

# **Interim Findings on the National PMTCT Pilot Sites**



**HEALTH  
SYSTEMS  
TRUST**



**DEPARTMENT OF HEALTH**  
*Republic of South Africa*

## **Lessons and Recommendations**

# **Interim Findings on the National PMTCT Pilot Sites Lessons and Recommendations**

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February 2002

ISBN #: 1-919743-64-2

This report has been produced by the Health Systems Trust for the national Department of Health. It is part of HST's commissioned role to help develop and co-ordinate a research and evaluation programme for the national PMTCT learning sites.

The research and this report were funded by the Department of Health (SA)  
and the Henry J. Kaiser Family Foundation (USA).



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*Funders of the Health Systems Trust include*  
Department of Health (South Africa)  
Department for International Development (UK)  
Henry J. Kaiser Family Foundation (USA)  
Commission of the European Union  
Rockefeller Foundation  
UNICEF

The information contained in this publication may be freely distributed and reproduced,  
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**Acknowledgements:** This report would not have been possible without the cooperation and support of many individuals in the national and provincial Departments of Health, as well as managers and service providers at the site level. They are too numerous to mention by name, but we would like to extend our deep appreciation and thanks to them all.

**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
DD	Deputy Director
DoH	Department of Health
EPI	Expanded Programme on Immunisation
HEART	Highly Effective Antiretroviral Therapy
HIV	Human Immunodeficiency Virus
HST	Health Systems Trust
IEC	Information, Education and Communication
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
PPASA	Planned Parenthood Association of South Africa
PWA	People living With AIDS
SAINT	South African Intrapartum Nevirapine Trial
TAC	Treatment Action Campaign
UNICEF	United Nations Children's Fund
UWC	University of the Western Cape
VCT	Voluntary Counselling and Testing
WHO	World Health Organisation

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# EXECUTIVE SUMMARY

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## BACKGROUND TO THE REPORT

This report primarily describes the process, progress and extent of service implementation in the 18 pilot PMTCT sites, so as to help improve the effectiveness and efficiency of PMTCT services and inform any planned expansion of the programme. Data and information are based on discussions and interviews with managers, co-ordinators and clinicians; site visits; routine statistics; document reviews; and attendance of national PMTCT steering committee meetings.

The report does not provide data on the impact of the programme on HIV transmission or health outcomes, mainly because the programme is still too young for this. However, Section 6 presents and discusses what is currently known about mother-to-child transmission, including the proven efficacy of NVP. It also discusses the effects of different forms of infant feeding on HIV transmission and child health, and raises a number of important policy issues.

## OVERVIEW OF THE PILOT PROGRAMME

193 health facilities (hospitals, midwife obstetric units, community health centres and clinics) are currently part of the national PMTCT pilot programme. They cover approximately 6 090 antenatal bookings per month, which translates to about 9% of the total number of country-wide bookings.

The full figure for access to PMTCT in South Africa is considerably more. Some provinces have already begun to expand their services, and together with a number of clinical research sites, the full proportion of pregnant women in this country with access to HIV counselling, testing and NVP may be as high as 15%.

The rate at which pregnant women agree to be tested for HIV is currently 51% in the national PMTCT sites. This translates to about 3 133 pregnant women being tested per month, which is a very positive achievement. The testing uptake rate varies tremendously between provinces and sites (ranging from 17% to 90%), and the reasons for these differences are described in this report. Overall, the HIV testing uptake rate is likely to improve over time.

Of the women agreeing to HIV testing, about 30% are HIV positive. On the basis of these VCT uptake and sero-positivity rates, it is estimated that 6 343 HIV positive pregnant women have been identified in the national PMTCT sites. However, the recorded number of HIV positive women who have delivered with the administration of NVP to both mother and baby is 1 932. Some of the reasons for this large difference in numbers are:

- Because HIV testing usually occurs several months before delivery, at any given point in time, the cumulative number of identified HIV positive pregnant women will be more than the cumulative number of deliveries (especially at the beginning of a programme).
- Women accessing the PMTCT service antenatally may deliver elsewhere.
- An under-recording of statistics in the labour wards.

## **PROGRESS WITH IMPLEMENTATION AND LESSONS LEARNT**

The experience with implementation has varied considerably, with some provinces and sites doing well, whilst others have struggled. Many of the difficulties and constraints to full and effective implementation were identified as being systemic in nature, and relate to the poor functioning of the health care system in general (as opposed to the functioning of the PMTCT programme specifically).

At the core of the differences between provinces and sites are the large inequities in health care infrastructure within the country.

### **Systems and infrastructure**

In order to improve the quality and sustainability of PMTCT services, and to ensure a smooth and effective expansion of the programme, these broader health systems issues must be addressed concurrently. The report lists these challenges under the three headings of human, management and physical infrastructure in Section 7.1 of the report.

#### **Human infrastructure**

Human resources are the bed-rock of a well functioning health system and PMTCT programme. Staffing needs to be adequate in terms of both quality and quantity.

- Minimum staffing levels for midwives, nurses, doctors and lay counsellors need to be established, and the national and provincial Departments of Health, particularly their Human Resource Directorates, must develop and implement a plan to reach these staffing levels.
- Lay counsellors are central to the programme. Some provinces, however, are still not employing them, and many of the 18 sites lack sufficient numbers. The involvement, support and clinical leadership of doctors in some sites also needs to be improved.
- The inconsistent management, training and remuneration of different kinds of lay workers within and between provinces needs to be addressed.
- Developing and sustaining staff competencies and attitudes remains an

unfinished challenge in most of the current sites. A carefully developed training plan will be essential for the successful expansion of the PMTCT programme.

- Improving the regular support and supervision of frontline staff and the attitudes of health workers (at the same time as developing their knowledge and skills) will be important elements of a comprehensive training strategy.
- The deficiencies in undergraduate nurse and medical training institutions must be addressed as soon as possible so as to reduce the intensity of in-service training required.

### **Management infrastructure**

A functional health system with effective sub-district health management teams capable of integrating community-based, clinic-based and hospital-based services is critical. The ideal sub-district health system would also help integrate PMTCT services into other related health programmes in a way that will maximize efficiency and effectiveness.

- The active interest and support of senior managers in the PMTCT programme has led to faster and more effective implementation in some sites. However, the level and standard of leadership and management varies between the provinces.
- The slow progress with the establishment of a functional sub-district health system capable of integrating PHC delivery needs to be speeded up.
- The areas of management identified in the report as requiring priority attention are human resource management and programme evaluation. There have been no significant problems with the management of supplies and equipment.
- NGOs and local PWA support groups are potentially invaluable role-players within a PMTCT programme. Managers at all levels of the health system need to continue to develop an environment that is more enabling for effective partnerships between government, NGOs and civil society.

### **Physical infrastructure**

Inadequate physical space and privacy has hampered the ability to provide adequate counselling and HIV testing services, as well as intra-partum (childbirth) care in many facilities. In rural sites, the difficulties and expense of simply getting to health facilities remain major barriers to adequate coverage of the programme as well as to adequate continuity of care.

- Plans to upgrade the physical infrastructure of PHC facilities and district hospitals across the country need to be expedited.

## **PMTCT service delivery issues**

Section 7.2 of the report lists the lessons and recommendations that are specific to the PMTCT service. Important issues to highlight include:

- 'Counselling' has been too strongly associated with consent for an HIV test, and needs to incorporate a broader set of activities that include: empowering pregnant women with knowledge and information (e.g. about their childbirth, HIV, MTCT and infant feeding); providing ongoing psychological and

emotional support to HIV positive women as well as advice on disclosure; and facilitating access to community support groups, welfare grants etc.

- Efforts to provide 'couple HIV testing' as well as community-targeted interventions to address stigma, ignorance and prejudice, are important but relatively neglected components of the PMTCT programme that need to be strengthened.
- The option of using rapid saliva tests as an alternative to rapid blood tests should be explored as this could relieve some of the workload on professional staff.
- In view of the recognized clinical efficacy of NVP, operational research is required to determine whether the NVP that is dispensed is taken correctly; whether midwives and doctors pro-actively ask women in labour about their HIV status and self-administration of NVP; and whether labour wards are able to provide adequate patient confidentiality regarding HIV status.
- Some lack of clarity about the clinical and obstetric management of HIV positive women in labour needs to be addressed.
- Guidelines on post-partum care need to be modified as they are currently unrealistic. Sites should develop their own targets and guidelines that are context-based and feasible.
- Patient-held records are essential for adequate continuity of care. The need to protect patient confidentiality about HIV status needs to be balanced against the need to promote continuity of care and the desire to encourage a greater openness about HIV status.

## **EXPANDING THE PMTCT PROGRAMME**

There are no good reasons for delaying a phased expansion of PMTCT services in all provinces. The pilot sites have already generated a lot of useful and important lessons that can now be put to use.

The systemic weaknesses and infrastructural constraints identified by this evaluation are not reasons for delaying action, but are important for informing the planning and expansion of PMTCT services.

Plans for expansion must therefore simultaneously address the systemic and infrastructural constraints in order to avoid a multiplication of poor and/or non-sustained service delivery, as well as to reduce levels of health care inequity. As with other services, the full potential of the PMTCT programme to reduce the number of HIV infected babies and improve overall health status will only be realized if the health system is capable of delivering the service optimally.

While it would be wrong for the systemic and infrastructural constraints to be used as reasons for non-expansion, reducing the challenge of implementing a country-wide PMTCT programme to the administration of NVP is misleading. The impression created that implementing the PMTCT programme is as easy as dispensing aspirin, fails to



convey the many genuine complexities that are outlined in this report.

It would be more useful to highlight the potential of the PMTCT programme to act as an engine or catalyst for the improvement of the health system and of primary health care services in general. This is described in Section 6.3 of this report. Failing to conceptualize the PMTCT programme in this broader and catalytic role could represent a missed opportunity for the country, or even worse, result in the PMTCT programme undermining other essential areas of PHC.

The temptation to adopt a rapid and vertical approach to expanding coverage across the country, particularly given the intense media and public pressure, should be resisted. A more measured and phased approach would ensure better sustainability and coverage; help strengthen the health care system as a whole; invigorate the broader HIV/AIDS programme; and raise the general standard of maternal and child health care. However, it is contingent upon government to develop a coherent, transparent and credible plan.

While a phased and systematic expansion of comprehensive PMTCT services is being planned, NVP can and should be provided immediately to all pregnant women who are already known to be HIV positive, with appropriate counselling and information.

Given the differences in capacity and infrastructure, it would be reasonable for provinces to expand the provision of PMTCT services at different speeds. For provinces that are currently struggling with implementation in their two learning sites, a plan for expansion should include and begin with a strengthening of provincial management and support structures and the continued improvement of services in the learning sites.

With political and senior management commitment at both the national and provincial level, it should be possible for all provinces to begin implementing PMTCT services in some new sites by the middle of 2002.

A more appropriate budgeting formula will be required to ensure that historically under-resourced areas receive a more equitable share of funding and support, should there be an expansion of the programme. The 'gap' between existing resources and a minimum standard of health care infrastructure (especially in terms of human resources) should be measured in every sub-district across the country to help ensure that this gap is narrowed in the fullness of time.

Within provinces, the variation in health care infrastructure and other factors necessitates a more context-based approach to planning and implementation. Local conditions and problems require local solutions, and the formation of an effective 'sub-district health system' offers the best organizational framework for the delivery of the PMTCT programme and of PHC in general.

## INFANT FEEDING AND CHILD HEALTH

With all the publicity surrounding government's position on NVP, the more important and serious issue of its policy on infant feeding and providing free formula has been neglected.

The current policy needs to be reconsidered, as there is a danger that it may do more harm than good in many communities. When one looks at overall child health as an outcome, instead of just HIV transmission, the benefits and advantages of promoting free formula become questionable. The downside of promoting formula feeding, and government subsidizing it are explained and discussed in section 6.2 of this report.

Although the long-term aim should be to enable all HIV positive women to provide safe and affordable *exclusive* formula feeding, under the current circumstances, the policy may lead to higher rates of mortality and morbidity due to other diseases, as well as higher rates of mixed feeding.

A national commission of experts should be urgently set up to review the current policy and guidelines on infant feeding and mother-to-child transmission.

One option that must receive serious and urgent attention is the post-natal administration of short-course antiretroviral treatment to mothers and/or babies as a strategy for making breastfeeding safe.

Finally, the imperative to save babies from HIV should provoke a broader and urgent response from government and civil society to address child poverty, the unacceptable levels of child care and child mortality from easy-to-prevent causes.

# INTRODUCTION

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At the end of 2000, a decision was taken by the government of South Africa to implement a pilot programme for the prevention of mother-to-child transmission (PMTCT) of HIV. This resulted in two pilot sites being selected per province for the implementation of a PMTCT protocol developed by the national DoH. The pilot programme was largely funded by national conditional grants to each province.

An evaluation and research framework was developed, presented to MinMec and endorsed in July 2001. The Health Systems Trust was requested to help co-ordinate and implement this evaluation and research framework, where a particular emphasis was placed on ensuring that the lessons learnt from the implementation of PMTCT services be analysed and documented.


The areas of implementation that the research and evaluation was expected to cover, included assessing the provision of:

- voluntary HIV testing to pregnant women
- short course Nevirapine (NVP) to HIV positive pregnant women
- appropriate counselling and support for safe infant feeding practices
- follow-up care to mother-child pairs after delivery.

This report does not provide any primary data on the impact of the PMTCT programme on HIV transmission or health outcomes in the 18 pilot sites (mainly because the programme is still too young and also because this will require the initiation of complex research studies). However, in view of the various policy debates surrounding this pilot programme, this report does discuss a number of policy issues related to the significance of PMTCT services within the wider context of the health care system, as well as HIV transmission and maternal and child health.

With both the experiences from the pilot sites as well as a review of health policy in relation to PMTCT, the report discusses and makes recommendations on the improvement of existing PMTCT services as well as on the establishment of an efficient, effective and sustainable PMTCT service across the whole country. Again, it tries to do this from the broader context of the health system as a whole.

The primary data and information for this report were based on numerous discussions and interviews with managers, co-ordinators and clinicians involved in the PMTCT programme. Site visits, document reviews, attendance of the national PMTCT Steering Committee meetings and some provincial PMTCT committee meetings have also



contributed. In order to ensure that the discussion on the broader policy issues are informed by a sound public health, clinical and scientific grounding, the international literature has been used.

A dossier of progress on PMTCT implementation for each province has been developed in an incremental fashion since September 2001, and a summary of some of this information is provided in Appendix 2.

Additional activities conducted by the Health Systems Trust have included working in close conjunction with the national DoH to establish a system of routine data collection, and defining a minimum set of data items and indicators for the national PMTCT programme. At the present moment there are still some shortcomings with the quality of routine data, and these are noted in the report.

Finally, a number of discrete research projects have also been commissioned and initiated by the Health Systems Trust in conjunction with the DoH and other agencies. The state of these research activities is described in Appendix 4.

# THE PROCESS AND PROGRESS OF IMPLEMENTATION

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The implementation of 18 PMTCT pilot sites is a complex process that has involved:

- The development of a PMTCT protocol which includes a set of clinical and patient care guidelines
- Financing and budgeting for, amongst other things, medicines, HIV testing kits, personnel and formula milk
- The selection of sites and their preparation
- The procurement of medicines, HIV testing kits and formula milk powder, as well as the establishment of appropriate supply, distribution and storage systems
- Training of clinical and management personnel across 9 provinces and 18 sites
- The creation of new posts at the provincial level to support the implementation of the programme
- The recruitment and deployment of lay counsellors
- The development of a routine information and monitoring system.

The national Directorate: HIV/AIDS, together with their provincial counterparts, have worked hard and tirelessly to initiate and implement the above actions smoothly and efficiently. Nonetheless, many constraints and difficulties have been experienced, some of which partly explain why many sites only began implementing the programme in the latter half of 2001. It is important to understand these constraints and difficulties within the broader context of the health care system:

- The fact that the health care system is still undergoing significant transformation, reorganisation and structural change
- The difficulty of a national Directorate having to work with and through nine separate and different provincial DoHs of varying capacity
- Insufficient co-ordination and communication between the different units and divisions of the public health care system

- A rigid and inefficient bureaucratic environment that constrains the rapid implementation of new programmes
- The challenge of the national Directorate HIV/AIDS having to work under multiple, competing and urgent demands, many of which are made in a way that disrupts attempts to establish stable, effective and efficient management
- Sub-optimal management/technical capacity at the national level, as well as in many provinces, to implement a programme as complex as PMTCT within the difficult environment described above
- Understaffing and poor infrastructure of the health care system in many parts of the country
- Low morale and poor motivation amongst many frontline health care providers
- The continued denial and stigma about HIV/AIDS in the public as a whole.

Some may dispute this description of the broader context within which the national PMTCT programme was implemented, or decry it as convenient excuses for the Directorate: HIV/AIDS. However, few would argue against the fact that the *general* organisational and management efficiency of the public health care system as a whole is a fundamental, underlying determinant of the success or otherwise of the national PMTCT programme. The quality and effectiveness of PMTCT services reflects the functioning of the health care system as a whole, and not just the dedicated management of the PMTCT programme within a single division of the public health care system.

Having said all of this, the fact that all 18 sites have implemented some degree of a comprehensive PMTCT service within the timespan described above, can be considered a positive achievement.

# 3

## **OVERVIEW OF SITES**

Province	Site	Start Date	Bookings per month	Antenatal HIV testing sites	Deliveries	F/up Care
Gauteng	Natalspruit Natalspruit hospital and J. Dumane CHC	May 2001	300	Hospital and CHC	Hospital and CHC	Hospital and CHC
	Kalafong Kalafong Hospital and Pretoria West MOU	June 2001	300	Hospital and clinic	Hospital	Hospital and clinic
Western Cape	Guguletu Guguletu MOU and 8 clinics in Nyanga district	Jan 2001	380	MOU	MOU and Mowbray Maternity Hospital	MOU and 8 clinics
	Paarl Paarl Hospital, T C Newman CHC and 17 surrounding clinics	May 2001	270	Hospital and CHC	Hospital	Hospital, CHC and clinics
Northern Province	Mankweng Mankweng Hospital and 19 clinics (many of which are small, isolated, under-resourced and understaffed)	Aug 2001 in hospital and 6 clinics. Extended to 19 clinics in Dec 2001	725	Hospital and clinics	Hospital (few clinic deliveries; significant number of home deliveries)	Hospital and clinics
	Siloam Siloam Hospital and 6 out of 17 clinics (some of which are small, isolated, under-resourced and understaffed).	Middle of Nov 2001	80	Hospital and clinics	Hospital	Hospital and clinics
Mpumalanga	Shongwe Shongwe Hospital and 9 out of 23 surrounding clinics	Sept 2001, but no VCT in clinics yet.	100	Hospital	Hospital	Hospital and clinics
	Evander Evander Hospital, Lebohong CHC and Embalenhle clinic	October 2001	140	Hospital, CHC and clinic	Hospital, few deliveries at the clinic	Hospital, CHC and clinic
Free State	Virginia Virginia Hospital and 8 clinics	July 2001	340	Hospital and clinics	Hospital	Hospital and clinics
	Frankfort Frankfort Hospital and 8 clinics	August 2001	200	Hospital and clinics	Hospital	Hospital and clinics



KwaZulu-Natal	Durban King Edward VIII Hospital and Kwamashu Polyclinic, Prince Mysheni Hospital and feeder clinics in section D and K, Umlazi	June 2001	1000	Hospitals, CHC and clinics	Hospitals and CHC	Hospitals, CHC and clinics
	Pietermaritzburg Grey's Hospital, Northdale Hospital and Sabantu and Northdale clinics, Edendale Hospital and Imbalenhle and Taylors Halt clinics, Church of Scotland Hospital	July 2001	725	Hospitals and clinics	Hospitals and clinics	Hospitals and clinics
Eastern Cape	East London Complex Frere Hospital and 29 clinics, Cecilia Makiwane Hospital and 19 clinics.	July 2001	950	Hospitals and clinics	Hospitals	Hospitals and clinics
	Umzimkulu Sub-district Rietvlei Hospital and 12 clinics (many of which are small, isolated, under-resourced and understaffed)	July 2001, but no VCT in clinics yet.	70	Rietvlei Hospital	Rietvlei Hospital (few clinic deliveries; several home deliveries)	Rietvlei Hospital
Northern Cape	Galashewe Galashewe Day Hospital, Kimberley Hospital, Masakhane clinic and Roodepan clinic	August 2001	150	Day Hospital, Hospital and clinics	Day Hospital and hospital	Day Hospital, hospital and clinics
	De Aar De Aar Day Hospital, Motana clinic, Amalia clinic, Normzwakazi clinic and one CHC	August 2001	50	Day Hospital, clinics and CHC	Day Hospital	Day Hospital, CHC and clinics
North West	Thlabane Rustenberg Hospital, Thlabane Health centre and 4 clinics	July 2001 (Rustenberg only started in Dec 2001)	100	CHC and clinics	CHC	CHC and clinics
	Lehurutshe Lehurutshe District Hospital and 21 surrounding clinics	July 2001	210	Hospital and clinics	Hospital	Hospital and clinics
TOTAL			6090			

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## COVERAGE AND UPTAKE OF PMTCT SERVICES

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21 hospitals (4 tertiary, 8 regional and 9 district), 12 MOUs/CHCs/Day Hospitals/ Polyclinics, and about 160 clinics currently provide antenatal counselling, rapid on-site HIV testing and the dispensing of NVP as part of the national PMTCT programme. Of these sites, the hospitals, the MOUs/CHCs/Day Hospitals /Polyclinics and a few clinics provide intra-partum care.

The approximate number of bookings in total per month is 6 090. This comes to about 9% of the total number of countrywide bookings per month (based on the National Indicator for expected deliveries which is 820 781 for 2002). A full breakdown of these figures province by province is provided in Appendix 1.

The true figure for access in South Africa is, however, considerably more. The Western Cape has extended its coverage of PMTCT services to 30 sites, and Gauteng has initiated six additional PMTCT sites. In addition, a number of research sites have been providing a PMTCT service as part of their work – these include Baragwanath Hospital and its surrounding clinics in Soweto, and the Hlabisa health district in KwaZulu-Natal. Finally, as reported in the newspapers recently, many hospitals and doctors across the country are prescribing NVP to pregnant women known to be HIV positive.

By adding in these sites, a rough estimate of the proportion of pregnant women in this country with access to HIV counselling, testing and NVP is 12-15%.

The numbers of women who agree to be tested, however, are considerably less. Approximately 51% of pregnant women in the national PMTCT sites have agreed to an HIV test. This translates to a figure of 3 133 per month. There is however significant variation between the provinces, as well as between the different sites (see Appendix 1).

The province with the highest testing uptake rate is the Western Cape, which has been operating for the longest length of time, followed by KwaZulu-Natal. In the Eastern Cape, the testing uptake rate in East London is only 28%, whilst the rate in the under-resourced rural site in the Umzimkulu site is 90%. The provinces with the poorest rates are Mpumalanga and the Northern Province. The rates for the two sites in Mpumalanga are 19% in Shongwe and 22% in Evander, and reflect the inability of staff to cope with the patient load due to the lack of lay counsellors. In the Northern Province the rate in Mankweng is 18% and in Siloam it is 17%. It is important to note

that these two provinces were among the last to commence PMTCT services, and that there is a natural tendency in all sites for the initial months of a PMTCT service to have low HIV testing uptake rates. Other reasons for differences in the uptake of VCT are discussed later.

