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**Loss to follow up in HIV exposed infants in the PMTCT programme in
Hurungwe District, Zimbabwe.**

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Abbreviations

ARV	Anti-Retroviral
AIDS	Acquired Immuno Deficiency Syndrome
DNA	Deoxyribonucleic Acid
EPI	Expanded Programme on Immunization
HIV	Human Immuno Virus
PCR	Polymerase Chain Reaction
PMTCT	Prevention of Mother to Child Transmission of HIV
UNAIDS	United Nations mission on HIV/ AIDS
UN	United Nations
UNICEF	United Nations Children’s Fund
UNIGASS	United Nations General Assembly Special session on HIV/AIDS
WHO	World Health Organization

Definition of terms

Attitudes- is determined by the individual's beliefs about outcomes or attributes of performing the behavior (behavioral beliefs) weighted by evaluation of those outcomes or attributes¹.

Conceptual equivalence- to have the same meanings within the cognitive systems of the people studied².

Functional equivalence- refers to attitudes, behaviors or situations that serve the same function in both cultures².

Loss to Follow up- occurs when potential study subjects refuse or discontinue participation once the study is in progress³.

Matching- to avoid the confounding effect , the controls are often chosen to have the same distribution as the cases in terms of characteristics such as age and sex³.

Mid Upper Arm Circumference (MUAC)- The circumference of the mid-upper arm is measured on a straight left arm (in right-handed people) midway between the tip of the shoulder (acromion) and the tip of the elbow (olecranon). It measures **acute malnutrition** or **wasting** in children aged 6–59 months. The mid-upper-arm circumference (MUAC) tape is a plastic strip, marked with measurements in millimetres. MUAC < 115mm indicates that the child is severely malnourished; MUAC < 125mm indicates that the child is moderately malnourished⁴.

1 Chapter 1

1.1 Introduction

The World Health Organization (WHO) estimates that a total of 10 million babies have been born infected with HIV since the start of the epidemic and each day more than 1500 children become infected worldwide. Over 90% of these acquire the infection from their mothers⁵. In the absence of intervention, the risk of mother to child transmission (MTCT) of HIV is 15-30% in non-breastfeeding population. Breastfeeding increases the risk of MTCT transmission to 20-45%⁶. The risk of MTCT can be reduced to below 2% by interventions that include ARV prophylaxis, caesarian section and alternatives to breastfeeding.⁷

Sub Saharan Africa, which has just over 10% of the world's population, is worst affected, accounts for two thirds of the people living with HIV, and accounting for 90% of all the cases of MTCT of HIV. An Estimated 2.5 million children were living with HIV at the end of 2009, 2.3 million of them in sub-Saharan Africa⁸. In 2011 globally, an estimated 330,000 new infections were in children and between 10-12% of babies become infected each day through mother to child transmission of HIV⁹.

1.1.1 The Zimbabwe Situation

In Zimbabwe, 13,1% of the adult population between 15-49 years is infected with HIV.¹⁰ The total number of people both adults and children living with HIV in Zimbabwe by 2010 was estimated at 1, 168,263 comprising about 414,338 men and 608,700 women. This figure is projected to increase to 1,187,087 by 2015¹¹. It is also estimated that about 61,461 new

infections are likely to occur in 2010 with a projected increase in annual new infections to 65,215 in 2015. The estimated number of AIDS related deaths in 2010, was 71,299 with a projected decrease to about 51,808 deaths in 2015. It is also estimated that 14,152 children are likely to be infected by HIV in 2010. The number of children infected by HIV annually is expected to decrease to 11,162 by 2015¹¹. The challenge for the nation is to meet the Millennium Development Goals of reducing child mortality by a magnitude of two thirds between 2000 and 2015. The Zimbabwean government introduced the PMTCT programme as it works towards achieving this target¹².

1.1.2 The Prevention of Mother to Child Transmission (PMTCT) of HIV

The Millennium Development Goals (MDGs) adopted by the UN General Assembly in 2000 committed the international community to reducing child mortality, improving maternal health, and combating HIV/AIDS, malaria and other diseases by 2015. In June 2001, the United Nations General Assembly Special Session on HIV/AIDS (UNGASS) further declared its commitment to reducing the proportion of HIV-infected infants by 20 percent by 2005 and by 50 percent by 2010. However, the PMTCT UNGASS targets were for 2010 and were developed before the concept of universal access and the new, more effective PMTCT interventions. In addition, the MDGs do not provide specificity with regard to what needs to be achieved in the areas of the prevention of MTCT and paediatric HIV¹³. Zimbabwe was among the countries that were represented at the high level meeting during the 65th Session of the United Nations General Assembly held in June 2011 to review progress made in the HIV and AIDS response since 2001. The Member States including Zimbabwe adopted Resolution 65/277, “Political Declaration on HIV and AIDS: Intensifying our

Efforts to Eliminate HIV and AIDS”. This historic agreement reinvigorated previous commitments and set concrete targets for 2015 that Zimbabwe incorporated in her latest strategic plan for HIV and AIDS (ZNASP 2011-2015)¹¹.

1.1.3 The PMTCT programme in Zimbabwe

The PMTCT programme was introduced in Zimbabwe as a pilot project between 1999 and 2001 at three sites. Lessons learnt from the pilot were incorporated before the programme was rolled out to be a national programme. The main goal of the PMTCT programme is to contribute to the reduction of infant morbidity and mortality by providing pregnant women and their families with integrated comprehensive and high quality PMTCT services that are linked to care and support. The PMTCT programme in Zimbabwe is adopted from WHO the comprehensive four pronged strategic approach to preventing mother to child transmission of HIV, which includes; primary prevention of HIV, prevention of unintended pregnancies, prevention of mother to child transmission of HIV using antiretroviral drugs and provide care, follow up and psychosocial support to HIV infected women and their babies/families¹⁴.

The PMTCT programme targets as described by ZNAPS (2011-2015) are:

- HIV incidence reduced among children from 30% in 2010 to less than 5% by 2015
- HIV and AIDS related mortality reduced by 38% from 13,393 for children (2009) to 8,304 by 2015¹⁵

The PMTCT program has been one of the strongest pillars of the HIV and AIDS responses in Zimbabwe. It is integrated within the broader framework of reproductive health service provision¹⁶. As of December 2009, 59% of HIV positive pregnant women received ARVS for prophylaxis whilst 35% of HIV exposed infants received prophylactic ARVs¹⁷. Furthermore, a total of 4 498 DNA

PCR tests were conducted among HIV exposed infants by December 2009¹⁸. The proportion of estimated HIV positive pregnant women receiving ARVs for prophylaxis increased from 84% in 2010 to 98 % in 2011. Hence, universal access to ARVs for PMTCT prophylaxis was achieved for both 2010 and 2011²⁵. The proportion of HIV infected pregnant women who received MER during pregnancy was 69.6 % (31165) in 2010. Meanwhile, there was an increase in the proportion of HIV exposed infants on ARV prophylaxis from 74% in 2010 to 94 % in 2011. PMTCT programme has rapidly expanded with 95 % (1560) of the facilities in the public sector offering services. An increase in the proportion of PMTCT sites offering comprehensive services was noted from 77% (1200) in 2010 to 89 % (1390) in 2011¹¹. There was accelerated training of health workers in MER such that there was an increase in the cumulative number of health workers trained. Early Infant Diagnosis (EID) services have expanded rapidly, resulting in an increase in HIV exposed infants tested from 16 532 in 2010 to 34,667 in 2011. Number of sites performing DBS collection increased from 48 in 2009, to 379 sites in 2010 and 964 sites in 2011. There were low numbers of treatment eligible mothers initiating ART due to incompetency of some health care workers in WHO clinical staging and lack of CD4 machines at some sites. There were inadequate community mobilization and demand generation activities in the face of such barriers as user fees. In addition, late bookings and home deliveries presented missed opportunities for PMTCT. Low male uptake was negatively affecting female uptake of PMTCT services. Furthermore, commodity insecurity was encountered with stock outs of ARVs at some sites. Loss of follow up of HIV exposed infants was a major challenge; leading to low HIV testing rates of testing and fewer numbers going on cotrimoxazole prophylaxis.

