

# Case Studies

## from 9 PMTCT

### Pilot Sites



HEALTH  
SYSTEMS  
TRUST



DEPARTMENT OF HEALTH  
*Republic of South Africa*

# Case Studies from 9 PMTCT Pilot Sites

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**Cover photograph:** The hand of baby Simon Grobler, who has been adopted after being given up by his HIV positive mother, is fortunate to be HIV negative.

#### **Abbreviations used in this publication:**

ATICC	AIDS Training, Information and Counselling Centre
CCLO	Chief Community Liaison Officer
DoH	Department of Health
HIV	Human Immunodeficiency Virus
HST	Health Systems Trust
ISDS	Initiative for Sub-District Support
MCWH / MCH	Maternal, Child (and Women's) Health
MOU	Midwife Obstetric Unit
NAPWA	National Association of People With AIDS
NGO	Non-Government Organisation
NVP	Nevirapine
PHC	Primary Health Care
PMTCT	Prevention of Mother-to-Child-Transmission
PWA	People living With AIDS
SAINT	South African Intrapartum Nevirapine Trial
TAC	Treatment Action Campaign
UNICEF	United Nations Children's Fund
VCT	Voluntary Counselling and Testing
WHO	World Health Organisation



# INTRODUCTION

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These case studies were conducted by Health Systems Trust researchers and external consultants between September 2001 and March 2002 as part of the national evaluation of the 18 PMTCT pilot sites. They were used to inform the first official interim report of the national PMTCT pilot programme that was published in February 2002.

The case studies have been compiled into a single document because they provide further, in-depth information about the experience of implementing the PMTCT programme. They also provide important historical and baseline documentation of the PMTCT service, which can be used to inform future evaluations of MCH/PMTCT services and health systems development.

The sources of information include interviews with provincial managers, PMTCT site co-ordinators, nursing staff, lay counsellors and antenatal clients accessing the services. Additional information was gained from record reviews of provincial reports as well as routine data collected for monitoring purposes.

These case studies bear testimony to the reality of implementing this programme within different and diverse contexts. There are many descriptions of struggles and frustrations, yet an overarching sense of dedication and commitment is clearly present.

These case studies offer essential information on what is 'actually happening' at the facility level. The experiences highlighted hold lessons for the continuing improvement and management of PMTCT services in the pilot sites. It is hoped that programme leaders at all levels will reflect on this information and that further sharing of experiences will be facilitated.

It is also hoped that some of these detailed case studies may provide the media and the public with a richer and more in-depth understanding of the challenges to implementing this complex but important health programme.

While it is clear that certain sites are functioning better than others, those that are struggling often do so as a consequence of the underlying inequities in the health care system. This should call for further support and resource provision, rather than criticism.

By making these case studies available, the Health Systems Trust is encouraging other research organisations and analysts to make use of this raw (mostly unedited), but rich information for further outputs that will facilitate the improvement of health care in this country.

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## 1. SHONGWE SITE

### i. Shongwe Hospital

#### Organisation and Management

Support for the programme from the provincial level is poor. This is largely due to the interpersonal conflicts between the CCLO and the AIDS projects co-ordinator around roles and responsibilities. Perhaps with the new appointment of the Director of HIV/AIDS, this situation can be resolved and progress can take place with regard to the employment of lay counsellors.

At the site level, the co-ordinator is highly supportive of the two staff responsible for PMTCT at the antenatal clinic. She is aware of the tremendous pressure on them and assists with group education, collecting data and transporting formula to the feeder clinics.

#### Facility preparation

The PMTCT programme officially started in September 2001. It is housed in the old maternity building that has been renovated to accommodate the antenatal clinic and rooms for counselling. Given that there are only 2 sisters and no lay counsellors, waiting times are long and some clients leave before being tested. The sisters have therefore requested televisions for the waiting room.

No preparation has occurred in the maternity section of the hospital and there is presently no place in the postnatal ward where women can prepare formula. The nurses have raised this as a problem with the matron but no changes have been made thus far.

#### Training of staff

Initial training of staff from both Shongwe Hospital and Evander Hospital took place over one day in July 2001 by clinicians from Baragwanath Hospital. Further training in VCT and MTCT was conducted by PMTCT co-ordinators from the provincial office in September 2001. Further training was conducted by the CCLO in November 2001. One of the co-ordinators has designed a 5-day training course for staff involved in the PMTCT programme but this has not been implemented yet. This is partly due to power struggles between the co-ordinators and their unclear role definitions.

At present there are 3 nurses in the antenatal ward and one sister from the labour ward who have received PMTCT training. This poses a problem as the staff in the labour ward are frequently moved to other areas of the hospital and replaced by staff that are not familiar with the PMTCT protocol and monitoring requirements.

## HIV Counselling and Testing

There are no lay counsellors at Shongwe Hospital nor at any of the feeder clinics. National money has been made available for 11 counsellors who have already been selected. It is unclear what is delaying their appointments. There are plans to involve an NGO in the management of the lay counsellors but no official agreements have been reached.

Group education takes place in a small room with walls lined from floor to ceiling in tins of formula. This makes the room incredibly hot with very little ventilation. Counselling is facilitated by one of the antenatal clinic sister with assistance from the site co-ordinator when necessary. The average number of clients attending the session per day is 6. The session is open to new booking clients as well as women returning for follow up visits. The group education takes place in the morning and individual sessions follow throughout the day.

Despite counselling being available at the feeder clinics, there is no testing or supply of nevirapine, therefore many women come directly to Shongwe Hospital for antenatal care.

### *Feedback from a group education session:*

The nurses created a calm environment in which clients were encouraged to share and all opinions and ideas were acknowledged. Being away from the main hospital, this clinic is fairly private and quiet. The session began with the nurse describing the procedures for testing and details of the PMTCT programme. Options for infant feeding were included in this discussion.

The following issues were raised during this counselling session:

- Two of the women suggested that all pregnant women should be offered nevirapine regardless of HIV status as testing was considered a barrier to acceptance of the programme. The following scenario was described: a woman is tested at 12 weeks and is found to be HIV negative. She contracts HIV sometime later in her pregnancy but is not accepted to the programme because her initial test was negative. This was used as a motivation to provide universal access to nevirapine and all women in the group approved of this option. One woman expressed the following sentiment: “We will all get AIDS at some stage”.
- Regarding infant feeding, a woman shared that breastfeeding was natural for her and part of her culture. If she chose formula feeding, she was concerned about what she would do once the 6 months of free formula ended, and stated: “Where do we get milk then?”
- In response to this concern, the sisters suggested that they develop a tool to assess the socio-economic status of women to determine whether they should receive free formula beyond 6 months.
- The women were asked whether they would prefer counselling from lay counsellors or nurses (their only experience has been of nurses). The overwhelming response was that they preferred counselling from nurses, as they trusted that it would be kept confidential. Their reasoning behind this

decision was that lay counsellors come from their communities and social networks at church, etc.

100% of women receive post-test counselling, indicating that results are given the same day as testing. This is partly due to the severe shortage of staff to cope with follow-up visits, but also because of the distances that women have to travel.

The number of women attending the antenatal clinic since the start of the programme has remained fairly constant at approximately 100 per month. It is important to note that this figure ('number of attendees') includes first time bookings as well as follow-up visits. If we take this figure of total number of attendees as the denominator in the VCT uptake rate, it appears that only 19% accept testing. However, if we consider the number of women consenting to counselling, (which may be a more accurate representation of first time bookings) 100% of these women accept testing. This figure has remained constant over the first four months of the programme and may be an indication of the high quality of counselling services. It would be important to monitor whether this rate changes when lay counsellors take over most of the counselling load.

It is important that the actual number of bookings be recorded for future reports. A verbal figure of 50, for the number of bookings per month was obtained during the visit, which would make the uptake rate 39%. According to the monthly figures, it appears that the uptake rate has declined considerably since the start of the programme, from 33% in September to 9% in December. This is most likely because the denominator used to calculate this rate includes follow-up clients, whose number would naturally have increased since the start of the programme.

Of the women accepting a test, from the start of the programme, 45% were HIV positive (the range over the four months is 39-57%). The rate for Mpumalanga province is 29.7% (2000), which places Shongwe Hospital in a high prevalence area.

## **Obstetric care**

Antenatal care is provided in the old maternity building where the PMTCT programme is housed. This building is separate from the main hospital. The clinic is open 5 days per week for bookings and follow-up visits. Of the women who tested positive during 2001, 77% were dispensed nevirapine. This rate has remained high since the start of the programme and indicates good compliance with follow-up visits during pregnancy.

With regard to referral networks between the feeder clinics and the hospital, the nurses have encountered situations where women are referred from the feeder clinics (where there is no testing being done at present) because of complications during pregnancy, however, they are missed by the PMTCT programme at the hospital because they are admitted straight to the antenatal ward in the main hospital. It was suggested a PMTCT trained nurse should visit the antenatal ward to conduct counselling there in order to avoid these missed opportunities.

It has come to the attention of the nurses that some clients are being tested by private practitioners and then coming to Shongwe Hospital for nevirapine. The sisters are concerned about the quality of counselling given by the private practitioners and are planning to meet with them to discuss the matter.



All women on the PMTCT programme must deliver at Shongwe Hospital, as the feeder clinics do not keep supplies of nevirapine. The sisters and doctors interviewed in the labour ward were aware of revised obstetric practices relating to the PMTCT programme, despite the fact that only one sister has been trained in this unit.

There is no obstetrician at Shongwe Hospital and only one doctor performs caesarean sections. To date only 2 caesarean sections have been performed on women in the PMTCT programme.

There was confusion amongst the staff regarding treatment of an infant if the mother did not get nevirapine. Some staff believed that if the mother did not get nevirapine then the infant should not get it either. This resulted in one baby missing treatment but the problem was picked up by the PMTCT co-ordinator and the situation was clarified.

On a visit to the labour ward, it was noted that the procedure for treating the baby is to give nevirapine syrup immediately after delivery. This is contrary to the protocol, which recommends treating the baby 48-72 hours post delivery. The dose given to the baby is recorded in the labour ward register and not the infant nevirapine register. Since September there have been 19 babies born to women on the programme. 89% of these babies received nevirapine.

### **Monitoring and follow up care**

Statistics are sent by the information officer on a monthly basis to the provincial office via email. One of the co-ordinators then compiles these into a monthly report. The nurses in the antenatal, labour and postnatal wards are not involved in the reporting of data. The data from these wards is collected by the PMTCT co-ordinator and sent together with the antenatal clinic data to the provincial office. On closer examination of the site report it was noted that the monthly totals do not correlate with the grand totals for 2001. These errors have occurred in the figures relating to nevirapine dispensing for mothers and infants, as well as choice of feeding method.

Due to the shortage of staff, the nurses are not using the blood register to record HIV tests and results. They feel that this is a repetition of the counselling register which also records test results. Once lay counsellors have been appointed, the nurses will use begin to use the blood register.

In order to track women, the letters 'SH' are written on their antenatal card to indicate involvement in the programme. The RTHC of the baby also has the same marking. During visits to the antenatal wards we found women who were on the programme but did not have the PMTCT marking on their card. This may result in the mother and infant missing out on treatment. Having a nurse from the antenatal clinic who visits the antenatal ward on a daily basis may help to avert these problems with communication between the antenatal clinic and the maternity section of the hospital.

The sisters from the antenatal clinic visit all women on the PMTCT programme in the postnatal ward prior to discharge. During this visit they reinforce infant feeding options and follow up care. There is no data on follow up visits for infants to date.

## Infant feeding practices

The predominant feeding choice in this site is formula feeding. 68% of the women who have delivered chose exclusive formula feeding. The nurses reported having difficulty monitoring women who choose to exclusively breast feed as they don't return for follow up visits at Shongwe Hospital and there is no reporting system set up at the feeder clinics.

Women who choose formula feeding come regularly to the hospital for formula and are therefore captured in the monitoring system. This may be one reason for the high figure for formula feeding, as many women who breastfeed are not included in the statistics from Shongwe Hospital.

## Supplies

There have been no problems with the delivery of supplies to this clinic. Ordering is done directly with the provincial office.

Formula is the only supply that is available in the nine feeder clinics. It is delivered to Shongwe Hospital and nurses from Shongwe Hospital then distribute it to the feeder clinics according to client load.

## ii Kamhlushwa Clinic

This is one of the feeder clinics for Shongwe Hospital. There are two registered nurses managing this facility, a comprehensive community health centre. They see approximately 8-10 antenatal clients per day. Information about the PMTCT programme is given during the booking visit and women are advised to attend Shongwe Hospital for testing and access to nevirapine. Very few deliveries take place at this facility, as it is not open 24 hours per day. There are presently two babies on the PMTCT programme who receive follow up care at this facility. The formula is delivered by the PMTCT co-ordinator at Shongwe Hospital.

The two nurses at this clinic feel that they would be unable to provide counselling and testing with their present staff quota and workload. The clinic is also not equipped with space for counselling as there are only 2 consulting rooms that are used by the nurses for clinical assessments.

## General comments

This site appears to be managing well given the constraints on staff with no lay counsellors. On site management provided by the site co-ordinator is excellent. This has resulted in high morale amongst staff despite the difficult circumstances.

The counselling appears to be thorough and the environment is private and supportive enabling women to make informed choices around testing. Consequently, 100% of women who receive counselling consent to be tested.

A high proportion of women who test positive receive nevirapine (77%) indicating good follow-up and tracking of clients in the antenatal clinic.

The following areas require attention:

- Absence of lay counsellors and shortage of staff in the antenatal clinic.
- Inadequate numbers of staff that have received training, especially in the maternity section of the hospital.
- Due to PMTCT services not being offered at the feeder clinics, women are missed if they are referred to the hospital late in pregnancy and do not attend the antenatal clinic.
- The figure for 'number of attendees' which is used to calculate the VCT uptake rate includes booking clients as well as those returning for follow-up visits. This gives us an inaccurate estimate of VCT uptake.
- Communication between the antenatal clinic and the rest of the maternity section is poor, as women who are on the programme are not identified in the antenatal and labour wards. Either the marking on the card should be used consistently or the labour ward should receive a list of women on the programme each month to enable them to identify clients.
- The interpersonal conflicts between the provincial co-ordinators to be resolved in order for progress to occur at this site.
- Once services are rolled-out to the feeder clinics it will be important for there to be a well functioning communication network in order to obtain accurate statistics of clients seen at these facilities.

## 2. DURBAN SITE

### i. King Edward VIII Hospital, Durban

King Edward VIII Hospital (KEH) is situated in Durban. KEH is a 1600 bed, public sector, tertiary academic hospital that serves as the main referral hospital for KwaZulu-Natal and the Eastern Cape. As part of a planned down-scaling, KEH is anticipated to become an 800 bed regional facility. General surgical and medical services, including full maternity and paediatric services, are provided at KEH.

The PMTCT programme officially started at KEH in May 2001 and drew upon infrastructure established during recent research trials like the SAINT study. Other HIV/AIDS services and programmes at KEH include a separate VCT programme, the Philani HIV Family Clinic (Outpatient), a post-exposure prophylaxis programme, and various ongoing medical research and trials.

### Organisation and Management

The Durban site co-ordinator is an academician based at the Nelson Mandela School of Medicine, which is adjacent to King Edward VIII Hospital. This proximity and the co-ordinator's management style appears to allow for regular communication with staff at the KEH site. Within KEH, PMTCT supervision and administrative assistance is also provided by one of the doctors who is based in the hospital superintendent's office. Each of the KEH clinics or wards involved in the programme has a co-ordinator who has received PMTCT training. These clinic co-ordinators are professional nurses with other duties.

The understanding of the PMTCT programme was generally found to be excellent. The bulk of the responsibility for daily management lies with the professional nurse co-ordinators and certain professional nurses in each clinic who have been trained in PMTCT. The acting Provincial AIDS Unit co-ordinator, visits the site once a month to collect data and generally assists in supervision from Pietermaritzburg.

### Training of staff

Within the antenatal clinic (ANC), 7 staff members had received training in PMTCT conducted by the University of Natal Medical School. This included 3 lay counsellors who are based in a space adjacent to the ANC and 4 nurses (3 professional and 1 enrolled nursing assistant (ENA)).

The labour ward co-ordinator was unable to recall the number of nurses who have received specific training in PMTCT, stating that the rapid turnover of staff makes it difficult to recall who has received training and who has not. It was not possible to ascertain the number of nursery staff that have received training. A sister on one of the

postnatal wards indicated that she was not aware of any postnatal ward staff who had received MTCT training. All interviewed stated that more training was necessary. An impression shared in several of the clinics was that doctors are not adequately trained in PMTCT.

Although rotation of nursing staff is stated to officially occur every 3 months, many nurses suggested that turnover of staff is more frequent. This is particularly true for the labour ward, where a turnover rate of once a month was considered routine. High turnover was also linked to leave for overseas work and interdepartmental transfers. The staff turnover rate is lower in the antenatal clinic, at which several nurses have remained since the start of the PMTCT programme.

## **HIV Counselling and Testing**

Four full-time lay counsellors have been employed for the PMTCT programme at KEH. Three started in June or July 2001; the remaining counsellor, who focuses on infant feeding options, started in January 2002. Three received training from ATTIC; one received training at the University of Natal. Two counsellors are based in a space (roughly 4 x 10 metres) adjacent to the ANC and focus mainly on pre- and post-test counselling. The third counsellor focuses on infant feeding and the fourth works primarily in a neonatal follow-up clinic and assists a KEH doctor. Although several nurses, particularly ANC nurses, have counselling training, lay counsellors perform the bulk of counselling. This includes counselling on the labour ward for women who avoided results before or missed the PMTCT programme during antenatal visits.

Following general group health education provided by nurses, first-time ANC attendees are directed to the counsellors' office, where they receive group pre-test MTCT and infant feeding information and education. The capacity of the counselling office is roughly 18-20 people per group session. Individual patients are then called one by one to semi-private cubicles to discuss specific questions and offer informed consent. Patients then return to the ANC, and have their blood drawn by phlebotomists for routine ANC tests and, if consented, for an HIV test. A professional nurse performs rapid tests on these blood samples back in the counsellors' office. This nurse has not rotated since the start of the PMTCT programme and is covered by another trained nurse in the event of sick leave. Following the completion of routine ANC services, patients have the choice to return to the counsellors' office for post-test counselling. The sister in charge has taken a keen interest in encouraging patients to go for post-test counselling while they wait in the ANC.

Nurses and lay counsellors report that a significant number of patients don't immediately return for their results. They report that most patients want time to think about the test and/or learn the results, resulting in very few patients who either test on the same day as being pre-test counselled, or return for results on the same day as the test.

The counsellors' office does not provide adequate privacy for patients. Both cubicles lack doors and are separated by partitions that do not extend to the ceiling. Patients who exit from individual counselling must walk past the open cubicles and the group of patients waiting in the common space. Counsellors insist that it is very easy for patients in the group to guess the status of a woman who has just received post-test counselling based on her emotional state. This lack of privacy may contribute to a

patient's refusal to return for their results. Lay counsellors believe that the major reason that patients refuse to take the test or fail to return for test results is fear; fear of death and, perhaps more importantly, fear of being stigmatised by those close to them.

The counsellors mentioned that the acting provincial co-ordinator has promised to seal the cubicles (i.e. doors and full-extended partitions) to ensure privacy. The counsellors also want another cubicle given current space constraints.

Counsellors provide patients with their results on a slip of paper from an HIV Test Record Register. The counsellors keep a carbon copy of this register. Overall, the counsellors felt that they lacked continuity of care with their patients. This is due to the large patient volume and the fact that many patients present to KEH late in their pregnancy resulting in less time to develop trust before delivery.

