

Review
of the Implementation of the Programme for the
Prevention Of Parent-To-Child-Transmission Of HIV in
The Gambia
March 2004 – May 2006



Final Report

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This report was compiled for the National AIDS Secretariat by the CIAM Monitoring and Evaluation Team. For further information:

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1. Executive summary

In 2004, the government of The Gambia received funding from the Global Fund to Fight AIDS Tuberculosis and Malaria (GFATM) to implement a treatment and care programme for People Living With HIV/AIDS (PLWHA). One of the six objectives of this project focuses on providing increased access to prevention of Parent-To-Child Transmission (PTCT) services for pregnant mothers in the Gambia.

Since the introduction of the project in March 2004, 12 facilities within the public and NGO sectors are delivering PTCT services. Monitoring reports have revealed that the delivery of PTCT has faced several challenges, notably, varying uptake of voluntary counselling and testing (VCT) services; low uptake of anti-retroviral prophylaxis by pregnant women and difficulties in community follow-up of HIV positive women due to high levels of stigma. Other related issues hampering programme effectiveness include low staffing levels and the absence of strong communication strategies on PTCT.

This review of the PTCT programme was commissioned to assess coverage, and to determine underlying factors for the low uptake of PTCT services and to identify strategies to improve uptake of these services. The objectives of the review were to: (i) provide evidence based data to guide policy decisions; (ii) strengthen the current implementation process nationwide and (iii) inform the process of developing a full proposal for the Global Fund Round 6.

Review data comprised 34 individual interviews with HIV positive women, and service providers and 21 focus group discussions (FGDs) with service providers and stakeholders at the community level. Quantitative data was extracted from registers at health facility level and 208 exit interviews were conducted with pregnant women attending antenatal clinics.

The review period covered March 2004 to May 2006. Key findings were as follows. Out of 25,734 women attending Reproductive and Child Health (RCH) clinics for first antenatal visits, 61.6% completed the full VCT process. 697 of the women tested were HIV positive and of these 25.8% received anti-retroviral (ARV) prophylaxis and 14.8% of their children received nevirapine syrup. Fifty-one infants were due to be tested for HIV at 18 months between October 2005 and May 2006. Of these 20 were tested and 2 (10%) were HIV positive.

The uptake of PTCT services is limited by high fall out rates amongst pregnant women following the first antenatal visit and low rates of delivery at health facilities. Factors that were found to influence this included: the low level of knowledge and awareness of PTCT related issues and services offered by the programme, and high rates of stigma and negative perceptions of people living with HIV/AIDS. There is limited understanding of the benefits of the programme and HIV positive women are reluctant to be followed-up at home and disclose their status at time of delivery. Procedures for delivery of ARV prophylaxis, infant feeding counseling and postpartum care and support for HIV-positive mothers are inadequate. However, mothers appreciated the attitude and behaviour of PTCT staff and there is an interest and willingness amongst PTCT staff to improve service delivery and quality of care.

The key recommendations of the review are: (1) to improve integration of PTCT services into RCH services at facility level, outreach posts and community level; (2) to develop integrated communication strategies that include health education, counseling, behavior change and community mobilization to encourage and sustain participation in the PTCT programme; (3) to introduce a simplified, comprehensive and integrated PTCT registration system that will facilitate client tracking and record all relevant information; (4) to develop a mechanism for providing professional development for RCH staff and ensure that all RCH staff receive PTCT training on an ongoing-basis; (5) to strengthen communication activities by adopting innovative strategies that address stigma reduction issues, male involvement and positive living with HIV/AIDS; (6) To improve counseling skills of service providers and extend counseling sessions to address the needs of the HIV positive mother and infant feeding related issues; and (7) to review protocols and distribution strategies for ARV prophylaxis to both pregnant mothers and infants.

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5. List of acronyms and abbreviations

ANC	Ante Natal Clinic
APRC	Alliance for Patriotic Reorientation and Construction
ARI	Accelerated Rapid Implementation
ARV	Anti Retroviral Therapy
BCC	Behaviour Change Communication
CHN	Community Health Nurse
CHW	Community Health Worker
CIAM	Centre for Innovation against Malaria
DOSH	Department of State for Health
FGD	Focus Group Discussions
FK	Faji Kunda
GFPA	Gambia Family Planning Association
GFATM	Global Fund to Fight AIDS, Tuberculosis and Malaria
HARRP	HIV/AIDS Rapid Response Project
HIV	Human Immunodeficiency syndrome
HOC	Hands on Care
IEC	Information Education and Communication
NACP	National AIDS Control Programme
NAS	National AIDS Secretariat
NGO	Non-governmental organisation
OI	Opportunistic infection
PHC	Primary Health Care
PLWHA	People Living With HIV/AIDS
MRC	Medical Research Council
PTCT	Parent-to-Child-Transmission
RCH	Reproductive Child Health
SJGH	Sulayman Junkung General Hospital
TB	Tuberculosis
STI	Sexually Transmitted Infections
TBA	Traditional Birth Attendants
VCT	Voluntary Counselling and Testing

6. Introduction and objectives

6.1. Introduction

The Gambia is defined as a country with low HIV prevalence. HIV-1 is the predominant virus driving the epidemic. In 2004, the estimated HIV prevalence rate was 2.1% for HIV 1 and 0.9% for HIV 2. In 2005, the reported HIV prevalence showed a declining trend with HIV-1 estimated at 1.1% and HIV-2 at 0.6% (DOSHS Sentinel Surveillance Bulletin, 2006). However it is too early to state whether this declining trend will be sustained.

In 2004, the government of The Gambia started implementing the GFATM funded HIV/AIDS Project to complement existing prevention programmes with high quality treatment and care programmes for People Living With HIV/AIDS. The goal of the project is to “*provide the highest standard of available treatment, care and support to PLWHA, which is accessible and affordable in order to live in dignity and maintain a positive and productive life free from discrimination and stigma. This in turn will lead to a favourable environment that will empower people living with HIV/AIDS to contribute to development and ensure appropriate prevention of HIV infection*”. The main emphasis of the project is on expanding access to the range of HIV/AIDS related services at facility and community level, specifically Voluntary Counselling and Testing (VCT), prevention of Parent-To-Child Transmission (PTCT) of HIV/AIDS, prevention and treatment of Opportunistic Infections (OI), access to Anti-retroviral Therapy (ART) and community based care for PLWHA.

One of six objectives being implemented, namely is, “*to provide access to the prevention of Parent-To-Child Transmission (PTCT) for 80% of pregnant mothers in the Gambia by 2008*”, aims to integrate PTCT services into existing RCH clinics nationwide to reduce HIV perinatal transmission and to address the needs of eligible women for care through access to Anti-retroviral (ARV) Therapy.

Currently, there are 12 facilities within the public and NGO sectors accredited to deliver PTCT services. The majority of these are located in the Western Health Division. Since the commencement of implementation of the GFATM grant in 2004, the delivery of PTCT, based on monitoring reports, has faced several challenges such as varying uptake of VCT services; low uptake of anti-retroviral prophylaxis by pregnant women and difficulties in following up HIV positive women in communities due to high levels of stigma. Other related issues hampering programme effectiveness include low staffing levels and the absence of strong communication strategies on PTCT.

As a consequence, the outcome/ coverage levels of the PTCT programme, as assessed by the number of HIV infected women receiving an adequate course of ARV prophylaxis to reduce the risk of PTCT has failed to meet national targets. At the end of March 2006, the cumulative total number of HIV positive women who had received ARV prophylaxis stood at 174 compared with a target of 250.

As a prerequisite to improving the efficiency and effectiveness of the scaling up process for the PTCT intervention the NAS Project Management Team commissioned a review of the PTCT programme to assess coverage, to determine underlying factors for the low uptake of PTCT services and to identify strategies to improve uptake of these services. The review took into consideration existing relevant policy documents, rigorously explored underlying factors that influence the uptake of the services such as awareness of the benefits of the programme and user perception of the services. A sound understanding of these is critical for the scaling up process and the development of sustainable strategies that are likely to have an impact on reducing perinatal HIV transmission.

6.2. Objectives

The objectives of the review were to: (i) provide evidence based data to guide policy decisions; (ii) strengthen the current implementation process nationwide and (iii) inform the process of developing a full proposal for the Global Fund Round 6. The Terms of Reference for the review is attached in Annex 1.

7. Methodology

7.1. The review team

The review team comprised of two teams of investigators. The qualitative team consisted of five members lead by the CIAM Social Scientist and included an independent PTCT trainer, two PTCT nurses working with RCH clinics targeted by the study, and a field assistant from the MRC Malaria Programme with experience in qualitative research. The quantitative team comprised of five members including a Researcher from University of The Gambia, CIAM Monitoring and Evaluation Officer and 3 field investigators.

All field investigators participated in two independent series of training exercises facilitated by senior members of the study team. The purpose of this training was to familiarise them with the scope of work and tools of the study as well as adopt standardised terminologies and interview techniques. For a full list of the members of the review team, see Annex 2.

Ethical approval was obtained from the Joint Gambia Government/Medical Research Council Ethics Committee.

7.2. Scope of the review

The study was consists of three parts. The first part, the qualitative arm, consisted of individual interviews and focus group discussions with beneficiaries and service providers in health facilities and at community level and stakeholders in communities. The beneficiaries comprised HIV infected women (HIV+ women who accepted and who did not take ARV), and women of childbearing age. Service providers comprised PTCT team members from 4 facilities including, PTCT nurses, laboratory technicians/assistants, and pharmacy assistants/dispensing assistants, and where available, the ART accredited physician and health workers at the community level. Stakeholders at the community level were also interviewed and these included male members of the community and male and female community leaders. A total of 34 individual interviews and 21 focus group discussions were conducted.

For the second part, the quantitative arm of the study, data collected by the PTCT programme covering the period April 2004 to the end of March 2006 was reviewed in order to assess programme performance. Sources of this data included Antenatal, VCT, PTCT, Clinical and Laboratory registers. Exit interviews of women attending antenatal clinics implementing PTCT were also conducted. Overall, the review collected substantial amounts of qualitative and quantitative data and information to providing important insights into the underlying factors that influence uptake of PTCT services from the perspectives of both users and providers.

The third part will consist of a central level review. This will take the form of a desk review of key documents and interviews of programme staff. This component of the study will take place in October 2006.

7.3. Target area

The quantitative assessment was conducted in all 12 facilities implementing the PTCT programme. The facilities are listed in Table 1 below.

Table 1. Distribution of PTCT centres.

Government Hospital	Government RCH clinic	Private/NGO clinic
1. Sulayman Junkung General Hospital (SJGH)	1. Faji Kunda Health Centre	1. Hands on Care (HOC) Clinic
2. Royal Victoria Teaching Hospital (RVTH)	2. Brikama Health Centre	2. Medical Research Council (MRC)
3. Farafenni APRC Hospital	3. Essau Health Centre	3. Gambia Family Planning Association (GFPA)
	4. Soma health Centre	
	5. Bansang Health Centre	
	6. Basse Health Centre	

For the qualitative arm of the study, interviews were conducted with respondents from four health facilities and the key Primary Health Care (PHC) villages/communities receiving outreach services from these health facilities. The facilities and PHC communities are listed in Table 2 below.

Table 2. Selected RCH Clinics and their target PHC communities

RCH Clinic	PHC village/communities targeted
Hands on Care Clinic	Pirang Farato
Sulayman Junkung General Hospital	Sangajorr Kanilai
Essau Health Centre	Kanuma Medina Serign Mass Fass Njaga Choi
Faji Kunda	Faji Kunda Sinchu Baliya

7.4. Methodology

Two different sets of data were collected for the evaluation: 1) Qualitative primary data obtained from open-ended individual interviews with beneficiaries and service providers as well as focus group discussions (FGDs) with service providers, women of child bearing age and other stake holders at the community level and 2) quantitative data extracted from registers at health facility level. The data were collected in 2 different surveys. Qualitative data was collected during a three-week survey in June 2006. Quantitative data was collected during a four-week survey in June and July 2006. For a list of places visited during the two surveys, see Annex III.

7.4.1. Data collection in relation to open-ended individual interviews and focus group discussions

Information was obtained through interviews and group meetings with key stakeholders (i.e. implementers/providers, users and community members) at health facility and community level from the Greater Banjul area, Western Division, and the North Bank Division.

Data collected included semi-structured individual interviews and Focus Group Discussions (FGD). The list below relates to the data collection methods with the different categories and numbers of informants as well as location.

- Individual interviews at health facility level
 - 5 PTCT nurses
 - 4 Lab technicians/ lab assistants
 - 3 Pharmacy technicians/ dispensing assistants
 - 1 Social worker
 - 2 ARV accredited Physicians
- Individual interviews at health facility level
 - 12 HIV+ mothers who received ARV prophylaxis
 - 7 HIV+ mothers who did not receive ARV prophylaxis
- Focus Group discussions at health facility level
 - 4 FGDs with PTCT team members
- Focus Group discussions at community level
 - 1 FGD with PLWHA from Santa Yalla and Nganiya Killing Support groups
 - 4 FGDs with women of child bearing age
 - 4 FGDs with community health workers
 - 2 FGDs with male community leaders
 - 2 FGDs with female community leaders
 - 2 FGDs with male community members
 - 2 FGDs with grandmothers

Open-ended interviews: A comprehensive guide of topics for reference in open ended interviews with HIV positive women registered with the PTCT programme and PTCT staff at health facility level were prepared in advance and used according to the specific interest/function of each person interviewed. The guide was used to allow for scrutiny of matters of particular relevance as uncovered in the course of the discussion. The guide for PTCT staff addressed the nature and quality of support received from higher levels in the health system (including training, supervision and working conditions), the knowledge about, and services provided in, the prevention of PTCT and recommendations for improvement of PTCT coverage and services. The guides for HIV positive women registered with the PTCT programme addressed the nature and perceived quality of PTCT services, knowledge about PTCT including infant feeding in the context of HIV, factors affecting uptake of PTCT services and recommendations for improvement of PTCT services. For guidelines used to interview HIV positive women and service providers, see Annex VIII.

Focus group discussions: Guidelines for FGDs were developed and pre-tested in advance. The guidelines included topics for discussion and these related to participants' knowledge and views about different elements of PTCT services, and perceptions and views around the role of different stakeholders in the provision of care for pregnant women living with HIV. For guidelines used to conduct the FGDs, see Annex VIII.

The findings from the qualitative surveys are presented in Section 8.2 of this report.

▪ ***Data collection from health facility records***

In order to carry out a preliminary assessment of coverage and achievements at outcome and impact level of PTCT program, the review targeted 9 public health facilities (3 hospitals and 6 RCH clinics) and 2 private/NGO clinics all of which provide PTCT related services. The data that was collected covered the period March 2004 to May 2006. The sources of information (i.e. registers and tally sheets) and recorded indicators are listed below. To optimise quality and standardisation of data collection, pre-defined summary forms were prepared and the field assistants trained and tested in their use before the survey was conducted.

The following indicators considered relevant to the assessment of coverage of the programme were extracted from the registers. The findings from an analysis of health facility records and results from exit interviews are presented in Section 8.1 of this report.

- *VCT Register and Laboratory based VCT Register*
 - Number of pregnant women seen who received individual pre-test counselling for PTCT as a percentage of total number of newly registered antenatal consultations
 - Number of pregnant women seen who were tested for HIV as a percentage of total number of pregnant women who were pre-test counselled.
 - Number of pregnant women seen who received post-test counselling and their test result for HIV as a percentage of total number of pregnant women who were tested.
 - Number of pregnant women seen who tested positive for HIV (HIV 1 and HIV 2) as a percentage of total number of pregnant women who were tested.
- *PTCT and Clinical register*
 - Number of HIV positive women who received anti-retroviral prophylaxis as a percentage of total number of women who tested positive in the facility
 - Number of infants born to registered HIV positive mothers as a percentage of total number of women who tested positive in the facility
 - Number of infants born to registered HIV positive mothers seen who received ARV prophylaxis as a percentage of total number of infants born to HIV positive women in the facility.
 - Number of matched mother-infant pair seen in the health facility who received ARV prophylaxis as a percentage of total number of HIV positive women registered in the facility
 - Number of mothers who opted for replacement feeds as a proportion of all mothers who were counselled
 - Number of mothers who opted for exclusive breastfeeding as a proportion of all mothers who were counselled
 - Number of infants who were tested for HIV at 18 months positive mothers as a percentage of infants born to HIV positive women
 - Number of infants who tested positive for HIV as a percentage of infants tested at 18 months

A summary of the data collected from health registers is presented in Annex VII.