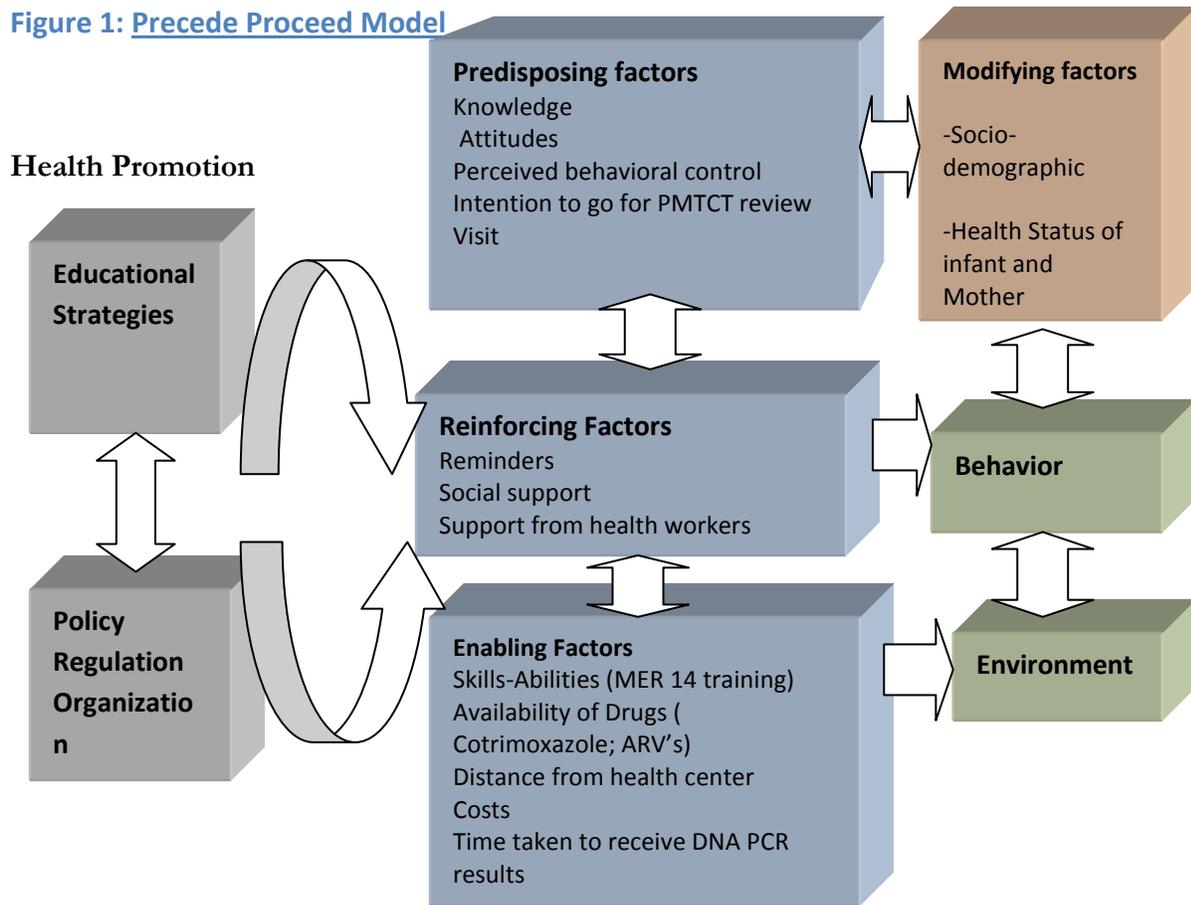
1.1.3.1 Hurungwe District

Hurungwe District is one of the 7 Districts in Mashonaland West province. Hurungwe District has a total population of 336 209 of which 79 525 are women of child bearing age, 51 199 under 5 years and 10 252 under one year of age¹⁹. The number of expected pregnancies per year in Hurungwe district is

15138. There are 32 health care facilities in Hurungwe District which all offer comprehensive PMTCT services. Pregnant women booking for first ANC visit was 2967 for the year 2011. Percentage of pregnant women tested for HIV at ANC stood at 110.7% (3283). In 2011, total institutional deliveries stood at 1933 and total home deliveries stood at 524. In the same year total deliveries by HIV positive women stood at 272 and those identified during post natal care (PNC) were 18. The percentage of HIV exposed infants with Deoxyribo-Nucleic Acid Polymerase Chain Reaction (DNA PCR) test results received and given to client was 52.8% (153)¹⁹. This bottle neck makes it difficult for children below 1 year that are eligible for Antiretroviral Therapy (ART) to receive life saving treatment.

1.1.1 Conceptual Framework

Figure 1: Precede Proceed Model



Adapted from Green and Kreuter, 2008

The Educational and Ecological Assessment of the PRECEDE - PROCEED model was used to explain the variation in review visits attendance by mother infant pairs in the PMTCT programme and subsequent cases of loss to follow up among this group in Huringwe District. The PRECEDE framework was developed in the 1970s by Green and colleagues³³. The acronym stands for Predisposing, Reinforcing, and Enabling Constructs in Educational/Environmental Diagnosis and Evaluation. This approach addressed a concern among some professionals that health education was focused too much on implementing programs and too little on designing interventions that were strategically planned to meet demonstrated needs³⁴. In 1991, PROCEED (Policy, Regulatory, and

Organizational Constructs in Educational and Environmental Development) was added to the framework to recognize the importance of environmental factors as determinants of health and health behaviors. As appreciation of the impact of health related behavior on health grew, so did recognition of these behaviors, non attendance of review visits by HIV exposed infants that leads to eventual loss to follow up are influenced by powerful forces outside the individual such as media, politics and social inequalities. More ecological approaches to Health Promotion are needed to understand and address these larger contextual determinates of health and health behavior.

The PRECEDE-PROCEED Model co postulates that behaviour is a product of Predisposing, Enabling and Reinforcing factors. Constructs from the Theory of Planned Behaviour by Ajzen, 1991 (Behaviour intention, Subjective Norms and Attitudes towards Behaviour) was incorporated into the model. Loss to follow up among HIV exposed infants is being proposed to be influenced by modifying factors such as socio-demographics (age, marital status, family size, source of income). Again the health status of the infant and mother are contributors to loss to follow up as those that are healthier might tend to be more likely to default. This study focused on individual, interpersonal, community and organizational levels. Individual factors were mainly be predisposing factors, while the enabling factors were looked at organizational level, while the community and interpersonal factors were comprise mainly of reinforcing factors. Thus the notion of an ecological approach this was taken to delineate the factors associated with loss to follow up among HIV exposed infants in Hurungwe District.

1.2 Problem Statement

Ongoing follow-up of HIV exposed infants after delivery constitutes an essential part of PMTCT programs. Worldwide, high rates of loss to follow-up (LFU) of HIV exposed infants after birth have been described. According to UNAIDS loss to follow up rates of more than 15% in the follow up of HIV exposed infants must be regarded as unacceptable¹⁴. In Hurungwe District out of the 148 exposed infants in the exposed infants register 73,6% (109) at Karoi Hospital were lost to follow up as of October 2011. Thus making it difficult to measure the success of the PMTCT programme in regards to prevention of HIV infection of infants exposed to HIV through the provision of single dose Nevirapine (sdNVP) and Zidovudine for 7 or 28 days, exposed infants started on Cotrimoxazole, infants less than 2 months tested (DNA PCR) and received results, and other key PMTCT prevention strategies such as exclusive breastfeeding for six months.

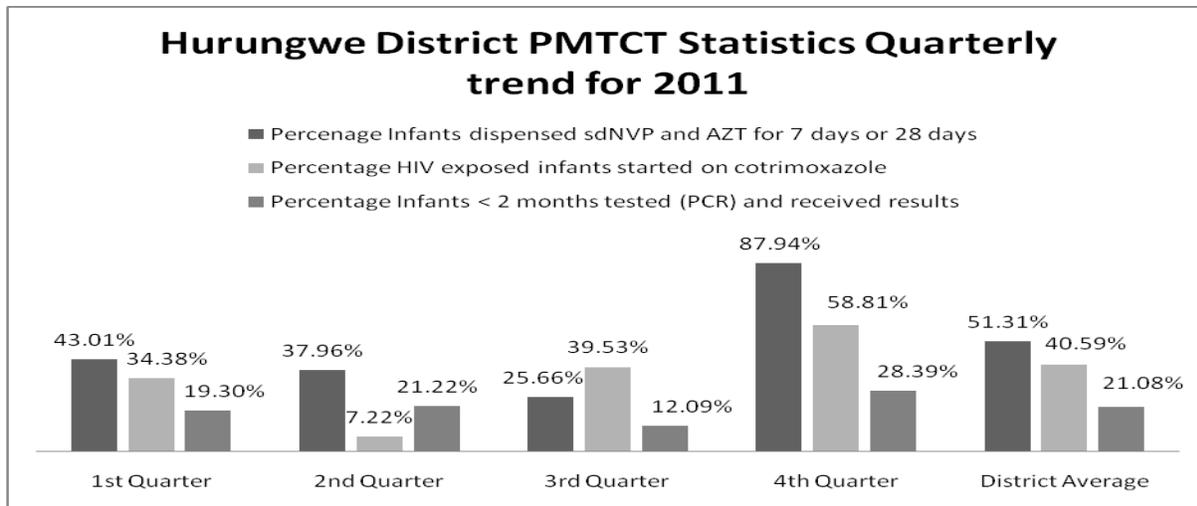


Figure 2: PMTCT Quarterly Statistics Trends for 2011

Figure 2 indicates attrition of infants in the PMTCT programme when they are dispensed with single dose Nevirapine and Zidovudine for 7 to 28 days (51.31%) soon after birth, started on

cotrimoxazole at 6 weeks (40.59%) and finally infants less than 2 months tested (DNA PCR) and received results. The number of infants receiving their HIV result is remarkably lower than the mothers that are being enrolled in the PMTCT programme.

2.3 *Justification of the Study*

- a) Despite the introduction of early infant HIV diagnosis through the use of DNA PCR at 6 weeks, rather than testing the infant for HIV at 18 months as previously practiced, the loss to follow up rate in HIV exposed infants is still high in Hurungwe District; it is not clear why this trend persists. This study was conducted to get a better insight into the reasons for loss to follow up in HIV exposed infants in Hurungwe District. It was also hoped to describe the reasons for loss to follow up in other Districts in Zimbabwe.
- b) A better understanding of the characteristics (socio-demographic, predisposing, enabling and reinforcing factors) of women and children lost to follow and those still coming for PMTCT reviews was needed.

