## IMPACT OF PRE-CONCEPTION KNOWLEDGE OF POSITIVE HIV STATUS ON UPTAKE OF PMTCT INTERVENTIONS AND INFANT HIV FREE SURVIVAL

DISSERTATION IN PART FULFILLMENT OF POST-GRADUATE DIPLOMA IN BIO-MEDICAL RESEARCH METHODOLOGY

**INVESTIGATOR:** 

DR. EMILY WANGUI KAMAU REGISTRATION NUMBER W61/69405/2011 MBCHB-NBI

#### DECLARATION

This dissertation is my original work, and has not been presented for a degree in any university nor published anywhere.

Signature _	
Date	
	Dr. Emily Wangui Kamau
	MBChB
This disser	tation is submitted with the approval of my supervisor.
Signature	
Date	
	Dr.John Kinuthia
	MBChB, MMED (Obs&Gyn), MPH

#### **Dedication:**

This book is dedicated to the glory and honour of GOD, without whom I would not be alive, let alone accomplish the work in this book. To my spiritual parents, Apostle Jane and Pastor Waithera, your labour in GOD has not been in vain.

#### Acknowledgments:

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#### ACRONYMS

AIDS - Acquired Immune Deficiency Syndrome

- ANC- Antenatal Clinic
- ARVs- Anti-Retroviral Drugs
- ART-Anti-retroviral Therapy
- AZT- Zidovudine
- CCC-Comprehensive Care Centre
- CD4- Cluster of Differentiation on T helper Cells
- DBS- Dried Blood Spot
- DNA PCR- Deoxyribonucleic acid Polymerase Chain Reaction
- HAART- Highly Active Anti-Retroviral Therapy
- HIV- Human Immunodeficiency Virus
- MTCT- Mother to Child Transmission
- PMTCT- Prevention of Mother to Child Transmission
- SPSS- Statistical Package for Social Sciences
- **3TC-** Lamivudine
- Sd-NVP-Single dose Nevirapine
- **NVP-Nevirapine**
- **UN- United Nations**
- WHO- World Health Organisation

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#### **DEFINITION OF TERMS**

A HIV exposed infant: an infant born to a HIV positive woman

**Mother-To-Child Transmission (MTCT)or vertical transmission** of HIV is HIV infection from an HIV infected woman to her child during pregnancy, labour and delivery and during breastfeeding

Pre-conception knowledge of HIV status: knowledge of HIV status before pregnancy

**HIV positive infant**: an infant who has tested positive for HIV by Deoxyribonucleic Acid Polymerase Chain Reaction (DNA PCR) testing or by rapid antibody testing after the age of 18 months

**Prevention of Mother-Child-Transmission of HIV (PMTCT)**: interventions taken by a mother and /or her infant to prevent vertical transmission of HIV

### THE IMPACT OF PRE-CONCEPTION KNOWLEDGE OF POSITIVE HIV STATUS ON UPTAKE OF PMTCT INTERVENTIONS AND INFANT HIV FREE SURVIVAL

#### Abstract

#### Background

Majority of HIV positive women in Kenya learn of their HIV status when they are tested at Ante-natal clinics. Knowledge of positive status prior to pregnancy allows utilization of interventions such as preconception anti-retroviral drugs to minimize risk of mother-to-child transmission of HIV. It is unclear to what extent women who know they are HIV infected seek and utilize interventions that reduce risk of vertical HIV transmission. The aim of this study is to determine the impact of pre-conception knowledge of positive HIV status on uptake of Prevention of Mother-to-child Transmission interventions and infant HIV free survival at Naivasha District Hospital.

#### Methodology

This will be a retrospective cohort study targeting mother-infant pairs presenting at Naivasha District Hospital Maternal and Child Health Clinic and the Comprehensive Care Clinic for HIV care. A questionnaire will be administered to collect data on socio-demographics characteristics, timing of knowledge of maternal HIV status, uptake of PMTCT interventions and infant HIV status. Kaplan-Meier analysis, Cox proportional hazard models and multivariate analysis will be utilized to assess the relationship between pre-conception knowledge of HIV and uptake of PMTCT interventions and infant HIV free survival.

#### Significance:

This study will provide useful data to health care workers and policy makers on utility of preconception care on efforts towards elimination of paediatric HIV in the country.

#### BACKGROUND

Mother-To-Child Transmission (MTCT) of HIV accounts for 90% of the HIV seen in the paediatric age group. Transmission of HIV from an infected woman to her child can occur during pregnancy, labour and delivery and during breastfeeding. In the absence of any intervention the rate of MTCT is about 15–30% without breastfeeding and increases to 45% with prolonged breastfeeding<sup>1</sup>. Anti-retroviral drugs such as Zidovidine given during pregnancy, labour and delivery and to the infant can reduce these rates by 67%<sup>2</sup> and when combined with elective caesarean section and avoidance of all breastfeeding MTCT rates are as low as 1-2%<sup>3</sup>. In order for these interventions to be taken up, women must have knowledge of their HIV status. They must also be offered drugs, counselled on infant feeding, undergo safe delivery and their infants must be offered Anti-Retroviral drugs.

To successfully prevent Mother-to-child Transmission of HIV, a comprehensive approach must be employed. This comprehensive approach involves prevention of HIV acquisition in HIV negative women, prevention of unintended pregnancies in HIV positive women, prevention of transmission of HIV from HIV positive pregnant and lactating women to their infants and provision of care and support to HIV infected and affected families. The Kenyan PMTCT program has adopted the WHO comprehensive approach towards Prevention of Mother-to-Child Transmission which has these four components. PMTCT interventions are found within each of these components. The 2009 WHO guidelines for Use of Antiretroviral drugs for treating pregnant women and preventing infection in infantsrecommend starting prophylactic anti-retroviral drugs from 14 weeks gestation<sup>4</sup>.

#### Figure 1: WHO comprehensive approach to Prevention of Mother-Child Transmission of HIV



Despite the fact that women have a higher HIV prevalence than men in Kenya and HIV prevalence among pregnant women is 9%<sup>5</sup>, there has been very little emphasis on the first two prongs of PMTCT, whose interventions target women who are not pregnant. Implementing these interventions has the potential to result in reduction of HIV prevalence among women in the reproductive age (including those pregnant).

Studies show that with knowledge of their HIV-positive status, women were less likely to desire future pregnancies<sup>6</sup>. Knowledge of HIV positive status prior to pregnancy allows enrolment into care where they can have the right information given to them on how best to plan for pregnancies without transmitting HIV to their infants and HIV uninfected partners, and also re-infecting themselves in cases where their partners are also HIV negative.

Majority of women in Kenya discover they are HIV positive when they present to the antenatal clinic and are offered a HIV test. Data from the Kenya AIDS indicator survey<sup>5</sup> shows that 66.1% of women who had ever been tested for HIV were tested at Ante-natal clinic.