As with all the Durban locations, the denominator used to calculate the VCT uptake rate is the number of women pre-test counselled, not the number of bookings. The rationale provided by clinic staff and supervisors is that all women who attend the ANC are provided group pre-test counselling; hence, it is believed, the number of bookings and the number of patients pre-test counselled are equivalent. However, by failing to account for patients who do not participate in group pre-test counselling, this approach may artificially inflate the VCT uptake rate.

Lay counsellors stress that current staffing levels are currently adequate but will likely be strained as the MTCT programme is expanded. Currently, each counsellor sees 7-8 patients per day. Counsellors stressed that they lack mechanisms for support. Although they receive support from the PMTCT co-ordinators, they feel that there is a need for an administrative supervisor. Major issues include the unexplained deduction of roughly R600 from their monthly salaries and the delay in the provision of salaries. An administrative supervisor who can serve as a mentor and an advocate for counsellors may prevent the rapid burnout and turnover of counsellors and thereby prevent poor uptake of VCT services. A mentorship system, which is being developed by the Provincial Department of Health, may help address some of the counsellors' needs. Lay counsellors and nurses of different categories had equal levels of insight into the logistics and challenges of the programme and the needs of the patients.

It was stated that doctors lack pre-post test counselling skills and frequently provide misinformation to patients and/or state that they have performed pre-post test counselling when in fact nurses feel they have not. Anecdotal evidence suggests that some doctors perform a HIV test without patient consent and subsequently fail to protect patient confidentiality by writing test results in easily accessible patient records. Some nurses claim that doctors are performing HIV rapid tests either incorrectly or against current PMTCT protocol, e.g. using the Smartcheck test alone and counselling based on the results of that solitary rapid test.

### **Antenatal care**

The ANC operates 5 days a week from 7 am to 4 pm. Patient volume averages 50 per day, including repeat visits and first-time bookings and excluding patients who are seen for gynaecology outpatient services in the same facility. Staff include 6 professional nurses (including the Sister-in-charge and one professional nurse dedicated to rapid

HIV testing), 2 staff nurses, 1 enrolled nursing assistant (ENA), 2 general assistants (GA), 1 clerk, and 2 phlebotomists. Four doctors rotate through the ANC per day.

All women who test positive are provided relevant prophylactic drugs and multivitamins. However, patients sometimes do not receive multivitamins from the dispensary and are mistakenly provided other medication instead. Nurses make appointments for follow-up and nevirapine dispensation appropriately. Of note, a stamped PMTCT Baby Health Record (white card) is given to patients at the time of nevirapine dispensation. However, counsellors and nurses noted that patients often lost this card when they presented in labour.

ANC staff requested that at least 4-5 more professional nurses, with counselling experience, were needed to cope with the patient volume. Limited space and poorly trained doctors were listed as significant problems for the PMTCT programme within the ANC.

### **Intra-partum care**

There are approximately 450-550 deliveries per month at KEH. This includes roughly 40-45 caesarean sections per month. The labour ward consists of 22 general beds, 4 ICU beds, and 5 high care beds. The staff size increased this month and, for the daytime, currently consists of a pool of 22 professional nurses, 6 staff nurses, 6 ENAs, 6 GAs, and 3 porters.

The sister-in-charge was very familiar with the PMTCT protocol. The high turnover of nursing staff results in inadequate training levels for the other nurses. It is estimated that a total of 45 professional nurses, i.e. roughly 20 more professional nurses than are currently allocated, would be needed to ensure adequate provision of services. Hospital-wide and departmental in-service training sessions are frequent. However, only a few nurses can go to any one session due to staffing shortage.

Nurses and counsellors report that a significant percentage of PMTCT patients present in labour not knowing their HIV status. In these situations, the nurses call the trained labour ward nurses to perform HIV tests. Counsellors mentioned that privacy is hard to achieve in the labour ward. Doctors are not familiar with the PMTCT protocol and periodically test patients without their consent. Some nurses are not happy with a few lay counsellors who are perceived to pressure the patients to know their status.

### **Post-delivery care**

All babies of HIV positive women are brought to the nursery following delivery. A sister-in-charge at one of the three postnatal wards did not seem very familiar with PMTCT protocol, stating that she and others had yet to receive PMTCT training. A handwritten informal record of HIV positive patients was kept in the back of a regular register on one of the postnatal wards. Staff who do not have proper confidential registers for mothers on the PMTCT programme will develop their own informal and less confidential records.

## Monitoring

Upon presentation at the ANC, a patient is given a Maternity Case Record (green folder) which has a MTCT stamp placed on an inside page.

Nurses and counsellors reported a relatively low incidence of MTCT stamp alteration among patients. It is perceived that the incidence of alteration or destruction of the MTCT stamp has decreased over time. This may be a reflection of the counselling efforts of staff. It was perceived that patients were very aware of what the various symbols on the MTCT stamp symbolised.

The number of bookings, though recorded by the ANC clerk, is not recorded as a distinct data item in any of the MTCT registers. As noted earlier, using numbers of women pre-test counselled as a proxy for bookings may inflate the VCT uptake rate. At KEH, it would be helpful to differentiate those who are first-time KEH bookings from those who are repeat visitors for data analysis purposes. First-time bookings and a few repeat bookings who wish to receive counselling again are the ones who are directed to receive pre-test counselling.

According to the co-ordinator at the University of Natal, long-term follow-up data is not collected and recorded adequately. Appropriate registers and training for long-term follow-up data collection are needed. The Provincial AIDS Unit Co-ordinator, collects data once a month. This data is combined with data from other sites in the province.

## Follow up care

Patients are encouraged to receive follow-up care at the clinics. Nurses report that patients tend to lose the Baby Health Record (white card). This is believed to be due to the stigma associated with a card that is given only to HIV positive women. It is also likely due to the fact that the card is provided to women at the time of nevirapine dispensation rather than postnatal. Nurses also feel that the card is partly a duplication of the baby's Road to Health Card (white and green card).

## Infant feeding practices

Infant feeding options are discussed by the infant feeding lay counsellor during the group pre-test counselling session. Depending on the emotional state of the patient, the infant feeding counsellor discusses options with the patient either after the general post-test counselling session or when patients return to pick up their nevirapine. The infant feeding counsellor also makes regular visits to the postnatal wards, discussing infant feeding practices with all women regardless of enrolment in the PMTCT programme. This may help to reduce stigmatisation associated with talking with only one patient. The infant feeding counsellor appears to understand and follow the PMTCT protocol regarding advice.

The infant feeding counsellor states that patients and staff are confused by conflicting messages regarding the point at which they can safely start feeding solids to infants. She claims that several nurses tell mothers to start solids at 4 months. The counsellor, however, advises patients to wait until 6 months to start solids.



The preference for breastfeeding and formula feeding is said to be roughly equal around the time of delivery. However, the infant feeding counsellor suggests that many women who initially opt for exclusive breastfeeding tend to shift to formula feeding well before 6 months. This may be due to pressure from family and friends at home to formula feed; stigma associated with exclusive breastfeeding; difficulty in expressing milk; and, perhaps most importantly, the mothers' return to work which occurs roughly 3 months after delivery. This information highlights the need for more emphasis on education regarding a safe transition from breastfeeding to formula feeding. As with other sites, counsellors note that many patients, particularly indigent ones, who were not part of the PMTCT programme ask for the free formula post-delivery.

## Supplies

Nevirapine for pregnant women is ordered as a Schedule 5/6 drug from the KEH pharmacy and stored at the ANC. Nevirapine is actually a Schedule 4 drug but it is handled as a Schedule 5/6 drug for control purposes. There are adequate supplies according to the nurses. Nurses have complained that patients are provided the wrong medications on occasion by the dispensary, especially with regards to multivitamins.

According to the labour and ANC sisters-in-charge, there is no available stock of the rapid Smartcheck test. The labour ward reports long delays in obtaining supplies of gel required for ultrasound.

## ii. Prince Mshyeni Hospital, Durban

Prince Mshyeni Memorial Hospital (PMMH) is a provincial hospital roughly 20 kilometres southwest of Durban. PMMH serves as a referral hospital, particularly for the Umlazi area. Services include a 40 bed antenatal ward, a 40 bed labour ward, five postnatal wards, a neonatal unit, a paediatric ward and paediatric outpatient services. The tertiary referral centre, King Edward VIII Hospital, is roughly 15 kilometres away.

## Organisation and Management

The Durban site co-ordinator, is based at the Nelson Mandela School of Medicine, which is 20 minutes away from PMMH. She is perceived as the main supervisor for this location. Within PMMH, one of the matrons provides PMTCT supervision. The understanding of PMTCT generally and standard operating protocol specifically was above average among those interviewed. The bulk of the responsibility for daily PMTCT management lies with certain professional nurses in each clinic who have been trained in PMTCT. Nurses of different categories and lay counsellors generally had equal levels of insight into the logistics and challenges of the programme and the needs of the patients. The acting Provincial AIDS Unit co-ordinator, visits PMMH once a month to collect data and assists with supervision. The administrative clerk at the Provincial AIDS Unit, also serves a resource for PMMH.

## Training of staff

According to the matron each maternal and child ward has at least one person officially trained in MTCT. Many nurses and counsellors recently attended a one-day MTCT update workshop organised by the University of Natal. In addition to daily team briefings on each ward, there are general hospital-wide and departmental in-service training sessions every month and every week, respectively. Although these are not always specific to MTCT, they provide an opportunity for regular updates. The need for more professional nurses to be trained was discussed, particularly for those nurses who cover night shifts.

According to the matron there is under-staffing of professional nurses, particularly with counselling training, in the antenatal clinic. There is a need for more professional and trained staff nurses in the labour ward specifically. The need for trained professional nurses for weekend and night shifts was stressed.

## HIV Counselling and Testing

There are three full-time PMTCT counsellors, one of whom is dedicated to infant feeding. There is also a professional nurse with training in counselling who works with and supervises the counsellors. Until recently, the infant feeding counsellor moved through each of the five postnatal wards (1 per day) during the week, devoting one day a week to a group education session in the pre-test counselling phase. On February 18, 2002, the lay counsellors started a new system in which each of the three lay counsellors takes turns with the infant feeding education duties. Although it had been underway for less than a week at the time of the evaluation, the counsellors stated that this system was working well. Counsellors mentioned that they are recognised from the antenatal clinic when they visit the post-natal wards. In order to protect patient confidentiality and reduce stigma, the counsellors talk with everyone individually and do not close the curtains surrounding patients' beds. Achieving privacy is very difficult on these wards. Some patients in the wards opt to visit the antenatal clinic where the counsellors are based on their own to ensure their confidentiality.

After patients have registered and had their vital observations and bloods drawn, they participate in a group education session provided by a professional nurse. Using the MTCT stamps on the patients' Antenatal Records, the lay counsellors then screen for those who have not participated in the MTCT programme or for those who have not yet decided about taking the test. Those patients who are willing are then brought into a small room for group pre-test counselling. The counsellors state that an average of 10-15 patients a day participate in these pre-test counselling sessions. Following pre-test counselling, each individual then meets with the professional nurse for individual counselling and, if consented, for HIV testing. Until recently, lay counsellors used to perform tests as well.

Post-test counselling is the responsibility of the lay counsellors. According to the matron and the counsellors, PMMH is understaffed for post-test counselling services. No VCT is performed in the labour ward, although nurses claim that some doctors insist on knowing a patient's HIV status before providing care and, occasionally, urge that a rapid test be performed. The hospital recently started to devote one half-day per week

(every Thursday, 1-4 pm) solely to postnatal clinics visits and follow-up counselling. The follow-up counselling is meant to include a discussion of infant feeding options.

Lay counsellors at PMMH share the concern that there is not adequate mentorship and/or administrative supervision. Slow returns on payslips and slow responses to complaints are perceived as aggravating. They feel undermined by the title of 'consultant' as opposed to counsellor on their payslips. They request more training and more counsellors. Counsellors at PMMH claim an average case load of 14-15 patients a day each, including ongoing counselling.

## Obstetric care

The antenatal clinic operates Monday-Friday, from 7 am to 4 pm with the exception of Thursday afternoons (1-4 pm), when the clinic is dedicated to postnatal clinic follow up. The matron stated that patients who present after 12 noon are not seen at the antenatal clinic unless they are in unstable condition. The waiting room is large, with a seating capacity of 60-70.

There is a separate 40 bed antenatal ward at PMMH reserved for patients with pregnancy complications. According to nurses, there is frequently an excess of patients in the antenatal ward. Excess antenatal patients are placed in a postnatal ward that has 10 extra beds. 3 doctors (excluding consultants), 4 professional nurses, 2 staff nurses, 2 enrolled nursing assistants, and 3 general assistants (including cleaners) staff the antenatal clinic.

There are approximately 950 deliveries per month. In addition to 3 doctors (2 assigned to cover caesarean sections, 1 to cover the ward), there are 19 professional nurses, 3 enrolled nursing assistants, and 8 general assistants assigned to the labour ward. The labour ward, which has a 40 bed capacity, lacks linen for any of its beds, and according to the nurses, lacks an adequate supply of CTG machines. The enrolled nursing assistants (ENAs) perform the vital examinations on patients. The nurses generally seemed aware of the revised obstetric practices relevant to HIV positive women.

Nurses in the PMMH labour ward do not provide nevirapine syrup to infants. Nearly all eligible infants receive the syrup upon arrival in the nursery or the postnatal ward. The percentage of enrolled patients who deliver at Prince Mshyeni, 96%, is very high compared to other locations within Durban. This may be a reflection of the fact that the hospital has the only labour ward in the immediate area and has several feeder clinics providing deliveries. In other words, the patients who deliver at Prince Mshyeni may not have received antenatal care at the hospital and may be falsely elevating the numerator. The relationship between patients and staff at Prince Mshyeni's antenatal clinic may also be a reason for this high rate.

The nursery has a staff pool of 5 doctors (including one consultant), 14 professional nurses, 10 staff nurses, 5 enrolled nursing assistants, and 3 general assistants.

## Monitoring and follow up care

The same system described for KEH is used at PMMH. The nurses and counsellors generally understand the monitoring system and manage the PMTCT registers securely. The provincial co-ordinator visits the site once a month to collect data. Nurses and counsellors report that many patients alter or disfigure the MTCT stamps on their antenatal cards. Where alteration has occurred, counsellors state that patients are motivated by fear of loss of confidentiality. Patients notice any changes in records and quickly ascribe meaning, whether correctly or incorrectly, to those changes.

Counsellors note that the patients who alter their MTCT stamps tend to be those who sense that they are at high risk of having HIV and who also perceive stigma in their local community. Counsellors note that patients' anxieties decrease after they are reminded that neither 'HIV' nor 'AIDS' are listed on the stamps and that the stamps are important for assuring proper care.

The follow-up of mothers and children needs to be improved. According to the nurses stationed in the nursery, mothers and children return to the PMMH for routine follow up visits at 6, 10 and 14 weeks. However, immunisations are not provided at these visits; patients are referred to peripheral clinics to receive immunisations with the same time schedule. If true, duplicate follow up visits are clearly wasteful and difficult for patients.

Counsellors state that women who are not able to attend the newly introduced Thursday afternoon postnatal clinics, paediatric and medical outpatient clinics are available. However, the latter two clinics are often overcrowded and provide no continuity for patients. It is unclear if appropriate support, including infant feeding support, is available at the regular paediatric and medical outpatient clinics.

## Infant feeding practices

Infant feeding education is provided during group pre-test counselling. All the counsellors now share infant feeding counselling duties. Counsellors are well-informed with regards to infant feeding options and appear to have an attitude that respects patients' choices. Currently, patients who opt for formula feeding must collect formula tins from a dietician located at a far end of the hospital. Counsellors and nurses insist that tins for formula feeding should be provided to patients at the antenatal clinic or another location close to maternity services for increased privacy and ease for patients.

Nurses offered several anecdotes regarding abuse of formula supplies. In one example, corroborated by two nurses, a mother enrolled in the PMTCT programme shared her baby with an unenrolled woman who also wanted free formula tins for her family. The social impact of the provision of free formula tins for some and not others, based on HIV status, is clearly problematic.

## Supplies

According to the matron and other staff, supplies are generally easily available from the hospital dispensary. Since the provision of Trioplex Multivitamins started last month, supplies have generally been available without delay.

### **iii. Umlazi Section D Clinic, Durban**

Umlazi Section D Clinic is roughly 5 kilometres away from Prince Mshyeni Memorial Hospital. It provides antenatal care. The number of patient visits to the antenatal clinic ranges from 40 to 90 per day.

#### **Organisation and Management**

One of the nursing sisters is the site co-ordinator for PMTCT at the clinic. The University of Natal is the main PMTCT resource for her and the clinic. The acting co-ordinator at the Provincial HIV/AIDS Unit, visits monthly to collect PMTCT data. The administrative clerk at the Provincial HIV/AIDS Action Unit also serves as a resource. Administrative and supply procurement assistance are provided by nearby Prince Mshyeni Memorial Hospital.

#### **Training of staff**

Only the PMTCT clinic co-ordinator and one other nursing sister have received PMTCT training. However, the second trained sister was recently transferred to Umlazi Section V Clinic. These nurses participated in the initial PMTCT 2 day workshop last year and the general update at Prince Mshyeni Memorial Hospital, both of which were organised by the University of Natal. The co-ordinator conducts general in-service training every Monday in addition to occasional workshops focused on PMTCT for the staff at her clinic. While she felt confident in her ability to train other staff, the sister-in-charge felt that the other staff had much to learn about the concepts behind the PMTCT programme.

There is a staffing pool of 12 professional nurses, 3 staff nurses, 1 enrolled nursing assistant, and 1 auxiliary service officer (ASO). Of the 12 professional nurses, 3 are employed on a part-time basis and do not participate in the antenatal clinic. This leaves a pool of 9 professional nurses available for PMTCT activities. One of the available professional nurses has advanced midwifery training. Despite the official policy of staff rotation every 3 months, the co-ordinator states that the turnover of staff is higher.

There are 3 lay counsellors. One focuses on postnatal follow-up visits full-time, while the other two work in the antenatal clinic. There are also 4 cleaners, 5 security guards, and 1 gardener on staff. Doctors from PMMH used to visit the clinic on a rotating basis (Monday-Friday, 2-3 hours per day). This practice was suspended temporarily for reasons unclear to the sister-in-charge. However, the co-ordinator was told by the hospital that the doctors would resume their visits in March 2002. Finally, a group of 4 lay health educators ('Nompilo') travel through the clinic area roughly once a month.

#### **HIV Counselling and Testing**

Following registration, vital observations, routine tests and a history-taking (all conducted by a professional or staff nurse), a patient typically joins other patients in a central waiting area in the antenatal clinic to receive group education. The group education session, conducted once a day and usually by a professional nurse, contains general information for pregnant women, including a brief discussion of infant feeding

options and the PMTCT programme. According to the co-ordinator all women participating in the group education session then receive individual counselling. The individual counselling, conducted by one of the two lay counsellors takes place in a room directly adjacent to and visible from the common waiting area. During the individual counselling session, the lay counsellor reviews the MTCT stamp on the patient's antenatal record and obtains informed consent.

Initially, based on their availability and the pressures on the nursing staff, the counsellors occasionally performed the rapid HIV tests on patient's blood (drawn by professional nurses). However, since the update provided by the University of Natal in early February 2002, nurses are now solely responsible for drawing and testing patient's blood. In the current algorithm, the lay counsellor delivers signed informed consent forms to a professional nurse. This nurse, usually the site co-ordinator, then performs the rapid tests on blood collected earlier in the morning for routine blood tests. The tests are performed in a batch and only for patients for whom signed consents are available. Results are provided to one of the lay counsellors and patients are counselled the same day or later depending on patient preference.