A nationally defined target for the uptake of HIV testing amongst pregnant women has not been established. However, as a rule of thumb, any site managing an HIV testing rate of > 80% can be considered to be doing 'very well' (a testing rate of > 95% would be unrealistic, and would suggest possible 'coercion', as opposed to 'encouragement'). Sites with a testing rate between 60%-80% can be classified as doing 'reasonably well', while those below 60% need to be targeted for extra support. Based on the available *cumulative* statistics, the success of VCT uptake is as such:

HIV testing rate	Sites
> 80%	Umzimkulu, Durban, Paarl, Guguletu, De Aar
60 - 80%	Natalspruit, Pietermaritzburg
< 60%	Kalafong, Shongwe, Evander, Virginia, Frankfort, East London, Kimberley, Thlabane, Lehurutshe, Mankweng, Siloam

Of the women agreeing to HIV testing, 30% have been HIV+, which is higher than the national HIV prevalence of women attending antenatal clinics of about 22%. Table 1 shows the variation between provinces and how the HIV positive rate in the PMTCT sites compare with their provincial average. The reasons why PMTCT sero-positivity is usually higher than the underlying provincial HIV prevalence are:

- > a testing bias towards pregnant women with signs, symptoms or a history suggestive of HIV infection
- > women who know or suspect they are HIV positive may be coming to the national sites from outside
- > the national PMTCT site might have a higher true prevalence rate than the province as a whole.

In the very few sites where the PMTCT sero-positivity rate is lower than the underlying provincial antenatal HIV prevalence, the likely reasons are that the site prevalence is actually less than the provincial average, or that women who suspect themselves to be HIV positive may avoid seeking care in the PMTCT sites.

Table 1

Province	Site	PMTCT sero-positivity rate	HIV prevalence (2000 antenatal HIV surveillance)
Gauteng	Natalsspruit Kalafong	33%	29.4%
		43%	
Western Cape	Guguletu Paarl	21%	8.7%
		8%	
Northern Province	Mankweng Siloam	17%	13.2%
		0%	
Mpumalanga	Shongwe Evander	47%	29.7%
		39%	
Free State	Virginia Frankfort	32%	27.9%
		23%	
KwaZulu-Natal	Durban Pietermaritzburg	44%	36.2%
		34%	
Eastern Cape	East London Complex Umzimkulu Sub-district	25%	20.2%
		35%	
Northern Cape	Galashewe De Aar	32%	11.2%
		5%	
North West	Thlabane Lehurutshe	42%	22.9%
		17%	

On the basis of these VCT uptake and sero-positivity rates, a total of 6 343 HIV+ pregnant women have had the chance of being administered NVP in the national PMTCT sites (see Appendix 1 for provincial breakdown). However, the recorded number of HIV+ women who have delivered with the correct administration of NVP to both mother and baby is only 1 932 (figure excludes data from Gauteng which is not available). The reasons for this large difference in numbers are:

- Firstly, because HIV testing typically occurs several months before delivery, at any given point in time, the cumulative number of identified HIV+ pregnant women will be more than the cumulative number of deliveries (especially at the beginning of a programme).
- Secondly, it is possible that women accessing the PMTCT service antenatally may deliver elsewhere.
- Thirdly, there may be an under-recording of figures in the labour wards.
- Finally, some HIV positive women may go to another clinic for a second HIV test in the hope that the second test will be negative – while women can be tested for HIV more than once, they can only deliver once!

# IMPLEMENTING THE PMTCT PROGRAMME - LESSONS LEARNT

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This section focuses on different aspects of the PMTCT programme in order to draw out the key findings, lessons and experiences that may assist in strengthening the current programme, and informing a possible expansion of PMTCT services to other sites.

## 5.1 Uptake of HIV testing amongst pregnant women

There are three broad sets of factors determining the HIV testing rate. These are:

- > The availability and accessibility of counselling and testing facilities
- > The quality of encouragement and counselling
- > Community factors.

### **The availability and accessibility of counselling and testing facilities**

#### **Human resources**

HIV counselling and testing is a difficult and time-consuming procedure. Suggested *minimum* standards for counselling as part of a PMTCT service include the need to provide an average of 60 minutes of initial pre- and post-test counselling, together with two further antenatal counselling sessions of an average of 30 minutes each. There is no way in which existing staff, with other clinical and public health duties, can cope with such an increase in workload.

For example, some of the clinics surrounding Shongwe Hospital in Mpumalanga have to provide a comprehensive PHC service with only 2 – 4 nurses. In another rural clinic, the unavailability of lay counsellors and the shortage of staff, meant that there was only one nurse available to do all the education, counselling and testing, resulting in long waiting times, and consequently, a poor uptake rate.

As a consequence the employment of 'lay counsellors' to support health workers is a cornerstone of the PMTCT programme. However, some provinces (Northern Province

and Mpumalanga) have not yet established a system for the recruitment, management and remuneration of lay counsellors, and in other sites, there are still not enough lay counsellors to provide a quality PMTCT service.

Table D in Appendix 2 describes how provinces have recruited, deployed and remunerated 'lay counsellors' using different approaches. Some difference in the way provinces organise the availability of a cadre of 'lay counsellors' is appropriate. However, the remuneration rates of lay counsellors range from zero to R2 800 per month, and this magnitude of difference between provinces may be inappropriate.

In many provinces the recruitment of lay PMTCT counsellors occurs in an unclear and unco-ordinated policy environment for lay health volunteers/workers in general. As a consequence, lay PMTCT counsellors, home based carers, VCT counsellors, DOTS supervisors and "traditional" community health workers are being paid differently. This inconsistency has led to charges of unfairness and a general unhappiness of those lay health workers who are on the lower end of the remuneration scale. On the other hand, those provinces that have stated a desire to adopt a uniform and co-ordinated system, have effectively delayed the recruitment and deployment of paid lay PMTCT counsellors.

Some provinces have also cited bureaucratic, administrative and labour relations difficulties with the recruitment and remuneration of lay workers, and are therefore employing a strategy of funding NGOs to recruit, manage and remunerate lay workers.

While insufficient lay counselling capacity has been a significant rate-limiting step to the uptake of HIV testing and the improved quality of counselling, the provision of HIV counselling services cannot be left as the sole responsibility of 'lay counsellors'. At one of the national PMTCT Steering Committee meetings, the need to discourage professional health workers from thinking that they can abdicate their counselling and education responsibilities to lay counsellors was discussed. In any case, in some sites, clients have simply refused to be counselled (or even informed about HIV and MTCT) by a lay worker, and have demanded to be informed and counselled by a trained health worker. As one site co-ordinator said, "in our area we have the educated intellectuals – they will not see a lay counsellor – they refuse".

Lay counsellors are currently barred from performing the rapid on-site HIV diagnostic test, which is estimated to take an average time of 30 minutes per client, placing this burden squarely on the shoulders of nurses.<sup>1</sup> One province is planning to adopt the use of a rapid saliva test which can be conducted by lay counsellors, and which could therefore free up nursing staff from the activity.

Therefore, in spite of the recruitment of 'lay counsellors', the HIV testing component of the PMTCT programme constitutes a considerable increase in workload for antenatal professional health workers. Those facilities that were already under-staffed, are struggling to provide a good service without compromising other services. While it is possible that time may be created through efficiency gains, there are concerns that the increase in workload (without additional staff) may result in a deterioration of the quality of care elsewhere, and to stress and burn-out amongst some staff.

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1 In some facilities, lay counsellors are performing the on-site site testing despite the regulation barring them.

Another human resource problem has been 'staff rotation' policies that have led to a high turn-over of staff. As a consequence many provincial HIV units have had to constantly reorganise and reschedule new training interventions for health workers operating in the PMTCT facilities, a problem that seems to cut across and affect other health services.

Even without the rotation of staff, in most sites, organising and providing appropriate training to all nurses is an unfinished challenge. For example in one of the larger urban sites with more than twenty PHC facilities, despite the involvement of local universities and NGOs, and despite a heavy emphasis on training, only 75% of all professional nurses had received formal training in PMTCT and HIV counselling by the end of 2001, and no staff nurses or enrolled nurses had been trained yet.

Part of the reason why the training of staff is such a big challenge is because the base knowledge and counselling skills of staff is poor, resulting in the need for intensive training interventions spread over several days, rather than shorter training interventions that can reach a larger number of staff in a given time. This knowledge and skills base is known to vary across different parts of the country, and is a reflection of the varied quality of training institutions and their students. An important strategy that must therefore be implemented straight away is to ensure that HIV counselling and PMTCT are taught thoroughly and effectively in all undergraduate health sciences training institutions.

### **Medical input and support**

Sites have had varied experiences with the role and involvement of doctors. The benefit of doctors being a visible and pro-active part of the PMTCT programme has been described in a number of sites. On the other side of the coin, sites with a lack of interest and support from doctors have experienced problems.

In some sites such as Durban, Pietermaritzburg, Rietvlei and East London, senior doctors play a leading and catalytic role. In other sites, doctors do not appear to be significant, especially in the antenatal period. This is partly because doctors generally play a limited role in antenatal care (except for high-risk pregnancies), and because traditionally, counselling and patient education has not been considered part of the medical role in the public sector. However, there has been a feeling in several sites that doctors have not played a clinical leadership role, are uninterested or, 'have been left out of the training on PMTCT'.

It appears that while doctors are not always central to the provision of direct patient care, they are central to a well-functioning obstetric service and have an important clinical leadership, quality control and training role, which supports and sustains the programme.

### **Physical space**

Another significant challenge of all 18 sites has been overcoming the lack of physical space and furniture to provide counselling in a comfortable and private manner. In the larger facilities (e.g. academic, regional and even district hospitals), it has usually been possible to identify spare rooms that can be used for the dedicated purpose of pre- and post-test counselling.

However, many clinics have had to resort to counselling in inappropriate places (e.g. outside in a car, in the clinic kitchen or in a room with no privacy), whilst waiting for longer-term solutions. Purchasing pre-fabricated huts or containers as makeshift consulting rooms and building partitions to create more rooms, are some of the solutions pursued by provinces. One site has gone to the lengths of renovating, painting and refurbishing an existing building to create dedicated HIV counselling rooms which are private, comfortable, spacious and of a first-world standard.

The difference in the comfort and privacy of counselling facilities in the different sites is a stark reminder of the vast inequities that exist within the public health sector. In some facilities, the lack of space means that two nurses may have to share the same room and consult patients from opposite ends of the same table.

### **Testing kits**

The availability of testing kits does not appear to have been a problem in any of the sites. Although a formal, external evaluation of the use of rapid testing kits has not been conducted, there have been no indications of any problems with the reliability of the rapid HIV test results.

### **The arrangement of space, patient flow and waiting times**

The need to provide room and time for PMTCT services is a challenge to the organisation of space, patient flow and time management in many facilities. Space and time needs to be found for individual counselling, group information and education sessions, obstetric examinations, the handling of blood specimens, child follow-up consultations and the secure storage of formula milk powder.

In terms of antenatal care, the organisation of dedicated days or times in the week for antenatal care (especially for the first antenatal booking service) has been found to be a time-saving strategy that also allows pregnant women to meet each other as a group. However, this has resulted in an uneven spread of HIV testing and counselling needs across the week. On these 'antenatal booking days', the volume of required counselling and testing may simply out-strip the number of counsellors and space available. Many clients refuse to wait in a queue and decline to be tested or counselled as a result.

In order to make testing and counselling more accessible, it may be necessary to spread out the antenatal care workload across the week, and abandon the practice of concentrating antenatal patients in one or two days of the week. Doing this, however, will result in losing certain advantages such as the efficiency of collecting blood specimens in one go, and providing group health education to pregnant women. In some clinics blood specimens for antenatal booking are only collected once a week (due to a lack of transport), and in such situations, changing this arrangement would not be feasible or desirable.

In some of the larger facilities which have been able to provide dedicated space and rooms for HIV counselling and testing, a problem that has cropped up is the lack of anonymity of the rooms which easily become associated with HIV testing. In some sites, there are even signs pointing to HIV testing rooms, which is likely to act as a deterrent to patients.



## The quality of encouragement and counselling

Unlike with 'standard' VCT services that wait passively for clients to request HIV counselling and testing, a PMTCT programme requires a more pro-active approach whereby *all* pregnant women are actively counselled about the benefits of HIV testing.

This includes providing all pregnant women and community members with information about the benefits of testing in pregnancy. A general approach has been to offer information and education to groups of clients, after which individuals are invited to go for individual counselling and HIV testing if they agree. However, there seems to be room for improving other sources of information on PMTCT such as leaflets and posters in the local language. One notable exception is a series of patient leaflets designed by the Free State DoH.

Facilities where morale and motivation is low, or where there is a denial towards HIV amongst staff, may not provide adequate encouragement for pregnant women to choose to test. The morale, motivation and attitudes of staff toward HIV are therefore important factors that need to be optimised to improve uptake rates and the quality of counselling.

Provinces have embarked upon different strategies for the provision of training, relying significantly on NGOs such as PPASA, Lifeline and university departments. Many ATICCs have also been brought in to help provide training.

To date there has been little formal evaluation of the quality and effectiveness of the training. Preliminary research conducted in the national VCT sites and in some PMTCT sites indicates that some of the training that has been provided is not culturally appropriate; provides theoretical information at the expense of improving skills and practice; and does not adequately deal with the attitudes, prejudices and denial of the trainees themselves. A further weakness is the lack of ongoing in-service training and support for staff and lay counsellors working in the programme.

A pointer to the current inadequacy of counselling and testing are reports that few pregnant women disclose their status to their partner or families. This reflects inadequate attention paid to empowering the client to disclose their HIV positive status, a lack of effort or capacity to provide 'couple counselling and testing' as well as the degree of stigma, ignorance and prejudice in the community.

Many sites have also noted the importance and benefit of local PWA support groups for clients who have tested positive. Where they exist, they provide an invaluable source of support to HIV positive pregnant women. Where they do not exist, efforts must be made to establish them.

The burn-out of staff providing HIV testing services on a regular basis has been recognised in all sites. Providing supportive supervision to counsellors, arranging peer support groups, and in a few places, formal de-briefing sessions with trained psychologists or social workers are some of the efforts being made to help staff cope with the emotional and psychological stress of conducting HIV tests. These efforts are important for the quality and sustainability of HIV testing services and require strengthening.

Language is another factor that influences the quality and accessibility of counselling. For sites that cater for clients from a mix of language groups, there have been reports

of occasions when a counsellor with the appropriate language was not available. Other characteristics of counsellors such as their age and gender have also been noted as potential factors that influence the uptake and accessibility of counselling services.

### **Community factors**

The extent of denial and stigma in the community impacts on the uptake of HIV testing, the disclosure of HIV test results to sexual partners and families, and on desired changes in behaviour after testing. Many of the sites have commented that community education and mobilisation is an important, but relatively neglected aspect of the PMTCT programme to maximise coverage of women, promote couple testing and disclosure as well as setting up PWA support groups. Some provinces and sites have organised community meetings and IEC campaigns that have used local radio, print media and local advertisements which seems to have helped overcome stigma, denial, prejudice and ignorance.

## **5.2 The administration of NVP to mothers**

The national PMTCT protocol stipulates that pregnant women who are 28 weeks or more in their gestation be given a tablet of NVP for self-administration in the event of going into labour. Women are asked to self-administer NVP because the earlier it is taken during active labour, the more effective it will be. Should the mother's dose of NVP be taken within two hours of delivery, the baby should be given an extra dose of NVP immediately after delivery (with a 'normal' dose between 24 and 72 hours after delivery). Should a mother take NVP without going into 'active labour', she should be provided with a second NVP tablet. All midwives, nurses and doctors working in labour wards are expected to enquire and ensure that all HIV positive women in labour have correctly self-administered their NVP tablet, and if not, to administer NVP in the labour ward.

Although this evaluation was not designed to review the clinical efficacy of NVP, its side-effects or the potential for creating resistance, Appendix 5 provides a summary of the latest international scientific consensus on the latter two issues. There are, however, a number of operational issues related to the administration of NVP that are important to evaluate.

### **The self-administration of NVP**

At the present moment research has not been conducted to formally assess the treatment literacy of patients or the correctness of NVP self-administration. Many sites however report a high number of women who require NVP to be dispensed in the labour ward, which suggests that tablets are not correctly self-administered or are lost; or that women forget to take the tablet when they go into labour.

A possible concern about the self-administration of NVP is that NVP tablets may be marketed and sold as a cure for HIV/AIDS. However, this has not been reported in any of the sites and is unlikely if women have been appropriately counselled. In any case, women are only dispensed one tablet at a time.

### **Multiple dispensing**

Some women require multiple doses of NVP because they may take the tablet when not in active labour. It is not known how many women take multiple doses of NVP during a single pregnancy. Neither is the effect of this in terms of creating NVP resistance known.

### **Active enquiry about the correct self-administration of NVP in the labour ward**

The failure to make proper enquiries during labour about the correct self-administration of NVP could effectively amount to a 'missed opportunity' to prevent vertical transmission.

It is possible that in the busy environment of a labour ward, especially one that is under-staffed, staff may not ask pregnant HIV women if they have taken their NVP. The attitude and knowledge of staff about the PMTCT programme are also important factors. Staff who have no interest in the PMTCT programme or who are reluctant to deal with HIV/AIDS, may not want to identify women who are HIV positive.

On the other hand, pregnant women may not be in a psychological or emotional state to correctly recall if they took their NVP tablet correctly. Of greater concern is the fact that HIV positive women in labour may not be readily identifiable because of their reluctance to reveal their HIV status in delivery rooms that lack privacy, or to staff who have not been involved in their antenatal counselling and care. The poor state of some labour wards where patient privacy may only amount to a flimsy curtain between beds is a barrier to adequate care during labour in general, but especially for women who are HIV positive.

A formal evaluation of these aspects of the PMTCT programme has not yet been made. However, anecdotal reports suggest that 'missed opportunities' are not a big problem. In a number of sites, the considerable amount of NVP dispensed within health facilities suggests that staff are pro-actively asking women whether they have taken NVP. On the other hand, the discrepancy between the numbers of HIV positive women diagnosed in the antenatal period and the number of HIV positive deliveries might suggest that some HIV positive women are not being identified in labour, or that because of the busy nature of labour wards, NVP is being dispensed without being recorded.

## **5.3 Obstetric practices**

In addition to the administration of NVP, there are a number of obstetric interventions that must be practiced for the correct and safe care of HIV positive women in labour. To start with, there should be strict adherence to all the precautions and safety procedures for the protection of staff from occupational exposure. These precautions and safety procedures should furthermore be applied universally to all women regardless of their known HIV status.

Secondly, there are certain obstetric practices that can minimise the risk of vertical transmission of HIV. These include avoiding the artificial rupture of membranes, minimising the duration of ruptured membranes, minimising the duration of active labour (especially in the second stage) and avoiding instrumental or assisted vaginal

deliveries. Although performing elective caesarian sections reduces the rate of transmission, this is not part of the current PMTCT protocol due to the unfeasibility of this option.

The correct implementation of the practices described above will depend on the general staffing levels, expertise, experience and capacity of doctors and midwives within the sites. Although there has not yet been an in-depth review of clinical obstetric practice in the PMTCT sites, the sub-optimal staffing levels and certain indicators of the quality of care in some facilities suggests that the general standard of obstetric care is inadequate.

Finally, in one site, obstetric staff indicated that there was no difference in clinical practice or clinical protocols for known HIV positive women, because of the practice of taking universal precautions. In other words, all pregnant women in labour were managed as though they were potentially HIV positive. In other sites, however, there was an understanding that obstetric practice was different for women known to be HIV positive. This reveals a lack of clarity around the clinical guidelines for the care of HIV positive women in labour.

#### **5.4 The paediatric administration of NVP**

The national PMTCT protocol stipulates that the babies of all HIV positive mothers receive a dose of NVP suspension between 24 and 72 hours after delivery. If the mother only received her dose of NVP within 2 hours of delivery, the baby should actually receive two doses of NVP.

Several facilities have cited some difficulties with the administration of NVP due to the fact that many women are discharged home before 24 hours have elapsed after delivery. As a consequence some sites are dispensing the dose of NVP suspension 12 hours after delivery. Pharmacokinetic studies conducted at the University of Natal have suggested that this should be as efficacious as waiting 24 hours after delivery.

Immediately after birth, there are three places that a baby is likely to be taken to: the postnatal ward with the mother; the nursery (without the mother), or the special/intensive care unit. In order to make sure that all eligible babies receive the right dose of NVP at the right time, it is important that some continuity of care is established between the labour ward and the postnatal ward, nursery and special care unit. The extent to which drug charts and patient case notes clearly indicate to postnatal nursing staff which newborns must receive NVP before discharge or within 72 hours of delivery needs to be evaluated.

#### **5.5 Post-delivery follow-up and continuity of care**

The national PMTCT protocol makes it clear that care must extend beyond the point of delivery for both mother and child. All women are recommended to go for a postnatal check-up 3-14 days after discharge, and further visits are recommended every two weeks in the first month and once a month thereafter. These visits should provide medical care as required, permit access to free formula, as well as provide ongoing clinical care and support for infant feeding.

Infants of HIV positive women are recommended to be followed-up weekly during the 1<sup>st</sup> month of life, and monthly thereafter, until the age of 12 months. After that they should be monitored 3 monthly until they are two years of age, unless the child is ill. In addition, co-trimoxazole prophylaxis is to be provided from 6 weeks of age. At 12 months, an HIV test will be conducted. If this is negative, co-trimoxazole prophylaxis will be stopped. For children who are HIV-positive, co-trimoxazole will be stopped if they are well and growing. If the infant has had pneumocystis infection, more than two episodes of pneumonia, an AIDS-defining illness or is not growing well, co-trimoxazole will be continued for life.

There is currently little information on the uptake, frequency and regularity of follow-up visits. Many sites however have recognised that providing ongoing care to mothers and children is a formidable challenge. The challenges to providing follow-up care are numerous, and include:

- Poor access to health facilities due to long distances and a lack of affordable transport
- Poor patient records which make it difficult to maintain a continuity of care
- Long waiting times and queues
- Patient mobility in and out of the sites.

In some sites, free formula is only made available at the delivery facility. For women who live far from the hospital or MOU, the lack of availability of free formula at a nearby clinic can make it expensive and difficult for her to get her formula.

Difficulties with follow-up and continuity of care tend to be more acute in sites where there is poor communication between antenatal services, hospitals and clinics, where patient mobility is high and where there has been a relative over-emphasis on the obstetric aspect of the PMTCT programme in relation to out-patient child health and medical services.

Although there are massive infrastructural barriers to the full implementation of the follow-up guidelines of the national PMTCT protocol, the Paarl site in the Western Cape (a well resourced and low prevalence site) offers an example of excellent care. During the antenatal period, mothers are counselled and advised to choose a clinic for their follow-up. Sometimes mothers will choose a clinic distant from their homes in order to protect their confidentiality. The PMTCT site manager will then take the mother to the clinic to introduce her to the clinic staff. A special register allows for these patients to be followed up over time. This arrangement would be impossible in many of the rural sites.

Anecdotal reports of the patient-held cards of HIV positive women being lost or defaced to protect their confidentiality indicates that some women do not want to disclose their HIV status after delivery. In order to get around this problem, health workers have been devising all manner of coded terms and markers of HIV positivity that will be recognised by health workers, but not by members of the general public. There have been concerns that such actions to protect patient confidentiality may re-inforce stigma and silence, as well as undermine the continuity of patient care across different service providers.

## 5.6 Organisation and management

Experience from all the sites has pointed to the fundamental importance of leadership and effective management as key ingredients of successful PMTCT sites. This is unsurprising given the fact that the programme requires the recruitment of new staff (PMTCT co-ordinators and lay counsellors), the creation of physical space for counselling, the training of staff in HIV, MTCT and infant feeding, the establishment of linkages and referral systems between different parts of the health care system, community mobilisation and the regular supply of medicines, testing kits and formula.

