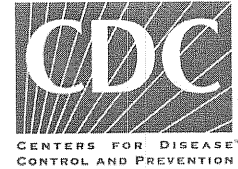


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**Implementing a rural programme of prevention of mother-to-child transmission of HIV in Kouga LSA, South Africa: a pre-post evaluation**

**Final report: Kouga LSA PMTCT programme implementation**

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## A. Acronyms and Abbreviations Used

AIDS	Acquired Immune Deficiency Syndrome
ANC	Antenatal care
ART	Antiretroviral therapy
ARV	Antiretroviral
AZT	Azidothymidine
CBOs	Community-based organizations
CDC	United States Centers for Disease Control and Prevention
CHC	Community Health Centre
CD4	Cell Differentiation
CCT	Confidential counselling and testing
CHWs	Community health workers
CLO	Community Liaison Officer
CR	Case Registers
CT	Counselling and testing
DHIS	District Health Information System
EC DOH	Eastern Cape Department of Health
ECSECC	Eastern Cape Socio-Economic Consultative Council
EPI	Expanded Programme on Immunisation
ELISA	Enzyme-Linked ImmunoSorbent Assay
FBO	Faith Based Organisation
FHI	Family Health International
FP	Family planning
HIV	Human immunodeficiency virus
HSRC	Human Sciences Research Council of South Africa
IMCI	Integrated Management of Childhood Illnesses
LSA	Local Service Area
MCH	Maternal and child health
MTCT	Mother-to-child transmission of HIV
NPO	Non-Profit organisation
NVP	Nevirapine
PCR	Polymerase chain reaction
PEP	Post-exposure prophylaxis
PEPFAR	(United States) President's Emergency Plan for AIDS Relief

PLWHA	Person living with HIV and AIDS
PMTCT	Prevention of mother-to-child transmission of HIV
PN	Professional Nurse
PNC	Postnatal care
SAHA	Social Aspects of HIV/AIDS and Health Research Programme
SC	Site Coordinators
sdNVP	Single-dose Nevirapine
SGFs	Support Group Facilitators
SPSS	Statistical Package for Social Services
SS	Summary Sheets
StatsSA	Statistics South Africa
STI	Sexually transmitted infection
TBA	Traditional birth attendants
THP	Traditional Health Practitioner
VCT	Voluntary counselling and testing
UNAIDS	Joint United Nations Programme on AIDS
WHO	World Health Organisation

## B. Executive Summary

**Background:** Baseline assessment of missed opportunities for PMTCT was conducted in the Kouga LSA in 2007 to gather information on the status of PMTCT programme implementation prior to initiating programme strengthening activities. Identified gaps in the PMTCT programme were staff shortage, lack of guidelines, stock outs, no monitoring and evaluation system, lack of training and poor data collection methods. Interventions included provision of guidelines and policies, monitoring and evaluation by development of operational plans, establishing support group facilitators, training of staff (lay counsellors and nurses on VCT/PMTCT, M&E and dual therapy) and appointment of staff (professional and enrolled nurses, and a data capturer). After these interventions, a post assessment was conducted in 2009 in the same health facilities using same methods employed during baseline assessment in order to determine whether there were any improvements brought about by the programme strengthening activities. This report presents the pre-post assessment results.

**Methods:** A pre-post design was used. Questionnaires and checklists were based on Family Health International tools (2003), adapted for use in South Africa, and pilot-tested after adaptation. At time 1 and 2 interviews were conducted with the PMTCT programme coordinator or clinic manager at each PMTCT site (n=20), heads of maternity wards at each delivery facility (n=4), and at least one other nurse (n=9) or lay counsellor (n=18). Health service assessment included 20 clinics during the pre- and 22 during post assessment. Exit interviews were conducted with convenient samples of: 296 ANC's at baseline and 239 at follow up; 70 HIV-positive PNC's at baseline and 142 at follow up. Nine support groups were formed at baseline and only four participated during post assessment and had few participants and therefore could not allow pre-post assessments. In terms of case registers, a total of 22 PMTCT sites in Kouga LSA were visited first in April 2008. for the mid-term review and again in January 2009 for the follow-up review.

### Key findings

#### Health service assessment

On-site counselling and HIV testing, referral to ART site were done by all facilities. However at least 2 health workers were trained on PMTCT per facility in 7 (41%) pre- and 15 (68%) post assessment. Daily availability of VCT was recorded in 16 (89%) pre- and in all facilities post assessment. NVP prophylaxis was given to HIV positive pregnant women at 28 weeks of gestation in 17 (94%) pre- and in all facilities post assessment. ANC counselling on infant feeding was done in 15 (83%) pre- and in all facilities post assessment. PCR testing for infants born to HIV positive mothers was done in 13 (72%) of infants pre- and in all infants during post assessment. Six facilities (35%) reported having support groups for positive women pre and 15 (68%) post assessment. In general, there was an improvement in compliance of PHC clinics with national PMTCT criteria. Safe obstetric practices were generally observed in delivery sites. The four delivery sites complied with PMTCT delivery criteria. About 90% of managers (18) were aware of the national PMTCT guidelines whereas only 70% (14) were aware on provincial guidelines.

#### Exit interviews

Pre-post assessment of ANC's showed that there was a significant increase in the number of women who were tested for HIV during the previous pregnancy ( $p=0.000$ ), and those that knew their HIV



test results ( $p=0.000$ ). Waiting period at facilities was cited as a serious concern. The nurses were described as friendly to their clients and this promotes trust. However, the issue of punctuality calls for nurses to arrive at work on time.

Pre-post assessment of PNCs showed that there was a significant: increase in the number of women who were aware of the PMTCT programme ( $p<0.001$ ); improvement in the experiences or feelings about HIV pre- and post test counselling, with significantly more women feeling relaxed about pre test counselling at post assessment ( $p=0.010$ ) and increase in the proportion of women who were aware of VCT before coming to the clinic at post assessment ( $p=0.013$ ). There was no significant improvement in the proportion of women who were given medication to prevent MTCT, the period at which the medication was taken (before or during labour began), the proportion of infants who received NVP within 3 days of birth, the proportion of women who disclosed their status to someone, infant feeding practices, counselling time and the preferred place of delivery during both pre- and post assessments.

### **Health information system assessment**

Major gaps were identified in data capturing at health facilities. Data elements recorded on ANC and PNC case registers showed discordance with monthly summary sheets and DHIS data. Nurses data collection and collation as a burden as there are several registers, some of which record data repeatedly. Nurses were taught how to calculate indicators and a manual that contained definitions of indicators was provided to them. There were facilities that did not have all guidelines, protocols and policies on HIV management.

### **Support groups**

Pre-post assessment to determine improvements brought about by support groups could not be made due to the fact that five out of nine clinics that participated during baseline were still struggling to get women to join the support groups for fear of stigmatization or those that had managed to were experiencing low turn up as a result of the harvest season. Even the clinics that managed to get women to join the support groups had very small numbers

### **Conclusions and recommendations**

In order to strengthen PMTCT service delivery, all newly appointed health personnel should be trained on PMTCT/VCT. Data capturing and collation system needs to be improved by redesigning case registers, reducing the number of registers and capturing reliable data on computers to eliminate the burden of duplicated data requirements. Implementation of new PMTCT guidelines, assisting nurses in understanding missed opportunities, addressing staff development needs, and supportive supervision will assist in strengthening service delivery.

Facilities should have all guidelines/protocols/policies for disease management and the documents should be accessible to all health care staff at the facility. Since lack of some documents may suggest unfamiliarity of some staff with those documents, clinic managers need to ensure that all staff are familiar with latest documents and that patient care is practised according to latest documents. Heavy workload of nurses can be alleviated by utilising lay counsellors more effectively in pretest and post test counselling. Utilising technology in data capturing and collation will save time and cost of paper-based registers. Nurses should trust administrative staff to assist in data collation. Post natal and infant follow up, PCR testing and giving NVP syrup to infants within

3 hours of birth needs to be strengthened. AFASS criteria are to be taken into consideration when advising and giving infant formula to mothers and caretakers. Missed opportunities need to be reduced significantly to ensure desired coverage of uptake and accelerated service delivery.

## 1. Introduction

Paediatric HIV remains an important public health problem in HIV high-burden countries, with more than 90% of new HIV infections in children occurring through mother-to-child-transmission (MTCT) (Global Expanded Inter-agency Task Team on prevention of HIV in pregnant women, 2007). In Sub-Saharan Africa, from 20% to 43% of babies born to HIV-positive mothers become infected with the virus (Jackson, 2002). In South Africa in 2006, an estimated 38 000 children acquired HIV infection around the time of birth, and an additional 26 000 children were infected through breastfeeding (UNAIDS, 2005). The South African *National Strategic Plan (NSP) on HIV & AIDS and STIs, 2007-2011* aims to reduce MTCT to less than 5% of infants born to HIV-positive women by 2011 (DoH, 2007). This target can be achieved by using a combination of interventions, including antiretroviral (ARV) prophylaxis given to HIV positive women during pregnancy and labour and to their infants in the first weeks of life; obstetric interventions including elective caesarean delivery (prior to the onset of labour and rupture of membranes) and complete avoidance of breastfeeding (WHO, 2006). The risk of MTCT can be reduced to under 2% by these interventions (UNAIDS, 2006).

In high income countries, these interventions have led to new HIV infections in children becoming increasingly rare. In many resource-constrained settings, however, elective caesarean delivery is seldom feasible and it is often neither acceptable nor safe for mothers to refrain from breastfeeding. Current international PMTCT guidelines recommend that HIV-positive women avoid all breastfeeding when replacement feeding is acceptable, feasible, affordable, sustainable, and safe (AFASS). In the absence of AFASS conditions, that breastfeeding continues (in combination with complementary feeding) after six months (Kuhn *et al.* 2007). In recent years, it has been shown that exclusive breastfeeding carries a lower risk of HIV transmission than mixed feeding, leading to increasing promotion of exclusive breastfeeding in resource-constrained settings (Doherty *et al.* 2003; Coovadia *et al.* 2007; Piwoz *et al.* 2007). In resource poor settings, the efforts to prevent HIV infection in infants initially focused on reducing MTCT around the time of labour and delivery, which accounts for one to two thirds of overall transmission, depending on whether the mother breastfeeds. Infant feeding patterns are a very important determinant of MTCT. For mothers using replacement feeding there is obviously no transmission through breastfeeding.

Obstacles facing PMTCT in resource-limited countries include the lack of healthcare infrastructure, limited manpower, and competing public health priorities with the limited healthcare budget (Paintsil & Andiman, 2009). Since 2002, there has been progress with implementing single-dose Nevirapine-based PMTCT programmes in South Africa. However, PMTCT interventions rely on functioning health systems (FHI, 2003). A 2002 evaluation of PMTCT pilot sites found that 85% of pregnant women tested received their HIV test result, but only 55% of HIV-positive women received Nevirapine prophylaxis.<sup>1</sup> A study on the implementation of single-dose Nevirapine for prevention of MTCT of HIV in Cape Town found that obstacles included health policy, health services, and health-seeking behaviour (Delva *et al.* 2007). In the rural Eastern Cape, several studies have shown that despite the availability of free health care, socio-economic constraints, poor roads and telecommunications, and an under-developed transport system are barriers to PMTCT service provision (Peltzer *et al.* 2007; Nkonki *et al.* 2007). Health systems failures account for many missed opportunities, including non-availability of counsellors or supplies, incorrect health education, and not providing women with Nevirapine (ECSECC, 2007).

Globally, renewed efforts are required to increase access to comprehensive, integrated programmes to prevent HIV infection in infants and young children and to use antenatal and postnatal services as an opportunity for women to access services to improve their own health. In South Africa, the NSP and the revised 2008 PMTCT guidelines provide a major impetus for reducing missed opportunities for PMTCT.

A baseline assessment of missed opportunities for PMTCT, funded by the US Centers for Disease Control and Prevention, was conducted in the Kouga LSA in 2007 to gather information on the status of PMTCT programme implementation prior to initiating programme strengthening activities. The baseline assessment showed that reducing missed opportunities for PMTCT requires strengthening of the formal health sector, intersectoral liaison, and greater community support. Priority areas that require strengthening in the formal health sector include HIV counselling and testing; family planning and nutrition counselling; infant follow-up; human resources; and monitoring and evaluation (Rispel *et al*, 2009). Intersectoral liaison included strengthening relationship between the formal and informal health sectors. Community support included providing psychosocial support to HIV positive women via support groups. Following the baseline assessment, interventions to strengthen the PMTCT programme in accordance with the above-mentioned priority areas were implemented in 2008. A follow up assessment was conducted in 2009 in order to determine whether there were any improvements brought about by these programme strengthening activities. This report presents the baseline/post assessment results.

## 2. Structural arrangement

An MOU was signed between the Eastern Cape provincial Department of Health and the HSRC on technical support of PMTCT activities in Kouga LSA. In addition, the provincial Department of Health has committed itself in writing that nurses appointed by the HSRC for a year will be taken over by the province at the end of their one-year contract of appointment.

A steering committee comprising sub-district manager, section heads, nutrition, PMTCT, care & support; regional training centre, PHC manager, councilor, municipality; district HIV & PMTCT manager, provincial HIV & PMTCT manager was established. Stakeholder meetings were regularly held with the established PMTCT steering committee on issues of PMTCT implementation.