7.4.2. Data from Antenatal Exit Interviews

A questionnaire was designed to capture data on the process of counseling and testing of pregnant women attending antenatal clinics at sites implementing PTCT. There were also questions to assess their knowledge of PTCT. During training, the questionnaires were translated into three local languages (Mandinka, Wolof and Fula) and back-translated to ensure consistency.

To achieve a 95% confidence estimate with a 10% confidence limit, we required a sample size of 192 pregnant women based on an estimated number of 42,000 maternities per year in The Gambia. All women attending the antenatal clinic on the day of the survey constituted the sampling frame.

The purpose of the study was explained to individual women and verbal consent obtained. Each woman was interviewed after her clinic consultation. A total of 208 women were interviewed. For the exit interview questionnaire, see Annex V.

7.5. Limitations of the data

The main limitations with respect to quantitative data from the registers were as follows:

- a. Inconsistencies in registers: An HIV test result would often be indicated for a woman whom it is reported declined to take the test. The review of the registers revealed an ad hoc introduction of new columns and variables with time.
- b. Incompleteness of registers especially PTCT registers: Data such as age, sex and reason for accepting VCT were often missing. In the PTCT register, data on infant feeding date and place of birth, infant feeding option chosen, frequency and quantity of replacement feeding distributed and ARV uptake was often missing.

c. Inconsistency between registers:

- i) VCT registers and Laboratory registers. There were instances where a positive result in the VCT register would not be reflected in the lab register. In other instances, changes to a positive result made to the VCT register after a confirmatory test would not be applied to the lab register.
- ii) VCT registers and PTCT registers: Some women who tested positive and were recorded in the VCT register, were not transferred to the PTCT register. Similarly, due to inconsistent numbering, it was difficult to trace some women in the PTCT register to the VCT register.

The main limitation of the qualitative data was that the majority of HIV positive women who did not take the ARV drug could not be traced. Therefore the views of those interviewed may not be representative of HIV positive women enrolled in the PTCT programme who did not take the drug.

Picture 1: Community meeting of men



8. Findings and analysis

8.1. Quantitative Data: Analysis of VCT using Register-based Data

The targets used to assess the performance of the project were derived from two sources:

- The original project proposal submitted to the GFATM; and
- The signed grant agreement with the Global Fund.

8.1.1. Uptake of VCT by antenatal women

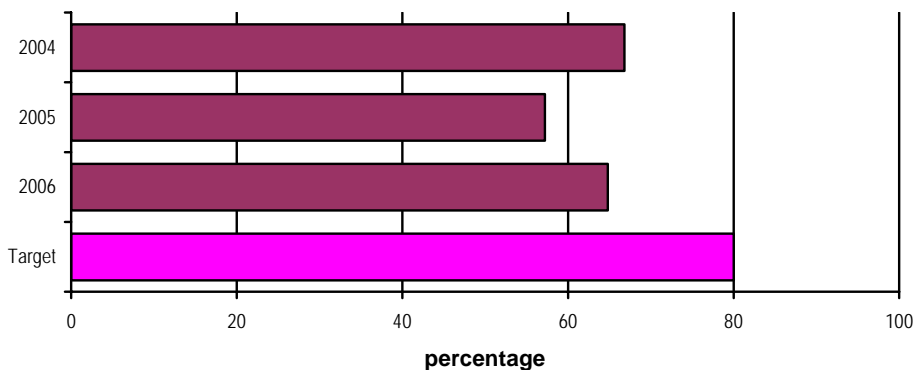
On review of the facility based registers the following observations were noted:

Following entry to the VCT process, coverage for individual components of the full VCT process was high.

- The percentage of newly registered women who were pre-test counseled was 87.8%, 84.3% and 93.3% for 2004, 2005 and 2006 respectively.
- The percentage of women who were pre-test counseled and went on to have an HIV test was 82.5%, 81.7% and 78.9% for 2004, 2005 and 2006 respectively.
- The percentage of women who were tested for HIV and received post-test counseling and their results was 92.1%, 83.7% and 88.1% for 2004, 2005 and 2006 respectively.

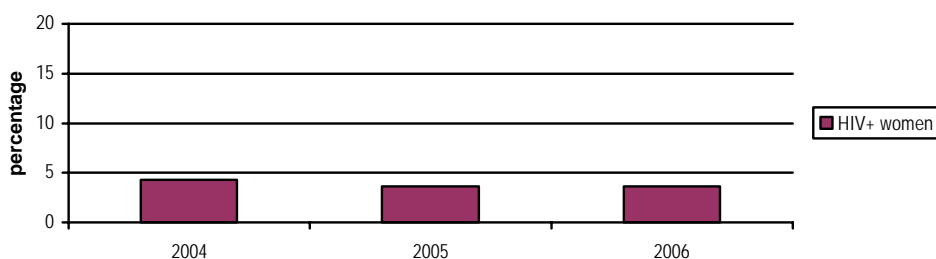
However, the percentage of newly registered antenatal women who completed the full VCT process (pre-test, HIV test and post-test) was low. Uptake was 66.8%, 57.2% and 64.8% in 2004, 2005 and 2006 respectively.

Figure 1: Percentage of newly registered antenatal women completing full VCT process.



Of those tested, the percentage of antenatal women who were HIV positive was 4.3%, 3.6% and 3.6% in 2004, 2005 and 2006 respectively (Figure 2).

Figure 2: Percentage of antenatal women tested that was HIV positive.¹



¹ Does not include data from MRC. MRC does not provide routine antenatal care including VCT.

8.1.2. Uptake of ARV prophylaxis

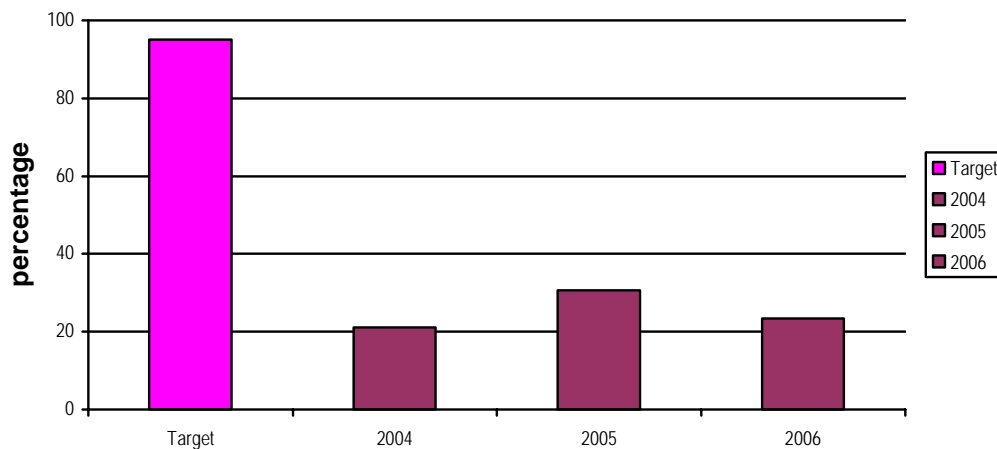
Picture 2: ARV prophylaxis (Nevirapine – trade name Viramune)



Although HIV positive pregnant women were given nevirapine/AZT at 36 weeks gestation (before onset of labour) there was no confirmation in the registers as to whether or not these drugs were ingested at the time of delivery.

The figure below shows that fewer than 30% of HIV positive women received ARVs over the 3 years. The percentages of HIV positive women who received ARVs in 2004 – 2006 were 21.1%, 30.7% and 23.4% respectively.

Figure 3: Percentage of HIV positive women seen in health facilities who received ARVs 2004-2006



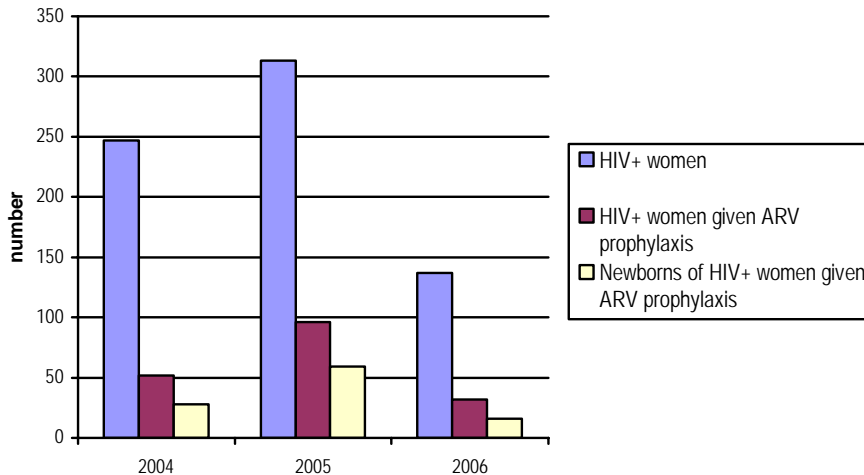
The number of confirmed deliveries recorded in PTCT registers as a percentage of HIV positive women seen in the facility were 21.9%, 26.2% and 19.7% 2004, 2005 and 2006 respectively. These figures are slightly lower than the rates reported for uptake of ARV prophylaxis, suggesting that almost all patients followed up through to delivery may be getting ARVs.

Coverage rates for infants of HIV positive women with confirmed deliveries that received nevirapine/AZT, were at 51.9%, 72.0% and 59.3% in 2004, 2005 and 2006 respectively.

Record keeping was generally poor and it is possible that more women and babies received ARV prophylaxis. In the absence of records, this cannot however be verified.

The figure below presents the actual numbers of newly registered ANC mothers who tested positive and the numbers of HIV positive women and their newborns who received ARV prophylaxis between 2004 and 2006. A key finding is the steep decline seen on numbers of HIV positive women who went on to receive ARV before delivery.

Figure 4: Number of HIV+ women and their newborns receiving preventive measures

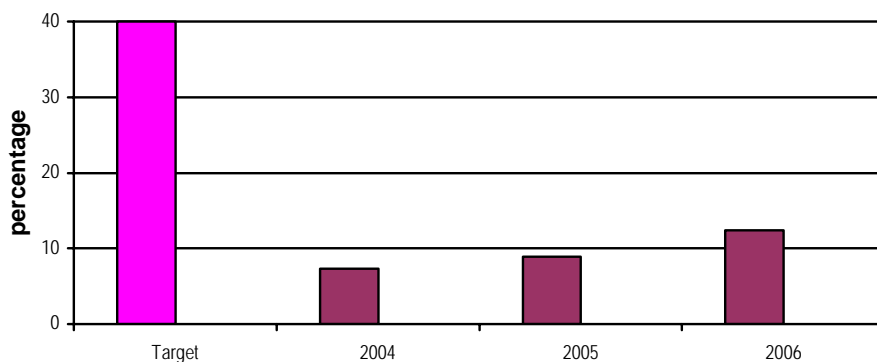


8.1.3. Uptake of replacement feeding

The uptake of replacement feeding was analysed using two approaches: (i) the percentage of HIV positive mothers who were given replacement feeds, and (ii) the percentage of mothers with confirmed deliveries, that is mothers who are accessible to the system, who opted for replacement feeds.

In terms of women diagnosed HIV positive as part of the programme and therefore eligible to receive replacement feeds, the uptake for 2004, 2005 and 2006 was 7.3%, 8.9%, and 12.4% respectively. Of those women whose deliveries were confirmed by project staff, the uptake of replacement feeding over the same period was 33.3%, 34.1% and 63.0%.

Figure 5: Percentage of HIV positive mothers who gave replacement feeds.



8.1.4. Follow up and HIV testing of infants

Information on infants tested at 18 months was only available from one PTCT Centre, namely, Hands on Care. At this centre, the register contained information on 20 children that had been tested for HIV. There was evidence that 10 (50%) of the mothers and their babies had received ARV prophylaxis. In this group, none of the children was HIV positive. For the remaining 10, PTCT staff reported that they had also received ARV prophylaxis but this could not be confirmed from the register. Two (20%) of the children tested in this group were HIV positive. PTCT staff reported that these children had been receiving mixed feeding.

In 2005, two other infants had PCR done at MRC before they were 18 months of age. One was HIV positive and the other HIV negative.

Tables 3 and 4 provide a summary of key findings presented by year (Table 3) and for the whole study period (Table 4).

Table 3: PTCT programme coverage indicators¹

Indicator	2004 (Mar-Dec)		2005 (Jan-Dec)		2006 (Jan-May)	
	Number	Percentage (%)	Number	Percentage (%)	Number	Percentage (%)
Total number of newly registered antenatal women	7898		12723		5113	
Number of pregnant women who had pre-test counseling (as a percentage of newly registered antenatal women)	6933	87.8	10724	84.3	4771	93.3
Number of pregnant women who had a HIV test (as a percentage of antenatal women who were pre-test counseled)	5723 ²	82.5	8694 ²	81.7	3764 ²	78.9
Number of pregnant women who had post test counseling (as a percentage of antenatal women who had a HIV test)	5272	92.1	7274	83.7	3315	88.1
Number of pregnant women who had post test counseling (as a percentage of newly registered antenatal women)	5272	66.8	7274	57.2	3315	64.8
Total number of HIV positive pregnant women (as a percentage of pregnant women who had a HIV test)	247	4.3	313	3.6	137	3.6
Number of HIV positive pregnant women that received ARV prophylaxis (as a percentage of HIV positive pregnant women)	52 ³	21.1	96 ³	30.7	32 ³	23.4
Total number of confirmed deliveries (as a percentage of HIV positive pregnant women)	54	21.9	82	26.2	27	19.7
Number of infants given ARV prophylaxis (as a percentage of confirmed deliveries)	28	51.9	59	72.0	16	59.3
Number of infants tested for HIV at 18 months	-	-	11	-	9	-
Number of HIV positive infants	0	-	2 ⁴	18.2	0	-
Matched pair had ARV prophylaxis (as a percentage of confirmed deliveries)	29	46.8	49	67.1	13	54.2
Number of mothers given replacement feeds (as a percentage of confirmed deliveries)	18	33.3	28	34.1	17	63.0

¹ The VCT data in this table does not include data from MRC as the institution does not provide antenatal VCT services. However, data on HIV positive women and infants includes MRC data.

² The total number of pregnant women who accepted to have a HIV test was 6174 in 2004, 9245 in 2005 and 3979 in 2006 (VCT registers). However, the number of pregnant women with test results in the register was 5723 in 2004, 8694 in 2005 and 3764 in 2006. Thus, not all pregnant women who accepted to have a HIV test actually had one.

³ HIV positive pregnant women were given Nevirapine and or AZT at 36 weeks gestation. There was no consistent confirmation of actual ingestion of the drugs in the registers.

⁴ Two other infants had PCR at MRC before 18 months of age. One was HIV positive and the other HIV negative.

Table 4: Summary of PTCT coverage indicators (March 2004 – May 2006)¹

Indicator	Mar 2004 – May 2006	
	Number	Percentage (%)
Total number of newly registered antenatal women	25734	
Pregnant women who had pre-test counseling	22428	87.2
Pregnant women who had a HIV test	18181	70.6
Pregnant women who had post test counseling	15861	61.6
Total number of HIV positive pregnant women	697	
HIV positive pregnant women that received ARV prophylaxis	180	25.8
Total number of confirmed deliveries	163	23.4
Number of infants given ARV prophylaxis	103	14.8
Number of mothers given replacement feeds	63	9.0
Total number of infants eligible for HIV testing at 18 months	47²	
Number of infants tested for HIV at 18 months	20	42.6
Number of infants tested who were HIV positive	2 ³	10.0

¹ The VCT data in this table does not include data from MRC as the institution does not provide antenatal VCT services. However, data on HIV positive women and infants includes MRC data.

² Total number of confirmed deliveries as at November 2004 (to be eligible for HIV testing at 18 months of age by May 2006)

³ Two other infants had PCR done at MRC before 18 months of age. One was HIV positive and the other HIV negative

8.2. Quantitative Data: Analysis of Exit Interviews of Antenatal Clients

8.2.1. Characteristics of Antenatal Clients

A total of 208 women were interviewed following their antenatal consultation on the day of the survey. Thirty seven percent of women were attending clinic for the first time while 14.4% had 4 or more antenatal visits. A small percentage of women (5.3%) had also attended another antenatal clinic in the index pregnancy. The distribution of the age and gravidity of the antenatal women is shown in Table 5 below.