### Provincial leadership and management

Sites with the involvement of the highest levels of provincial government have been most successful in implementing the PMTCT programme. The role of senior managers is important in integrating the programme horizontally, sharing the workload across a number of departmental units and avoiding the trap of locating the programme within a narrow and vertical management system. The establishment of functional multi-unit steering committees appears to have worked well in getting the provincial department as a whole to pull together. Senior managers are also required to play more of a strategic role in balancing the requirements of the PMTCT programme with the requirements of other HIV and PHC services.

The presence of a dedicated 'driver' at the provincial level is critical. However the skills and qualities of such a person are important. The driver needs to have not only the technical proficiency to understand the clinical and public health aspects of the programme, but also the seniority and authority to make and implement the required decisions. Alternatively s/he needs to work with other people at the provincial level with the required skills and competencies.

In some provinces however, conflict around turf and a lack of clarity about roles and responsibilities has weakened provincial capacity to implement the programme.

An important ingredient has been the availability of a local pool of PMTCT 'experts' and clinicians who can be drawn upon to provide training and support. The Western Cape for example has had the benefit of academics and consultants from the University of Cape Town, in addition to local NGOs to support their sites. In Gauteng and Durban, expertise located in Baragwanath and King Edward Hospital VIII have been able to provide support. In other provinces however, there is still a need to increase the training capacity required to continuously improve the quality of services, and this will be essential should there be an expansion of services to other sites.

Provincial PMTCT co-ordinators also need to have the authority and technical legitimacy to work with and through the different role-players at the site level.

The creation of a CCLO post has been useful for most provinces, although some provinces have taken a long time to appoint people to the posts. Concerns about the short-term contractual nature of the post and its relative lack of seniority have been expressed. In some provinces too much responsibility has been placed on the shoulders of the CCLO. Provinces whose Directors of PHC and Directors of HIV and MCWH have taken active leadership roles, with the CCLO operating under their supervision, have shown quicker and more effective implementation.

## Site preparation and management

The careful preparation of sites prior to implementation appears to be an ingredient of success. Ideal site preparation starts with careful planning, staff training and orientation, the recruitment of lay counsellors (preferably done with and through a credible NGO), the training of lay counsellors, community mobilisation and the establishment of adequate physical space and privacy.

A PMTCT service requires leadership and good co-ordination within the site. Actions at the community level, counselling and testing in antenatal clinics, delivery care and NVP administration in labour wards, and postnatal care in clinics must ideally form part of a seamless continuum.

Those PMTCT 'sites' that were identified as a network consisting of a hospital and its feeder CHCs/clinics were better suited to deliver a comprehensive PMTCT service than those sites that essentially consisted of single, isolated facilities. Provinces that establish viable health sub-districts (in line with the WHO District Health System model) with sub-district health management teams will have the best chance of expanding PMTCT services.

A good functional relationship between clinics, PHC programmes and hospitals is important. The Thlabane site in the North West struggled to implement the PMTCT programme for a long time because of the non-participation of Rustenberg Hospital. In Gauteng, the focus on hospitals and relative neglect of their links to clinics has caused weaknesses and problems.

## Training and Human Resource Development

The effective organisation and provision of training is possibly the most important function of national and provincial management. Unless the available human resources at site and facility level have the correct and appropriate knowledge, skills and attitudes, the PMTCT programme is only partially effective.

Although there has been a tremendous amount of training in the PMTCT sites, human resource development remains a key challenge (Appendix 2, Section B describes some of these activities province by province). Some of the findings include:

- Provinces with ready and easy access to academic and technical experts are at a distinct advantage over those that don't.
- The tendency for provinces to manage and organise their own training interventions is an appropriate delegation of responsibility from the national office. However, some provinces require the national office to facilitate support from non-government agencies and academic/tertiary institutions (e.g. from some of the better resourced provinces).
- In spite of training, some nurses and counsellors have difficulties with aspects of HIV counselling, and correctly advising women about infant feeding, which suggests the need to evaluate and strengthen existing training interventions.
- In terms of the content of training, the focus to date has been on HIV counselling and testing and on vertical transmission. There is a need to balance this with more training on infant feeding and child health.

- Off-site, formal classroom-based training (usually for the development of knowledge and understanding) needs to be complimented with more on-site in-service training with a focus on skills development and problem solving.
- Doctors are inadequately targeted for training in some sites, and they are not being fully used as trainers of other staff.
- The balance between providing in-depth quality training versus rapid training to achieve a faster coverage of staff needs to be weighed up carefully on a site by site basis. The baseline capacities for staff to develop new knowledge and skills varies across the country, and ideally training would be tailored accordingly.
- Some provinces have taken the initiative to engage with nurse training institutions so as to develop undergraduate curricula that cover PMTCT.

### **Supply and distribution of consumables and equipment**

In general, there have been few problems with the supply and distribution of NVP, testing kits and formula. Although there were delays with the transfer of the conditional grant, provinces made other arrangements to purchase the supplies and equipment required so that they could start-up their sites quickly. For example, in the Northern Province, the provincial pharmacy budget was used. In Mpumalanga, due to the delay in transferring national funds, initial supplies were provided from Gauteng. Many provinces also drew on their provincial VCT programmes, especially for making available rapid testing kits and for providing training.

### **Budgets and Funding**


The conditional grant allocated from the national government to the provinces was held up for a considerable length of time due to administrative blockages. Funding did not actually reach the provinces until September/October 2001. In order to move ahead with the implementation of PMTCT services, provincial funds were used during the initial phases of development. However, the implementation of PMTCT services was delayed in provinces without ready access to other sources of funding.

The provincial PMTCT budgets from the national grant were calculated on the basis of HIV prevalence and the number of deliveries expected. Management capacity, rurality, the level of health care infrastructure and staffing levels were not adequately factored into the apportioning of budgets to the provinces. Money was not available in the national grant to upgrade facilities, and provincial budgets had to be used for this.

### **Routine monitoring and health information systems**

All 18 national sites are currently providing some data on a routine basis. Frontline providers are responsible for collecting data which is sent to PMTCT site co-ordinators and/or provincial PMTCT co-ordinators on a weekly basis. However, much of the quality and reliability of this data is poor. Not all provinces used the same data definitions or calculated indicators using the same numerator and denominator (see notes in Appendix 1).





A nationally defined data set with clearly defined indicators was only finalised in December 2001. Consultants have now been funded by the national DoH to provide support and training to each of the provinces and the 18 sites to ensure good quality and standardised routine data collection.

# 6

## IMPACT OF THE NATIONAL PMTCT PROGRAMME

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While an evaluation of the process of implementation is important for identifying lessons that can help improve efficiency, effectiveness and sustainability, it is also useful to have some idea of the impact of the programme on improving health status.

The PMTCT programme should be evaluated on the basis of two primary goals. The first is in terms of reducing the rate and overall numbers of HIV transmission from mother to child. The second, and perhaps more importantly, is in terms of its contribution to improving the health status of children and mothers, whether HIV positive or HIV negative.

Relevant indicators of the first goal include the vertical transmission rate, and the numbers and relative proportion of HIV positive pregnancies. The vertical transmission rate will be reduced by the effectiveness of implementing the national PMTCT protocol. The numbers and relative proportion of HIV positive pregnancies, on the other hand, will be reduced by the effectiveness of HIV prevention and family planning strategies. These latter two strategies seem to have been inadequately highlighted in current debates about MTCT.

As far as improving overall child health is concerned, whilst preventing HIV transmission to children is clearly an important intervention, other interventions that will also have a big impact include:

- Addressing child malnutrition and poverty
- Improving immunisation coverage rates and the quality of primary level child health clinical care
- Improving the care of children at home
- Improving maternal health outcomes and female literacy rates.

These interventions are mentioned in order to stress the point that PMTCT services are but one of several interventions required to attain acceptable standards of child and maternal health in the country. Children who are saved from HIV but who die from malnutrition and other preventable causes reduce the full benefit of the PMTCT programme.

Measuring the impact of the PMTCT programme is difficult and methodologically complex. Quantifying vertical transmission rates is complicated by the difficulties of following up children so that their long-term outcomes can be recorded. In addition, determining the HIV status of children is complicated by the presence of maternal antibodies and by the fact that testing for viral DNA/RNA is expensive. The challenges of measuring the impact of PMTCT services on overall child health are even greater, and would require a significant amount of funding and research management capacity. A group of epidemiologists, scientists and statisticians is being convened to discuss the worthwhile, affordable and feasible options to measure the impact of PMTCT services, and to report their recommendations to the national DoH in due course.

However, it is possible to make some inferences about vertical transmission rates based on knowledge and information that has been generated from various other studies.

## 6.1 Vertical Transmission Rates

The diagram on page 28 explains how a PMTCT programme might impact on vertical transmission rates. It is based on a consideration of what might happen to 100 HIV positive pregnant women under different situations.<sup>2</sup>

The first column on the left of the diagram describes what would typically happen to 100 HIV positive pregnant women *with no PMTCT intervention*, and where infant feeding practices continue unchanged. Although there has been limited research on infant feeding practices, it is known that most women provide breastmilk with other foods within the first few months of life and that many of those women who initiate breastfeeding often continue to do so for up to a year, or even longer. The second column describes what would typically happen to 100 HIV positive pregnant women *who receive the NVP protocol*, but where infant feeding practices continue unchanged. The third column describes what would happen to 100 HIV positive pregnant women *who receive the NVP protocol and provide exclusive formula feeding*.

### *Transmission rates before delivery*

Before delivery, about 7 out of 100 women will infect their children with HIV. On an individual basis, the risk is greatest in women who have a high viral load, or who have an infection of the internal lining of the uterus (chorio-amnionitis). Antiretroviral medication taken by women could reduce the risk of transmission to almost zero given proper compliance.

### *During labour and delivery*

During labour and delivery, approximately 16 more babies will become infected, if no PMTCT interventions take place (first column). In other words, 16 out of 100 HIV positive pregnant women will infect their children during labour and delivery, in addition to the 7 babies who would have been infected during the antenatal period.

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<sup>2</sup> It must be emphasised that these rates are approximations based on various research studies that have shown different rates of vertical transmission.

The administration of NVP to mother and baby (see second column in the diagram) reduces the rate of intra-partum transmission. Instead of 16 women infecting their children, proper NVP administration will reduce this number to about 6. In other words, with NVP administration, approximately 13 out of a 100 HIV positive women will transmit HIV to their baby (seven before delivery and six around labour).

Several factors influence the risk of transmission during labour and delivery. A high maternal viral load increases the risk (e.g. with newly infected women and women with late-stage HIV infection). Antiretroviral medication reduces viral load and the risk of transmission. Various obstetric factors also affect the risk of transmission. For example, caesarian sections are protective; traumatic or instrumental deliveries, prolonged labour and a prolonged duration of ruptured membranes are harmful.

However, on average, at the time of birth, the difference between non-intervention and correctly administering NVP during and after labour is that about 10 out of 100 babies born to known HIV positive pregnant women will be saved from HIV infection.

#### *After delivery*


After delivery, HIV transmission occurs through breastfeeding. If breastfeeding is completely avoided, there will be no postnatal transmission of HIV. In a group of a 100 HIV positive pregnant women who receive the correct administration of NVP and who completely avoid any breastfeeding, HIV will be transmitted to 13 out of 100 of their babies (see column 3).

If, on the other hand, breastfeeding continues, the number of children that will be infected will depend on:

- the duration of breastfeeding (the longer the period of breastfeeding, the higher the risk of transmission and the larger the number of children infected);
- whether there is mixed feeding (non-exclusive breastfeeding increases the risk of transmission – this is thought to be because mixed feeding causes some reaction in the lining of the intestines which makes it easier for the virus to infect the baby);
- frequency of conditions such as mastitis and cracked nipples which increase the risk of transmission; and
- maternal viral load.

On average, with the normal infant feeding practices described above, approximately six further cases of HIV transmission will occur in the 6 months after delivery (column 1). This figure will increase by a further two by 12 months, resulting in a total HIV transmission rate of approximately 31% 12 months after delivery in the *non-intervention group*.

In the second group, approximately seven further cases of HIV transmission will occur between birth and 6 months through normal infant feeding practices. The number of HIV infections due to breastmilk is slightly higher in the column 2 group because there are a larger number of uninfected babies at risk of HIV infection at the time of birth. If breastfeeding continues after six months, the cumulative number of babies infected will be about 22 at the end of a year (column 2).



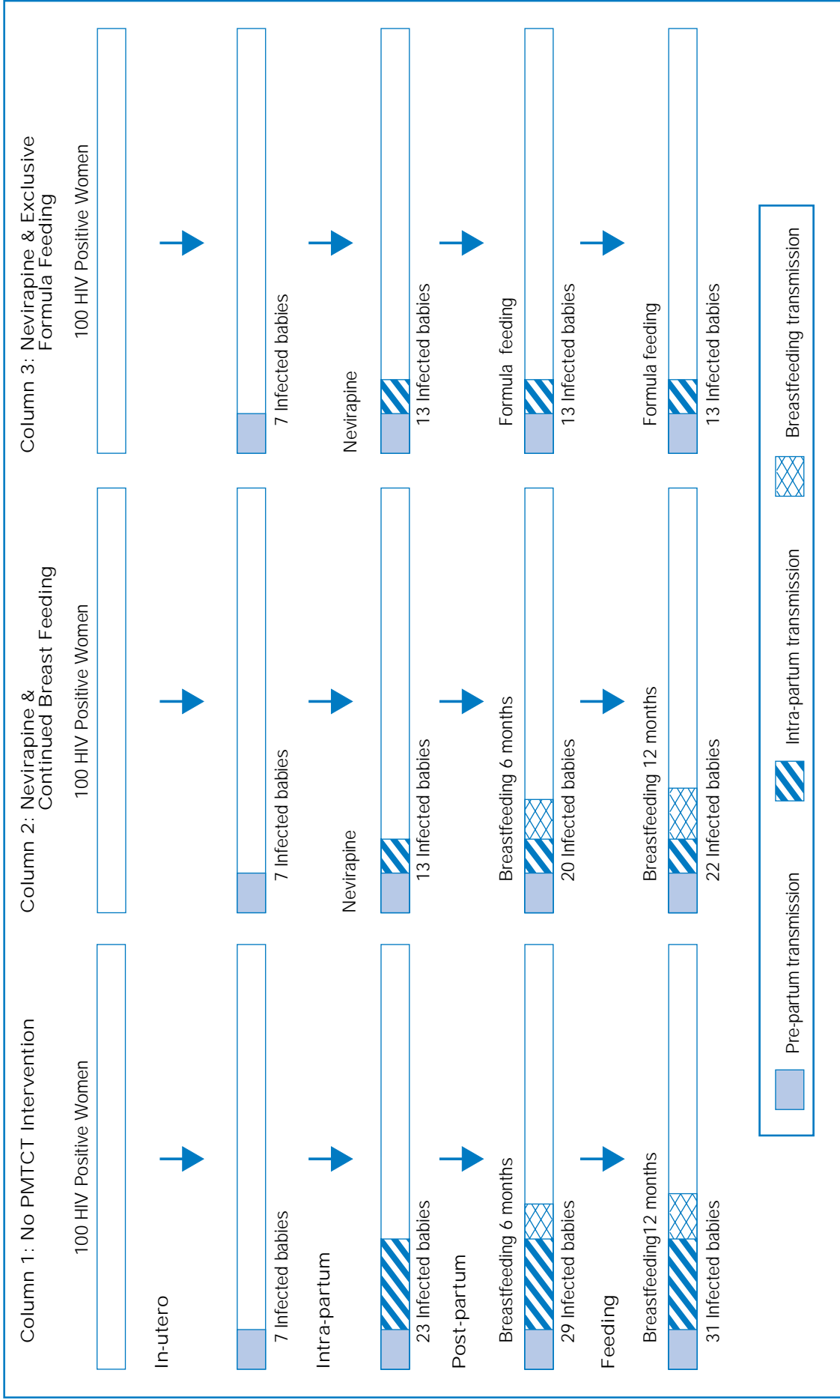
In the ideal world of perfect implementation, where NVP is administered and where women are able to exclusively formula feed safely, overall vertical transmission could be reduced from 29% at 6 months to about 13%. In other words, approximately 16 out of every 100 babies born to HIV positive pregnant women would be protected from HIV infection in a world of perfect implementation.

If, however, there is incomplete coverage of HIV positive women with NVP, unsafe obstetric practices and mixed feeding, the overall transmission rate will be higher than 13% and the number of babies saved from HIV will be less.

The rates of HIV transmission in the two groups that provide breastmilk (columns 1 and 2) could be reduced significantly if breastmilk is provided *exclusively* in the first six months. This would mean that the difference in the numbers of babies protected from HIV between columns 2 and 3 will be less.

The figures described above relate specifically to HIV transmission rates. However, the PMTCT programme also needs to be assessed in terms of its impact on overall child health. Because there is a higher risk of mortality and morbidity associated with formula feeding, the benefits of reducing vertical transmission rates through replacement feeding need to be balanced against the harmful effects of formula feeding.

Vertical Transmission Rates



## 6.2 Infant feeding

From the perspective of reducing postnatal HIV transmission, all HIV positive women should be encouraged and supported to provide exclusive formula feeding. The longer a woman breastfeeds, the higher the chance of transmitting HIV to her child (the risk is highest in the first five months of breastfeeding).

With this in mind, the government has offered to provide six months of free formula to all HIV positive mothers should they choose to avoid breastfeeding. However, the avoidance of breastfeeding and the promotion of formula feeding are not without their own risks.

### The benefits of breastfeeding

Breastmilk is the best source of nutrition for the first 4 – 6 months of life. In addition, it provides protection from a number of infectious diseases. Infants who are not breastfed and who receive formula milk, have a 6 fold increased risk of dying in the first 2 months of life; a 4 fold increase between 2-3 months, and a 2.5 fold increase between 4-5 months compared to those who are breastfed.<sup>3</sup> UNICEF estimates that 1.5 million non-HIV related deaths per year can be prevented globally through breastfeeding.<sup>4</sup>

In addition, the unsafe and unhygienic preparation of formula feeding carries the risk of causing diarrhoeal disease, and consequently, malnutrition in infants. A WHO report concluded that full or partial breastfeeding would reduce current childhood deaths from diarrhoea by 66%. In addition, it has been estimated that a 40% increase in breastfeeding in those regions with short breastfeeding duration, such as Latin America, could prevent up to 15% of diarrhoeal deaths.

The benefits of breastfeeding for HIV infected children should also be considered. The 13% of HIV-infected infants at birth (column 2 in previous diagram) are likely to do much better on breastmilk than on formula for the same reasons mentioned above.

Finally, breastfeeding also contributes to reduced fertility and better family spacing, another factor that has been shown to correlate strongly with child mortality and nutrition rates. The desirability of reducing fertility in HIV positive women is a particularly important benefit that will be lost as a consequence of formula feeding.

### Spillover effect

Although the current policy is only to target free formula to women who are HIV positive, there is good reason to be concerned that the promotion of formula feeding through the PMTCT programme could spill-over into the HIV negative population.<sup>5</sup> Evidence of 'spill-over' is becoming apparent in Botswana, Kenya, Namibia and Uganda where efforts to promote breastfeeding have declined as a result of formula feeding

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3 WHO collaborative study on the role of breastfeeding on the prevention of Infant mortality. Effect of breastfeeding on infant and child mortality due to infectious diseases in less developed countries: a pooled analysis. *Lancet* 2000; **355**: 451-455.

4 UNICEF. State of the World's Children 1997. UNICEF, New York, 1997.

5 Nicoll A, Newell ML, Peckham C, Luo C, Savage F. Infant feeding and HIV-1 infection. *AIDS* 2000; **14** (suppl 3): S57-S74.

interventions to prevent HIV transmission.<sup>6</sup> This effect may be greater when free or subsidised formula is available.

Anecdotal reports from a number of the South African learning sites already suggest two forms of spill-over. First, some nurses report that women are providing some of the free formula to siblings and other family members. As with experiences of other 'food aid' programmes, supplies may be consumed by other members in the family instead of the intended beneficiary. Secondly, there have been reports that some free formula is being re-cycled and sold off in the community.

### **Assessing risk**

In the context of South Africa's high prevalence of child malnutrition, high infant mortality rates and continued cholera outbreaks, there is a very real risk that the promotion of formula feeding could do more harm than good in some communities.

The national PMTCT protocol therefore advises nurses to assess the socio-economic, environmental and home circumstances of HIV positive pregnant women during antenatal counselling in order to help them advise on the safest and most appropriate method of infant feeding. If the risks of formula feeding and non-breastfeeding are considered to outweigh the risks of HIV transmission through breastfeeding, then the HIV positive woman should be advised to *exclusively* breastfeed her child.

However, many nurses and counsellors are struggling to weigh up the relative risks and benefits, and to make reasonably accurate assessments of socio-economic conditions and the feasibility of preparing safe formula feeds. Even where socio-economic conditions are favourable, providing safe and exclusive formula feeding is difficult. Research in Khayelitsha showed the practice of formula feeding to be fraught with difficulties: women received inadequate information about how to make formula feeding safe, and most formula feeds were prepared incorrectly.<sup>7</sup>

Some sites have developed checklists of various factors to help make a more objective assessment of the woman's circumstances so as to make the right choice. However, the validity, accuracy and effectiveness of these tools still need to be evaluated.

Part of the problem is that the balance of risks between HIV transmission and the harmful effects of formula feeding is simply not known. Although the international tendency has been to promote formula feeding as part of a package of PMTCT services, more people are questioning the appropriateness of this trend, and calling for greater debate.

It is interesting to note that a study from Kenya found that formula fed infants had a 40% reduction in HIV transmission compared to a group of breastfed infants. However, the overall 24 month mortality rates were similar in both groups. The study also found that during the first 3 months of life, infants in the formula fed group had increased rates of diarrhoea, dehydration and respiratory infections. What is of particular concern is that the mothers recruited for this study had access to clean water, free formula, and

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6 Latham MC, Kisanga O. Breastfeeding and HIV – a four country study. Paper presented at 17th International Congress of Nutrition, Vienna, August 2001, abstract no: 3.03.012.

7 Chopra M, Schaay N, Sanders D, Puoane T, Piwoz E, Dunnett L. HIV and Infant feeding: Summary of findings and recommendations from a formative research study with the Khayelitsha MTCT programme, South Africa. Draft Report, May 2000.



received frequent and regular support in the form of home visits by health workers. This suggests that gains made from preventing mother-to-child transmission of HIV by implementing exclusive formula feeding were negated by deaths from other causes.

### **Social and cultural factors**

Apart from socio-economic considerations, a number of socio-cultural factors affect infant feeding practices. It is apparent that most women provide mixed feeding with breastmilk, and that this practice is informed by traditional socio-cultural norms which are often enforced by older women in the community, particularly mother-in-laws. Women who therefore choose to exclusively breastfeed may face tremendous social pressures at home to mix feed, and actually find that they are unable to implement their choice based on the advice and counselling received.

There are also socio-cultural constraints to the provision of exclusive formula feeding. Many informants, for example, have described the maternal instinct to provide comfort to a crying child by putting her to the breast. This is all the more likely under socio-economic situations where the practical difficulties of boiling water and preparing safe formula feeds, would make putting a crying child to the breast difficult to resist. In addition, the stigma attached to formula feeding can make it difficult for women to carry out their decision to exclusively formula feed.

#### *The cost of formula and making it freely available*

Apart from the dangers of replacing breastmilk with free formula, there are concerns about the policy to provide formula to mothers for free. One reason for this is that those women who cannot afford to purchase formula are precisely those who are most at risk of the harmful and potentially lethal effects of formula feeding. Although free infant formula reduces the financial burden of replacement feeding, the costs for fuel, collecting water and sterilising feeding implements have to be met by the woman.