## 3. Interventions

**Table 1: Process of audit and intervention**

	<b>Problem audit from baseline assessment</b>	<b>Interventions implemented</b>
<i>HIV Counselling and Testing uptake</i>	Based on the District Health Information System (DHIS) data reported for the 20 study clinics over a four months period, 66% of first ANC visits get tested for HIV, but with huge differences among clinics, e.g. Addo was only 20%, whereas Humansdorp clinic was 94%.	<ul style="list-style-type: none"> <li>• Facilitating training on provider initiated counselling and testing to all pregnant women who attend the Kouga LSA health care facilities</li> <li>• Implementing operational clinic plans</li> </ul>
<i>PMTCT guidelines</i>	National and provincial PMTCT (related) guidelines were often missing in clinics.	<ul style="list-style-type: none"> <li>• Support with improving access to user-friendly guidelines (ranging from clinical care to supervision)</li> </ul> <p>Clinics were provided with the missing policies and guidelines. A system to improve the availability of policies and guidelines was agreed upon, photocopies were made of all missing guidelines and provided to all clinics.</p>

<p><i>Training needs</i></p>	<ul style="list-style-type: none"> <li>• Training of health care professionals</li> <li>• Community health worker/ lay counsellor training</li> </ul> <p>Health care professionals will be trained in consultation with the ECDOH using project money and according to national guidelines and standards (including uniformity between national and provincial guidelines, e.g. on breastfeeding). The training will include inter alia, updates on PMTCT, VCT, ARV prophylaxis, post-partum counselling, infant feeding counselling (within safer infant feeding counselling, increase emphasis on the dangers of mixed feeding), nutrition counselling (nutritional support to mother and infant, including Vitamin A), family planning (post delivery, postnatal care), traditional health practices and ART updates.</p> <ul style="list-style-type: none"> <li>•</li> </ul>	<p><b>Training</b></p> <ul style="list-style-type: none"> <li>-PCR testing</li> <li>-Lay counselor – adherence counseling, 2 days (by HST); Mar 2008</li> <li>-Lay counselor – provider initiated testing, 2 days (AITICC)</li> <li>-Lay counselor, 5 day, refresher course on provider initiated testing (2 days) (n=28)</li> <li>-Lay counselor –full training for new LC, 3 weeks, VCT/PMTCT (n=30)</li> <li>-Professional nurses 2 weeks PMTCT/VCT</li> <li>-Professional nurses- M &amp; E training</li> <li>-Professional nurses- dual therapy</li> </ul> <p>In line with national guidelines for training of community care givers/ lay counsellors' training was provided to facilitate community mobilisation and encourage women to access ANC early, encourage counselling and testing, VCT, aspects of PMTCT, encourage delivery in health facilities by promoting the use of health facilities for delivery among pregnant women, their families (including mothers and mothers-in-law), and husbands or partners and aspects of infant feeding, nutrition counselling, family planning, traditional health practices and health. Further, the role of lay counsellors as part of the health system was clarified and strengthened</p>
<p><i>Family planning (FP) counselling</i></p>	<p>The formal health sector assessment showed that there was confusion regarding family planning guidelines in delivery facilities.</p> <p>This finding was supported in the interviews with HIV positive women using PNC services. Only 56% of these women had been counselled about family planning, with the remainder (44.3%) not receiving any family planning advice or counselling from a provider</p>	<p>A special training on family planning was conducted for health care providers</p> <p>A meeting with clinic managers also included addressing family planning guidelines</p>
<p><i>Follow-up of infants needs attention</i></p>	<p>The routine DHIS system shows that few babies are tested, despite the ability to do Polymerase Chain Reaction (PCR) tests at clinics. There is generally the need to strengthen the referral system and to ensure that the clinics and hospitals work in unison with improved outcomes for mothers and their babies</p>	<p>The researchers will provide technical support to strengthen the existing follow-up and monitoring system of children and facilitate in uniform and appropriate HIV coding for children. The approach will include appointment and training of staff and facilitating the resolution of bottle-necks and system challenges. By doing so infants born to HIV positive women will be tested for HIV at 6 to 14 weeks after delivery using PCR and at 12 or 18 months to determine their infection status using anti-body testing. Children who are HIV positive will be referred to the local health services by the trained health care professionals'.</p>

<p><i>Infant feeding practices are a cause for concern</i></p>	<p>This study revealed that formula feeding was the most (82.6%) reported infant feeding option. Few women reported mixed feeding, although health care providers highlighted challenges with infant feeding practices. There was also confusion among health care providers regarding the guidelines on exclusive breastfeeding. The differences in women reported versus staff perceived practices could neither be studied, nor verified in this assessment. The entire study area had formula supply problems in the period prior to the baseline assessment, but the interviews with women did not explore difficulties with feeding choices/practices.</p>	<p>Infant feeding formula stock out were addressed in stake holder meetings</p> <p>The establishment of peer support groups included a module on infant feeding addressing appropriate infant feeding methods</p>
<p><i>Support groups were almost non existent:</i></p>	<p>Only 5.7% of the respondents belonged to a support group. This is of concern as support groups have been shown to provide an environment where people who experience similar life stressors or affliction can share information, knowledge, ideas and experiences. Support groups also assist in dealing with stigma, isolation, loneliness and other consequences of being HIV positive and provide a sense of belonging, facilitate and enable expressions and sharing of feelings, relieve stress, provide emotional and mutual support, improve members' insight of HIV and AIDS and promote positive living.</p>	<ul style="list-style-type: none"> <li>- Expanding peer support for HIV positive women through formation of support groups for HIV positive pregnant women and new mothers Support groups for HIV infected mothers</li> </ul> <p>Establishing support groups for HIV infected mothers in half of the clinics which were ready to do so. Existing lay counselors have in their scope of practice outreach activities. Ten female lay counselors some of whom, had gone through the PMTCT programme themselves, were trained as site coordinators for the support groups. Ten support group facilitators were also trained to be peer educators and engaged in the project full-time for a year.</p>
<p><i>Human resource issues require attention</i></p>	<p>There were many reported staff vacancies, but this information remains outstanding as formal organisational structures have not been finalised. Although training has occurred, there is need for additional training of professional nurses. New staff need to be trained and there must be a formal system of updating existing staff on new/ revised guidelines. Lay counsellors need comprehensive training, role clarification and supervisory support. A formal supervisory system needs to be established</p>	<p><u>Recruitment and appointment of staff</u></p> <p>19 nurses (n=15 professional and 4 enrolled) and one admin/data capturer for the LSA PMTCT coordinating office have been employed by the HSRC in Kouga LSA. Nurses are contracted by the HSRC for a period of one year, receiving government equivalent salaries, and they sign a secondment agreement between the Eastern Cape Department of Health, the District Health office, and the district municipality</p>

	<p>and communicated.</p> <p>The vacancy rate of nurses was over 40% in clinics in Cacadu district. According to the district health barometre (Barron et al.,) the nurse clinical workload was in Cacadu district in 2006/7 more than 40 patients a day; much higher than compared to the national South African nurse clinical workload of 26.9 patients a day.</p>	
<p><i>Monitoring and evaluation (M &amp;E) system</i></p>	<p>The current M &amp; E reporting system consists of numerous data entry registers, integration of information is difficult and accuracy and quality of information submitted is doubtful. The confidential share code system creates numerous problems in practice, and this needs to be resolved.</p>	<p>Monitoring and evaluation support</p> <p>A two-day workshop with clinic supervisors and their clinic managers/teams was held in March 2008 and each clinic developed an operational plan for its own PMTCT implementation on the various PMTCT indicators. For each indicator (e.g. low VCT, low Nevirapine uptake, low PCR uptake, weakness in M &amp;E) targets for the end of 2008 were formulated with details of actions of interventions. Operational plans also take into consideration the implementation of dual therapy and routine testing.</p> <p>A PMTCT operational plan for each clinic was designed, with targets and how to achieve them. These were discussed with clinic managers and clinic supervisors.</p> <p>PMTCT programme evaluation was conducted, also addressing problems pointed out by auditors (e.g. no records of a number of PMTCT clinic activities, lack of guidelines) and M &amp; E.</p>
<p><i>Strengthen community mobilisation</i></p>	<p>Few NGOs operate in the area, and the interviews revealed weak, organisations with broad focus areas and with no or poor links to existing services. These organisations could benefit from capacity building in HIV and AIDS in order to support PMTCT programme strengthening</p>	<p><b>PMTCT community mobilization</b></p> <ul style="list-style-type: none"> <li>-Clinic awareness day on PMTCT programme was supported</li> <li>-Lay counselors engaged in outreach activities, including site coordinators for support groups of HIV infected mothers</li> <li>-Awareness training of clinic health committees on PMTCT</li> </ul> <p>Training intervention with 116 traditional health practitioners was completed in November 2007. As part of this training four maternity staff of the hospitals in the project area were invited but only one attended the one day designed joint training between traditional health practitioners and maternity staff. The training, over a period of 4 days, included the following modules: (i) HIV and AIDS; (ii) prevention of HIV transmission from mother to child; (iii) antenatal care; (iv) obstetric care; (v) postpartum care; (vi) counselling on safe infant feeding; (vii) status and role of TBAs; (viii) traditional medicine and rituals in delivery and infant care; and (ix) monitoring and follow-up.</p>

		<p>Modules <i>vii - ix</i> includes skilled birth attendants from the nearest hospital. An evaluation of the training intervention of 112 traditional health practitioners was completed in March 2008. This included a pre-training and a post training (six months after the training) assessment with a structured questionnaire.</p> <p><i>Training of THPs (TBAs &amp; Herbalists/Diviners)</i></p> <p>One hundred THPs have already been trained as part of the programme. The objectives of the TBA training intervention are to:</p> <ul style="list-style-type: none"> <li>• Encourage women to access antenatal care early and attend regularly</li> <li>• Encourage women to go for HIV testing</li> <li>• Encourage women to get post test counselling services</li> <li>• Provide post test psychosocial support</li> <li>• Encourage all women to deliver at health facilities or at least by trained attendant</li> <li>• Conduct risk assessment and refer higher risk deliveries to health facilities</li> <li>• Encourage all women to go to the clinic within 72 hours if delivered outside of clinic (infants of HIV positive women can then receive the infant dose of Nevirapine)</li> <li>• Encourage women to go to the clinic to get infant feeding counselling and support, growth monitoring, and immunization</li> </ul>
Dual therapy	<ul style="list-style-type: none"> <li>• Moving from mono to dual therapy in line with the new national guidelines and increase provision of ARV prophylaxis</li> </ul>	Training interventions were implemented

## 4. Methods

### 4.1. Study setting

The Kouga local service area (LSA), situated in the area around the Nelson Mandela Bay Municipality in the Cacadu District in the Eastern Cape, was selected for PMTCT programme strengthening by the Eastern Cape Department of Health. The Cacadu District had a population of just over 400 000 and an estimated HIV prevalence of 19.9% in 2007 (Family Health International, 2003). There are 20 fixed clinics (including one, community health centre (CHC) providing primary health care (PHC) services, complemented by six satellite clinics and nine mobile service points. Delivery services are provided by three hospitals and the CHC. The CHC is the only facility in the Kouga LSA that provides integrated antenatal, delivery and postnatal services.



#### **4.2. Sampling**

The assessment included all fixed PHC clinics and hospitals in the Kouga LSA. Questionnaires and checklists were based on Family Health International tools (2003), adapted for use in South Africa, and pilot-tested after adaptation. At time 1 and 2 interviews were conducted with the PMTCT programme coordinator or clinic manager at each PMTCT site (n=20), heads of maternity wards at each delivery facility (n=4), and at least one other nurse (n=9) or lay counsellor (n=18). The selection of health workers was based on their availability on the day of the site visit.

#### **4.3. Data collection methods and procedure**

Structured questionnaires were used to collect data. The questionnaires focused on service provision and management; infrastructure, equipment and supplies; human resources and the health information system. Site visits were conducted to each health facility to assess infrastructure, the availability of policies, guidelines, pharmaceuticals, equipment, and supplies. The research team members conducted all interviews, after written informed consent was obtained from each respondent. Information on PMTCT service use was extracted from the District Health Information System (DHIS). The HSRC research ethics committee and the Eastern Cape Department of Health approved the protocol, questionnaires and consent forms in advance.

#### **4.4. Surveys of ANC and PNC PMTCT women**

Exit interviews were conducted with 296 pregnant women at baseline and 239 at time 2 (post intervention /assessment) who used antenatal clinic services during the assessment period using a brief structured questionnaire that explored perceptions of services and the PMTCT programme. Clinic staff recruited a convenience sample of 70 HIV-positive women at baseline and 142 at time 2 who had used PMTCT services previously. These women were interviewed using a semi-structured questionnaire that explored HIV & AIDS knowledge, perceptions of PMTCT, infant feeding, coping and support.

#### **4.5. Support groups**

To address the lack of support for HIV-positive women during pregnancy and after giving birth, PMTCT support groups were formed in nine of the 20 PMTCT sites in the Kouga LSA. A PMTCT support group training programme was implemented with these groups and evaluated three months later. It was hoped that this programme would increase the number of pregnant women who receive HIV counselling and testing and receive their results; increase the number of women who disclose their status to their families; increase the number of women who access antiretroviral treatment (ART) and adhere to it; increase the knowledge and number of new mothers who make the correct infant feeding choice and adhere to it and decrease the infection rate on babies during pregnancy, delivery and post natal care. Lay counsellors employed by the Department of Health and two HIV mothers chosen from the community and had gone through the PMTCT programme were trained on how to establish and recruit eligible women to the support groups. HIV-positive women participating in support groups were invited to answer a questionnaire at their first meeting to assess their knowledge of HIV transmission, prevention and practices regarding infant feeding and then asked them again after three months to assess whether their knowledge and practices had improved.

In each clinic, a VCT and PMTCT trained lay counsellor was chosen to be a Site Coordinator (SC). HIV-positive mothers, who themselves had participated in the PMTCT programme were trained as Support Group Facilitators (SGFs). SCs and SGFs were required to be fluent in English and the major local languages (isiXhosa and Afrikaans). The SGFs worked in the clinic to which they had been assigned on Antenatal Clinic and immunisation days, and recruited pregnant women and new mothers and referred them to the support groups. At all nine clinics participating in the support group programme, all HIV-positive pregnant women and mothers of children under two years of age who take part in support groups, and who provide informed consent were invited to take part in answering the questionnaire. Data were collected by the SCs at the mothers' first visit to a support group (before she is exposed to the intervention) and again three months later. Program participation was defined as one or more visits to the support groups. Participants were interviewed in their language of choice.

The following standard PMTCT indicators were used as outcome measures:

- The number of women who know about HIV transmission occurs from the mother to the baby
- The number of women who disclose their status to their families;
- The number of new mothers who make an informed choice about infant feeding practices and adhere to their chosen feeding option;
- Factors that influence a woman's choice of infant feeding and the challenges that cause them to or not to deviate from that choice.

