LINKAGES BETWEEN PMTCT, ART AND WELLNESS SERVICES:
An Assessment of Uptake of ART and Wellness Services by Women Attending PMTCT at selected ANC Clinics in Soweto.

A Research Report Submitted to the Faculty of Health Sciences, University of the Witwatersrand, Johannesburg, in partial fulfilment of the requirements for the Degree of Master of Public Health.

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Declaration

I, Annette Mulenga Ching’andu declare that this research report is my own work. It is being submitted in partial fulfilment for the degree of Masters of Public Health in the field of Maternal and Child Health, at the University of the Witwatersrand, Johannesburg. It has not been submitted before for any degree or examination at this or any other University.

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24 day of August, 2010
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“I can do all things through Christ who strengthens me.” Philippians 4:13

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To my husband, I say natotela sana mukwayi, for being patient with me, putting up with my stressing and for your ceaseless encouragement.
Table of Contents

Declaration.............................................................................................................. i
Acknowledgements............................................................................................... ii
Table of Contents.................................................................................................. iii
Acronyms............................................................................................................... v
Definition of Key Terms........................................................................................... vi
Chapter 1: Background and Introduction .............................................................. 5
  1.1 Introduction ...................................................................................................... 5
    1.1.1 Background information ......................................................................... 5
    1.1.2 PMTCT Services Provided by PHRU ...................................................... 7
    1.1.3 Statement of the Problem ...................................................................... 8
    1.1.4 Justification of the Study .................................................................... 9
    1.1.5 Literature Review .............................................................................. 9
  1.2 Study Objectives .......................................................................................... 13
    Study Aim: .................................................................................................. 13
    Specific Objectives: .................................................................................. 13
Chapter 2: Methodology ...................................................................................... 15
  2.1 Methodology .............................................................................................. 15
    2.1.1 Study Design ...................................................................................... 15
    2.1.2 Study Population .............................................................................. 15
    2.1.3 Sampling Frame .............................................................................. 15
    2.1.4 Study Sampling .............................................................................. 17
    2.1.5 Data collection ................................................................................. 18
    2.1.6 Quantitative Data ............................................................................ 19
    2.1.7 Qualitative Data ............................................................................ 19
    2.1.8 Measurement .................................................................................. 20
  2.2 Pilot Study .................................................................................................. 20
  2.3 Limitations of the Study ............................................................................ 21
  2.4 Data Processing Methods and Data Analysis .............................................. 22
  2.5 Ethical Considerations .............................................................................. 22
Chapter 3: Utilisation of Services ......................................................................... 24
  3.1 Presentation of Results ............................................................................. 24
    3.1.1 Utilisation of PMTCT Services .......................................................... 24
    3.1.2 Referral of Pregnant Women from PMTCT to ART and Wellness ....... 29
    3.1.3 Uptake of ART Services by Pregnant Women .................................. 31
  3.2 Standard Referral Procedures ................................................................... 33
  3.3 Health Worker Perceptions on PMTCT Service ........................................ 35
    3.3.1 Why Services were utilised .............................................................. 35
    3.3.2 Possible barriers to service utilisation ............................................. 36
    3.3.3 Suggested measures to improve PMTCT service utilisation .......... 37
    3.3.4 Improvements Suggested for ART Services .................................... 39
    3.3.5 Suggestions for Wellness Services .................................................. 40
    3.3.6 Suggestions to Improve Referral Systems ...................................... 41
Chapter 4: Discussion of Results ........................................................................ 43
  4.1 Discussion .................................................................................................. 43
4.1.1. PMTCT Linkages to ART Services .......................................................... 43
4.1.2. PMTCT Linkages to Wellness ............................................................ 50
4.1.3. Referral Systems and Data Management Practices .......................... 52
4.1.4. Potential Implications Resulting from Poor Linkages and Service Utilisation 53

Chapter 5: Conclusions and Recommendations .............................................. 56
5.1. Conclusion ................................................................................................. 56
5.2. Recommendations .................................................................................. 58
   Short Term Improvements .......................................................................... 58
   Long Term Improvements ......................................................................... 59
   References .................................................................................................. 60

Annexures ....................................................................................................... 65

Annexure 1: Record Review Tool for PMTCT Clinics ........................................ 65
Annexure 2: Record Review Tool for Wellness and ART Clinics .......................... 67
Annexure 3: Participant Information Sheet ...................................................... 68
Annexure 4: Participant Consent Form ............................................................. 69
Annexure 5: Key Informant Interview Guide .................................................... 70
Annexure 6: Referral Systems Tool for Key Informants .................................... 71
Annexure 7: Ethical Clearance - Witwatersrand Committee for Research on Human Subjects (Medical) ................................................................. 73
Annexure 8: Ethical Clearance - Gauteng Province, Department of Health - Directorate for Policy Planning and Research .......................................................... 74
Annexure 9: Authorisation to Access Pimville Clinic ........................................ 75
Annexure 10: Permission to Access Lillian Ngoyi Clinic ................................... 76
Annexure 11: Services to which referred by level of CD4 Count at Government Run PMTCT Service Points ................................................................. 77