The free provision of formula may instead give underprivileged HIV-infected women a false sense of security in being able to provide safe replacement feeding. Informed and reasoned choice on infant feeding may also be compromised by the fact that formula is free. The mere distribution of formula by health workers may also be seen as an endorsement of the product. Under such conditions, HIV positive women, regardless of their socio-economic conditions, may be more likely to opt for formula feeding for the wrong reasons.<sup>8</sup>

At the present moment is not known if particular types of mixed feeding carry greater risks for HIV transmission. However, it would be reasonable to hypothesise that mixing breastmilk with clean water would be less risky than mixing breastmilk with porridge or formula milk, because the latter two complimentary foods are more likely to cause a reaction of the intestinal lining. The presence of free formula within a culture that strongly endorses and promotes mixed breastfeeding may then lead not only to higher rates of mixed feeding with breastmilk, but more dangerous forms of mixed feeding.

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8 Dabis F, Leroy V, Bequet L, et al. Assessment of peri-partum and post-partum interventions to prevent mother-to-child transmission (PMTCT) of HIV-1 and improve survival in Africa. Presented at the 3rd conference on Global Strategies for the prevention of HIV transmission from mothers to infants, Uganda, September 2001.

Finally, although the formula milk powder is made available to HIV positive women for free, it remains a cost born by society and government. The financial expense of milk powder was estimated in 2000 to range between \$72-\$120 for 6 months supply<sup>9</sup> (and will cost more in rand terms due to the depreciation of the currency), and is not an insignificant amount of money.

Another current debate is whether formula milk should be made freely available to women for longer than six months. The suggestion arises from the fact that after six months of formula feeding, mothers will suddenly lose a substantial source of their infant's nutritional requirements.

From 6-12 months, milk is still the main food for infants, and while babies should receive weaning foods, weaning foods should not replace milk. A child aged 6 - 12 months needs at least 500-800ml milk each day, in addition to other foods. Milk provides 50% or more of the energy, protein and iron, and most of the Vitamin A and C requirements, and may continue to provide up to a third of the energy, protein and iron requirements of children aged 12-24 months.

Many of the HIV positive mothers who have been provided free formula for six months would normally have been breastfeeding for at least up to a year. With the cessation of free formula and the non-availability of breastmilk, the child suddenly becomes at risk of malnutrition, unless the mother is able to afford her own supply of formula and other appropriate foods.

On the other hand, the provision of free formula for more than six months would constitute a significant rise in expenditure and increase the frequency of the harmful effects of formula feeding.

### **Infant feeding choices in the PMTCT sites**

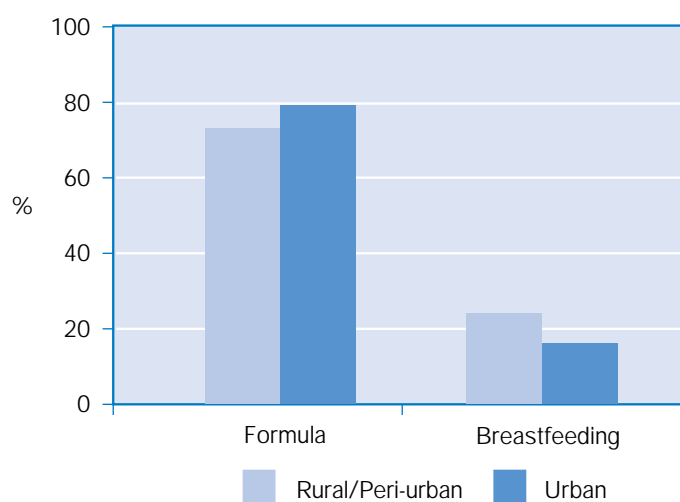
In terms of the actual choices that are made, the data from the routine monitoring system of the PMTCT programme shows a significant variation from site to site. The data refers to feeding choice collected soon after delivery, and is not data on actual feeding practices at home. One must be cautious about these figures as it is probable that the stated preferences of women reflect the views and opinions of providers and programme managers. In other words, patients will say what they think the nurse or counsellor wants to hear, rather than what the woman actually thinks or does at home. The table below shows that most women state a preference to formula feed soon after delivery, with a slightly higher proportion of women indicating a preference to breastfeed in the rural sites.

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9 Wilkinson D, Floyd K, Gilks CF. National and provincial estimated costs and cost effectiveness of a programme to reduce mother-to-child HIV transmission in South Africa. *S Afr Med J.* 2000; 90: 794-8.

Province	Site	Start Date	Rural/Urban	Exclusively formula feeding	Exclusively breast-feeding
Gauteng	Natalspruit Kalafong	May 2001	Urban/Peri-urban	96%	3%
		June 2001	Urban/Peri-urban	85%	15%
Western Cape	Guguletu Paarl District	Jan 2001	Urban/Peri-urban	95%	4%
		May 2001	Rural/Peri-urban	73%	27%
Northern Province	Mankweng Siloam	Aug 2001	Urban/Peri-urban	73%	7%
		Mid Nov 2001	Rural	N/A	N/A
Mpumalanga	Shongwe Evander	Sept 2001	Rural	74%	26%
		Oct 2001	Urban	89%	11%
Free State	Virginia Frankfort	July 2001	Urban	77%	23%
		Aug 2001	Rural	68%	32%
KwaZulu Natal	Durban Pietermaritzburg	June 2001	Urban	40%	42%
		June 2001	Rural	65%	35%
Eastern Cape	East London complex Umzimkulu	Oct 2001	Urban	69%	31%
		Oct 2001	Rural	54%	46%
Northern Cape	Kimberley De Aar	Aug 2001	Urban	82%	8%
		Aug 2001	Rural	100%	0%
North West	Thlabane Lehurutshe	July 2001	Urban	81%	19%
		July 2001	Rural	79%	0%

Comparison of infant feeding choices between Rural/Peri-urban and Urban sites



## 6.3 Beyond vertical transmission

Apart from reducing the rate of HIV infection in children, a PMTCT programme has the potential to improve the quality and delivery of other maternal and child health services as well as other HIV sub-programmes.

For example, the PMTCT programme can be implemented in a way that will improve the overall quality of antenatal and labour ward care. It could also be used to help promote better use of antenatal care services and earlier booking. The emphasis on the follow-up care of mothers and children could act as a stimulus for improving the general quality of child health care and the clinical care of patients with HIV/AIDS. Ensuring a regular supply of NVP and HIV testing kits, may also address the erratic and irregular supply of other medicines and supplies.

Rectifying the systemic weaknesses of the health care system that are currently constraining the effective and efficient delivery of PMTCT services would benefit other services. The PMTCT programme could therefore be used as a catalyst for addressing generic deficiencies such as the poor physical infrastructure of health facilities and inadequate staffing levels.

By striving to create an optimal PMTCT programme, the communication, linkages and referral systems between mobiles, clinics, CHCs, MOUs and hospitals would be strengthened and improve the general efficiency and effectiveness of the health care system.

Fourthly, any actions and commitment towards reducing the vertical transmission of HIV *without* other actions and commitment to make it possible for HIV positive mothers to provide safe formula feeding *and* ongoing child care should be untenable. In this way the PMTCT programme can accentuate the imperative for the basic needs of all households to be met.

Finally, and of huge significance is the potential for the PMTCT programme to break through the denial and stigma of HIV within communities. By linking a tangible benefit to HIV testing, the PMTCT programme can help bring HIV much more into the open, and confront communities with the reality of the epidemic. By emphasising couple counselling and testing within the PMTCT programme, there is also a potential for directly addressing HIV with men. The lay counsellors that are recruited and trained through the PMTCT programme will also be resources for the education and mobilisation of their communities. In this way, the PMTCT programme can act as an engine for broader HIV prevention.

On the other hand, a PMTCT programme that is implemented narrowly and vertically could undermine the development of the health care system and the delivery of integrated health services. Resources could also be diverted away from interventions that would have a bigger positive impact on overall health.

# CONCLUSIONS AND RECOMMENDATIONS

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## 7.1 ADDRESSING THE ISSUES OF SYSTEMS AND INFRASTRUCTURE

PMTCT implementation varies between provinces and from site to site considerably. Some provinces and sites are doing well, whilst others are struggling.

Those sites that are struggling to provide good PMTCT services tend to be those that operate within a context of poor health care delivery in general and a poorly functioning health care system. At the core of the differences between sites and provinces are the large inequities in health care infrastructure within the country.

The differential level of capacity between some of the urban sites (with academic/tertiary support, good physical infrastructure and adequate staffing levels) and some of the rural sites (where several clinics lack electricity, working telephones, space and adequate staffing levels and where hospitals may lack, amongst other things, sufficient doctors) is large. The moral and political imperative of preventing mother-to-child HIV transmission offers South Africa an opportunity to redress the unacceptable inequities within the health care system with more vigour and urgency.

Many of the difficulties and constraints identified in the pilot sites are systemic in nature, and relate to the functionality of the health care system as a whole (as opposed to the functionality of the PMTCT programme specifically). In order to improve the quality and sustainability of PMTCT services, and to ensure that any expansion of PMTCT services runs smoothly, these systemic issues must be addressed.

Because of the significant differences in functionality and health care infrastructure between provinces, recommendations and actions to improve the current PMTCT services, as well as an expansion of the programme, should be developed on a province by province basis.

It is useful to consider the issue of systems and health care infrastructure in terms of three dimensions:

- Human infrastructure
- Physical infrastructure
- Management infrastructure.

### **Human infrastructure**

The presence and availability of adequate human infrastructure is the most important ingredient of a successful PMTCT programme. The term 'human infrastructure' incorporates staffing levels, staffing mix and staff competencies and motivation.

#### *Staffing levels*

Services that run with inadequate staff don't run well. In all facilities, the PMTCT programme has entailed an increase in workload and clinical responsibilities. In a few sites, this additional workload has not been compensated for by any additional staff, and has resulted in stress and possibly, a deterioration in the overall quality of care provided. In most sites the PMTCT programme has been accompanied by the recruitment of lay counsellors, although some sites still do not have enough lay counsellors. Nurse and medical staffing levels have been mostly unchanged.

In order to sustain the current PMTCT programme, as well as expand it to new sites, minimum staffing levels for midwives, nurses, doctors and lay HIV workers need to be established for clinics and hospitals, based on workload and need. The national and provincial Departments of Health, particularly their Human Resource Directorates, must then be tasked with developing and implementing a plan to reach these staffing levels.

Minimum staffing levels for PMTCT counselling should be based on the following norms: Initial pre- and post-test counselling - average of 60 minutes per client; follow-up counselling and support - an average of 30 minutes per visit on two separate occasions for HIV positive women; a maximum of 8 clients seen per day per counsellor.

#### *Staff mix*

Lay counsellors are a critical element of the PMTCT programme (as well as of other programmes within the broader national HIV strategy). The recruitment and training of lay HIV counsellors to work in close collaboration with professional staff has been a very positive feature of the PMTCT programme.

The lack of co-ordination and consistency in the management, training and remuneration of different kinds of lay workers needs to be addressed. One recommendation is to move towards the concept of generic 'lay community HIV workers' who would form a pool of human resources at the sub-district level to support the full range of HIV/TB sub-programmes in a more integrated manner.

Although the quality of service provided by lay counsellors has not been formally evaluated, it is clear that they provide a critical service. However, it is important to note that a comprehensive PMTCT programme requires a mix of clinic nurses, midwives, obstetric and paediatric ward staff and doctors playing complimentary roles. In some sites, the involvement and support of doctors who should be providing important

clinical leadership within the PMTCT programme, needs to be improved. In addition, the post-partum care and support of mothers with HIV and their children requires better links between PMTCT services with welfare and nutrition staff.

#### *Staff competencies, morale and motivation*

Training and human capacity development is critical for the development of adequate staff competencies, morale and motivation. Unfortunately, many staff do not have a strong foundation of knowledge and skills in HIV and PHC. Extensive and fairly lengthy training interventions have therefore been required, and arranging this has required a big effort. In many sites, despite major training efforts, not all relevant staff have been covered. The sheer volume of training required in the pilot sites points to a major challenge should provinces expand the programme to new sites.

A number of lessons have been learnt about training. In terms of content, there is a need to balance the focus on HIV counselling and testing with more training on infant feeding and child health. Off-site, formal classroom-based training needs to be complimented with more on-site, in-service training with a focus on skills development, local problem solving and on changing attitudes towards HIV.

Without regular support and supervision of frontline staff, the positive impact of training is not sustained. Support and supervision, as well as organising peer support groups, is required to help prevent staff burn-out. Providing effective and appropriate support and supervision to frontline staff is a highly skilled job that should also be part of a human resource development plan.

A pool of experts and trainers with the commitment and time to provide training is needed in each province, especially if the PMTCT programme is to be expanded. The availability of skilled clinicians capable of providing good care to HIV positive mothers is limited, especially in the rural areas. Clinicians in academic/tertiary institutions with HIV expertise should be deployed to develop capacity in district hospitals and rural areas through outreach programmes.

Finally, a strategy to ensure that HIV counselling, PMTCT and infant feeding is taught thoroughly and effectively in all undergraduate nurse and medical training institutions must be developed and implemented immediately.

### **Management infrastructure**

Good management and a functional provincial DoH is a key factor determining the success, efficiency, effectiveness and sustainability of the PMTCT programme. Provincial leadership has been shown to make a big difference. Where senior managers have taken an active interest in the PMTCT programme, faster and more effective implementation has usually followed.

Senior managers are important for integrating the programme horizontally across the department and creating an enabling bureaucratic environment for programmatic staff. In some provinces and sites, tension between personalities and conflict about roles and responsibilities amongst managers has impeded progress with implementation. On the other hand, provinces with effective multi-departmental steering committees were able to establish support systems that helped make the sites work.

Strong technical capacity and the presence of experienced clinicians with a commitment to HIV within the provincial PMTCT management structures is also an important component of provincial capacity.

At the site level, effective sub-district leadership and management as well as the presence of a PMTCT driver is important. The support and involvement of local medical staff, the sub-district HIV, MCH and Health Information System(HIS) managers and hospital matrons are equally important. The lack of integration between hospitals and clinics, or between local authority and provincial facilities, undermines the programme. All this requires effective and integrated management at the sub-district level.

NGOs are important potential role-players in the recruitment, training, remuneration, support and supervision of lay counsellors. The importance and benefit of local PWA support groups has also been noted in several facilities. A more pro-active development of NGOs and PWA support groups in those sites that currently lack them is recommended. However, it will be necessary to improve the capacity within the DoH to work with NGOs efficiently, effectively and in the spirit of partnership.

Effective management is dependent on the availability of accurate and relevant data and information. Although the quality of data is improving, in most provinces and sites, there is a need to strengthen data capture, data management and programme evaluation skills.

Unco-ordinated training, the maldistribution of staff and inappropriate staff rotation policies point to the need for improved human resource management at all levels of the health system.

The fact that many provinces did not develop site-specific plans and budgets, as well as the lack of reporting to Pretoria on the national grant, suggests a need to strengthen financial management.

Finally, the slow progress with the establishment of functional health sub-districts with decentralised management structures capable of integrating PHC delivery is a weakness that will also constrain any expansion of the PMTCT programme. This requires the public health care sector to urgently speed up its structural re-organisation, and the establishment of a functional 'sub-district health system'.

#### *Physical infrastructure*

The importance of physical infrastructure has been reflected in two ways. First of all, the inadequate amount of physical space and privacy has hampered the ability of many facilities to provide adequate counselling and HIV testing services. Many provinces have therefore spent substantial amounts of money to renovate facilities or establish new spaces.

In addition, the lack of physical infrastructure has been felt in terms of access to facilities. In many of the rural sites, the difficulties and expense of simply getting to health facilities that provide antenatal, delivery and postnatal care remain major barriers to adequate coverage of the programme as well as to adequate continuity of care.

Provinces need to plan and budget for the creation of adequate space for HIV counselling and testing services in other sites.



## 7.2 Improving the quality of PMTCT services

### Counselling and testing

The uptake of HIV testing is a rate-limiting step within the PMTCT programme. The recruitment of lay counsellors to assist with HIV counselling and testing has therefore received a great deal of attention. The term 'counselling' has consequently become strongly associated with the gaining of consent for an HIV test. However, other dimensions of counselling need to be strengthened. These include the empowerment of women with clear and accessible information about HIV/AIDS, childbirth, child care and infant nutrition; advice and information about social security entitlements and sources of community support; ongoing emotional and psychological support to women who now have to live with the knowledge of being HIV positive; and advice to women about disclosure.

Efforts and capacity to provide 'couple HIV testing' as well as community-targeted interventions to address stigma, ignorance and prejudice in the community, also need to be strengthened as adjuncts to the services targeting pregnant women. In this way the PMTCT programme can become a potent adult HIV prevention programme.

Finally, on a practical note, the option of using rapid saliva tests as an alternative to rapid blood spot tests should be explored as this could relieve some of the workload on professional staff.

### Care during labour

In terms of clinical policy, there are no reasons to question the clinical efficacy of NVP and the international consensus that the drug is safe and sound. The main recommendation related to NVP is to implement some operational research to determine whether:

- NVP is dispensed and actually self-administered correctly
- midwives and doctors pro-actively ask women about their HIV status and self-administration of NVP during labour (so as to avoid 'missed opportunities')
- labour wards are able to provide adequate patient confidentiality and privacy regarding HIV status.

In addition, clearer policies and guidelines on the clinical management of HIV positive women in labour and the appropriateness of applying revised obstetric guidelines universally are required. The potential impact of revised obstetric practices resulting in higher caesarian sections should also be monitored.

A rapid audit of obstetric care and the continuity of care between the labour ward and the postnatal care of babies is being conducted in a sample of labour wards, and will provide a clearer picture of these issues soon.

Finally, the clinical guidelines on the timing of the paediatric dose of NVP after delivery needs to be reviewed given that many women leave the health facility within 24 hours of delivery.

## Post-partum care

The policy and guidelines on the post-partum care of children born of women with HIV needs to be looked at again as current guidelines are largely unrealistic. Sites should rather develop their own targets for follow-up care that are realistic and feasible.

Patient held records are essential for adequate continuity of care. At the present moment, the need to protect patient confidentiality about HIV status is given greater weight than the need to promote continuity of care and encourage a greater openness about HIV status within the health care setting.

Several public health specialists have been questioning the appropriateness of prescribing prophylactic co-trimoxazole. Unless there are sound public health grounds for doing so, the DoH may want to re-consider this policy. Using co-trimoxazole as an incentive for attending follow-up care is inappropriate.

## 7.3 Using the PMTCT programme as an engine for improving the quality of health care

As described earlier, the PMTCT programme incorporates a unique collection of services and activities that when put together, has the potential to act as an engine or catalyst for the improvement of primary health care services in general.

Apart from demanding an improvement of the infrastructure of the health care system, as described above, the PMTCT programme can help catalyse the improvement of clinical aspects of the health care system. By acting as an entry point for improving the quality of:

- obstetric services
- HIV counselling and post-test care and support
- clinical care for patient with HIV/AIDS
- child health care and nutrition.

Linking the PMTCT programme to these other areas of patient care is important not just to maximise the full potential of the programme, but also to help avoid the possible 'neglect' of other essential maternal and child health services. Failing to conceptualise the PMTCT programme in this broader and catalytic role could represent a tremendous missed opportunity for the country.

While it would be tempting to adopt a rapid and vertical approach to the immediate coverage of PMTCT services across the country, a slower but ultimately more effective and more sustainable approach could realise the potential for the PMTCT programme to revitalise the entire health care system, invigorate the broader HIV/AIDS programme and raise the general standard of maternal and child health services. This would not only benefit the broader population, but is of particular importance for the postnatal care and well-being of the mother-child clients of the PMTCT programme who will be receiving this care from the general PHC services. However, the case for expanding the PMTCT programme in a holistic and systems-building manner should not be interpreted or used as an argument for inaction and delay in expanding the state's

capacity to prevent mother-to-child transmission.

## 7.4 Infant feeding

With all the publicity surrounding government's position on antiretrovirals, the more important and serious issue of its policy on infant feeding and providing free formula has been neglected. Infant feeding is probably *the* major policy issue for the government.

The current policy to provide free formula needs to be reconsidered. There is a real danger that it may do more harm than good in many communities. While the long-term aim is to make it possible for all HIV positive women to provide safe and affordable *exclusive* formula feeding, under the current social, economic, environmental and cultural circumstances, the policy may contribute to higher rates of mortality and morbidity due to other diseases, as well as higher rates of mixed feeding.

A national commission of experts should be urgently set up to discuss infant feeding in the context of HIV and mother-to-child transmission. There is a very delicate balance between avoiding HIV transmission through breastfeeding with avoiding the harmful effects of promoting free formula.

Some public health specialists would recommend that the DoH no longer make formula freely available, but continue to thoroughly inform all women about the risks and benefits of different feeding options, and encourage exclusive formula feeding only for those mothers who are able to afford the formula themselves. Such a policy should also be complimented with a strategy to enable women to provide *exclusive* breastfeeding (as opposed to the norm of mixed feeding with breastmilk). Other public health specialists would recommend that government continue to provide free formula, but to target this to communities and households that would be able to exclusively formula feed safely.

An option that should receive serious attention is the postnatal administration of antiretroviral medication to mothers and/or babies as a deliberate strategy for making breastfeeding a safe option.

If formula is going to continue to be made available for free, it is then obligatory that it is made easily accessible. While it may be unwise to provide a full six months worth of free formula to a mother on discharge, it would be wrong to provide an initial supply of formula and then make it expensive and difficult to receive continued supplies.

Finally, the imperative to save babies from HIV should also provoke a much broader and urgent response from the government and civil society to address the unacceptable levels of child poverty and mortality due to preventable causes. The commission should therefore adopt a broader perspective that incorporates the country's response to household food security, poverty alleviation, access to social welfare grants, care systems for orphans and the provision of clean water to all households.

## 7.5 Expanding the PMTCT programme

The initial focus on two learning sites per province has given national and provincial management the opportunity to learn from their experiences, as well as improve the PMTCT guidelines. There have been many lessons learnt, as well as the development of training and IEC materials and tools to support programme management.

With this in mind, there are now no good reasons for delaying the gradual and phased expansion of PMTCT services.

Given the differences in capacity and infrastructure, it would be reasonable for provinces to expand the provision of PMTCT services at different speeds. What is important is for the expansion to be properly planned, implemented strategically and systematically, and that it takes into account the many lessons that have been learned.

For provinces that are currently struggling with implementation in their two learning sites, a plan for expansion should include and begin with a strengthening of provincial management and support structures and the continued improvement of services in the learning sites. These provinces should be targeted by the national DoH for support and capacity development.


Plans for expansion must also address the many systemic and infrastructural constraints that have been identified in order to avoid a multiplication of poor and/or non-sustainable service delivery, as well as to reduce the levels of health care inequity. The lack of optimal health systems infrastructure is therefore *not* a reason for delaying the expansion of PMTCT services, but should rather inform the strategic expansion of PMTCT services. Without paying some attention to the systems and infrastructure issues, the expansion of PMTCT services may not be cost effective or sustainable. In addition, leaving the poor state of health care infrastructure unattended to in many parts of the country will result in the existing inequities in health care being widened even further by an expansion of PMTCT services.

A more appropriate budgeting formula will be required to ensure that sites and provinces that are historically under-resourced receive a more equitable share of funding and support should there be an expansion of the programme. The 'gap' between existing resources and a minimum standard of health care infrastructure (especially in terms of human resources) should be measured in every sub-district across the country to ensure that this is addressed in the fullness of time.