#### **4.6. Case registers**

A total of 22 PMTCT sites in Kouga LSA were visited first in April 2008. for the mid-term review and again in January 2009 for the follow-up review. Prior to the clinic visits, appointments were made with the PHC coordinator. The PHC coordinators informed the sisters in charge of the various clinics about the PMTCT mid-term reviews. As part of the review, interviews were conducted with the sisters in charge of various clinics. In addition, about six local people were trained to conduct interviews with the pregnant women who had come for ANC services and HIV positive mothers who have brought their babies for immunization. HSRC researchers oversaw the work done by the local field workers. Confidentiality issues were explained and patients and sisters in charge gave informed consent before the interview proceeded.

During both the mid-term and follow-up review, data was collected from the Case Registers (CR) in the health care facilities using a tool that was developed with data elements for the PMTCT programme. A Professional Nurse (PN) who is in charge of the PMTCT programme was requested to provide the researchers with all the registers that has PMTCT data, and monthly Summary Sheets (SS). The district information manager was also requested to provide DHIS data for the period assessed. Using the data elements, patient counts were done by the researcher and professional nurse for the month that was being assessed. Below are some of the PMTCT registers that were perused in order to get the monthly figures for the indicators: PMTCT register, tick register, drug register, PCR register, and CD4 count register etc. In order to check data reliability and validity, the information obtained from the case registers was compared with the information recorded on the monthly summary sheet. The current report does not show data recorded on DHIS due to the unavailability of the necessary information to inform the report.

#### **4.7. Health information system assessment**

All facility PNs in charge of PMTCT were interviewed and requested to provide their assessment of the health information system. They were asked how they perceived data collection and collation, and the amount of time they spent collating data in CR. PNs were also asked whether the manual with definitions of data elements and indicators were provided, and how to do calculations for indicators. Nurses were requested to provide the number of CR at the facility, and to indicate whether data was captured repeatedly in CR.

## 5. Results

### 5.1 Health care services assessment

Thirteen of the twenty clinics (13/20; 65%) provided antenatal care (ANC) services on five days per week, and five clinics (5/20; 25%) provided ANC on only one day per week. New and follow-up ANC appointments were generally provided on the same days (13/20; 65%). HIV test results were available on the day of testing at all clinics, except in cases where discordant rapid test results required laboratory confirmation. Nurses' reported case load ranged from 10 or less (7/9; 78%) to 60 or more (1/9; 11%) clients per nurse per day.

PMTCT sites surveyed met most of the national PMTCT criteria (Table 1). Of the fourteen applicable criteria (excluding infant ARV prophylaxis) only two criteria were met in all clinics, namely the provision of HIV voluntary counselling and testing (VCT), and referral of HIV-positive women to an antiretroviral treatment (ART) site. Only six clinics had support groups for pregnant HIV-positive women.

**Table 2: Compliance of PHC Clinics in the Kouga LSA with National PMTCT criteria pre-post (n=18; n=22 clinics)**

Clinics meeting criterion	Baseline	Post*
	N(%)	N(%)
On-site counselling for HIV testing	18/18 (100)	22/22 (100)
On-site HIV testing	17/18 (94)	22/22 (100)
Private room in which voluntary counselling and testing (VCT) can be conducted	17/18 (94)	14/22 (64)
Daily availability of VCT	16/18 (89)	22/22 (100)
Referral to an ART site	18/18 (100)	22/22 (100)
CD4 count testing	17/18 (94)	22/22 (100)
Nevirapine prophylaxis given to HIV-positive pregnant women at 28 weeks gestation	17/18 (94)	22/22 (100)
Nevirapine prophylaxis given to neonates within 72 hours of birth	5/18 (28)	2/22 (9)
Antenatal counselling on infant feeding	15/18 (83)	22/22 (100)
Postnatal counselling and support for infant feeding	15/17 (89)	22/22 (100)
Adequate supply of free infant formula	10/16 (63)	20/22 (91)
PCR testing for infants for HIV infection	13/18 (72)	22/22 (100)
At least two health workers trained in PMTCT per facility	7/17 (41)	15/22 (68)
A support group specific to HIV-positive mothers and pregnant women	6/17 (35)	15/22 (68)

\*=post assessment

In general, the four delivery facilities complied with the PMTCT delivery site criteria, including providing HIV counselling in labour and post-partum, having a written policy for routine care of pregnant women, using a confidential share code to identify HIV-positive women, providing

Nevirapine for HIV-positive pregnant women and their babies, vitamin A administration and immunisation. However, only two of the four delivery facilities made explicit family planning appointments for women after delivery. All four facilities reported infant feeding counselling, but staff were uncertain of whether HIV-positive women should be advised to breastfeed for four or six months, and whether formula feed should be given by bottle or by cup.

Safe obstetric practices were generally observed, with staff at all four delivery facilities reporting that they performed episiotomies only occasionally, avoided performing artificial rupture of membranes, and limited the number of vaginal examinations performed. However staff had limited knowledge of the vaginal examination guidelines.

### PMTCT guidelines

Ninety percent of managers (18/20) were aware of the national PMTCT guidelines, but only 70% (14/20) were aware of the provincial guidelines. Guidelines on PMTCT, VCT, sexually transmitted infection (STI) management, and family planning for HIV-positive women were available at more than 80% (16/20) of clinics. Guidelines for infant feeding counselling, integrated management of childhood illnesses (adapted to HIV), and baby friendly facilities were also available at most of the clinics. However, only one in every two clinics surveyed had a written policy on confidentiality.

**Table 3: Awareness and/or availability of PMTCT policies and guidelines at clinics in the Kouga LSA**

	Baseline	Post
Criterion	%	
Awareness of national PMTCT guidelines	90	No question on this
Awareness of provincial PMTCT guidelines	70	No question on this
Availability of policies or guidelines (are these provincial or national guidelines) – the figures on post assessment suggest that the situation deteriorated, how did you work out your figures? Further, no data on some policies at post assessment		
PMTCT (with ARVs)	94.4	86.4
VCT	94.7	63.6
HIV infant feeding counselling	76.5	81.8
Integrated Management of Childhood illnesses (IMCI) adapted to HIV	72.2	No question on this
Baby friendly	76.5	No question on this
Guidelines on the management of STI	100	77.3
Guidelines on family planning for HIV-positive women	88.9	50
HIV and AIDS	94.7	No question on this
Written policy on confidentiality	53.3	No question on this

## 5.2. Training needs

Professional nurses (45%) and Lay counsellors (28%) were the job titles most frequently identified in the post-intervention survey of 123 health care workers. The majority of all health care workers attended training in VCT (59.3%), PMTCT (54.5%) and infant feeding for PMTCT (50.4%). Training that were most frequently not undertaken and identified as training needs, were mother-to-mother (75%), dual therapy (70%), family planning (68%), ARV for PMTCT (60%) and revised PMTCT guidelines (54%).

As formal training records were not available, it was not possible to verify the extent of health worker training in PMTCT service provision. Nurses reported training ranging in duration from one day on specific topics (e.g. HIV counselling) to more comprehensive training over two weeks. Of the nurses interviewed, seven in nine reported feeling confident about counselling HIV-positive women about infant feeding options, but only 56% (10/18) of the lay health counsellors reported that their training had equipped them to provide information to patients about PMTCT. Eight out of nine nurses interviewed (89%) requested additional training in paediatric HIV management, ART provision, family planning service provision, PMTCT, and VCT. Lay counsellors requested additional training on PMTCT services, basic counselling skills, antenatal care, VCT, family planning and supervision.

### 5.2.1. Training and support

It was difficult to determine the exact number of health care providers who have been trained in PMTCT service provision. The reported training varied from one day in specific aspects (e.g. HIV counselling) to more comprehensive training of two weeks. The majority of managers interviewed (70%) indicated that there was a formal system in place to provide supervision for providers in the VCT/PMTCT programme. When asked to describe the system, responses varied from regular talks (as there is no time for meetings), observation of counselling session, to checking records and bi-monthly visits by the LSA PMTCT coordinator.

Fifty percent indicated that there is a meeting between supervisors and lay counsellors, and the frequency varied from once a week to once every few months. The majority of managers indicated that there is a formal mechanism in place to provide updates of information on VCT/MTCT for staff.

**Table 4: Training received by lay health counsellors interviewed (n=18)**

Based on the baseline report lay counsellors expressed the need to be trained in the following topics:

Training topic	Number of yes responses	%
Basic counselling	16	88.9
VCT and PMTCT	10	55.6
Nutrition counselling	8	44.4
Infant feeding counselling and support for HIV-positive women	9	52.9

Family planning service provision	4	22.2
Counsellor supervision	3	16.7
Record-keeping practices for PMTCT services	4	22.2

Not done during baseline. Post assessment data presented

Only 10 lay health counsellors (55.6%) reported that the training they received equipped them to provide information to patients about PMTCT. They requested additional in-depth training in:

- PMTCT services
- Basic counselling
- Antenatal care
- VCT
- First aid
- Family planning service provision
- HIV counsellor supervision

### 5.2.2. Mid- term analysis

In response to the baseline report's situational analysis, the training of lay counsellors (LCs) began in May 2008. LCs were trained on VCT, PMTCT and dual therapy. Lay counsellors that had been trained before, received a refresher course on counselling skills. The VCT training is based on the TASO model of counselling. This model equips the lay counsellors to be able to:

- Enhance VCT clients' understanding of the practical implications of HIV infection and disease
- Identify practical ways of preventing HIV infection and disease
- Facilitate understanding of practical strategies for implementing behaviour change

These are core necessities in counselling clients before they take an HIV test and after they have taken the test. Before the test, they need to understand the implications of being infected and after the test they need to implement behaviour change whether the test comes out negative or positive.

Dual therapy training was given to them because it was a new system that was being implemented by the Department of Health for positive mothers.

Training course	Duration	No. of people trained
VCT and PMTCT	Three weeks	30
Dual Therapy	Four days	45

A follow-up on the lay counsellor trainings still needs to be done in Kouga. Lay counsellors were trained only in the topics mentioned above. They never managed to receive trainings in the other areas. During the post intervention analysis eighteen of them managed to respond to the questionnaire. On their experience of the VCT for PMTCT training, sixteen of them which constitute 88.9% responded that the training equipped them well for the execution of their duties. The second training which they received, Dual Therapy was not reported on in the baseline study. The biggest problem experienced with lay counsellors is that they leave the system regularly because of better opportunities and the fact that they are not recognised by the system as employees. Steps have been taken recently by the Eastern Cape Department of Health to include

them by including them in the persal system of payment. That is a positive step towards recognising them as employees. I would recommend that the lay counsellors receive the other trainings as they requested. A process of mentoring them and supervising needs to begin as well to assist them deal with the trauma they deal with everyday. Included here is a copy of a trauma questionnaire that I developed to help them deal with the stress. It needs to be translated to isiXhosa and Afrikaans for easy administration.

**Table 5: qualitative assessment from mid-term and follow-up assessment:**

Issues/problems	Mid term	Follow up
Dual Therapy	N/A	<ul style="list-style-type: none"> <li>Dual therapy has been introduced in most clinics and is up and running. (<i>Introduction of Dual therapy last year.</i>)</li> </ul>
AZT	N/A	<ul style="list-style-type: none"> <li>AZT is now given to patients in most clinics (<i>started using AZT immediately.</i>)</li> </ul>
Monitoring and evaluation	<ul style="list-style-type: none"> <li>The routine DHIS system shows that few babies are tested, despite the ability to do Polymerase Chain reaction (PCR) tests at clinics. There is generally the need to strengthen the referral system and to ensure that the clinics and hospitals work in unison with improved outcomes for mothers and their babies</li> <li>Few women reported mixed feeding, although health care providers highlighted challenges with infant feeding practices. There was also confusion among health care providers regarding the guidelines on exclusive breastfeeding.</li> <li>The entire study area had formula supply problems in the period prior to the baseline assessment, but the interviews with women did not explore difficulties with feeding choices/ practices.</li> <li><i>Support groups were almost non-existent: Only 5.7% of the respondents belonged to a support group. This is of concern as support groups have been shown to provide an environment where people who experience similar life stressors or affliction can</i></li> </ul>	<ul style="list-style-type: none"> <li>The clinics report that the PMTCT programme is going well. (<i>Programme is improving, many women are enrolled in the programme, and patients come on their own to ask for test.</i>)</li> <li>Most babies born to HIV positive mothers test negative for PCR. (<i>Willing to test. PCR is negative</i>)</li> <li>The challenge though is still with stigma as a lot of mothers are not disclosing their status. (<i>There is a problem of disclosing especially to family members</i>)</li> <li>The registers are helpful because they contain more information about the patient. (<i>More information about the patient because of the registers.</i>), (<i>With all the registers you can determine how many people are on the programme.</i>)</li> <li>As a method to follow up on babies, most clinics have decided they will give mothers half the number of tins they are supposed to get or one in order for them to come back for the rest after the first tins have been used. (<i>Instead of giving them 6 tins of milk ,we supply them with 1 tin per week, when returning back to the clinic they need to bring the empty tin back to clinic to receive another one(marked the tin with date issued and name of baby)</i>)</li> <li>Other clinics write the mothers' names on the board for defaulters in the clinics. (<i>Place the names on the board for those defaulting. Follow-ups have improved because of that.</i>)</li> <li>Only a small proportion of women are mixed feeding which is seasonal worker as they are said</li> </ul>