Table 5: Characteristics of antenatal clients

Characteristics	% (n=208)
Age (years)	
<20	18 (37)
20-24	33 (68)
25-29	27 (56)
30-34	14 (28)
>34	9 (19)
% (n=207)	
Number of pregnancies	
1	25 (51)
2	20 (42)
3	17 (35)
4	16 (34)
5-7	15 (30)
8-10	7 (15)

Picture 3: Pregnant women receiving a group counselling session



8.2.2. Experience with counselling and testing

The majority of women, 87%, reported that they had been offered pre-test counselling in the current or a previous pregnancy. Out of 184 women, 95%, were offered pre-test counselling for the first time in the current pregnancy. Eleven women had also been offered pre-test counselling in a previous pregnancy. Only one woman was offered pre-test counselling in a previous pregnancy but not during the current pregnancy.

The majority of women, 97%, who were offered pre-test counselling were pre-test counselled. Considering all women interviewed, 86% received pre-test counselling. Thirty six percent of women who received pre-test counselling felt they had the opportunity to ask questions during the counselling session. Of those who asked questions, 91% were satisfied with the answers they received.

8.2.2.1. Reasons given for taking an HIV test

A large percentage of women, 83%, who received pre-test counselling went on to have the HIV test. 75% of women who took the test did so because they wanted to know their HIV status (Table 6).

Table 6: Reasons for taking HIV test

Reasons for taking HIV test	% (n=153)
To know HIV status	75 (115)
To know if one is healthy	5 (7)
To protect oneself from HIV	4 (6)
Husband has other wives	3 (4)
Others are doing it	3 (4)
It is a routine	1 (2)
I was sick	1 (2)
To have treatment if positive	0.6 (1)
Others	4 (6)
No reason given	4 (6)

Twelve percent of women did not have the HIV test after counselling for reasons presented in Table 7 below.

Twenty one percent of women indicated they needed consent from their husbands before taking the test. However, only 9% of women declined to have a HIV test because they had not obtained the consent of their husbands. One woman did not take the test because her husband had forbidden her to do so.

Table 7: Reasons for not having an HIV test.

Reasons for not having a HIV test	% (n=22)
Need husband's consent	18 (4)
Laboratory was not working	14 (3)
Did not want to know status	9 (2)
Was faithful to husband	9 (2)
Certainly did not have HIV	5 (1)
Needed time to consider test	5 (1)
Had done test elsewhere	5 (1)
Positive result would have bad effect on self	5 (1)
Husband refused	5 (1)
Not used to the test	5 (1)
No reason given	23 (5)

Women were asked what they perceived as the benefit of knowing their HIV status (Table 8). The majority of respondents, 61%, did so because they wanted to prevent parent to child transmission of HIV. Only two women reported the availability of treatment for those who were HIV positive, as a benefit of knowing one's HIV status.

Among twelve women who did not have the HIV test, (58%), also reported prevention of perinatal transmission as the main benefit of knowing one's HIV status.

Table 8: Perceived benefits of knowing HIV status

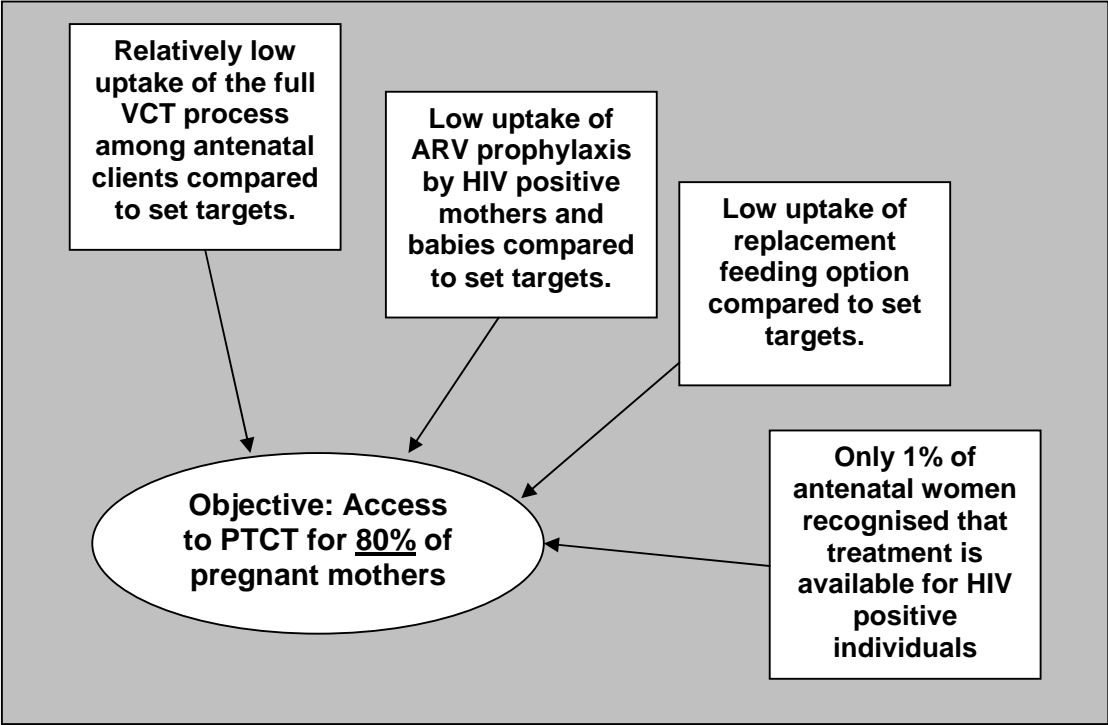
Perceived benefit of knowing HIV status	% (n=171)
Prevent HIV transmission from mother to infant	63 (107)
Take steps to maintain good health	14 (23)
Peace of mind	4 (7)
Treatment available if positive	1 (2)
Others	6 (11)
Do not know	12 (21)

Questions to assess knowledge of the prevention of PTCT were answered by 124 of the antenatal women at 7 of the 11 facilities surveyed (Table 9). Most women, 75%, knew that HIV could be transmitted to the baby from the mother. A smaller percentage, 58%, knew that drugs could be used to protect the unborn child from HIV. However, only 32% knew that the drugs should be taken during labour. Similarly, relatively fewer women, knew that infants could be protected from HIV infection by giving them drugs, 28%, and avoiding breastfeeding, 34%.

Table 9: Knowledge of Prevention of PTCT

Pregnant women who know that...	% (n=124)
Unborn baby can get HIV from mother	75 (93)
Drugs can protect unborn baby from HIV	58 (72)
Drugs for the protection of unborn baby are given during labour	32 (39)
Infant can get HIV from breastfeeding	57 (70)
Drugs can be given to newborn to protect it from HIV	28 (35)
Avoiding breastfeeding protects infant from HIV	34 (42)

Figure 6: Summary of key findings from quantitative data



The low uptake of ARV prophylaxis is likely to limit the impact of the PTCT programme. The results of the exit interviews suggest that the women are not well informed about ARV prophylaxis and especially that the need to take the drug during labour and also given to the newborn.

8.3. Qualitative Data: Analysis of individual interviews and FGDs

The findings have been divided into two major sections:

- Provision of PTCT services to pregnant women attending antenatal clinics
- Perception of service providers on PTCT services

Section 8.3.1 and 8.3.2. provide a user perspective and service provider perspective respectively. For each section, observations, strengths and weaknesses are presented systematically. Based on identified strengths and weakness the report proposes the options for change referring to programmatic adjustments that are likely to improve the effectiveness of PTCT service provision.

8.3.1. *Provision of PTCT services to pregnant women attending antenatal clinics*

Information presented in this section originates from semi-structured individual interviews with 19 HIV positive mothers who were registered with the PTCT programme, 12 PTCT team members, as well as 17 community-based FGDs with different categories of respondents including members of HIV/AIDS support groups and women of child bearing age (see Section 3.4.1. for detailed list of categories).

8.3.1.1. *Underlying beliefs and attitudes around PTCT*

Individual interviews with HIV positive mothers: All HIV positive mothers interviewed were aware of the modes of transmission and prevention of HIV. The modes of transmission most often mentioned were through unprotected sex with an infected partner, and through the use of a sharp object such as a blade that had previously been used by an infected person. The majority of women were familiar with the routes for transmission of HIV between mother and child that is “during pregnancy, during delivery and during labour”.

Additional probing revealed that none of the HIV positive women interviewed believed that transmission of HIV between a mother and child was inevitable. They believed that something can be done to prevent the transmission of the virus. They suggested a mother should be able to protect her child from being infected with the virus if she adhered to advice given to her by health personnel. This would involve taking the “*drug that is given during labour*” that is ARV prophylaxis, and adhering to the infant feeding option opted for, either breastfeeding for 6 months and then weaning the child of the breast or opting for replacement feeding from birth.

“Yes, if the woman has the virus and has not tested or has not taken any drug during labour, she can transmit the virus to her baby. Secondly, during delivery and during breastfeeding if she doesn’t comply with the 6 months exclusive breastfeeding she can infect her baby”. **HIV positive mother from Brikama**

FGDs: FGD participants were generally knowledgeable about the modes of transmission and prevention of the HIV virus. Knowledge on the transmission of HIV from mother to child was limited and some respondents, especially male members and grandmothers tended to hold the view that PTCT was only possible during delivery and breastfeeding or during breastfeeding alone. According to grandmothers from Fass Njaga Choi, “if something is wrong with the mother, if the baby breastfeeds the baby will also get it. Therefore a mother with HIV should not breastfeed.”

The majority of women of childbearing age tended to share the views of HIV positive women that HIV transmission from mother to child can be prevented if the mother takes the drug given to her or if she avoided breastfeeding. Women of child bearing age from Kanilai narrated a community sensitisation meeting at their village where a woman living with HIV explained about what she had done to prevent her child from becoming infected.

In the remaining FGDs the opinion was mixed. Some participants felt that transmission was inevitable whilst others did not share that opinion. At Fass Njaga Choi one mother noted “*the child will be born positive because during delivery the child is born in a pool of the mother’s blood* and this she added puts those who deliver women at home at risk. However, another mother felt that “*if the mother does not breastfeed, the baby will not have the disease*” and that to prevent transmission of the virus from mother to child, the child should be given other foods and not breast milk.

On the other hand, women from Farato and men from Kanuma were categorical in their belief that HIV transmission is inevitable between mother and child. Male community leaders at Farato said that they were informed at a meeting that if a mother is infected with HIV she will transmit the virus to her child and they thought that this was more likely during delivery and breastfeeding.

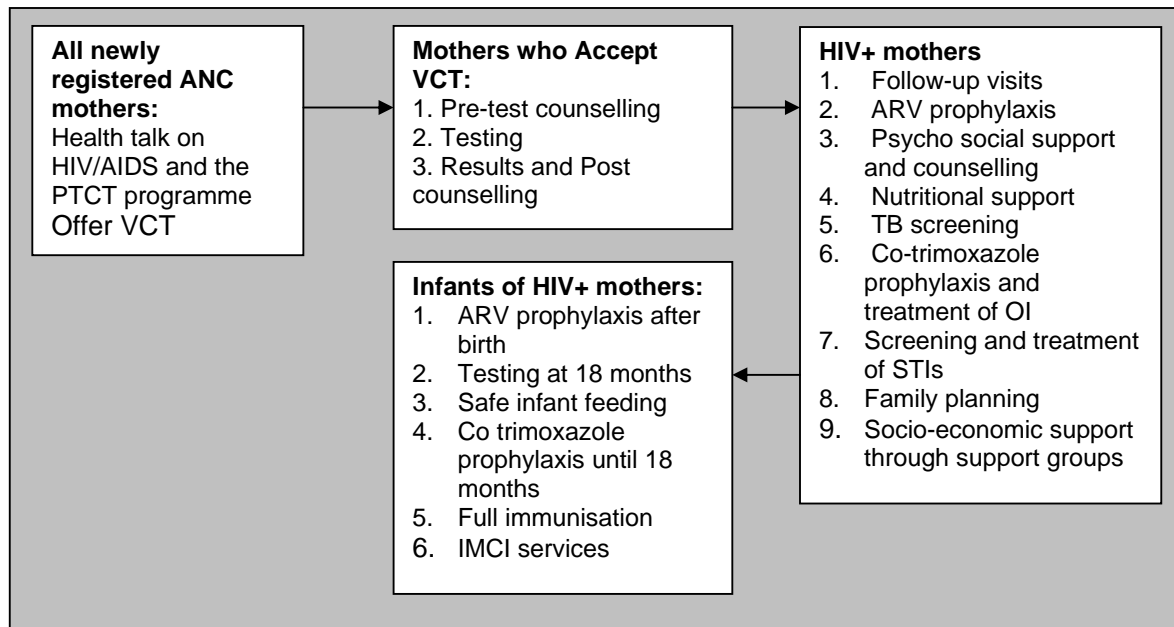
Community Health Workers were better informed about how HIV transmission could be prevented. Most CHWs were aware of the drug a woman can take to reduce the risk of transmission and some referred to infant feeding options recommended for breastfeeding mothers infected with HIV.

When asked about sources of information on HIV, most participants revealed that they received information on HIV from the radio and television, only women of childbearing age referred to the health facility as a source of information and some community health workers had attended trainings sessions on HIV/AIDS transmission and prevention and PTCT.

8.3.1.2. Awareness of the programme, quality of care of HIV positive pregnant women

The following scheme outlines the process that a woman follows when participating in the PTCT programme.

Figure 6. Illustrative model of services provided by the PTCT programme.



Individual interviews: Both groups of mothers who took and did not take ARV were asked to describe the services they received from the PTCT program. The typical description was as follows: *It is a programme where pregnant mothers attending ANC are offered testing for HIV. They are also counselled on how HIV is transmitted. When a mother is found to be HIV positive,*

she is counselled on infant feeding and positive living and told about the ARV prophylaxis. Very few mothers mentioned that they ever received follow-up visits or any other services with the exception of mothers in Brikama attending the HOC clinic. When HIV positive mothers who do not attend the HOC clinic were asked what happens when you come to the clinic the typical response was *“the drug that they gave me and my child, nothing else”*. Some HIV positive mothers indicated that they continued to receive antenatal services from outreach services and were referred to the RCH clinic for blood tests and ARV prophylaxis only.

According to HIV positive women who attended the Brikama HOC clinic, the services offered were quite different.

“If we come here they help us with drugs and food. Sometimes they give it to you to take at the onset of labour so that the baby will not be infected. After delivery, you should bring your baby to be given the drop to protect him from this disease. They will also ask you if you want to breastfeed or not. If you want to breastfeed they will tell you to do so for 6 months and wean the baby. If you don’t want to breastfeed at all, then they will provide food like milk for the feeding of the baby.”

“The services offered to me is numerous I cannot say all because if you come to this clinic for treatment you don’t pay money. The nurse supplies you drugs for any complaint. If you are going home you are given return fares for transport. The nurses don’t separate us from the other patients. We sit under the same waiting shed so that the people around may not speculate about us so we all sit and when you are called you go and answer.”

HIV positive Women from HOC describe the services

At the HOC clinic, HIV positive mothers are given monthly appointments during which they are examined by a physician, supplied with a monthly supply of antibiotics, paracetamol and vitamin supplements and infant formula where necessary. Money to cover transport costs is also provided.

This is in stark contrast to other facilities where PTCT nurses reported that they sometime cover from their own resources transport expenses of patients to encourage them to meet appointments. Women only see a physician when this is deemed necessary and not as a matter of routine. A few mothers registered at Faji Kunda Health Centre who had been referred to HOC wished that the services offered there could be provided at Faji Kunda Health Centre.

When asked what they felt about the services offered, most of the HIV positive women interviewed expressed general satisfaction with PTCT services and appreciated the attention, concern and courtesy displayed to them by PTCT staff during counselling sessions and when they attended RCH clinics.

A few mothers lamented that some of their health concerns were not being addressed and some felt that they should be reviewed monthly by a physician and receive drugs that would help slow down the progression of the disease. In Faji Kunda and Essau HIV positive mothers are referred to RVTH for further treatment where necessary. These missions to Banjul were referred to as often tiresome and fruitless.

“My main concern is the treatment, we are not given any medicine. If there is any medicine to help me because if someone tells you that you have a disease and you don’t take any medication, it might get worse. But if you are getting medicine every month to drink then it might not disturb you that much.” **HIV positive mother, Essau.**

“What I came to ask them was since I have no complaints and you people say that I have the disease and I am sitting like that without taking any medication will it not worsen whilst I just sit? They said no that it is not going to be a problem. But if you are concerned what we can tell you is to report whatever problem you may have even a headache we will give you treatment or medicine for it.” **HIV positive mother, Faji Kunda**

Focus group discussions: With the exception of women from Farato, most of the women of child bearing age interviewed particularly those who were recently and currently pregnant were aware of the programme and some had been offered VCT and taken an HIV test.