1.4 *Purpose of the Study*

- a) Loss to follow up of HIV exposed infants is a major challenge being faced by the PMTCT programme in Hurungwe District it was hoped that through investigating the factors associated with loss to follow up this study was able to delineate key strategies that can be implemented to tackle this problem.

1.5 Objective

To investigate the factors associated with loss to follow up (LFU) among HIV exposed infants in 3 health care centers in Hurungwe District.

1.5.1 Specific Objectives

1. To assess the predisposing factors that are associated with loss to follow up in exposed infants.
2. To determine the enabling factors that are associated with loss to follow up in HIV exposed infants.
3. To determine the reinforcing factors that are associated with loss to follow up in HIV exposed infants.

1.6 Research Questions

1.6.1 Primary question

What are the factors associated with loss to follow up in HIV exposed infants in the PMTCT programme in Hurungwe District?

1.6.2 Secondary questions

- a. Is intention to utilize routine Child health/EPI services associated with loss to follow of HIV exposed infants in the PMTCT programme?
- b. Are there support structures that are associated with loss to follow up of HIV exposed infant in the PMTCT programme?

1.7 Hypothesis

H₀: Loss to follow up is independent of intention to utilize routine child health services.

H_a: Loss to follow up is dependent on intention to utilize routine child health services.

2 Chapter 2

2.1 Literature Review

Mother to child transmission of HIV is an important source of infection for infants. Mother to child transmission takes place either transplacentally (30 – 50 %), intrapartum (50 – 70%) or through breast milk (16 -26%)²⁰. Risk of transmission depends on several factors, which can be maternal or infant.

2.1.1 Early Infant Diagnosis

Data from low and middle recourse countries where HIV infected children have been identified early and given treatment revealed that the treated children did not develop AIDS and had normal child development. In Zimbabwe HIV testing for exposed children has been done at 18 months as rapid test done earlier detect maternal antibodies. With the availability of new technology DNA PCR, it is now possible to test children at 6 weeks or earlier. According to Zvitambo in Zimbabwe, most HIV positive infants die during the first year of life²². Studies conducted in South Africa have shown that starting ART before 12 weeks of age reduces early mortality by 75%⁷. It therefore becomes imperative to identify and treat HIV infected infants at an early stage. DNA PCR is the preferred virological method for infants below one year (from 6 weeks). It amplifies the DNA from the HIV and it is highly sensitive and specific^{23,24}.

2.1.2 Follow up Care for HIV-Exposed infants

HIV exposed infants are at increased risk of malnutrition, illness and death, even if they are not HIV-infected. Postnatal, immunization and weighing visits and sick mothers or sick child visits are used to identify HIV-exposed children and provide appropriate care and referral²⁵. In a study conducted in Tanzania aimed at introducing EID pilot program using HIV DNA Polymerase Chain Reaction (PCR) testing with the intention of making EID nationally available based on lessons learned on the first 6 months of implementation indicated that health services were poorly equipped to retain infants for longitudinal follow up. High rate of loss to follow-up to obtain DNA PCR results, also infection status after breastfeeding cessation was not obtained.

2.1.3 Demographics

In a study to determine the predictors and impact of loss to follow-up in a HIV Perinatal transmission cohort in Malawi found that parents of infants lost to follow-up tended to be less educated ($p < 0,001$) and more likely to be in farming occupations although an educated group, teachers and students, were also significantly less likely to return. It was highlighted that losses to follow-up can impact the observed transmission rate and the risk associations²⁶.

In a study conducted in Zambezia, Mozambique the predictors of successful follow-up were larger household size (OR=1,3; 95% CI, 1,09-1,53), independent maternal source of income (OR=10,8; 95% CI, (3,42-34,0) shorter distance from the hospital (OR=2,14; 95% CI, (1,01-4,51) and maternal receipt of ART (OR=3,15; 95% CI, (1,02-9,73)²⁷.

In a study conducted in Johannesburg South Africa it was noted that high unemployment rates, poor access to state financial grants and poor paternal support may deny mothers the necessary resources to attend clinic visits²⁸.

2.1.4 Health related factors

In an evaluation of a 5-year programme to prevent MTCT of HIV infection in Northern Uganda, Reasons for dropout were infant death and lack of understanding of the importance of follow-up. Risk of death or LFU was higher among infants with no or incomplete intrapartum prophylaxis (OR=1,9; CI 1,07-3,36) and of weaning age <6 months (OR 2,55; 95% CI 1,42-4,58), and lower in infants with diagnosed acute illness (OR 0,3, 95% CI (0,16-0,55)²⁹.

2.1.5 System related factors

In a study to investigate the cost of early infant diagnosis in PMTCT programs in low resource settings found that lost to follow up rate in the PMTCT program indicated that the number of infants available for earlier HIV testing would be 3 fold higher than at 12 months of age and concluded that additional investment by government to access an earlier HIV diagnosis for infants could triple the effectiveness of PMTCT programs to identify HIV infected children for medical management and improved quality and quantity of life³⁰. In a study in Tanzania the median time between blood draw for PCR testing and receipt of test results by the parents or guardian was 5 weeks (range <1 week to 14 weeks) among children who tested PCR positive and 10 weeks (range <1 week to 21 weeks) for those that tested negative³¹. In a review of the HIV exposed infant register in a district hospital and two rural health centers in Buhera district, Zimbabwe. It was indicated that clinic registers overestimate the number of defaulters. Patient held records were more reliably completed by clinic staff, providing better evidence for the field effectiveness of PMTCT programs³¹.

3 Chapter 3

3.1 Methodology

3.1.1 Study Setting

The study was carried out in Chidamoyo Mission Hospital, Hurungwe Rural Hospital and Chikangwe Clinic in Hurungwe District, Mashonaland West Province in Zimbabwe.

3.1.2 Study Design

An unmatched 1:1 Case Control study design was conducted.

3.1.2.1 Case

According to the Ministry of Health and Child Welfare any HIV exposed infant who has defaulted regular reviews (Postnatal Care, 6 weeks extended nevirapine, DNA PCR at 6 weeks and routine EPI schedule) for 3 months or more before and during the course of the study.

3.1.2.2 Control

In this study a control was any infant who was HIV exposed and was still coming for their regular reviews for the period under study (less than 3 months) during the course of this study. An infant who came for a visit (as indicated on the baby card/patient card) but was not registered in the infant exposed register was regarded as a control (therefore removed from the defaulters list).

3.1.3 Inclusion criteria

Infants born to HIV positive mothers during antenatal care at the 3 selected PMTCT sites (Chidamoyo Mission Hospital, Hurungwe Rural Hospital and Chikangwe Clinic) in Hurungwe District who agreed to be enrolled in the study were included. Infants whose mothers were not available but their legal guardian was available were included in the study.

3.1.4 Exclusion Criteria

Any mother who had transferred out of the District before or during the study was excluded.

Mothers who refused to consent or assent their involvement in the study were excluded.

3.1.5 Sampling Frame

This consisted of all mothers-infant pairs who are within the catchment area of the health facilities that were studied (Chidamoyo Mission Hospital, Chikangwe Clinic and Hurungwe Rural Hospital) who were confirmed HIV positive during pregnancy and found in the registers. They are 32 health centers in Hurungwe District three were purposively sampled those with the highest PMTCT coverage formed the study clusters from which the study units were derived so as to reach the required sample size. A list of cases and controls was compiled before actual data collection was conducted at each health center selected for the study.

3.1.6 Sample Size

At 95% confidence interval, 80% power and 50% exposure in the control group. Loss to follow up with infants with acute illness was found to have an odds ratio of 0.30 (Odds ratio was found in a study conducted by Ahoua L et al, 2006 in an evaluation of a 5-year programme to prevent MTCT of HIV infection in Northern Uganda) using STATCAL with a 1:1 unmatched case-control design the number of cases was 56 and controls 56 the total number of study participants was 112.

Expecting a 10% non-response rate in the study participants the sample size was adjusted to 124 making the required number of cases to increase to 62 and controls to become also 62. Eventually a sample size of 112 was reached in this study.

3.1.1 Sampling Technique

Simple random sampling was used to select study units from the sampling frame (mother-infant pairs found in the Exposed Infants Register). A lottery method without replacement was used to select study units from the sampling frame. The sampling procedure was repeated if mothers of infant exposed to HIV could not be traced or were deceased during the process of follow up and data collection. A proportionate number of cases (21) and controls (21) were selected for each health center derived from the total number of HIV exposed infants that are found in the registers in each health center to make up the required sample size per facility (n=42).

3.1.2 Data Collection instruments

Triangulation is when we approach a problem from different angles at the same time. In this manner, information from different independent sources can be cross-checked. This was used to approach the problem of loss to follow up from different angles through the use of four data collection techniques at the same time. The data collection instruments that were used are review of registers; observation in the measurement of MUAC and interviewer administered structured questionnaire.

Table 1: Data collection instruments

Data Collection techniques	Data Collection Tools
Review of records	Using PMTCT registers, HIV Exposed Infants Registers, ANC registers, MER 14 Monthly Summary reports
Observing	Eyes (Mid Upper Arm Circumference-MUAC) Observation Checklist
Administering written questionnaires	Interviewer Administered Structured Questionnaire

3.1.3 Data Collection

Data was collected through an interviewer administered questionnaire. The questionnaire was pre-tested before administration to the study population. Participants were randomly selected from the infants exposed register using the lottery method.