	<p>share information, knowledge, ideas and experiences.</p> <ul style="list-style-type: none"> <li>The confidential share code system creates numerous problems in practice, and this needs to be resolved.</li> </ul>	<p>to sell the free formula that they receive from the clinic. (<i>Seasonal workers. Selling of milk. Mixed-feeding</i>)</p> <ul style="list-style-type: none"> <li>A few women come late for their ANC at 34 weeks. (<i>Quite a few women come for ANC around 34 weeks</i>)</li> <li>Coding of cards has changed to stamping, instead of writing on the card, it is now stamped. This is done to prevent women from changing or erasing the code from the card. (<i>Coding change to stamping.</i>)</li> </ul>
<b>Health services</b>	<ul style="list-style-type: none"> <li>The majority of the pregnant women interviewed (73.6%) indicated that they were provided HIV counselling upon arrival. Voluntary counselling and Testing (VCT) services are available at all facilities, but more effort is needed to make it available to 100% of pregnant women.</li> <li>FP should receive more attention in the package of services provided. In this regard, guidelines need to be developed or made available and more staff training should be provided.</li> </ul>	<ul style="list-style-type: none"> <li>Not much has changed; there is still shortage of staff in most clinics. (<i>Provision of more staff to assist with the implementation of the PMTCT programme</i>)</li> <li>Need for lay counsellors to be trained. (<i>Have training for the new LC.</i>)</li> <li>Extending the clinics as they are small and there is not enough space to cater all the patients (<i>Extend the clinic</i>)</li> </ul>
<b>Benefits of PMTCT</b>	N/A	<ul style="list-style-type: none"> <li>Most mothers prefer formula feeding from the beginning. (<i>Everybody is opting for formula feeding</i>)</li> <li>Most babies are born HIV negative and their mothers also bring them for PCR testing. (They also come after delivery for PCR and the babies are born negative.)</li> </ul>
<b>Challenges with clients</b>	N/A	<ul style="list-style-type: none"> <li>Some women are still persistent about receiving formula from the clinic as they do not want to be because of the stigma behind. (<i>Patients do not want to be seen receiving milk because it is associated with their status</i>)</li> <li>Mothers are selling the formula milk (<i>Mother's selling the milk that they get at the clinic.</i>)</li> <li>Mix feeding (<i>Alcohol is a serious problem in this community. When mother's are drunk they mix-feed.</i>) Ravinia and St Francis Bay. Other clinics report cases of mix feeding due to stigma. (<i>There is a problem of disclosing especially to family members</i>) Sandrift</li> </ul>
<b>Challenges with staff</b>	<ul style="list-style-type: none"> <li>Although training has occurred, there is need for</li> </ul>	<ul style="list-style-type: none"> <li>Only one clinic reported not to have trained staff in PMTCT. (<i>Staff has not been trained on VCT</i>)</li> </ul>



	additional training of professional nurses. New staff needs to be trained and there must be a formal system of updating existing staff on new/ revised guidelines. Lay counsellors need comprehensive training, role clarification and supervisory support	and PMTCT) Joubertina <ul style="list-style-type: none"> <li>The biggest challenge though with all the clinics is understaffing. (<i>Provision of at least one more staff</i>)</li> </ul>
What can be done to improve the service?	<ul style="list-style-type: none"> <li>Recruitment and appointment of staff</li> <li>Technical support to ensure PMTCT programme strengthening</li> <li>Training of health care professionals</li> <li>Community care givers/ lay counsellor training</li> <li>Monitor the number of children in Kouga LSA of the Eastern Cape who become infected with HIV during the first year of life</li> <li>General Monitoring and evaluation (M &amp;E) support</li> </ul>	<p>Not much has changed from the previous needs for improvement</p> <ul style="list-style-type: none"> <li>Provision of staff is still a major need in almost all the clinics</li> <li>Extension of clinics or infrastructure is again emphasised as clinics do not seem to have enough space.</li> <li>Three clinics mentioned they would appreciate if HSRC can assist in forming support groups for HIV positive women. (<i>Paterson, Louterwater and Thornhill</i>)</li> <li>Doctors must be in the clinic on a daily basis. (<i>Lukhanyiso</i>)</li> <li>ARV clinic dispense onsite. (<i>Lukhanyiso</i>)</li> <li>Provision of enough milk stock. (<i>Loerie</i>)</li> <li>Educational DVDs and TV. (<i>Misgund</i>)</li> <li>Every staff member must get training on VCT and PMTCT. (<i>Joubertina</i>)</li> <li>Provision of a photocopy machine. (<i>St Francis Bay</i>)</li> </ul>

### 5.3 ANC Exit Survey

#### 5.3.1 ANC clients' experience at the facility

The majority of the respondents spent less than one hour for an ANC visit (52.3%) and generally felt the amount of time spent was reasonable (62.8%). During post assessment, the majority of respondents spent more than an hour for an ANC visit (84.2%) and the general feeling was it was too much (51.5%). Almost all women interviewed indicated that they would come back to the facility for care during baseline (99.3%) and (92.9%) during post assessment. The reasons included were: no alternative facility (52.6%) and (16.4%) post assessment, the nursing staff are friendly and kind (35.8%; 11.3%) and the service is good (11.2%;). Participants mentioned that the providers they had seen on the day of the visit were friendly (98.6%). Suggestions for improvement of PMTCT services are highlighted in Table 6 below. During post assessment participants requested nurses to be punctual for work (9.2%). We performed statistical calculations to determine if there were significant differences between the pre and post assessment using Pearson Chi-square. The

Chi-square value was 49.4 with 7 degree of freedom and the difference was highly significant ( $p < 0.001$ ). The major contributors to the difference between pre and post assessment were educating the community about the available health services and reducing the waiting time for clients at the facilities.

**Table 6: ANC clients suggestions for PMTCT service improvement (n=296;239)**

	Baseline	Post-assessment
	N (%)	N (%)
Increase number of staff including doctors, nurses and counsellors	95 (33.2)	57 (23.8)
Educate community about the available health services and HIV/AIDS counselling	35 (12.2)	2 (0.8)
Increase number of ambulances available	19 (6.6)	8 (3.2)
Extension of service hours at the clinic	13 (4.5)	0
Reduce waiting time	13 (4.5)	33 (13.8)
Extension of the clinic/ hospital buildings	7 (2.4)	8 (3.2)
Improve privacy	4 (1.4)	3 (.0)

Pearson Chi-square  $p < 0.001$ .

### 5.3.2. ANC clients reported access to health facilities

The most common means of transport to get to a hospital or clinic was walking (86.6%; 92.9%), followed by taxi (7.8%; 4.6%) and transport with a friend or family member (5.4%; 1.7%). The majority (87.8%; 84.5%) indicated that it took them less than half an hour to get to the clinic, 9.8% and 13%; 2.5%; 13% took between 30 minutes to 60 minutes, and very few travelled beyond one hour (2.4%; 2.5%). The majority of the respondents indicated that if they went into labour during the day (98.6%; 96.6%) or night (96.3%; 97.1%) they would be able to get to their health care facilities using the ambulance (91.6%; 84.5% during the day and 86.8%; 82.4 during the night). More than 50% said it would take them about one hour to get to the facility during the day (56.7%) and 49.5% post assessment; and during the night (54.2%; 46%).

### 5.3.3 Previous delivery experiences

The majority (70.4%; 62.7%) of women had given birth previously. Table 19 summarises the delivery experiences of these women. Most women gave birth at a health facility (93.4%; 90.6%) and their babies were delivered by nurses (48.6%; 69.4%) and doctors (38.3%; 23.6%). Almost all plan to give birth at hospital/clinic (98.3%; 99.2). There was a significant decline in the proportion of women who were delivered by a doctor pre and post assessment ( $p=0.004$ ).

**Table 7: Delivery experiences of ANC clients interviewed**

	Baseline	Post assessment	
Items	N (%)	N (%)	p-value
Place of delivery			

Hospital	170 (93.4)	135 (90.6)	0.352
At home	12 (6.6)	14 (9.4)	0.348
<b>Person who delivered previous baby</b>			
Doctor	70 (38.3)	35 (23.6)	0.004*
Midwife	89 (48.6)	102 (69.4)	
TBA	3 (1.6)	2 (1.4)	
Family member	3 (1.6)	6 (4.1)	
Other	18 (9.8)	2 (1.4)	
Intention to give birth at hospital/clinic	291 (98.3)	235 (99.2)	

t-test p<0.05

Most women gave birth at health facility (93.4%; 90.6%) and their babies were delivered by nurses (48.6%; 69.4%) and doctors (38.3%; 23.6%). Almost all plan to give birth at hospital/clinic (98.3%; 99.2).

### 5.3.4 Voluntary counselling and testing

Just over a quarter of the respondents (27%) were tested for HIV during last pregnancy and they all knew the results of their HIV test during the last pregnancy (27%). During post assessment, 66.7% were tested for HIV during last pregnancy and all (66.7%) knew the results of their HIV test during the last pregnancy. There was a significant increase in the number of women who were tested for HIV during the previous pregnancy (p=0.000), and those that new their HIV test results (p=0.000). The majority of the respondents (73.6%; 95%) indicated that they were provided HIV counselling upon arrival for less than half an hour (58.7%). During post assessment, the majority of the respondents (33.4%) indicated that they were provided HIV counselling upon arrival for less than half an hour and the difference was significant (p=0.000). They did not dislike anything during counselling (99.1%; 97%) and preferred that HIV/AIDS be discussed during ANC visit (84.1%; 56.8%) in order to gain information (87.2%; 44.2%), for personal benefit (8.8%; 8.8%) and to reduce the impact of HIV/AIDS (4.0%; 1.6%).

The majority of ANC clients interviewed were aware of HIV counselling and testing before coming to the facility (63.1%; 72.8%) and came to know about this through friends and relatives (41.5%; 7.7%), community health workers (37.7%; 15.6%), media (15.3%; 9.6) and community meetings (5.5%) and 15.8% (post assessment at school. An overwhelming majority of the respondents (94.6%;95.4%) indicated that they would refer a friend or a sister who is pregnant to the facility given the fact that the facility provides VCT and the reasons thereof were: to be informed of HIV status (63.3%; 24.1), nursing staff are friendly and kind (25.5%; 10.5%), to reduce the impact of HIV/AIDS (4.2%; 5.4), and there is no alternative facility (1.8%; 3.2%). This is shown in Table 8. There was a highly significant difference between pre and post assessment, p<0.001. The differences were mainly attributed to the length of the counselling period.

**Table 8: Voluntary Counselling and Testing**

	Baseline	Post assessment	p-value
<b>HIV testing during last pregnancy</b>	<b>N (%)</b>	<b>N (%)</b>	
<i>Tested for HIV during last pregnancy</i>	79 (27.0)	98 (66.7)	0.000
<i>Knew the results of HIV test during last pregnancy</i>	79 (27.0)	98 (66.7)	0.000
<b>How long did the nurse (or other staff) talk to you during the HIV counselling?</b>			

<1/2 hour	174(58.7)	71 (33.4)	0.000
1/2 - 1 hour	20(13.4)	135 (63.4)	
1-2 hours	6(2.0)	4 (1.9)	
> 2 hours	1(0.3)	3 (1.4)	
Offered HIV counselling upon arrival	217 (73.6)	227 (95.4)	

t-test p<0.05

## 5.4 PNC Exit Survey

### 5.4.1. PMTCT/HIV knowledge increased at post assessment

There was a significant increase in the number of women who were aware of the PMTCT programme post assessment (p<0.001). There were no significant differences in the sources of information regarding PMTCT.

**Table 9: HIV and PMTCT knowledge**

	Baseline	Post
<b>Items</b>	<b>N (%)</b>	<b>N (%)</b>
Have you heard about the PMTCT program?	28 (40.0)	*112 (77.8)
<b>If so, where did you hear about it?</b>	<b>N (%)</b>	<b>N (%)</b>
<i>At the clinic</i>	24 (34.3)	111 (92.5)
<i>At the hospital</i>	1 (1.4)	6 (5.0)
Other (Radio/community)		3 (2.5)
Can an HIV-positive mother infect her baby with HIV during pregnancy?	37(54.4)	153(69.9)
Can an HIV-positive mother infect her baby with HIV during delivery?	43(63.2)	159(72.6)
Can an HIV-positive mother infect her baby with HIV during breastfeeding?	55 (79.7)	176(80.4)

\*p<0.001

### 5.4.2 Experiences of HIV pre-post test counselling improved at follow up

There was a significant improvement in the experiences or feelings about HIV pre- and post test counselling, with significantly more women feeling relaxed about pretest counselling post assessment (p=0.010). However, a high proportion of HIV positive women still feel nervous during pre-test counselling.

**Table 10: Experiences of HIV pre- and post-test counselling**

	Baseline	Post
<b>Experience/Feelings about HIV pre-test counselling</b>	<b>N (%)</b>	
<i>Nervous</i>	41 (58.6)	67 (49.3)
<i>Relaxed</i>	21 (30.0)	65 (47.8)*
<i>Never received HIV pre-test counselling</i>	8 (11.4)	4 (2.9)
<b>Experience/Feelings about HIV post-test counselling</b>	<b>N (%)</b>	<b>N (%)</b>
<i>Miserable</i>	29 (41.4)	34 (26.8)
<i>Confident/good</i>	23 (32.8)	54 (42.5)

<i>Did not want to accept the result</i>	5 (7.4)	2 (1.5)
<i>Accepted the situation with little panic</i>	7 (10.0)	5 (3.9)
<i>Never received post-test counselling</i>	6 (8.5)	17 (13.4)

\*p=0.010

#### 5.4.3. Reported disclosure

The proportion of women who disclosed their status to someone did not seem to improve post assessment and the proportion of those that disclosed to their husband/partner still form a low percentage. Most of them disclosed to their partner/husband compared to family members, but there were no significant differences. Out of those that disclosed their HIV status, the majority felt relieved, but the difference was not significant. The proportion of women who were devastated after disclosure indicated a need for further intervention on disclosure.

**Table 11: Disclosure of HIV-positive status**

	Baseline	Post
	N (%)	N (%)
Had disclosed their HIV-test result to someone	63 (92.6)	118 (84.3)
<b>Person who they had disclosed to:</b>		
Partner/Husband	32 (50.8)	77 (30.9)
Mother	11 (17.5)	43 (17.3)
Sister	5 (7.9)	40 (16.1)
Other family members	5 (7.9)	51 (20.5)
Friends	6 (9.5)	26 (10.4)
Other (specify)	4 (6.3)	4 (1.6)
<b>Experience following disclosure</b>		
Relieved	47 (67.1)	68 (62.9)
Devastated	12 (17.1)	30 (27.7)
Nothing	5 (7.1)	4 (3.7)
Had not disclosed their HIV status to anybody	6 (8.5)	6 (5.5)

NB: Post test % for “person who they disclosed to” do not add up to 100% as respondents might have disclosed to more than one person.

#### 5.4.6 Delivery experiences and post-natal care

A health facility was the preferred place of delivery during both pre- and post assessment. Most deliveries were done by nurses. However the differences were not significant.