This practice of batch testing, which the co-ordinator reports works well, is unique compared to other Durban PMTCT pilot locations. In a busy antenatal clinic, the advantages of improved clinic efficiency and time management are obvious. However, concerns regarding the possibility of mixing samples given the batching technique, the ethics of obtaining patient consent post-blood draw, and the potential impact of sample storage techniques and storage time on test sensitivity and specificity should be addressed and reconciled with testing practices at other locations.

Staff report that many patients opt to return for both testing and results at a later date. According to the co-ordinator, a significant number of patients fail to return, or ask to postpone knowing test results when they do return. Staff feel that patients' fear of knowing and/or lack of support at home explain this hesitation in learning of test results. These reasons may also explain the commonly seen defacement of MTCT stamps on patients' antenatal cards. All post-test counselling is performed by one of the two lay counsellors assigned to the antenatal clinic. Space for counselling is limited and affords little confidentiality to patients. Counsellors use a staff tea-room and a converted storage space, neither of which has a desk. The rooms are adjacent to the common waiting area; women who learn of their results must exit these rooms directly into the often crowded waiting areas.

## **Obstetric care**

The antenatal clinic operates Monday-Friday, from 7 am to 4 pm. There are no designated times or days for first-time visits. All women who attend are registered in the main clinic building then directed to the adjacent antenatal clinic, a free-standing structure built recently. Unstable or complicated patients are referred to Prince Mshyeni Memorial Hospital or King Edward VIII Hospital. The waiting room is medium-sized, with a seating capacity of 40. The staff encourage all patients to attend the antenatal clinic at least 4 times before delivery. During physical examinations, nurses provide personalised health education to patients, often reinforcing messages provided during

the group education and individual pre-test counselling sessions. The co-ordinator reports that continuity of care exists with many of the patients. Nurses assign dates for return visits to patients.

All patients from Umlazi Section D Clinic are referred to Prince Mshyeni Memorial Hospital or another hospital for delivery. All participating patients greater than 32 weeks are provided with nevirapine and informed to self-administer nevirapine at the onset of labour.

### **Monitoring and follow up care**

First-time and repeat antenatal visits are recorded in separate registers, both of which are created by hand. The co-ordinator feels that while the registers work well, new standardised printed registers would work much better. The Men in Maternity Programme provided the antenatal clinic with such a register which is now full. All PMTCT registers appear to be used properly. However, they are kept in a side room that is only semi-secure. Staff feel that the PMTCT programme's Baby Health Record (white card) is largely duplicative of information recorded in the child's 'Road to Health' card (white/green).

The co-ordinator states that many patients are aware that the new MTCT stamp contains information on HIV status, perhaps explaining why patients initially defaced many stamps. However, according to the co-ordinator, the incidence of MTCT stamp destruction has declined as patients have grown accustomed to it.

Another issue faced by clinic staff was the timing of placing the MTCT stamp and its impact on patient confidentiality and acceptance. Initially, the stamp was placed before patients were individually counselled. Now, stamps are placed directly after individual pre-test counselling. This practice seems to have improved monitoring efforts by addressing the meaning of the stamp as part of individual MTCT counselling for the patient.

Mothers and children who attended Umlazi Section D Clinic for antenatal care are asked to return for follow-up visits 2 weeks after delivery and then after 6, 10, and 14 weeks. A nurse trained in PMTCT is available at the well-baby clinic.

### **Infant feeding practices**

One lay counsellor is assigned to the well-baby clinic for infant feeding education. The space for staff in the well-baby clinic is extremely limited. Within the open hall converted for well-baby check-ups and with the use of a few curtains, it appears extremely difficult to provide confidential infant feeding education to patients. Staff report that many women initially opt for exclusive breastfeeding yet find it difficult to maintain this practice given familial pressure, stigma, and lack of social support. The co-ordinator noted that many women who refused HIV testing during antenatal care or come from an area beyond the catchment area visit the clinic asking for free formula for their children. Many patients who are not participating in the PMTCT programme supposedly voice their resentment and jealousy of women who receive the free formula. For those women experiencing difficulty maintaining exclusive breastfeeding in the face of job, family, or community pressures, nurses recommend that exclusive breastfeeding be maintained for at least 3 months with a rapid transition to formula

feeding. The co-ordinator reports that community members have quickly attached HIV/AIDS stigmas to formula feeding. The extent and rapidity of stigmatisation is exemplified by anecdotal evidence from clinic staff that some lay people already identify Pelargon formula packaging and the yellowish colour and consistency of the formula with HIV infection.

Infant feeding options are also sometimes discussed when mothers and children receive immunisations from another professional nurse in the clinic. The administration of immunisations represent an excellent opportunity to listen to patients and provide guidance regarding all kinds of behaviours, including feeding practices. However, the sisters note that patients try to please nurses by "...telling us what they think we want to hear" with regards to infant feeding practices.

The lay counsellor interviewed seemed very knowledgeable about the pros and cons of the exclusive breastfeeding and formula feeding options. The co-ordinator stated that she and the counsellors generally encourage women to exclusively breastfeed, given the economic and social situation of many patients. However, staff report that many patients admit to mixed feeding. Reasons that staff have heard from patients include the inability to express breastmilk regularly, family pressure, especially from mothers and mothers-in-law, and the economic pressure to return to work soon after delivery.

## Supplies

The co-ordinator appears to have experienced few problems in ordering nevirapine from the pharmacy at PMMH. The clinic also receives iron, Bactrim, and Folic Acid from the same pharmacy with little difficulty. Phlebotomy supplies are provided by the hospital regularly. They have not, however, received adequate supplies of diflucan or nystatin cream. The clinic has neither an ultrasound machine nor a fax. Staff feel that an ultrasound machine would be helpful in confirming gestational age (currently based on LMP and physical exam), especially since trained doctors are expected to resume clinic visits soon. The co-ordinator feels that a fax machine would aid tremendously with communication with the hospital, other clinics and the PMTCT programme co-ordinators. A driver collects Blood samples (for routine tests and for confirmatory ELISA tests) from Prince Mshyeni Memorial Hospital every Wednesday.

## iv. Kwamashu Polyclinic

Kwamashu Polyclinic is a large provincial clinic located roughly 20 kilometres north of Durban. In addition to general medical and surgical care, the clinic offers antenatal care, intra-partum care, postnatal follow-ups, and general paediatric care. Complicated cases are referred to nearby Mahatma Gandhi Hospital or to King Edward VIII Hospital. The PMTCT pilot started in April 2001.

## Organisation and Management

The Durban site co-ordinator, is based at the Nelson Mandela School of Medicine, which is 20 minutes away. She is perceived as the main supervisor for this location. Within the polyclinic, one of the sisters provides PMTCT supervision. The understanding of PMTCT generally and the standard operating protocol specifically



was excellent among those interviewed. The bulk of the responsibility for daily PMTCT management lies with certain professional nurses in each clinic who have been trained in PMTCT.

There are roughly 84 nurses and 6 lay counsellors on staff at Kwamashu Polyclinic. Four of the six counsellors are designated to PMTCT activities and, as with other pilot locations, are paid through 1 year contracts by the provincial government. For *all* activities relating to the PMTCT pilot, there is a pool of about 19-20 professional nurses, 2 staff nurses, 2 auxiliary nurses, and 1 auxiliary service officer available. However, according to the co-ordinator there is a shortage of staff. Rapid rotation of staff and transfers have caused a dire situation in her perspective. For instance, during March 2002, only 15 professional nurses and 5 staff in other categories would be available to cover the antenatal, labour, and postnatal duties. To reduce the loss of trained staff due to rotations, there is a policy that professional nurses with advanced midwifery training do not rotate out of the labour ward as frequently as other staff.

The antenatal clinic typically needs at least 6 professional nurses, 1 staff, and 1 auxiliary nurse on duty in the day. The labour ward typically needs 5-7 professional nurses on duty each day and 2-4 each night. The postnatal clinic usually has 1 professional nurse and 1 auxiliary nurse on duty. Obstetricians from King Edward VIII Hospital are available in the labour ward twice a week for 2 hours per day. They rotate these duties on a monthly basis.

### **Training of staff**

Approximately 22 nurses from Kwamashu attended a 2 \_ day workshop organised by the University of Natal in April 2001. Thirty to forty staff have attended updates since then. It is not known whether the staff who attended the updates were different from the staff who attended the initial workshop. Though the co-ordinator feels that a significant number of staff have received training, she thinks that the rotation and loss of staff mean that many staff still do not have adequate knowledge of the PMTCT programme. She provides general in-service training once a week.

### **HIV Counselling and Testing**

There are 4 lay counsellors designated for PMTCT counselling. One of these counsellors was assigned to infant feeding education in December 2001 and is based at the well-baby clinic at nearby Rydavale. The remaining three counsellors work in the antenatal section. They provide a group education and pre-test counselling session (approximately 45 minutes) once every morning for all patients. Patients who are interested in receiving individual counselling and taking the test are encouraged to see the counsellors. The lay counsellors occupy three cubicles in the main antenatal clinic waiting area. Confidentiality is difficult to maintain. At times, patients who are waiting in the clinic are not more than three feet from the curtained cubicles where other patients receive individual pre-test counselling and discuss testing.

Nurses perform the tests. Lay counsellors perform post-test counselling. Staff report that many patients opt to return at a later date to take the test, or to return at a later date for test results if they have taken the test. The post-test counselling rates, for both HIV positive and negative patients are generally much lower than other locations within

Durban. From June to December 2001, only 54% and 58% of those who tested HIV negative and positive, respectively, received post-test counselling. This may have been largely due to the under-staffing of counsellors early in the programme. After September 2001, when 2 additional counsellors started at Kwamashu, the post-test counselling rates increased substantially. The low rates of return for post-test counselling, regardless of status, may reflect poor follow-up of those patients who opt to return at a later date for results and/or lack of space at the clinic.

## Obstetric care

The clinic operates from 7 am to 4 pm Monday to Friday. Mondays and Tuesdays are reserved for first-time visits. Wednesday through Friday are generally reserved for repeat visits. Staff interviewed are generally aware of the standard operating protocol for the PMTCT programme. The percentage of post-test counselled HIV positive patients who receive nevirapine, 77%, is comparable to other locations. The waiting area is congested and affords little confidentiality to patients who opt to speak with staff about HIV testing. The seating capacity of the antenatal waiting area is roughly 40 patients.

There are approximately 155 deliveries per month at Kwamashu. In 2001, there were 1808 live births and 37 stillbirths. Based on clinic records, 126 babies have received nevirapine at Kwamashu to date. The percentage of patients who deliver at Kwamashu is low, nearly 59%, and has decreased in recent months. This rate is comparable to other Durban locations (with the exception of Prince Mshyeni) and is likely due to a combination of reasons, including the fact that some patients enrolled recently have not yet delivered and that many patients deliver someplace else. The co-ordinator reports that it is very rare for Kwamashu patients to take nevirapine during false labour.

Patients are discharged an average of 2 hours after delivery if there are no complications. At the longest, patients stay 8-10 hours, usually only when they deliver at night. This practice has come about since the provision of food for inpatients was discontinued in 1997. The heavy patient load also creates a pressure to discharge patients quickly. Patients are told to return for follow-up visits within 72 hours. When they return, professional nurses provide infants with nevirapine syrup and counsellors are called to discuss infant feeding options with the mothers. According to records, 95% of eligible babies receive nevirapine within 72 hours of birth, probably indicating that most mothers are able to return for follow-up visits shortly after delivery and discharge. It is unknown how many babies receive nevirapine directly post-delivery before being discharged, i.e. within 2 hours of delivery.

Caesarean sections are not performed at Kwamashu. Labour ward policy is to treat all patients with universal precautions. Artificial rupture of membranes is occasionally used, instrumental deliveries are extremely rare, and roughly one-quarter of patients receive episiotomies. At Kwamashu, episiotomies are generally used for primiparous patients, especially when the patient is very young.

## Monitoring and follow up care

The standardised MTCT stamp is used in Kwamashu. Like other locations, counsellors state that patients are motivated by the fear of stigma/loss of confidentiality when they alter the MTCT stamp. The nurses and counsellors generally seem to understand the monitoring system and manage the PMTCT registers securely.

Up to 6 weeks post-delivery, patients are followed at Kwamashu clinic. Thereafter, at 6, 10, 14 weeks and every month afterwards, patients are seen at the well-baby clinic in adjacent Rydavale. As with other locations in Durban, data for follow-up was not readily available. At Kwamashu, the data registers for follow-up care were not being properly used by staff. Anecdotally, it appears that more and more patients steadily fail to follow-up as time passes from the date of delivery. As was noted in other locations, the Baby Health Record is seen as redundant and leads to stigmatisation of mothers and children. This may explain why patients seem to “lose” this card before attending follow-up visits.

## Infant feeding practices

There is a sense that both nurses and counsellors are well informed about infant feeding options. The lay counsellor dedicated to infant feeding support sees patients starting at the 6 week post-delivery follow-up visit in the well-baby clinic. The other counsellors and nurses provide guidance directly post-delivery when patients are in the post-natal ward. According to registers, more patients opt for exclusive breastfeeding (59%) than formula feeding (35%) at Kwamashu when compared to Prince Mshyeni (49% and 48% respectively) and the Durban average (42% and 41% respectively). The counsellor interviewed admits that many patients are encouraged to exclusively breastfeed given counsellors' worries about lack of clean water in the communities.

## 3. PIETERMARITZBURG SITE

### i. Church of Scotland Hospital, Tugela Ferry

Church of Scotland Hospital is situated in the province of KwaZulu-Natal approximately 150 kilometres northwest of Pietermaritzburg. The closest town, Tugela Ferry, is in an isolated, rural part of the province with poor roads and unreliable communication infrastructure.

Church of Scotland Hospital has been chosen as the rural PMTCT Programme facility for the Pietermaritzburg site. Church of Scotland is the district hospital with 13 feeder clinics spread throughout the district. Full maternity and paediatric services are available at the hospital as well as general medical and surgical care. The bed capacity of the hospital is 300. The hospital has seven full-time doctors, four of which are community service interns. There is no specialist obstetrician or paediatrician and only one of the doctors performs caesarean sections. The tertiary referral centre is in Pietermaritzburg, 1½ hours away. Comprehensive primary care services are provided by the feeder clinics. These include antenatal, postnatal and paediatric care.

The antenatal HIV sero-prevalence rate for KwaZulu-Natal is estimated to be 36.2%.<sup>1</sup> This is the highest prevalence rate in the country. The PMTCT programme started at Church of Scotland Hospital in June 2001. Presently, only the hospital is offering the PMTCT programme but it is expected to spread to the feeder clinics during 2002.

This hospital has established programmes to care for patients with HIV/AIDS that were initiated by one of the doctors. These include a home-based care programme employing 200 home-based carers and the building of a hospice, with overseas funding, on a piece of land adjacent to the hospital. This building is due to be completed in March 2002.

## Organisation and Management

Support for this site from the provincial level is excellent. The CCLO visits the site on a monthly basis and arranges regular update workshops in Pietermaritzburg to bring together all the counsellors and nursing staff involved in the programme.

At the site level, there is a PMTCT co-ordinator who is one of the antenatal clinic sisters. One of the doctors, who has worked at the hospital for 12 years, has taken a keen interest in establishing programmes to care for people with HIV/AIDS. He is highly supportive of the PMTCT programme and it has naturally formed part of the other AIDS programmes already active at the hospital. This doctor keeps his own statistics of the PMTCT programme in order to monitor its progress and he meets regularly with the lay counsellors to provide support and training where necessary.

The overall impression one gets of management of the PMTCT programme at this site is that the lay counsellors have substantially greater responsibility than the nurses. The lay counsellors facilitate the group and individual counselling, perform the rapid tests, control the ordering of supplies, maintain the PMTCT registers, and compile monthly data for the provincial office. The lay counsellors had far greater insight than the nurses into the challenges facing the programme and the needs of clients. When speaking to the nurses they gave the impression that they saw PMTCT as a 'lay counsellor programme'. They were unable to answer questions related to logistics and supplies and referred me to the lay counsellors.

## Training of staff

No official training of doctors has occurred but they have reviewed the PMTCT manual and report being sufficiently informed about the programme. 4 out of 25 nurses working in the maternity section have received training at Grey's Hospital in Pietermaritzburg. There has been no rotation of staff out of the maternity section to date, however, this policy is changing and staff will have to rotate as from March 2002. This may result in greater training needs amongst maternity staff.

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1 2000 Antenatal HIV Survey, Department of Health

## HIV Counselling and Testing

Four full-time lay counsellors were employed at the start of the programme and are paid by the province. They perform all the counselling for the antenatal clients at the hospital. This is done in the form of a group session for all new clients, followed by individual sessions where further details regarding the PMTCT programme are given and consent for testing is obtained.

Space for counselling is a problem in this facility as the rooms usually used for counselling are occupied by doctors on Tuesdays and Wednesdays. On these occasions there are long waits for the 2 remaining free rooms. There are plans to partition one of the waiting rooms to create counselling space.

The counsellors are well paid in comparison to other provinces and they are dedicated and enthusiastic about their work. This is reflected in the VCT uptake rate, which from the start of the programme in June till December 2001 was 86%. It is important to note that the denominator used to calculate this rate is the number of women pre-test counselled and not the number of bookings. Consequently this figure is may be inflated.

It was brought to my attention that the counsellors themselves are performing the rapid HIV tests and not the nursing staff. This was authorised by the medical staff as a way to reduce the workload of nursing staff in the antenatal clinic. The lay counsellors have been trained to perform the test and appeared comfortable with this responsibility.

## Obstetric care

The antenatal clinic operates 5 days per week. All women who test positive are seen by one of the doctors and are given the relevant prophylactic drugs and multivitamins.

Since the start of the programme 18% of the women tested were HIV positive. This rate has fluctuated within a range of 14-22%. This is well below the provincial prevalence rate of 36.2%. Of the women who tested positive, 60% received nevirapine at the antenatal clinic.

There are approximately 200 deliveries per month at this hospital. Most deliveries are performed at the hospital due to the poor communication (unreliable phone and radio lines) between the clinics and the hospital, as well as the limited operating hours of the clinics.

The nurses seemed aware of obstetric practices relevant to women with HIV. They were familiar with the PMTCT protocol and were giving the infant nevirapine syrup at the appropriate time. The total number of babies born to HIV positive women since the start of the programme is 158. 100% of these babies received nevirapine syrup. This is an excellent achievement that may attest to the advantages of not rotating maternity staff to other wards in the hospital, enabling a functional team to develop. It will be necessary to monitor this rate once the new staff policy takes effect.

## Monitoring and follow up care

There is a stamp with the letters MTCT on the inside of the antenatal card of women on the programme. A square on this card is marked with a tick if a woman is positive.

The number of bookings is not presently being recorded as a regular data item. The number of women pre-test counselled is being used as a proxy for bookings as all new women are supposed to attend the group education session. It is important that the correct figure for bookings be used in future reports.

Data is collected once a month by the CCLO, and this is combined with the other sites in the province.

The counsellors reported that many women do not return for follow up care after delivery because of the poor public transportation and long distances to the hospital from the surrounding villages. They are willing to do home visits but there is no transport available for this.