3.1.4 Design of Instruments

The data collection instruments were developed according to the educational diagnosis of the PRECEDE-PROCEED Model by Green and Kreuter with an addition of constructs from the Theory of Planned Behavior. The interviewer administered questionnaire was designed in English and Shona to bring out conceptual and functional equivalence² improving the validity of the instruments.

3.1.5 Pre-test

A pre-test was conducted to assess the instruments content validity and consistence of items to the objectives of the study. Confusing questions were eliminated.

3.1.6 Study Variables

3.1.6.1 Outcome variables

Figure 3: Dependent Variable

Variable	How to measure	Information source
<i>Follow up status</i>	Infants that do not come for their Cotrimoxazole prophylaxis and Extended Nevirapine prophylaxis for 3 months will be regarded as lost to follow up.	Dispensary register, Exposed infants Registers/Patients treatment cards

3.1.6.2 Independent variables

Figure 4: Independent Variables

Variable	How to measure	Information source
Modifying Factors		
<i>Socio-demographics</i>	Was assessed by a battery of questions focusing on demographics' (age, marital status family size,) and social aspects (monthly income, employment status, religion,).	Mothers self reports
<i>Health status of infant and mother</i>	Was assessed by checking patient cards for both infant and mother for frequency of illness. Assessing if both had fallen ill in the past 2 weeks and what remedial measures did they take (health seeking behavior). Nutrition status of the infant was assessed by measuring the Mid-Upper Arm Circumference (MUAC). Breastfeeding status was also be assessed together with mothers ability to properly breastfeed on first attempt.	Mothers self report/patient cards/Child Health cards/MUAC
Predisposing Factors		
<i>Knowledge on need of PMTCT review visits by HIV exposed infants.</i>	Was assessed by means of a battery of questions focusing on breastfeeding practices, probing for knowledge on the need for review visits.	Mothers self reports

<i>Attitude/Outcome expectation</i>	Was measured by way using larger or lesser extent question. In which participants was asked their opinions on accessing health care services for PMTCT for their HIV exposed infants.	Mothers self reports
<i>Values and norms</i>	Was assessed by asking questions on how the community views certain issues and how it perceives: exclusive breastfeeding, giving birth to an HIV exposed infant.	Mothers self reports
<i>Intention</i>	Was assessed by asking questions on readiness of PMTCT mothers to take their infants for regular reviews at their respective health care centers.	Mothers self reports
Enabling Factors		
<i>Skills abilities</i>	Was assessed by asking if they feel they need any training for them to fully participate in the PMTCT programme.	Health worker self reports
<i>Distance to the health center</i>	Was assessed by asking participants how far it is to their local health center and whether they feel that this distance is adequate for them to walk and receive PMTCT services.	Mothers self reports
Reinforcing Factors		
<i>Social influence</i>	Was assessed by five items in which the participants were assessed for the support they get from others. The perceived support from family, local political leadership and friends.	Mothers self reports
<i>Reminders</i>	Was assessed by asking the participants if they ever get reminders or encouragements for them to take their infant for early infant diagnosis or drug resupply when they are due.	Mothers self reports

3.1.7 Data entry

Questionnaire was checked for completeness and quality before being entered in to EPI Info version 3.5.1. Specific codes were assigned to each variable under measurement. Data was checked for double entries as part of quality control and consistency check of the validity of the data.

Table 2: Example of Codes to be used during data entry

Variable	Definition	Codes
Cstatus	Follow up Status	0= Control 1= Case
Bintent	Behavioral Intention	0= Low behavioral intention 1= High behavioral intention
NutriStatus	Nutrition Status	0= Poor Nutrition status 1= Good Nutrition status

3.1.8 Data Analysis

Quantitative data was summarized and analyzed using Epi-Info version 3.5.1 to:

- Generate frequencies and means of variables
- Calculate measures of association
- Carry out stratified analysis to asses for confounding and effect modification.
- Perform logistic regression analysis to control for confounding if present.

3.1.9 Permission

Permission to carry out this study was sought from the Provincial Medical Director Mashonaland West, the department of community medicine and the District Medical Officer for Hurungwe District.

3.1.10 Ethical Consideration

Ethical approval was sought from the Joint Research Ethics Committee and the Medical Research Council of Zimbabwe. A written informed consent was obtained from all study participants using a consent form (See Appendix 1). No force, coercion or persuasion by any means was used to recruit study participants. Study participants were allowed to terminate their participation at any time they feel like doing so. The consent forms and filled questionnaires were stored separately under lock and key by the Principal Investigator at the Karoi District Hospital where analysis was done by the Principal Investigator. Confidentiality was assured and maintained throughout the study.

4 Chapter 4

4.1 Findings

4.1.1 Socio-demographic

Table 3: Socio-demographics

Characteristic of variables	Case (n=56) %	Control (n=56) %	OR	95% CI
Age of Mother				
18-30	51.8 (29)	66.1 (37)	0.55	(0.24;1.27)
31-48	48.2 (27)	33.9 (19)		
Median	30	28.5		
Education				
None	23.2 (13)	7.1 (4)	3.93	(1.08;15.53)
Primary	35.7 (20)	12.5 (7)	3.89	(1.37;11.44)
Secondary	41.1 (23)	80.4 (45)	0.17	(0.07;0.43)
Age of Infant*				
3-4	52.9 (27)	58.3 (28)		
10-20	47.1 (24)	41.7 (20)	0.80	(0.34;1.92)
Median	9	7		
Marital Status				
Single	5.4 (3)	3.6 (2)	1.53	(0.2;13.7)
Married	48.5(47)	51.5 (50)	0.63	(0.18;2.12)
Divorced	5.4 (3)	7.1 (4)	0.74	(0.12;4.15)
Widowed	5.4 (3)	0 (0)	undefined	
Family Size				
0-4	42.9 (24)	60.7 (34)		
5-9	57.1 (32)	39.3 (22)		
Median	5	4	0.49	(0.21;1.10)
Mothers source of Income				
Formal	0 (0)	10.7 (6)	undefined	
Informal	46.4 (26)	50 (28)	0.87	(0.39;1.95)
None	53.6 (30)	39.3 (22)	1.78	(0.79;4.06)

*Age of infant is in months

A total of 56 cases and 56 controls were enrolled into the study. The median age for mothers

included in the study was 30 years for cases and 29 years for controls. With increase of age the odds

of her infant being lost to follow up was less likely (0.55), although at 95% CI this was not

significant. Having a secondary education was significantly protective at 97% CI (0.07; 0.43), this odds ratio of 0.17 reflects a strong negative association.

4.1.2 Health Status of infant and mother

Table 4: Health Status of Infant

Characteristics of variables	Case (n=56)	%	Control (n=56)	%	OR	95% CI
Mother took ARV's during labour	38.9 (35)		61.1 (55)		0.0303	(0.0039;0.2355)
Baby received Nevirapine during labour	60.7 (34)		98.2 (55)		0.2208	(0.0848;0.5746)
Current Health Status of baby						
Alive and ill	1.8 (1)		42.9 (24)		0.02	(0.00;0.18)
Alive and well	92.9 (52)		57.1 (32)		9.75	(2.84;36.76)
Dead	5.4 (3)		0 (0)		undefined	
Fallen sick any time since birth	50 (28)		69.6 (39)		0.4359	(0.2010;0.9215)
Baby is on Extended Nevirapine	14.8 (8)		91.1 (51)		0.0474	(0.0177;0.1271)
Baby is on Cotrimoxazole prophylaxis	4.3 (8)		41.1 (23)		0.2391	(0.0954;0.5992)
Good Nutrition (MUAC>125)						
Median	130		135		0.76	(0.30;1.92)
Mean	134		138.9			
Mode	130		130			

Mothers who took ARVs during labour were less likely to be lost to follow up (0.0303). This protective association was statistically significant at 95% CI. Again babies who receive Nevirapine were significantly less likely to be lost to follow up. 42.9% (24) of the controls were alive and ill compared to 1.8%(1) of cases. Infants who were alive and well were significantly more likely to be lost to follow up (9.75). 5.4% (3) of infants had deceased. Infants who were receiving extended

Nevirapine and Cotrimoxazole were less likely to be lost to follow up with odd's ratio of 0.0171 and 0.2391 which were statistically significant. Infants with good nutrition 0.76 were less likely to be lost to follow up however this was not statistically significant.

4.1.3 Predisposing factors

Table 5: Predisposing Factors

Characteristics of variables	Case (n=56) %	Control (n=56) %	OR	95% CI
HIV can be transmitted by breastfeeding				
Yes	80.4 (45)	91.1 (51)	0.4011	(0.1295;1.2423)
No	19.6 (11)	8.9 (5)		
MTCT be reduced by ARVs				
Yes	83.9 (47)	91.1 (51)	0.5120	(0.160;1.679)
No	16.1 (9)	8.9 (5)		
Our religion prohibit use of modern medicine				
Yes	62.5 (35)	7.1 (4)	12.1034	
No	37.5 (21)	92.9 (52)	(3.8550;38.0012)	
It is culturally acceptable to exclusively breastfeed				
Yes	23.2 (13)	67.9 (38)	0.3269	(0.1502;07114)
No	76.8 (43)	32.1 (18)		
To a Large extent HIV can be prevented from mother to infant				
Yes	25 (14)	91.1 (51)	0.1579	(0.0692;0.3602)
No	75 (42)	8.9 (5)		
Behavioural Intention				
Likely to take child for review and resupply of drugs				
Yes	43 (23)	89.3 (50)	0.2556	(0.1133;0.5663)
No	57 (33)	10.7 (6)		

Knowledge that HIV can be transmitted by breastfeeding was higher among controls (91.1%) compared to cases (80.4%). Odds ratio was protective (OR: 0.3929). Again knowledge levels that ARVs can reduce mother to child transmission was also high. Prohibition of use of modern medicine was strongly associated (OR: 12.1034) with loss to follow up. Mother infant pairs for communities that accept exclusive breastfeeding for six months were less likely to be lost to follow

up (OR:0.3269). Mothers that had high behavioural intention to visit health care centres were less likely to be lost to follow up (OR: 0.2556).