With coherent and committed political and senior management leadership at the national and provincial levels, it should be possible for all provinces to begin implementing PMTCT services in some new sites by the middle of 2002.

The variation in health care infrastructure, geography, population density, HIV prevalence and socio-economic status necessitates a more context-based approach to planning and implementation. Local conditions and problems require local solutions. The formation of an effective 'sub-district health system' offers the best organisational framework for the delivery of PMTCT services and of PHC in general.

In order for provinces to gradually expand the provision of PMTCT services, as individual sites 'mature', provincial management should hand over the day-to-day



management of PMTCT services and their ongoing development to district and sub-district management structures. With the provincial office increasingly playing a supportive and monitoring role, sub-district and district health management teams should implement continuous quality improvement cycles based on routine monitoring and local operational research. Implementation in this regard can be considered as an ongoing process of continual improvement.

The PMTCT programme demonstrates the need to integrate community-based, clinic, CHC and hospital care as part of a seamless continuum of care. Any expansion of the PMTCT programme should therefore be based on a sub-district model. Targeting individual facilities, as opposed to sub-district areas, for any expansion of PMTCT services should ideally be resisted. Planning the expansion of the PMTCT programme on the basis of 'health sub-districts' will also offer a better framework for addressing the many systemic issues at the same time.

A phased and systematic expansion of comprehensive PMTCT services should be combined with the *immediate* provision of NVP to pregnant women already known to be HIV positive. However, in doing so, it would be important to avoid reinforcing the current portrayal of the PMTCT programme as being only about the administration of NVP.

Finally, there is still a need to continue to learn from the 18 learning sites, and these sites should continue to host in-depth research.

## Appendix 1: Provincial Statistics

Table 1 provides a summary of cumulative data per site, per province, from the onset of the programme. This data was obtained from the learning sites and all efforts were made to verify the quality of the data.

Province	Site	Start Date	Average no. of booking visits p/m	Average no. of pregnant women counselled p/m	Average no. of HIV tests p/m	Average no. of HIV+ pregnant women identified p/m	Cumulative Counselling uptake rate (i.e. average p/m)	Cumulative Testing uptake rate (average p/m)	Cumulative HIV positive rate amongst pregnant women
Gauteng	Nataispruit	May 2001	302	302	205	68	100%	68%	33%
	Kalafong	June 2001	295	295	69	30	100%	23%	43%
Western Cape	Guguletu	Jan 2001	377	372	304	65	99%	81%	21%
	Paarl District	May 2001	273	261	261	22	96%	96%	8%
Northern Province	Mankweng	Aug 2001	725	331	134	23	46%	18%	17%
	Siloam	Mid Nov 2001	82	17	14	0	21%	17%	0%
Mpumalanga	Shongwe	Sept 2001	102	19	19	9	19%	19%	47%
	Evander	Oct 2001	138	35	31	12	25%	22%	39%
Free State	Virginia	July 2001	341	246	122	39	72%	36%	32%
	Frankfort	Aug 2001	204	133	98	23	65%	48%	23%
KwaZulu-Natal	Durban	June 2001	997	997	814	355	100%	82%	44%
	Pietermaritzburg	June 2001	725	725	510	171	100%	70%	34%
Eastern Cape	East London Complex	Oct 2001	949	585	266	66	62%	28%	25%
	Umziminkulu	Oct 2001	67	67	60	21	100%	90%	35%

Province	Site	Start Date	Average no. of booking visits p/m	Average no. of pregnant women counselled p/m	Average no. of HIV tests p/m	Average no. of HIV+ pregnant women identified p/m	Cumulative Counselling uptake rate (i.e. average p/m)	Cumulative Testing uptake rate (average p/m)	Cumulative HIV positive rate amongst pregnant women
Northern Cape	Kimberley	Aug 2001	153	37	37	12	24%	24%	32%
	De Aar <sup>a</sup>	Aug 2001	46	79	42	2	<sup>a</sup> 172%	91%	5%
North West	Tlhabane	July 2001	98	26	26	11	27%	27%	42%
	Lehurutshe	July 2001	208	130	121	20	63%	58%	17%
TOTAL			6 082	4 657	3 133	949	77%	51%	30%

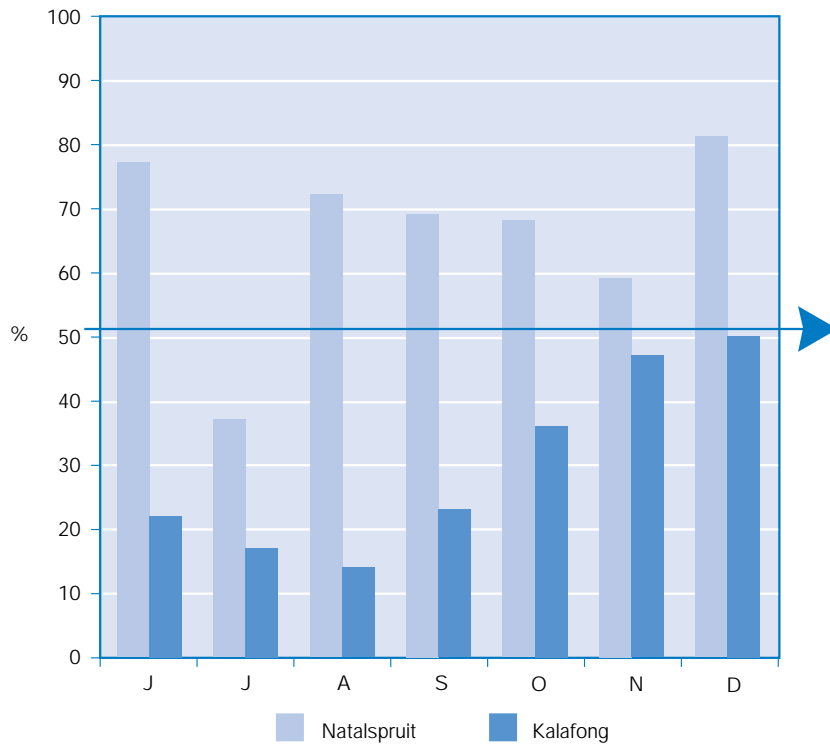
Notes on Table 1: HIV positive rate amongst pregnant women refers to the percentage of women who consented to voluntary testing, and tested positive. (Expressed as an average per month since the onset of the programme)

<sup>a</sup> All antenatal women were offered VCT with onset of programme – not only first visits

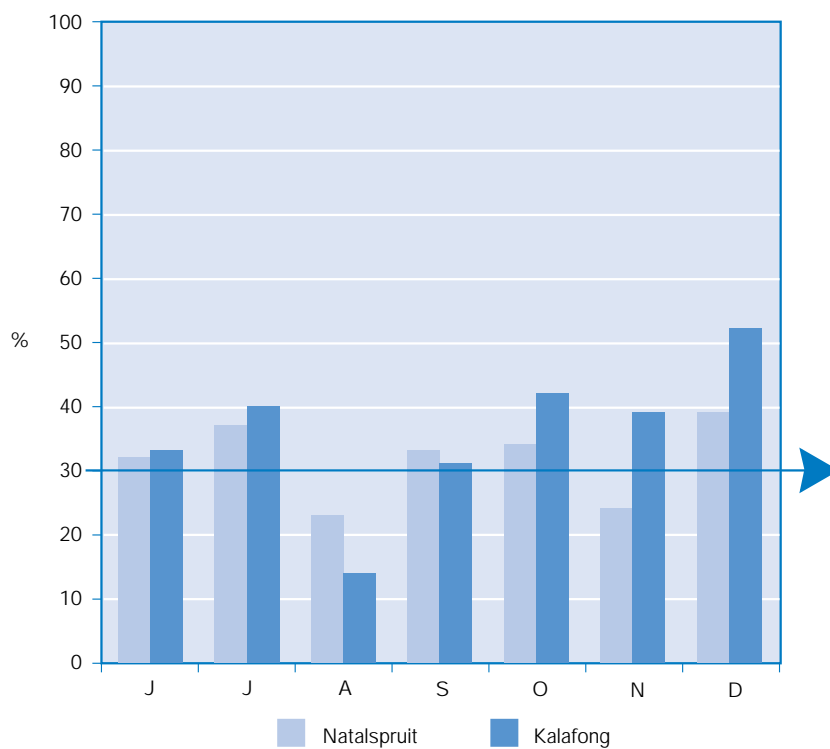
## Gauteng:

= National Average →

Voluntary Testing Uptake: Gauteng  
June - December 2001



HIV positive rate amongst pregnant women: Gauteng  
June - December 2001

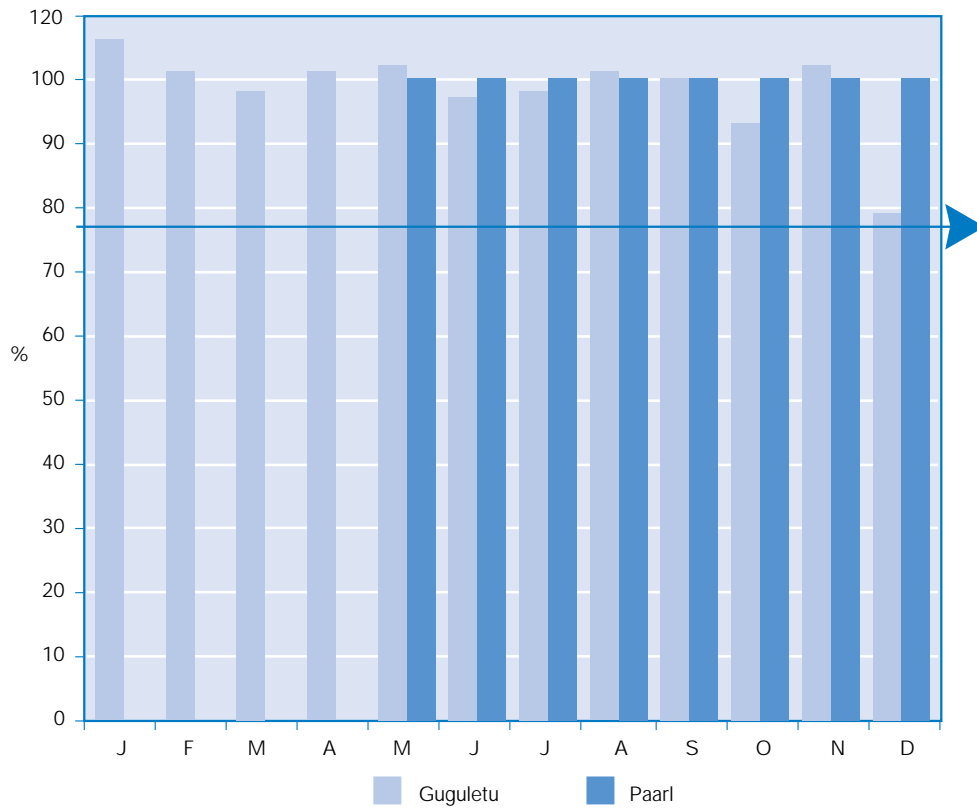




## Western Cape:

= National Average

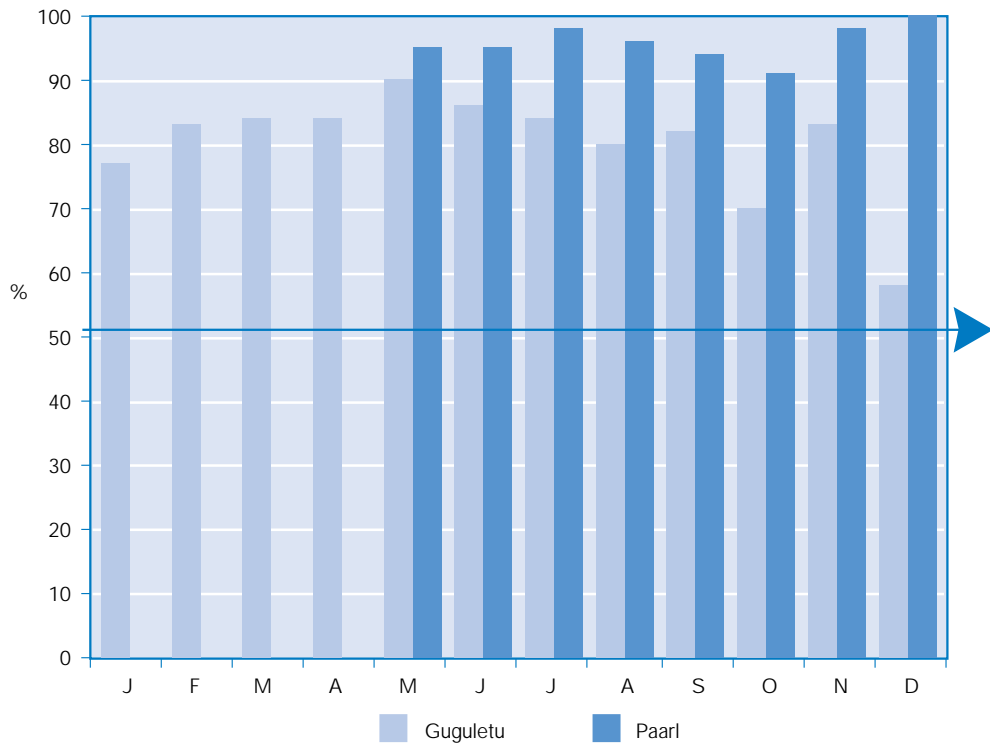
### Voluntary Counselling Uptake: Western Cape January - December 2001



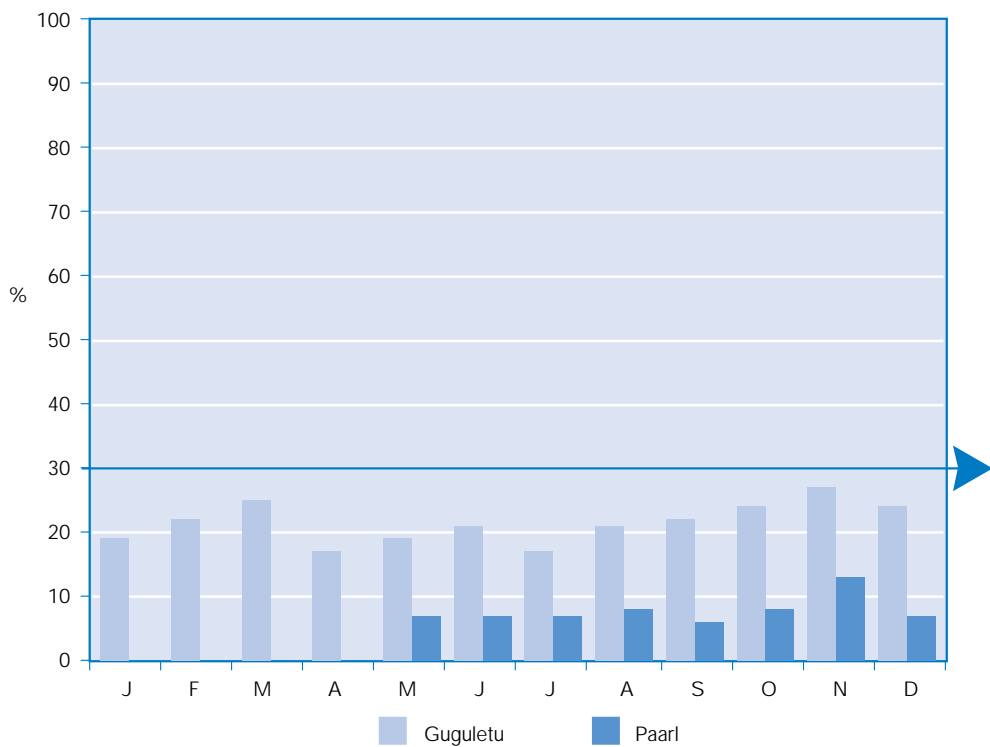
Notes: VC uptake is calculated to determine the number of pregnant women who accepted Voluntary Counselling during their first antenatal visit. However an uptake figure of over 100% indicates that women entered the programme during follow-up antenatal visits. These figures should stabilise over a period of time. It might also be an indication that pregnant women from other facilities are utilising the learning sites to access the PMTCT programme.

Voluntary Testing Uptake: Western Cape  
January - December 2001

= National Average



HIV positive rate amongst pregnant women: Western Cape  
January - December 2001

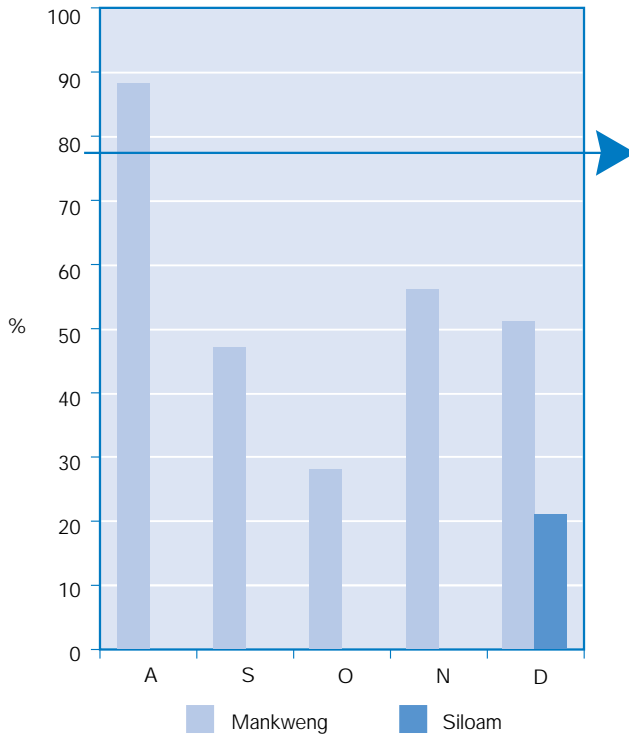


**Northern Province:**

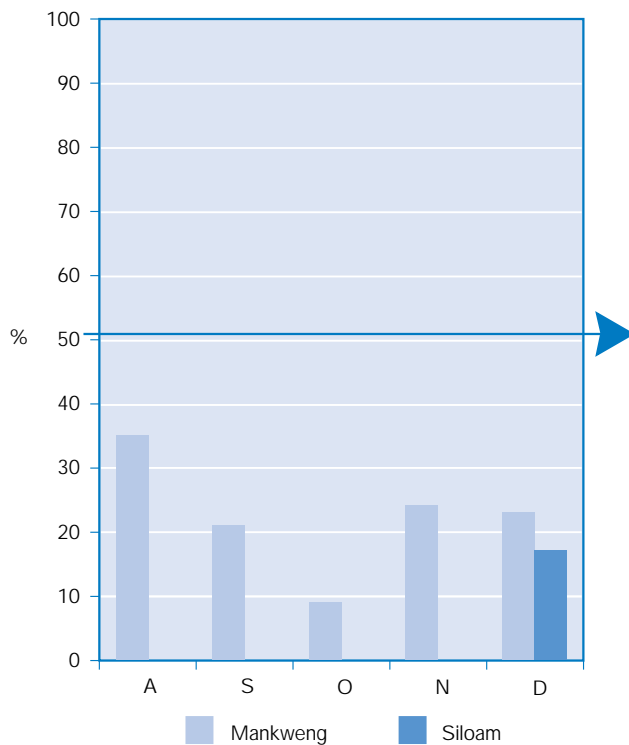
= National Average



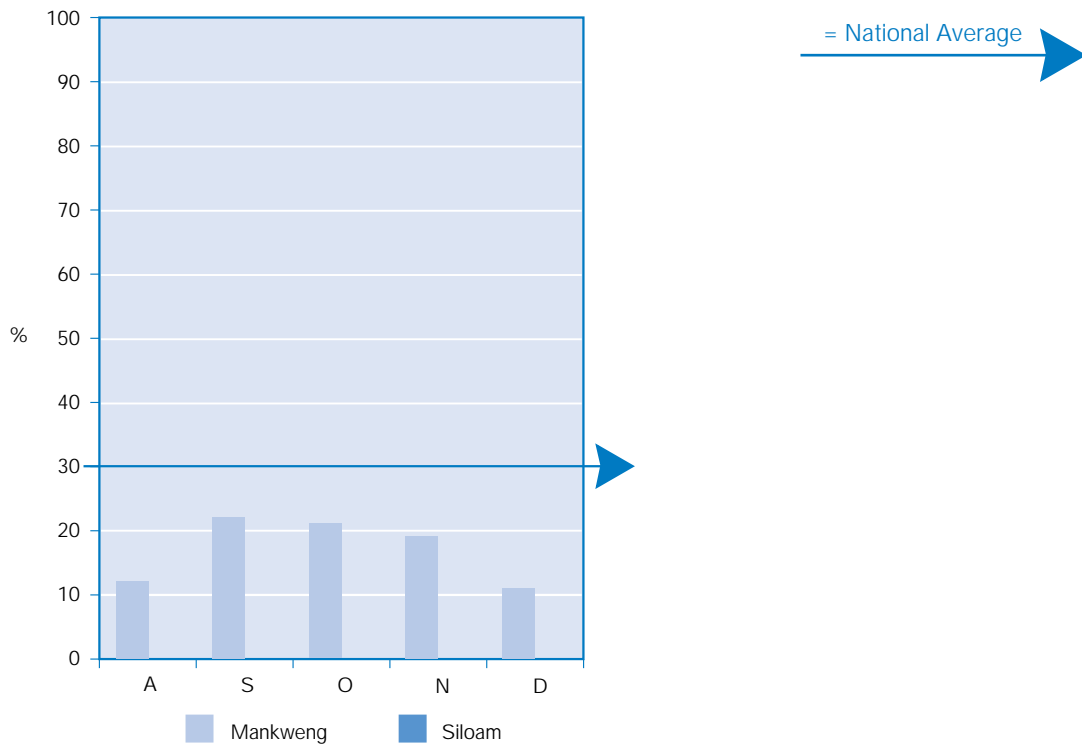
Voluntary Counselling Uptake: Northern Province  
August - December 2001



Voluntary Testing Uptake: Northern Province  
August - December 2001

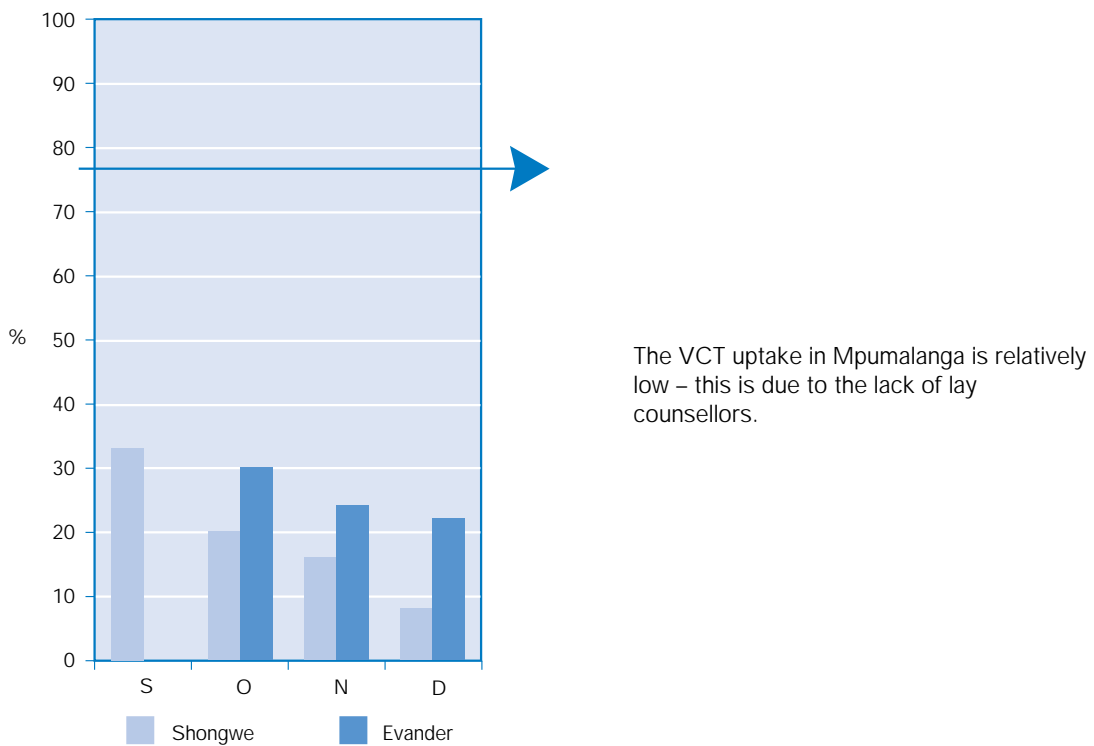


HIV positive rate amongst pregnant women: Northern Province  
August - December 2001