Male community leaders from Farato were aware of the PTCT programme and one man referred to clinics ran by HOC at two nearby communities where pregnant mothers are offered VCT and referred to a meeting held at the village where staff of HOC discussed problems they were having with HIV positive mothers. Staff of HOC had informed them that these women *“usually would not follow their advice. They are told not to breastfeed their babies and when they go for their follow ups, they will sometimes find them breastfeeding and when asked the mothers say they felt sorry for the baby”*.

From the remaining meetings with both male and female community leaders, some respondents had not heard of the PTCT programme and those who had heard about it had limited information about it. A number of respondents referred to the drug given to pregnant women to reduce the risk of transmission as *Fansidar*

Most CHWs¹, especially those from the HOC catchment area were aware of the programme and had received some training on PTCT. However, although some of the Community Health Workers from Bwiam and Medina Serign Mass, had heard of the programme none had been formally informed about it.

“We had a workshop on PTCT....but before that we did not know anything about PTCT. We used to help women during labour with our bare hands but know we are told to use cotton and gloves that they supply us with.” **Community Health Worker, Bwiam**

8.3.1.3. *Attitudes towards and Uptake of HIV testing*

All pregnant mothers presenting at antenatal clinics at an RCH clinic offering PTCT services are offered VCT services at booking using an opt in model. Mothers usually attend a group counselling session and after they accept to be tested they undergo the full VCT process that is, they are pre test counselled, tested and post test counselled at which time the test result is disclosed to them. At all RCH clinics visited, with the exception of Hands on Care and Faji Kunda Health Centre, all the RCH clinics visited give pregnant mothers their test results the same day.

Individual interviews: HIV testing was generally considered very important in preventing HIV/AIDS. Almost all of the HIV positive mothers (those who accepted and did not receive ARV prophylaxis) interviewed felt that a pregnant woman should know her HIV status so that she can protect her child from being infected and get treatment for herself. According to two HIV positive women who received ARV prophylaxis one mother from Brikama noted *“the benefits are that when you test and have the virus you are told how to protect yourself and your baby during pregnancy.*

¹ These include Village Health Workers, Traditional Birth Attendants and Community Health Nurses.

"It is important because if she has the virus and did not know her status she can infect her baby...it is not good to know your HIV status as positive and you don't protect the innocent baby...the nurse sent me for an HIV test and I consented because I wanted a live healthy baby". HIV positive mother from Bwiam.

Picture 4: Mother having her blood taken



According to a woman from Faji Kunda who did not receive ARV, her motivation to get tested was *"if I had not tested my blood, I would not have known what I have, I would be going with it till it destroy me so for one to test your blood is a very good thing"*. One woman from Bwiam who did not receive ARV indicated that she was not informed about what the test was for and was not aware she was HIV positive even though she was on the PTCT register and had been referred to HOC for support.

Women were asked whether they felt that they should get their husband's approval prior to testing. Most HIV positive women responded in the affirmative even though in actual fact some of their husbands were not informed before they took the test. Even where a husband does not consent, the general consensus was that the woman should take the test if she wants to regardless of her husband's opinion in order to protect herself and her unborn child.

Focus group discussions: All groups of participants, men, women of child bearing age, CHWs and community leaders felt overwhelmingly that it was important for a pregnant woman to know her status so as to protect her child from acquiring the virus and to protect herself from infecting others. Some felt that not only pregnant women should be tested. According to a woman from Fass Njaga Choi village *"even if you are not pregnant you should go and check your blood and when you know you don't have it you try harder to prevent yourself"* and a CHW from Medina Serign Mass added *"it is beneficial for couples to know their status. If the woman is infected she can protect her child and her husband. If there is a second wife she should go with the husband for a test and if one of them happens to be positive they can still go ahead with the marriage and be using a condom"*

When asked whether a woman should inform her husbands before taking an HIV test, most women of child bearing age responded affirmatively and added that the woman should get tested whether her husband consented or not. Some added that men should also be encouraged to get

tested to know their HIV status. However, women from Kanilai and Farato indicated that men are usually reluctant to take an HIV test and a woman from Kanilai remarked that “*men in Foni do not believe that AIDs exists*” and “*some men feel ashamed to do an HIV test*”. Some men also shared the view that both men and women should be tested and one man from Farato was supportive of his two wives taking an HIV test without informing him. “*I said it was good that’s what they should do because if you go to the doctor you should do whatever he asks you to do.*”

8.3.1.4. Determinants and context of stigma in relation to PTCT services

Perceptions around disclosure of HIV status to husbands

Individual interviews: HIV positive women interviewed appeared to be very reluctant to disclose their HIV status to anyone including their husbands.

“I did not tell anyone. I am not ready to disclose to anyone. Because if you disclose it to someone, the person might go around spreading and tell people that this is what you have. I can choose not to tell any other person but can tell the doctors who care for people or who are taking care of people.” HIV positive mother from Essau

Although some felt that a woman should inform her husband if she is HIV positive only 4 of the women interviewed (2 from Faji Kunda and 2 from Brikama) had actually done so. The majority cited fear of being divorced or abandoned as the reason for not disclosing their status. They also disclosed that they feared being branded as promiscuous and bringing the disease into the family.

Amongst those women who had disclosed their status to their husbands, none of them have been divorced nor encountered problems so far. One of the women who had disclosed to her husband had informed other members of her family.

Another woman from Brikama reported that after disclosing her status to her husband, she returned with him to the clinic. However, her husband has not consented to do the test and following a first course of treatment has refused to return to the health facility claiming, “*he has no ill health. I have made it clear to him that if he refuses to take his medication, I will not sleep with him.*”

A number of the husbands of HIV positive mothers interviewed had died prior to the interview. All these mothers said that they suspected that their husbands had died of AIDS, however, none of their husbands had disclosed their status to them nor had they any confirmation of what their husbands had died of.

Two women suggested that a woman could disclose to her mother but neither had done so although one woman had disclosed her status to her father.

It was clear from the interviews with HIV positive women that the fear of disclosure to their husbands affects their demand for health care and sometimes forces them to indulge in at risk infant feeding practices. Three out of the four women who disclosed their status to their husbands indicated that their husbands supported them to seek care. Although it cannot be assumed that all women who disclose would be given equal support, the focus group asked men, women of child bearing age and stakeholders at the community what they felt should be the role of a man whose wife is HIV positive.

The overwhelming view was that a man whose wife is HIV positive should get tested, protect himself if necessary, protect her status, support his wife morally and financially “*so that she will live longer*” and above all not abandon her.

Community's perceptions of women living with HIV

In an effort to further explore the level of stigma and discrimination faced by women living with HIV and underlying community perceptions about PLWHA in order to see how these may deter a woman from participating in a PTCT program, participants were asked how communities perceive women who are HIV positive.

Individual interviews: According to women living with HIV, common forms of stigma experienced by women whose HIV status is known or who is suspected of having HIV are gossip mongering, name-calling and abandonment. Women with HIV are assumed to have been promiscuous and despite the wide awareness of how HIV is transmitted, people still tend to put a physical distance between themselves and a person suspected of having HIV/AIDS for fear of getting infected through casual contact. According to a woman from Bwiam, *"if they know that you have it they will run away from you because they will think you will transmit the disease to them"* and this had led to her declining follow-up visits from the social worker attached to the PTCT programme at SJGH. Women, because they are usually the first to know about their HIV status, are usually blamed for *"bringing HIV into the household"*.

"You know the social worker comes to my place and asks for me. You know the wolof, soon they will start saying this man comes here too much and we don't know what he is coming for. So I have given him my mobile number so if there is a meeting he will let me know and I will meet them at the clinic". **HIV positive woman, Bwiam**

Focus group discussions: The reports obtained from the focus group discussions acknowledged the fears of the HIV positive women. Men, women of child bearing age and community leaders all confirmed that in their communities, people who are thin and emaciated are suspected of living with HIV. Any woman suspected of being infected will be pointed at, isolated and gossiped about even though the majority concluded that a person with HIV needs support and *"talking to, to keep their mind steady"* and that fear of stigma and discrimination should not stop a woman from seeking health care.

"You will have a problem, if it was me I will not even go to the public tap to get water. A lot of women meet at the tap. I will be afraid to go out there. Secondly the village has two bantabas, you will not be able to go to any because whenever you approach people will say, do you know what is wrong with that person, she has HIV/AIDS. People like me don't keep a secret, the first person will tell another and that person will tell another and you will hear someone saying that she did not stick to her partner." **Woman from Fass Njaga Choi**

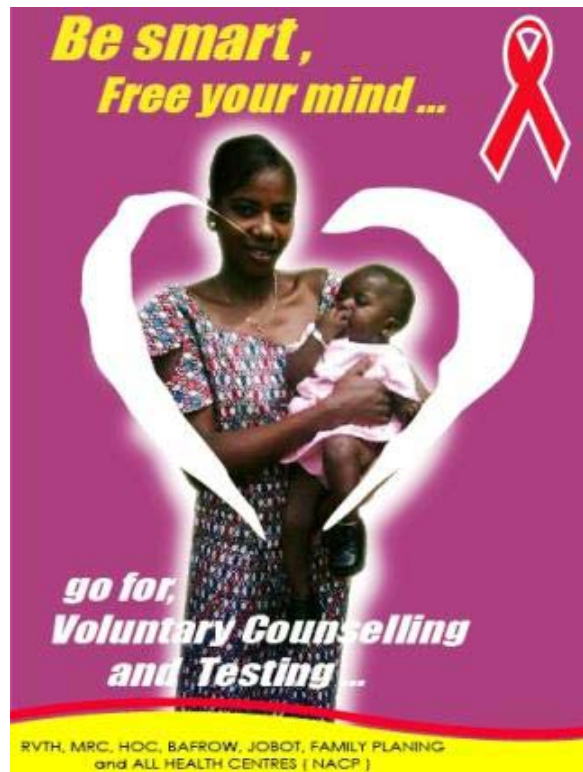
"Someone that has it will not be regarded as serious. People will think that she is playful and one can get it in so many ways. But once it shows in your body people will run away because they think that when they eat with you they will have it and that's not how it is transmitted." **Community leader, Farato**

According to a woman from Kanilai *"If you know that you are HIV positive you should go to the hospital before people start talking about you."*

Respondents were asked what type of support communities should give women who are HIV positive. The majority endorsed the fact that HIV positive women should not be abandoned and should be given psycho-social support. However some felt this would be unlikely and an HIV positive woman could only count on the support of her husband and close members of her family.

"The support that the people in the community should give you is that they should not run away from you. They should get you by their side and talk to you and give you hope. A woman with HIV should be encouraged and shown love and we should give whatever help we can so that her mind can be steady and be encouraged to seek health care." **Community leader, Sinchu Baliya**

Picture 5: VCT promotion poster



8.3.1.5. Perception of confidentiality issues related to improving linkage between community and facility level for shared care of pregnant women

It is suggested that to improve linkages between community and facility levels of shared care for pregnant women living with the virus, CHWs particularly TBAs should be informed about HIV positive women living in their catchment area. HIV positive women were asked their views about other health workers at the community and facility level knowing their status. The response was mixed. The majority trust only nurses working in health centres with information about their HIV status. Some felt that a health worker, community based or not should only be informed if he/she can be of help and support to them.

One mother from Bwiam noted *"If I disclose to her [the Community Health Worker from her village] may be she will not have any drug to help me so there is no need to tell her"*. Another woman from Essau explained, *"I could also tell the TBA because they offer help and assistance. But the issue is that you would tell them and the word would be spread all over the place."* Others were categorical in their reluctance to disclose to other health workers apart from those involved with the PTCT program, Faji Kunda woman *"in my opinion, the only one I can trust is my husband. Apart from my husband, I trust the nurse but not a community nurse in the community."* Essau mother *"I think it should be only the health worker in the facility because they know how to care for you and what medicine to give but the people in the community don't know, if they know they will spread the news."*

Focus group discussions: Women of child bearing age and community leaders interviewed held the view that CHWs should be aware of those HIV positive women who live in communities they serve. In addition to providing community sensitisation on HIV/AIDS, they revealed that CHWs should be able to support pregnant women living with HIV by helping them with medication, conducting home visits for counselling, and accompanying them to hospital where necessary.

For their part, CHWs suggested that they should be made aware of a pregnant woman's HIV status in order to be able to protect themselves and offer assistance. Although some of them advise women to take an HIV test, they complained that they are rarely informed of the outcome. Only one of the CHWs revealed that she was aware of an HIV positive woman living in her community, and for reasons unknown to her, she is no longer in contact with the patient. The patient herself had disclosed her status to her.

Community Health Workers indicated that some of the reasons why HIV positive pregnant women would not disclose to them was that in spite of the fact that they have been trained on the importance of client confidentiality, these women fear that they may disclose their status to others, as one CHW concluded *"in the end the whole community will be pointing fingers at them saying they are HIV positive"*, and that they were generally underrated.

"They believe that there is no point in telling someone who cannot help them. They have under rated us, if they come to us during labour we assist them. I do not see why they cannot tell us their other problems". "We should know their status because we are working together in the sense that we assist them in labour and without knowing their status will not stop us assisting them. We should know their status to protect ourselves but they never tell us." **Community Health Worker, Medina Serign Mass**

8.3.1.6. Uptake of ARV prophylaxis and reasons for low uptake

A key objective of the study was to find out about the reasons for the low uptake of ARV prophylaxis amongst pregnant women enrolled in the PTCT programme. Both mothers who took ARV and did not take ARV were selected from the PTCT registers and appointments made to interview them to explore amongst other things, the reasons for their actions. The plan was to interview 12 mothers each. However it was difficult to get consent to be interviewed particularly from women who did not take the drug and only 7 women were interviewed. At SJGH and HOC, some women promised to attend the interview but did not turn up; at HOC, one mother appeared at the clinic on the day of the interview but declined to be interviewed and at SJGH one mother ended an interview before completion.

Table 10: Interviews conducted amongst HIV positive women

RCH Clinic	Took ARV	Did not take ARV
Hands On Care	3	1
SJGH	3	2
Essau	4	0
Faji Kunda	2	4
TOTAL	12	7

According to women who took ant-retro viral prophylaxis, the motivation to do so was to improve their own health and in the majority of cases to protect their children from being infected with the virus. All the babies of mothers who took ARV prophylaxis also received their dose of ARV prophylaxis.

"Because I was told that I have the HIV virus and to protect my baby is to take the ARV drug, that's why I took it. It is to protect my baby because for me I am already infected and there is no cure.....that is why I went back to the nurse."
HIV positive mother from Bwiam

"The tablet is very beneficial because if I had not drank it, I have breastfed my child for 6 months and that is a long period so she could have been infected. But the tablet that I drank was circulating in my blood for the 6 months I was breastfeeding. You see, by the will of Allah my baby doesn't have the disease."
HIV positive mother from Brikama

Amongst the mothers who did not take the drug the reasons for not doing so were varied. One woman revealed that her reason for not taking it was because *"she did not believe in the drug"*. This individual also added that the nurses did not make it clear to her that both her and her child were to take the drug. For three women, it appears that their reasons for not taking the drug were for factors beyond their control. For one mother, when she went into labour, she was away from home and was unable to retrieve her ARV Tablet. One of the three mothers referred to another facility for their prophylaxis cited lack of financial resources as her reason for not going to collect her drug. Five out of the seven children whose mothers did not receive ARV prophylaxis received their dose of ARV. All mothers who did not receive ARV prophylaxis reported that if they became pregnant again they would take the drug.

"They say that this disease kills. So that is why people don't take the drug. There are a lot of people who are afraid to go to the clinic because if people see you there, they may think that you have this disease and to disclose is the problem even for us we have to force ourselves to come to the clinic." **HIV positive mother from Brikama**

"Many people believe that AIDS does not exist if you tell them they will tell you that you are joking. When some women are told at the clinic that they are HIV positive they are in a state of denial about the disease. And when they become pregnant they do not tell their husbands about the disease. They should invite us women who have the disease in the counselling rooms to counsel pregnant women with HIV about preventing PTCT." **HIV positive mother from Brikama**

Table 11: Reasons for non-uptake of ARV prophylaxis by HIV positive mothers

Reason for not taking drug?	Did baby receive ARV?	Would mother accept ARVs in future pregnancies?
Delivered before given drug (but would have taken it otherwise) (FK)	Yes	Yes
Mother from Faji Kunda, asked to go to Brikama for drug but delivered at Faji Kunda before collecting drug (FK)	No	Yes
Mother from Faji kunda told to go to Brikama to collect drug but did not go (FK)	No	Would take it in future Does not wish to have anymore children. Her child is very sick at the moment and mother regrets why she did not take the drug at the time. Would advice all HIV+ mothers to take drug.
Mother delivered before given drug. Had requested for it and told to wait for next appointment. (FK)	Yes	Yes
Did not believe the drug could help her (SJGH)	Yes	Does not wish to have any more children
Mix up with other patient of same name. Mother delivered before next appointment where she would have received the drug (SJGH)	Yes	Yes
Went into labour and did not have drug with her (HOC)	Yes	Yes

According to women who took ARV prophylaxis, lack of belief that AIDS exist, denial of your HIV status and a propagation of the notion that HIV kills, were probable reasons why a woman may not take the drug and be lost to follow-up.