WHO guidelines of use of Antiretroviral drugs for treating pregnant women and preventing infection in infants, recommend starting prophylactic anti-retroviral drugs from 14 weeks gestation and treatment at any time irrespective of gestation<sup>4</sup>. In Kenya, most women visit Ante-natal clinic for the first time in their 3<sup>rd</sup> trimester. The median gestation at which the first antenatal visit occurs among Kenyan women is 5.7 months with only 15% of women obtaining Ante-natal care in the first trimester of pregnancy<sup>7</sup>. The implications of this, is that more women, will discover that they are HIV positive in the third trimester of their pregnancy and will not be able to take up all PMTCT interventions as required. Also, they will not have sufficient time to process, and therefore come to terms with the diagnosis of HIV, and the risk of transmission to their unborn child, so as to fully take up PMTCT interventions.

A successful PMTCT programme has the potential to not only avert HIV infections in infant but also to enhance maternal survival. Maternal survival and child survival are closely linked. Studies show that the risk of death of infants who have HIV positive mothers to be 2.9 throughout childhood. This is increased to 3.9 with maternal death, within two years of maternal death<sup>8</sup>. Infant HIV free survival has been used as an outcome measure of effectiveness of PMTCT. Studies done in South Africa looked at 9 month old infant HIV free survival and estimated it at  $65-84\%^{10}$ , whereas in Rwanda infant HIV free survival for 9-24 month old infants was estimated at  $91.4\%^{11}$ . In Malawi, infant HIV free survival for 18-24 month old infants was estimated at  $66\%^{9}$ .

#### Benefits of knowledge of HIV status prior to pregnancy and implications for PMTCT:

Women who are test positive for HIV before pregnancy are enrolled into HIV care programs and benefit from clinical staging (WHO clinical staging), TB screening, immunological staging using CD4 counts, viral loads and co-trimoxazole prophylaxis. This allows women to carefully plan their pregnancies when their viral loads are low so as to reduce transmission of HIV to their infants. In addition, the women are counselled to initiate antenatal care early providing optimum opportunity to implement strategies to attempt to prevent transmission to the child. These include use of anti-retroviral drugs, counselling on infant feeding and safe delivery practices. Mothers also learn importance of early infant diagnosis and infant HIV testing at 18 months of age.

#### Justification:

Most resources in PMTCT have been directed towards interventions to reduce mother to child transmission when a woman is already pregnant. There has been less focus in ensuring women desiring pregnancy learn their HIV status. Consequently, majority of HIV infected women learn their HIV status when they begin attending antenatal care clinics. Since most women begin attending antenatal care clinic late in their pregnancy, these newly identified HIV positive women may fail to receive anti-retroviral drugs for optimal period or receive adequate counseling on infant feeding and importance of facility delivery which may impact negatively on efforts to prevent paediatric HIV.

However, it is unclear if women who know their HIV status before pregnancy are more likely to utilize PMTCT services and are more adherent compared to those who learn of their HIV status during pregnancy. Findings of the study will help to sensitize health care workers and policymakers on the importance pre-pregnancy care and how it can lead to a HIV free surviving paediatric population.

#### **Research Question**

What is the impact of pre-conception knowledge of positive HIV status on maternal and infant PMTCT intervention uptake and infant HIV free survival?

#### **General Objective:**

To determine the impact of pre-conception knowledge of positive HIV status on uptake of PMTCT interventions and infant HIV free survival.

#### **Specific Objectives:**

- 1. To determine the proportion of women with knowledge of positive HIV status before last pregnancy among HIV positive women whose infants are at least 18 months .
- 2. To compare uptake of Prevention of Mother to Child Transmission interventions among women with pre-conception knowledge of positive HIV status and those identified at ANC. Specific PMTCT interventions evaluated will include : contraception to prevent unintended pregnancy or delay pregnancy if maternal health poor, use of ARVS, facility deliveries, infant feeding choices, infant ARV and cotrimoxazole prophylaxis.
- 3. To compare infant HIV free survival between women with preconception knowledge of positive HIV status and those identified during pregnancy among HIV positive women whose infants are at least 18 months.

#### **METHODOLOGY:**

#### **Study Design**

This study was be a retrospective cohort study employing review of hospital records and structured interviews.

#### **Study Site**

The study site was Naivasha District Hospital Comprehensive care Centre and Maternal and Child Health clinic. Naivasha District Hospital is the second largest hospital in Nakuru county, Rift Valley province. It is a level 4 public Hospital run by the Ministry of Medical Services, located in Lakeview Sub location of Sokoni location.

The PMTCT programme at Naivasha District Hospital began in the year 2004. Women enrolled in the PMTCT programme are followed up at the Maternal and Child Health clinic during pregnancy and the first six months after delivery and thereafter sent to comprehensive care centre for follow up and care. There were 415 HIV exposed infants born on follow up at the hospital in the years 2010 and 2011.

This hospital was chosen for this study for two reasons. First, Naivasha lies in Rift Valley province which has the 2<sup>nd</sup> highest number of HIV infected adults in the country. Secondly, the PMTCT programme had not been evaluated since it began in the year 2004.

#### **Study Population**

#### **Source Population:**

The hospital is located in Naivasha district, in Nakuru County formerly in Rift Valley province and has a population of approximately 38,000 people. Data from the 2007 Kenya AIDS Indicator Survey indicates that Rift Valley province has the third highest HIV prevalence at 6.8%. The hospital conducts an estimated 7 deliveries daily and attends to

approximately 150 women in its maternal and child health clinic on a daily basis. Approximately 7 women test positive for HIV every month. Children born to HIV positive women are followed up at this maternal and child health clinic until the age of 18 months where they are then referred to the Comprehensive Care Clinic if they test positive for HIV and discharged from the clinic if they test negative.

#### **Study Population**

The study sample was drawn from the population of HIV exposed infants aged at least 18 months together with their mothers.

#### **Eligibility Criteria**

#### **Inclusion Criteria**

1. HIV positive mothers of infants aged at least 18 months

#### **Exclusion Criteria**

- 1. Mothers who are debilitated or in comatose state.
- 2. Infants whose primary caregiver is not their mother

#### **Study Procedures**

#### Recruitment

Women with infants aged at least 18 months were approached during their routine visits at the Comprehensive Care Centre for their HIV care or, at the Mother and Child Health Clinic (MCH) as they brought their infants for immunisation or follow up care offered to HIV exposed infants.

Hospital records of mothers and infants enrolled into the PMTCT programme were perused for contact information and appointments dates for routine visits for care at the CCC after obtaining institutional approval. Those whose routine visits were scheduled during the period of data collection were approached as they attend the CCC for care. Those whose appointments are not scheduled during the period of the study were contacted via telephone, informed about the study and invited to the clinic to participate in the study. Among these women, only those who provide written consent at the health facility were interviewed. These women were reimbursed for transport costs.

Women and HIV exposed infants who are lost to follow up, were contacted via telephone, informed about the study and invited to the health facility for care and possible participation in the study. HIV exposed infants who had not been previously tested for HIV, were offered testing. Infants found to be HIV infected were referred to the paediatric HIV clinic for care.

#### Consenting

Institutional approval was sought to review records of HIV positive mothers and their infants.