**Table 12: Delivery Experiences**

	Baseline	Post
Item	N(%)	N(%)
<b>Place of delivery</b>		
<i>Home or another person's home</i>	1 (1.4)	10 (7.1)
<i>Health facility</i>	66 (94.3)	131 (92.9)
<i>Other</i>	3 (4.3)	0 (0.0)

Person who assisted with the delivery of baby		
<i>Doctor</i>	14 (20.3)	33 (23.4)
<i>Nurse/midwife</i>	54 (78.3)	95 (67.4)
<i>Other</i>	1 (1.4)	13 (9.2)

There was no significant difference in the proportion of women who were given medication to prevent MTCT pre- and post assessment. Concerning the period at which the medication was taken (before or during labour began) there was no significant improvement. The majority of women took the drug before labour began. The proportion of infants who received NVP within 3 days of birth did not improve significantly post assessment.

**Table 13: ARVs and Nevirapine**

Items	N (%)	N(%)
Whether provided with a drug to prevent mother to child transmission of HIV	60 (88.2)	125 (89.3)
Whether partner/husband informed that drug must be taken	41 (66.1)	96 (74.4)
<b>When did you take (or were given) the drug?</b>	<b>N (%)</b>	<b>N (%)</b>
<i>Before labour began</i>	50 (82.0)	97 (77.0)
<i>Onset of labour</i>	10 (16.4)	25 (19.8)
<i>When baby was born</i>	1 (1.6)	3 (2.4)
Did this baby receive a syrup medicine within 3 days after s/he was born to prevent mother to child transmission?	51 (77.3)	127 (90.7)

#### 5.4.7 Infant feeding practices

Infant feeding practices remained the same pre- and post assessment. Exclusive formula feeding was the preferred feeding option practiced by most women.

**Table 14: Infant feeding practices**

Whether infant feeding options given during counselling	N(%)	N(%)
<i>No, not offered</i>	9 (12.8)	6 (4.8)
<i>Yes, Formula exclusively</i>	18 (25.7)	
<i>Yes, Breastfeeding exclusively</i>	41 (58.6)	
<i>Yes, cup feeding only</i>	2 (2.6)	
<b>Reported feeding option practised</b>	<b>N(%)</b>	
<i>Exclusive breastfeeding</i>	15 (21.4)	20 (14.3)
<i>Exclusive formula feed (bottle with nipple)</i>	57 (82.6)	120 (85.7)
<i>Mixed feeding (breast feeding &amp; plain water or other liquids or solid or mushy food)?</i>	1 (1.5)	7(5)

NB: Baseline and post assessment questions are different

The proportion of women who were aware of VCT before coming to the clinic was significantly higher post assessment ( $p=0.013$ ). There was no significant improvement in the counselling time.

**Table 15: Voluntary Counselling and Testing**

	Baseline	Post
	N (%)	N (%)
Aware of VCT before coming to clinic	186 (63.1)	174 (72.8)*

Offered HIV counselling at clinic	217 (73.6)	
Prenatal visit time in minutes [M, SD]	Not asked	149 (101)
HIV counselling time in minutes [M, SD]	Not asked	32 (24)
Was the counselling time enough		
-too much	98 (33.1)	123 (51.7)
-just enough	186 (62.8)	103 (43.3)
-too short	12 (4.1)	12 (5.0)

\*p=0.013

### 5.5. Missed opportunities for PMTCT

Of 296 antenatal care attendees interviewed, 74% reported that they were offered HIV counselling and testing. Forty-three percent of those with a previous pregnancy (79 out of 183) reported that they had been tested for HIV during their last pregnancy.

The standard PMTCT protocol specifies that HIV-positive pregnant women should be supplied with Nevirapine at 28 weeks gestation, to be taken at the onset of labour. However, of the 70 HIV-positive mothers interviewed, only 28 (40%) were aware of the PMTCT programme; 13 (18%) reported that they had not been given Nevirapine during ANC visits; and 17 (24%) reported that their baby had not been given Nevirapine syrup within 3 days of delivery. Although most HIV-positive mothers knew how HIV transmission occurred, 27% incorrectly believed that if a woman was infected with HIV, her baby would *always* become infected.

Staff in the delivery facilities were uncertain of family planning guidelines for HIV-positive women. This was confirmed in the interviews with HIV-positive women. Only 56% reported that they had received family planning advice or counselling. Although 80% of HIV-positive women reported using some form of contraception, only 16% reported using condoms.

Most HIV-positive mothers (83%) reported using formula feeding. Few HIV-positive women reported mixed feeding, although health care workers reported challenges with promoting the recommended infant feeding practices. More than half of the HIV-positive mothers interviewed did not believe that traditional medicines could harm an unborn baby (43 out of 70), and half reported using gripe water to pacify their babies (34 out of 70).

The frequency of missed opportunities for PMTCT estimated from DHIS information on the 20 clinics for the period April to July 2007 (Table 16) differed from estimates based on reports by antenatal and postnatal service users. According to the DHIS, 76% of ANC attendees received HIV counselling at an ANC visit, with 67% undergoing HIV testing. Eighteen percent of pregnant women who accepted testing were HIV-positive and were thus eligible for PMTCT services, but the number of packs of Nevirapine distributed at 28 weeks gestation was far less than the number of pregnant women with HIV-positive results. The number of packs of Nevirapine distributed, expressed as a percent of the number of pregnant women who tested HIV-positive, was 56%, ranging from 20% at a remote rural clinic to 94% at an urban clinic.

Table 16 shows elected indicators of the Kouga LSA prevention of mother-to-child transmission of HIV Programme at pre-intervention (April to July 2007; July to Dec 2007) and post-intervention (Oct 2008 to Jan 2009)

**Table 16: PMTCT indicators at PHC PMTCT site level (n=20;22)**

Indicator	Pre-intervention (July to Dec 2007) (6 months)	Post-intervention (Oct 2008 to Jan 2009) (4 months)
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	N	%	N	%
ANC 1 <sup>st</sup> visit	1333	100%	1165	100
ANC pre-counseled HIV	988	74%/first bookers	1012	87%/first bookers
ANC tested for HIV	874	66%/first bookers 88%/pre-test counseled	1017	87%/first bookers 100%/pre-test counseled
ANC client tested HIV+ new	158	18.1%	210	21%
Accept NVP (ANC)	134	85%/HIV +	178	85%/HIV+
Collect NVP (ANC)	90	57%/HIV+	163	78%/HIV+
PCR 6 weeks	63	40%/HIV+	182	87%/HIV+
PCR positive	11	18%	23	13%
HIV test 9 ms	16		37	
HIV + 9 ms	9	56%	7	19%

## 5.6. Case registers

### 5.6.1. Indicator results for data collected during mid-term and follow-up review

#### 5.6.1.1. Antenatal and Postnatal Care Indicator Results

Table 17 shows data recorded during the mid-term review which took place in April 2008 and the follow-up review conducted in January 2009. The figures appearing on table 17 reflect data recorded on various indicators by the 22 facilities in Kouga LSA. In assessing the correctness of the data, a comparison was made between data recorded on case registers, monthly summary sheets and DHIS for the same period. Table 17 shows that even though data for the same period was analyzed, it does not tally at all levels. In some instance, data has either been over recorded on case registers and monthly summary sheets or case registers and DHIS. The data recorded by most of the facilities only tallies at two levels. It is either that data recorded on case registers tallies with data recorded on DHIS (not monthly summary sheets) or data recorded on monthly summary sheets tallies with data recorded on DHIS (not case registers). There is also instances whereby DHIS data does not tally with data recorded on case registers and monthly summary sheets (See addendum 1: table 22-24).

**Table 17: ANC Indicators**

INDICATOR	MID-TERM REVIEW			FOLLOW-UP REVIEW		
	Case registers results	Monthly summary sheet results	DHIS results	Case registers results	Monthly summary sheet results	DHIS results
(1)1 <sup>st</sup> ANC visit	237	12	-	317	261	333
(2)Women counselled for VCT (pre-test	233	184	324	333	268	316



counselled)						
(3) ANC tested for HIV	269	252	320	333	266	311
(4) Women testing positive	54	59	51	66	51	63
(5) Women retested				39	56	-
(6) Women testing positive on retest				5	0	-
(7) HIV positive women with CD4 result	51	18	-	32	49	-
(8) HIV positive women receiving ART	6	11	27	21	18	63
(9) HIV positive women with CD4 cell count under $\leq 200$	18	10	-	13	14	-
(10) AZT courses dispensed to pregnant women at ANC	-	-	-	83	68	-
(11) NVP tablets dispensed to pregnant women at ANC	30	34	26	51	50	59
(12) pregnant women receiving prophylaxis – Cotrimoxazole	81	0	-	38	12	-

#### 5.6.1.2. Maternity indicators

Table 18 shows data elements recorded on maternity indicators. There is very limited data on this as many clinics do not offer maternity services, only hospitals and Community Health Centres do. All the Kouga LSA facilities have no data on this except for Joubertina and Kruisfontein. However, the limited number in terms of the maternity service provision does not make a difference in data recording. Data provided by the two facilities does not tally on case registers, monthly summary sheets and DHIS.

**Table 18: Maternity indicators: Joubertina and Kruisfontein**

INDICATOR	MID-TERM REVIEW			FOLLOW-UP REVIEW		
	Case registers	Monthly summary sheet	DHIS	Case registers	Monthly summary sheet	DHIS
(1) Women established positive (at delivery)	-	-	-	2	2	-
(2) Women on ART at delivery	-	-	-	-	-	-
(3) Women on AZT > 4weeks	-	-	-	-	-	-

(4) Women on AZT <4weeks	-	-	-	-	-	-
(5) sdNVP tablets issued in labour ward	1	0	0	0	-	1
(6) Infants given NVP and AZT	0	0	-	2	0	0
(7) HIV positive mothers choosing to formula feed	0	-	10	0	-	30
(8) Live births to women with HIV	0	0	0	2	0	0
(9) No of family planning issued postpartum	0	0	-	19	0	-

### 5.6.1.3. Infant Indicators

Table 19 shows data elements recorded on infant indicators with lots of data recording discrepancies. Data recorded on case registers does not tally with data recorded on monthly summary sheets and DHIS. There are higher figures recorded on indicator 7 (HIV exposed infants exclusively formula fed) however, data presents lot of discrepancies.

**Table 19: Infant Indicators**

INDICATOR	MID-TERM REVIEW			FOLLOW-UP REVIEW		
	Case registers	Monthly summary sheet	DHIS	Case registers	Monthly summary sheet	DHIS
(1) HIV positive mothers presenting at EPI (Expanded Programme on Immunization) clinic at the six week visit	-	-	-	10	16	-
(2) PCR tests done by the six week immunization visit	32	42	41	28	40	41
(3) PCR tests positive at EPI clinic	1	3	3	4	2	7
(4) PCR tests given to mothers at EPI clinic	-	-	-	4	-	-
(5) Mothers established positive	-	-	-	21	-	-
(6) Mothers established negative	-	-	-	46	-	-
(7) HIV exposed infants exclusively formula fed	165	274	255	217	314	345
(8) HIV exposed infants exclusively breast fed	21	16	13	7	12	17
(9) HIV exposed infants exclusively formula fed (recall	-	-	-	-	-	-

period = last 24 hours)						
(10) Infants referred to ART site	6	0	-	-	-	-

### 5.7. Health information system assessment

Professional nurses perceive data collection and collation as a burden and a lot of work for them (63.3%) (See Table 20). Data collection is paper-based in all the facilities. 72.7% reported duplication of data collection in different registers. The number of registers used for data collection varied from 3 to 9. It takes less than three hours (if done daily) to more than a day for PNs to collate data in registers. According to 59% of PNs, a manual with definitions of data elements was provided. PNs were informed about the indicators to be calculated (86.3%).

**Table 20: Assessment of data collection by PNs (n = 22)**

	Post assessment N (%)
Data collection and collation a lot of work to PNs	14 (63.6)
Data collection method – paper based	22 (100)
Duplicated data collection in different registers	16 (72.7)
Number of registers used	
3	5 (22.7)
4-5	10 (45.4)
6-9	7 (31.8)
Period it takes to collate monthly data	
<3hours	2 (9)
3 hours – 1 day	12 (54.5)
> 1day	8 (36.3)
A manual with definitions of data elements was provided	13 (59)
Mention made of indicators to be calculated	19 (86.3)

Managers reported that existing data collection systems did not enable ongoing follow-up of HIV-positive pregnant women from the antenatal period, through labour and delivery to the postnatal period because antenatal and postnatal care was provided at clinics, while deliveries took place in hospitals and the CHC. Although women are given a record of ANC visits, the confidential share code system, which uses the name of the grandmother to code the HIV status of the pregnant woman, contributed to difficulties in follow-up because many women gave different names at antenatal visits and at delivery. This made it difficult to determine the mother's HIV status and to assign the correct code to her newborn baby. Although 72% of PHC clinics provided polymerase chain reaction (PCR) testing of babies born to HIV-positive women, information from the DHIS showed that the number of infants tested for HIV by PCR at 6 weeks and at 9 months was low in relation to the number of women who tested HIV-positive at an ANC visit, confirming that many babies born to HIV-positive women were lost to follow-up by the PMTCT programme.

### 5.8. Support groups

The knowledge levels of HIV positive new mothers (women with babies below the age of two years) and pregnant women on HIV transmission, prevention, feeding practices etc were assessed using a structured questionnaire administered by the support group (SG) project manager (see Table 21). Women from seven, out of the nine clinics/sites, were included. The eligibility criteria used was that women had to be HIV positive, be pregnant or new mothers and be part of the support groups. The questionnaires were administered according to availability of participants and because the numbers were very low, less than 10 per site, all 32 women from the nine clinics were included.