Focus group discussions: Women of child bearing age and CHWs were generally more aware than any of the other groups about the existence of ARV prophylaxis. Those who were aware of the existence of ARV prophylaxis were well informed about its benefits. Men and community leaders had limited knowledge about the existence of ARV prophylaxis and some confused it with *Fansidar*. Women of childbearing age from Farato had never heard about ARV drugs for pregnant women.

“When you drink it, the disease is put in one place like someone who is in prison so the baby will not come in contact with it”. **Woman from Faji Kunda**

During the focus group discussions, further insight was gained for why some women may refuse themselves access to ARV prophylaxis. According to most women of childbearing age in particular, fear of disclosure was the principle reason why a woman would avoid health care and this was detrimental to her health and would allow the disease to continue to spread through generations.

“You know we used to hear that when a positive woman goes to the health facility and leaves the nurses will tell each other “did you see the client that just left, be careful of her, she is HIV positive”. That is why many individuals are afraid to go to the hospital. There are some who believe that AIDS does not exist and when they are diagnosed HIV positive they never return to the hospital again.” **Women from Kanilai**

Most of the CHWs interviewed had heard of the existence of ARV prophylaxis but none had actually seen the drug.

8.3.1.7. *Perceptions on infant feeding*

The National PTCT Policy recommends that all HIV positive mothers be counselled to enable them to make informed decisions and about infant feeding. This involves offering the option of exclusive breastfeeding with early weaning at 6 months or providing free formula milk for a period of 6 months. Additional nutrition supplements are given to lactating mothers and infants after stopping breastfeeding.

Individual interviews: There is evidence that HIV positive mothers are counselled on infant feeding options. Whilst some of them believe that an HIV positive mother should not breastfeed her child, all the mothers interviewed with one exception reported that they opted to breastfeed for 6 months and then wean the infant. One of the mothers who opted to breastfeed had weaned before 6 months because of a breast abscess. Whilst there appears to be stigma attached to a mother not breastfeeding her child, some of the interviews suggest that mothers are breastfeeding because they are told to do so by the PTCT nurses.

Picture 6: Mother and child



Some mothers interviewed had difficulty in weaning at 6 months because their husbands would not approve and getting his approval could result in the likelihood of disclosure.

"I was told to breastfeed for six months and stop, I replied that a woman cannot take the decision to stop breastfeeding at 6 months and that I would have to sit and discuss it with my husband. [has not disclosed to husband yet] if he agrees then I will stop at six months but if he refuses I will not have the powers. However I feel that a woman with HIV should not breastfeed at all".

HIV positive mother from Bwiam

"I was told that you can breastfeed for 6 months and stop and you will be provided with milk or you can choose not to breastfeed but give milk till the baby gets strong...when I delivered I did not give my child anything not even the breast...I asked someone to call the nurse for me and I asked her whether I can breastfeed or what will happen to the milk they told me about. But the nurse [name mentioned] told me to wash my breast and start breastfeeding till 6 months and then stop. Then she will give me milk. I said OK."

HIV positive mother from Essau

Only two of the mothers interviewed mentioned that mixed feeding was proscribed, the majority were not aware of the dangers associated with mixed feeding. Some interviews provided evidence that some mothers were actually practicing mixed feeding for fear of involuntarily disclosing their status to their spouses if seen to be feeding their infants with only formula.

"When I delivered, the nurse told me to exclusively breastfeed for six months and after six months I should not breastfeed but instead give milk. But sometimes when my spouse is in the house I use to give my breast, but if he is not around I use to prepare food and give her. You give milk, you should give more milk and stop the breast. I was breastfeeding and giving milk but I gave more milk".

Brikama mother

Focus group discussions: The general perception of most of the participants interviewed was that an HIV positive mother should not breastfeed her child. Some men even suggested that mother and child should be separated and that the government should support these mothers with replacement feeding.

Community leaders in Farato, were not aware of how a woman should feed her child and when the two options were proposed considered that *"to breastfeed the child to 6 months will be difficult so the best thing is to start from the beginning with substitutes like formula so the baby will get used to it.* They all agreed that since there was some possibility that a mother can transmit the virus to her child, then the best option was not to breastfeed at all.

Most men and women of childbearing age suggested that a woman who is not breastfeeding would be assumed to be HIV positive. However older women argued that breastfeeding was also discouraged for other conditions other than HIV/AIDS and that they would not automatically assume that a woman not breastfeeding was infected with HIV. A few women suggested that an HIV positive mother could get a non-infected relative to breastfeed her child.

Community health workers were well informed about the recommended feeding options for infant feeding in the context of HIV but none were aware of the dangers of mixed feeding. According to them, breastfeeding is discouraged for women with conditions other than HIV, so in their communities it would not be considered unusual for a woman not to breastfeed her newborn child. However, they would find a woman who looks well and unsick and not breastfeeding as is the

case with HIV, to be very unusual. As one TBA indicated, “*you look healthy and just deliver and do not breastfeed, there is no way people will not point fingers at you.*”

Suggestions to improve services:

Suggestions made by HIV positive women and other focus group participants to improve PTCT services:

- Strengthen counselling services and care and treatment component for women living with HIV.
- Broaden community sensitisation activities to address stigma and discrimination against women living with HIV and raise awareness on PTCT
- Mobilise communities in support of women living with HIV at the community level
- Active involvement of women living with HIV in PTCT service delivery, especially post-test counselling.

Based on the above observations the following strengths and weaknesses have been identified:

Strengths

- Many HIV positive women know that HIV could be transmitted from mother to child.
- Mothers commonly know the important PTCT preventive measures.
- HIV positive mothers recognised the importance of knowing their HIV status.
- Both mothers who took ARV prophylaxis and those who did not take ARV prophylaxis acknowledged the beneficial effects of the drug on reducing the risk of transmission of HIV from mother to child.
- Mothers reported no serious side effects of ARV prophylaxis in children.
- Mothers confirmed that counselling on how HIV is transmitted from mother to child and options for prevention of PTCT was practised at RCH clinics.
- Most mothers were aware of two infant feeding options for children under 6 months in the context of HIV.
- The room and environment for pre-test and post-test counselling was highly appreciated by most mothers.
- The behaviour and attitude of ANC staff was highly appreciated by almost all HIV positive mothers interviewed.

Weaknesses

- Few HIV positive mothers were aware of the dangers of mixed feeding.
- Mothers were generally reluctant to disclose their status and receive home visits.
- A significant number of mothers who wished to take ARV drugs were delivering before they had been supplied with the drug.
- The knowledge about the PTCT programme and the benefits of ARV prophylaxis was low amongst the general population.
- Few men and community leaders know about the modes of transmission of HIV from mother to child.
- Some mothers receive only one antenatal consultation before delivery.
- At Faji kunda, some mothers bring their infants for ARV prophylaxis later than the desired time.
- With the exception of those receiving care from HOC, HIV care and treatment from the other RCH clinics was considered inadequate by most of the HIV positive mothers.

- Services are more accessible to women than men and few partners of women who are found to be HIV positive are getting tested.
- Lack of awareness amongst HIV positive mothers of the dangers associated with mixed feeding.

8.3.2. Perception of Service providers on PTCT services

Information for this chapter originates from open-ended individual interviews with PTCT nurses, pharmacists, physicians and laboratory technicians and focus group discussions with PTCT team members and focuses on the provision of PTCT services and integrated mechanisms and procedures supporting them such as training and supervision.

8.3.2.1. Knowledge about the PTCT programme

All service providers interviewed were knowledgeable about the need for the PTCT programme and its major components. They were able to explicitly describe their roles as members of the PTCT team.

The typical PTCT team comprises of a PTCT nurse who is usually the officer-in-charge of the RCH clinic, care nurses (who are usually nurse midwives), lay counsellors (nurse attendants), a laboratory technician/assistant and a pharmacy technician/dispensing assistant. The PTCT nurse and care nurses usually conduct pre and post-test counselling and lay counsellors conduct the group counselling sessions. PTCT nurses were also familiar with the ARV prophylaxis regimen and safe practices to reduce risk of transmission during delivery.

All members of the PTCT team with the exception of the pharmacy technician at Faji Kunda had received training in PTCT, VCT. All PTCT nurses had been at their posts since the onset of the PTCT program.

At each RCH clinic visited the main counselling room was equipped with the following reference materials: STI treatment manual, Home Based Care manual, HIV treatment manual, National PTCT protocol, Counselling Checklist, and at least one of the following two posters on HIV and PTCT. One counselling room had exposed an information sheet on the dosage for ARV prophylaxis.

8.3.2.2. Perception of the quality of PTCT services

Interviews with PTCT staff revealed that most RCH clinics adhered to the procedure for service provision in the PTCT program. PTCT staff described their main responsibilities to include: 1) conducting pre and post test counselling, 2) conducting rapid HIV tests, reading and interpreting results, 3) registering PTCT recipients, 4) follow up of mothers who are identified HIV+ to include counselling on positive living, infant feeding options, family planning and partner management, 5) management of ARV drugs including storing, distributing and requisition, and 6) care and treatment of opportunistic infections.

PTCT staff felt that they were offering good quality PTCT services *“because we monitor mothers throughout pregnancy, and then we also monitor their appointments, if the mother misses an appointment and she allows us to visit her at home, we do that and then we send her a reminder or if we cannot visit her we remind her to come for your ARV. When the mother delivers we give the new baby too the ARV and if it is possible we visit her at home for post natal care in the first week after delivery as convenient and we advise her to come back to the facility if she has any problems during that period”*. The quality of PTCT services was also rated highly because beneficiaries were receiving services free of charge. The integration of PTCT services into routine

RCH services was seen as a factor that would assure sustainability in the long-term, when resources from GFATM ends.

A large part of PTCT staff time particularly PTCT nurse's time was spent providing counselling to mother's attending pre and post-test counselling sessions. At each RCH clinic 5-7 members would be trained in counselling but often there would be one counsellor during an ANC session providing pre- and post-test counselling to approximately 30-60 women. These sessions usually addressed information on HIV/AIDS, how the virus is transmitted, prevention of PTCT and informing clients about the services offered by the PTCT programme. Counsellors relied on a checklist of items to cover during counselling sessions and no additional audio visual aids and IEC support materials were available. Only HOC used PLWHA as counsellors.

"You have a lot of clients around waiting and you are alone in the counselling room working. Sometimes you have up to 30 or more a day and if you keep on talking you can tell them nonsense and this would affect the quality of care."
PTCT Nurse.

PTCT staff recognised that the targets for PTCT should be antenatal mothers, their partners, adolescents and youths. Antenatal mothers are the predominant group accepting VCT followed by patients with TB and STIs. PTCT staff considered men to be a strategic target for PTCT and VCT and lamented the fact that very few men participated in the programme because antenatal clinics were not male-friendly. Women who were invited for VCT were reluctant to inform their partners about couple counselling and HIV positive women were afraid of the consequences of disclosure.

"If you look at reproductive health, it covers both the girl, boy, the man, and the woman. But the ante-natal clinic is not man-friendly we have to accept that and as a result most of the partners shy away because you don't want to meet someone who recognises you."
PTCT Counsellor

"Just this morning I was telling the group of women I was counselling if they told their partners about couple counselling, very few said they had done so and most said that their partners had travelled. So I said to them, is it that all of you who come on Tuesday your husbands have travelled and they just laughed."
PTCT Counsellor

The general perception was that lack of male partner involvement in the programme and limited capacity to attract them was impeding efforts to follow-up HIV positive women and work effectively with them to reduce PTCT.

"Lack of disclosure makes it difficult for us, because we follow-up a woman who is positive but the husband does not know. You go to the compound you find the couple sitting down and you want to speak to the wife. The husband does not know you and you want to give information to the wife to come to the clinic. It is not easy. So this makes it very difficult for us sometimes to follow-up."
PTCT Social Worker.

Some PTCT staff argued that lack of awareness of the existence and dangers of HIV was not the problem just a general reluctance by men to be involved with antenatal issues. For example, at one health facility, men regular went for condom supplies and when health workers offered to counsel them they would reply, "if that [name of nurse] was around she will just give me my condoms and I go without talking too much."

“this programme is not PTCT but Father to mother to child, so the men should be sensitised to be involved. If the men do not know anything about the programme it will be difficult for the women to cope.” **PTCT Pharmacy Technician**

To alleviate this problem, nurses suggested that HIV positive women who wanted to disclose their status to their partners should be supported in doing so. PTCT nurses felt that with their knowledge about HIV and counselling skills, they were better equipped to do so in a manner that would elicit a supportive response from the partner. Men should also be encouraged to participate actively in matters related to pregnancy, such as accompanying their wives to antenatal clinics, and men who do so should be used as role models as part of peer education activities.

“I had a similar case, a lady said to me “I will call my husband and you tell him my status because I cannot tell him at home that I am HIV positive”. I invited the couple and they came here and I had to explain to the husband that his wife had asked me to disclose her status to him and they are still married. We tested the husband and he was negative but he is still giving support to the wife. They have no problem.” **PTCT Nurse**

It was repeatedly brought up during interviews that the follow-up and provision of primary care to HIV positive mothers enrolled in the programme were the weakest links in the PTCT program. According to PTCT staff, upon enrolment into the program, a mother would be asked whether she would accept home visits and where this was approved she would be visited *“to find out her problems, to monitor how she is coping with breastfeeding”* and where applicable *“why she is not coming for appointments”*. Nurses reported that the majority of mothers would not accept a home visit, and lack of adequate resources for transportation and communication hampered efforts to follow-up those mothers who wished to be visited at home. Follow-up activities were usually facilitated at PTCT staff’s own costs. PTCT staff also noted that postnatal HIV positive mothers rarely came to RCH clinics for PTCT services *“because they are not told what services exist for the mother after delivery.”*

Community sensitisation on the PTCT programme is rarely carried out and PTCT staff mentioned that they would like to be involved in more of this to ensure that communities are well informed and aware about issues related to PTCT. One PTCT team has initiated visits to schools within their catchment area to give talks on HIV/AIDS. The lack of involvement of CHWs particularly TBAs who play a major role in promoting infant feeding and ante natal care practices was highlighted. PTCT staff from HOC, claimed that in some areas of the country TBAs who were not full informed about infant feeding options in the context of HIV were putting pressure on newly delivered mothers to exclusive breastfeed which could influence the mother’s choice to breastfeed or not to breastfeed.

Few operational problems were noted during the interviews. In almost all of the sites, PTCT staff reported that ARV supplies were adequate and at one centre, the Pharmacy Technician reported that ARV prophylaxis was being wasted because of lack of demand. A raised awareness of the risk of exposure to HIV during delivery amongst health workers and increased use of medical supplies and practice of preventive measures to reduce transmission of virus was resulting in inadequate delivery kits and gloves at some health facilities. Some general frustrations by laboratory technicians relate to irregular electricity supplies, water shortages and frequent delays in receiving confirmatory test results due to reported shortages of test kits at RVTH.

PTCT staff reported that the concept of shared confidentiality was presenting an ethical dilemma for them. They acknowledged the importance of maintaining a patients HIV test results confidential and were aware of the policy of informing *“only those health workers who needed to know”*, such as counsellors and health and social service workers, in order to provide appropriate care. They added however, that they were confused about the confidentiality policy and the lack of clarity about who needed to know and who did not.

“These home based care people who are going to care for somebody who is HIV positive I think they need to know. But some people say they do not.”
PTCT Counsellor

8.3.2.3. Reasons for low uptake of ARV prophylaxis

PTCT nurses were asked to give reasons for the low uptake of ARV prophylaxis. A number of reasons were given. Firstly, fear of implications of disclosure from spouses and stigmatisation of HIV positive women at the community level. For this reason, HIV positive women did not want to be seen at the RCH clinic or being associated with a nurse known to be working in the field of HIV/AIDS and for this reason would reject home visits as well. Secondly, poverty *“coming here is a problem because they say that they cannot afford to come to clinic because of transportation problem.”* Thirdly, some women are living in denial, *“a woman denies her status in the counselling room she can accept that she is positive but she is in denial of her status if she leaves she will never come back for the services”* and fourthly, in some facilities Senegalese pregnant women attending one AN consultation who tested positive would give a local Gambian address and would not be traced on follow-up. Finally, the initial message that *“HIV Kills”* still rings loud in people’s ears. Some patient’s upon hearing that they are HIV positive just *“ran away”*.