**Mpumalanga:**

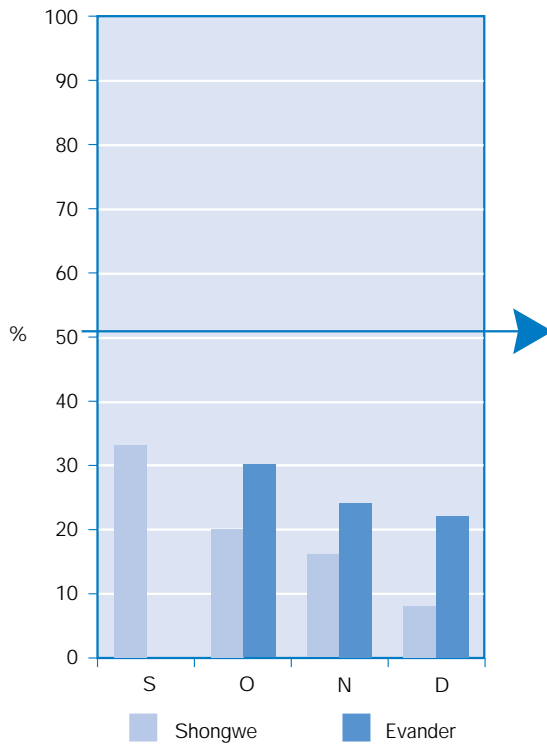
Voluntary Counselling Uptake: Mpumalanga  
September - December 2001



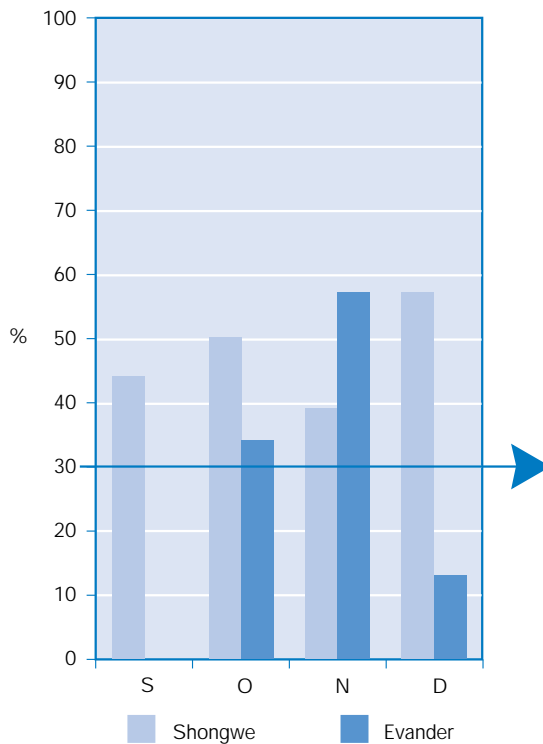
The VCT uptake in Mpumalanga is relatively low – this is due to the lack of lay counsellors.

Voluntary Testing Uptake: Mpumalanga  
September - December 2001

= National Average



HIV positive rate amongst pregnant women: Mpumalanga  
September - December 2001



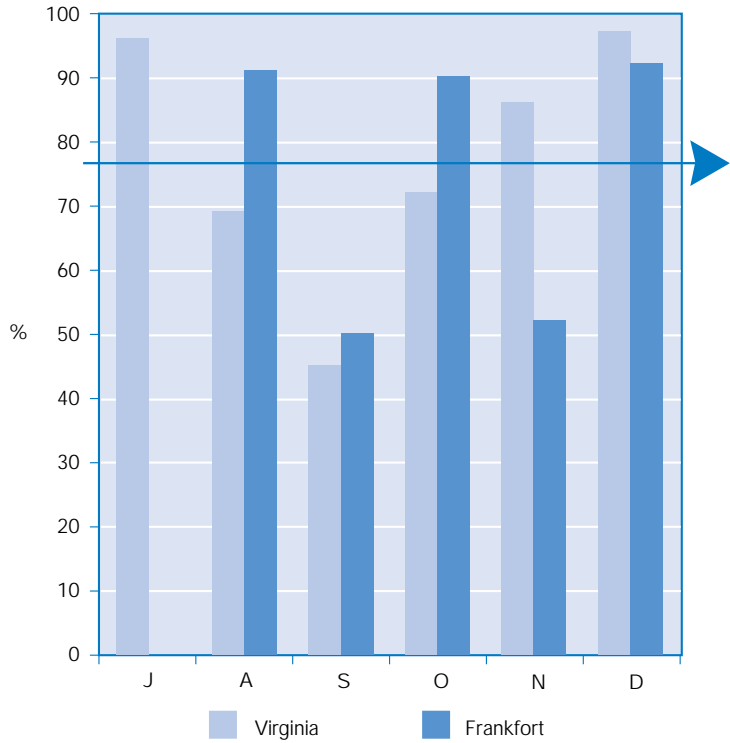
Although the HIV positive rate seems high, it is important to note that the number of pregnant women who voluntarily accepted counselling and testing was very low.

**Free State:**

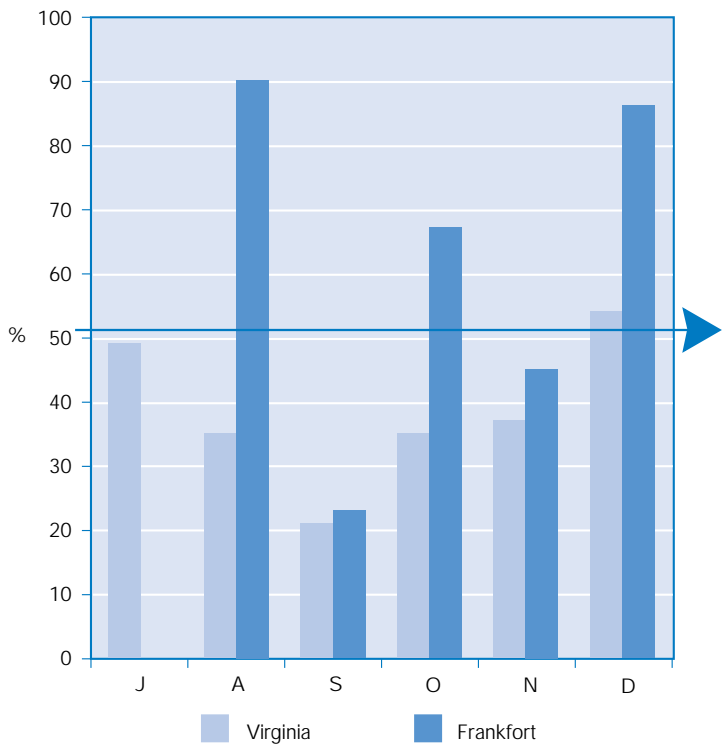
= National Average



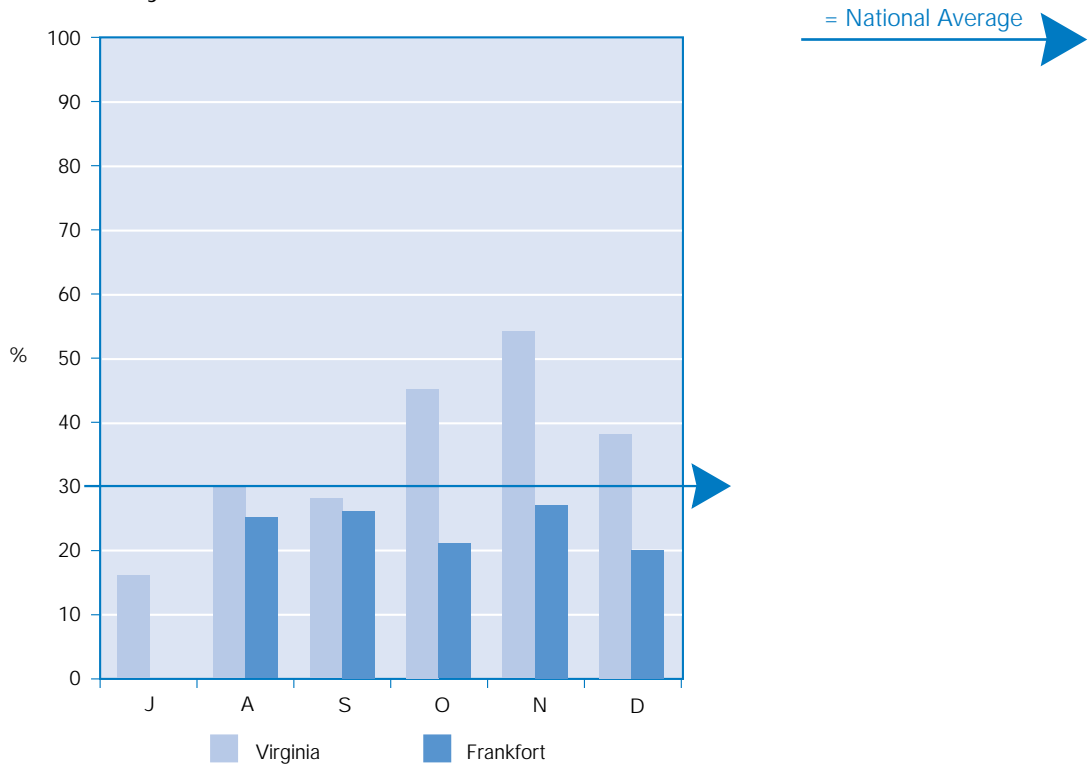
Voluntary Counselling Uptake: Free State  
July - December 2001



Voluntary Testing Uptake: Free State  
July - December 2001



### HIV positive rate amongst pregnant women: Free State July - December 2001

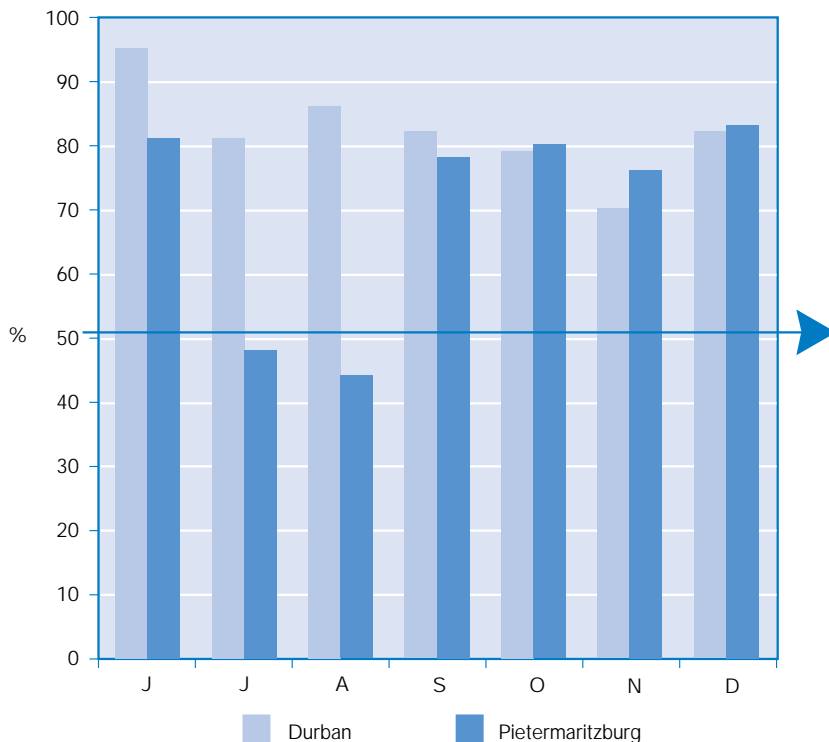


The HIV positive rate amongst pregnant women in Frankfort seems to be about 10% lower than in Virginia. Virginia is predominately a mining area while Frankfort is classified as rural, which may explain the difference.

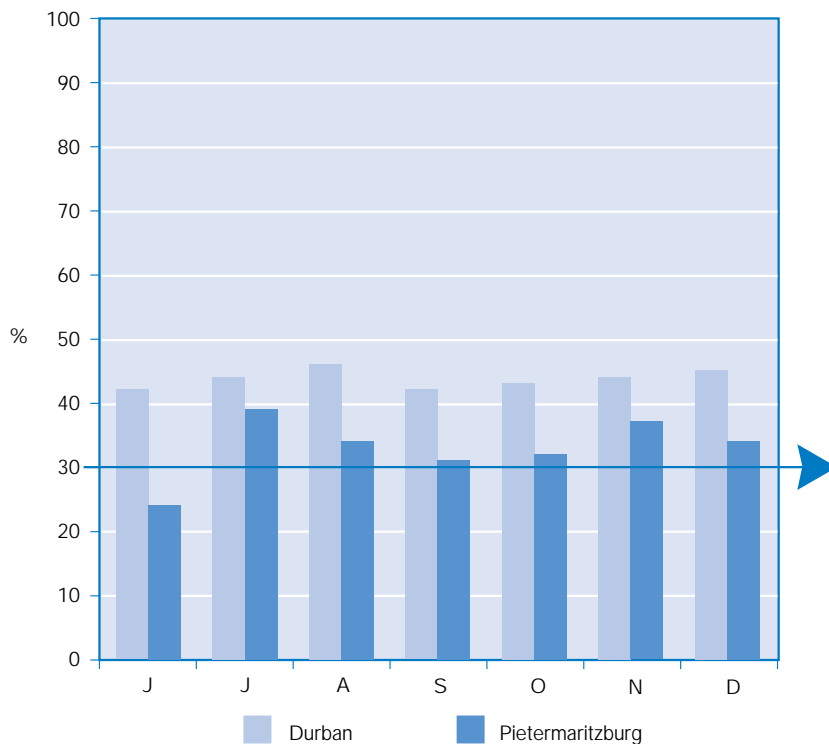
## KwaZulu-Natal:

= National Average

Voluntary Testing Uptake: KwaZulu-Natal  
June - December 2001



HIV positive rate amongst pregnant women: KwaZulu-Natal  
June - December 2001

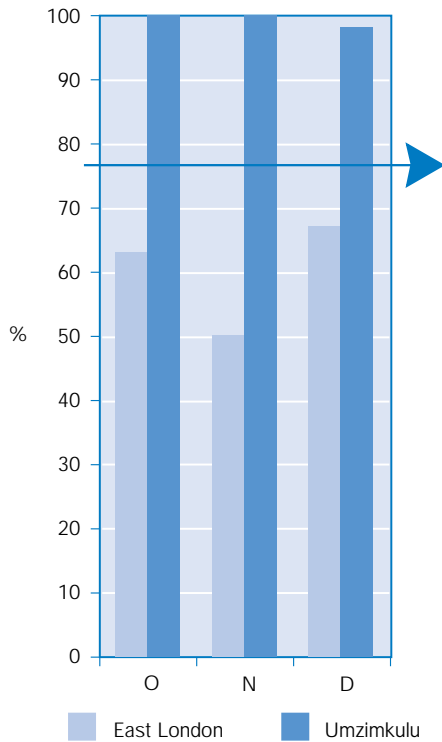




## Eastern Cape:

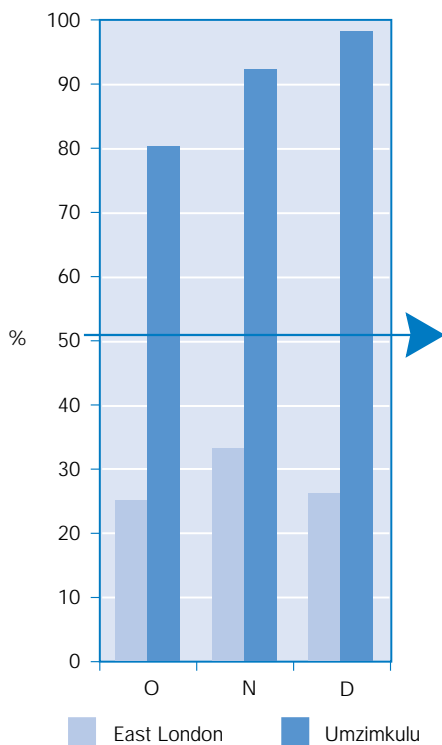
= National Average

Voluntary Counselling Uptake: Eastern Cape  
October - December 2001

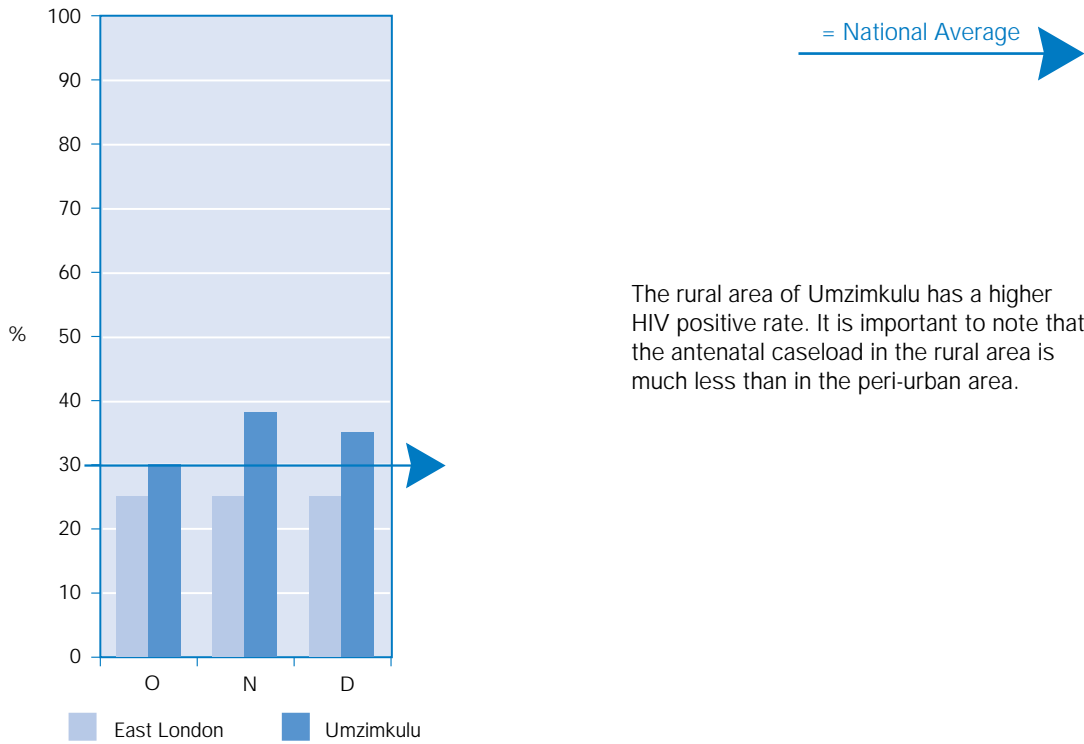


The percentage of pregnant women consenting to counselling for HIV in Umzimkulu (rural area) is much higher than in the East London Complex. However the EL complex is serving approximately 13 times more pregnant women per month.

Voluntary Testing Uptake: Eastern Cape  
October - December 2001



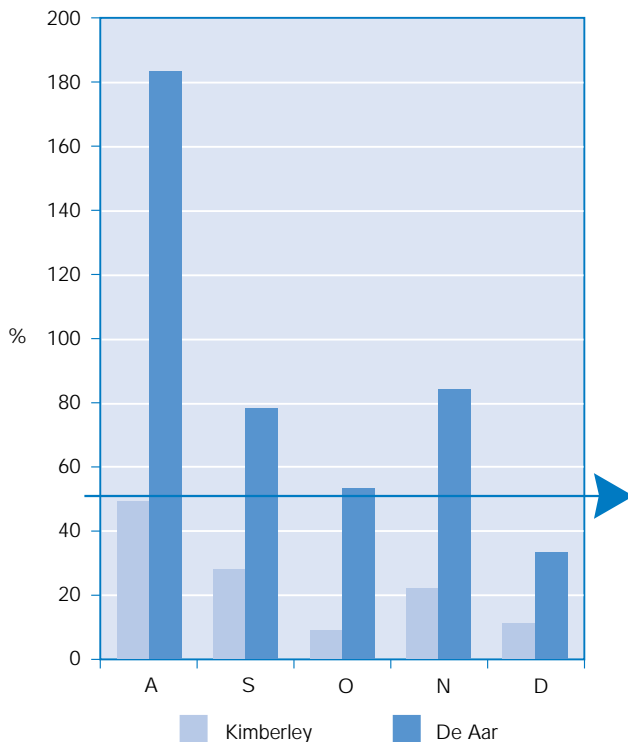
HIV positive rate amongst pregnant women: Eastern Cape  
October - December 2001



The rural area of Umzimkulu has a higher HIV positive rate. It is important to note that the antenatal caseload in the rural area is much less than in the peri-urban area.

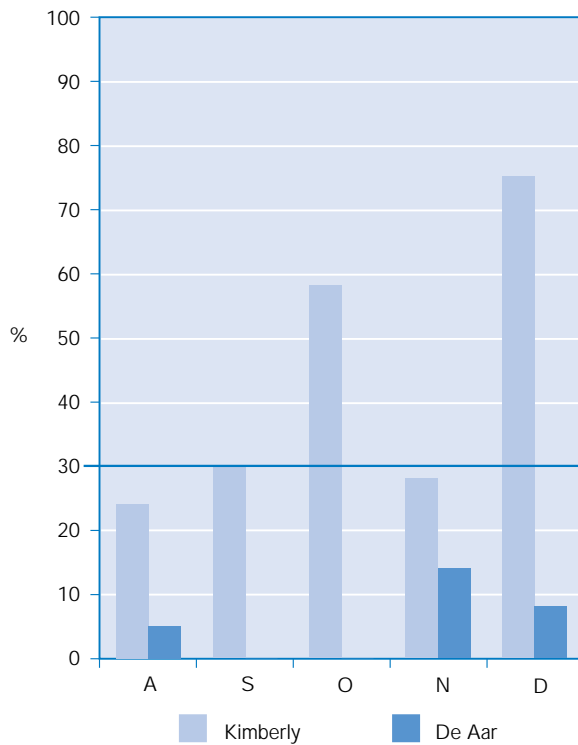
**Northern Cape:**

Voluntary Testing Uptake: Northern Cape  
August - December 2001



The percentage of pregnant women agreeing to VCT in De Aar is very high in August. This is due to the fact that with the onset of the programme, the service was offered to all pregnant women. The indicator is however calculated with 'First antenatal booking visits' as the denominator. The 'normal' pattern should start emerging approximately 6-7 months after the programme onset. Another factor to consider is the influx of pregnant women from other clinics to the learning site.