### **Infant feeding practices**

In the group education session information is given about infant feeding options. Formula feeding is not encouraged because the water supply to the surrounding areas is not deemed safe. Women are advised to breastfeed exclusively if they choose to breastfeed. It was noted that certain viewpoints of the counsellors appear to be influencing the choice of feeding in this site. They feel that women are not educated enough to follow the instructions for formula feeding and they believe that the surrounding community associates formula feeding with being HIV positive. These influences are reflected in the data, which indicates that since the start of the programme, 76% of women chose to breastfeed. This requires serious attention. Retraining of the counsellors may be necessary to reinforce basic counselling skills and prevent undue coercion in decision making.

One innovative practice that is occurring in this site is that women who choose exclusive breastfeeding are given free formula for three months after cessation of breastfeeding (they are advised to stop breastfeeding at 6 months). The aim of this practice is to encourage early cessation of breastfeeding and to avoid continued mixed feeding.

### **Supplies**

There are generally no problems with the delivery of supplies to this site. There was one occasion where the supply of formula ran out as the number of babies on the register was higher than that expected by the provincial CCLO. This problem has been rectified and has not occurred again. The stock of Vitamin A for babies has never reached this facility. The CCLO is aware of this but there seems to be a problem with the ordering of this vitamin.

The nurses reported a communication problem with regard to the ordering of supplies, as there is no external phone line in the antenatal clinic. They have to go to the administration building to make telephone calls.

The Oral Quick HIV test is due to be supplied to the sites in this province from March 2002. The manufacturers are conducting training on the use of this test in Durban during February. This test can be performed by lay counsellors and will ease the workload of nurses in sites where they are currently performing the rapid HIV blood test.

## General comments

- Support from the provincial office appears to be regular and responsive to the needs of staff at the site.
- The interest of doctors is an invaluable resource as they provide stability and a genuine interest in the progress of the programme.
- The total number of women pre-test counselled, and not the number of bookings, is being used to calculate the VCT uptake rate. This has resulted in a probable inflation of this rate.
- The lay counsellors are taking on a large proportion of the responsibility for this programme with little support from the nursing staff.
- The counsellor's own views and opinions around infant feeding appear to be influencing the choices that mothers make. Updating of counsellors skills with specific emphasis on objectivity may be necessary.

## ii. Edendale Hospital, Pietermaritzburg

### Organisation and Management

Edendale hospital is a tertiary referral hospital situated in a township area close to Pietermaritzburg. The PMTCT facilities in the Pietermaritzburg site are overseen by a doctor at Grey's Hospital. He provides technical support and co-ordinates the training of medical and nursing staff.

The site is co-ordinated by both a nursing staff member and a doctor working in the paediatric clinic. This has resulted in well functioning networks between the antenatal clinic, the labour ward and the paediatric clinic with good follow up and tracking of patients. The PMTCT programme started at this hospital in July 2001.

### Facility preparation

No specific preparation of this facility has been done to accommodate the PMTCT programme. Consequently, space for counselling is a problem as doctors occupy many of the consulting rooms. The counsellors have resorted to using spaces in the waiting rooms, which do not ensure privacy and are therefore not appropriate for individual counselling.

### Training of staff

Only one nurse has been trained in this facility. She has been assigned to the PMTCT programme and works closely with the lay counsellors, performs the rapid tests, authorises nevirapine and manages statistics for the site.

No training of labour ward staff has occurred.

## **HIV Counselling and Testing**

There are four full-time lay counsellors who are paid by the province. The lay counsellors cover the antenatal clinic, labour ward and paediatric clinic thereby providing continuity of care and good follow up of clients.

Group education is offered on a Tuesday (the only day when bookings are accepted) and may occur on other days if there are sufficient clients to warrant a session. Results are given on the same day as testing.

Using the figure of 'total number pre-test counselled' to calculate the VCT uptake rate from July to December 2001, only 42% of women who were pre-test counselled choose to be tested. This aggregated rate is very poor, however, if we consider the monthly rates, tremendous improvement has been made from an uptake rate of 13% in July to a rate of 83% in December. This is an encouraging indication of progress and perhaps improvements in counselling quality or greater awareness about the programme.

## **Obstetric care**

The antenatal clinic operates every day except Wednesday. Booking visits are only accepted on Tuesday. This places a huge load on counsellors on this day.

All patients who are HIV positive are seen by a doctor in the antenatal clinic.

## **Monitoring and follow up care**

As with all sites in this province, women who have been counselled, have a stamp on the inside cover of their antenatal card. A tick is placed in a box on the stamp to indicate a positive test result. These cards are client held and many women on the programme return for follow up visits with the stamp rubbed off or the page torn out of their card. It appears that this marking is considered by women to be a sign of HIV positive status. Careful thought is needed to design a marking that does not stigmatise women and deter them from participating in the programme.

Data for this facility is recorded by the lay counsellors and sent to the provincial office on a monthly basis by the sister assigned to the programme.

The paediatric clinic is managed by a paediatrician who is actively involved in the PMTCT programme. One of the lay counsellors visits the paediatric clinic every day to follow up on infants on the programme. There are no figures to date on follow up rates of infants but the lay counsellors report that most women on the programme choose to come to the hospital rather than the feeder clinics for follow up.

Women on the programme are referred to the CDC clinic post delivery for continued care and management of their HIV illness.

## **Feeding practices**

The predominant choice of feeding in this site is formula with 89% of women choosing this method. The area surrounding this hospital is a peri-urban informal settlement with a reliable, clean water supply. The nurses reported wanting feeding cups to give to women who choose this method.



## Supplies

There have generally been few problems with supplies. The hospital ran out of testing kits on one occasion but this problem seems to have been resolved with the provincial office.

## General comments

- There is excellent co-ordination between different services in the hospital that are involved in the programme.
- Space for counselling is a problem
- Insufficient numbers of nurses have been trained.

### iii. Imbalenhle Clinic, Pietermaritzburg

#### Organisation and Management

Support from the provincial level is good. There are regular visits by the CCLO and he is very accessible as the provincial offices are in Pietermaritzburg. There is a site co-ordinator who works in the antenatal clinic. PMTCT services commenced at this clinic in September 2001.

#### Training of staff

Two nurses at this clinic have been trained at Grey's Hospital, one of them being the co-ordinator.

#### HIV Counselling and Testing

There are two full-time lay counsellors at this clinic who are paid by the provincial AIDS office. The counsellors were trained by ATTIC. No problems were reported with space for counselling as there are consulting rooms available for this purpose.

There do not appear to be any problems with waiting times as many women go straight to the hospitals for booking resulting in a lighter antenatal load at the clinics. The procedure for counselling is a group session given by the lay counsellors, followed by individual counselling by both nurses and lay counsellors. All women are given their results the same day as testing.

Since the start of the programme in September 2001, the VCT uptake rate (based on the total number of women pre-test counselled) was 74%. This rate has decreased from 90% in September to 65% in December. The nurses felt that perhaps women were discouraging each other from being tested. One nurse reported a client stating: "If we have HIV we don't want to leave an orphan behind, we should both die".

#### Obstetric care

Once tested, only 46% of women actually receive nevirapine. This is cause for serious concern. The nurses are not sure what the reasons for this are. They suggested that women who have tested positive might want to hide their status and avoid disclosure.

They therefore attend a different clinic after testing and hide their status. Consequently follow up rates during pregnancy for women who have tested positive are reported to be poor.

Very few deliveries occur at this clinic (approximately 7 per month) as the facility is not open 24 hours per day.

### **Monitoring and follow up care**

As with Church of Scotland, all women on the programme have a stamp inside their folder with the letters MTCT. A tick is placed in a box on the stamp to indicate a positive test result. The nurses have noticed that some women who have tested positive, tear out the back page of the folder where the stamp is placed, or they rub off the stamp, and attend another clinic where their status is not known. This appears to be a problem throughout the Pietermaritzburg PMTCT facilities and requires urgent attention.

The clinic statistics are collated by the lay counsellors and then given to the co-ordinator who phones them through to Grey's Hospital on a monthly basis.

There is no indication on the RTHC that the baby is on the PMTCT programme. This is a cause for concern as the recommended prophylaxis against opportunistic infections, ongoing counselling and vitamins are not being given to many mothers and infants. The mother is supposed to hand in her folder that indicates her involvement in the programme, however, many women do not bring their folders so it is proving difficult to follow up on infants in the programme.

Most women who book at the Imbalenhle clinic actually deliver at Edendale Hospital and continue to receive follow up care for themselves and their infants at the hospital. The clinic therefore has minimal data regarding follow up of infants.

All women who test positive are referred to the Edendale CDC clinic for follow up and management of their HIV illness post delivery.

### **Feeding practices**

As with Edendale Hospital, the majority of women in this site choose formula feeding. Between September and December 2001, 53% of women chose to formula feed. The nurses suspect that the actual figure is much higher because many women attend Edendale Hospital for their follow up and obtain formula there, rather than coming to the clinic.

### **Supplies**

There have been few problems with supplies except for multivitamins for mothers and Vitamin A for infants, which have never reached the facility.

### **General comments**

- The nurses in the meeting were strongly supportive of mass treatment for all pregnant women with nevirapine due to the poor rate of follow up and stigma associated with the PMTCT marking in the antenatal folder.

## 4. RIETVLEI SITE

### i. Rietvlei Hospital

#### Background

Rietvlei is a district hospital situated in the rural Umzimkulu sub-district of the Eastern Cape. This sub-district is somewhat separate from the rest of the Eastern Cape as it is surrounded geographically by KwaZulu-Natal province. Movement of patients between health facilities in these two provinces is therefore very common in this area.

The Rietvlei site consists of Rietvlei hospital and Rietvlei clinic, situated 500m from the hospital. Rietvlei hospital has 13 feeder clinics, however, only one is part of the programme at this stage. The hospital is poorly resourced and is physically dilapidated and in disrepair. There are a total of 7 doctors at the hospital, one community service intern and 6 medical officers.

#### Site Organisation and Management

Management at the provincial level consists of a CCLO who is based in Bisho. The CCLO is reported to visit the site infrequently, when there is a workshop planned or when statistics are needed for a report. There is no regular meeting between site personnel and provincial managers to discuss progress at the site.

The superintendent of the hospital and his wife have shown a keen interest in the programme despite the challenges they have faced. They have attempted to direct the programme and support staff yet they are demoralised by the lack of input from the provincial level despite calls for assistance. There was a general feeling amongst staff that they are facing a constant struggle with this programme yet the response from the provincial level has mostly been criticism.

The main issue raised by managers at the hospital was the lack of direction and support from the provincial level. Responsibility appears to be shifting from provincial to district level without the necessary support and training. With regard to expansion of the programme to the feeder clinics, the province considered this to be the role of the district managers and had assumed that this process was underway. A visit by the provincial co-ordinators in March revealed that no expansion of the programme to feeder clinics had occurred, despite indication of this progress in site reports. The province is now taking a more proactive role in guiding the expansion of the programme and plans to visit the site more frequently in order to address problem areas. The provincial MCH co-ordinator has also been brought into the programme in order to promote integration of the programme within MCWH services.

There is no co-ordinator at the site level who is responsible for this programme. Many

individuals display an interest in the programme yet there is no clear leadership or accountability. This may be a major factor behind the lack of progress since the initiation of the programme. Since the recent meeting between provincial leaders and site personnel, it was decided that a PMTCT site co-ordinator should be appointed. The person identified for this position is presently the district TB co-ordinator. As this is a full time position, it was felt that this person could cope with the co-ordination of both TB and the PMTCT programme. This position will start in April.

### **Facility preparation**

Minimal changes were made to Rietvlei hospital in preparation for this programme. The scan room within the labour ward was turned into the counselling room, but no further adjustments were made. The space for counselling remains inadequate as only one nurse at a time can counsel.

The Rietvlei clinic underwent substantial renovations recently. The clinic was housed in a wooden pre-fabricated structure and had only 2 consulting rooms. The new clinic is a brick building with 4 examination rooms although only one has walls to the ceiling, and is therefore the only room used for counselling.

### **Training of staff**

Two matrons from the labour ward and two district managers were sent to Cape Town in 2001 to attend a Winter School course at the University of the Western Cape on PMTCT. The expectation from the province was that these individuals would conduct training for other members of staff on return to their facilities. A few in-service training sessions have been held in the hospital and the district managers have conducted some workshops with clinic staff. There are still huge gaps in the training of clinic staff and this has not been actively addressed due to the delays in expanding the programme to the clinics.

The matron stated that nurses are generally not interested in participating in the PMTCT programme until they have been trained. Therefore in-service training is done whenever staff rotation has occurred in order to inform new staff about the programme. Staff are rotated roughly every 2-3 months. The most recent in-service training that was done included representatives from every ward in the hospital. This was due to the fact that many nurses are coming into contact with women or infants on the programme in wards outside of the maternity section and they felt they needed to be informed about it.

The Obstetric Support Programme of ISDS has been an invaluable resource for this district. Training such as the Perinatal Education Programme (PEP) is run regularly and various other modules have been added. Although PMTCT is not a module on its own, the instructors running these courses are obstetric/MCH experts who provide essential support to the health professionals at this site and are able to answer questions and clarify concerns regarding the PMTCT programme. The PEP course is subsidised by Medical Education for South African Blacks and HST in order for all health professionals to have access to this much needed education. In the labour ward there are 3 midwives with advanced midwifery qualifications.

## HIV Counselling and Testing

The lack of lay counsellors is having a detrimental impact on the programme at this site. This is of serious concern given that funds directed for counsellors are available at the provincial level. This situation is extremely frustrating for nurses as they hear about other provinces where lay counsellors are primarily responsible for counselling; yet in this site they carry the burden of the whole programme virtually alone.

The superintendent of the hospital expressed concern that the counselling component of PMTCT has been regarded nationally as the responsibility of lay counsellors. In areas such as Rietvlei, where there are no lay counsellors, this viewpoint has resulted in nurses being reluctant to assist with counselling because it is not deemed part of their role.

There is an NGO, Bambisanani, which is active in the area and has trained lay counsellors, however, they have not begun work as no funds have been transferred to this organisation for salaries. The provincial co-ordinator is presently liaising with this NGO to determine how many lay counsellors have been trained and whether more training is needed to supply lay counsellors for the feeder clinics. The plan is for the province to direct funding to this NGO for lay counsellor salaries. It is hoped that this contract will be in place by the end of April.

NAPWA has also been involved in this area training PWAs in counselling skills. Two individuals from NAPWA have been volunteering as VCT counsellors in the OPD department yet their interest seems to be waning due to the lack of compensation.

At the hospital there are 5 registered nurses assigned to the labour ward and only two have received formal counselling training. The rest of the staff have been given in-service training covering counselling and PMTCT. Counselling in the labour and antenatal ward is performed by the two trained sisters. The decision was made to assign responsibility for the PMTCT programme to these two sisters to promote continuity of care and to ensure confidentiality of patient information. These two sisters work opposite shifts so there is always one on duty each day. It was reported that other sisters find this frustrating, as they would also like to be involved in the programme.

There is a high load of counselling and testing at the hospital as many clients have received antenatal care at one of the feeder clinics that does not test and their first contact with the programme is therefore at the labour ward. The maternity matron reported that nurses in the labour ward frequently work overtime to ensure that the amount of time spent on counselling does not negatively impact on their care of other women in the ward.

A group education session is held at the hospital every day for women in the antenatal ward. Information about PMTCT is given during this session. Following this, individual counselling is offered to new clients. There is only one private room for counselling in the hospital labour ward.

At Rietvlei clinic there are two registered nurses providing comprehensive PHC services. This clinic is considered to be part of the PMTCT site in so far as it offers counselling and testing services. It does not, however, keep stocks of nevirapine or infant formula. Testing services began at the clinic in November and at the hospital in October 2001.

Nurses from the clinic phone the hospital to alert them if they are sending a client for nevirapine or formula milk.

A group education session is held at the clinic on Thursdays for the booking clients. This session is conducted by a volunteer counsellor from NAPWA. Following this individual counselling is offered by one of the sisters. There is one room available for counselling at the clinic, as it is the only room with walls that extend to the ceiling. This small clinic is extremely noisy due to the immunisation clinic that is held every day. The design of the clinic, with walls that do not extend to the ceiling, enables noise to travel easily within the building making the environment most unsuitable for counselling. In the grounds surrounding the clinic are rondawels that are presently not being used for any purpose. These will be utilised for counselling once lay counsellors have been employed.

Due to the shortage of staff, only one nurse is available daily for antenatal care. Post test counselling and test results are therefore not available the same day as testing and women are advised to return the following day. The drop out rate at this stage is very high, as many women have to travel far to reach the clinic and do not return for test results. This situation is extremely demoralising for nurses as they would like to offer a high quality service but are unable to due to staff constraints. During the month of December 2001, the nurse responsible for antenatal care was on leave. No replacement nurse was arranged which left one nurse running the entire clinic alone. The remaining nurse had not received PMTCT training therefore no women were accepted onto the programme during December. This is an extreme example of the dire staff shortages and poor coverage of PMTCT training in this province.

The counselling uptake rate in this site has consistently been 100%, an indication that all booking clients are counselled. This is feasible in this site due to the low number of clients accessing the service. In comparison, the post-test counselling rate (85%) is considerably lower in Rietvlei than in the East London Complex (100%). This may be due to the extreme shortage of staff at the Rietvlei site, which prevents them from providing test results the same day as testing.

The testing uptake rate has remained high at an average of 98%, in comparison with 28% at the East London Complex, which is serving approximately 13 times more pregnant women per month.

The HIV positive rate amongst pregnant women in Rietvlei is 35%. This is 10% higher than the East London Complex and may be attributed to the antenatal caseload, which is considerably lower in the Rietvlei site. Due to the difficulties in accessing this site, women who are more motivated to be tested and perhaps more concerned about their status may be seeking care and therefore impacting on the high prevalence rate.

Repeat rapid testing of positive results is not done consistently in this site. All positive results obtained on a rapid test kit should be confirmed using a different rapid test kit. In this way, discordant results can be identified and sent for Elisa confirmation. Some nurses interviewed appeared to be aware of this practice, however, this was not being recorded in the testing registers.

## Obstetric care

Antenatal care is provided at the Rietvlei clinic. Clients may attend any day from Monday to Friday although booking clients are encouraged to attend on Thursday to facilitate group education and to accommodate dire staff shortages. The average number of booking clients attending on a Thursday is 20. An average of 3-4 antenatal clients attend daily for follow up care. Ongoing counselling is available during these visits.

Antenatal clients with high-risk pregnancies or complications are referred to the hospital for further care. There are no obstetricians at the hospital and one doctor is assigned to the maternity section.

The figure for booking visits for this site includes Rietvlei Hospital and Rietvlei clinic. This figure remains small in relation to the number of bookings at the other site in this province, the East London Complex (949 per month). Average number of bookings per month between the start of the programme (October) and December was 67. This has increased slightly between January and March 2002, to an average of 88 clients per month, as more clients have been seen at the clinic since the renovations. The programme is clearly not reaching all pregnant women in the district due to the limited number of facilities offering this service.

Most of the counselling and testing done at the hospital takes place during the late gestational period or early in labour. The sisters are consistent about asking women in labour if they have been counselled and tested.

There are many women who present at the labour ward in advanced labour and testing is therefore only done post-partum. If a women tests HIV positive post-partum, nevirapine syrup is still given to the infant (two doses).

Knowledge of revised obstetric practices appeared to be good, although it was reported that a high number of episiotomies are performed (approximately 50% of deliveries). Women on the programme who have had previous caesarean sections and may be eligible for a VBAC are usually sent for another caesarean section. The motivation behind this is to avoid a long and possibly difficult labour.

The nurses reported that maintaining confidentiality within the labour ward is difficult as there are no private wards and only one room for counselling. Other mothers see the babies on the programme being given the nevirapine syrup and being fed with formula milk and they raise questions. This situation places both the HIV positive mother and the nurses in an awkward position.