“There is a song that traditional communicators sing that says “AIDS naa ta kan tuurubang” meaning AIDS has come to wipe us all out. AIDS has come to finish us, there is no cure. So when a layman comes for counselling what ever you tell him, it will not convince him because all he believes is that he if he has HIV he is finished.” **PTCT Social Worker**

According to PTCT staff, in cases where mother’s who present to health facilities for delivery and forget their ARV drug, vomit the drug on ingestion or have not yet been given their supply, the policy of keeping ARV drugs in the care of one person, the PTCT nurse, sometimes resulted in some mothers missing the opportunity to take the drug if the PTCT nurse was absent. At HOC, a solution has been identified, where midwives living close to the health facility also have access to ARV prophylaxis. Such situations are confounded where a mother has been given her ARV dose and she delivers in a non-PTCT facility and the baby risks missing the opportunity to take its dose of ARV. In such cases:

“so I personally believe that all the midwives in this country should know something about ARV prophylaxis in pregnancy.” **PTCT Nurse**

8.3.2.4. Motivating and de-motivating factors

The majority of staff interviewed were committed to do their jobs well and gained great satisfaction from providing care to HIV positive women and protecting their children from getting infected. According to a PTCT nurse she enjoyed *“supporting an HIV positive mother through the ante natal period, seeing that she delivers safely a live birth and the baby is protected, and after delivery the baby is tested and is found to be negative”*. Most of the staff were poorly motivated by the working conditions which included low salaries, limited opportunities for in-service training, lack of transport and communication facilities, irregular supervision, non-response to complaints related to working conditions and heavy workload.

"If you are on maternity duty, you have to cover the labour ward, the antenatal ward, the postnatal ward and sometimes the post caesarean section ward you alone from there you are in the counselling room it is very tiring. PTCT Nurse

In the early days of the programme, all PTCT staff received training in PTCT and VCT. New staff posted to PTCT centres have not been formally trained or sensitised on elements of the program. Staff argued that to keep abreast with evolving information and techniques for care and management of HIV/AIDS they would require on-going in service training particularly in HIV care and counselling of patients who needed psychological support.

PTCT staff were asked to describe their feelings about supervision activities. Staff admitted to receiving supervisory visits from staff of NACP during which registers and working conditions are reviewed and ARV stocks checked. Staff expressed that these visits were irregular and complained that constraints were largely not acted upon.

A responsibility allowance for DOSH staff working with the PTCT programme has been introduced. NGO staff involved with the PTCT programme do not receive this allowance. Rather than motivate staff as was intended, PTCT staff felt *"the money is not enough"* and that this responsibility allowance was affecting collaboration between PTCT staff and non-PTCT staff working at RCH clinics and affecting service delivery. Non-PTCT staff would sometimes refuse to offer PTCT services in the absence of PTCT staff.

"We are not happy about it because we are all working nurses though some are trained on PTCT and others are not but they should pay us all. The best thing is if our salaries could be increased that would be good. Those who are not paid feel bad and if they have patients with STIs they refer them to those that are paid and if the PTCT nurse is not there, they will refuse to attend to them and ask the patient to come another time." PTCT Counsellor

"An individual in a clinic receives D3000-00 and you want me to help you when I know that the D3000-00 when it comes is for you only. If you are not there no one does your job for you. This is what happened when [name] went away on leave, the PPTCT programme was nearly handicapped over there. PTCT Counsellor

PTCT staff suggested that responsibility allowances should be given to all RCH staff for they were in one way or other involved with the PTCT programme and that alternatives measures of staff motivation such as career development, salary revision, improved staff working conditions, need to be urgently put in place.

For their part, staff of HOC argued that as they support the DOSH with providing PTCT services at Brikama Health Centre, they should also be entitled to an allowance.

"PTCT is a national programme. The DOSH only thinks of us when they have students who want to come and visit us. That's the time you know we are recognised by DOSH, because their students are coming. But when it comes to providing benefits they always say to HOC, you are private." PTCT Staff

Suggestions to improve services

To improve PTCT services PTCT staff made the following proposals:

- Establishment of home-based care teams to provide support for patients at the community level.
- Use of Community Multidisciplinary facilitation teams to raise community awareness on PTCT.
- Community sensitisation to raise awareness amongst men of the dangers of STIs and the importance of partner management.
- Community sensitisation of community leaders and religious leaders on the importance of PTCT.
- Harmonisation and provision of positive messages on HIV/AIDS and PTCT.
- Revision of the shared confidentiality policy.
- Strengthen PLWHA support groups to implement income-generating activities for active Women Living with HIV/AIDs.
- Increase number of staff at RCH clinics.
- Training of all basic staff such as nurse attendants and public health officers at RCH clinics on PTCT.
- Use training incentives as a mechanism for motivating and retaining staff.
- Introduction of male peer support groups to promote male involvement in matters of pregnancy and discuss issues related to HIV/AIDs.
- Introduction of RCH/PTCT field days to highlight issues related to PTCT.
- Training and involvement of TBAs in follow-up of HIV infected mothers where acceptable.
- Upgrading of the HOC RCH clinic to a model clinic/learning centre for teaching in PTCT.

The abovementioned observations and characteristics of the PTCT service provision point to the following strengths and weaknesses of the service provision:

Strengths

- Training has been provided for all relevant PTCT staff members at health facility level
- PTCT staff are well informed about the content of the PTCT programme and strategy.
- High level of willingness among PTCT staff to work hard
- There is an interest and willingness amongst most staff to improve service delivery and quality of care.

Weakness

- Staff motivation is very low and working conditions unsatisfactory in relation to workload, salaries, career opportunities, and supervision.
- Lack of behaviour change materials for patient counselling and communication at facility level.
- RCH clinics are understaffed and staff workload results in frustration and poor quality service delivery.
- Out of all staff delivering RCH services, only staff seconded to the PTCT programme provide care for HIV positive women and are aware of their status.
- Availability of staff time per pregnant mother may not be sufficient to cater for proper counselling.
- Lack of tools and support materials for PTCT related behaviour change and counselling.
- Lack of adequate resources allocated to facilitate pro-active follow-up of HIV positive pregnant and lactating mothers.

- Some health facilities are not able to meet demand for medical supplies to reduce transmission of HIV during delivery.
- Supervision between NACP and health facility staff is insufficient in terms of quality and frequency.
- Community sensitisation activities not implemented to ensure coverage and acceptance of the program.
- Referral systems for follow-up care not very effective.

8.4. Proposed options for change

The following options for change as perceived by the review team are proposed on the basis of previously presented weaknesses and refer to programmatic adjustments at the health facility and community levels which could assist in improving the uptake of PTCT services and facilitate scaling up of the programme nationwide.

Facility level options include:

- To continue in-service training to increase number of trained staff and train replacements for those who leave or are transferred.
- To support the development of PTCT/BC support materials such as job aids and facility based and community based counselling cards.
- To integrate PTCT into the curriculum of medical and nursing schools to ensure that trainees receive adequate exposure to PTCT.
- To introduce supportive supervision that recognises staff achievements, builds skills and addresses the needs of service providers.
- To review ANC protocols to ensure that pregnant women and babies receive ARV prophylaxis on time.
- To refer women to ART centres that are accessible and acceptable to the patient, for comprehensive HIV care.
- To continue to promote partner management and couple counselling.
- To strengthen skills in infant feeding counselling, so that providers are able to help clients deal with challenging situations associated with infant feeding and ensure that providers and clients fully understand the dangers of mixed feeding.
- To target men directly for IEC on PTCT and infant feeding counselling.
- To support and empower women to communicate with their partners.
- To establish a learning centre for PTCT in the Gambia using the HOC clinic as a model.

Community level options include:

- To develop counselling expertise in community institutions outside the clinic setting.
- To expand health education and behaviour change activities outside the clinic setting.
- To strengthen community sensitisation about PTCT especially the probability and factors associated with HIV transmission from mother-to-child and how to live positively with HIV/AIDS.
- Consider the use of WLHWA as peer counsellors
- To maintain dialogue with the community so as to inform them on the purpose and availability of PTCT services.
- To explore the feasibility of training TBAs to oversee use of ARV prophylaxis.
- To explore innovative strategies for promoting male involvement in matters of pregnancy as a sustainable community norm.
- To encourage support and services to families and community groups who care for people/women living with HIV/AIDS.

9. Conclusion and Recommendations

HIV prevalence in the Gambia is relatively low. The PTCT programme aims to offer all HIV positive women a full care package during pregnancy, labour and after birth to control the further spread of HIV in The Gambia. Cost effective measures now exist to prevent PTCT.

In this study, the uptake of VCT uptakes was high. However, once women are diagnosed as being HIV positive, a significant number do not come back to the centre for other PTCT services and follow-up care and treatment. Consequently, the uptake of ARV prophylaxis amongst both HIV positive pregnant mothers and infants is very low compared to set national targets. The key reasons given for this are: (i) Low level of awareness at the community level of the existence of the programme and PTCT preventive measures; (ii) poor involvement of men in the reproductive health and PTCT related issues; (iii) fear of disclosure of HIV status especially to husbands, non-PTCT staff at health facilities and the community at large, and (iv) persistently high stigma levels at community level.

The following recommendations represent the review team's perceptions of changes that would need to be considered in order to ensure that implementation of the PTCT programme for pregnant women is strengthened with an emphasis on (i) institutional integration at both health facility and community levels, (ii) capacity building activities for health personnel are strengthened for improved delivery of PTCT programme at facility level and, (iii) there is an increase awareness of and demand for PTCT services at community level.

Six main entry points for action-oriented recommendations relate to (i) cross cutting issues, (ii) training, (iii) Behavior change and Communication/Information Education and Communication, (v) Voluntary testing and counseling, (vi) Provision of ARV prophylaxis and (vii) Infant feeding counseling.

Cross-cutting issues:

- Move away from a vertical programme approach to integrating PTCT into routine RCH services.
- To develop a system for motivating all members of the RCH team in both public and NGO facilities delivering PTCT services rather than just PTCT staff.
- To conduct supportive supervisory visits with central level RCH team.
- To develop and pilot a PTCT register that records the following information: whether ARV given to mother/date/place/type of delivery/weight/sex/outcome of birth/ARV uptake (baby), date counselled on infant feeding, option selected, frequency and quantity of replacement given up to 24 months.
- To set-up a registration system that facilitates and allows for tracking of HIV positive women and follow-up visits.
- To train primary data collectors in completion of registers and other monitoring tools.

Training:

- To develop a mechanism for providing professional development for RCH staff using alternative training approaches to workshops.
- To introduce PTCT into the pre-service training curriculum of all training institutions.
- To conduct on-the-job training on PTCT for all staff working in RCH clinics.

Behaviour Change Communication (BCC)/ Information Education & Communication (IEC):

- To develop a comprehensive multi level IEC/BCC strategy that uses different channels of communication to address stigma reduction issues, male involvement and positive living with HIV/AIDS.
- To develop PTCT/BCC support materials such as job aids and counselling materials to support VCT activities.

Voluntary testing and counselling:

- To explore the HOC model² for conducting VCT at outreach health posts.
- To explore the GFPA male centred communication strategy³ for increasing male involvement and uptake of VCT and PTCT related services.
- To use community based structures such as Multi Disciplinary Facilitation Teams and Divisional AIDS Committees to mobilise men for VCT services.
- To advocate for increased awareness and involvement in PTCT activities targeting opinion leaders.

Provision of ARV prophylaxis:

- To strengthen links between facility and community systems for delivering PTCT services in order to encourage HIV positive mothers to attend RCH clinics and ensure that those mothers who deliver at home take their ARV prophylaxis.
- To review ARV protocols and distribution strategy to provide ARV prophylaxis at first communication of positive result.
- To extend counselling sessions to address the needs of the HIV positive mother.
- To adopt an RCH approach to all deliveries (all team members involved in delivery of PTCT services including Community Health Workers, should be aware of HIV status of pregnant women).
- To introduce a system of assessment of all newly diagnosed HIV positive pregnant women by a senior care nurse or physician for treatment and care.

Infant feeding counselling:

- To review guidance on infant feeding practices.
- To strengthen skills in infant feeding counselling including emphasising the dangers associated with mixed feeding.

² With this model, pregnant mother's attending antenatal clinics at an outreach post who wish to be tested for HIV are pre-test counselled and tested on-site instead of being referred to the base clinic for testing. The test results are given to the mother during the next clinic session.

³ This is a strategy for increasing male involvement in reproductive health issues. It uses a number of approaches such as advocacy towards male opinions leaders, training of religious leaders and other decision makers and IEC/BCC strategies targeting men, to raise awareness on RH issues such as family planning, safe motherhood, HIV/AIDS and STIs.

10. Annexes

Annex I:	Terms of Reference
Annex II:	Evaluation team members
Annex III:	List of places visited
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Annex I : Terms of Reference

Background

The Gambia is defined as a country with low HIV prevalence with HIV-1 as the predominant virus driving the epidemic. In 2004, the estimated HIV prevalence rate was 2.1% for HIV 1 and 0.9% for HIV 2. In 2005, the reported HIV prevalence showed a declining trend with HIV-1 estimated at 1.1% and HIV-2 at 0.6% (DOSH Sentinel Surveillance Bulletin, 2006). However it is too early to state whether this declining trend will be sustained. The change in reported prevalence rates was complex. In some sites the reduction was minimal, whereas in others it was impressive and in other sites no changes were recorded. Furthermore, unlike previous reports where the highest rates were found in rural settlements, for the first time, in 2005, urban settlements, notably Brikama, had the highest recorded prevalence rates.

The PTCT programme, from the outset, was set up as part of the Reproductive Child Health (RCH) Unit. A National Taskforce was set up in 2001. Since then a National Policy and protocols have been developed to guide PTCT programming. In April 2004, PTCT services were first delivered as part of the Accelerated Rapid Implementation (ARI) strategy as part of the implementation of the World Bank funded HIV/AIDS Rapid Response Project (HARRP). During the ARI, 3 new PTCT centres were set up in Brikama, Sulayman Junkung Hospital and Fajjikunda. A total of 554 pregnant women received pre-test counselling of which just under 70% received post-test counselling. Of the 7 HIV positive pregnant women who delivered during this period, 6 received ARV prophylaxis along with their infants.

With the advent of more affordable anti-retroviral (ARV) drugs, and with additional funding available under the GFATM, the Government, in 2003, successfully applied for and secured funds to address a major programming gap, the provision of comprehensive treatment and care programmes for PLWHA. The GFATM funded HIV/AIDS project was approved in May 2004. Funding and implementation for the five-year project commenced late 2004.

The GFATM funded HIV/AIDS Project seeks to complement existing prevention programmes with high quality treatment and care programmes for PLWHA. It is hoped that the implementation of this project would prolong the lives of PLWHA so as to mitigate the devastating effect of the epidemic on the socio-economic development goals of the country and increase acceptance of the disease as a chronic illness that can be treated and thereby reduce stigma. The main emphasis of the project is on expanding access to the range of HIV/AIDS related services at facility and community level, specifically Voluntary Counselling and Testing (VCT), prevention of Parent-To-Child Transmission (PTCT) of HIV/AIDS, prevention and treatment of Opportunistic Infections (OI), access to Anti-retroviral Therapy (ART) and community based care for PLWHA.

The goal of the GFATM funded HIV/AIDS Project is to “provide the highest standard of available treatment, care and support to PLWHA, which is accessible and affordable in order to live in dignity and maintain a positive and productive life free from discrimination and stigma. This in turn will lead to a favourable environment that will empower people living with HIV/AIDS to contribute to development and ensure appropriate prevention of HIV infection”.

One of 6 objectives being implemented, namely, “to provide access to the prevention of Parent-To-Child Transmission (PTCT) for 80% of pregnant mothers in the Gambia by 2008”, focuses on integrating PTCT services into existing RCH clinics nationwide to reduce HIV perinatal transmission and to address the needs of eligible women for care through access to ARV Therapy”.

CIAM is assisting the NAS to monitor the activities of Sub-recipients and part of its responsibilities includes undertaking operational research studies to address emerging concerns.

Component to be evaluated.

In this review exercise, the PTCT programme will be reviewed as follows:

- *Capacity of the health system and health personnel to support the delivery of PTCT services.*
- *The health information system for monitoring the delivery of PTCT services and*
- *The provision of PTCT services to pregnant women attending antenatal clinics*

Justification

This review is important for several reasons. Currently, there are 12 facilities in the public and NGO sectors accredited to deliver PTCT services with the majority located in the Western Division.