HIV positive rate amongst pregnant women: Northern Cape  
August - December 2001

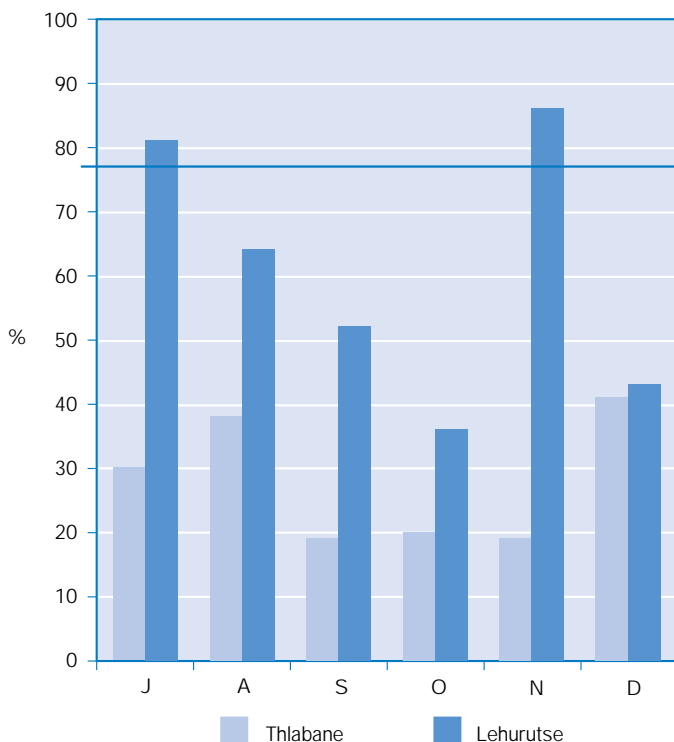


= National Average →

The HIV positive rate for Kimberley seems very high. The number of pregnant women tested was in fact very low. High HIV+ rates with low VCT uptake are not necessarily a true indication of the HIV prevalence. It is expected that the HIV+ rate will decrease with an increase in VCT uptake.

**North West:**

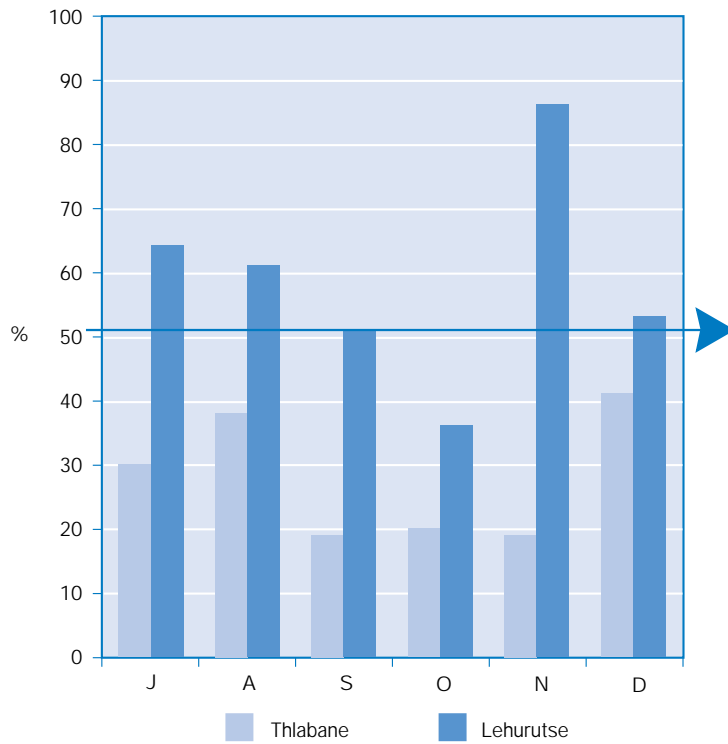
Voluntary Counselling Uptake: North West  
July - December 2001



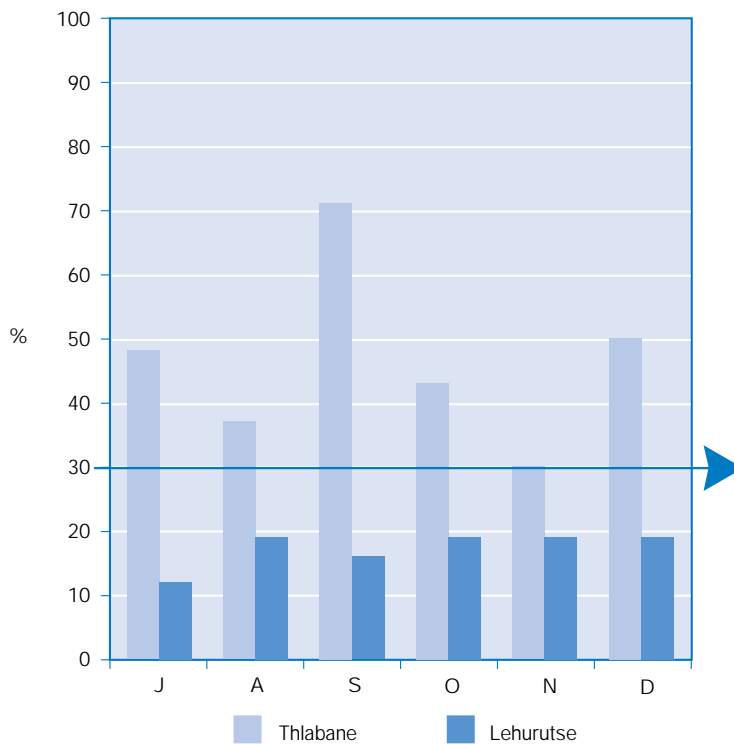
The VCT uptake in Thlabane, the urban site, seems very low. The quality of the data is also questionable as a major difference was found between data collected for the PMTCT programme and routinely collected data for PHC. The main reason for this seems to be the constant change in data collection forms. The VCT uptake in November for Lehurutse seems to be higher than the rest. The number of clients seen during this month was however significantly lower than the other months.

Voluntary Testing Uptake: North West  
July - December 2001

= National Average



HIV positive rate amongst pregnant women: North West  
July - December 2001



The high HIV positive rate for Thlabane can be misleading, as the number of pregnant women tested was very low.

Table 2

Province	Site	Total no. of HIV+ women identified	Total no. of HIV+ women delivered with NVP	Average no. of HIV+ women identified p/month	Average no. of HIV+ women delivering with NVP p/month	Percentage of HIV+ positive women identified, delivered with NVP since onset of program
Gauteng	Natalspruit	473	*	68	*	*
	Kalafong	182	*	30	*	*
Western Cape	Guguletu	779	210	65	18	27%
	Paarl District	176	83	22	10	47%
Northern Province	Mankweng	115	14	23	3	12%
	Siloam	0	0	0	0	0
Mpumalanga	Shongwe	35	19	9	4	54%
	Evander	36	9	12	3	25%
Free State	Virginia	234	100	39	17	43%
	Frankfort	114	34	23	7	30%
KwaZulu-Natal	Durban	2485	793	355	113	32%
	Pietermaritzburg	1198	457	171	65	38%
Eastern Cape	East London Complex	199	87	66	29	44%
	Umzimkulu	62	24	21	8	39%
Northern Cape	Kimberley	60	25	12	5	42%
	De Aar	12	6	2	1	50%
North West	Thlabane	65	32	11	5	49%
	Lehurutshe	120	39	20	7	33%
TOTAL		6345	*1932	949	295	30%

\* Data not available for Gauteng. Totals thus exclude Gauteng.

## Appendix 2: Provincial Notes<sup>1</sup>

### Table A: Provincial Organisation, Management and Technical Support/Guidance

The organisation and management of PMTCT programs are key ingredients to their success.

#### Gauteng

The Deputy Director (DD) for HIV/AIDS and the provincial medical advisor play key leadership roles in administering the programme, training and providing technical guidance. The CCLO was appointed in August 2001, but the appointment of the admin officer for the PMTCT programme has not been finalised yet. The existence of an experienced medical doctor as part of the provincial HIV/AIDS unit management team is a strength of Gauteng. There appears to be keen interest from top management in the programme, and a desire to see a gradual expansion of PMTCT services.

At the level of the region and site, management appears to be much weaker. Too much of the PMTCT programme is being channelled through a narrow and vertical management system, without enough horizontal linkages between different parts of the health care system. Relations between the Kalafong site and provincial management have been difficult, and within sites, there have been some tensions noticed between doctors, hospital managers, nurses and regional co-ordinators. The province has recognised the need to strengthen the links between the facilities where deliveries take place, and clinics where antenatal care and post-delivery follow-up takes place.

A recent review of the province's HIV/AIDS programme commissioned by top management has signalled the commitment of the DoH to address the many organisational weaknesses of the health care system in Gauteng.

Academic and non-governmental technical support has been made available by the Baragwanath complex and the Peri-Natal HIV Research Unit. A provincial steering committee meets regularly.

#### Western Cape

The PMTCT programme in the province precedes the national pilot programme. Khayelitsha PMTCT services started in January 1999 and provided important lessons. National sites are a small part of a much larger provincial PMTCT programme.

The Chief Director for HIV/AIDS has been very involved in the initiation, development and implementation of the PMTCT programme, together with a strong team of HIV managers/co-ordinators at Director and DD level. Strong provincial administrative infrastructure is in place. Weekly meetings of PMTCT managers and monthly meetings of the steering committee that includes stakeholders from PMTCT sites, referral

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<sup>1</sup> This appendix provides an overview of the 18 national PMTCT sites based on national reports, provincial reports and interviews undertaken by HST. More detailed situation analyses of the 18 sites are still underway and will be completed in the coming months. Due to the time pressures for producing this report, some of the facts contained in the tables could not be validated.

hospitals, district managers, academics and specialists take place. Involvement of specialists and academics has been a particular strength of the programme.

Health managers in Guguletu were prompted to develop the PMTCT programme by grass-roots interests before the national initiative was proposed. Day-to-day co-ordination of the programme is by the district manager and medical officer with support from a provincial team and local NGOs active in HIV. Teams are established for budgeting, selecting counsellors, training staff, monitoring and organising supplies. Hiring of dedicated a PMTCT programme manager was delayed by difficulty in advertising for the position, and the person was appointed 5 months after the programme started. Extensive support was received from the University of Cape Town specialists in the departments of obstetrics, paediatrics and medicine.

In Paarl, programme planning preceded announcement of the national initiative. The provincial Chief Director for Rural Health has an office in Paarl and has provided full support to the programme. A regional steering committee with broad representation from all involved stakeholders was effective in initiating the programme. The programme manager was hired only as the programme started. Support from obstetrician at Paarl Regional Hospital. Programme affiliated with Tygerberg Hospital from University of Stellenbosch.

## **Northern Province**

A provincial Steering Committee formed in late 2000 brought together relevant role players, under the chair of a Chief Director. A smaller 'task team' sub-committee was formed with members from Health Promotion, HIV/AIDS Directorate, Nutrition and Medunsa public health and paediatric specialists. The provincial team met monthly and the task team met every two weeks. Site steering committees were also formed, and a detailed situation analysis was done for each site in early 2001. However, provincial restructuring and administrative delays appear to have been reasons for delayed implementation. In July the MEC applied intense pressure to start at Mankweng; so with no lay counsellors in place and only six of 19 facilities prepared, Mankweng started PMTCT service in August 2001. To date there are still no lay counsellors, apparently because the budget from national government did not provide money to pay for lay counsellors. The plan is now to obtain money from national NGO grants but there has been confusion and conflict over whom to fund and how to get the funds to the appropriate NGO.

The main co-ordinator of the programme is a nurse seconded to the CCLLO position. There appear to be tensions and disagreements amongst provincial role players which is hampering progress. Roles and responsibilities are not clearly defined, and due to certain problematic relationships, the Steering Committee meetings have become largely ineffective. Many meetings are poorly attended, and rarely is a quorum present. Meetings have also been changed at short notice, minutes are not always taken and many decisions are not followed through. A research committee exists, and is working to develop an agreement with the management team to inform the analysis and collection of routine data.

The instability and turnover of provincial leadership has had a negative impact. The MEC has been supportive, but both the Superintendent General and Chief Director

of Public Health have left since efforts started to develop the PMTCT programme. The recent (Nov 2001) appointment of a Director of HIV/AIDS should help to stabilise provincial management as well as reduce the tensions that exist within the steering committee.

Apart from the support and involvement of Medunsa specialists, UNICEF has been very active in supporting the programme. UNICEF are funding action research into the development of a communication strategy for the province. NAPWA is also assisting the programme with the establishment of support groups.

## **Mpumalanga**

Provincial leadership and management is undergoing significant difficulties. The area of HIV/AIDS seems to be characterised by underlying tension, confusion, disagreement and a lack of coherent leadership. This has led to low morale amongst senior managers.

As far as the PMTCT programme is concerned, the CCLO was hired in August 2001. His background was in education with little experience in health care. A senior nurse with nursing, midwifery, teaching and data management experience was seconded to act as AIDS Projects Co-ordinator and was brought into the PMTCT programme to assist the CCLO and help with staff training. She has made a positive contribution to the programme, but unfortunately conflict about roles, responsibilities and accountability has evolved. The PMTCT programme is suffering as a result. The recent (Jan 2002) appointment of a medical doctor to the position of Director: HIV/AIDS may help to improve the situation.

At the local level, site co-ordinators who are sisters are expected to manage the implementation of PMTCT services. These are nurses with other duties and responsibilities. Because the province hasn't been able to recruit any lay counsellors to the PMTCT programme, site co-ordinators are having to implement the service instead of playing a training, support and supervision role.

There appears to have been minimal involvement of the academic/regional complex at Witbank.

## **Free State**

The PMTCT programme has been primarily managed and implemented through the provincial MCH and Nutrition programme, with the DD for MCH and Nutrition supervising the CCLO co-ordinator. This has had the benefit of integrating MCH and Nutrition services into the PMTCT programme right from the beginning. Recently, the position of a Director for HIV/AIDS was created and filled by the province, and the PMTCT programme will now come under the overall management of the new Director. There is a provincial steering committee established to provide oversight. The Director for health programmes and the administrative sections of the province have also been able to provide a positive enabling environment for the PMTCT co-ordinators to get on with their responsibilities.

The Free State province is blessed with stable leadership. There is relatively little conflict within the DoH, and the MEC provides dynamic leadership to the DoH, as well as the PMTCT programme in particular. In addition, the province is moving smoothly towards



the establishment of a District Health System which will assist the PMTCT programme.

At the site level, implementation committees have been set up and they report to the provincial steering committee on a monthly basis. The Virginia site is much more active and better organised than the Frankfort site.

Some external technical support has been provided by ISDS (Health Systems Trust) as well as some research conducted by Department of Community Health, University of the Free State. ATICCs and the Township AIDS Programme have been used to help provide training around HIV counselling and testing. There is a recognition that the medical school needs to be drawn more into supporting the programme.

## **KwaZulu-Natal**

Provincial oversight has largely been provided by the Obstetrics Department at University of Natal, in close collaboration with provincial HIV/AIDS co-ordinators/managers. The University of Natal involvement was built on the experience gained from the SAINT research trial. Neither the nationally funded CCLO nor the data management post had been filled by the end of November 2001, but there are plans by the DoH to create one PMTCT co-ordinator and two administrative positions.

The Durban site is co-ordinated by the University of Natal Obstetrics Department. The Pietermaritzburg site is primarily led and co-ordinated by the senior paediatrician at Grey's Hospital. Both sites seem to have established good teams involving all the required roleplayers to support and sustain the PMTCT service. Compared to other provinces, much of the leadership and initiative is provided by management at the site level, with the provincial office providing support – this arrangement seems to be working well and has helped establish good local ownership of the programme.

There is active support and interest from the HoD and the MEC. Research and technical support from the Africa Centre in Hlabisa has also been made available.

## **Eastern Cape**

Strong management is provided by the Director: HIV/AIDS, with the support of a DD for HIV/AIDS and the CCLO.

However, in the last two years, the EC has been troubled by an unstable senior management. Both the HoD and the MEC have been suspended for most of last year, and a number of other senior posts are vacant. There is low morale, coupled with low levels of administrative and management capacity inherited from the past.

Site level management has been good, with strong leadership and support provided by medical staff in both sites. Nurses, midwives, lab technicians and lay counsellors have all been targeted for training, and this has helped create strong and committed local teams.

External support: Two local universities, Rhodes and Fort Hare, assist with training in MTCT and VCT. UNICEF are offering support in research and the development of a communication strategy. UWC and HST are developing operational research projects to assess the quality of infant feeding counselling and infant feeding practices. The Equity Project has been assisting the DoH to improve their routine data collection and management.

## **Northern Cape**

The PMTCT programme has been managed through the Directorate: MCWH. The Deputy Director for MCWH works closely with the appointed CCLO, who started in May 2001 before the sites formally opened. The CCLO spends 70% of time in the provincial office and 30% of time at sites. She provides a very hands-on approach, which has benefited the sites. Local government was included in programme planning, helping to establish a co-operative working relationship at site level. Local specialists in obstetrics and paediatrics from Kimberley Hospital are very involved, as well as provincial managers of laboratory and pharmaceutical services. Initial conflict and tension between the MCWH and HIV/AIDS units over turf seems to have been resolved recently.

The HoD has been very committed to the HIV/AIDS and PMTCT programme, and there is an open-door policy for the DD and members of the PMTCT steering committee, especially during start-up. He has helped to fast-track certain actions such as facility improvements.

Site development started with establishment of a local steering committee representing all stakeholders. Site management has been decentralised to district managers for direct oversight of service. Hospital sisters are in charge of PMTCT service and report to site managers, who in turn report to the district manager, who reports to the provincial DD and CCLO.

## **North West**

The Director of Health Programmes initiated the PMTCT programme and is very committed to HIV/AIDS generally, and PMTCT specifically. A Deputy Director: HIV/AIDS was hired in June 2001 and has a hands-on approach to PMTCT service development and management. He is currently acting as overall manager. The co-ordinator for Home Based Care has been seconded to the PMTCT programme and is assisting the CCLO, a professional nurse with limited management experience, who was hired in August 2001. Because the CCLO did not have clearance to drive government vehicles her ability to visit sites was limited. She is responsible for collecting and collating weekly data reports from two sites.

The programme is run in close collaboration with other departments, including MCWH, Home Based Care, VCT, Pharmacy, EPI, Nutrition, Health Education and Promotion. There is a good working relationship among the departments who meet monthly to co-ordinate efforts and activities. There are good working relationships between provincial, district and local authority staff.

There is no significant non-governmental support to the programme. The Baragwanath PMTCT research unit have provided some support.

## **Table B: Training of Staff – Nurses, Midwives and Doctors**

The term 'training' is used generically to refer to any activity designed to inform and improve the capacity of health workers and lay counsellors to provide a quality PMTCT service. It includes the provision of formal training programmes, on-site training and the provision and dissemination of information. This report provides a very superficial thumbnail sketch of some of the training activities and initiatives in the different provinces.

### **Gauteng**

Training and information has been provided by the Perinatal HIV Research Unit at Baragwanath Hospital. The provincial medical advisor has also been providing training and information sessions, especially in terms of follow-up care.

A variety of training materials exist.

### **Western Cape**

There is a great depth and breadth of technical expertise in the WC that has been used. At Guguletu, specialists in paediatrics, obstetrics and medicine gave many of the introductory lectures.

At Guguletu, a committee was appointed to train clinic staff. For several months weekly meetings were held with lectures on PMTCT and HIV. Nurses, midwives, clerks, cleaners and community members attended. A second series of lectures was held just before implementation, focusing on operational issues – drug administration; ante-, intra- and post-partum care; monitoring, follow-up. At Paarl, the district manager and clinical specialists have helped to co-ordinate training.

Training materials have been developed. Short *aide-mémoires* for staff are being developed.

### **Northern Province**

Most of the training has been happening in the Mankweng site. Training had not started at Siloam by November 2001.

Most people trained in counselling were nurses. Training programmes were designed mainly for clinic staff, not hospital staff. Few doctors trained in VCT and PMTCT (doctors were perceived as being too busy to be trained). A one-week PMTCT top-up training has been offered for VCT trained counsellors.

Training is done by VCT master trainers from the Department of HIV/AIDS, using a manual developed by the Department of Community Health in consultation with clinical specialists and UNAIDS/WHO. However, training has been impaired because no funds have been made available for trainers or photocopying materials.

### **Mpumalanga**

Initial staff training was organised by clinicians/researchers from Baragwanath. A one-day session with staff from both sites was held in July 2001. Doctors, nurses and lay counsellors attended the session. Further training has been done in two stages – initially in VCT, then top-up training in MTCT. Trainees have included 46 Professional Nurses

(PNs), 15 Enrolled Nurses (ENs) and 12 health promotion practitioners in Shongwe.

A five-day training programme has now been developed which incorporates HIV counselling and testing, PMTCT, community marketing, data management and follow-up care of mothers and children. An additional 2-day course stressing nutrition and advanced data management is being developed.

Nurses at some feeder clinics and one community health centre have been PMTCT trained. Nurses at Shongwe maternity, infant and out-patient ward trained on PMTCT. Health promoters at Shongwe Hospital are PMTCT trained.

### **Free State**

Professional nurses in the various sites have received training on VCT, with additional top-up training on other PMTCT issues. The Township AIDS Programme and local ATICCs have been employed to provide training, but not all the training has been considered to be of adequate quality by provincial management. There is a recognised need to develop training and information targeted at medical staff.

### **KwaZulu-Natal**

Lots of training has been done in both sites for nurses, mostly organised through site level management. In Durban, a structured and phased approach to training was implemented. Doctors from some facilities attend continuing education on HIV/AIDS in Durban organised by the Harvard AIDS Institute.

The problem of unstable staff means that there is a constant need to provide training.

### **Eastern Cape**

A lot of emphasis has been placed on training a wide spectrum of staff (nurses, doctors, lab technicians etc.). Initial PMTCT training was funded by the Provincial DoH for 12 people who attended a one-week training course on PMTCT at the UWC Winter School. Training of nurses in VCT has been done by Rhodes University, psychology department. The ATTIC in East London is also doing training. The aim is to have 2 PNs trained in VCT per clinic/facility. There is a growing recognition that staff nurses, enrolled nurses and even nursing assistants should also be targeted for training. Laboratory technicians have been used to provide training in the use of rapid testing kits.

The provincial DoH have also initiated discussions with nurse training institutions to develop appropriate undergraduate training in PMTCT and HIV counselling, which is a very positive development.

### **Northern Cape**

The Northern Cape made use of the expertise and resources at Baragwanath. In September 2000, a team from Baragwanath organised a training and development programme. James Macintyre from Baragwanath made numerous visits to assist in training. In April 2001, six people from Northern Cape went to Baragwanath, including site directors and two sisters from each site. Sisters said the experience was extremely helpful. Sisters who travelled to Baragwanath were then responsible for educating the other staff.

There are many health workers who have been trained as VCT counsellors according to the national training standards. Additional top-up training on MTCT has been provided with the assistance of Baragwanath Hospital.

Few doctors have been trained in PMTCT. Several training sessions have been held but many doctors have been unable to attend. It is a difficult process with interns and community-service doctors rotating through the service.

Plans have been developed for training in monitoring and data management.

### **North West**

In June, a clinician from Baragwanath came for a two-day training session. These sessions were 'information sessions', with nurses, laboratory and health promotion staff from both sites in attendance. A one-day workshop was run by national trainers and included 200-300 attendees from all levels of the health service. In the clinics and hospitals only the professional nurses had been oriented to PMTCT. No training of mobile staff has been done.