Eligible mothers willing to participate in the study gave written consent prior to interviews. Written consent were obtained once the mothers had the aims of the study, study procedures, benefits of participating in the study, risks and alternatives to the study fully explained to them. Mothers were informed that participation was voluntary, and that there would be no penalty if they chose not to participate in the study. Also, they were explained to that they were free not to answer any questions and they could opt out of the study at any time.

Mothers who were invited to the health facility for the interview via telephone were reimbursed for transport whether or not they consented to the study, to cater for their transport costs.

#### Questionnaire

Mothers who consented to participate in the study were interviewed using the structured questionnaire in appendix 2. The questionnaire contains questions which seek to obtain information on timing of HIV diagnosis, the PMTCT interventions offered to the mother and her infant, including HIV testing and current health status of her infant. In addition, we abstracted data on infant HIV status, ARV drug use and immunisation status from maternal and infant records. Interviews took a maximum of 30 minutes per participant.

#### Sample size calculation:

The  $2^{nd}$  objective was used to determine the sample size as it is likely to give a highest sample size. The outcome measure which was used to determine the sample size is HIV free survival in infants.

The formula used was Fisher formula with finite population correction. The number of women who tested positive for HIV from 2010 to 2012 total to 215 from health records on site. The formula is as shown below:

n = 
$$Z^{2}XP X (1-P)$$
  
 $D^{2}X(N-1) + Z^{2}P (1-P)$ 

Where

n = sample size

N=source population: population of women who tested positive for HIV in the year 2010-2012, which are 215

Z=is the confidence interval set at 95%

P=expected prevalence of HIV free survival, from van Lettow et al is 66% at 18-24 months

D=degree of precision which is \_+5%

=215X1.96 X 0.66(1-0.66)

 $0.05^{2}(215-1)+0.66(1-0.66)$ 

= 132

#### **Sampling Procedure:**

All eligible women recruited into PMTCT programme in the year 2010 were consecutively enrolled into the study.

#### **Data Analysis:**

Data obtained from questionnaires was coded and entered into preformed Access spreadsheets and analysed using Statistical Package for Social Sciences computer package.

Descriptive statistics such as mean, standard deviation, mean, median and range were used for continuous variables. Categorical data was summarized using proportions and tabulated using frequency tables. The (Chi-square)  $X_2$  test was used to assess any association between categorical variables. Univariate analysis was used to describe the role of pre-conception knowledge of HIV status on uptake of PMTCT interventions, specifically,contraception to prevent unintended pregnancy or delay pregnancy if maternal health poor, use of ARVS, facility deliveries, infant feeding choices, infant ARV and co-trimoxazole prophylaxis. Survival analyses were performed compaing infants of mothers with and without preconception knowledge of positive HIV status.

#### **Ethical Considerations**

The study was conducted after getting the approval from the Ethics and Research Committee Kenyatta National Hospital and University of Nairobi. In addition, we sought approval from the Medical Superintendent Naivasha District Hospital.

We only enrolled mothers who gave voluntary consent to take part in the study. Mothers who were enrolled were informed that their decision to participate in the research would not affect healthcare services provided to them and that they would be free to withdraw from the study at any stage without penalty. Also, mothers were informed that there would be no additional costs for participation in the study.

The interviewee had the details of the study fully explained to them before recruitment of the study followed by consent through signing of the written informed consent form attached (APPENDIX B1 and B2). Mothers were only be recruited into the study after confirmation of consent through signing the consent form even where verbal consent was sought via telephone.

#### RESULTS

A total 146 HIV positive women who tested positive for HIV between March 2010 and March 2011were invited to participate in the study, 13 declined. The flowchart below represents the recruitment process.





A total of 133 HIV positive mothers aged between 17 and 44 years were enrolled in the study along with infants delivered during the last pregnancy. The mean age (SD) of the participants was 30.6 years (SD 5.3). The demographic characteristics of the participating mothers are summarized in table 1.

#### **Demographic characteristics**

The modal age group was between 25 and 34 years with 66.4% of the participants being in this age group (table 1). Eighty (61.1%) mothers reported that the highest level of education attained was primary level education. Most (n = 88, 67.2%) mothers were married or had ever been married (separated/ divorced = 13.7%, widowed = 2.3%).

	N=133	
	Number (n)	Percent (%)
Age group		
<25 years	19	14.5
25-34 years	87	66.41
35-44 years	25	19.08
Education level		
Primary school	80	61.1
Secondary school	42	32.1
College/university	6	4.6
None	3	2.3
Marital status		
Single	22	16.8
Married	88	67.2
Separated/divorced	18	13.7
Widowed	3	2.3

#### Table 1: Demographic characteristics of study participants

#### **Knowledge of HIV status**

Sixty-six (51.6%) women reported that they had been tested for HIV before the last pregnancy and 90 (96.8%) of the women who were married reported that their partners were aware of the participants HIV status (table 2). Five (3.8%) mothers were currently pregnant. Among the mothers who were aware of their partner's HIV status, 51% reported that the partner was HIV positive.

	Number (n)	Dorcont (0/)
Is your portnon or your of your HIN status	Number (II)	reitent (70)
is your partner aware of your HIV status		
(N=93)		
Yes	90	96.8
No	3	3.2
Partner HIV status		
(N=100)		
Positive	51	51
Negative	30	30
Not done	9	9
Don't know	4	4
N/A	6	6
Tested before conceiving (last pregnancy)		
(N=129)		
Yes	66	51.2
No	63	48.8

# Table 2: Knowledge of HIV status among mothers in Naivasha County Hospital HIV clinic

#### **Preconception knowledge of HIV status**

Figure 1 shows that 63 (48.8%) mothers were aware of their HIV status prior to conception of the last pregnancy that resulted in a delivery.





Pregnancy intentions and family planning

Although only five (3.8%) mothers were currently pregnant,59 (44.4%) mothers indicated that they had intentions to have more children in future and 86 (85.1%) partners wanted to have more children. Seventy-four (69.2%) participants had discussed future pregnancy intentions with their partners. Most mothers (n = 97, 77%) were currently on a family planning method. Figure 2 shows that injectable Depo-Provera was the most commonly used family planning method. Condoms were used by 22.6% of the mothers and 10.4% used dual family planning methods which included use of a condom alongside a second method of contraception.

#### Figure 4: Family planning methods used by HIV positive mothers in Naivasha District



#### Hospital(N=133)

# Uptake of PMTCT interventions among women with pre-conception knowledge of HIV status and those identified at ANC

The uptake of PMTCT interventions are presented in Table 3, according to maternal preconception awareness of HIV status. Of the PMTCT interventions evaluated, only maternal CD4 counts prior to pregnancy was significantly associated with preconception knowledge of HIV status. The odds of CD4 count testing among women who were unaware of HIV status was 0.04 times (95% CI 0.01-0.11) that among mothers who reported that they were aware of HIV positive status prior to last pregnancy.