Figure 1: PMTCT Cascade ............................................................................... 25
Figure 2: PMTCT Linkages to ART - Retention of ART Eligible Pregnant Women in the PMTCT programme ................................................................. 28
Figure 3: Depiction of Patient Flow and Linkages between PMTCT, ART and Wellness services ................................................................. 30

Table 1: Clinics by Type of Services Rendered ............................................... 16
Table 2: Cadres of Key Informants Interviewed .............................................. 17
Table 3: PMTCT Linkages to ART and Wellness ............................................ 26
Table 4: PMTCT to ART Linkages by type of clinic ..................................... 27
Table 5: The uptake of ART among HIV positive pregnant women of first ANC visit from January to March 2008 at selected clinics in SOWETO, Gauteng ................. 32
Table 6: Proportion of Women who Accessed ART by Type of Facility ........... 33
Table 7: Status of Referral to ART in PMTCT Register by CD4 Count ............ 34
### Acronyms

<table>
<thead>
<tr>
<th>Acronym</th>
<th>Description</th>
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<tr>
<td>AIDS</td>
<td>Acquired Immune Deficiency Syndrome</td>
</tr>
<tr>
<td>AFASS</td>
<td>Acceptable, Feasible, Affordable, Sustainable and Safe</td>
</tr>
<tr>
<td>ANC</td>
<td>Antenatal Care</td>
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<tr>
<td>ART</td>
<td>Antiretroviral Therapy</td>
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<tr>
<td>CCMT</td>
<td>Comprehensive Care, Management and Treatment</td>
</tr>
<tr>
<td>EBF</td>
<td>Exclusive Breast Feeding</td>
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<tr>
<td>EFF</td>
<td>Exclusive Formula Feeding</td>
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<tr>
<td>HIV</td>
<td>Human Immunodeficiency Virus</td>
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<tr>
<td>KII</td>
<td>Key Informant Interview</td>
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<tr>
<td>MTCT</td>
<td>Mother to Child Transmission</td>
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<tr>
<td>NSP</td>
<td>National Strategic Plan</td>
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<tr>
<td>NVP</td>
<td>Nevirapine</td>
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<tr>
<td>PHC</td>
<td>Primary Health Care</td>
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<tr>
<td>PHRU</td>
<td>Perinatal HIV Research Unit</td>
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<tr>
<td>PMTCT</td>
<td>Prevention of Mother to Child Transmission of HIV</td>
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<tr>
<td>STI</td>
<td>Sexually Transmitted Infection</td>
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<tr>
<td>VCT</td>
<td>Voluntary Counselling and Testing</td>
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Definition of Key Terms

**ART:** General term used to refer to Antiretroviral Therapy which is medication given to HIV positive patients whose disease progression has reached a stage where medication is required. Initiation of treatment is prompted by either CD4 cell count or by clinical staging using guidelines provided by the World Health Organisation.

**CCMT:** Comprehensive Care Management and Treatment of HIV is the term used to refer to the health services which aim to prevent HIV infection and guide the continuum of care given to those already infected with HIV. Health services included in CCMT are voluntary counselling and HIV testing, medical care and treatment, psychosocial support; nutritional assistance; social support; and home- and community-based care services.

**CD4:** Measure of CD4 T cells per cubic millimetre of blood. A count of 200 cells/mm$^3$ or less presents significant risk of opportunistic infections and is commonly used as a proxy indication of when to begin ART.

**Wellness:** Services offered to HIV positive individuals who have a CD4 count above the ART initiation threshold. These services include CD4 count monitoring, psychosocial support (which can be delivered through support groups), nutrition counselling, HIV & AIDS education and treatment of opportunistic infections. They form part of the Comprehensive, Care, Management and Treatment package for HIV.

**Referral service:** A service recommended to a patient which is not offered at that particular service point. Typically accompanied by a referral letter or form to present at the service point to which they are being referred.

**Out referral of patients:** Patients referred from a given service to another. This can be an onsite referral where the service to which the patient is referred is on the same premises as the clinic doing the referring or it can be a referral to a clinic off the premises.
Executive Summary

Due to the high prevalence of HIV in South Africa, all pregnant women are offered an HIV test as part of the package of services offered during antenatal care (ANC). All women who present to an ANC clinic for the first time for that given pregnancy are given group talks about HIV and the availability of services to protect their children from HIV through Prevention of Mother to Child Transmission (PMTCT) services. Following these group discussions, all the women are then counselled on a one on one basis and are offered an HIV test. Women who decide not to take the test can opt out of testing at this stage, those who do go ahead and test are also offered post test counselling after which their test result is given to them. All HIV tests are conducted using rapid HIV test kits which make results known within 15 minutes, the results are given to the women on the same day of testing.