### **Table C: Facility Preparation and HIV Counselling and Testing Practices**

#### **Gauteng**

Group information is followed by an individual counselling session. Results are given the same day by counsellors, but many women request to return another day for the result (partly because of long waiting times).

#### **Western Cape**

Guguletu clinic had sufficient space for counselling and testing, but there is little privacy in the antenatal clinic and post-partum ward for continuing education. Paarl refurbished unused buildings on the clinic grounds to create space for counselling and testing. The antenatal clinic had ample space for providing confidential service.

At the booking visit, all patients undergo group education followed by individual counselling. They are then offered HIV testing.

Patients who wish to participate in the PMTCT programme are offered any combination of immediate or delayed HIV testing and results.

In Guguletu, circling the letter 'Y' under Blood Precautions on the patient held card identifies the patient as HIV+.

In Paarl, patients do not hold their antenatal folders. The hospital keeps all patient folders because the ante-natal service for the entire district is more or less completely centralised to the MOU. Folders include stickers identifying the patient's sero-status.

#### **Northern Province**

Mankweng Hospital's antenatal clinic is poorly designed for a PMTCT programme. Renovations were completed to establish an education area in the waiting room and provide privacy in examination rooms. At least one clinic underwent a small renovation to turn unused sleeping quarters into a counselling and testing area for the clinic sister.

In the small clinics, nurses responsible for general PHC are responsible for antenatal care, and PMTCT is integrated into their general duties. At Mankweng Hospital, there is a dedicated antenatal clinic with dedicated midwives.

There is some debate amongst programme co-ordinators about the difference between consent for counselling and consent for testing. In Mankweng, clinic nurses do individual education and counselling before offering HIV testing. Nurses in the hospital do group education and then individual counselling before offering HIV testing.

Charts are encrypted with a code to indicate HIV status without risk of loss of confidentiality on patient-retained records.

## **Mpumalanga**

Lebohang Clinic at Evander had no space for counselling and 3 toilets were converted into counselling rooms. Private contractors used provincial money to complete the work. Site improvement was complete in mid-October. Embalenthle Clinic at Evander started facility renovation in mid-October. A former maternity building has been renovated for Shongwe's programme centre.

Shongwe Hospital's affiliated clinic – Kamhloshwa - has two nurses who provide PHC to 1800 patients per month. Of these, 130 patients a month attend for antenatal care. The clinic has two rooms which are insufficient for PMTCT services. In contrast, the clinic at Naas sees 4000 patients per month, of which 400 seek antenatal care. They also do 60 deliveries per month. There are 7 professional nurses, tele-medicine services and sufficient space for a MTCT programme.

Current practice is group education and counselling, followed by offering women individual counselling and testing by antenatal clinic sisters. Poor uptake for this service (38% at Evander and 27% at Shongwe) is explained in part by mothers feeling embarrassed to volunteer for VCT when asked to step out of large group. Programme staff are therefore considering offering *all* women individual counselling before offering HIV testing, but this will require additional counselling staff. Patient charts are marked to indicate HIV status.

At Shongwe, 'SH' followed by a number is written in the corner of the chart. The number represents the number of HIV patients diagnosed in the programme. For example, 'SH45' would be the 45<sup>th</sup> patient diagnosed as HIV positive at Shongwe. The Road-to-Health-Chart (RTHC) is marked with a paediatric folder number and letter-number designation on the mother's folder. In this way mothers and babies can be linked. Other sites are designated as follows: Lebohang - LEB, Embalenthle - EMB. Feeder clinics will get similar letter codes.

## **Free State**

A thorough audit of the physical structure of all clinics was conducted, and expansions/renovations to clinics in both sites have been completed or are in progress.

All pregnant women are offered group education about the PMTCT programme at the booking visit. Individual counselling is then made available following the group session.

## **KwaZulu-Natal**

Inadequate space and privacy for counselling is a problem. Plans to subdivide waiting rooms, use empty wards and to purchase 'containers' to create space for counselling have been developed.

Different approaches are used. In Durban, counsellors encourage clients not to receive results the same day as their pre-test counselling. This is because the programme wants to allow women the time to internalise the education and pre-test counselling they have received. If they agree to a test, it will often take place on a subsequent visit. HIV counselling and testing services in some facilities are conducted in a separate place from where antenatal care is provided.

## **Eastern Cape**

Rietvlei Hospital's poor physical infrastructure and physical inaccessibility poses a major challenge. Most of the feeder clinics are in a poor state of repair and are small and cramped. Some clinics in the area are not even proper, formal structures.

Group counselling session is usually provided in the ANC waiting room, followed by individual counselling during the antenatal assessment. Lack of privacy makes individual counselling difficult.

## **Northern Cape**

At Galashewe Day Hospital (GDH), renovations were required to provide privacy. Ideas came from Baragwanath, and the DDG was very supportive and signed off on plans after 2 days. Construction was completed in 6 weeks. Renovations cost R200 000 and were drawn from the provincial capital improvement fund. Nurses pitched in to prepare the site quickly. They came in during off-hours to assemble furniture and furnish their examination rooms, and there is great pride among GDH staff.

Patients are offered MTCT testing at the first visit. Individual education and counselling is by a trained nurse or lay health worker. Doctors come to GDH and see every patient at their booking visit. The visit with the doctor precedes HIV test results. A social worker plans to start support groups at GDH.

Clinics mark patient held cards with a code/stamp to indicate the need for follow-up care. The hospital uses a numeric code to indicate charts of HIV+ women.

## **North West**

Lehurutshe has inadequate space. In mobile clinics, VCT is done in cars. Of 19 primary health centres, only 5 have sufficient space, 14 do not have space.

Poor uptake of VCT denotes the need for a re-look at the marketing of the programme and the way HIV testing is offered and encouraged.

**Table D: Lay Counsellors**

Province	Number and availability	Employment and training	Remuneration
Gauteng	3 PMTCT counsellors per site (for hospital and clinics). Some sites also have VCT counsellors.	Lay counsellors employed by DoH. There are also local NGOs who employ counsellors and the province has a pro-active strategy to work more closely with NGOs in the HIV/AIDS field. Province uses NGOs to help with training of lay counsellors.	Payment differs between VCT, HBC and MTCT. PMTCT counsellors are paid R500 per month. Four counsellors have resigned because of poor remuneration.
Western Cape	8 at Gugulethu 6 at Paarl MOU. Many other HIV/AIDS lay workers operating on other aspects of HIV/AIDS.	Gugulethu – lay counsellors are selected by a committee of community members, PMTCT co-ordinators and clinic staff. ATICC has been used to help with training. Paarl – the recruitment, management and supervision of lay counsellors is done by a local NGO that works in very close collaboration with the DoH staff.	Province pays for all lay counsellors with money transferred to NGOs. Currently, counsellors are paid R2500 per month.
Northern Province	None at present. 20 lay counsellors have been identified for training in Mankweng.	Plan is to employ lay counsellors through PPASA.	PPASA and DoH intend to pay counsellors R1500 per month.
Mpumalanga	Shongwe - 11 counsellors have been trained but have not started work yet. Embalenthle - 2 are working without pay. Evander - no lay counsellors at present.	Funds for counsellors, derived from national government conditional grant, will be channelled through the HIV/AIDS department. Counsellors trained in two stages – initially in VCT, then top-up training in MTCT.	Salary has not yet been determined. Counsellors were asked to sign a document indicating their willingness to work, at present, without pay. Appears unlikely that province will contribute top-up money in excess of funds supplied by national government.
Free State	Virginia - 12 lay counsellors at clinics. Frankfort - 14 lay counsellors at clinics	Payment and management of lay counsellors organised through a DoH contract with NPPHCN. Clinic steering committees recruited and selected lay counsellors.	Payment is a stipend of R500 per month (considered to be inadequate; there are fears of drop out).



KwaZulu-Natal	30 counsellors in total for both sites (21 in Pietermaritzburg and 9 in Durban)	Counsellors are employed as casual workers by the DoH. Initially counsellors in Pietermaritzburg employed by an NGO, but when the NGO ran out of funds, the DoH took them over. Some lay counsellor training has been conducted by ATICC.	Counsellors remunerated at rate of R2 800 month. The Provincial CCLLO manages the counsellors.
Eastern Cape	50 in the Frere Hospital site and 94 in the Mdantsane site 72 in the Rietvlei site	Counsellors are currently voluntary, managed and supervised by local site managers, with assistance from the provincial DoH.	Presently voluntary. Negotiations ongoing with NGOs regarding payment. No full-time paid counsellors at present.
Northern Cape	3 lay PMTCT counsellors in the Galashewe Day Hospital and 3 lay PMTCT counsellors in the De Aar site.	Provincial DoH is currently managing payment of lay counsellors. Efforts are being made to forge a relationship with a local NGO. Training has been provided with the assistance of non-governmental agencies. A provincial HIV/AIDS worker has been conducting training of lay counsellors.	Pay is set according to the national recommendation of R500 per month. Counsellors feel this is too low and are currently filing a grievance with the labour board. Provincial managers would like to raise the stipend to push salary to R800 (according to DDG) or R1500 (according to DD MCWH).
North West	In Rustenberg, nurses are doing the bulk of counselling. In Zeerust 42 lay counsellors were trained for VCT, and some have now had top-up training on MTCT.	Provincial DoH is currently managing payment of lay counsellors. In 2001, Lifeline was given a R1 million grant to conduct VCT training.	At present there is no pay for lay home based carers, DOTS supervisors or lay VCT and PMTCT counsellors. They are all volunteers, and are not even compensated for meals or travel. Province is working on a scheme to pay counsellors and to link them to NGOs who will employ them through grants from government.

## **Table E: Marketing and Community Preparation**

### **Gauteng**

Currently information posters are displayed at sites. Pamphlets are being designed and are adapted from those used by the Perinatal HIV Research Unit at Baragwanath Hospital.

### **Western Cape**

Little social marketing strategy was needed to promote PMTCT given the widespread support for the programme in the communities. Community action initiated by TAC provided stimulus for Guguletu's MTCT programme.

In Paarl, community meetings and radio programs were used to introduce PMTCT.

### **Northern Province**

HIV is viewed as stigmatising but the PMTCT service is a magnet attracting patients to sites for nevirapine therapy.

Staff had initial meetings with community-based organisations, headmen, local council, police and schools in Siloam. The community is very supportive. Radio announcements were put on hold in Mankweng until formal opening.

### **Mpumalanga**

Community leaders have promoted PMTCT. There is a reluctance to use radio or other promotional efforts that might entice people to come to MTCT sites from outside the catchment area. There is a concern that too much publicity will bring in too many patients. Health promotion staff are currently engaged in surveys and focus group discussions in both Evander and Shongwe to assess community attitudes to PMTCT.

### **Free State**

Formal launch and celebration of PMTCT service has been accompanied by local radio talks, banners in front of clinics, information on electricity and water bills, and meetings with mayor, councillors, traditional healers and teachers.

### **KwaZulu-Natal**

Information available predominantly at antenatal clinics.

### **Eastern Cape**

Vigorous community mobilisation.

In Mdantsane area, the community was already sensitised by ABBA Trust programme. Use of local radio stations and newspapers, live radio telephone interviews with the Director: HIV/AIDS, locally developed posters on VCT and MTCT in clinics and shops, and meetings with key community people, hospital board members, church organisations. A float with banners carrying MTCT messages was organised for the programme's official launch.

Meetings with chiefs in the Rietvlei area. Noticeable increase in VCT uptake compared to urban sites.

### **Northern Cape**

Marketing has included a radio campaign through the DoH slot, church meetings and a road show in Kimberley. There appears to be good community support with no apparent resistance.

### **North West**

Community level PMTCT promotion was started in June with daily health talks delivered at antenatal, district and local authority clinics. Health talks were given by nurses at each site and included one hour of lecture and time for questions.

Radio promotion was started in Rustenberg.

## **Table E: Post-delivery Care**

### **Gauteng**

The role of PHC clinics needs to be strengthened and staff appropriately trained. Free formula is only available at the present moment from the site of delivery and not at PHC clinics, although there are plans to change this.

### **Western Cape**

Mothers receive two tins of formula prior to discharge.

In Paarl, mothers are asked to choose their desired clinic for follow-up. Sometimes mothers will select a clinic distant from their homes to maintain confidentiality. The PMTCT programme manager will sometimes even take a mother to the clinic to introduce her to the clinic staff. A detailed register for mother and child follow-up is kept at the clinics.

### **Northern Province**

Most deliveries are at hospital and not at clinics, resulting in difficulty in follow-up. Strategy being developed to improve communication between clinics and hospitals.

Lack of transport is a problem in the rural areas.

### **Mpumalanga**

Clinics in Shongwe site provide service to both mothers and babies. Paediatric service is being organised at feeder clinics. Formula was initially sent to these clinics on a case-by-case basis. As feeder clinics become increasingly part of the PMTCT programme, formula and co-trimoxazole will be sent to them routinely.

## **Free State**

Nutritionist employed to deal with infant feeding issues. Networking with welfare sector around poverty alleviation for mothers.

## **KwaZulu-Natal**

Problems experienced with follow-up as almost all deliveries occur in hospitals which have poor communications network with PHC clinics. Method of tracking women is not used consistently making it difficult for staff to identify babies on the programme.

## **Eastern Cape**

Follow-up of children is expected to be poor because of poor and difficult access to PHC clinics and the very poor standard of PHC. Low immunization coverage rates indicate the lack of an acceptable standard of basic PHC.

## **Northern Cape**

Follow-up rates are poor, as women don't return for visits. The PMTCT code on the infant's card may be a reason for the poor follow-up.

## **North West**

Formula is made available at discharge after delivery, after which it is distributed at the clinics. Paediatric care at clinic is provided by doctors.

## **Appendix 3: Site reports**

### **Shongwe Hospital, Mpumalanga, January 2002**

#### **Site organisation and management**

Support for the programme from the provincial level is poor. This is largely due to the interpersonal conflicts between staff at the provincial office around roles and responsibilities. A Director of HIV/AIDS has been appointed recently and it is hoped that this situation will be resolved.

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 counselling, collecting data and transporting formula to the feeder clinics.

#### **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 the Provincial Office in September 2001. No training has been done since this time.

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 or 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.

The number of women attending the antenatal clinic since the start of the programme has remained fairly constant at approximately 100 per month. The VCT uptake rate (average per month) is 19%. This has declined considerably since the start of the programme, from 33% in September to 9% in December. This may be 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, 47% 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.

#### **Delivery services**

All women on the PMTCT programme must deliver at Shongwe Hospital, as the feeder clinics do not keep supplies of nevirapine. There is no obstetrician at Shongwe Hospital.

Since September there have been 19 babies born to women on the programme. 89% of these babies received nevirapine.

### **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 breastfeed 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 (there are presently only 2 babies receiving formula at a feeder clinic) 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.

### **Feeder Clinics**

Kamhlushwa Clinic 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. Very few deliveries take place at this facility, as it is not open 24 hours/day.

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.

The following areas require attention:

- Absence of lay counsellors and shortage of staff in the antenatal clinic.
- Decline in VCT uptake rate since the start of the programme.
- Inadequate numbers of staff that have received training, especially in the maternity section of the hospital.
- 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.

- 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.

## **Pietermaritzburg PMTCT Sites, January 2002**

Three facilities were visited within the Pietermaritzburg PMTCT site. One rural hospital, one peri-urban hospital and one feeder clinic. General impressions from the three facilities are summarized below.

### **Management**

- Support for these sites from the provincial level is consistent and responsive to the needs of staff. The CCLO visits the sites 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 in each site who is one of the antenatal clinic sisters. This person assists with the co-ordination of data collection and supplies.
- In comparison with Mpumalanga, co-ordination and management of the PMTCT programme in this province appears to have become the responsibility of the lay counsellors. Nurses are minimally involved in counselling and monitoring of the programme.
- The presence of senior doctors has proven to be a valuable resource for the site in terms of technical support, training skills and leadership. This has added to the improved functioning of the facilities in this site.

### **Training**

- No training of doctors has occurred but they have reviewed the PMTCT protocol
- Training of nurses was conducted at Grey's Hospital. Inadequate numbers of nurses have been trained, especially in the labour wards. In the rural hospital, 4 out of 25 maternity staff have received training.
- Rotation of staff sometimes leaves units without any PMTCT trained staff.

### **Counselling**

- Each facility has full-time lay counsellors who are well paid and managed by the provincial office. They have all received training by ATTIC and regular follow up and support is provided by the provincial office. The HIV testing uptake rate for the Pietermaritzburg site is 70%.
- Space for counselling is a problem in all three facilities and this has resulted in long waiting times for patients.
- Women in all three facilities visited are given their results the same day as

testing. This indicates a lack of choice on the part of women regarding the appropriate time for them to receive results.

### **Ante-natal care**

- All women who test positive are seen by one of the doctors and are given the relevant prophylactic drugs and multivitamins.
- The cumulative HIV positive rate amongst pregnant women in this site is 34%. This is slightly below the provincial rate of 36.2%.

### **Obstetric practices**

- Nurses in these facilities reported being aware of revised obstetric practices relating to HIV positive women.
- Infants appear to be given nevirapine syrup within the appropriate time period following delivery. In the rural hospital, 100% of infants born to HIV positive women received nevirapine.
- Very few deliveries occur at the feeder clinics as they are not open 24 hours/day. This has led to difficulties in the tracking of clients between the antenatal clinics and labour wards in the hospitals and may have led to missed opportunities for nevirapine administration.

### **Infant feeding practices**

- In the group counselling session information is given about infant feeding options.
- Since the start of the programme 65% of women in this site have chosen exclusive formula feeding and 35% have chosen exclusive breastfeeding.
- In the rural hospital, 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.

### **Monitoring**

- Monitoring of clients (a stamp with 'MTCT' in the folder) appears to be a deterrent to accessing care, measured by compliance with follow-up visits. The nurses report that women who test positive deface their antenatal card in order to hide the stamp.



- Figures are not being kept for the number of first time bookings. The number pre-test counselled has been used as the denominator for calculating the VCT uptake rate for this province.

## **Supplies**

- There are generally no problems with the delivery of supplies to these sites.
- Supplies of multivitamins for mother and vitamin A for infants have not reached any of the sites in this province. There appears to be a problem with the coding of these items at the pharmacy level.
- 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.

## Appendix 4: Additional Research Agenda

Research Topic	Description of Research	Anticipated research outputs	Status
Implementation of PMTCT Services	In-depth descriptive studies of the implementation of PMTCT services in at least one site per province. Will include a variation of well resourced and poorly resourced sites.	Further lessons learnt about implementation, organisation and management of PMTCT services at the site level.	Several sites have already been visited by researchers (WC, Mpumalanga, KZN, Gauteng and FS). Remaining provinces will be covered. Structured reports allowing site comparisons will be designed to allow an easy generation of the lessons learnt, and a description of the implementation and operational challenges that exist.
Changes in infant feeding practices	Repeat cross-sectional survey of case and control sites to determine the effect of the PMTCT programme on infant feeding practices. Will be based on a 10 minute dietary survey of 1800 mothers attending immunization clinics.	Will describe the trend in infant feeding practices over the next 18 months, and provided it will be possible to maintain non-PMTCT control sites, it will suggest what impact the PMTCT programme has had on infant feeding practices.	UNICEF have helped to fund this through HST. A questionnaire and research protocol has been developed. A request for survey organisations to submit applications to conduct the survey was put out in early January 2002.
Qualitative research on infant feeding practices	Narrative research methods, together with traditional focus group discussions and a questionnaire survey in three provinces (NP, NW and KZN).	Will describe the determinants of infant feeding choices and infant feeding practices, and help explain why there may be differences between choices and practices. Will be critical for informing appropriate infant feeding counselling and IEC strategies.	Research has already commenced in the NP. Further research already planned for KZN and NW. Being conducted by the Human Sciences research Council, under guidance of Health Systems Trust, UNICEF and DoH.
Follow-up of mother-child pairs post delivery	Cohort follow-up of PMTCT mother-child pairs and control mother-child pairs to document infant feeding practices, health indicators, vertical transmission, growth patterns and health seeking patterns.	This will give us detailed information about what actually happens to mothers and children after delivery. An active cohort study design will help ensure that mother-child pairs are not lost to follow-up.	Research protocol for one site in the Eastern Cape has already been developed. Fieldworkers and field coordinators have been identified and recruited. A rural site in the WC will also be incorporated, as well as an urban site in Durban.

Costing the PMTCT programme	In-depth costing of direct (e.g. formula, testing kits, lay counsellors and medicines) and indirect costs (e.g. nurse time, opportunity costs) of the programme. Four sites being selected (high HIV prevalence-good infrastructure; high HIV prevalence-poor infrastructure; low HIV prevalence-good infrastructure).	Proper assessment of the costs of the programme.	Meeting of health economics experts held in December to discuss and formulate key research questions. Protocol has been developed and research will be commissioned by HST. Researchers will consist of ABT Consultants and HEARD (University of Natal).
Quality of antenatal counselling moment	Structured participant observation of counselling in the antenatal period.	Structured and in-depth understanding of the counselling issues.	Protocol and proposal developed. Research being planned for implementation in one site at present.
Rapid evaluation of obstetric care in a sample of PMTCT sites	Structured evaluation of the obstetric practices relating to HIV positive women.	More detailed understanding of the implementation of the revised obstetric guidelines.	To be designed.
Effect of PMTCT programme on vertical transmission	Periodic cross-sectional surveys of general population in case-control sites, or cohort studies or modelling studies.	Assess the impact of the programme on averting HIV transmission.	A group of statisticians, epidemiologists and health economists are being convened by the Medical research Council to advise on the best way forward. Meeting scheduled for mid-February.

## Appendix 5: Nevirapine

No significant adverse effects have been recognized in either mothers or babies taking single-dose nevirapine as part of a PMTCT regimen.

Severe liver and skin complications have been noted in patients taking nevirapine as part of a prolonged, combination treatment programme. These complications have not been noted in mothers or babies taking nevirapine as part of a single-dose PMTCT regimen.

Nevirapine resistance has been noted in women taking nevirapine as part of a PMTCT regimen. The clinical significance of this observation is unclear.

In the HIVNET 012 study done in Uganda and the PACTG 316 study done in the United States, mothers received a single dose of nevirapine during labour. In the HIVNET 012 study, 23% of mothers had evidence of nevirapine resistance 6-weeks after receiving the drug. These resistant mutations were no longer present after 13-18 months in 4 mothers studied. In the PACTG 316 study, 13% of mothers treated with nevirapine in labour were found to have nevirapine-resistant virus. In the SAINT Trial done in South Africa, mothers in the nevirapine treatment group received a dose of nevirapine during labour and a second dose after delivery. Data on resistance is not available.

Many types of virus exist in all people with HIV infection. Wild-type virus is the most common. It is the strongest virus, reproducing better than other types. Nevirapine-resistant virus is present in small numbers, even in people who have never been treated with nevirapine. When someone with predominant wild-type virus is treated with nevirapine, wild-type virus is suppressed and nevirapine-resistant virus is able to grow. With single-dose nevirapine, the impact of the nevirapine is relatively short. Because nevirapine-resistant virus is not as strong (or capable of reproducing) as wild-type virus, over time wild-type virus will again become the most common type of virus in circulation. A mother should be able to use nevirapine for future pregnancy PMTCT treatment once wild-type virus becomes the most common virus in circulation. To date, there are no reports from clinical studies testing this hypothesis.

The present data on resistance is incomplete. More research is required on the effect of resistance on:

- The clinical outcome of mothers and their babies
- The ability for NVP to be used on HIV positive women who may have further pregnancies in the future
- The efficacy of any HEART (highly effective antiretroviral therapy) of which NVP is one of the drugs.

However, the incompleteness of the data at this point, does not construe a reason for delaying the expansion of the national PMTCT programme.