Following a normal vaginal delivery, mothers are usually discharged after 12-24 hours. However, mothers on the PMTCT programme are kept in the hospital longer so that the nevirapine syrup is given to the infant 48-72 hours following delivery according to the protocol.

## Monitoring and follow up care

There seemed to be some incongruence within this site around the method used to track women. In the labour ward the words 'NVP yes' is written on the mothers' antenatal card to indicate involvement in the programme, however, in the outpatients department and at the clinic the word MTCT is written on the card. It is vital that a

consistent method is used to track women to prevent missed opportunities for counselling and provision of nevirapine.

The registers for this programme are excessive and repetitive. For example, test results are recorded on the counselling register and the blood test register. Many other data items are recorded on more than one register and with the shortage of staff these registers are extremely time consuming.

Information management support is needed with streamlining registers and developing appropriate data flow mechanisms. At present data is captured by the 2 nurses in the labour ward with PMTCT training and is then sent through to the provincial co-ordinator on a monthly basis. Since the recent meeting with the provincial co-ordinator, it was decided that data should be sent from the facilities to the district office for review and then sent to the provincial office. From April all data will be sent to the district office by the new PMTCT co-ordinator.

Follow up is proving to be a serious challenge in this site as none of the feeder clinics are supplying formula as yet. Women on the programme must return to the hospital to access the free formula. Transport to the hospital from the surrounding areas is expensive and time consuming therefore women who may have opted to formula feed are forced to mix feed if they are unable to afford the regular hospital visits. A further issue that the nurses have had to face are reports that formula milk is being sold in the surrounding areas. Initially women were being issued 8 tins of formula on discharge from the hospital in order save on return visits. Since these reports, which are unsubstantiated, mothers are only being issued 4 tins on discharge, which last approximately 3-4 weeks.

One of the reasons given for delaying the supply of formula milk to the clinics is the lack of security and potential for theft of the formula supplies. It is not clear whether this concern is being addressed by the district managers.

With regard to the collection of follow up data, information on infants who are formula fed may be recorded during return visits for formula, however, women who choose to breastfeed are usually followed up at the feeder clinics which are not part of the programme and are therefore not capturing data for the programme. If this situation continues it will be impossible to measure the impact of the programme in this site as very few infants will undergo HIV testing. Apart from measuring the impact of the programme, follow up care is also necessary to provide ongoing counselling and support for infant feeding. In a poorly resourced rural area such as this, where safe formula feeding is virtually impossible, ongoing support and monitoring of infants is essential. The first follow up visit at the hospital for the baby, if a woman has chosen to breastfeed, is at 6 weeks, when the bactrim prophylaxis is given. The nurses at the hospital expressed grave concern that the policy of providing free formula has resulted in women who choose to breastfeed being seriously disadvantaged.

In order to make formula more accessible to the clinics. A form has been designed for clinics to use to order formula for babies on the programme. This form will be used in 4 out of the 13 feeder clinics from March. Formula will be ordered from the district office in Umzimkulu. The maternity matron expressed concern that the hospital is not being kept informed about expansion of the programme to the clinics. She has heard that formula was available at one clinic by a patient, yet this information had not been



given by the district managers responsible for the programme. Clear lines of communication are needed between the district managers and the hospital staff so that patients can be given correct information regarding follow up care.

The paediatric ward is keeping a record of infants on the programme who have been admitted to the hospital in order to keep track of the outcome of these infants. This information is given to the labour ward at the end of each month to be combined with data for the monthly report.

It was decided by the hospital managers that the first testing of infants would occur at 6 months, rather than the national protocol suggestion of 9 months. The reasoning behind this decision is that mothers may not return regularly to the hospital once the provision of free formula is terminated. Given the far distances that mothers have to travel to reach the hospital, it was decided that earlier testing would be advisable to assure an adequate level of follow up.

### **Infant feeding**

The predominant choice of infant feeding method in this site is formula feeding. Between October and December 2001, 54% of women chose formula feeding. Between January and March 2002 this rate has increased dramatically to 79%. This is concerning given that the predominant source of water supply in this area is from rivers and the risk of contamination of the water is great. The present difficulty in accessing the formula at facilities encourages mixed feeding to be a necessary option.

### **Community involvement and response**


At the start of the programme a launch was held to inform the surrounding community. This was well attended by local chiefs and leaders. Since this event there have been no efforts to involve the communities or to increase awareness about this programme. This is largely due to the feeling amongst health providers that they are already struggling to manage and they don't want to encourage patients to take part in a programme that is not functioning well.

### **Supplies**

There have been relatively few problems with the delivery of supplies to this site. Adequate stocks of formula and nevirapine have been available, however, problems arose with the testing kits that were only available in the labour ward in February 2002. Before this time all testing was done by the hospital laboratory. It was not entirely clear whether this was because of limited stock or lack of nurse training.

Key points and general impressions

- Shortage of staff is a serious issue impacting on the ability of this site to provide a quality PMTCT programme.
- The limited numbers of nursing staff that have received training has led to a huge responsibility being placed on a few individuals, and the collapse of the programme when those trained individuals are on leave.

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- The dedication and enthusiasm of the staff is commendable in the face of growing criticism from the province.
  - The lack of lay counsellors has seriously impinged on the numbers of women that can be accepted into the programme, as all the counselling is done by nurses with numerous other clinical duties.
  - The lack of support and direction from the province has resulted in minimal progress at this site. A recent meeting between the province and the site has led to the appointment of a site co-ordinator and the promise of more regular site visits by provincial managers.
  - The failure of the programme to be expanded to feeder clinic has resulted in low coverage of the service in the district and difficulties in accessing formula supplies.
  - The predominant choice of formula feeding is concerning given the inadequacy of counselling services, the unreliable water supply and the limited accessibility of formula milk.

## 5. VIRGINIA SITE

### Virginia Hospital, Rearabetswe Clinic and Khotalang clinic

Virginia is situated in the heart of the mining region of the central Free State Province. The Virginia site began offering PMTCT services in July 2001. The site consists of Virginia Hospital, 8 fixed PHC clinics and 2 mobile clinics.

#### Organisation and Management

The province is well resourced in terms of personnel for this programme. There is a provincial level CCLO who is enthusiastic though struggling with the responsibility and expectations placed on her. The Virginia district Hospital has a full-time PMTCT co-ordinator who is based in Welkom, and the clinics have a PMTCT co-ordinator who is a senior nursing sister at the Virginia Municipal clinic. Both of these co-ordinators are extremely dedicated and have achieved a remarkable level of training amongst staff within a limited time period.

The province also has health information officers in each district who are responsible for entering data into the HISP software. This eases the load on the co-ordinators and allows them to focus on organisation and systems issues.

#### Facility preparation

In the initial planning by the province, resources were set aside to expand the facilities offering PMTCT. These facilities were visited by architects last year and plans were drawn up to extend the buildings. No progress has been made since then and the staff are not sure when the renovations will actually begin.

At the Virginia Provincial Hospital counselling is performed in an old ward in the maternity section. This ward is used for postnatal women when there is an overflow from the main wards. This is the only space available for counselling and is extremely hot as one side is made of fibreglass through which the sun streams. The lay counsellors are very unsatisfied with this arrangement, as they have no space of their own that is private and comfortable.

At Rearabetswe clinic there are three counsellors, but only 1 room available for counselling. They have to take turns to use the room, which results in long waiting times for clients. At Khotalang clinic there are 5 lay counsellors but no space has been set aside for them. They are using the nursery and consulting rooms of professional staff who are on leave.

The only facility that has adequate space for counselling is the Oliver Tambo clinic. This clinic was built in 2000, after VCT was introduced into clinics, and has three rooms dedicated to counselling.

## Training of staff

The co-ordinator for the provincial hospital and the co-ordinator for the PHC clinics both visited the PMTCT site in Khayelitsha in the Western Cape in 2001. The purpose of this visit was to observe how the PMTCT programmes have been implemented in the Western Cape. Following this visit, they were requested to design a training manual for the Free State based on information gathered in the Western Cape. A 3-day training course on PMTCT was held in Virginia. A large proportion of nurses from the provincial hospital and the PHC clinics were trained.

An interview with a midwife in the provincial hospital revealed that the training course was perhaps not extensive enough to give the staff a thorough introduction to the programme. The midwife shared that she “does not feel fully involved in it” and that further training would make her more motivated to take an active role in the programme. The training received by nurses focused exclusively on clinical requirements of the PMTCT protocol and did not include counselling skills. As a result, counselling is regarded as being primarily a lay counsellor task and nurses are not actively involved in this aspect of the programme.

There appears to be minimal involvement of doctors in this site and none have received training. There are no doctors present in the PHC clinics and the district hospital has one community service intern working in the labour ward. No senior doctors at the hospital appear to have taken an active interest in the programme.

In the labour ward at the provincial hospital there are two midwives on duty for each shift with one assistant nurse. This severe shortage of staff limits the time for continuing in-service training and education. The PMTCT co-ordinator for this facility visits once a week but tends to spend more time with the lay counsellors, as they are more available than the nursing staff for continuing education.

At the Provincial Hospital, the co-ordinator has designed a flow chart with the protocol for intra and post-partum care of a woman on the programme. This is placed in all delivery rooms as well as the antenatal and postnatal wards. It is a visible way to remind staff that may not have received formal training, of the programme, and serves as a way to update staff on the PMTCT protocol on a regular basis.

At the PHC clinics another flow chart has been designed with the protocol for counselling, testing and nevirapine dispensing. This is situated in all consulting rooms and is an accessible format for nurses to refer to during a busy clinic session. These protocols raise awareness about the programme at the facility level and are a means to promote integration of the PMTCT programme into PHC services.

The nurses reported that mixed messages from the government and media are causing confusion. They are sometimes asked questions by clients based on information in the media and they are unsure how to respond. They feel that there should be an explicit policy from the DoH on the PMTCT programme so that they can be clear about what to advise clients.

## HIV Counselling and Testing

The counsellors in the Free State Province were trained as VCT counsellors and not specifically as PMTCT counsellors. The training was conducted by the Township AIDS Project (TAP) and ATTIC.

Facility	Number of counsellors	Training	Payment and management
Virginia Provincial Hospital	2 (both female)	One trained by ATTIC the other by TAP (Township AIDS Project). Both training programmes are 3 weeks long.	One of the counsellors was a volunteer from April to July 2001 after which NPPHCN took over payment and a second counsellor was employed.
Rearabetswe clinic	3 (2 females 1 male)	Trained by ATTIC and TAP	Paid by NPPHCN
Kothalang clinic	5 (3 females and 2 males)	1 Trained by ATTIC, 4 by TAP	Paid by NPPHCN
Oliver Tambo clinic	6	Trained by ATTIC and TAP	Paid by NPPHCN

The training course consisted of a broad introduction to HIV/AIDS and did not include PMTCT in any detail. The PMTCT co-ordinator therefore had to conduct further top-up training on PMTCT for all of the counsellors prior to them starting work in the PMTCT clinics. These counsellors are responsible for all aspects of VCT, not only PMTCT. This appears to have caused some confusion, as the various VCT services are very vertical in nature: TB, STDs, HIV and PMTCT. The issue was also raised by the counsellors that training them to address single issues in a vertical and compartmentalised way makes them too focused in their style ie. only focusing on STIs if they are counselling a women with STIs and not including general health promoting behaviours.

There have also been problems in the facilities with the payment of the various cadres of lay workers: DOTS supporters, VCT counsellors and home based carers, as each of these groups has a different salary structure and conditions of service. This is resulting in conflicts and tension between these groups.

The VCT counsellors (who are responsible for PMTCT counselling) are paid a stipend of R500 per month by the NGO, NPPHCN. There appears to be some uncertainty regarding who takes responsibility for managing the counsellors, the NGO or the clinical staff working with them. The NPPHCN attempted to take on a management and supportive role but encountered resistance from nursing staff who believed that it was their role to manage the counsellors. Nursing staff reported being left out of the meetings between the lay counsellors and the NPPHCN. The meetings were arranged without consultation with nursing staff, at times that are not convenient. On one occasion the counsellors were requested to attend a meeting on the same day that the clinic does antenatal bookings, the day with the highest counselling load. This resulted in tension between the clinic staff and the NGO. The nursing staff were also not informed about the specific content of the lay counsellor training.

During an interview with the lay counsellors at Kothalang clinic, they reported that the issue of management and support has not been clarified in the contract with the NPPHCN. The counsellors expected the NGO to provide support and mentoring for them. However, this has not yet occurred. One counsellor said that he found counselling a lot harder than he had expected: “we have a heavy load to carry”. This sentiment was shared by others in the group who had all experienced signs of burn out. They gave an example of meeting one of their client’s in a supermarket with their partner and described how hard it was to know that the client’s partner was not aware of their status. Carrying this information around with them and not being able to share it was a drain on them. They had started sharing with each other when they needed some support but they believed that this should come from the NGO or a more experienced professional.

The procedure for counselling in these facilities involves a group education session given in the morning, followed by an individual session that all booking clients have to attend before they are seen by the midwife for a clinical assessment. There are plans to establish a support group as a means of dealing with ongoing support for women on the programme.

The cumulative counselling uptake rate for the Virginia site is 72%. This rate fluctuated substantially over the 6 months since the project started. In July it was 96%, it dropped to 45% in September and rose again to 97% in December. Exploring this in more depth with the staff it was noted that at the start of the programme the figure for the number of first antenatal bookings included those women returning for follow up visits who had not had a chance to be on the programme when they first booked. Once all the follow up clients had come into contact with the programme, the counselling uptake rate was calculated with first antenatal bookings only and it consequently decreased. The testing uptake rate since the start of the programme is 36%. This has shown a similar trend to the counselling uptake with the rate declining in the first few months and recovering to 50% in December. The HIV positive rate amongst women in this site is 32%. This is considerably higher than the provincial rate (27.9%) and the rate in the other site, Frankfort (23%), which is in the rural northern part of the province. The known use of commercial sex workers by mine workers in Virginia may contribute to the higher rate in this site.

With regard to the rapid test, one of the nurses interviewed expressed that she felt the rapid test was too quick and doesn’t allow enough time for the woman to process her choice and the possible consequences, or to share this with family or partners. She stated: “it’s more convenient for the staff, but for the patient it’s more traumatic.” This is particularly pertinent as many women are given their test results on the same day.

Women are advised that if they test negative they may return later in their pregnancy for a further test if they wish. This emphasises the ‘window period’ and reinforces the importance of behaviour change.

Ongoing counselling and support during the antenatal period is provided by the lay counsellors. They also perform home visits to women on the programme that default on their antenatal clinic visits. They reported that women appreciate the home visits as they often have unanswered questions that can be dealt with in the privacy of their homes. Through this practice the clinics have been able to maintain an excellent rate of

antenatal clinic attendance. Consequently, of those women who did not get their results that same day as testing, 60% returned at a later date for the result.

The issue of nurse vs. lay counsellors was discussed in some detail. The nurses believed that the choice of counsellor is the most important factor enabling a client to trust and feel comfortable. A counsellor should be someone who is a known and respected member of the community. They emphasised that choice of counsellors is vital to ensure high quality service.

## **Obstetric care**

In the facilities visited, antenatal bookings are restricted to two days per week. This results in high numbers on those days and a consequent shortage of space for counselling.

In terms of revised obstetric practices, the midwives reported that a high proportion of women on the programme are primigravid and many of them require an episiotomy. The midwives feel torn between adhering to the protocol and dealing with the challenges faced in the clinical setting. They criticised the protocol as being too theoretical and out of touch with the realities of the clinical setting. The co-ordinator felt that this was a matter of experience rather than a problem with the protocol. It would be important for the rapid appraisal of obstetric practices to collect information on parity of women on the programme in order to ascertain whether this is a broad problem that needs to be addressed.

The midwives shared that most women on the programme are unable to disclose their status to the labour ward staff. The staff can tell a woman's status from her card and spend time trying to find out if they have taken their nevirapine whilst coping with a busy labour ward. Sometimes the lay counsellors are called in to assist but this remains a problem.

## **Monitoring and follow up care**

In order to track women on the programme the nurses write 'PMTCT' on the mother's antenatal card and on the baby's RTHC. It was decided at one of the provincial meetings that all folders of women on the programme should be kept in a separate cupboard to those of the rest of the clients. This was an attempt to protect confidentiality but it has actually had the opposite effect as when a woman comes to the clinic her card has to be fetched from another area and this has led to a certain amount of stigma. It is interesting to note that only folders of women on the PMTCT programme are kept in a separate place, not all clients with HIV. This was discussed in some detail at the information management meeting and it was suggested that the lay counsellors approach the nursing staff with their concern and suggest that this practice be changed.

Data management appears to be progressing well with support from an HST consultant. A meeting was held in February to discuss the data collection tools and to decide on any changes to the existing tools. The following reasons were given to change the existing tools:

- To match existing PHC data collection tools
- Excessive numbers of registers for this programme

- Duplication between registers
- Elements not well defined
- Not context specific

There was a suggestion to have 2 registers, one for the mother and one for the baby. The data elements for the mothers register were discussed. The data will be collected through a tick sheet. This option will be piloted in both sites from March 2002.

The issue of why we need to capture the patient's name was discussed. At present it is being captured on three different registers before the women even accepts to be on the programme. The participants were challenged to consider why the name is being recorded and whether the information will be useful in any way. On a visit to one of the facilities a discrepancy between the number of tests recorded in the counselling register and in the blood register was found. There was an idea to use the consent form to record testing and results. This would be the only form with the client's name on it that would be used as a means to track the client if they return at a later date for the result.

The storage and control of nevirapine was discussed as people were questioning the necessity of keeping a schedule 4 drug in the schedule 7 cupboard and keeping a register as well as a stock book for nevirapine dispensing. The co-ordinators were requested to discuss this with their staff and to bring suggestions to the next meeting.

This was a very productive meeting in which the participants grappled with issues and suggested changes in an open and honest manner. They were weary of suggesting changes to things seen as being "instructions" from national. However, they were reassured that these are just suggestions and were encouraged to make things suitable to their specific context. A lively debate was generated in which site co-ordinators were able to challenge the provincial CCEO. There appears to be a good relationship between health information officers and facility staff and they are keen to involve communities in the process.

February will be the first month that the data is captured in the HISP software. The data is collated daily and captured weekly into the HISP programme by the information officers. It is sent through to the provincial office on a monthly basis.

The Virginia area is an active mining region and many workers come from neighbouring countries such as Lesotho and Mozambique. The compounds where the miners live do not accommodate their families. This encourages the use of commercial sex workers. The wives/partners of miners visit from time to time, particularly when they are pregnant in order to receive better health services. After delivery the women return home and are not able to be traced for follow up. At Rearabetswe clinic not a single child has been followed up beyond six months as they have all left the area. This poses serious problems for monitoring the effectiveness of the programme and has led to despondency among the nursing staff as they cannot see the results of their efforts.



## Infant feeding

In the Virginia site, from the start of the programme, 77% of women have chosen formula feeding and 23% breastfeeding. Despite the high figure for choice of formula feeding, nurses reported that many women who may have chosen formula feeding before delivery, actually practice breastfeeding for fear of disclosure.

One woman on the PMTCT programme was interviewed at the provincial hospital. She had attended 8 antenatal visits and expressed having received good support from the nursing staff. She had however, not been able to disclose her status to anyone and had therefore chosen to breastfeed as formula feeding would be met with questioning from her family.

Women who choose to formula feed are given magnesium sulphate to stop breast milk production.

The accessibility of formula for women from the surrounding farming areas is a problem as these areas are serviced by mobile clinics. This service is erratic as there are frequently problems with transport.