**Table 21: Pre- and post-intervention participants' responses on HIV infection prevention of babies by their mothers**

Variable	Pre-intervention Yes N (%)	Post-intervention Yes N (%)
<b>Marital status</b>		
Single	27 (77.1)	5 (62.5)
Married	4 (11.4)	1 (12.5)
Cohabiting	1 (2.9)	2 (25.0)
Widowed	2 (5.7)	0
<b>Source of income</b>		
Employed	7 (20.0)	2 (25.0)
Family support	14 (40.0)	4 (50.0)
Child support grant	19 (54.3)	5 (62.5)
<b>MTCT of HIV</b>		
Sometimes	28 (80.0)	6 (75.0)
Never	4 (11.4)	0
Always	1 (2.9)	1 (12.5)
Can an HIV positive pregnant woman transmit HIV to her baby during pregnancy?	19 (54.3)	3 (37.5)
Can an HIV positive pregnant woman transmit HIV to her baby during delivery?	24 (68.6)	7 (87.5)
Can an HIV positive pregnant woman transmit HIV to her baby during breastfeeding?	26 (74.3)	7 (87.5)
<b>HIV Prevention</b>		
Can HIV infection be prevented through proper delivery?	19 (54.3)	7 (87.5)
Can HIV infection be prevented by avoiding breastfeeding?	23 (65.7)	4 (50.0)
Can HIV infection be prevented by exclusively breastfeeding for 6 months?	16 (45.7)	4 (50.0)
Can HIV infection be prevented by exclusively formula feeding?	23 (65.7)	7 (87.5)
Can HIV infection be prevented by taking ARVs during pregnancy?	15 (42.9)	3 (37.5)
Can HIV infection be prevented by taking ARVs during delivery?	21 (60.0)	4 (50.0)
Can HIV infection be prevented by giving the baby NVP syrup within 72 hours after delivery?	20 (57.1)	5 (62.5)
<b>Infant feeding choice</b>		

Exclusive breastfeeding	7 (20.0)	1 (12.5)
Exclusive formula feeding	25 (71.4)	5 (62.5)
<b>Formula feeding method</b>		
Bottle only	24 (68.6)	5 (62.5)
Both bottle & cup	4 (11.4)	1 (12.5)

None of the participants was below the age of 18 as their ages started from 20 – 42 years with 24 (75.0%) of them unmarried but with partners, two widowed (6.3%) and four married (12.5%). Only seven (21.9%) participants were employed with 13 (40.6%) dependent on their families for support while 17 (53.1%) received child support grant. Seven of the respondents have ever been involved in a support group before and 21 (65.6%) ever talked with a healthcare worker about Prevention of Mother-to-Child Transmission (PMTCT) of HIV. When the participants were asked if a mother may transmit the virus to her baby, 25 (78.1%) responded that sometimes while four (12.5%) responded never. When asked if an HIV positive woman can infect her baby during pregnancy, delivery or breastfeeding, 17 (53.1%), 23 (71.9%) and 25 (78.1%) of the participants responded in the affirmative, respectively. When asked if HIV can be prevented through proper delivery, avoiding breastfeeding, 23 (71.9%), and 22 (68.8%) responded yes, respectively.

Four (12.5%) of the participants revealed that they have not disclosed their status to their partners/husbands because they were afraid they may chase them out of the house. When the participants were asked which feeding method they had chosen for their babies, seven (21.9%) had chosen exclusive breastfeeding while 22 (68.8%) had chosen formula feeding with 21 (65.6%) using a bottle and four (12.5%) using both a bottle and a cup for feeding. Of the formula feeding mothers, six (18.8%) admitted to keeping leftover formula feed with three (9.4%) keeping it for less than an hour and two (6.3%) kept it for more than 2 hours. When the participants were asked at what age a baby should be started on solids, two (6.3%) responded that at less than three months, three (9.4%) said at 3 months while 23 (71.9%) said that at six months. When the participants were asked if women in their community are expected to breastfeed their babies, five (62.5%) said yes and also mentioned that community members disapprove of those women who do not.

The knowledge levels of HIV positive new mothers (women with babies below the age of two years) and pregnant women on HIV transmission, prevention, feeding practices etc were assessed using a structured questionnaire administered by the support group (SG) project manager. Women from seven, out of the nine clinics/sites, were included. The eligibility criteria used was that women had to be HIV positive, be pregnant or new mothers and be part of the support groups. The questionnaires were administered according to availability of participants and because the numbers were very low, less than 5 per site, all available women, 3 pregnant and 14 new mothers, were included.

None of the participants was below the age of 18 as their ages started from 20 – 38 with 14 (82.4%) of them unmarried but with partners, two widowed and one married. Only 6 (35.3%) participants are employed with 10 (58.8%) dependent on their families for support while 35.3% receive child support grant. Six of the respondents have ever been involved in a support group before and 14 (82.4%) ever talked with a healthcare worker about Prevention of Mother-to-Child Transmission (PMTCT) of HIV. When the participants were asked if a mother may transmit the virus to her baby, 13 (76.5%) responded that sometimes while 2 (11.8%) responded never. When asked if an HIV positive woman can infect her baby during pregnancy, delivery or breastfeeding, 52.9%, 76.5% and 88.2% of the participants responded in the affirmative, respectively. When asked if HIV can be prevented through proper delivery and avoiding breastfeeding, 82.4% and 94.1% responded yes, respectively.

Two (11.8%) of the participants revealed that they have not disclosed their status to their partners/husbands because they are afraid they may leave them. When the participants were asked which feeding method they had chosen for their babies, three (17.6%) had chosen exclusive breastfeeding while 11 (64.7%) had chosen formula feeding with 47.1% using a bottle and 17.6% using both a bottle and a mug for that purpose. Of the formula feeding mothers, 35.3% admitted to keeping leftover formula feed with 5.9% keeping it for less than 30 minutes, 17.6% kept it for an hour and 11.8% kept it for more than 2 hours. When the participants were asked at what age a baby should be started on solids, two (11.8%) responded at less than and at 3 months, respectively while 70.6% responded at six months.

A follow up assessment three months later on the HIV knowledge levels of HIV positive women who have been attending support groups in nine clinics in the Kouga LSA for more than three months was conducted. Data could only be collected from four of the nine clinics as some were still struggling to get women to join the support groups for fear of stigmatization or those that had managed to were experiencing low turn up as a result of the harvest season. Even the clinics that managed to get women to join the support groups had very little numbers

All the participants had told somebody about their HIV status with all, except, one saying that they had told their husbands/partners. When the participants were asked whether anyone has treated them badly because of their HIV status, two (25.0%) said yes. When asked how they feel about being HIV positive, four (50.0%) said they feel hurt while another four said they do not really care. As these were new mothers, when asked which form of infant feeding they had chosen, five (62.5%) said that they chose exclusive formula feeding while one was practicing exclusive breastfeeding. The reasons cited by the participants for choosing a particular form of feeding was to protect the baby from infection 4 (50.0%) or that the health worker advised so 3 (37.5%). When asked whether they think left over formula should be kept for the next feed, they all said no, with the exception of one, who practices this and mentioned that she keeps it for less than 30 minutes. All mothers mentioned that a baby should be started on solids at the age of six months and more.

When asked if women in their community are expected to breastfeed their babies, five (62.5%) said yes and also mentioned that community members disapprove of those women who do not.

## **6. DISCUSSION**

### **6.1 Process of audit and intervention**

The assessment identified a need for additional training of professional nurses, and a need for a formal system to update staff on new or revised guidelines. Lay counsellors need comprehensive training, role clarification and supervisory support. A formal supervisory system needs to be established and communicated.

### **6.2 Uptake of C & T**

A critical starting point for ensuring universal PMTCT access is the elimination of missed opportunities (Perez et al. 2004). These included provision of VCT to pregnant women and the provision of ARV prophylaxis to HIV-positive women and their babies. Despite the availability of VCT services at clinics, only 67.5% of pregnant women were tested, representing a missed opportunity of 32.5% for VCT. As knowledge of the woman's HIV status is a pre-requisite for effective PMTCT programme implementation, this resulted in missed opportunities at all

subsequent health service contacts. [according to DHIS it is 32.2, not 43, as suggested]. HIV testing enables access to PMTCT interventions (Konki et al. 2007) such as treatment and support.

A study on the implementation of single-dose Nevirapine for prevention of MTCT of HIV in Cape Town found that obstacles included health policy (resource constraints, inadequate planning and preparation, role players not consulted, tardy HIV counselling training for staff, limited training facilities, lack of logistics), health services (staff shortage, increased workload, few, small VCT rooms, low quality of counselling, lack of follow-up support, absenteeism among counsellors), and health-seeking behaviour (inadequate knowledge/awareness, lack of partner involvement/serostatus disclosure, social stigma, shock/denial, low compliance, low socio-economic status) (Delva *et al.* 2006).

### **6.3 Missed opportunities**

#### **Family planning**

Interviews with HIV-positive women found that 44% had missed opportunities for family planning counselling after delivery and 84% were not using condoms. This highlights the importance of family planning and HIV service integration and ensuring women's access to reproductive health choices and care during pregnancy and childbirth. Family planning and reproductive choices should receive more attention in PMTCT programme implementation and staff need to be provided with training.

#### **PCR testing**

The DHIS showed that few babies were tested for HIV infection despite the availability of PCR testing at clinics. There is a need to strengthen the referral system and to ensure stronger coordination between clinics and delivery sites in order to improve mother and baby outcomes.

#### **Infant feeding**

Although 83% of HIV-positive women reported formula feeding, lay health counsellors lacked confidence in their ability to counsel mothers about infant feeding practices and nurses were uncertain about exclusive breastfeeding guidelines. The use of gripe water and other traditional medicines is an area that needs to be addressed in infant feeding guidelines. Introducing other drinks may predispose the infant to infections. The assessment identified a need for additional training of professional nurses, and a need for a formal system to update staff on new or revised guidelines. Lay counsellors need comprehensive training, role clarification and supervisory support. A formal supervisory system needs to be established and communicated.

### **6.4 Support groups**

The lack of participation of HIV-positive women in support groups is a major concern, as participation in support groups assists HIV-positive women in dealing with stigma and isolation, provides emotional support, improves HIV knowledge and promotes positive living (Miller & Cole, 1998; Summers, Robinson, Capps, Zisook, Atkinson, McCutchan *et al.*, 2000).

HIV-positive women need education, counselling and support during pregnancy (Besser, 2002). While HIV positive new mothers may expect support from family, friends, partners and the health care system, they may not get it (Besser, 2004). Support groups, therefore, may act as a safe haven for such women where they can share their experiences, talk about HIV, and learn from other infected individuals (Summers et al., 2000). In this study, the low numbers of women who have

been involved in the support groups may be attributed to fear of stigmatisation. Stigma associated with HIV/AIDS causes many people to not disclose their status, fearful of finding more information about HIV and asking for support (Visser *et al.*, 2005). The low numbers of HIV positive new mothers and pregnant women who participated in this study, even three months after the initiation of the support groups, may be attributed to some women being afraid of being stigmatized by community members, not wanting their HIV status known. Another reason was that most people were trying to make a living at the time the study was conducted year by taking up part time jobs as it was orange harvesting season. With all new things, people are sceptical to accept and change is not easily accepted. In a country where gender discrimination and inequality is still rife, women are made to feel inferior to their male counterparts and disempowered and the situation is worse for women living in traditional African communities (Visser *et al.* 2005).

The knowledge levels of the participants about HIV prevention from the mother to the baby is quite high. This is confirmed by the reasons given by the participants for choosing a certain form of feeding, with half mentioning protecting their babies from HIV infection as a reason. The results in this study are contrary to what was found by Doherty *et al.* (2006), where young, unmarried and unemployed mothers had a difficult time with protecting the decisions they had made on infant feeding. These authors also discovered that the young and unemployed mothers' fear of disclosure of their HIV status and stigma made them unable to resist family and community norms that encourage early introduction of fluids and foods. In this study, the disclosure rate amongst these women was quite high, with almost all of them having told the husband or partner about their HIV positive status. A study conducted in Cape Town by Simbayi *et al.* (2007) showed a significant relation between fear of potential adverse reactions and non-disclosure to sex partners. It seems that most of the participants have accepted their HIV positive status. Even so, cultural influences seem to place a burden on HIV positive women who do not breastfeed their babies. This was observed in a study conducted in Tanzania where women who chose to exclusively breastfeed had not disclosed their status to anyone, including their partners, some lived with their extended families and none of them were employed (Leshabari *et al.* 2007).

## 6.5 M & E

Monitoring and evaluation of PMTCT programmes at each stage is crucial in identifying strategies for improving coverage where necessary (Reithinger *et al.* 2007). Poor data collection from several case registers based on indicators compromises monitoring (Reithinger *et al.* 2007). Positive women who refuse counselling and testing may give a wrong picture of coverage. (Stringer *et al.* 2005; Sherman *et al.* 2004). Indicators used in PMTCT programmes are quantitative and may omit crucial information on follow up. As was the case in this study, infant follow up needs attention. Developed countries succeeded in eradicating AIDS in children by ensuring high service coverage and by systematically targeting each risk factor (US Public Health Service Task Force, 2005).

Discrepancies between information reported by HIV-positive women at postnatal visits and the DHIS reflect challenges in the monitoring and evaluation (M&E) system. Furthermore, the share-code made it extremely difficult for health care workers to determine which women needed to be followed up. Other challenges to M&E reported by managers included a lack of time for data entry, insufficient staff, a lack of recent training, and migration of clients to other areas. The reporting system consisted of numerous data entry registers, further hindering the integration of information, and raising doubts about the accuracy and quality of the information submitted.

Health care facility indicators and information collected at healthcare facilities are essential to monitoring and evaluation, and providing quality healthcare services to patients. From the indicator results presented on table 17, 18 and 19, there seems to be very little change in terms of



the way facilities in Kouga LSA have been recording data during mid-term review and follow-up review. Only less than a handful clinics (St Francis Bay, Moses Mabida, Lukhanyiso and Kareedouw) seems to be better with data recording because most of the time they present data with fewer discrepancies. Kareedouw clinic has been consistently recording tallying data on most of the indicators. With regard to ANC and PNC indicators, we get the impression that data is not recorded on women who are “retested on HIV” and “women who turned HIV positive on retest”. Having data for this indicator will actually inform the health care providers on the number of patients to receive ART. There seems to be a big challenge with regard to data recording for maternity indicators. The few facilities that provide the maternity service are not recording data on the most important indicators like “women established positive at delivery; “women on ART at delivery etc”. In terms of the infant indicators, there are high figures recorded on “HIV exposed infants exclusively formula fed” however, the data presents lot of discrepancies. UNICEF (2008) estimates that not breastfeeding (formula feeding) is responsible for 1.5 million child deaths per year. Therefore, it could be concluded that the wrong-recorded figures by the healthcare providers lead to a miscount of formula to be supplied to the facilities. The shortage of milk at facility really hampers the PMTCT objective of having fewer (none) infants infected with HIV. Due to shortage of milk at some health care facilities, many mothers who chose to exclusively formula feed ends up facing challenges of mixed feeding.