### Table 3: Comparison of PMTCT intervention uptake between women with and without

	Preconception HIV status					
	Aware N=63	Unaware N=66	– OR	95%	6 CI	р
CD 4 counts prior to						•
pregnancy						
Yes	40(63.5)	4(6.1)	1.0 (Ref)			
No	22(34.9)	62(93.9)	0.04	0.01	0.11	< 0.001
Child on ARVs						
Yes	5(7.9)	6(9.1)	1.0 (Ref)			
No	14(22.2)	20(30.3)	0.84	0.21	3.3	0.803
Infant breastfed						
Yes	57(90.5)	62(93.9)	1.0 (Ref)			
No	5(7.9)	3(4.5)	1.81	0.41	7.93	0.429
Feeding method						
Breast feeding only without	45(71.4)	54(81.8)	1.0 (Ref)			
fluids						
Mixed feeding (breast &	6(9.5)	3(4.5)	2.40	0.57	10.14	0.234
cow's milk)		~ /				
Formula feeds	4(6.3)	2(3,0)	2.40	0.42	13.71	0.325
Infant on ARVs	(0.0)	2(0:0)		01.2	10111	0.020
	58(92.1)	57(86.4)	1.0 (Ref)			
No	3(4.8)	7(10.6)	0.42	0.1	1 71	0.226
Delivery	5(4.0)	/(10.0)	0.72	0.1	1./1	0.220
Public health facility	50(79.4)	A9(7A 2)	1.0 (Ref)			
Private health facility	7(11.1)	3(4.5)	2 29	0.56	935	0.25
Home	6(9.5)	14(21.2)	0.42	0.50	1.18	0.23
Programov intentions	0(9.5)	14(21.2)	0.42	0.15	1.10	0.1
Desires more children	23(36.5)	34(51.5)	1.0 (Ref)			
No desire for more children	23(50.3) 38(60.3)	37(48.5)	1.0 (Ref)	0.86	3 56	0 1 1 0
On family planning	30(00.3)	52(40.5)	1.70	0.00	5.50	0.117
	50(79.4)	11(667)	10(Paf)			
No	12(10.0)	44(00.7) 17(25.8)	1.0 (Ref)	0.27	1 44	0 268
Infant co-trimovazole	12(19.0)	17(23.8)	0.02	0.27	1.44	0.208
nronhylaxis						
Yes	57(90.5)	59(89.4)	10(Ref)			
No	6(9.5)	7(10.6)	0.89	0.28	2.8	0 838
Maternal ARV during	0(2.5)	,(10.0)	0.07	0.20	2.0	0.050
pregnancy						
Yes	59(93.6)	56(84.8)	1.0 (Ref)			
No	4(6.3)	8(12.1)	0.91	0.55	1.50	0.705

### preconception knowledge of positive HIV status

#### Infant HIV testing

As shown in table 4, two infant deaths were reported while 18 children tested HIV positive by 18 months. Most (99.2%) children received ARV prophylaxis. Breast feeding was initiated in 93.1% of the infants.

	N=133	
	Number	Percent
Infant alive		
Yes	131	98.5
No	2	1.5
Infant sex		
Male	73	55.3
Female	59	44.7
Child breastfed		
Yes	121	93.1
No	9	6.9
Child received ARVs		
Yes	118	92.2
No	10	7.8
Child tested		
Yes	130	98.5
No	2	1.5
HIV results		
Negative	109	85.8
Positive	18	14.2
CD4 done		
(N=18)		
Yes	8	25
No	24	75
Child on ARVs among those who tested positive		
(N=18)		
Yes	11	61.1
No	7	38.9

Table 4:	Characteristics	of	infants	of	HIV	positive	mothers	in	Naivasha	District
Hospital										

#### **Infant feeding**

The most common mode of infant feeding was exclusive breastfeeding reported in 86.3% of the infants born to HIV positive mothers (Figure 5). Replacement feeding with formula was reported in 6% of the infants.





#### **District Hospital (N=133)**

#### HIV testing in HIV exposed infants

Of the 133 infants of HIV positive mothers, 81 had HIV DNA PCR tests done, 8 (9.9%) of these turned positive. At 18 months, 15(12%) of the infants tested positive for HIV. These are represented in table 5.

	N=133	
	Number	Percent
DBS results		
Positive	8	9.9
Negative	73	90.1
HIV antibody tests		
Yes	119	96.7
No	4	3.3
HIV antibody results		
Positive	15	12
Negative	110	88

Table 5: HIV test results for infants of HIV positive mothers in Naivasha DistrictHospital

# Comparison of PMTCT interventions in infants with and without pre-conception knowledge of positive HIV status

As shown in table 6, infants of mothers with no preconception knowledge of positive HIV status were more likely to be exclusively breastfed for the first six months of their lives in comparison to those who had knowledge of their HIV status prior to pregnancy. In addition, more infants from mothers with no preconception knowledge of positive HIV status turned HIV positive than those whose mothers had prior knowledge. However, this differences were not significantly different.

		Preconception knowledge of positive				
		HIV status (N=133)				
		Aware		Unaware		
		n	%	Ν	%	P value
	Breastfeeding without any other fluid even water	45	81.8%	54	91.5%	0.309
Mode of infant feeding for first 6 months of	Breastfeeding with water only	0	0.0%	0	0.0%	
life	Mixed feeding	6	10.9%	3	5.1%	
	Cow's milk only	0	0.0%	0	0.0%	
	Formula milk only	4	7.3%	2	3.4%	
DBS result	Positive	3	7.5%	5	12.8%	0.433
	Negative	37	92.5%	34	87.2%	
Antibody test results	Positive	6	10.0%	8	12.9%	0.615
	Negative	54	90.0%	54	87.1%	
Is infant alive	Yes	63	100.0%	64	97.0%	0.164
	No	0	0.0%	2	3.0%	

## Table 6: Comparison of PMTCT interventions in infants of mothers with and without pre-conception knowledge of positive HIV status

#### Infant HIV free survival

The overall infant survival rates at 18 months were high with only two deaths occurring in the infants of HIV positive mothers in the study (Figure 6). The first death was a still birth and the second death occurred at 15 months and resulted from an accident that was unrelated to HIV diagnosis. The HIV free survival rate at 18 months was 86.5% compared to HIV free rates of 95.5% at 6 months and 91.7% at 9 months.

Figure 6: Overall survival and HIV free survival in children born to HIV positive



mothers in Naivasha

# Infant HIV free survival between women with preconception knowledge of positive HIV status and those identified during pregnancy

Figure 7 shows HIV free survival rates according to maternal preconception knowledge of HIV status. The HIV free survival rates were slightly lower in infants of mothers with no preconception knowledge of HIV at all ages up to 18 months. At the 18 month point the HIV free survival in infants of mothers with preconception knowledge of HIV status was 95% compared to 92% in infants of mothers with no knowledge of HIV status.

Figure 7: Comparison of HIV free survival in infants born to women with and without preconception knowledge of positive HIV status



#### DISCUSSION

This study provides a comparison of PMTCT uptake and infant HIV free survival between women with and without preconception of positive HIV status. Few women get into pregnancy knowing their HIV status. Less than a half (48%) of these women in this study were knowledgeable about their HIV status prior conception. This finding is higher than that found in the Kenya Aids Indicator Survey of 2012, which found that 38% were found to be HIV positive before their last pregnancy.