## Community involvement and response

This site has developed a variety of innovative methods to involve the surrounding communities in the programme. Through the information management meeting it was decided that every month the facility co-ordinators would design graphs of the HIV testing uptake rate and HIV positive rate. These will be displayed in the clinic waiting rooms and used as a visual aid during group education sessions to make the issue of HIV/AIDS more tangible to clients.

Outside each of the facilities offering the PMTCT programme there is a billboard with a picture of a mother and baby and the slogan 'Have healthy, happy babies' written in Sotho and English. At the Virginia Provincial Hospital there are posters displayed on the walls advertising the PMTCT programme and giving information about nevirapine.

Pamphlets were designed by the provincial office at the start of the programme and these were sent for translation into Sotho. These pamphlets have not yet reached the facilities and the staff are upset about this as they were promised them months ago. They are concerned that they have no information to give out to clients and many clients request information on the programme that they can take home and read in their own time.

There is a community health forum in the Kothalang area that meets once a month in the clinic after hours. The PMTCT co-ordinator for the clinics gives a report on the progress of the PMTCT programme. This has proven to be an effective way to involve existing community structures and to dispel mixed messages from the media.

## Impact of the PMTCT programme on general health services

The nurses in the clinics reported that more men have been coming in for testing since the start of the PMTCT programme. It is important to note that all of the clinics visited had at least one male counsellor and this may encourage more men to seek counselling. The opening hours of the clinic are however, a deterrent to men seeking testing as

many of the men in this area work on the mines and claim to receive testing from the mining hospital. There is no formal referral network between the mining hospital and the rest of the health services.

In the facilities visited, all women who present for booking are sent for counselling prior to being seen by the midwife. The nurses believe that counselling should be seen as part of regular antenatal care and not something that is associated with HIV/AIDS. Consequently, the counselling uptake rate for many of the facilities is 100%. The nurses raised the issue that the pressure on women to be counselled and tested may actually lead to some women not attending antenatal care.

#### Key points and general impressions of the visit

- The site has a high level of capacity amongst facility co-ordinators and staff are well supported and updated on a regular basis.
- Information about the programme is visible in consulting rooms as well as outside the facilities.
- Laudable attempts have been made to involve surrounding communities through existing community structures.
- A uniform policy on payment of lay workers is vital to prevent conflict and tension between these cadres of workers.
- The use of VCT counsellors for the PMTCT programme is not ideal as they are very narrow in their approach to counselling clients as a consequence of the vertical nature of their training.
- Clarification is needed around the management and support of lay counsellors in order to prevent burnout of these essential personnel.
- Unmet promises by the provincial office for things such as extensions to clinic buildings, televisions for the waiting rooms and educational pamphlets for clients are discouraging for staff and are limiting the quality of the service.
- There is a severe shortage of space for counselling in almost all of the facilities. This requires prompt action to prevent demotivation and possible dropouts of the counsellors.
- The inability of women to disclose their HIV status appears to be a problem hampering the use of formula feeding in this well resourced urban area. This reflects the social context of the surrounding communities and should be a focus of the community health forum.
- The high mobility of this mining community presents a challenge to the follow up care of women and children.

## 6. FRANKFORT SITE

### Organisation and Management

In order to assist in the process of implementing the PMTCT programme, steering committees were established at both the provincial and district levels. Both steering committees hold monthly meetings and provide representation for a broad range of stakeholders with interest in the PMTCT programme.

There appears to be the need for increased support from provincial and district level representatives. Although government representatives involved in the programme stated that they visit the sites often, those at the sites suggest that the amount of support has noticeably decreased since the beginning of the programme. Although there were a number of teething issues that had to be addressed at the start of the PMTCT pilot, personnel at the site level expressed a desire for a continued support from the province and district.

Despite the expressed need for greater attention and support the relationship between the provincial co-ordinators and site personnel appears to be good. Good communication lines were reported to exist between the province and the district.

There are also good relations among the clinics and between the hospital and clinics. Meetings are held monthly but if problems arise they also talk over the phone to sort issues out.

The communication lines between the 8 clinics involved in the Frankfort pilot appear in good working order. A strong connection was noted between certain subsets of clinics due to the particular referral arrangement and supply and distribution systems in place at these clinics. For example, because as doctor services are offered at Philani but not at Frankfort and Phahameng Clinics, clients in need of specialised care are referred to Philani Clinic. Similarly, Frankfort and Phahameng Clinics order medical supplies and drugs from Philani clinic as only Philani Clinic gets supplies directly from Frankfort Hospital. These three clinics are further connected through monthly staff meetings where PMTCT is one item on the agenda.

### Clinic involvement in the PMTCT Programme

Clinics play a key role in the PMTCT programme. At the Frankfort site, there are eight clinics involved in the pilot project.

There are both benefits and disadvantages to this setup. A major benefit is that it places emphasis at the PHC level and may serve as a valuable opportunity to integrate PMTCT with other related services at this level of health care delivery. A disadvantage is the potential lack of quality control and consistency among clinics in addition to the potential for confusion between clinics and the hospital. There is a need to ensure that all clinics are up to par, that clinics are using a similar PMTCT system, and that there are good communication lines among participating health care facilities.

Due to differences in the capacity of clinics, it may be difficult to maintain a consistent level of quality in the delivery of the PMTCT programme. For example, it has been noted that some of the clinics are too small to offer sufficient privacy and confidentiality

during individual counselling sessions. The lack of space also impinges on the efficient use of counsellor time in at least one of the clinics where three counsellors must share the same counselling room. Although discussions are underway to expand some of the clinics there have been no indications of when this might happen.

The accessibility of services in the clinics in Frankfort is an issue. Although the number of days on which certain services are offered was expanded at the commencement of the PMTCT project, the community seems to lack awareness of this change. For example, in one of the clinics antenatal care was offered only on Wednesdays but this service was expanded to the rest of the week. Most women, however, still come to the clinic for antenatal care on Wednesdays. This hinders the ability of clinic staff to provide a responsive and quality PMTCT service to these clients.

### **Hospital involvement in the PMTCT Programme**

Frankfort Hospital is involved in the delivery component of the PMTCT programme.

At the maternity ward there is always one sister and one nursing assistant on duty. There are also two lay counsellors assigned to the hospital who serve to provide supplementary information and counselling to those women who present for delivery. This assistance is intended to complement the support that HIV-positive mothers have already received at the clinic level.

The two lay counsellors are only at the maternity ward from 8am-1pm and are not around on weekends or holidays. When the lay counsellors are not available, the sister and nurse on duty provide any needed counselling.

### **Staffing**

No additional staff members, other than the lay counsellors were added at the start of the programme. There are 14 lay counsellors involved in the PMTCT programme.

The lay counsellors are members of the community who have received training in basic HIV/AIDS, PMTCT, and HIV counselling. These counsellors are allocated to particular clinics within the pilot site and remain at that clinic unless circumstances require a rotation of the counsellors between or among the clinics. There are anywhere between one and three counsellors at each clinic depending on the size of the clientele at the clinic. There are also two lay counsellors positioned at Frankfort Hospital to provide additional counselling services to clients when they come in to deliver.

In addition to the training provided to the lay counsellors all clinic staff were informed about the PMTCT programme and provided with training.

One interviewee suggested that the staff in the maternity ward at Frankfort Hospital need more training. However, as they are short of staff it is difficult to relieve staff from their standard responsibilities for training purposes.

There is an emphasis on ongoing training. The current group of PMTCT counsellors will be the first group to receive training in a wide variety of services. The rationale for this approach is to help reduce fragmentation among HIV services.

Most interviewees expressed the feeling that they had received adequate training and some suggested that ongoing training would be appreciated.

Staff morale and commitment was reported to be high.

There has been some discontent among the lay counsellors concerning the lack of remuneration for their work. A meeting was held recently between the counsellors and the provincial and district PMTCT co-ordinators to resolve this issue. During this meeting it was agreed that the counsellors will be paid R500 per month. Although this is welcomed as a positive change, concern was raised whether the proposed pay will be sufficient to retain the counsellors. With their level of training and experience, it is possible that they may decide to leave their current position for a better paying job within the private sector.

Remuneration of the lay counsellors will be provided through an NGO. The national government funds will not cover remuneration for lay counsellors. Hence funds for remunerating lay counsellors must come out of provincial budgets.

The counsellors report having sufficient time to provide a quality service to clients in the PMTCT service and most seem to feel that they have received adequate training to provide this service. Strain, however, appears to be felt by the nursing staff at the clinics and at the maternity ward of Frankfort Hospital. Unlike the lay counsellors, the nurses have many responsibilities other than the PMTCT programme. Although the lay counsellors help ease the burden imposed by the PMTCT programme, the new service still means less time for the nurses to provide their normal set of services.

At the clinic level, the professional nurses must do the HIV testing and dispense NVP. No additional nursing personnel were taken on at the onset of the PMTCT programme.

At the start of the programme tensions existed between the nursing staff and the lay counsellors at the clinic. Initially, the nursing staff did not appreciate the assistance provided by the lay counsellors. This was associated, at least in part, by the fact that the lay counsellors were provided with training on HIV/AIDS and the PMTCT programme before this training was given to the clinic sisters. Thus, at the beginning of the PMTCT pilot project, the clinic sisters were required to supervise the lay counsellors on a programme with which they were not entirely familiar.

Tension was also created between the lay counsellors and the professional nursing staff by the lay counsellors' sporadic attendance at the clinics. This seeming lack of commitment to the PMTCT programme was linked to the absence of payment for lay counsellors. It was suggested that without receiving some of remuneration, the lay counsellors would not feel a strong obligation to treat their involvement in the programme as a "real" job. With the introduction of remuneration, however, this situation is expected to improve.

There is a need to clarify what is expected from the lay counsellors and to ensure that they are given adequate feedback about their involvement in the PMTCT programme.

An on-site mentor collects data from the sites and also provides programme-related support for the lay counsellors. Although he seems to have good relations with the counsellors, it was indicated that perhaps he could be more direct when confronting problems at the clinics and that it would be helpful if his meetings with the counsellors were by appointment rather than arranged spontaneously. The on-site mentor is a professional nurse at one of the clinics involved in the PMTCT pilot programme. It

was suggested that his position as a health care provider makes his position as on-site mentor more acceptable than it would be if an outsider were to fill this role. The fact that the on-site mentor also acts as a health provider at one of the clinics, however, means that he must divide his time between his duties at the clinic and his duties to the PMTCT programme.

There are no formal support systems in place for counsellors or other staff members to discuss personal issues that arise from their involvement in the PTCT programme. The lay counsellors, however, hold informal meetings to discuss their thoughts and feelings about the programme.

There is very little involvement of doctors in the PMTCT programme. Although doctors visit some of the clinics involved in the programme, this is to render services unrelated to the PMTCT programme. At Frankfort Hospital, the involvement of doctors is limited to their role in complicated deliveries. Doctors at the site were provided with training on the PMTCT protocol and are, therefore, aware of the procedures they should avoid during delivery.

The hospital manager and one of the sisters provide support for the staff at Frankfort Hospital. This system of support is reported to work well. In addition, monthly meetings are held to discuss PMTCT. There are, however, no special meetings for staff to sit down and discuss their personal feelings about the PMTCT programme. One interviewee suggested that as staff at Frankfort Hospital are not directly involved in the counselling component of the PMTCT programme, their involvement may not lead to the same sort of emotional strain as experienced by the lay counsellors.

## **HIV Counselling and Testing**

Group information sessions are offered at the clinics to all people in the waiting area. Pregnant women are then provided with the opportunity to receive individual pre-test counselling.

If a client desires to receive pre-test counselling she can usually receive it on the same day as the group information session. Should there be more women interested in receiving an individual pre-test counselling session than time permits, appointments can be made for women to be tested on another day.

The number of women who can be pre-counselled in one day relates to the number of personnel available to provide counselling and HIV-testing at the facilities. It also relates to the number of available rooms in which to offer counselling services. At some of the busier clinics where there are 2-3 counsellors available, these counsellors must share a common room for counselling. As noted above, clients tend to come on a particular day during the week for antenatal care. Encouraging clients to come on alternate days of the week would relieve some of the pressure on staff and allow more clients to receive individual pre-test counselling on the day of their visit.

Some clients may have difficulty getting their test results on the day of testing because they can only get transport to the clinic late.

There was some doubt expressed over the quality of counselling. For example, some clients who arrived at an appointment for HIV-testing stated that they had not consented

to the test. In addition, it was reported that a patient arrived at Frankfort Hospital without having received post-test counselling at the clinic level.

Although VCT is available at the clinics for the partners at PMTCT participants, very few seem to take up this option.

### **Infant feeding**

If a woman has chosen to formula feed her infant, two tins of formula feed are given to her at discharge from the hospital. Further tins of formula feed are then supplied at the clinic level.

More women are opting to formula feed than to exclusively breastfeed. As breast feeding is the normal mode of infant feeding in the community, some women express concern over stigmatisation if they opt to formula feed their infants.

### **Monitoring and follow-up care**

There is a standardised set of monitoring forms used at all the clinics. An on-site mentor collects the data from the clinics and the hospital on a weekly basis and passes this information to the district level. The information is then passed from the district to the provincial level. This process is reported to be running smoothly. However, some potential areas of improvement were noted. Two such areas of improvement include the need for better photocopying facilities and the usefulness of a computer to reduce the amount of work that needs to be done by hand. It was also noted that the provincial government is awaiting software from the national government that will enable the former to analyse the raw data being collected from the pilot site.

Concern was expressed about the extent of confidentiality with regards to record keeping. Some of the clinics lack adequate storage facilities and client records are not placed in locked cupboards.

Follow-up after delivery is provided at the clinic level where women can receive monitoring and treatment for opportunistic infections and treatment for TB. Although counselling is offered at the clinics following the post-test counselling session, it does not seem that many women take up this option. A common method of identifying women on the programme is used at the clinics and Frankfort Hospital.

A major challenge faced by the programme relates to the lack of care and support available to the mothers involved in the programme. Apparently, a step-down facility is to be established at the hospital for people with chronic illnesses and this service will also likely be able to help people with HIV/AIDS.

One interviewee stated that one of the difficult aspects of working in the programme is that there is very little in the way of care and support services to recommend to those women who request them.

One way to increase support for the mothers would be to ensure that treatment for opportunistic infections and psychological support are readily available. For example, it was suggested that a food package be offered to the women on the programme. This would provide the mothers with greater incentives to get them involved in the programme. It is also important as a means to show women and the community at

large that mothers as well as infants are valued. Apparently there is a great deal of enthusiasm for this initiative among the lay counsellors but there are financial constraints to putting it into practice.

At one of the clinics it was reported that they are awaiting clinical protocols concerning how to manage opportunistic infections should they arise in clients on the programme.

For those women who stay in the same area during the duration of the programme, they almost always remain at the same clinic. There are some difficulties with follow-up if the women have come from outside of the catchment area. These women are generally lost to follow-up when they return home following delivery.

## **Community involvement**

A number of initiatives have been taken at the Frankfort site to foster community support and mobilisation. These measures include the raising of billboards with the PMTCT logo and message in front of each clinic at the Frankfort pilot site, and the design of pamphlets and posters in local languages.

A number of meetings were held to help raise people's awareness of the PMTCT pilot project. Evidence suggests that these information sessions had a positive effect. For example, prospective participants were already requesting the service before the programme was implemented in August 2001. However, there seems to have been little effort made to sustain community awareness since the commencement of the pilot.

Despite initiatives taken to increase awareness in the community, people with HIV/AIDS are still stigmatised within the community. This has negative effects on the PMTCT programme. One consequence of continued stigma is that it makes women less likely to disclose their status to their partners and families. This creates difficulties for the women when it comes time to make a decision concerning whether or not she wishes to breastfeed or formula feed her child.

## **Supply and Distribution System**

Overall, the system of supply and distribution is working well.

Frankfort Hospital orders drugs from a medical depot and the clinics, in turn, send orders for supplies to Frankfort Hospital. Of the eight clinics involved in the programme, Philani and Villiers take orders for three of the clinics (themselves and two nearby clinics). The other two clinics in the programme, Cornelia and Tweeling, order drugs only for themselves. At the moment they have adequate supplies other than bactrim which has been out of stock since the programme started.

There were delays in the distribution of NVP to at least one of the clinics at the start of programme but this problem seems to have been resolved.

Tweeling and Cornelia have problems with the transport of blood specimens to Kroonstad for the verification of conflicting HIV-rapid test results.

A budgetary issue has arisen with regards to the payment for supplies. All stock for the PMTCT programme is supposed to come from the provincial budget rather than from the hospital budget. Despite this arrangement, Frankfort Hospital has had to purchase stock for the pilot project and are still waiting for reimbursement from the province.



## 7. KALAFONG SITE

### Organisation and Management

There is a considerable amount of restructuring underway at all levels of government in the Gauteng province. Part of this restructuring process has been the movement of staff to new positions. In relation to the PMTCT programme in Gauteng, a shift in key personnel took place just prior to the official start of the PMTCT pilot project. Two of the positions affected were the provincial co-ordinator for MCH and the regional co-ordinator for HIV/AIDS and STIs. One interviewee said that the transfer of government staff played a role in delaying the implementation of the PMTCT programme.

National support for the PMTCT programme was stated as minimal. One of the regional representatives could only recall a single meeting about the PMTCT pilot with national representatives. She also noted that there should have been a provincial representative present to prevent the region receiving mixed messages about the PMTCT pilot from the national and provincial levels. Communication between the province and region was reported as good.

Tension and communication problems, however, exist between the region and the site. The choice of the pilot sites in Pretoria was described as 'imposed' by one regional informant. Reservations were greatest concerning the selection of Kalafong Hospital (KH).

The major reservation was that KH is an academic hospital where patients must be referred and where there are a number of research studies being conducted.

Although there was less hesitation expressed at the choice of Pretoria West (PW), this pilot site was also described as a poor choice due to it being outside of normal public transportation routes and hence difficult to access for those clients without a car.

Staff at both pilot sites mentioned difficulties in trying to attend meetings called by the regional office due to uncertainty over meeting dates and times. They described the situation where several staff members from the sites would end up sitting and waiting for a meeting, only to find out later that the meeting had been delayed or postponed to another date. This was described as particularly problematic because personnel at the pilot sites are already under time pressure and sometimes have to make special arrangements to attend the meetings. For site personnel who miss the meetings, few attempts have been made by the regional office to find out why they could not attend and to inform them about what was discussed. Interviewees suggest that the lack of adequate communication lines have hurt the relationship between staff at the pilot sites and personnel at the regional level.

In addition to the problem of setting meeting dates and times, some interviewees suggested that the meetings are not very helpful. For example, one interviewee stated

that the meetings seem to lack purpose and that due to the time constraints of staff, some issues would be better discussed over the phone.

One interviewee reported that PMTCT counsellors receive R500 per month while counsellors at VCT sites are paid R1500 per month. Not only do PMTCT lay counsellors receive less than their VCT counterparts, but they are paid less for their involvement in the PMTCT programme than they received in their previous work for an NGO. Concern was expressed that the pay issue would cause counsellors to quit the PMTCT programme. Counsellors themselves expressed dissatisfaction with the remuneration that they receive for their involvement in the PMTCT programme.

## **HIV Counselling and Testing**

Two lay counsellors per site provide PMTCT counselling services. These counsellors have received training in basic HIV/AIDS, PMTCT, and VCT. The training provided was reported to be adequate.

Private rooms that enable a confidential counselling service are available at both pilot sites.

VCT for the partners of PMTCT clients is also available at both pilot sites. However, very little use of this service is reported. Interviewees related this to hesitation on the part of PMTCT clients to disclose their HIV status to partners.