Findings of this study revealed that nurses are overwhelmed with their work and as a result they view data collection as a burden. Coupled with the discordant data that was recorded in case registers, monthly sheets and DHIS, there is a need to pilot the use of administrative personnel for data collation. The number of registers that are paper-based and repeat recordings that need to be done manually perpetuates errors in recording. The high patient: nurse ratio may encourage nurses to focus on patient care and to neglect proper data recording. The mistrust between nurses and lay counsellors worsens the workload of nurses. Lay counsellors could be utilised for pre and post test counselling as they are trained on confidentiality issues. Some clinics have computers, but the staff is computer illiterate.

## 6.6 Disclosure

Even though accepting to be tested for HIV is a key step in the prevention of HIV infection, disclosing one’s HIV positive result to a partner and others still remains a challenge for many, especially for women. The WHO and CDC (Medley *et al.* 2004) emphasise the disclosure of an HIV positive result to a spouse or a sexual partner as an important HIV prevention goal. They suggest that when couples know their HIV status they can engage in sexual relations that reduce the chances of re-infection in the case that one or both partners are HIV positive. Couples can also make informed decisions on how to prevent unplanned pregnancies or to prevent MTCT in the event they plan to have children. Uptake of care and support services such as adherence to ARV treatment improves where one has disclosed their status to close networks (Fitzgerald *et al.* 2006).

However, for theory to translate into reality there are a number of factors that need to be considered in order for women to find it easier to disclose their HIV positive results to others such as their partner, family members and friends. Discussing the decision with a partner or family about going for an HIV test should be the first step in the disclosure process. However this is not as easy in reality. According to Jackson (2002) married women in most of Africa can rarely make decisions about HIV testing and the uptake of ARVs or changing their feeding practices without wider family involvement, particularly that of their spouse. This could be one of the many reasons as to why women find it difficult to disclose their HIV positive results if, in the first instance, the decision to go for an HIV test was not shared with the partner and the result comes out positive. The

assumption made by Jackson (2002) is that if people are told they may ask or guess a result and it might be difficult for an HIV positive woman then to hide a positive result.

Given these difficulties, the pre- and post- test counselling sessions that are offered to women during their first ANC visit should emphasise the benefits of disclosing one's HIV result especially to a partner and to close family members. This is especially important for those women who test HIV positive as they have to disclose to their partners in order to take measures that will prevent them from infecting their partner in case he is negative or re-infecting him in case he is also positive. It is equally important for women who test HIV negative to disclose to their sexual partners especially where the status of the other partner is not known. Additionally, the involvement of men in the counselling process plays an important role in helping women to disclose their results (Noble 2007). Couple counselling would facilitate discussion about how both partners felt about going for an HIV test, establish ways in which they could share their test results and potentially reduce the potential for blame.

Confidentiality is also important in the process of disclosure of HIV results. For most of the women interviewed their worry was (and is) that their HIV positive result will not remain a secret if they shared it with others. The study revealed that most women would thus not disclose their HIV positive results to some of their family members or friends due to fear of betrayal. Only half of the women interviewed suggested that if they found out that they were HIV positive they would share their results with their partner and a quarter of the women interviewed suggested would share the result with a family member or a friend.

## **6.7 ANC and PNC experiences**

There was a significant increase in the number of women who were tested for HIV during the previous pregnancy ( $p=0.000$ ), and those that new their HIV test results ( $p=0.000$ ). Waiting period at facilities was cited as a serious concern. The nurses were described as friendly to their clients and this promotes trust. However, the issue of punctuality calls for nurses to arrive at work on time. The significant improvement in clients' experiences at the facilities is an indication that service delivery is improving. Access to facilities during delivery is a concern as born before arrivals may remain high. The high proportion of women intending to deliver at facilities is encouraging. All women who were tested during the previous pregnancy knew their results – a positive effect of the PMTCT programme.

## **7. CONCLUSION AND RECOMMENDATIONS**

Prevention of new HIV infections is a critical imperative for South Africa, and PMTCT is one of the most effective HIV prevention interventions. In order to reduce missed opportunities for PMTCT, we propose a framework based on a modification of the 1978 Alma Ata Declaration, consisting of formal health system strengthening, intersectoral liaison, and enhancing community capacity in support of PMTCT implementation (Figure 1).

*Formal health system strengthening* is an underlying requisite for PMTCT programme strengthening as it ensures its integration into existing PHC services. Many PHC clinic managers already function as PMTCT programme champions, and so a brief orientation could be used to help staff understand the concept of missed opportunities and to develop strategies for reducing these, within the context of comprehensive PHC. Formal health system strengthening should also include

the implementation of the new PMTCT guidelines, addressing staff development needs, implementing supportive supervision and strengthening the M&E system.

The health information systems needs to be strengthened by reducing the number of registers. This will call for redesigning of the registers at provincial level. Training nurses to be computer literate will reduce the unnecessary burden of manual data capturing as it is easier to collate data using computer software such as Excel.

The workload of nurses can be reduced by delegating responsibilities such as pre-and post test counselling to lay counsellors. The lay counsellors will develop a trusting relationship with communities as health care workers. The recommendation will be to include pre- and post test counselling in the list of responsibilities of lay counsellors. As part of succession planning and to alleviate shortage of nursing staff, lay counsellors who do well could be targeted for training as future nurses.

Due to the slow progress on patient data recording, there is definitely a need for further training on the importance of data recording and how to record accurate patient information. National and global indicators are reported based on healthcare facility indicators, it is therefore necessary to improve data recording at facility level. Knowledge sharing sessions amongst healthcare facilities might also assist with a better data recording system by healthcare providers.

The assessment identified a need for additional training of professional nurses, and a need for a formal system to update staff on new or revised guidelines. Lay counsellors need comprehensive training, role clarification and supervisory support. A formal supervisory system needs to be established and communicated.

### **Support groups**

Since this was still a new initiative, something that had not yet taken root and might not have been viewed as being of any value to those who are eligible to join or it being labelled as a women's thing, therefore something of no use, more education and information needs to be sent out to the communities about the importance of the support groups, not only for the HIV positive women but for their families and communities at large. Emphasis should be made that HIV positive women do not, cannot and should not function in isolation but should be treated with compassion and understanding by all those close to them. Families of HIV positive women, therefore, should be encouraged to also attend support groups as the information they may receive would help them understand how to live with the disease. The health personnel should be involved by emphasizing to the HIV positive women the benefits of being a part of a group, encouraging them to join such groups.

## REFERENCES

- Besser, M.J. (2002). Mothers-to Mothers-to-be: Peer counselling, education and support for women in pregnancy in Cape Town, South Africa. International Conference on AIDS, July 7-12, abstract no. Mo0rF1031.
- Besser, M.J., Ebdon, M. & Kirsten, T. (2004). The mothers' programs: Mothers' Creations – a successful income generation project for women living with HIV. International Conference on AIDS, July 11-16, abstract no. TuPeD5276.
- Black V, Brook S, Chersich M. (2009). Effect of Human Immunodeficiency virus treatment on maternal mortality at a tertiary centre in South Africa: 5-year audit. *Obstetrics and gynecology* Aug 114(2) Part 1; 292-299.
- Coovadia HM, Rollins NC, Bland RM, Little K, Bennish ML, Newell ML (2007). Mother-to-child transmission of HIV-1 infection during exclusive breastfeeding in the first 6 months of life: an intervention cohort study. *Lancet* 369: 1107-1116.
- Delva W, Draper B, Temmerman M. Implementation of single-dose Nevirapine for prevention of MTCT of HIV—lessons from Cape Town. *South African Medical Journal* 2006; 96(8):706, 708-9
- Doherty T, Besser M, Donohue S, Kamoga N, Stoops N, Williamson L, Visser R. An evaluation of the prevention of mother-to-child transmission (PMTCT) of HIV initiative in South Africa: lessons and key recommendations. Durban: Health Systems Trust, 2003.
- Doherty, T., Chopra, M., Nkonki, L., Jackson, D. & Greiner, T. (2006) Effect of the HIV epidemic on infant feeding in South Africa: "When they see me coming with the tins they laugh at me". *Bulletin of World Health Organisation*, 84 (2): 90-96.
- Eastern Cape Socio-Economic Consultative Council (ECSECC). District Socio-Economic Profile: Cacadu. East London: ECSECC, 2007.
- Family Health International. Baseline Assessment Tools for Preventing Mother-to-Child Transmission (PMTCT) of HIV. Arlington, Virginia, USA: Institute for HIV/AIDS, 2003.
- Fitzgerald, M., Collumbien, M., Gumede, Z. & Hosegood, V. Getting around disclosure: social status and support of patients enrolled in an ART programme in rural South Africa. [Online], Available: <http://www.aids2006.org/pag/Abstracts.aspx?AID=11694> 1/18/2008
- Global Expanded Inter-agency Task Team on Prevention of HIV Infection in Pregnant Women, Mothers and their Children. Report Card on Prevention of Mother-to-Child Transmission of HIV and Paediatric HIV Care and Treatment in Low- and Middle-Income Countries: Progress on Scaling-up 2004-2006. Johannesburg: Conference booklet for the PMTCT High Level Global Partners Forum 2007, 2007.
- Jackson, H. (2002). AIDS Africa - Continent in Crisis. Harare. Zimbabwe: SAFAIDS. Global HIV/AIDS news and analysis 12 August 2009
- Kuhn L, Sinkala M, Kankas C, Semrau K, Kasonde P, Scott N, Mwiya M, Vwalika C, Walter J, Tsai WY, Aldrovandi GM, Thea DM. High uptake of exclusive breastfeeding and reduced early post-natal HIV transmission. *PLoS One* 2007; 12: e1363-e1363.
- Leshabari, S.C., Blystad, A. & Moland, K.M. (2007). Difficult choices: Infant feeding experiences of HIV-positive mothers in northern Tanzania. *Journal of Social Aspects of HIV/AIDS*, 4 (1): 544 – 555.

Medley, A., Garcia-Moreno, C., McGill, S. & Maman, S. (2004). Rates, barriers and outcomes of HIV serostatus disclosure among women in developing countries. *Bulletin of World Health Organization* 82(4):299-307, Baltimore: USA.

Miller GE, Cole SW (1998). Social relationships and the progression of human immunodeficiency virus infection: A review of evidence and possible underlying mechanisms. *Annual Behavioural Medicine* 1998; 18: 49-57.

National Department of Health. HIV and AIDS and STI Strategic Plan for South Africa, 2007-2011. Pretoria: Department of Health, 2007.

Nkonki LL., Doherty TM, Chopra M, Schaay N. Kendall C. Missed opportunities for participation in prevention of mother-to-child transmission programmes: simplicity of Nevirapine does not necessarily lead to optimal uptake. A qualitative study. *AIDS Research and Therapy* 2007 Nov 22; 4: 27.

Noble, R. (2007). *Preventing Mother to Child Transmission in Practice*. [Online], Available: <http://www.avert.org/pmtct-hiv/9/20/2007>

Paintsil E, Andiman WA. (2009) Update on successes and challenges regarding mother-to-child transmission of HIV. *Curr Opin Pediatr*,21(1), 94-101.

Peltzer K, Mosala T, Shisana O, Nqeketo A, Mngqundaniso N. Barriers to prevention of HIV transmission from mother to child (PMTCT) in a resource-poor setting in the Eastern Cape, South Africa. *African Journal of Reproductive Health* 2007; 11; 57-66.

Perez, Freddy, Mukotekwa, Tarisai, Miller, Anna, Orne-Gliemann, Joanna, Glenshaw, Monica, Chitsike, Inam & Dabis, François. Implementing a rural programme of prevention of mother-to-child transmission of HIV in Zimbabwe: first 18 months of experience. *Tropical Medicine & International Health* 9 (7), 774-783. doi: 10.1111/j.1365-3156.2004.01264.x

Piwoz EG, Humphrey JH, Tavengwa NV, Iliff PJ, Marinda ET, Zunguza CD, Nathoo KJ, Mutasa K, Moulton LH, Ward BJ. The impact of safer breastfeeding practices on postnatal HIV-I transmission in Zimbabwe. *American Journal of Public Health* 2007; 97: 1249-1254.

Recommendations for use of antiretroviral drugs in pregnant HIV-1 infected women for maternal health and interventions to reduce perinatal HIV-1 transmission in the United States. Washington: US Public Health service Task Force, 2005. In Bulletin of the World Health Organisation, 2008. Bull World Health Organ vol. 86 (1) Geneva Jan. [www.scielosp.org/scielo.php?pid=S0042-96862008000100016&script=sci-arttext&tlng=en](http://www.scielosp.org/scielo.php?pid=S0042-96862008000100016&script=sci-arttext&tlng=en)

Reithinger R, Megazzini k, Durako SJ, Harris R, Vermund SH 2007. Monitoring and evaluation of programmes to prevent mother-to-child transmission of HIV in Africa. *British Medical Journal* 334(2 June) :1143-1146. [www.bmj.com/cgi/content/full/334/7604/1143](http://www.bmj.com/cgi/content/full/334/7604/1143) accessed 14 August 2009.

Simbayi, L.C., Kalichman, S.C., Strebel, A., Cloete, A., Henda, N. & Nqeketo, A. (2007). Disclosure of HIV status to sex partners and sexual risk behaviours among HIV-positive man and women, Cape Town, South Africa. *Sexually Transmitted Infections*, 83: 29 – 34.

Skinner D, Mfecane S, Gumede T, Henda N, Davids A. Barriers to accessing PMTCT services in a rural area of South Africa. *African Journal of AIDS Research* 2005; 4(2): 115–123.

Summers, J., Robinson, R.C.L., Zisook, S., Atkinson, J.H., McCutchan, E., Deutsch, R., Patterson, T. & Grant, I. (2000). The influence of HIV-related support groups in survival in women who lived with HIV: A pilot study. *Psychosomatics*, 41: 262 – 268.