Most women discover that they are HIV positive when tested at the ANC during pregnancy. In the Kenya AIDS Indicator Survey 2012<sup>12</sup>, over half of women (55%) who ever received a HIV test were last tested in an Ante-Natal Clinic. This leaves little room and time for women to process a HIV diagnosis. These women are then forced to take ARVs to prevent HIV in their unborn child without fully understanding how this diagnosis will change their lives. However, testing at ANC enables even the woman's partner to be tested for HIV for those women who are able to disclose their HIV status to their partners. It may provide one explanation for why many (96%) of the women who were surveyed in this study were aware of their partner's HIV status. Men should be encouraged to accompany their partner's to the Ante-Natal Clinic and offered the opt out test in the same manner that women are offered the test, in this way make HIV testing less intimidating and increase coverage of HIV testing.

Among the HIV positive women surveyed in this study, eighty eight percent had intentions to have another child. Most of these were women who had knowledge of their HIV status before pregnancy. This brings out an urgent need to make pre-conception care for HIV infected mothers a priority for women who attend the Comprehensive Care Centre in the hospital. As part of pre-conception care, mothers should have CD4 counts done, where possible viral load should be included. Mothers who had pre-conception knowledge of HIV status prior to pregnancy were more likely to have had their CD 4 counts done than those who did not have knowledge of positive HIV status before pregnancy.

Over half (77%) of the women surveyed, were on family planning. Despite such high contraceptive takes, less than a quarter (22%) of these women utilized condoms despite there being discordant couple rates of 30% for the women who had knowledge of the HIV status of their partners. This is comparable to the most recent Kenya AIDS Indicator Survey that found condom use at 28% for HIV infected women. Again, focus needs to be shifted towards educating mothers on the importance of using condoms to prevent horizontal transmission of HIV for HIV discordant couples and the for prevention of re-infection for HIV concordant couples.

Most HIV positive mothers in this study delivered their infants in hospital. There were more home deliveries from women without preconception knowledge of positive HIV status (21.2%) than those with preconception knowledge of positive HIV status (9.5%).

Exclusive breast feeding rates among the infants in this study (86%) is higher than the country prevalence which stands at 32% according to the 2008 Kenya Demographic Health Survey<sup>13</sup>. The rates of mixed feeding were low at 7.7%. Of note is that the number of infants who were mix fed among women with preconception knowledge of positive HIV status were 3 times more the infants of women without preconception knowledge of positive HIV status. They were also less women with preconception knowledge of HIV status who were breastfeeding their infants exclusively for the first 6 months of life. This reveals that there is need to adequately train women who attend the PMTCT program at Naivasha District Hospital on how to feed their infants and reassure them that breastfeeding can be made safe with the use of ARVs and on the risks of increasing the chances of HIV transmission to their infants with mixed feeding.

As regards use of ARVs in mothers and infants attending the PMTCT program at Naivasha District Hospital, uptake was comparable in both groups of women. Majority of the women used ARVs for prophylaxis. However, to achieve the country target have eliminating prevention of mother to child transmission of HIV by 2015, all women must take ARVs either for prophylaxis or their own health. What is noteworthy is that even amongst women who had knowledge of their positive HIV status prior to conception, there were some who did not utilise ARVs. These may have been women who despite being aware of a positive HIV status, were not enrolled into HIV care and follow up. These may also have been women who could have been in denial of their HIV diagnosis and hence did not initiate follow up. The overall number of infants on ARV prophylaxis was 92%. There were more infants from mothers who were aware of their positive HIV status before pregnancy who took this prophylaxis than mothers who were not aware of their HIV status before pregnancy. However, uptake of co-trimoxazole prophylaxis in infants was similar between the two groups of infants.

The overall infant HIV free survival rate at 18 months was 86% is higher than that which Van Lettow et al<sup>9</sup> found in Malawi (68%).Women with preconception knowledge of positive HIV had slightly higher infant HIV free survival compared to women with no preconception knowledge of HIV status before pregnancy. There were two deaths that occurred among the infants of HIV positive mothers enrolled in the study. These two children were of mothers without preconception knowledge of positive HIV status. Preconception knowledge of positive HIV status by mother was not significantly associated with these deaths.

#### CONCLUSIONS

- Less than half (48%) of the HIV positive women enrolled in the study were aware of their HIV status before pregnancy.
- 2. The differences in uptake of PMTCT interventions between women with and without preconception knowledge of positive HIV status are not significantly different. Hence, preconception knowledge of positive HIV status is not a factor associated with uptake of PMTCT interventions such as contraception to prevent unintended pregnancy or delay pregnancy if maternal health poor, use of ARVS, facility deliveries, infant feeding choices, infant ARV and co-trimoxazole prophylaxis. It is only positively associated with uptake of CD 4 count testing in HIV positive women in this study.
- 3. Infant HIV free survival was higher among women with preconception knowledge of positive HIV status than those without preconception knowledge of positive status.

#### Recommendations

Make preconception care available to women who are enrolled in the PMTCT programme at Naivasha District Hospital

Women should be encouraged to discuss intentions for pregnancy and have CD4 counts and viral loads as part and parcel of preparation for pregnancy. They should also be counseled on contraceptives until viral loads and CD4 counts are acceptable to avoid vertical transmission of HIV.

#### **Study Limitations**

Retrospective studies rely heavily on complete records. Incomplete records presented a challenge in data collection. Hence we carried out corroborative interviews with mothers and reviewing antenatal and maternity registers where records are incomplete to obtain missing information.

Omission of infants lost to follow up because they do not routinely visit hospitals or may be deceased was one of limitations faced. We carried out patient tracking by looking for names and phone numbers of all mothers of all children enrolled in the PMTCT programme, we invited them to come to the hospital for an interview.

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## Appendix A: BUDGET

DESCRIPTION	CHARGES	NUMBER	OTHER DETAILS	TOTAL
				COST
RESEARCH	500/- PER	20 DAYS	WILL REQUIRE 1 MONTHS TO	10.000
ASSISTANTANT	DAY	20 21115	COMPLETE DATA COLLECTION-5	10,000
			working days x 4 weeks	
	200/ DED			6.000
DATA ENTRY CLEPK	300/- PER	20 DAYS		6,000
CLEKK	DAT			
TRANSPORT FOR	500/- PER	20 DAYS	TO SUPERVISE AND CONDUCT	10,000
PRINCIPAL	RETURN		INTERVIEWS	
INVESTIGATOR	TRIP			
STATIONEREY	30/- PER	200	PHOTOCOPY AT 3/- PER PAGE FOR	6050
	COPY		10 PAGES TOTAL 30/- PLUS 50/-	
			FOR PRINTING( AT 5/- PER PAGE	
			FOR 10 PAGES)	
PHONE CALLS AND	150	20 DAV	50 MINUTES TALKING TO	3 000
COMMUNICATION	MINUTES	20 DA I	MOTHERS PER DAY-10 MINUTES	3,000
	PER DAY.		FOR 5 MOTHERS/DAY, 50	
	AT 1/- PER		MINUTES	
	MINUTE			
TRANSPORT FOR	500 PER	3500		3,500
COMMUNITY	DAY	Como os		
HEALTH WORKERS		Same as		
TRACKING		above		
PATIENTS LOST TO				
FOLLOW UP-TO BE				
DONE OVER 7				
DAIS				
	TOTALS			40,000