4.1.4 Enabling factors

Table 6: Enabling Factors

Characteristics of variables	Case (n=56) %	Control (n=56) %	OR	95% CI
Time it takes to reach the health centre				
Time <101 minutes	53.6 (30)	50 (50)	1.15	(0.51;2.59)
Median	100	90		
Mean	120	103		
Mode	60	30		
Is the Distance considered to be far or near	58.9 (33)	55.4 (31)	0.8662	(0.412;1.8213)
Failed to go to the clinic due to lack of money	57.1 (32)	12.5 (7)	3.333	(1.5204;7.3082)
Failed to assess health services at clinic	51.8 (29)	7 (4)	5.2	(2.084;12.9748)
Money it costs to go to the clinic				
Money<\$3	76.4 (42)	91.1 (51)	0.32	(0.09;1.06)
Median	1	1		
Mean	1.6	1.25		
Mode	1	1		

The modal time it takes mother infant pairs to reach their respective health care facilities for cases was 60 minutes and controls 30 minutes. Cases had an average more time to reach their respective health centers (120 minutes) compared with controls (103 minutes). Again median time to reach the health facility for cases was 100 minutes compared to 90 minutes for controls. There was no statistical significance between the time that is taken by cases and controls to reach their respective health facilities. 58.9% of cases stated the distance they travel was far compared to 55.4% within the controls. The odds of mother-infant pairs being lost to follow up was greater due to lack of bus fare. A significant number of states having failed to assess services (4.447;43.395). The modal cost to go to their respective health centres by mother-infant pairs was a \$1.00.

4.1.5 Reinforcing Factors

Table 7: Reinforcing Factors

Characteristics of variables	Case (n=56) %	Control (n=56) %	OR	95% CI
Get reminders on the need to know your child's HIV status or resupply of drugs	17.9 (10)	80.4 (45)	0.1579	(0.0692;0.3602)
Disclosed status to partner	96.1 (49)	94.4 (51)	1.9043	(0.8652;4.2129)
Disclosed status to family members	89.3 (50)	91.1 (51)	1.2158	(0.4.89;3.6153)

80.4% of mothers within the control group got reminders on the need to know their exposed infants HIV status. Getting reminders had a significant protective effect (0.1579). Disclosure of one's HIV status to partner or family members did not have any significant association with loss to follow up.

5 Chapter 5

5.1 Discussion and Conclusion

5.1.1 Socio-demographics

Mother's of HIV exposed infants with a secondary school education are less likely (OR: 0.17) to be lost to follow up compared to their less educated counterparts. This is similar to studies conducted in Malawi that found out the less educated parents were more likely to be lost to follow up²⁶.

Educated mothers easily comprehend the health implications to their HIV exposed infant of being lost to follow up. However high education level itself can not exclusively explain high rates of loss to follow up for in a cohort study in Malawi found that parents of infants lost to follow up tend to be less educated as well and more likely to be in farming occupations although an educated group, teachers and students, were also significantly less likely to return²⁵. In this study no significant association was found with larger family size and independent maternal source of income as predictors of successful follow up as indicated in studies conducted in Zambezia, Mozambique.

Although not significant mother-infant pairs that were lost to follow up in this study were less likely to have a Family size of more than 5 people. With a smaller family size support structures to bring the exposed infant to the health facility are diminished and the exposed infant is more likely to be lost to follow up. Mother's of exposed infants were more likely to be lost to follow up due to them being unemployed and having no independent source of income.

5.1.2 Health status of mother and infant

ARV intake has a strong protective effect as mother-infant pairs who ingest ARVs during labour and delivery are less likely to be lost to follow up post partum, they are more likely to remain in constant contact with the health facility reducing chance of loss to follow up. This is consistent with studies conducted in Northern Uganda where loss to follow up was high among infants with no or incomplete post partum ARV prophylaxis. Infants that were alive and ill were less likely to be lost to follow up compared to infants that were alive and well. Babies on Cotrimoxazole prophylaxis had a strong protective effect in preventing the infant from being lost to follow up. Utilization of health care services enables constant contact with the health care facility reducing the chances of loss to follow up of mother infant pairs in the PMTCT programme.

5.1.3 Predisposing factors

Knowledge of HIV being transmitted through breastfeeding was protective, mother infant pairs who had knowledge about ARV's being able to reduce MTCT were more likely to have successful follow up outcomes. This was concurrent to a study conducted in Northern Uganda that indicated that lack of understanding of the importance of follow up were the reasons for dropout in the PMTCT programme²⁹. Having appropriate knowledge acts as a facilitating agent preventing loss to follow up. Religious beliefs that prohibit the use of modern medicine was more likely to make mother infant pairs to be lost to follow up. These religious groups form a special sub population that need tailor made interventions that will promote them to uptake health programmes. Mothers who come from communities that view exclusive breastfeeding to be acceptable were less likely to be lost to follow up as they would have support structures that have positive views towards

exclusive breastfeeding. Mothers with strong attitudes towards MTCT of HIV being able to be prevented were less likely to be lost to follow up with controls bearing this notion more (91.1%) compared to cases (25%). Behavioural intention among controls was higher as they were more likely to intend to visit health care services. The log odds of mothers that said they were likely to take their child for review and drug resupply were protective (OR: 0.2732) with cases less likely to intend to take their child for such visits, this was statistically significant at 95%CI (0.1215;0.6141). Thus we reject the null hypothesis and conclude that loss to follow up is dependent on intention to utilize routine child health services. Health promotion interventions to increase the behavioral intention of mother's of exposed infants to utilize child health services need to be strengthen.

5.1.4 Enabling Factors

Lack of money for transport and user fees to access health care services was strongly associated (OR:2.94) with mother infant pairs being lost to follow up. This is strongly compacted by lack of independent maternal income. The modal cost of transport to health centres is \$1-00, which at many times is out of reach. With the vastness of Hurungwe district they are only 32 health centres for a population of 336 209. The average time it takes those lost to follow to reach their respective clinic is 2 hours compared with controls which take 1 hour 30 minutes.

5.1.5 Reinforcing factors

The web of social relationships that surround mothers' of exposed infants has a bearing on whether they are lost to follow up or not. The provision of social support is one of the important functions of social relationships. In this study reminders' on the need to know their exposed infants HIV

status and resupply of drugs was found to be protective (OR: 0.1579). They is thus need to strengthen social support networks to curb loss to follow up of HIV exposed infants.

5.1.6 Limitations

Selection bias could have been possible because cases and controls were selected when mothers of HIV exposed infants volunteered to be included in the study. This study conducted door to door interviews with eligible participants in the study frame due to the inaccessibility of some areas some prospective study participants were left out. Due to the mobility of mothers, some were not available to be interviewed. Information bias might also have affected this study as some mother could not recall whether they received ARV's during labor or even their baby. Hospital cards in many scenarios were not available for cross checking. This study only covered 3 health care centers in one district of Mashonaland West its generalization to other districts of Zimbabwe might be limited.

5.2 Conclusion

The statistically significant factors associated with loss to follow up were having no secondary education, ARV intake during labour, religious beliefs, cultural acceptance of exclusive breastfeeding, behavioural intention, lack of money for transport and reminders from the social networks. It can be assumed that increasing the behavioural intention to utilize health care services for early infant diagnosis and resupply of drugs can reduce loss to follow up among HIV exposed infants.

5.3 Recommendations

These are the recommendations of this study:

1. The District Health Executive for Hurungwe district should formulate methods of improving its identification system of infants that are HIV exposed on first contact with a health worker. HIV exposed infants should be identified as they seek routine EPI and other essential health care services.
2. The District Health Executive for Hurungwe district should formulate interventions to increase the behavioural intention of mothers' of exposed infants to access care. Mothers should be given health education on the importance of early infant diagnosis and the need to prevent opportunistic infections through the use of extended Navirapine and Cotrimoxazole prophylaxis.
3. Health Promotion interventions should be tailor made for religious groups that prohibit the use of ARV's in the PMTCT programme as this acts as major facilitator for loss to follow up of HIV exposed infants.
4. Future studies should test PMTCT operational interventions that can be implemented to curb Loss to follow up of HIV exposed infants. Thus providing evidence to best practices that can be implemented to reduce the chances of loss to follow up of HIV exposed infants.

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Appendix 1: English Consent Form



University of Zimbabwe

Department of Community Medicine

Masters in Public Health (Health Promotion) Programme

Loss to follow up in HIV exposed infants in the PMTCT programme in Hurungwe District, Mashonaland West Province, Zimbabwe

2012

Principle Investigator: Mr George Machacha (MPH trainee)

Phone Number: 0773732856

Academic Supervisors: Mrs J. Maradzika, Dr J Chirenda

Field Supervisor: Mr G Kambondo (PHPO, MPH Graduate)

This consent form is meant to inform you as a potential research participant on the purpose, risks, and benefits of this research.