UNICEF, South Africa, "UNICEF and PMTCT in South Africa".

[http://www.unicef.org/southafrica/hiv\\_aids\\_809.html](http://www.unicef.org/southafrica/hiv_aids_809.html). Accessed 6 Aug 2008

United Nations. Rates of Mother-to-Child Transmission and the Impact of Different PMTCT Regimens. Report of a consultation organised by the UNAIDS Reference Group for Estimates, Modelling and Projections, February-March 2005. New York, USA: UNAIDS, 2005.

Visser, M., Mundell, J., de Villiers, A., Sikkema, K. & Jeffery, B. (2005). Development of structured support groups for HIV-positive women in South Africa. *Journal des Aspects Sociaux du VIH/SIDA*, 2 (3): 333 – 343.

World Health Organisation. Antiretroviral Drugs for Treating Pregnant Women and Preventing HIV Infections in Infants in Resource-Limited Settings: Towards Universal Access. Geneva, Switzerland: World Health Organisation, 2006.

World Health Organisation. HIV and Infant Feeding: Framework for Priority Action. Geneva, Switzerland: World Health Organisation, 2003.

World Health Organisation. Declaration of Alma Ata. (1978). International conference on primary health care, Alma-Ata, USSR, 6-12 September 1978. Geneva: WHO, 1978.

ADDENDUM A: PMTCT INDICATORS AND DATA ELEMENTS

KOUGA LSA INDICATOR RESULTS FOR MID-TERM REVIEW AND FOLLOW-UP REVIEW

Table 22: ANC Indicators

ANC AND PNC INDICATORS													
FACILITY NAME	REVIEW PERIOD	(1) No. of 1 <sup>st</sup> ANC visit	(2) No. women counselled for VCT (pre-test counselled)	(3) No. ANC tested for HIV	(5) No. of women testing positive	(6) No. women retested	(7) No. women testing positive on retest	(8) No. of HIV positive women with CD4 result	(9) No. of HIV positive women receiving ART	(10) No. HIV positive women with CD4 cell count under ≤500	(11) No. AZT courses dispensed to pregnant women at ANC	(12) No. of NVP tablets dispensed to pregnant women at ANC	(13) No. pregnant women receiving prophylaxis – bactrim
1. ST FRANCIS BAY	Mid-term review	20	20(-)20	20(20)20	0(0)0		0	0	0	0	0(0)0	0	0
	Follow-up assessments	14(12)12	12(12)14	12(11)14	4(4)2	2(2)	0(0)	4(6)	0(2)5	2(2)	4(4)	2(2)2	4
2. KIRKWOOD	Mid-term review	13	13(-)13	13(13)13	4(4)4		1	0	0	0	0(5)	0(5)	1
	Follow-up assessments	15(12)5	15(12)12	15(12)12	0(0)0	(5)	(0)	(0)	(0)0	(0)0	(0)	(0)0	0(0)
3. CLARKSON	Mid-term review	6	3(4)5	3(4)5	0(0)	0(0)	0(0)	0(0)	0(0)	0(0)	0(0)	0(0)	0(0)
	Follow-up assessments	5(7)7	5(7)7	5(7)7	2(2)2	0(1)	0(0)	0(3)	0(1)	0(0)	(1)	(1)1	0
4. THORNHILL	Mid-term review	23	(-)8	7(8)8	0(1)1		0	1(-)0	0	0	1(0)0	1(0)0	0
	Follow-up assessments	5(12)9	6(12)4	6(12)4	1(3)2	0(0)	0(0)	2(3)	0(0)1	0(0)	3(2)	4(2)1	23
5. BAYENIA	Mid-term review												
	Follow-up assessments												
6. JOUBERTINA	Mid-term review	4	4(-)4	4(4)4	0(-)1		0	0(-)2	0	0	0	0	0
	Follow-up assessments	7(3)5	7(3)5	7(3)5	3(0)2	4(0)	2(0)	3(0)	0(2)	0(0)	5(0)	0(2)2	0
7. PATENSIE	Mid-term review	2	9(11)8	9(8)8	2(1)1		0	0(0)0	0	0	0(0)0	0(0)0	0
	Follow-up assessments	25(-)8	25(-)8	25(-)0	6(-)0				0(-)5	0	0	0(-)5	0(0)
8. KRUISFONTEIN	Mid-term review	23	14(33)33	33(33)33	1(1)1		0(1)	0(0)2	0(0)	0(0)	2(2)2	2(2)2	0(0)
	Follow-up assessments	36(23)34	36(23)34	36(23)34	6(0)2	(2)	(0)	(0)	0(1)2	0(0)1	4(5)	2(2)2	0
9. PELLSSUS	Mid-term review		(-)28	(-)28	(-)8			(-)3				(-)0	
	Follow-up assessments	27(40)40	27(40)40	27(40)40	3(4)4	14(0)	(0)	(3)	0(4)	(0)	(6)	(5)4	1
10. LOUWATER	Mid-term review	6	6(-)6	12(12)12	1(1)1		1	0(-)0	1	1	0(0)0	0(0)0	1
	Follow-up assessments	11(12)6	11(12)6	11(12)6	1(1)0	(1)	(0)	(0)	0(1)	0	2(2)	1(1)1	1(1)2
11. BERGSIG	Mid-term review		5(-)5	4(5)5	1(0)0		0	0(-)0	0	0	0(-)0	0(-)0	0
	Follow-up assessments	11(8)4	11(2)2	11(2)2	1(0)0	(4)	(0)	(0)	0(1)	1(0)	3	1(1)1	0

ANC AND PNC INDICATORS CONT.													
FACILITY NAME	REVIEW PERIOD	(1) No. of 1 <sup>st</sup> ANC visit	(2) No. women counselled for VCT (pre-just counselled)	(3) No. ANC tested for HIV	(5) No. of women testing positive	(6) No. women retested	(7) No. women testing positive on retest	(8) No. of HIV positive women with positive women with	(9) No. of HIV positive women receiving ART	(10) No. HIV positive women with CD4 cell count	(11) No. AZT courses dispensed to pregnant women at	(12) No. of NVP tablets dispensed to pregnant women at	(13) No. pregnant women receiving prophylaxis –
12. MOSES MARIDA	Mid-term review	15	20(20)20	20(20)20	1(1)1			3(1)1	0(0)3	7(0)		4(3)3	73(0)
	Follow-up assessments	[-]13	13(13)13	13(13)13	5(2)12	(5)	0(0)	5(5)	(1)4	0(1)	11(10)	3(0)4	
13. SANDDRIF	Mid-term review		16(-)16	16(-)16	16(16)3			3	0(-)1	1		1(1)1	0
	Follow-up assessments	11(-)11	11(-)12	11(-)18	2(-)2	3	0	2	0	0		0	
14. PATERSON	Mid-term review	9(-)-	9(-)7	7(1)7	2(1)1			2(1)	1(-)0	1		0(0)0	0
	Follow-up assessments	6(-)21	6(-)21	6(-)19	1(-)6			0	(-)3	0	5	5(-)3	
15. LUKHANYISO	Mid-term review	23	23(23)23	18(19)23	4(5)5			1(5)	1(0)2	1(0)		2(5)5	
	Follow-up assessments	26(20)25	26(20)20	26(20)20	3(8)8	0(4)	0(0)	0(8)	21(10)10	0(7)	13(10)	8(10)10	0
16. STORNSRIVIER	Mid-term review		(-)3	(-)3	0				0			0	
	Follow-up assessments	9(6)6	9(6)6	9(6)6	0(0)0	0(3)	0(0)	0(0)	(-)1	0(0)	1(1)	1	
17. KAREEDOUW clinic	Mid-term review	12(12)	26(26)26	26(26)26	2(2)2			2(2)	1(1)1	0(0)		2(2)2	0(0)
	Follow-up assessments	15(15)15	15(15)15	15(15)15	4(4)4	0(3)	0(0)	3(4)	(1)4	1(1)	3(3)	5(4)4	
18. LOERIE	Mid-term review	12	12(-)12	12(12)12	3(3)3			3	1(-)1	0		1(1)1	1
	Follow-up assessments	8(-)8	12(-)12	12(-)12	12(-)3	3	1	0	0(-)1	2	2	2(-)1	
19. MISGUND	Mid-term review	4(0)	4(-)4	9(0)0	2(4)0			2	0	0		1(0)0	0
	Follow-up assessments	5(-)4	5(-)4	5(-)4	0(-)1	4	0	0	(-)2	0	0	1(-)2	
20. KWA NONZAMO	Mid-term review	35	31(33)33	34(33)33	10(9)9			0(0)	0(0)0	6(0)		7(8)0	0(0)
	Follow-up assessments	26(37)44	26(37)37	26(37)37	5(6)6	2(10)	2(0)	6(9)	(1)7	1(1)	15(15)	7(7)7	4(0)
21. ADDO	Mid-term review	11	18(15)15	3(15)15	3(4)4			3(0)	1(4)6	1(4)		6(6)6	
	Follow-up assessments	25(26)28	25(26)26	25(26)26	7(6)6	7(13)	0(1)	6(6)	(2)5	6(2)	6(5)	5(5)5	
22. HANKIE/MASAKHANE	Mid-term review	19(0)	0(19)19	19(19)19	2(6)6			2(8)	0(6)6	0(6)		3(6)6	1(0)
	Follow-up assessments	30(28)28	30(27)27	30(27)27	0(1)1	0(3)	0(0)	(2)	0(4)	0(1)	6(4)	5(4)4	

Table 23: Maternity indicators: Joubertina and Kruisfontein



### MATERNITY INDICATORS

FACILITY NAME	REVIEW PERIOD	(1) No. women established positive (at delivery)	(2) No. women on ART at delivery	(3) No. women on AZT > 4 weeks	(4) No. women on AZT < 4 weeks	(5) No. of sdNVP tablets issued in labour ward	(6) No. of infants given NVP and AZT	(7) No. HIV positive mothers choosing to formula feed	(8) Live births to women with HIV	(9) No of family planning issued postpartum
1. JOUBERTINA	Mid-term review				0(0)	0(0)	0(0)	(-)10	0(0)	0(0)
	Follow-up assessments	2(2)	0	0	0(-)1	2(-)0	0(-)5	2(-)0	19	
2. KRUISFONTEIN	Mid-term review		0		1(0)0	0(0)	0	0(0)	0(0)	0(0)
	Follow-up assessments					0	(-)25	0		

Table 24: Infant Indicators

FACILITY NAME	INFANT INDICATORS										100) No. infants referred to ART clinic
	1) No. of HIV positive infants presenting at EPI immunization visit (last 6 months)	2) No. PCR test done by the six weeks after positive result at EPI clinic	3) No. PCR test given to mothers at EPI clinic	4) No. mothers established positive	5) No. mothers established negative	6) No. mothers established at least 2 (hours)	7) No. of HIV exposed infants (last 6 months)	8) No. of HIV exposed infants exclusively breastfed (last 6 months)	9) No. of HIV exposed infants (last 6 months)	10) No. of HIV exposed infants (last 6 months)	
1. ST FRANCIS BAY	3018	0000	1	4	7	212223	0000	0	1	1	
2. KIRKWOOD	11311	0000	1	4	7	310914	2020	0	1	1	
3. CLARISON	1313	0000	0	0	0	511438	0120	0	0	0	
4. THORNHILL	131	01	0	0	0	181	0000	0	0	0	
5. KAYINA	1000	0000	0	0	0	5000	0000	0	0	0	
6. JOURETTA	0000	0	0	0	0	111	0	0	0	0	
7. PATENNE	1313	0000	0	0	0	5000	0000	0	0	0	
8. KINGSOTEN	3112	0000	3	6	0	121100	1000	0	0	0	
9. PELLERIS	0000	0000	0	0	0	0000	1000	0	0	0	
10. LOUWERWATER	1011	0000	0	0	0	0000	0000	0	0	0	
11. BERGEG	0131	0000	0	0	0	1313	122	0	0	0	
12. MOSES MARIBA	1025	0000	0	0	0	81414	100	0	0	0	
13. SANDRIP	0000	0122	0	0	0	102020	1111	0	0	0	
14. PATRISON	0000	0000	0	0	0	61000	1110	0	0	0	
15. LILIANANTISO	2122	2000	3	22	0	203838	4000	0	0	0	
16. STOKMSHVER	0	0	0	0	0	2176	0	0	0	0	
17. KARENGUW CHIK	2000	1000	0	0	0	21020	111	0	0	0	
18. LOEBE	0000	0000	0	0	0	1315	0	0	0	0	
19. MISOOND	1000	0000	0	0	0	3000	0000	0	0	0	
20. KWA NOKAZALO	0000	0000	0	0	0	6100	0000	0	0	0	
21. AIDOO	1111	0000	0	0	0	40141	1111	0	0	0	
22. KHAKEMASANE	0111	0111	0	0	0	0000	1000	0	0	0	
	181	000	0	0	0	0727	133	0	0	0	

**ADDENDUM B**

**Lay Counsellor Self-Evaluation Form**

**Please choose one and mark with an X.**

1. Do you find your mind going over and over a particular client after counseling?  
**YES NO**

--	--

2. Are you very easily disturbed by someone crying?

**YES NO**

--	--

3. Have you ever lost someone you know due to AIDS?

**YES NO**

--	--

4. Do you always want to know more about HIV/AIDS?

**YES NO**

--	--

5. Are you often agitated or irritable without knowing why?

**YES NO**

--	--

6. Have you become less social?

**YES NO**

--	--

7. Do you find yourself always educating others about HIV/AIDS no matter where you are?

**YES NO**

--	--

8. Are you related to anyone infected with HIV/AIDS?

**YES NO**

--	--

9. Do you have nightmares, dread going to sleep, have difficulty staying asleep, or awaken extremely early in the morning?

---

YES NO

--	--

10. Do you know your HIV status?

YES NO

--	--

11. Have you ever witnessed death by an AIDS infected patient?

YES NO

--	--

12. Do you find yourself wanting to leave your job just because you feel you cannot take it anymore

YES NO

--	--

13. Do you find yourself feeling guilty because you could not help a client

YES NO

--	--