Since the commencement of the implementation of the GFTAM grant in 2004 the delivery of PTCT, based on monitoring reports, has faced several challenges such as varying uptake of VCT services; low uptake of anti-retroviral drug by pregnant women and difficulties in community follow up HIV positive women due to high levels of stigma. Other related issues hampering programme effectiveness include low staffing levels and the absence of a strong communication strategy on PTCT.

As a consequence, the outcome/ coverage levels of the PTCT programme as assessed by the number of HIV infected women receiving adequate course of ARV prophylaxis to reduce the risk of PTCT has been failing to meet national targets.

At the end of March 2006, the cumulative total number of HIV positive women who had received ARV prophylaxis stood at 174 compared with a target of 250.

As a prerequisite to improving the efficiency and effectiveness of the scaling up process for the PTCT intervention it would be necessary to review the programme taking into consideration existing relevant documents, rigorously explore underlying factors that influence the uptake of the services such as awareness of the benefits of the programme and user perception of the services. A sound understanding of these is critical for the development of sustainable strategies that are likely to have an impact on reducing perinatal HIV transmission.

In view of this the NAS Project Management Team requested CIAM, the Monitoring Unit, to undertake a review of the PTCT programme to assess coverage and determine underlying factors for the low uptake of PTCT services and identify strategies to improve uptake of these services.

Objective

To review the PTCT programme in order to: (i) provide evidence based data to guide policy decisions; (ii) consolidate the current implementation process nationwide and (iii) inform the process of developing a full proposal to the Global Fund Round 6.

Scope of work

The review will cover the PTCT programme. Both quality and quantity of services will be addressed from the perspective of providers and users. Emphasis will be on *results, efficiency, and effectiveness* of the PTCT programme. This includes an assessment of a) service delivery

processes (efficiency), b) the extent to which the GFTAM objective has been achieved (effectiveness); c) the knowledge and perceptions of service providers and users and d) the level of service integration with the RCH services. More specifically, the review is expected to address the following

A. Capacity of the health system and health personnel to support the delivery of PTCT services.

- Identify the strengths and weaknesses of the existing draft National Policy and protocols, SOPs and propose ways to revise and strengthen them
- Assess the strengths and weaknesses of the institutional and structural framework for the coordination and implementation of PTCT services, centrally and at divisional and facility levels.
- Assess the quality and adequacy of supervision and monitoring of the PTCT programme in facilities and institutions.

B The health information system for monitoring the delivery of PTCT services

- Assess the documentation system for the recording of issues related to the implementation of the PTCT programme at central, divisional and facility levels and assess the strengths and weakness of linkages with the current Health Information System for HIV/AIDS.

C. The provision of PTCT services to pregnant women attending antenatal clinics

- Assess availability of all components of PTCT service delivery in health facilities.
- Assess the level of community awareness and perceptions of the PTCT programme
- Assess the current status of PTCT uptake in order to identify ways to improve uptake in line with national guidelines and targets set under the Global Fund.
- Assess the effectiveness of the implementation of the PTCT programme on beneficiaries.
- Assess existing partners and identify potential partners and opportunities for more effective delivery of the PTCT programme at community level.

Output

A detailed report with recommendations related to:

1. Strengthening of the implementation of the PTCT programme for pregnant women with emphasis on health systems capacity, institutional integration and long-term sustainability of supplies and inputs
2. Strengthening of capacity building activities for health personnel for improved delivery of PTCT programme at facility level
3. Increasing awareness of and demand for PTCT services at community level

Review approach

The review will be conducted in 2 phases:

- Desk review
- Quantitative data collection,
- Collection of qualitative primary data.

Desk Review

The research team will review available documents that have some bearing on policy issues or programming in relation to the PTCT programme.

Quantitative data collection

Data will cover the period from April 2004, from the onset of implementation of the PTCT programme in The Gambia up to the end of March 2006. This will make it possible to assess programme performance given that facilities started the programme at different times during this period. Relevant data to be collected and their sources are:

- From Antenatal Register: ANC attendance
- From PTCT, Clinical and Lab Registers: pregnant women pre-test counselled, acceptance of HIV testing, pregnant women returning for post test counselling, HIV prevalence amongst cohort of women tested, mother-child pairs receiving ARV and infants tested for HIV at 18 months

Quantitative data collection

Qualitative data about the programme and its performance. Such data will therefore be collected as primary data as part of the review in order *to inform the review process and optimise the quality and usefulness of its findings*. Target groups for the data collection are service providers (i.e. RCH workers at ANC clinics), users (i.e. pregnant women and mothers to newborn infants) and other stakeholders at community level (men, grandmothers and community based workers). Various qualitative methods (i.e. focus group discussions as well as structured, semi-structured and in-depth interviews) will be applied depending on target group and focus. Targeted service providers will be addressed at health facility level whereas targeted users and community stakeholders will be addressed in exit-interviews or at community level.

Action Plan

Time Line: May- October 2006

	2006																								
	May				Jun				Jul				Aug				Sep				Oct				
	1	2	3	4	1	2	3	4	1	2	3	4	1	2	3	4	1	2	3	4	1	2	3	4	
Preparatory meetings of Reference Group																									
Submit for Ethical approval																									
Finalise TORS and survey tools																									
Recruit data collectors																									
Training of data collectors and piloting of tools																									
Printing of survey tools																									
Conduct central level and quantitative survey																									
Data entry and cleaning of data for quantitative study																									
Analyse survey findings																									
Conduct qualitative study																									
Analyse qualitative study																									
Preliminary report on survey.)																									
Share report with Reference Group																									
Debriefing meeting with Reference Group																									
Finalise & submit report to NAS																									

Documents available

- National Health Policy
- National Reproductive Health Policy
- National Reproductive Health Strategic Plan, 2002-2007, 2003
- National HIV Policy
- National PTCT Policy, 2002-2007 DOSH, 2003
- National PTCT Protocols, 2002-2007 DOSH, 2003
- National PTCT SOPS
- PTCT Baseline Study

Annex II: Composition of Evaluation Team

Quantitative Team

- Samuel Anya, School of Medicine & Allied Health Sciences, University of The Gambia
- Dawda Joof, M & E Specialist, CIAM
- Gambia Sowe, Field Worker, CIAM
- Ebrima Sonko, Field Worker, CIAM
- Baba Galleh Jallow, SRN Nurse

Qualitative Team

- Kinday Samba, Social Scientist, CIAM
- Awa Sagnia, Independent PTCT trainer
- Nyima Camara, PTCT Nurse, HOC
- Nyima Sanyang, PTCT Nurse, Sulayman Junkung General Hospital
- Lamin Gibba, Field Assistant, MRC Malaria Programme

Annex III: List of places visited

Quantitative study	Qualitative Study	
<u>Health facilities</u>	<u>Health facilities</u>	<u>Communities</u>
1. Sulayman Junkung General Hospital	1. Hands on Care Clinic	Farato, Pirang
2. Royal Victoria Teaching Hospital	2. Sulayman Junkung General Hospital	Bondali, Sangajor, Kanilai
3. Farafenni APRC Hospital	3. Essau Health Centre	Kanuma, Medina Serign Mass, Fass Njaga Choi
4. Faji Kunda Health Centre	4. Faji Kunda Health Centre	Sinchu Baliya, Faji Kunda
5. Brikama Health Centre		
6. Essau Health Centre		
7. Soma Health Centre		
8. Bansang Health Centre		
9. Basse Health Centre		
10. Hands on Care Clinic		
11. GFPA Newfoyl Clinic		

Annex IV: Documents Available

- National Policy Guidelines for the Reduction of Parent-to-Child Transmission in The Gambia, DOSH, January 2004
- National Programme for the Prevention of Parent-to-Child-Transmission of HIV/AIDS, 2003-2008, DOSH, 2003
- National PTCT Protocol, DOSH, 2002

Annex V: Exit interview questionnaire

Individual Exit Interview guide for pregnant women attending the antenatal clinic:

Introduction to the evaluation mission [*The Interviewer*]

Greet the woman

Tell the woman your name and ask her for her name (Don't write the name). [If she seems uncomfortable, then ask at the end of the survey].

We are interested in how you felt about your just concluded clinic visit. The Department of Health is working hard to improve services at this centre. All the answers you give will be confidential. We hope to use all the answers you give to improve the health services in The Gambia.

We want to interview you, but it is not compulsory, we would like to have a little time to interview you because your contribution will be valuable. Can we interview you?

1 Yes []

0 No []

Q	BIOSOCIAL DATA	FILL OR TICK (as appropriate)
1.	What is your age? (cross check with ID card or Antenatal card)	years
2.	How many pregnancies have you had, including this one? (If this is the first pregnancy, write 1)	
3.	What is your marital status?	1 Single [] 2 Married [] 3 Other [] specify _____
4.	Where do you live?	
5.	What form of transportation did you use to get to this clinic today?	1 Walking [] 2 Car [] 3 Bus [] 4 Horse, donkey or other animal [] 5 Bicycle [] 6 Motorcycle [] 7 Other [] specify _____
6.	How long did it take you to get to this clinic today? Enter response in minutes (for example enter 1 hour 30 minutes as 90 minutes)	minutes
CLINIC VISIT TODAY		
7.	Is this your first visit to this clinic in this pregnancy?	1 Yes [] 0 No []
8.	Have you visited any other antenatal clinic in this pregnancy?	1 Yes [] specify _____ 0 No []
9.	Did you participate in any health talk today?	1 Yes [] 0 No [] skip to 11

10.	What were the topics of the talk? <i>Do not prompt [tick all the boxes that apply]</i>	Malaria [] HIV/AIDS [] PTCT [] Bed nets [] Anaemia [] Breastfeeding [] Tetanus toxoid [] Other [specify]
PRE-TEST COUNSELLING		
11.	Have you ever been offered individual pre-test counselling for HIV/AIDS?	1 Yes [] 0 No [] <i>skip to 23</i>
12.	If yes, when were you offered individual pre-test counselling? <i>Tick all that apply</i>	1 During this pregnancy [] 2 During a previous pregnancy []
13.	Have you been offered pre-test counselling during this pregnancy?	1 Yes, today [] 2 Yes, some other day [] 0 No [] <i>go to 23</i>
14.	If yes, did you receive pre-test counselling?	1 Yes <i>skip to 16</i> 0 No [] <i>go to 15</i>
15.	If no, why didn't you receive pre-test counselling? <i>enter response and skip to 23</i>	
16.	How long did you have to wait for the pre-test counselling? <i>Enter response in minutes (for example enter 1 hour 30 minutes as 90 minutes)</i>	minutes
17.	How much time did you spend with the counsellor?	minutes
18.	Did you have the opportunity to ask questions?	1 Yes [] 0 No []
19.	If yes, were you satisfied with the answers?	1 Yes [] 0 No []
HIV TEST		
20.	Did you take a HIV blood test?	1 Yes [] 0 No [] <i>skip to 22</i>
21.	If yes, why did you agree to take the test? <i>enter response and skip to 23</i>	
22.	Why didn't you accept to take the test?	
23.	What would convince you to take a HIV test in the future?	
24.	Did you need to have anyone's consent before taking the HIV blood test?	1 Yes [] from whom? _____ 0 No []
25.	What does a pregnant woman gain by knowing her HIV status?	
Number of Antenatal Visits		
26.	How many times have you attended the antenatal clinic? <i>Get this information from the antenatal card</i>	
Knowledge of PTCT		
27.	Can an unborn baby get HIV?	1 Yes [] 0 No []
28.	If yes, how?	1 From mother [] 2 Other [], specify _____

29.	Can a newborn baby get HIV?	1 Yes [] 0 No []
30.	If yes, how?	1 From breast milk [] 2 Other [], specify_____
31.	Can anything be done to prevent the unborn baby from getting HIV?	1 Yes [] 0 No []
32.	If yes, what can be done?	1 take drugs [] 2 other [], specify_____
33.	When should drugs be taken to prevent unborn baby from getting HIV?	1 During labour [] 2 Other [], specify_____
34.	Can anything be done to prevent a newborn baby from getting HIV?	1 Yes [] 0 No []
35.	If yes, what can be done	1 give newborn baby drugs [] 2 avoid breastfeeding 3 other [],specify_____

Annex VI: Quantitative data from health registers

Cumulative Data from VCT Registers (Jan 2004 – Dec 2004)

	New anc clients	Clients who received pre-test counselling	accepted HIV test ie consented to testt	clients with recorded test results (lab register)	Clients who received post test counselling	HIV-1 positive	HIV-2 positive	HIV-1&2 positive	HIV positive (type not specified)
Gfpa	475	459	428	391	326	10	1	1	0
Brikama	2816	2332	2120	1787	1566	23	10	12	36
RVTH	0	0	0	0	0	0	0	0	0
SJGH	777	565	525	524	479	17	11	4	2
Soma	0	0	0	0	0	0	0	0	0
Bansang	0	0	0	0	0	0	0	0	0
Basse	0	0	0	0	0	0	0	0	0
FF	0	0	0	0	0	0	0	0	0
Essau	0	0	0	0	0	0	0	0	0
HOC	0	64	56	55	7	27	10	6	2
Faji Kunda	3830	3513	3045	2966	2894	17	7	6	45
Total	7898	6933	6174	5723	5272	94	39	29	85

Cumulative Data from VCT Registers (Jan 2005 – Dec 2005)

	New anc clients	Clients who received pre-test counselling	accepted HIV test ie consented to testt	clients with recorded test results (lab register)	Clients who received post test counselling	HIV-1 positive	HIV-2 positive	HIV-1&2 positive	HIV positive (type not specified)
Gfpa	1003	765	494	382	348	8	2	1	1
Brikama	3380	2065	1876	1609	1595	27	8	11	17
RVTH	0	223	198	187	54	3	3	2	1
SJGH	816	567	465	475	418	27	3	6	0
Soma	497	391	357	320	282	7	1	1	1
Bansang	461	344	269	260	163	4	0	1	0
Basse	523	350	257	248	171	1	11	3	0
FF	809	798	541	519	299	9	3	1	0
Essau	1091	453	403	343	319	5	3	0	1
HOC	0	815	741	748	132	24	10	11	6
Faji Kunda	4143	3953	3644	3603	3493	57	7	4	17
Total	12723	10724	9245	8694	7274	172	49	41	44

Cumulative Data from VCT Registers (Jan 2006 – May 2006)

	New anc clients	Clients who received pre-test counselling	accepted HIV test ie consented to test	clients with recorded test results (lab register)	Clients who received post test counselling	HIV-1 positive	HIV-2 positive	HIV-1&2 positive	HIV positive (type not specified)
GFP A	522	514	338	333	299	2	3	2	0
Brikama	1226	494	453	383	377	6	0	2	4
RVTH	0	229	188	175	164	4	0	0	2
SJGH	282	203	180	179	176	9	5	2	0
Soma	266	208	188	160	136	4	1	0	0
Bansang	0	373	286	282	197	4	0	3	0
Basse	352	125	85	84	35	0	3	1	0
FF	578	538	510	493	406	4	3	3	0
Essau	523	333	295	239	214	3	0	2	0
HOC	0	579	368	352	262	10	2	4	3
MRC	0	0	0	0	0	0	0	0	0
Faji Kunda	1364	1175	1088	1084	1049	18	10	3	4
Total	5113	4771	3979	3764	3315	64	27	22	13

Data from PTCT registers

Cumulative data from PTCT registers (Jan 2004 – Dec 2004)

	HIV positive women (from VCT Register) ¹	Given nevirapine	Given AZT	NVP/AZT	Confirmed delivery	Infants of HIV positive mothers	Infant who received ARV prophylaxis	Matched pair that had ARV prophylaxis	Mothers given replacement feeds	Infants tested at 18 months
GFP A	12	3	0	0	4	4	2	0	2	0
Brikama	81	0	0	0	0	0	0	0	0	0
RVTH	0	0	0	0	0	0	0	0	0	0
SJGH	34	16	6	4	25	10	5	3	0	0
Soma	0	0	0	0	0	0	0	0	0	0
Bansang	0	0	0	0	0	0	0	0	0	0
Basse	0	0	0	0	0	0	0	0	0	0
FF	0	0	0	0	0	0	0	0	0	0
Essau	0	0	0	0	0	0	0			0
HOC	45	15	1	1	18	17	16	16	16	0
Faji Kunda	75	6	0	0	7	6	5	5	0	0
Total	247	40	7	5	54	37	28	24	18	0

¹ This number of HIV positive pregnant women was extracted from the VCT Register because the PTCT Register did not account for all HIV positive pregnant women.