#### Appendix B1: ENGLISH INFORMED CONSENT FORM

<u>**Title:**</u> Impact of pre-conception knowledge of HIV positive status on uptake of PMTCT interventions and infant HIV free survival at Naivasha District Hospital: outcomes of HIV exposed infants

#### Principal Investigator: Dr. E. Wangui Kamau

Supervisor: Dr. John Kinuthia

**Investigator Note:** Thank you for agreeing to read this form. It will help you decide whether to take part in this study

**Introduction:** Knowing your HIV status before one is pregnant is very important because it can help you take the right steps to improve your health and even plan for pregnancy and take all the steps needed to prevent HIV in children that you will give birth to. Not many women in Kenya know their HIV status before they fall pregnant. This study wants to find out how many women know they are HIV positive before they fall pregnant and how it affects how they take the services provided in hospital to prevent HIV in their infants and later on the HIV status and health of their babies once they are born. This will provide the people who plan these programmes information so as to improve the programmes.

**Procedure:** If you agree to be a part of this study, I will take some of your time about 45 minutes to ask you some questions about when you came to the knowledge of your HIV status, your decision about getting pregnant, care received before pregnancy, the PMTCT interventions received, HIV status of your baby and care provided. I will also look at your Mother and Child Welfare Booklet, and child's records to assist in collecting this information.

**Benefits:** After the interview I will explain to you what PMTCT is all about and allow you to ask any questions you have about it. If you have your baby with you, I will weigh your baby and give advice on the right way to feed your baby. Other women will benefit because the information you give will be given to the hospital managers and people who plan these programs so that they can improve on it and help other mothers within the programme.

**<u>Risks</u>**: Some of the questions asked may be personal and might make you feel a bit shy. We will however make you feel as comfortable as we can so that you don't feel too embarrassed.

<u>Confidentiality:</u> The information you give will be held in strict confidence and only used for the purpose of the study. Your name will not appear in any of the questionnaires we use to fill the information you provide.

**Voluntarines:** The care of your child willin no way affected if you decide not to participate in this study. You can also choose to discontinue from the study at any time or choose not to any certain questions

**<u>Compensation</u>**: If you had not planned to come to hospital today we will offer you bus-fare to come to hospital

I confirm that I have explained the study to the participant and answered any questions and concerns.

Investigator's signature\_\_\_\_\_

In case of any questions, queries and complaints concerning this study contact the Ethics Research Committee:

Contacts for ERC

Prof. A.N. Guantai, Secretary, KNH/UON-ERC, Kenyatta National Hospital, Hospital Rd, along Ngong Rd, P.O.Box 20723, Nairobi Tel: (020) 726300-9 Fax: 725272

To indicate that you understand the conditions of this study and that you consent to participate in it, please sign or put your thumbprint in the space provided below. I, confirm that the study has been fully explained to me and I give full consent to participate in it.

Signature/thumbprint\_\_\_\_\_

Investigator's signature

Date

#### Appendix B2: KISWAHILI INFORMED CONSENT FORM

#### <u>Fomu ya Idhini</u>

<u>Kichwa:</u> Jinsi ambavyo maarifa ya hali ya VVU kabla kupata mimba huathari (husaidia) matumizi ya miradi ya PMTCT kwa wamama walio na VVU na kufanya watoto wao wachanga kuishi bila VVU.

Mpelelezi: Daktari E. Wangui Kamau

Msimamizi: Daktari John Kinuthia

Mpelelezi angependa kukushukuru kwa wakati wako na kumpa nafasi ya kusoma fomu hii. Fomu hii itakupa maelezo kuhusu utafiti huu ambayo itakusaidia kuamua kama utahusika katika utafiti huu. Usipoelewa lugh hii, utatafsiriwa katika ile lugha ambayo unaelewa.

<u>Utangulizi:</u> Programu za Kuzuia watoto kupata virusi vya ukimwi (VVU) kutoka kwa mama yao ni ya muhimu sana. Kama wamama wanajua hali ya VVU kabla hawajapata VVU wanaweza kutumia miradi ya PMTCT ili wawe na afya nzuri na watoto wao waishi bila VVU na ukimwi. Utafiti huu unataka kuona kama ujuzi au maarifa ya hali ya VVU unaweza kusaidia wamama kuzingatia miradi ya VVU ili wawe na afya njema na watoto wao waishi bila ukimwi, ili programu hizi za PMTCT zizangatie sana kufanya wamama wajue hali yao ya VVU kabla hawajapata mimba na si kupata kujua wanapofuatilia clinic za uja uzito.

<u>Utaratibu</u>: Kama utakubali kuwa sehemu ya utafiti huu, nitakuuliza maswali, mengine yatakuwa nyeti, kuhusu baadhi ya hatua za PMTCTambazo ulipitia tangu wakati ambao uliandikishwa katika programu hii ya PMTCT. Maswali haya yatachukua muda ya dakika ishirini tu.

<u>Matokeo ya faida:</u> Baada ya utafiti huu nitakupa nafasi ya kuuliza maswali yoyote unayo. Utafiti huu kufasiriwa kwa wewe, timu ya usimamizi ya hospitali ya Naivasha and pia Chuo Kikuu cha Nairobi. Hii itasaidia wale wanaohusika katika mpango wa PMTCT kuboresha ubora wa mpango huu. Tutapima kilo ya mwanao na kukupa mawaidha kuhusu vile unavyofaa kumlisha mwanap.

<u>Usiri:</u> Kama utakubali kuwa sehemu ya utafiti huu, taarifa ambayo utatoa utatumiwa katika utafiti huu peke yake na wasiohusika kaatika kuchukua taarifa huu hawatapata kujua taarifa unayotupa. Majina yako hayatatumiwa katika fomu ya taarifa, na yataonekana tu katika fomu ya idhini.

Ningependa kusingatia kuwamatibabu yako au ya mtoto wako hautaathirika kutokana na uamuzi wako wa kukataa au kushiriki katika utafiti huu. Umepewa uhuru na nafasi ya kuacha kuhusika katika utafiti huu bila gharama yoyote wakati wowote utafiti huu unapoendelea.

<u>Malipo ya nauli</u>: Kama hukuwa umejipanga kuja hospitalini leo, tutakulipia nauli kulingana na vile huwa unalipa kuja hospitali.

Mimi mpelelezi wa utafiti huu ninathibitisha kuwa nimemwelezea mhusika wa utafiti huu kwa ukamilifu kuhusu kuhusika kwa utafiti.