Introduction: I am Mr G. Machacha. I am an MPH trainee with the University of Zimbabwe attached to Mashonaland West, Provincial Medical Director (PMD) conducting a research on Loss to follow up of HIV exposed infants in the PMTCT programme in Hurungwe District.

Purpose: I am making a follow up on the infants whose mothers were seen on the PMTCT programme so that I may be able to understand what is happening to their infants. I would like to compare the characteristics of mothers and infants that are lost to follow up and those still coming for their review visits.

Confidentiality: No names will be written on this questionnaire and no one else will be able to link the information you provide about yourself to your name. All the information from this study will be treated with utmost confidentiality. No names will be used in data analysis and in the report. All the information in the report will be anonymous. The information from this study will be used to strengthen the PMTCT programme.

Risk/Discomforts or Benefits: This research will involve asking of personal questions about you and your infant. It will take approximately 15 minutes to complete our interview. I will conduct a Mid Upper Arm Measurement on your infant to measure nutrition status and give you advice on the result. It is hoped that the results of this study will contribute to the improvement of the PMTCT programme in Hurungwe District. So feel free to air out your personal views of the program.

Alternative Procedures or Treatments: There are no interventions or treatments that will be done in this study.

Additional costs: You will not incur any expense for participating in this study.

Voluntary Participation: It would be appreciated if you can give honest answers to the questions and if you feel you are unable to give a correct answer it is allowed to say so. You are able to

terminate the interview if you are not comfortable with proceeding with the interview at any time during the course of the interview. Before you sign this form, please ask any question on any aspect that might be unclear to you. You may take as much time as necessary to think it over.

Authorization: I agree to participate in the above-mentioned study. I will give truthful information as required in the interview.

Signature..... Date..... Time.....
(Interviewee)

Signature..... Date..... Time.....
(Interviewer)

For any further information pertaining to this study, please feel free to contact me at:

University of Zimbabwe

College of Health Sciences

Department of community medicine

PO Box A178, Avondale

Harare

Zimbabwe

YOU WILL BE GIVEN A COPY OF THIS CONSENT FORM TO KEEP

If you have any questions concerning this study or consent from beyond those answer by the investigator, including questions about the research, your child rights as a research subject or research-related injuries: or if you feel that you have been treated unfairly and would like to talk to

someone other than a member of the research team, please feel free to contact the Medical Research Council of Zimbabwe on telephone 04-791792 or 791193.

Appendix 2: Shona Consent Form



University of Zimbabwe
Department of Community Medicine
Masters in Public Health (Health Promotion) Programme

Loss to follow up in HIV exposed infants in the PMTCT programme in Hurungwe District, Mashonaland West Province, Zimbabwe

2012

Principle Investigator: Mr George Machacha (MPH trainee)

Phone Number: 0773732856

Academic Supervisors: Mrs J. Maradzika, Dr J Chirenda

Field Supervisor: Mr G Kambondo (PHPO, MPH Graduate)

6 GWARO RECHITENDERANO

Kutanga: Ndinonzi George Machacha. Ndiri mudzidzi we Public Health pachikoro che University Of Zimbabwe. Parizvino ndiri kuhofisi kwaProvincial Medical Director Mashonaland West Province kwandiri kuita ongororo inotsvaka zvikonzero zvinosakisa kuti vana varimuchirongwa che PMTCT vasadzoka kuti vaonororwe. Kana vane chirwere vabatsirwe pachine nguva pachipatara nemaClinic ari muHurungwe.

Chinangwa cheongororo: Murikukumbirwa kuti muve nhengo yeongororo yekutsvaka zvikonzero zvinoita kuti vana vari muchirongwa chePMTCT vasadzoka kuti vaongororwe uye kuzichibidzika kubatsirwa kana paine chirwere. Nekudaro, Chinangwa chikuru cheongororo iyi ndichekuwana zvikonzero zvinotadzisa amai vemwana akazvarwa ari muchirongwa chePMTCT kuuya kukiriniki pamazuva avakatarirwa. Tirikuda kuziva musiano uripo pavana varikuuya kuzoonekwa nevasiri kuuya pamazuva akatarwa.

Zvichaitwa muongororo: Kana makasununguka kuva muongororo ino,ndichakubvunzai mibvunzo inogona kutora nguva iripakati pemaminitsi gumi kusvika gumi nemashanu kuti tipedze.Ndichakubvunzai mibvunzo yakanangana nemi uye maererano chirongwa chePMTCT. Ndichatarisawo makadhi ekurapwa kwenyu kana mandipa mvumo kuti ndione mazuva amakatarirwa, mapiritsi amunomwa pamwe nekuenda kwenyu kuchipatara pamazuva amakatarirwa. Makasununguka kubvunza mibvunzo pamunenge musinganzwisise.Kana muinemimwe mibvunzo pamusoro peongororo iyi, makasununguka kubvunza chero nguva.Kana tapedza hurukuro yedu, tichapakurirana ruzivo nezvePMTCT.

Njodzi dzamungasangana nadzo: Hapana njodzi yamungasangana nayo kuburikidza nekuva muongororo ino. Asi dzimwe dzenguva munogona kuzonzwa muchinyara kupindura mimwe

mibvunzo yacho. Kana paine mibvunzo yamusina kusununguka kupindura, makasununguka kuregedza kupindura.

Zvakanakira kuva muongororo ino:Hapana muhora wamuchawana kuburikidza nekuva muongororo ino asi kuti muchawana mukana wokudzidza zvakawanda maererano nezvePMTCT uyewo kukosha kwekuenda kukiriniki kunoonekwa nanamukoti pamazuva akatarwa.

Kuvimbika kwetsvakurudzo:Kuva kwenyu muongororo iyi hazvimanikidzwi, munoita nechido chenyu.Hapana zvamunoiwa kana mukati hamuchada kuva muongororo ino nyangwe.Zvese zvamuchazivisa pamusoro penyu hazvizoparadzirwa kune vamwe vanhu, zvinoperera pakati pedu. Bepa richashandiswa pakubvunza mibvunzo richangozivikanwa nenhamba pasina zita renyu. Nhamba idzodzi dzichachengeterwa pakasiyana negwaro rino ramuchazosayina kupa mvumo yokuti muve muongororo ino.

Kupindurwa kwemibvunzo: kana paine mibvunzo yamuchaona isina kujeka makasununguka kundibvunza ikozvino, chero pane imwe nguva. Makasununguka kutora nguva yekuti mumbofunga.

Mvumo: Kusayina kwamuchaita panzvimbo inotevera zvinoratidza kubvuma kuti maziviswa maererano neongororo iyi, hamuna kumanikidzwa kuva nechokuita nayo, uyezve kuti zvamaudzwa zvaita kuti mugone kunyatsonzwisisa zvamuri kukurudzirwa kuita uye muchitaura zvamunoziva. Zvamunenge mazivisa patsvakiridzo ino zvichabvumidza ini pamwe nevarairidzi vangu kuti tizvishandise muongororo ino bedzi.

Runyorwo rweMupinduri..... Zuva.....

Runyorwo rweMuongorori..... Zuva.....

Kana paine zvamunoda kunzwisisa, ivai makasununguka kundinyorera pa kero inoti:

University of Zimbabwe
College of Health Sciences
Department of community medicine
PO Box A178, Avondale
Harare
Zimbabwe

MUCHAPIHWA RIMWE GWARO RECHITENDERANO KUTI MUGARE NARO

Kana muine imwe mibvunzo isina kupindurwa nemuongorori, kana mibvunzo yakanangana nekubatwa kwamaitwa mutsvakurudzo iyi, kana kodzero dzenyu, kana kusabatwa zvakanaka kwamunenge maitwa makasununguka kubata veMedical Research Council of Zimbabwe panhamba dzerunhare dzinoti: 04-791792 or 04-791193

Appendix 3: English Assent form (Parental Consent)



University of Zimbabwe
Department of Community Medicine
Masters in Public Health (Health Promotion) Programme

Loss to follow up in HIV exposed infants in the PMTCT programme in Hurungwe District, Mashonaland West Province, Zimbabwe

2012

Principle Investigator: Mr George Machacha (MPH trainee)

Phone Number: 0773732856

Academic Supervisors: Mrs J. Maradzika, Dr J Chirenda

Field Supervisor: Mr G Kambondo (PHPO, MPH Graduate)

This consent form is meant to inform you as the Guardian of a potential research participant the purpose, risks, and benefits of this research.

Introduction: I am Mr G. Machacha. I am an MPH trainee with the University of Zimbabwe attached to Mashonaland West, Provincial Medical Director (PMD) conducting a research on Loss to follow up of HIV exposed infants in the PMTCT programme in Hurungwe District.

Purpose: You are being asked to allow your child to participate in a study that is making a follow up on the infants whose mothers were seen on the PMTCT programme so that I may be able to understand what is happening to their infants. I would like to compare the characteristics of mothers and infants that are lost to follow up and those still coming for their review visits. This study is meant to come up with reason why HIV exposed infants are lost to follow up in the PMTCT programme so as to come up with strategies to improve the delivery of the programme. This study will involve 124 participants in Hurungwe District.

Confidentiality: No names will be written on this questionnaire and no one else will be able to link the information your child will provide and herself. All the information from this study will be treated with utmost confidentiality. No names will be used in data analysis and in the report. All the information in the report will be anonymous. The information from this study will be used to strengthen the PMTCT programme.