### **Kalafong**

Due to the fact that KH is a referral hospital, there is a greater chance that clients attending KH have already received HIV testing and counselling. Depending on the way that uptake rate for the PMTCT programme is calculated; this may cause the statistics at KH to reflect a different picture of uptake than at a non-referral site such as PW. A couple of interviewees raised the point that low uptake rates at KH might, at least in part, be due to a different denominator being used.

In a discussion about the low uptake rate at KH, one interviewee warned that the provincial target may be unreasonable and potentially harmful if it makes counsellors feel the need to “push” the programme in order to meet the targeted level set by the province. She suggested that the uptake rate at KH is not inconsistent with rates reported in some other studies and that pushing for higher acceptance rates may threaten confidentiality and the woman’s right to refuse.

Finally, low uptake at the site has been associated with a “myth” stemmed from untrue allegations made about HIV-related research being conducted at KH. The allegations suggested that 8 HIV trial-related deaths had occurred while in fact only one had occurred, and it was not related to the HIV trials. The bad press received by KH has led to the belief among community members that if you are HIV positive and go to KH you may never come back.

### **Pretoria West**

PW deals with clients by appointment only. There are no group pre-test information sessions offered - only individual sessions. Group counselling sessions were offered at the start of the programme but women disliked the lack of privacy. The use of only individual pre-test counselling has also reduced the strain on lay counsellors at the site.

## Staffing

A common complaint about the PMTCT programme is the lack of adequate staff to provide the service. Many interviewees stated that health facility personnel were already overburdened before the start of the PMTCT pilot project and that the addition of the programme has served to further increase the strain on staff. In particular, the need for additional nurses was identified as necessary to help cope with the added workload that has come with the PMTCT programme. There is a need for personnel who can devote more time to the PMTCT pilot project rather than having to juggle their time between the PMTCT programme and other duties. Although the lay counsellors have eased the burden of the PMTCT programme on staff members, considerable nurse involvement is still required. The shortage of staff members not only affects the ability of personnel to offer a quality service but also hinders their ability to attend PMTCT meetings and go for training.

One interviewee questioned whether the strain felt by personnel at the pilot sites might reflect, at least in part, poor management of staff at the facilities. No formal support systems are in place at either KH or PW for staff involved in the PMTCT programme.

### **Kalafong**

Two lay counsellors were the only additional staff added on at the commencement of the PMTCT programme.

Staff members at KH report being happy with the training provided but some personnel in management positions are still awaiting a promised course on counselling. Although no formal support or supervision is provided at the health facility, informal support can be sought from the sisters in charge.

A representative from the provincial office carried out an evaluation of the counselling component of the PMTCT programme soon after the commencement of the pilot. The evaluation pinpointed some aspects of the service that required improvement. On two occasions an on-site representative evaluated the content of the group information session given by the counsellors and healthcare workers. From these evaluations it was determined that the content of the talk was of sufficient quality.

The counsellors did not receive payment for their first three months of the programme. This issue, however, has since been resolved.

One of the paediatricians at the site had considerable involvement in the programme, especially when it was starting up. With this exception, however, there is limited doctor involvement in the PMTCT pilot project. An interviewee at the regional office felt that doctors at the site are overly critical of the programme and that they are more interested in pursuing their own research agendas than complying with the national protocol. Overall, there was a lack of commitment and common approach to the PMTCT programme.

Conversely, representatives from the site suggested that they were happy to be part of the project and that personnel at that regional office were making false statements to suggest that the research being conducted is in conflict with the national protocol.

Another issue raised concerned the disclosure of site statistics. A situation was described

where PMTCT nursing personnel were excluded from meetings where doctors presented information about the programme to high profile visitors. Concern was expressed that the information presented at these meetings was inaccurate.

### **Pretoria West**

There are two registered nurses working at the ANC, one working the day shift and the other working the night shift. These two sisters are the only ones who perform HIV testing, one of whom is solely responsible for data compiling. It was also indicated that the sisters are involved directly in the counselling component of the PMTCT programme.

There are two lay counsellors, one was seconded from an NGO and the other sent from the regional office. The number of counsellors is deemed sufficient, as the counselling load is not particularly great at PW. In addition to the lay counsellors PW was given an extra nurse to assist with general tasks at the clinic.

Training has been provided. However, it is difficult for both sisters to receive training, as one sister must always remain in the ANC.

A language barrier between counsellors and clients was noted. While most of the patients attending PW are Afrikaans speaking, neither of the counsellors can converse in this language. Apparently some patients request to have a translator present during their counselling sessions.

Doctors are not involved in the PMTCT programme at PW. They were invited to attend provincial training sessions but their attendance had been poor.

## **Effect on other services**

### **Kalafong**

Indication was given that the PMTCT programme is having an effect on other services. For example, patient waiting times have increased since the start of the pilot project. More attention needs to be focused on other levels of health care provision - such as the clinics and other hospitals - to ensure that Kalafong Hospital (KH) is not overburdened by PMTCT. The PMTCT programme is just one service among many offered at the hospital. Hence, it would not be fair for PMTCT to have a negative impact on the quality of care being provided to patients that are utilising other services at KH.

### **Pretoria West**

There was a feeling that the PMTCT programme, at least at the beginning, had an effect on the delivery of other services. Once they got more acquainted with the programme, it proved to be less time consuming.

## **Clinic involvement in the PMTCT Programme**

PHC clinics are not formally part of the PMTCT pilot project. Representatives from all clinics in the pilot catchment area, however, attended a workshop to inform them about the PMTCT pilot project.

Although it was suggested that clinic capacity in the Pretoria Region could sustain delivering PMTCT services, observations made during fieldwork might suggest otherwise.

An important feature about clinic capacity was indicated during one of the interviews. It was noted that the types of services offered at clinics in the Pretoria region remain fragmented despite the expressed desire to move towards a common level of service under a single authority (DHS). Local authority clinics still provide mostly preventative and promotive services and no curative services while the provincial clinics have progressed further towards the goal of rendering all services.

Interviewees associated the failure of local authority clinics to provide curative care with budgetary constraints and staff shortages. This lack of uniformity poses a significant challenge to an effective and equitable PMTCT programme especially at the rollout stage. Without ensuring uniform capacity across clinics, it is likely that those clinics with lower capacity will end up providing an inferior service.

## Community involvement

The associations between the pilot sites and the community appear to be quite limited. Attempts to promote the programme to the community seem to have been largely limited to the initial start-up of the pilot project.

Stigma is still a substantial problem and disclosure of HIV status is uncommon. Some interviewees provided anecdotal stories to illustrate how fear of HIV/AIDS and cultural norms related to motherhood are deleterious to the PMTCT programme. For example, fear of one's HIV status becoming known to family and/or community members prevents some women from joining or adhering to the PMTCT programme. Additionally, pressure exerted by family members to breastfeed prevents some women from using formula feed or causes them to mix formula feed with breastfeeding.

There is an increasing awareness among community members about HIV/AIDS and the PMTCT programme. However, the need to increase public awareness about basic health issues such as the importance of ANC and teenage pregnancy was noted.

Women play a much greater role than men in running and participating in the community programmes. As stated by one interviewee, "Men don't want to know [about HIV/AIDS]."

### Kalafong

To promote community awareness of the PMTCT programme, clients are advised to tell others about the programme. There are posters and pamphlets in the antenatal care unit. The pamphlets are mostly in English but they are trying to get them in at least one other language.

Members of the community are included on the hospital board, which holds regular, monthly meetings.

## Monitoring and follow-up care

The follow-up component of the PMTCT programme seems quite minimal. Following delivery of their infants, mothers visit the PMTCT pilot site for formula feed (if this is

their choice of infant feeding), further counselling (if desired) and infant HIV testing. It was reported that the clinics have been informed about the PMTCT programme and that mothers carry a card that identifies their involvement in the programme.

Care and support offered to HIV positive mothers seems minimal. Most interviewees seemed to know very little about the types of follow-up services offered at either the clinic level or in the community. Interviewees gave little indication of an established referral system between the PMTCT pilot project and those community services that offer care and support for people with HIV/AIDS.

At the clinic level the IMCI protocol is supposed to be followed. However, most nurses lack adequate training in the IMCI protocol. An issue over the budgetary aspects of the PMTCT programme was also raised. Apparently, the clinics wanted additional money for cotrimoxazole prophylaxis. However, as cotrimoxazole prophylaxis is supposed to be part of the regular service offered by the clinics rather than particular to the PMTCT pilot, the regional office refused this request. Contact between the regional office and the clinics concerning the status of the latter's involvement in follow-up seems minimal to non-existent.

### **Kalafong**

At Kalafong there is an immunology clinic (IC) that provides care and support to people with HIV/AIDS and to which clients in the PMTCT programme can be referred. The IC, however, is not formally linked with the PMTCT programme.

There seems to be little to no follow up offered through the PMTCT programme itself at KH. The major source of follow-up at the site relates to infant feeding. If a mother has chosen to formula feed her infant, formula feed must be obtained at the site. In addition, when retrieving formula feed, mothers are given the opportunity to talk with the dietician about safe feeding practices.

Difficulty in keeping track of mothers and infants on the programme was noted. Some participants were reported as being lost due to their failure to return to one of the pilot sites to deliver while others were reportedly lost during the postnatal stage. It was suggested that women may discontinue their involvement in the programme out of fear that by utilising services at a pilot site rather than at a local health care facility, that they may inadvertently reveal their HIV status to family members.

### **Pretoria West**

Only 50% of clients return to Pretoria West (PW) for post-delivery check-up. For those that do return, information is gathered to ensure that previous data has been correctly collected and that the programme protocol has been properly followed.

There are serious concerns about finding mothers and infants when it comes time to check the HIV status of the infants.

As at KH, the major form of follow-up at the PW pilot site relates to infant feeding. It was stated, however, that clients are told that they can return to PW for further counselling.

There is a ward at PW that has been designated as a step-down facility that is to be used by all hospitals in the area. Care for people with HIV/AIDS is to be included in the services offered at the facility.

No specific programmes are available for people with HIV/AIDS at Pretoria West but they can be referred to services in the community. However, there is no official referral system in place between the PMTCT programme and community services. In addition, the staff at PW seem to lack knowledge about the types of services available in the community for people with HIV/AIDS.

## **Infant feeding**

From the site statistics it seems that most mothers are choosing to formula feed their babies. It was not possible to determine whether women are sufficiently empowered to make this choice on their own. Most interviewees seemed to support that formula feeding was the most suitable option due to the difficulties of exclusively breastfeeding. Whether this opinion held by staff affects the way they counsel about infant feeding practices was not clear.

Infant feeding was voiced as one of the most challenging aspects of the PMTCT programme. Interviewees suggested that women face difficulties no matter whether they choose to formula feed or exclusively breastfeed their infants. Women who opt for formula feeding face criticism from their families and some women worry that using formula feed will reveal their HIV status. Conversely those women who choose to exclusively breastfeed may turn to mixed feeding due to personal constraints or pressure applied by family members to use a variety of feeding methods.

Some interviewees suggested that formula feed should be made available at the clinics rather than at the PMTCT pilot facilities. Moving distribution of formula feed to the clinic level would likely make this part of the programme more accessible to participants. In addition, it would serve to remove some of the pressure from the pilot sites, which already feel overburdened by their level of involvement in the PMTCT programme.

## **Integration of the Programme with existing services**

At the regional level, responsibility for the PMTCT programme falls under the co-ordinator of HIV/AIDS and STIs. At the present time, the co-ordinator for MCH has a very minimal role in the PMTCT programme. Attempts to increase her involvement have been slow as she has been preoccupied with other responsibilities.

At the provincial level there was greater co-ordination between MCH and PMTCT, at least during the initial phase of the PMTCT pilot project. During the planning phase of the PMTCT programme, the provincial co-ordinator of MCH came and introduced the concept of PMTCT to the relevant stakeholders in the Pretoria Region. In addition, she attended meetings in Pretoria on the PMTCT programme, was involved in organising provincial PMTCT meetings, and represented Gauteng province at national PMTCT meetings. However, the provincial co-ordinator of MCH changed posts before the official commencement of the pilot project.

## **Monitoring and Evaluation**

Overall, the registers for the programme are well kept. Data is collected on a daily basis and compiled on a daily, weekly, and monthly basis. It is sent to the regional office on a weekly and monthly basis. Data is recorded using pen and paper and, hence, must be transferred onto a computer at the regional level.

Personnel at both pilot sites described confusion over who at the regional office should be given the site statistics. They have recently been informed of a new arrangement that was made to ensure that information does not fall into the “wrong hands”.

## Referrals

There is limited communication between PW and Kalafong except during joint meetings about the PMTCT pilot project or in relation to the referral of complicated cases from PW to KH. If a woman receives antenatal care at PW and goes to KH to deliver or vice versa, these patients are generally lost in the system (in terms of consistent record keeping). Most women, however, usually attend the same facility for the duration of their involvement in the PMTCT programme.

### **Kalafong**

KH is the main site for delivery services for Atteridgeville and a referral site for PW, Mamelodi Hospital, Pretoria Academic Hospital (when full) and for hospitals outside of Pretoria Region and Gauteng Province. Approximately two thirds of women giving birth at KH are referred from other hospitals and only one third come from the immediate drainage area. Although KH is a referral hospital, HIV testing and counselling is not refused to someone who turned up at the site without a referral. If they test negative, however, the client will be requested to return to her local clinic.

The referral system between the obstetrics and gynaecology department and the clinics and other hospitals was reported to be excellent. Contact is made on a regular basis and the department is very involved with in-service training and implementation of programmes at other health care facilities.

The referral system between the immunology clinic and the ANC was also reported to be good.

### **Pretoria West**

Of those clients referred to the PMTCT programme from clinics in the catchment area, the sisters sometimes call from the clinics to let staff at PW know that there is someone interested in participating in the PMTCT programme. Some women come to PW for the PMTCT programme and receive the rest of their routine antenatal care at their local clinics.

## Supply and distribution system

Overall, the supply and distribution systems were reported to be working well at the sites.

A lack of vitamin A was noted at both sites.

A more efficient system for distributing HIV test kits would be to store them at the regional rather than provincial level. That way, if there is a sudden request from one of the sites for HIV test kits, this request can be met without going through the hassle of getting them from the province first.

There is a lack of knowledge concerning when a shipment of formula feed is going to arrive, who ordered it, and where it has come from. In addition, the documentation used for the shipment of formula feed is different from what is customarily used for



supplies received at KH. Some confusion was reported concerning whether formula feed shipments are for both KH and PW or just KH. A better system would involve Kalafong ordering its own supplies and being reimbursed by the government.

## **8. NATALSPRUIT SITE**

### **Organisation and Management**

There seem to be a fair number of staff involved in various aspects of the programme as well as a somewhat high degree of turnover in those people involved. For example, some government personnel involved in the programme had not been in their positions long and reported that they were still in the process of orientating themselves to the programme. Overall, however, there seemed to be good relations and communications at the regional office level and the sense that the turnover of staff is not a hindrance to the success of the pilot project.

Greater feedback from external review is needed at the regional level concerning how the programme is working.

Staff at the regional office are still trying to find their feet and there is a lot of work that needs to be done concerning finding ways to decentralise the programme to the district level. Also, adequate time is needed to find suitable people for the PMTCT programme and to then train these people.

The desire to increase the role of the clinics was expressed which includes the need to provide clinic nurses with the necessary training on the PMTCT protocol.

Provincial meetings provide an opportunity for representatives from the pilot sites to report how they are doing and to raise any problems encountered. The meetings also provide the opportunity for provincial representatives to keep pilot site personnel updated on the programme and what the province requires of the sites.

Good communications were reported between the pilot sites and the regional and provincial offices from both personnel at facility and provincial levels.

The relationship between the regional and provincial office was also reported to be in good working order.

Natalspruit Hospital (NH) was ready before Jabulane Dumane CHC (JD) but co-operation from staff at JD enabled the commencement of the pilot at that site when political pressure suddenly mounted to begin the programme.

Very positive relationship reported between JD and NH from personnel at both facilities.

### **Affect on other services**

'The programme takes us away from what we normally have to do.' Concern that a heavy workload with inadequate staff will demoralise personnel and hurt the quality of care provided.

## **Natalspruit**

The addition of the PMTCT programme has led to longer waiting times for all clients attending the ANC.

## **Clinic involvement in the PMTCT Programme**

Although clinics in the East Rand were workshopped on the PMTCT programme before it started, their involvement is still very minimal. The role of clinics seems to be limited to referring HIV positive pregnant women, or pregnant women who are likely to be HIV positive to the pilot sites and the provision of limited follow-up to the infants in the PMTCT programme.

Despite the hindrance created by this misunderstanding, this situation did offer some insight into the current status of clinics in the PMTCT programme. Namely, that clinic involvement in the PMTCT programme is minimal in the East Rand and that there are capacity issues at the clinic level that need to be addressed before the rollout of the programme can be carried out in a uniform manner.

### **J. Dumané**

Personnel at JD reported that clinic staff members have little knowledge about the PMTCT programme and that their involvement in the pilot is minimal. Staff at JD did, however, suggest that the clinic involvement in the pilot should be increased and that moving the programme to the clinic level would be helpful for the clients. At the same time, greater clinic involvement in the pilot will do little to alleviate one of the major obstacles faced by the programme, that of social stigma. Rather, other measures need to be taken to decrease stigma and thereby increase the number of women receiving HIV testing and counselling.

## **Natalspruit**

Low clinic involvement in the PMCT programme was described as problematic. Currently, there is little to no communication between NH and the clinics regarding the pilot project. One interviewee mentioned that some of the clinics may be offering HIV testing and then referring clients to NS or JD but was uncertain how many clinics may offer this service.

An Interviewee at ANC stated she does not know what is offered at the clinic level with regards to the PMTCT programme. Apparently there has been some attempt to send advertisements to the clinics. The interviewee suggested that formula feed, which is currently only available at NS and JD, should be supplied at the clinic level. This would remove some of the workload from NS and JD. It would also make formula feed more accessible for participants in the PMTCT programme, especially those who have to travel a considerable distance to the pilot sites.

The need to build capacity was noted to ensure that clinic staff members are not overwhelmed and overworked to the point that they develop negative feelings about the programme. There was a sense that if people from the hospitals and clinics come together to support and learn from one another, that this will increase the ability of health facilities to cope with the expansion of the programme.

## Staffing

The PMTCT programme has added to the workload of staff. No extra personnel other than the lay counsellors were added at the start of the programme. The people in charge of the programme at the ANC clinic must balance many other responsibilities with the PMTCT programme.

At regional level, it was mentioned that more lay counsellors are needed so as to expand counselling services – such as to the maternity wards.

### **J. Dumané**

There are 3 lay counsellors at the facility. Private rooms are available in the facility for individual counselling sessions. Lay counsellors are trained in basic HIV/AIDS, counselling and PMTCT protocol. They were trained alongside the registered nurses in VCT. Only nurses do the testing although the procedure for testing was explained to the counsellors as part of their training.

Lay counsellors were described as very enthusiastic and motivated. One interviewee expressed their belief that the counsellors' positive attitude towards the programme stems from the fact that they were volunteers. Hence, they were willing and interested in participating in the programme rather than being forced to become involved. It was also suggested that the quality of counselling is good although this was not substantiated with information about any evaluations conducted.

Subsequent training has been offered following the original training at the start of the programme. It was reported that a refresher training session was offered as recently as November 2001.