Sahihi

Nimepewa kibali kutoka Utafiti na Kamati za Maadili ya Kituo Kikuu cha Nairobi na Hospitali Kuu ya Kenyatta ya kufanya utafiti huu. Maoni juu ya masuala ya kimaadili inaweza kupatikana kutoka:

Prof. A.N. Guantai,

Katibu, KNH/UON-ERC,

Hospitali kuu ya Kenyatta,

Hospital Rd, karibu na Ngong Rd,

S.L.P. 20723, Nairobi

Nambari ya simu: (020) 726300-9

Fax: 725272

Kuonyesha ya kwamba umeelewa hali ya utafiti huu na umetupatia ridhaa ya kushiriki katika utafiti huu, tafadhali saini au weka kidole chako katika nafasi iliyotolewa hapo chini:

Mimi ninathibitisha kuwa utafiti huu umeelezwa kwangu mimi vizuri na ninaitikiea na kupeana ridhaa ya kuhusika katika utafiti huu

Sahihi yangu au kidole cha sahihi

\_\_\_\_\_

Sahihi ya mpelelezi

Tarehe

#### **Appendix C: QUESTIONNAIRE**

To be used in interviewing mothers or guardians of HIV exposed infants where mothers are deceased. Utilize records in addition.

Date \_\_\_\_\_

Study Code: \_\_\_\_\_

### Part I: MOTHER Socio-demographic Data of Mother

Section A: Socio-demographics

- 1. Age: \_\_\_\_\_ years
- 2. Number of years of education

#### 3. Level of education

- o Primary school
- o Secondary school
- o College/University
- o None

#### 4. Marital status

- o Single
- o married
- o Separated/divorced
- o Widowed

Section B: Knowledge about HIV status self and partner

#### 5. If married, is your partner aware of your HIV status?

- o Yes
- o No

#### **Partner HIV status**

- o Positive
- o Negative
- o Not done

N/A

#### 6. Where were you tested for HIV?

- o At Ante-Natal Clinic visits during pregnancy with this child
- o At Ante-Natal Clinic visits during a previous pregnancy
- o At a VCT center before I fell pregnant
- At hospital when my child fell ill
- o In a hospital ward when I fell ill before pregnancy
- Other, please specify \_\_\_\_\_\_
- 7. How long have you lived with HIV?\_\_\_\_\_

#### **Section C: Pregnancy intention**

#### 8. Are you currently pregnant?

- o Yes
- o No

#### 9. If you are not pregnant, are you on any family planning method?

- o Yes
- o No

#### **10. If please state method**

#### Method

- Injectable –depo provera
- o Permanent methods-Tubal ligation, husband had a vasectomy
- Oral contraceptive pills
- o Implants

- o IUCD
- o Condoms
- o Herbal
- o Dual method (any of the above in addition to condoms)
- Other, please specify\_\_\_\_\_
- 11. If no, why not? \_\_\_\_\_\_

Use the codes

- 1. Fear of side effects
- 2. I am currently not sexually active
- 3. My partner is reluctant for me to use it
- 4. Other

#### 12. Did you the plan pregnancy with this infant?

- o Yes
- o No

#### 13. Before knowing your HIV status, were you on Family Planning?

- o Yes
- o No

## 14. How has knowledge of positive HIV status affected your Family planning decisions?

- 1. I now use family planning to prevent pregnancy and didn't before
- 2. I now use condoms in addition to other methods
- 3. It had not made any difference
- 4. Other\_\_\_\_\_

#### 15. Do you desire to have more children?

- o Yes
- o No

#### 16. Do you know what your husband would feel about another pregnancy?

- o Yes
- o No

17. Have you discussed intentions to have another pregnancy with your husband?

- o Yes
- o NO

18. Have you received any advice from hospital on steps to take before you fall pregnant?

- o Yes
- o No

If yes, please specify

Use the codes below:

- 1. Take Ante-Retrovirals until CD4 counts are above 500
- 2. Come to **hospital** and have CD4 counts take before considering falling pregnant
- 3. Have the doctor examine you and determine you are healthy enough to fall pregnant
- 4. Other \_\_\_\_\_

#### 19. How has knowledge of your HIV status affected your desires for having children

Use the codes below

- 1. I don't desire any more children now
- 2. I fear falling pregnant because of transmission of HIV to my child
- 3. It has not made any difference
- 4. Other\_\_\_\_\_

Section D: Care before pregnancy

#### 20. I. Did you have CD4 counts loads taken before your last pregnancy?

Yes

No

If yes, what was the CD count?

a. \_\_\_/mm3

- Did you have viral load taken before your last pregnancy?
  - o Yes
  - o No

#### III.If yes, what was the viral load \_\_\_\_\_\_copies/mm3

#### 21. Have you had your CD4 count taken after pregnancy?

If yes, please state the new level

- 22. Were you advised on any measures you need to take before getting pregnant when living with HIV/AIDS? This is very non-specific
  - o Yes
  - o No

#### 23. Did you attend antenatal care clinic

- a. Yes
- b. No

If yes, where, how many visits

How many times did you attend ANC in the pregnancy with your infant?

#### 24. Where did you attend ANC?

- o Dispensary
- o Health Centre
- o Naivasha District Hospital
- o Private hospital
- o Other

## 25. Did you receive any counseling about how to prevent HIV infection in your infant during your ANC visits?

- o Yes
- o No

#### 26. Were you counseled on how to feed your infant?

- o Yes
- o No

## 27. I. Were you on Ante-Retrovirals prior to pregnancy with this infant? Place in

right place

- o Yes
- o No

#### II. Which regimen (utilize records to obtain this information)?

- o AZT+3TC+LPV-r
- o AZT+3TC+ABC
- o AZT+3TC+EFV
- o TDF+XTC+EFV
- o AZT+NVP+3TC

- o AZT+d4t+NVP
- Other, please specify\_\_\_\_\_

#### 28. When were ARV drugs initiated

- Before conception
- While attending the ANC
- o After delivery of my infant

## 29. If you were not on ARVS prior to pregnancy, did you take any ARVS during your pregnancy?

- o Yes
- o No

#### 30. If yes

- o during pregnancy
- o during labor/delivery
- o after delivery for a short period of time
- o during breastfeeding

#### Please specify which ones(from records)

- o AZT + 3TC during pregnancy
- o Sd NVP at the onset of labour
- o HAART
- o None taken
- o Other\_\_\_\_\_

#### 31. When in your pregnancy did you begin to take ARVs?\_\_\_\_weeks

#### 32. Did you have any illness during your pregnancy?

- o Yes
- o no

#### If yes specify

- o TB
- o Urinary Tract Infection
- Sexually Transmitted Illness
- o Malaria
- Other, please specifyIf yes, were you hospitalized?
- o Yes

o No

#### 33. Were you counseled on place of delivery?

- o Yes
- o No
- 34. When was the date of delivery\_\_\_\_\_

#### 35. When was the Estimated Date of Delivery (from records)

#### 36. Where did you deliver (place of delivery)

- Public health facility
- o Private health facility
- o Home

#### 37. How did you deliver your child?

- Normal Delivery
- o Elective C/S
- o Emergency C/S
- o Assisted delivery (use of forceps, vacuum)

#### If C/S reason for operation

- Complicated delivery
- Had a previous C/S
- Planned for PMTCT purposes
- Planned before delivery for other obstetric reasons besides PMTCT or previous C/S
- **38.** For mothers who delivered via emergency C/S or via normal delivery, how long did labour pains last until time of delivery?