Risk/Discomforts or Benefits: This research will involve asking of personal questions about your child and her infant. It will take approximately 10-15 minutes to complete our with her interview. I will conduct a Mid Upper Arm Measurement on her infant to measure nutrition status and give she will be advice on the result. It is hoped that the results of this study will contribute to the improvement of the PMTCT programme in Hurungwe District. So she should feel free to air out her personal views of the program.

Alternative Procedures or Treatments: There are no interventions or treatments that will be done in this study.

Additional costs: Your child will not incur any expense for participating in this study.

Voluntary Participation: It would be appreciated if your child can give honest answers to the questions and if she feels she is unable to give a correct answer it is allowed to say so. Your child is able to terminate the interview if she is not comfortable with proceeding with the interview at any time during the course of the interview. Before you as the Guardian of the child signs this form, please ask any question on any aspect that might be unclear to you. You may take as much time as necessary to think it over.

Authorization: Your signature indicates that you have read and understood the information provided above, have had all your questions answered, and have decided to allow your child to participate. The date you sign this document to enroll your child in this study, that is, today's date, MUST fall between the dates indicated on the approval stamp affixed to each page. These dates indicate that this form is valid when you enroll your child in the study but do not reflect how long your child may participate in the study. Each page of this Informed Consent Form is stamped to indicate the form's validity as approved by the MRCZ.

Name of Parent (please print)..... Date.....

Signature of Parent or legally authorized representative

..... Time.....

Relationship to the Participant.....

Signature of Researcher..... Date.....

For any further information pertaining to this study, please feel free to contact me at:

University of Zimbabwe
College of Health Sciences
Department of community medicine
PO Box A178, Avondale
Harare
Zimbabwe

YOU WILL BE GIVEN A COPY OF THIS CONSENT FORM TO KEEP

If you have any questions concerning this study or consent from beyond those answer by the investigator, including questions about the research, your child rights as a research subject or research-related injuries: or if you feel that you have been treated unfairly and would like to talk to someone other than a member of the research team, please feel free to contact the Medical Research Council of Zimbabwe on telephone 04-791792 or 791193.

Appendix 4 Acceptance of Child to Participate Form

I have made an informed decision to be a study participant in this research study without being forced in any way. I was given an opportunity to ask questions about this research. I have been given a consent form to keep.

Name of respondent.....Date.....Time.....

Signature of respondent.....

Name of interviewer.....

Appendix 5 Shona Assent (Parental Consent) form



University of Zimbabwe

Department of Community Medicine

Masters in Public Health (Health Promotion) Programme

Loss to follow up in HIV exposed infants in the PMTCT programme in Hurungwe District, Mashonaland West Province, Zimbabwe

2012

Principle Investigator: Mr George Machacha (MPH trainee)

Phone Number: 0773732856

Academic Supervisors: Mrs J. Maradzika, Dr J Chirenda

Field Supervisor: Mr G Kambondo (PHPO, MPH Graduate)

7 GWARO RECHITENDERANO

Kutanga: Ndinonzi George Machacha. Ndiri mudzidzi we Public Health pachikoro che University Of Zimbabwe. Parizvino ndiri kuhofisi kwaProvincial Medical Director Mashonaland West Province kwandiri kuita ongororo inotsvaka zvikonzero zvinosakisa kuti vana varimuchirongwa che PMTCT vasadzoka kuti vaonororwe. Kana vane chirwere vabatsirwe pachine nguva pachipatara nemaClinic ari muHurungwe.

Chinangwa cheongororo: Murikukumbirwa kuti mubvumire kuti mwana wenyu ave nhengo yeongororo yekutsvaka zvikonzero zvinoita kuti vana vanozvarwa vari muchirongwa chePMTCT vasadzoka kuti vaongororwe uye kuzichibidzika kubatsirwa kana paine chirwere. Nekudaro, Chinangwa chikuru cheongororo iyi ndichekuwana zvikonzero zvinotadzisa amai vemwana akazvarwa ari muchirongwa chePMTCT kuuya kukiriniki pamazuva avakatarirwa. Tirikuda kuziva musiano uripo pavana varikuuya kuzoonekwa nevasiri kuuya pamazuva akatarwa. Ongororo iyi ichaitwa muvanhu 124 muno muHurungwe.

Zvichaitwa muongororo: Makasununguka kuti mwana wenyu ave muongororo ino,ndichamubvunza mibvunzo inogona kutora nguva iripakati pemaminiti gumi kusvika gumi nemashanu kuti tipedze.Tichamubvunza mibvunzo yakanangana naiye uye maererano chirongwa chePMTCT. Ndichatarisawo makadhi ekurapwa kweke kana mandipa mvumo kuti ndione mazuva amatarirwa, mapiriti aanomwa pamwe nekuenda kweke kuchipatara pamazuva aatarirwa. Makasununguka kubvunza mibvunzo pamunenge musinganzwisise.Kana muinemimwe mibvunzo pamusoro peongororo iyi, makasununguka kubvunza chero nguva.Kana tapedza hurukuro yedu naye, tichamupakurira ruzivo nezvePMTCT.

Njodzi dzamungasangana nadzo Hapana njodzi ingasangana nemwana wenyu kuburikidza nekuva muongororo ino. Asi dzimwe dzenguva anogona kuzonzwa achinyara kupindura mimwe mibvunzo yacho. Kana paine mibvunzo yaasina kusununguka kupindura, akasununguka kuregedza kupindura.

Zvakanakira kuva muongororo ino:Hapana muhoro wamuchawana kana kuwanikwa nemwana wenyu kuburikidza nekuva muongororo ino asi kuti achawana mukana wokudzidza zvakawanda maererano nezvePMTCT uyewo kukosha kwekuenda kukiriniki kunoonekwa nanamukoti pamazuva akatarwa.

Kurapwa: Hakuna Kurapwa kuchaitwa muongororo ino.

Kuvimbika kwetsvakurudzo:Kuva kwemwana wenyu muongororo iyi hazvimanikidzwi, munoita nechido chenyu.Hapana zvamunoiwa kana mukati hamuchada kuva muongororo ino.Zvese zvaachazivisa pamusoro pake hazvizoparadzirwa kune vamwe vanhu, zvinoperera pakati pedu. Bepa richashandiswa pakubvunza mibvunzo richangozivikanwa nenhamba pasina zita rake. Nhamba idzodzi dzichachengeterwa pakasiyana negwaro rino ramuchazosayina kupa mvumo yokuti mwana ave muongororo ino.

Kupindurwa kwemibvunzo: kana paine mibvunzo yamuchaona isina kujeka makasununguka kundibvunza ikozvino, chero pane imwe nguva. Makasununguka kutora nguva yekuti mumbofunga.

Mvumo: Kusayina kwamuchaita panzvimbo inotevera zvinoratidza kubvuma kuti maziviswa maererano neongororo iyi, hamuna kumanikidzwa kuva nechokuita nayo, uyezve kuti zvamaudzwa zvaita kuti mugone kunyatsonzwisisa zvamuri kukurudzirwa imi nemwana wenyu kuita uye achitaura zvamunoziva. Zvaanenge azivisa mwana patsvakiridzo ino zvichabvumidza ini pamwe nevarairidzi vangu kuti tizvishandise muongororo ino bedzi.

Zita Remubereki..... Zuva.....

Runyorwo rweMubereki..... Nguva.....

Zita Remuongorori Zuva.....

Runyorwo rweMuongorori..... Nguva.....

Kana paine zvamunoda kunzwisisa, ivai makasununguka kundinyorera pa kero inoti:

University of Zimbabwe
College of Health Sciences
Department of community medicine
PO Box A178, Avondale
Harare
Zimbabwe

MUCHAPIHWA RIMWE GWARO RECHITENDERANO KUTI MUGARE NARO

Kana muine imwe mibvunzo isina kupindurwa nemuongorori, kana mibvunzo yakanangana nekubatwa kwamaitwa mutsvakurudzo iyi, kana kodzero dzenyu, kana kusabatwa zvakana kwamunenge maitwa makasununguka kubata veMedical Research Council of Zimbabwe panhamba dzerunhare dzinoti: 04-791792 or 04-791193

Appendix 6: Child Acceptance to Participate/Mvumo Yemwana

Mvumo Yemwana: Ndaita sarudzo yekuva nhengo yeongororo iyi pasina kumanikidzwa. Ndikanzwisisa vandaverenga zvese zvirimuchibvumirano. Ndawanawo mukana wekubvunza mibvunzo kuti ndinzwisise nezveongororo iyi. Ndichapiwa gwaro rechitenderano rekuti ndisare naro.

Zita Remupinduri Zuva Nguva.....

Runyoro Rwemupinduri Zuva Nguva.....

Appendix 6: Research Questionnaire

Research Questionnaire

I am from the Ministry of Health and child Welfare. We are making a follow up on the infants whom have been on the PMTCT programme so that we may be able to understand what is happening to the infants enrolled on the programme. We are going to ask you questions that may take up to 10 minutes. Are you agreeable to this? If you feel otherwise you are free to terminate this interview at any time.

Ndinoshandira Bhazi rezveHutano. Tirikutevera vana vavari mumuchirongwa chePMTCT, kuti tinzwisise zvirikusangana navo muchirongwa ichi. Tichakubvundzai mubvundzvo uchatora maminutes gumi. Muri kubvumirana nazvo here? Kana musinga wirirani nazvo munemumvumo yekuramba.