Cumulative data from PTCT registers (Jan 2005 – Dec 2005)

	HIV positive women (from VCT Register) ¹	Given nevirapine	Given AZT	NVP/AZT	Confirmed delivery	Infants of HIV positive mothers	Infant who received ARV prophylaxis	Matched pair that had ARV prophylaxis	Mothers given replacement feeds	Infants tested at 18 months
GfPA	12	2	0	0	2	3	1	1	1	0
Brikama	63	0	0	0	0	0	0	0	0	0
RVTH	9	2	0	0	2	2	2	2	0	0
SJGH	36	22	4	4	30	16	13	13	0	0
Soma	10	5	0	0	0	0	0	0	0	0
Bansang	5	1	0	0	1	1	1	1	0	0
Basse	15	3	5	1	3	3	2	2	0	0
FF	13	0	4	0	7	5	1	0	0	0
Essau	9	4	1	1	8	7	5	3	2	0
HOC	51	13	5	0	17	18	18	18	19	11
MRC	5 ²	3	0	0	0	8	7	-	6	0
Faji Kunda	85	16	0	0	12	12	9	9	0	0
Total	309	71	19	6	82	75	59	49	28	11

¹ This number of HIV positive pregnant women was extracted from the VCT Register because the PTCT Register did not account for all HIV positive pregnant women.

² MRC does not provide antenatal VCT services.

Cumulative data from PTCT registers (Jan 2006 – May 2006)

	HIV positive women (from VCT Register) ¹	Given nevirapine	Given AZT	NVP/AZT	Confirmed delivery	Infants of HIV positive mothers	Infant who received ARV prophylaxis	Matched pair that had ARV prophylaxis	Mothers given replacement feeds	Infants tested at 18 months
GFFA	7	0	0	0	0	0	0	0	8	0
Brikama	12	0	0	0	0	0	0	0	0	0
RVTH	6	2	0	0	1	1	1	1	0	0
SJGH	16	6	2	2	9	5	5	5	1	0
Soma	5	3	0	0	2	2	2	2	0	0
Bansang	7	0	0	0	1	1	0	0	1	0
Basse	4	0	1	1	1	0	0	0	0	0
FF	10	0	4	0	4	2	0	0	0	0
Essau	5	2	0	1	3	3	3	0	0	0
HOC	19	5	1	0	6	5	5	5	6	9
MRC	11 ²	1	1	0	0	3	0	0	1	0
Faji Kunda	35	0	0	0	0	0	0	0	0	0
Total	127	19	9	4	27	22	16	13	17	9

¹ This number of HIV positive pregnant women was extracted from the VCT Register because the PTCT Register did not account for all HIV positive pregnant women.

² MRC does not provide antenatal VCT services.

Annex VII: Qualitative data collection guides

Individual Interview guides:

A. HIV positive women who received ARV prophylaxis

1. What do you know about the PTCT program offered at this clinic?

- a) What do you know about how HIV is transmitted?
- b) What do you know about how HIV transmission can be prevented?
- c) I heard that some people believe that if a woman has the HIV virus, and becomes pregnant, her baby will also be born with the virus. What is your feeling about this?
- d) Is there anything a pregnant woman can do to prevent her child from getting the HIV virus?
- e) How do you feel your baby should be fed?
 - i) What information have you received so far on how your baby should be fed?
 - ii) What do you feel about this information?
- 2) What happens when you come to this clinic?
 - a) What do you like about the services offered at this centre? And Why?
 - b) What are you unhappy about? Why?
 - c) What would you like to be done additionally/more/better?
- 3) How do you feel about pregnant women taking an HIV test?
 - a) What do you think are the benefits of a pregnant woman knowing her HIV status?
 - b) What motivated you to take this test?
 - c) I understand that some women have to get their husband's approval before taking an HIV test? What do you feel about this?
- 4) What happened during your talk with the nurse *before* you went to the lab? What information were you given?
 - a) What did you talk about?
 - b) What did you understand about what the nurse/counsellor talked to you about?
 - c) Were things made clear to you?
 - d) How satisfied were you with the information you were given?
 - e) How did you feel about *how* the nurse talked with you?
 - f) How satisfied were you with the information you were given?
 - g) How satisfied were you with the room and area where the talk took place?
 - h) Is there anything else you would like to tell us about your session with the nurse/counsellor?
- 5) What happened during the talk with the nurse *after* you came from the lab? What information were you given? How well do you think the counsellor dealt with your concerns?
 - a) What did you talk about?
 - b) What did you understand about what the nurse/counsellor talked to you about?
 - c) Were things made clear for you?
 - d) How soon after you came from the lab did you receive your results?
 - e) If results were not received the same day, when did you receive them and what motivated you to come back for them?
 - f) How did you feel about your results?
 - g) How did you feel about *how* the nurse talked with you?

- h) Is there anything else you would like to tell us about your session with the nurse/counsellor?
- 6) What do you know about the drugs that pregnant women are given to prevent transmission of the HIV virus to their baby?
 - a) What do you feel are the benefits of taking this drug?
 - b) In this pregnancy, were you given any drug to prevent you transmitting the virus to your baby?
 - c) What did you do with the drug? (Make sure you get information on when the woman took the drug and where)
 - d) What motivated you to take this ARV drug?
 - e) I have heard that some HIV+ women do not come back to take there ARV drugs? Why do you think this is so?
 - f) What effect do you feel this drug has had on you and your infant?
 - g) Has you baby taken an ARV drug? What motivated you to get your baby to take this drug?
- 7) What is your opinion about sharing information on your HIV status?
 - a) Who have you spoken to about your status and what was their reaction?
 - b) Has your partner taken an HIV test? What motivated him to take this test?
 - c) With whom would you feel comfortable talking to about your HIV status and why?
 - d) Apart from the counsellor, how would you feel about other health workers at the community and facility level knowing your HIV status?
 - e) How do you think people in the community feel about pregnant women who are HIV+?
- 8) What are the major problems you are facing as a mother living with HIV?
 - a) How has the program addressed any of these needs?
 - b) What do you feel health workers should do to address these needs?
 - c) What suggestions do you have for the program in assisting mothers in the future?

B. HIV positive women who did not take ARV prophylaxis

1. What do you know about the PTCT program offered at this clinic?
 - a) What do you know about how HIV is transmitted?
 - b) What do you know about how HIV transmission can be prevented?
 - c) I heard that some people believe that if a woman has the HIV virus, and becomes pregnant, her baby will also be born with the virus. What is your feeling about this?
 - d) Is there anything a pregnant can woman do to prevent her child from getting the HIV virus?
 - e) How do you feel your baby should be fed?
 - i) What information have you received so far on how your baby should be fed?
 - ii) What do you feel about this information?
2. What happens when you come to this centre?
 - a) What do you like about the services offered at this centre? And Why?
 - b) What are you unhappy about? Why?
 - c) What would you like to be done additionally/more/better?
3. How do you feel about pregnant women taking an HIV test?

- a) What do you think are the benefits of a pregnant woman knowing her HIV status?
 - b) What motivated you to take this test?
 - c) I understand that some women have to get their husband's approval before taking and HIV test? What do you feel about this?
4. What happened during your talk with the nurse before you went to the lab? What information were you given?
 - a) What did you talk about?
 - b) What did you understand about what the nurse/counsellor talked to you about?
 - c) Were things made clear to you?
 - d) How satisfied were you with the information you were given?
 - e) How did you feel about *how* the nurse talked with you?
 - f) How satisfied were you with the information you were given?
 - g) How satisfied were you with the room and area where the talk took place?
 - h) Is there anything else you would like to tell us about your session with the nurse/counsellor?
 5. What happened during the talk with the nurse after you came from the lab? What information were you given? How well do you think the counsellor dealt with your concerns?
 - a) What did you talk about?
 - b) What did you understand about what the nurse/counsellor talked to you about?
 - c) Were things made clear for you?
 - d) How soon after you came from the lab did you receive your results?
 - e) If results were not received the same day, when did you receive them and what motivated you to come back for them?
 - f) How did you feel about your results?
 - g) How did you feel about *how* the nurse talked with you?
 - h) Is there anything else you would like to tell us about your session with the nurse/counsellor?
 6. What do you know about the drugs that pregnant women are given to prevent transmission of the HIV virus to their baby?
 - a) What do you feel are the benefits of taking this drug?
 - b) In this pregnancy, did the nurse talk to you about this drug or offer you any drug to prevent you transmitting the virus to your baby?
 - c) What did you do with the drug? Why did you not go back to take the drug? (Make sure you get information on why the woman did not take the drug)
 - d) Is there anything you feel can be done to convince you, make it easy for you to take this drug in the future?
 - e) Do you know of any women that have taken this drug? What do you think motivated them to take this drug?
 7. What is your opinion about sharing information on your HIV status?
 - a) Who have you spoken to about your status and what was their reaction?
 - b) Has your partner taken an HIV test? What motivated him to take this test?
 - c) With whom would you feel comfortable talking to about your HIV status and why?
 - d) Apart from the counsellor, how would you feel about other health workers at the community and facility level knowing your HIV status?
 - e) How do you think people in the community feel about pregnant women who are HIV+?
 8. What are the major problems you are facing as a mother living with HIV?

- a) How has the program addressed any of these needs?
- b) What do you feel health workers should do to address these needs?
- c) What suggestions do you have for the program in assisting mothers in the future?

C. Nurse in charge of PTCT service delivery

1. Describe your role as part of the PTCT team?
 - a) How long have you worked as part of the PTCT team?
 - b) How have you been prepared to take on these roles? What training, orientation, supervision, and resources have you received?
 - c) What additional support would you need to make your task easier?
 - d) What do you like or do not like about working in the RCH clinic?
 - e) What do you find to be the hardest things to cope with? What makes your job difficult? How well does the project help you deal with these situations?

2. What do you know about PTCT?
 - a) What are the different components of a PTCT program?
 - b) What do you think of the quality of these different services and how could they be improved?
 - c) Is there anything a pregnant woman can do to prevent her child from getting the HIV virus?
 - d) What are the benefits of ARV prophylaxis to the pregnant mother and her child?
 - e) What steps should you take during delivery to reduce the risk of MTCT?
 - f) How do you feel a mother with HIV should feed her baby? In your experience, what practices do HIV+ mothers usually favour and why?
 - g) What support would you give to a mother about infant feeding?
 - h) How would you deal with an HIV positive mother who chooses not to breastfeed her baby?

3. How would you deal with a pregnant mother who has accepted to take an HIV test?
 - a) If you receive a positive result from the lab, how would you communicate this result to your patient?
 - b) How do you deal with a patient who breaks down or is distressed after receiving the HIV result?
 - c) What in your opinion are the characteristics of a good counsellor?
 - d) What do you do about pregnant mother's who have taken the test and do not return for their results?
 - e) What do you do about pregnant mother's who know their HIV status and do not return to the clinic?

4. How do you get a patient to enrol and adhere to an ARV regimen?
 - a) What in your opinion are the reasons for the low uptake of ART amongst HIV+ pregnant women?
 - b) How do you support pregnant women once they return to their homes?

Focus group discussion guides:

A. Focus Group discussion with ANC PTCT Program staff

1. In your own words, what is this PTCT program all about? (Justification, goal and objectives)
 - a) How accessible are the services to patients who need them?
 - b) In your opinion, how appropriate are the services offered in meeting the needs of patients?
 - c) What are the critical areas that need to be addressed in order to expand the number of women who take up the services?
 - d) How well do you think PTCT services have been integrated into RCH services (antenatal services at facility level and outreach)
 - e) What should be the role of community based staff beyond sensitization on HIV/AIDS and PTCT?
2. How do you feel about working in an HIV care program?
 - a) How well do you feel you have been prepared for working in this program (probe for adequacy of training, supervision, resources at your disposal)
 - b) What aspects of your work do you enjoy and feel satisfied about? Why?
 - c) What aspects of your work do you have difficulty with? Why? How has the project assisted you in coping with these difficult situations?
 - d) What do you feel about the role of incentives for future sustainability of PTCT services?
 - e) What are the staffing constraints you are now facing and how could these be addressed to improve service delivery?
3. Are there any other critical issues that need to be addressed in order to improve and expand service delivery?

B. Community Health Workers (TBAs, VHWs, CHNs)

1. Before the implementation of the PTCT program, how did the community of view the issue of HIV/AIDS?
 - a) How have these views changed?
 - b) What in your opinion has been responsible for this change?
2. What do you know about PTCT?
 - a) How is HIV transmitted?
 - b) How is HIV transmitted between mother and child?
 - c) Some people believe that if a pregnant woman is HIV+, her child is going to be born HIV+, what is your knowledge about this? Where did you get this information?
 - d) What do you think a mother can do to prevent transmission of HIV to her baby?
 - e) What is ARV prophylaxis? What are the benefits of ARV?
 - f) How should a HIV+ mother feed her newborn baby?
 - g) What steps can you take to reduce the risk of transmission of the virus during pregnancy, delivery and the first few months of the infant's life?
2. What do you know about the PTCT program that is offered at _____ RCH clinic/hospital?
 - a) In your opinion, what is the purpose of the program? What services does the program offer?

- b) How have you been assisting the nurses to care for women who are HIV+ in this community? What do you think you should be doing more/better to support pregnant women who are HIV+?
 - c) What training have you received for your role in the project?
 - d) What do you think could be done to strengthen the links between what is done at the facility and here in the community?
 - e) What suggestions do you have for the program in the future?
3. In your opinion, why do you think a pregnant woman should know her HIV status? What are the benefits of this?
- a) Some women take an HIV test and they do not attend RCH clinics anymore. Why do you think this is so? What can you do to ensure that these women benefit from your care and nurses care?
 - b) How do you feel people in your community see women who are HIV+?
 - c) In your opinion, what would HIV+ women think about you being aware of their status?

C. Women of child-bearing age

1. What do you know about PTCT?
- a. How is HIV transmitted?
 - b. How is HIV transmitted between mother and child?
 - c. Some people believe that if a pregnant woman is HIV+, her child is going to be born HIV+, what is your knowledge about this? Why? Where did you get this information from?
 - d. What do you think a mother can do to prevent transmission of HIV to her baby?
 - e. What is ARV? What are the benefits of ARV?
 - f. How should an HIV+ mother feed her newborn baby? What are your feelings about mothers who choose not to breastfeed?
2. What do you know about the PTCT program that is offered at _____ RCH clinic/hospital?
- a. In your opinion, what is the purpose of the program?
 - b. Are you aware of anything the program is doing in the community to help pregnant women who are HIV+? How useful have these activities been?
 - c. What do you feel can be done as part of the program to help raise awareness on PTCT in the community?
 - d. What suggestions do you have for the program in the future?
3. In your opinion, why do you think a pregnant woman should know her HIV status? What are the benefits of this?
- a. What are your feelings about a woman taking an HIV test without her husband knowing?
 - b. If a man has a wife who is HIV+, what do you think his role should be?
 - c. How do you see pregnant women who are HIV+?
 - d. How do people in this community see pregnant women who are HIV+?
 - e. What should be done at community level to support pregnant women who are HIV+?
 - f. What role should community based health workers play in supporting pregnant women who are HIV+?

D. Community leaders, men and grandmothers

1. Before the implementation of the PTCT program, how did the community of view the issue of HIV/AIDS?
 - a. How have these views changed?
 - b. What in your opinion has been responsible for this change?
2. What do you know about PTCT?
 - a. How is HIV transmitted?
 - b. How is HIV transmitted between mother and child?
 - c. Some people believe that if a pregnant woman is HIV+, her child is going to be born HIV+, what is your knowledge about this? Why? Where did you get this information from?
 - d. What do you think a mother can do to prevent transmission of HIV to her baby?
 - e. What is ARV? What are the benefits of ARV?
 - f. How should a HIV+ mother feed her newborn baby?
3. What do you know about the PTCT program that is offered at _____ RCH clinic/hospital?
 - a. In your opinion, what is the purpose of the program?
 - b. Are you aware of anything the program is doing in the community to help pregnant women who are HIV+? How useful have these activities been?
 - c. What do you feel the can be done as part of the program to help raise awareness on PTCT in the community?
 - d. What suggestions do you have for the program in the future?
4. In your opinion, do you think a pregnant woman should know her HIV status? Why should or shouldn't she? What are the benefits of knowing her status?
 - a. What are your feelings about a woman taking an HIV test without her husband knowing?
 - b. If a man has a wife who is HIV+, what do you think his role should be?
 - c. How do you feel people in your community see women who are HIV+?
 - d. Is there any role for community health workers in supporting HIV+ women?
 - e. What is your role in supporting pregnant women and mothers who are HIV+?