#### 39. Did your water break before delivery of your child?

- o Yes
- o No

## If yes, what was the duration between your water breaking (drainage of liquour) and delivery <u>of your child?</u>

- 40. Did you experience any complications during delivery?
  - o Yes
  - o No

#### 41. Please choose complication experienced.

- 1. Perineal tear
- 2. Severe bleeding after delivery-requiring fluids or blood transfusion
- 3. Retained placenta
- 4. Other \_\_\_\_\_

#### PART II: INFANT

#### Information to be obtained from mother and infant health records

#### 42. Is infant alive?

- o Yes
- o No

#### If infant is deceased, at what age did infant die? Get actual

- Less than 60 days
- o 2 months-6months
- o 6-12 months
- o 12-18 months

#### 43. Gender of infant

- o Male
- o Female
- 44. Current Age of infant
- 45. What was the child's birth weight?

#### 46. Did you child receive Anti-Retrovirals after delivery?

- o Yes
- o No.

#### 47. If yes when were the drugs started?

#### 48. What drugs were given (from records)?

- o NVP syrup
- o AZT syrup
- o AZT+3TC

#### **49.** Is child still taking drugs?

- o Yes
- o No

#### **50.** Has your child tested for HIV?

o Yes

o No

#### 51. If yes, what is the HIV test result

- o negative
- o positive
- o no result

#### 52. If positive, has CD4 been done?

- o Yes
- o No

#### 53. If CD4 test done, please state the result( from records)

#### 54. Is child is on ARVs for treatment?

- o Yes
- o No

#### 55. If on treatment, please state drugs given

- o AZT, 3TC, NVP
- o AZT, 3TC, LPV/R
- o ABC,3TC,NVP
- o ABC,3TC,LPV/R
- Other

#### 56. Apart from ARVs did your infant take any other medication?

- o yes
- o no

#### If yes, please specify

- o Septrin
- o Multi-vitamins
- Other, please specify\_\_\_\_\_

57. When were these other medications started?

#### 58. Did you breastfeed your child?

- o Yes
- o No

## 59. How long did you breastfeed your baby without addition of any other fluids such as water?

- 60. When did you introduce other feeds to your child's diet?
- 61. Please state the method of feeding for your baby's first 6 months of life

- o Breastfeeding only without any other fluid even water
- o Breastfeeding with water only
- o Breastfeeding sometimes, cow's milk other times
- Cow's milk only without breast feeding
- Formula milk only without breast feeding
- o Does infant breastfeed after weaning
  - o Yes
  - o No
  - 0

62. At what age was DBS (DNA PCR) done?

#### 63. What was the DBS result?

- o Positive
- o Negative

#### 64. Has your child had an HIV antibody test done?

- o Yes
- o No

How many Antibody tests have been done?

Age at 1<sup>st</sup> HIV antibody test\_\_\_\_\_

Age at 2<sup>nd</sup> and final HIV antibody <u>test</u>

#### 65. What were the results of rapid antibody tests:

- o Positive
- o Negative

#### Part III: PMTCT Cascade checklist (as verification from documents/record)

Using mother and baby's health records where information is not gotten from interview and code as follows:

Code as follows: 1=yes, 2=no,

For questions 1-9 use ANC visits 1=1<sup>st</sup> visit 2=2<sup>nd</sup> visit 3=3<sup>rd</sup> visit 4=from 4<sup>th</sup> onwards

Gestational age at which mother was enrolled into PMTCT

HIV status of the infant\_\_\_\_\_

### PMTCT CASCADE CHECKLIST

	PMTCT intervention	Received	Comments
1.	HIV testing and counseling during ANC		
2.	Received results on the same day		
3.	WHO staging done		
4.	CD4 counts done		
5.	Provision of preventive ARVs		
6.	Counseled on infant feeding		
7.	Counseled on FP for PMTCT		
8.	Delivery of infant in hospital		
	(others column:1=C/S, 2=normal delivery,		
	3=assisted delivery)		
9.	Took ARVs during labour(others		
	column:1=HAART 2=AZT+3TC 3=others)		
10.	Took ARVs post-partum (others		
	column:1=HAART 2=AZT+3TC for 1 week,		
	3=others)		
11.	ARV prophylaxis in infant (others		
	column:1=NVP syrup until 6 months, 2=NVP		
	until cessation of breastfeeding, 3=AZT for 6		
	months)		
12.	Infant on septrin (for others column		
	1=appropriate dosage 2=overdose 3= under		
	dose)		
13.	Mode of infant feeding (others		
	column:1=exclusive breastfeeding 2=mixed		
	feeding, 3=complementary feeding)		
14.	Attendance of scheduled visits for mother		
	(others column write it as a fraction e.g.		
	14/15.		
15.	Attendance of scheduled visits for infant		

	(others column: write as a fraction)	
16.	HIV testing in infant at 6 weeks (for others	
	1=done on schedule 6-8 weeks, 2=above 8	
	weeks)	
17.	Results of PCR received (for others column:	
	1=within 2 weeks 2=received in 3-4 weeks	
	3=above 4 weeks later)	
18.	Mother currently on family planning	

#### **Part IV: Verbal autopsy**

#### For those whose infants who are deceased

Was DNA PCR done?

- o Yes
- o No

If yes, what was the result?

- o Positive
- o Negative

What were symptoms in child prior to death or diagnosis of child prior to death?

#### Code:

A:AIDS-like symptoms: severe wasting, recurrent pneumonias, oral thrush, failure to thrive, delayed milestones

B: Pneumonia: cough, difficulty in breathing, nasal flaring

C:Gastroenteritis: diarrhea, vomiting

D:Meningitis: convulsions, fever, loss of consciousness

E: Malaria: fever, history of travel, convulsions, pallor, anaemia, positive blood slide

F: Malnutrition: severe wasting with or without oedema, frequent infection

G: TB: cough for longer than 2 weeks, night sweats, fever, history of contact with PTB, severe wasting, failure to thrive

H: Other:\_\_\_\_\_

#### Part V: Loss to follow up

#### For mothers who ceased to attend PMTCT programme.

Timing of loss to follow up\_\_\_\_\_

- During pregnancy
- Within 6 weeks of delivery
- After DNA PCR testing

Was child born in a health facility?

- o Yes
- o No

Has child received vaccinations?

- o Yes
- o No

Are vaccinations received on schedule?

- o Yes
- o No

If no, please list vaccinations missed

Use the code below

- 1. BCG at birth
- 2. Polio at birth

- 3. Pentavalent 1-DTP,Hib,HBV,Oral polio
- 4. Pentavalent 2, Oral polio
- 5. Pentavalent 3, Polio
- 6. Measles
- 7. Pneumococcal

What are the reasons for loss to follow up?

- Infant deceased
- Change of health facility
- Child tested at 6 weeks and found to be negative
- Other, please specify