Interviewer's name

Date of interview

PMTCT site name Questionnaire No.

Status of Respondent <i>Tick appropriate box</i>	Case(indicate PMTCT No.) <input style="width: 40px; height: 20px; border: 1px solid black;" type="text"/> Date of Delivery _____ Day/Month/Year	Control (indicate PMTCT No.) <input style="width: 40px; height: 20px; border: 1px solid black;" type="text"/> Date Of Delivery _____ Day/Month/Year
----------------------------------------------------------------	-------------------------------------------------------------------------------------------------------------------------------------------------------------------------	-----------------------------------------------------------------------------------------------------------------------------------------------------------------------------

Demographic Characteristic of mothers

Marital Status (*Makaromwa here?*)

- Married
- Divorced
- Widowed
- Single (never married)
- Cohabiting

Level of Education (*Makasvika papi padano rekudzidza?*)

- None
- Primary
- Secondary
- Tertiary
- Others

Religion (specify): (*Sangano reSvondo ramunopinda rinonzi chii?*)

- Protestant (Catholic, Anglica, etc)
- Apostolic (White garments)
- Pentecostal (AFM, ZAOGA, etc)
- Others.....

Family Size (*mburi yenyu yakakura zvakadii?*).....

What is your age (*Makore enyu ekuzvarwa*)years

What is the age of the infant (*Makore emwana*).....years and months

What is your source of income (*Munowana sei cherviri?*)

- Formal
- Informal
- None

What is your husband's source of income (*Murume wenyu anoshanda kupi?*)

- Formal
- Informal
- None

What is your monthly income (*Mari yamunoshanda pamwedzi ingavike marii?*) \$.....

History of Exposure to ARV prophylaxis

Where did you deliver? (*Makasunungukira kupi?*).....

Did you take ARVs during labour? (*Makatora maARV pamakasununguka here?*) Yes/No
(Check records)

Duration of Labour (*Makatora nguva yakadii muchirwadziwa*).....hours

How did you deliver (*Makazvara mwana wenyu nezvira ipi?*)NVD/CS/ Vacuum
Suction?.....(Check delivery records)(*MuneCard rekubbukisa kwenbumbu?*)

Did the baby receive ARVs ? (*Mwana akawana maARVs here?*) Yes/No (Check records)

Baby's History

Birth weight (*Mwana airema zvakadii?*)gram (Check records)

Has he/she been admitted to hospital since birth? (*Mwana akambo pihwa mubheda kubvira
paakazvarwa here?*) Yes ___ No ___

Has your infant received any immunizations? (*Mwana wenyu akambo baina majekiseni ekudzivirira
zvirevere zvevana here?*) Yes ___ No ___

If not, why not? (*nembakayei, musinina kumbobaisa,?*)

-
- If yes, (a) BCG _____ Birth: Yes ___ No _____
(b) PENTA1 _____ 3Months Yes _____ No _____
c) PENTA2 _____ 4 Months Yes _____ No _____
d) PENTA3 _____ 5 Months Yes ___ No _____
e) Measles _____ 9 Months ___ Yes _____ No _____
f) DPT _____ 18months ___ Yes ___ -No _____
g) Others (specify and include date received).....Date.....

Check with the Child Health Card **Yes** () **No** ()

What is the current Health status of baby? (*Parizvino hutano hwemwana hurisei?*)

- a. Alive and well (*Mupenyu uye ane hutano hwakanaka*) _____
b. Alive and ill (*Mupenyu asi anorwara rwara*) _____
c. Dead (*Akafa*) _____ Cause of death (*Chikonzero chekufa*) _____ Date of death (*Zuva rekufa*) _____

If your child is alive and ill, what is the child's diagnosis? (*Kana mwana wenyu ari mupenyu asi achirwara rwara, ari kurwara nei?*) _____

Has the baby fallen sick since birth? (*Mwana akambo rwara here kubvira pakuzvarwa kwake?*) Yes/No

If yes, how many times was the baby sick? (*Kana akambo rwara, akarwara kangani?*).....

How many times were he/she admitted in hospital? (*akambo pibwa mubheda kangani kuchipatara?*)
.....

Did the baby suffer from any of these conditions? (*Mwana akambo rwara nezvirwere zvinotevera here?*)

- Persistent recurrent, diarrhoea: 2 loose stools/ day for more than 30days (*Kuita manyoka zvisinga peri?*)
- Fever lasting more than one month recurrent/ continuous (*Kupisa mumwiri, kunodarika mwedzi*)
- Pneumonia (*Mabayo*)
- Candidiasis: oral _____ (*Maronda emukanwa, aka cheneruka*)
- Delayed milestones (*kunonoka kukura, sezvinotarisirwa pamwana*)
- Regression of attained milestones (*kudzokera sbure pakukura kwemwana*)

Number of illness recorded on Hospital/clinic card (*Zvirwere zvinovirengeka paCard remwana*)
.....

Is your child on ARVs ? (*Mwana ari kuwana maARVs here?*) Yes ___ No ___

If yes, which (*Kana ari kuwana api acho?*) _____

Is baby on cotrimazole prophylaxis? (*Mwana ari kutora Cotrimoxazole here?*) Yes/ No

If yes, since when (*Kana ari kutora akatanga rini?*).....

Measure the Mid-Upper Arm Circumference (MUAC) of the infant.....

Predisposing Factors

Can HIV be transmitted to the child during pregnancy? (*Mwana ari mudumbu ano kwanisa kutapurirwa HIV naamai here?*)

- Yes
- No
- Don't know

Can HIV be transmitted to the child during breastfeeding? (*Mwana ano kwanisa kutapurirwa HIV mukuyamwa here?*)

- Yes
- No
- Don't know

Can HIV transmission from mother to child be reduced by Anti-retroviral Treatment? (*MaARVs ano kwanisa kuderedza kutapurirwa kweHIV kumwana ichibva kunaamai here?*)

- Yes
- No
- Don't Know

Can completely not breastfeeding reduce HIV transmission to the child? (*Kusayamwisa zwachose kunokwanisa kuderedza kutapurirwa kweHIV kumwana here?*)

- Yes
- No
- Don't know

Does your religion prohibit the use of modern medicine? (*Chitendero chenyu chinokurambidzai kushandisa mapiritsi?*)

- Yes
- No

Is it culturally acceptable in your society to exclusively breastfeed for Six months? (*Pachivanhu chenyu kuyamwisa mwana kwemwedzi mitanhatu zvinotabirwa zvakakanaka here nevanhu?*)

- Yes
- No

To what extent can HIV transmission to an infant be prevented from an HIV positive mother? (*Mikana wemwana kutapurirwa HIV kubvakunaamai wakakurasai?*)

- Less extent
- Large extent

Is it necessary for a mother to know the HIV status of her infant early? (*Munoona zvakakosha kuti amai vazive ropa remwana rakamirasei?*)

- Yes
- No
- Not sure

Do you feel that there are any benefits for knowing your child's HIV status? (*Zvinobatsira here kuziva mamiriro eropa remwana?*)

- Yes
- No
- Not sure

Enabling Factors

How long do you take to reach your local health center from your home? (*Munotoranguva yakareba sei kusvika kuClinic muchibva kumba?*)..... minutes

Do you consider this distance to be near or far? (*Munoona mufambo uyu wakaita sei?*)

- Near
- Far
- Not sure

How much money does it cost you to go to your local clinic (*kuno kuitirai marii kusvika kuClinic?*)
\$.....

Have you ever failed to go to the clinic due to lack of money? (*Makambotadzwa kuenda kuClinic nekushaina mari?*)

- Yes
- No

Have you ever gone to your local clinic and failed to receive health care services? (*makamboenda kuClinic mukashaina rubatsiro here?*)

- Yes
- No

What is the cost of receiving health care services for PMTCT at your local facility? (*Kubatsirwa kuClinic kwenyu kunoita marii?*)

Reinforcing Factors

Do you ever get any reminders on the need to take your infant for PMTCT review? (*munombwana micherechedzo yekuendesa mwana aonekwe mairirano nezvePMTCT here?*)

- Yes
- No

If yes, from whom (*Kubvakunani?*).....

Have you disclosed your HIV status to your partner? (*Makaudzwa murume nezvemamiriro eropa renyu here?*)

- Yes
- No

If no, can you elaborate why? (*nechikonzero chei musina?*).....

Have you disclosed your HIV status to your family members? (*makaudzwa vebukama nezveHIV status yenyu here?*)

- Yes
- No

If no, can you elaborate why? (*nechikonzero chei musina?*).....

Behavioral Intention

In the next 6 months how many times are you likely to go with your child to take his/her cotrimoxazole resupply (.....) **If child is taking cotrimoxazole**

In the next 6 months how many times are you likely to go with your child to take his/her extended nevirapine (.....) **If child is taking Nevirapine**

Are you likely to take your child for any Hospital review visit any time in the next 3 months Yes ()
No ()

If yes, how many times(.....)

Appendix 7: Permission to Proceed (PMD)

GP 204/44
Karoi District Hospital
P Bag 57
Karoi

22 June 2012

PMD Mash West
P Bag 139
Chinhoyi

Dear Sir

Re: Request for permission to carry out a study on Loss to Follow up among HIV exposed infants in Hurungwe District.

I am an MPH (Health Promotion) officer attached to Karoi Hospital and I am seeking authority to conduct a study on Loss to follow up among HIV exposed infants in Hurungwe District.

Thank You

Mr G Machacha