR GHS CORE VALUES

- PEOPLES-CENTERED SERVICES
- PROFESSIONALISM
- TEAM WORK
- INNOVATION/EXCELLENCE
- DISCIPLINE
- INTEGRITY

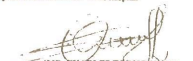
THE HEAD OF DEPARTMENT
DEPARTMENT OF HEALTH POLICY
PLANNING AND MANAGEMENT
SCHOOL OF PUBLIC HEALTH
UNIVERSITY OF GHANA
LEGON - ACCRA

RE: PERMISSION TO CONDUCT RESEARCH

We acknowledge receipt of your letter dated November 15, 2016 in relation to the above subject matter.

Management of the Ho Municipal Hospital would like to inform your outfit that approval has been given to Mr. Isaac Politae to carry out with his research in the hospital.

Thank you.


[MR. CHARLES TORKORNOO]
PRINCIPAL HEALTH SERV. ADM'TOR
for: MEDICAL SUPERINTENDENT
HO MUNICIPAL HOSPITAL

D. Data request form

APPENDIX 4 DATA REQUEST FORM



GHANA HEALTH SERVICE
DATA REQUEST FORMS



NAME: Samuel Felix
INSTITUTION: UNIVERSITY OF GHANA
PHONE: 0248906259 DATE OF REQUEST: 27-06-2017

SPECIFIC DATA REQUIRED

- ① Delivery Records: Gestation age, mode of delivery and Birth weight
- ② Hospital Catchment Population

REASON FOR REQUEST

To Complete Data Collection required to write an academic dissertation

EMAIL: ifo@tso.co.gh

SIGNATURE: [Signature]

DIRECTOR USE

APPROVED BY: [Signature] OFFICER ASSIGNED: Felix Anuobi

DATE ASSIGNED: 29/06/17 DATE COMPLETED: _____

REMARKS: _____

UNIVERSITY OF GHANA HEALTH SERVICES
MEMORANDUM

From: Paul S. ...
University of Ghana

0259-6259

27/June/2017

Total Mid (agnat), GPO attendance (2014, 2015 and Jan 2016), Total Pregnancy (2014, 2015, Jan 2016), Total
Total PMCI clients (2014, 2015, Jan 2016), Total
Below the profile for workers registered in NHIF
in 2014, 2015 and Jan 2016, Hospital population.

To complete Data Collection
required to write an academic
dissertation

infotize@yahoo.com


RECEIVED BY Felix Anuforo OFFICER ASSIGNED
DATE ASSIGNED 27/06/17 DATE COMPLETED
REMARKS

E. Request to access District health data

ISAAC FOLITSE

Department of Health Policy
Planning and Management
School of Public Health
University of Ghana
Legon
Greater Accra Region

Tel: 024-890-6259

Email: ifolitse@yahoo.com

June 23rd, 2017.

Municipal Director
Ho Municipal Health Directorate
Ministry of Health
Dear Sir,

REQUEST TO ACCESS DISTRICT DATA FOR RESEARCH PURPOSES

(TOPIC): Assessing Retention of women enrolled in PMTCT at the Ho Municipal Hospital

I would like to seek your consent to have access to **Facility Catchment Population** data for the **Ho Municipal Hospital**.

I have submitted and received approval to conduct research from the Ghana Health Service Ethical Review Committee, The Ghana AIDS/STI Control Programme and the Ho Municipal Hospital.

I have attached all three approval documents to this letter. The *Data Analysis Tool* that requires the use of this information has also been attached to this letter for your review.

I am therefore praying your urgent assistance to collect the relevant information needed to complete my research.

Thank you.

Yours Sincerely,



Isaac Folitse

(Principal Investigator)