Opportunities for follow-up training provide personnel with the chance to share problems they are experiencing in relation to the pilot with others. In particular, a workshop attended by the lay counsellors was mentioned. The counsellors gave very positive feedback about this workshop. One of the nursing staff at JD suggested that opportunities like the workshop are very important for the counsellors because they get affected by their work and need the chance to share their feelings with others.

Interviewees suggested that the stipend received by the lay counsellors is too low.

Suggested current level of staff involved in the PMTCT pilot is inadequate. In particular, there is the need for more registered nurses. Nurses involved in the pilot, in particular, are under a lot of pressure as they are trying to balance the PMTCT programme with many other duties. In addition, it is problematic to send staff members for training when their absence will create a shortage at the facility. The programme has also affected rotation of staff between day and night shifts. As certain staff members are trained on the PMTCT pilot, these staff members need to be preferably placed on the day shift when the programme is offered. This however, affects the normal rotation of staff and makes it less flexible for all personnel.

Lack of adequate support, recognition, feedback, and consultation were highlighted during the interviews. Personnel involved in the pilot project sense that a lot of people – whether people investigating the programme or at the government level - want to know how the programme is working but fail to ask staff members how they are doing.

## **Natalspruit**

There are 5 lay counsellors at NH. Private rooms are available for confidential individual counselling sessions.

The training received by counsellors and staff at ANC was reported as helpful in preparing them for their involvement in the PMTCT pilot. They received information about the PMTCT programme as far back as November 2001 and received training early in 2002. Some staff had also received counselling training in relation to family planning at an earlier date. However, not everyone in the ANC department has received training on the PMTCT programme although all staff members know about the project.

The lay counsellors apparently received a two-week counselling course and some had received training beforehand. Apparently a refresher course was provided although it is unclear whether all counsellors have received additional training or if their counselling skills have been evaluated.

Doctors have a minimal role in the programme. Doctors attended information meetings with other staff members about the PMTCT protocol. One member of the nursing staff noted that doctors are overworked and are generally rushing between departments. While one staff member reported good relations between doctors and other staff members, another suggested that the relationship is not exactly positive but that there is the sense that doctors want to help with the programme. One interviewee stated that staff members in the ANC and labour ward “can’t expect too much from the doctors as they have other demands”.

## **HIV Testing and Counselling**

Some disappointment that there was not an overwhelming response to the PMTCT programme when it first began. Seemingly, there is considerable fluctuation in the number of women joining the programme. Some women are asking if they can receive NVP without receiving counselling although this is not permitted under the national protocol. Apparently NVP can be purchased at pharmacies but concern was expressed that women who choose this option will miss out on key aspects of the programme: counselling and follow-up for the infants.

At the regional level, the lack of response to the PMTCT programme was identified more with fear of knowing one’s HIV status and of stigmatisation rather than a reflection of people in the community being ill-informed about the programme.

VCT is currently being piloted at some of the clinics. The uptake at the clinics seems as good as or better than at the pilot sites which suggests the benefits of trying to increase the involvement of the clinics in the PMTCT programme. The interviewee at the regional level who raised the issue of the VCT pilots was not sure why uptake statistics seem higher at the clinic level but suggested that it may have something to do with the level of privacy and the hours HIV testing is offered at the clinics. It seems important to investigate this issue further to develop a better understanding of how to increase the role clinics in the pilot and of the factors that lead women to consent to or refuse HIV testing.

## **J. Dumané**

HIV testing is offered Monday to Thursday. On Friday there is a postnatal clinic held at the facility.

The number of women who opt for testing and who receive their test results on the same day as testing varies. Apparently one reason for variance in the latter is that they sometimes have too many people requiring testing and counselling on a single day and as the process is time consuming, some clients may need to come back on another day. Those clients who come back on another day for testing or to receive test results are instructed to make an appointment before leaving. This is to ensure that the clients receive the same counsellor for pre- and post-test counselling.

It was suggested that in most instances the women who are anxious to know their test results immediately tend to be those women who have been tested previously at another facility. On the other hand, those women who are confronted with HIV testing for the first time sometimes wish to think about it first and return to the clinic at a later date for testing.

The importance of empowering the client was emphasised. This involves ensuring the client has all the necessary information and encouraging her to make sure that she receives all components of the programme. For example, clients are encouraged to check with labour ward staff to ensure that their infants have received NVP syrup and that formula feed is provided (if this is the feeding option the client has chosen).

Staff members voiced opinion that the VCT component is key to the success of the programme.

## **Natalspruit**

The number of people attending the ANC differs between Monday and Thursday with the busiest days being Monday and Tuesday. Even on the busier days, however, all women who request the test are able to receive it.

The number of clients who agree to join the PMTCT programme apparently fluctuates considerably. There are some days when a lot of women agree to be tested and other days when no more than half agree. Some of the women who refuse testing will change their minds and decide to receive testing at a later date. There was uncertainty with regards to why women refuse to test. Most clients who agree to HIV testing will get their results on the same day.

Some seem to be in denial that they might be infected. Although interviewees expressed an understanding that knowing one's HIV status can be a lot to face, they felt it a shame for the PMTCT programme to be available and have women refuse to participate. It was proposed that perhaps there is a lack of exposure to the programme so that people are uncertain of whether or not it is really available. There is interest in better understanding why women refuse testing so that they can "get through to patients" and get more women involved in the programme.

Strong sense from staff that people with HIV/AIDS should receive the same care and degree of respect from facility staff as other patients.

Resistance from some of the women in the programme to have their HIV status indicated, albeit in a discrete fashion, on their records. Although it was explained to these women that only select people know about the system of indicating HIV status, many are still afraid that their status will become known.

## **Monitoring and follow up care**

### **J. Dumané**

Following each individual counselling session, the lay counsellors have a form they fill out concerning the steps they have followed during their meeting with a client. On this form there is the option of checking a yes or no box concerning whether or not the client has agreed to receive counselling.

### **Natalspruit**

Information is collected and compiled everyday, Monday to Thursday, and at the end of the month, monthly statistics are calculated. The statistics are handwritten and then faxed to the regional office.

### **J. Dumané**

A postnatal clinic is held on the third day after delivery. Personnel at JD try to empower clients in the programme by ensuring that they are aware of what is available for their infants and by encouraging them to take the necessary action to ensure that their infants receive the care available.

Need for greater follow-up and support. If women do not turn up for their test results or do not complete the programme, these women need to be contacted. At the time being, however, there is no one designated to follow-up those women who fail to complete the PMTCT programme.

A support group is held in the afternoons on alternative Fridays when there is almost no one else around in the facility. The attendance at the support group is low but staff members expressed hope that participation will increase as word spreads.

Very little in terms of support and care is offered in the community. Apparently an NGO was offering home-based care but this was not in relation to JD or the PMTCT programme. TAC has approached JD about providing assistance with the pilot but nothing has happened yet due to TAC being preoccupied with legal matters.

### **Natalspruit**

After discharge following delivery, women can come to NH for further counselling and are encouraged to come to the facility at least once so as to allow staff to check to make sure they are continuing with exclusive breastfeeding or exclusive formula feeding. Generally, however, women only tend to come once following delivery and not all women even come back for this one appointment. Some women in the PMTCT programme complain of transportation problems – especially related to paying the taxi fare. The interviewee who raised this point, however, questioned the existence of transportation difficulties and suggested that transportation to the facility is good. Hence, she believed that coming to NH should only be a problem for those women who must travel long distances to participate in the programme.

There is a support group held on Fridays. Lay counsellors are involved in the running of this support group. Few women attend the support group. While one interviewee expressed confidence that group attendance will increase with time, another seemed less optimistic.

## Referrals

Some patients are referred from Germiston Hospital where they have often already received HIV testing. Those who have received HIV testing are re-tested at NH or JD before joining the PMTCT programme.

## Infant feeding

Overall, formula feeding seems to be the preferred method of infant feeding among clients in the PMTCT programme. The stigma attached to formula feeding and the difficulty experienced by mothers when trying to exclusively breastfeed were noted as highly problematic. It was suggested that the issue over infant feeding needs to be addressed at the community level where women are being criticised and sometimes stigmatised for deviating from customary infant feeding practices.

### Natalspruit

If women wish to breastfeed, they are counselled to exclusively breastfeed rather than mix feed. For those women who find they cannot maintain exclusive breastfeeding, they are encouraged to switch over to formula feeding. It would be interesting to know whether concern over mixed feeding is leading counsellors to urge mothers to choose the formula feeding option.

Interviewees reported that family members do not understand why HIV positive mothers need to exclusively breastfeed or formula feed. For example, some family members assume that the mothers are being lazy and are not taking proper care of their babies. The lack of support at home makes it difficult for a woman on the programme to pursue either of the recommended options.

## Community involvement

At the regional level, the need to intensify efforts to educate the community – particularly in relation to issues around disclosure of HIV status – was indicated.

### J. Dumané

TV coverage about the PMTCT programme at JD did not commence until the actual start of the pilot. Hence, when the pilot began, a lot of women attending the facility had not yet been exposed to the programme. If these women had a chance to think about the PMTCT programme in advance, they would not be put on the spot and would, therefore, be more likely to agree to HIV testing.

Knowledge of the PMTCT programme in the community could be improved. Efforts need to be made to increase awareness in the community and to allow community members to have their questions about HIV/AIDS and the PMTCT programme answered. Raising awareness at the community level will play an important role in increasing support for people with HIV, thereby, leading to greater disclosure and

encouraging women to participate in programme.

Information sessions are not held in the community nor is any form of campaign being run to increase awareness about the programme in the community. Rather, community members learn about the programme through the media, from attending the clinic, or from word of mouth. Efforts to better inform the community must be done in the proper way so that the information is presented in a positive rather than negative manner.

#### **Natalspruit**

There is the need for a lot more education to be provided to the community concerning HIV/AIDS and the PMTCT programme. Some pamphlets were made available when the programme started with some of these pamphlets being placed in the door of the ANC and in the hospital corridor to increase awareness about the programme. People who attend the clinic and are provided with written information are told to share it with others when they return to the community. It was not determined whether this approach is successful or whether clients might be hesitant to pass on information for fear that by doing so community members may figure out their HIV status.

### **Supply and distribution systems**

Formula feed is only available at JD and NH pilot sites. Bactrim (cotrimoxizole) is also available at the pilot sites. Although infants are supposed to receive cotrimoxizole at their respective clinics six weeks after birth, women are encouraged to return to the pilot sites if their clinic of attendance does not have cotrimoxizole.

#### **J. Dumané**

Still lack the multivitamin but everything else is fine.

#### **Natalspruit**

Supply and distribution described as good. Only items specified in the protocol that are yet to be received are the multivitamin and iron supplements.

One interviewee reported that some clients were bringing NVP back saying that it had expired. They are currently awaiting new stock but still have some NVP left that has not yet expired.



## 9. PAARL SITE

The Paarl District is a Peri Urban area 60 km from Cape Town. Towns included in the District are Paarl, Franschoek, and Wellington. Population approximate estimates 198,546 people.

Paarl East Hospital (T.C. Newman CHC) currently renders up to 97% of antenatal care services for the district with an average of 210 – 381 new bookings a month.

All the deliveries are done at the Regional Hospital in Paarl. Mothers and babies are then discharged to various Municipal Clinics as follows:

- (i) Paarl Municipality – 6 clinics  
[Pop. 160 000]
- (ii) Wellington – 3 and 1 PAWC CHC  
[Pop. 40 000]
- (iii) Boland District Municipality – Has 6 Mobile Clinics covering farm areas within the District and 3 clinics.

All the above-mentioned clinics render PHC services.

Patients are able to access care at the central hospital through public transportation and rides from ambulances and farmers.

This programme commenced on 10<sup>th</sup> May 2001 and was officially launched 29.04.2001.

### Site Organisation and Management

The co-ordinator has generated massive “buy-in” from providers. She holds a monthly meeting with PMTCT staff at the clinics and with counsellors.

Staff are well-motivated by the co-ordinator. She has a hands-on approach, assisting to fill in gaps, as needed. She visits the clinic sites regularly and gives positive feedback to keep staff motivated.

The goal is to not make the PMTCT programme a vertical programme, but to integrate it into entire health care system.

The Chief Director for Rural Health Services has his primary office in TC Newman CHC and is very supportive of PMTCT. He was instrumental in initiating the programme, pulling in provincial resources in early stages of development. He is able to engage other services to participate in the programme and is, in many respects, chiefly responsible for the broad-based support the programme enjoys. He attends many of the meetings.

The Regional co-ordinator was instrumental in establishing the programme She also attends many of the meetings. While the programme is district based, most of the services

are provided at TC Newman.

## **Budget**

Funds derived from national government and provincial authority. Money was late in arriving from national government. Initial development completed with local money.

## **HIV Counselling and Testing**

In the observation room where all the necessary urine, HB and routine blood tests are taken – an extra blood specimen is taken for PMTCT programme. These blood tubes are marked with a client's sticker. It is at this point that new clients are identified and invited in groups of 4 - 6 for the following information session.

This is done by a counsellor. Information is given on issues like:

- a) Testing for HIV – using rapid screening test
- b) Medication – nevirapine for Mother and baby and follow-up care of baby
- c) Different options of feeding using formula or breastfeeding
- d) Support Groups.

Clients are encouraged to actively participate in the question and answer session, where they also indicate what their views are of the programme. A few myths have come out of such a session i.e. that Pelargon is used for HIV/AIDS babies only - to mention only one.

Counsellors are lay-counsellors. Locally trained and hired by AGAPE, a Paarl based NGO. They are recruited and selected from the community with joint training by the region and AGAPE.

VCT programme predates MTCT programme. Top-up training was provided to VCT counsellors to make them MTCT-capable. All counsellors are able to provide VCT and MTCT service.

Counsellors benefit from support systems and Employee Assistance Programmes (EAP) recognising the stresses they will face. A psychologist meets with the counsellors monthly for a debriefing session. Counsellors are liberated from counselling people they know. The co-ordinator is active as a counsellor when her services are needed. She underwent the ATICC training course.

The counselling facility is an unused laundry room that was upgraded and renovated to provide infrastructure for counselling. Funding for the renovations came from provincial money.

The PMTCT programme employs six full-time counsellors at the hospital and one in the community. Each counsellor works five days per week, seeing 5-10 patients per day. To date, the counsellors have not been needed in the community clinics as babies have not returned for HIV testing.

Counsellors are paid R1000 per month for a 20-hour work week. Counsellors restricted from working more hours because of the strain associated with counselling. Many of the counsellors work more than their allotted hours, providing service evenings and weekends.

All clients are walked to a counselling section about 50m away from Gynae Dept. This section contains 4 private consulting rooms with a waiting area. It has been made up to be user friendly and colourful with new blinds and background music.

It is only after this private session that clients can then make an informed choice to accept and consent to VCT or not. The clients are then returned to Gynae Dept. with counsellors always handling files themselves and will indicate to sister doing the testing, those having given consent to testing, and those refusing. Blood of those who refuse testing are immediately removed from batch and discarded.

Clients then enter the general flow of the clinic to be seen by doctors and sisters as part of routine antenatal care. Sister responsible for blood testing then proceeds and results issued to clients last thing before they leave the facility and relevant post counselling done; for negative and positive results.

Results not given that day are given at subsequent visit. Partners of clients consenting to VCT are also encouraged to be tested; initially the uptake was slow, but is steadily beginning to increase. Clients attending the clinic thinking they were pregnant, who end up not being pregnant and have gone through the whole process are recorded as VCT and not MTCT.

There is an open-door policy for clients. Apart from counselling offered during the initial MTCT programme, counsellors are available to clients during all antenatal care visits. One counsellor is stationed at the antenatal clinic, in room 84. Patients are also welcome to go to the small building where the counselling service is housed.

Thus far 1 611 clients out of the 1 701 having booked agreed to be tested, making acceptance rate 95% and of these the positive rate is 7.6%.

Of the total sample of clients accepting VCT the age groups has been as follows:

13	–	19 years	=	26%
20	–	30 years	=	53%
		30+ years	=	21%

68% of this sample group are single mothers.

Of the positive sample according to age.

13	–	19 years	=	11%
20	–	30 years	=	76%
		30+ years	=	13%

## Obstetric care

Antenatal bookings are done daily. Currently MTCT is offered to all new bookings (however other clients who have missed this opportunity and wish to be part of the programme are included). No one is denied access to the programme.

Unbooked patients have an opportunity to access testing in the hospital, if they arrive in labour early. Unbooked patients constitute 3% of hospital deliveries.

## Gestation at booking

The sample of Patients booking and testing Positive was done

10 weeks and below	=	4%
11 – 20 weeks	=	14%
21 – 40 weeks	=	78%
Not recorded in register	=	4%

Of this positive sample 84% of clients are single mothers.

To date only 2 clients could access TOP service; though a few more wished to, but had booked too late.

There are dedicated staff in the antenatal clinic to provide PMTCT services. Approximately 200 patients are seen daily. Four sisters, one SN and many doctors provide care in the clinic. There is a SPN dedicated to the PMTCT programme and AGAPE counsellors attend the clinic daily. “We wouldn’t have coped without the extra staff”.

In general doctors have struggled to deal with counselling. The obstetrician heading the service is affiliated with Tygerberg. She has been a staunch supporter of the programme, both during development and implementation.

## Monitoring and follow up care

HIV status is entered on mother’s antenatal card by circling ‘Y’ under Blood Precautions. A ‘formula and PCP prophylaxis’ sticker is placed on baby’s RTHC.

At the antenatal clinic patients do not hold their charts. Charts are kept by the nurses and patients are called to see providers. Patients are not able to see other patients’ charts. Patients not electing HIV testing at the initial visit receive a sticker for PMTCT testing with “Rethink” circled in pencil. Patients with this designation are identified by care providers and sent to Room 84 to see the PMTCT counsellor.

Daily data capture is done in the following Registers; Counsellors Register, Antenatal Booking Register, Antenatal Nevirapine Register, Labour Ward Nevirapine Register and Baby Clinic Registers as prescribed. These are analysed monthly to provide a monthly programme indicator.

Data is collected at three sites - counselling centre, Gynae clinic, Hospital. No electronic data system in place. The co-ordinator does all calculations by hand.

Mothers are allowed to choose a clinic for follow-up. Sometimes mothers will select a clinic distant from their homes to maintain confidentiality. The co-ordinator will sometimes take mothers to that clinic to familiarise them with the providers.

A total number of 41 babies are on the clinic registers with another nine babies born in October expected to reach the clinics soon. Note this is a six-month progress report and therefore there will be no blood testing results available. Thus far 93% of babies are being followed up with the rest already having moved or poor clinic attendance, however one hopes to improve this in view of the 9-month testing coming up soon.

Follow up of infants is an important part of PMTCT, currently 2 cases of gastro and 4 of oral thrush have been reported and both related to formula fed babies. This also indicates that care of feeding utensils, preparation of feeds and messages of oral rehydration solution needs to be done during ANC and during postnatal care as these are preventable problems. The use of Bactrim as part of prophylaxis appears to have played an important role in reducing the incidence of other health problems.

### **Infant feeding practices**

With regards to feeding practices 71% of babies are on formula feeds, 29% are breast fed with 12% of these having mixed feeds at some stage. This will reveal interesting conclusions at 9/12 or 1 year HIV testing and the 12% having mixed feeds indicating a need to improve counselling during antenatal care on feeding options.

Western Cape PMTCT programmes are proscriptive with respect to formula feeding. Mothers are offered medication (Bromocriptine) for drying up breast milk. This will discourage future breastfeeding considerations. Initial evaluation of feeding practices suggests both breast and formula feeding mothers mix-feed. Formula is provided for 9 months.

The co-ordinator delivers formula to each of the three municipalities - Paarl, Boland and Wellington. From there it is distributed to individual clinics.