Women whose CD4 count is below the antiretroviral treatment (ART) initiation threshold are fast tracked onto ART, those whose CD4 is above the threshold should then be referred to other services which can help them maintain their health. These services are part of the Comprehensive Care, Management and Treatment (CCMT) approach. They include: CD4 count monitoring; treatment for opportunistic infections; social workers, and support groups for psychosocial support. For purposes of this study, these services are collectively referred to as Wellness services. Thus PMTCT should serve as a gateway to either ART or Wellness services.

This study therefore sought to describe the linkages between PMTCT, ART and Wellness by reviewing service utilisation levels and referral systems at sampled health facilities in Soweto.

Data for this study were collected via a cross sectional record review of PMTCT registers and an ART initiation register at sampled health facilities. PMTCT registers were reviewed for the period January to March 2008 to determine what service had been given to pregnant women who accessed PMTCT services for the first time during that period.

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1 In his speech on World AIDS Day (December 1\textsuperscript{st} 2009) President Jacob Zuma announced that CD4 count threshold for treatment initiation will be raised from 200 to 350 as of April 2010.
and which follow on services they had been referred to. ART registers were reviewed for the period January to August 2008 to determine which of the pregnant women who had been referred to ART from the PMTCT service points at the sampled clinics accessed the service. Key informant interviews were also conducted with staff at PMTCT, ANC, ART and voluntary counselling and testing (VCT) service points at the sampled facilities. Descriptive statistics were run using SPSS version 17.0, comparisons were done using OpenEpi and key informant interview data were thematically analysed using Atlas TI version 5.2.0.

Records at the PMTCT clinics showed that of the 1350 women who attended ANC clinics at the sampled facilities between January and March 2008, all but one agreed to test for HIV. Twenty-one percent (388) tested positive for HIV. Of these 388 HIV positive women, 20% (77 women) had CD4 counts below 200 and were therefore eligible for initiation of ART. Review of records at the ART clinic showed that only 23% (n = 18, N = 77) of all ART eligible women had accessed the service. Review of the PMTCT register also showed that a significant proportion, 37% (n = 144, N =388), of women who tested HIV positive did not return to the clinics for their CD4 count results. These women therefore missed opportunities to access other follow on services to which they could have been referred and possibly ART as 31% (24 women) of these women were also eligible for ART.

Review of records at Wellness services was not possible as no indications were made in the PMTCT registers of follow on services other than ART to which HIV positive women were referred.

Thus the greater majority of women who were eligible for ART (77% of the 77 eligible women) did not access ART which they required to help them maintain their physical wellbeing. These women missed the opportunity to access holistic health care services, it is not known if they accessed ART services at other health facilities. Without the required antiretroviral therapy, it is highly likely that their women’s health status deteriorated such that they faced higher chances of morbidity and ultimately mortality.
The review of records at both PMTCT and ART service points showed poor data management systems as referrals from PMTCT to ART were not always documented against client names in the PMTCT registers. Communication systems between the service points were also found to be poorly structured as there were no systematic feedback mechanisms on clients referred and seen. Linkages to Wellness services were even more poorly structured as no referrals to services which fall under Wellness were documented in the PMTCT registers.

Key informants interviewed suggested several possible reasons why PMTCT and ART services were not being fully utilised as was evidenced by the of 37% of women who were not retained in care as they did not return for CD4 results and the low ART utilisation rate of 23%. Possible reasons suggestions were: ignorance of the need to access ANC services, preference for traditional medicine, fear of stigmatisation within their communities and poor staff attitudes towards patients.

The key informants also suggested measures they thought could improve utilisation, these include hire of more staff, improved staff wages, improved interdepartmental communication and a bottom up approach to service improvement. A suggestion was also made to include PMTCT messaging in general HIV/AIDS information education communication material so as to raise awareness of the availability of PMTCT interventions.

Although there were linkages between PMTCT, ART and Wellness services, these linkages were poorly developed and drop out from services was high. Efforts to follow up on patients or to retain them in care were not well developed as the data management systems employed by the service points were not consistently used nor did they facilitate patient monitoring and follow-up. Furthermore, the structural and managerial separation of the ART service point from PMTCT as well as the lack of standard protocols for referral to Wellness introduced barriers to service utilisation for women who required these services.
The observed low service utilisation levels, and weak linkages between PMTCT, ART and Wellness can be therefore have been caused by patient related factors such as fear of stigmatisation and cost of accessing care; health worker factors such as poor staff attitudes, high work load and low morale; poor quality of services to clients; and the lack of integration of health services.

Improvements in linkages between service points as well as in patient monitoring, referral and follow up systems are required if services available to help women access holistic care and support are to be fully utilised. Further detailed research into patient related factors which may influence HIV positive pregnant women’ health seeking behaviour is also required.
Chapter 1: Background and Introduction

1.1 Introduction

1.1.1. Background information

South Africa is faced with one of the largest HIV pandemics on the African continent, there are over 5.5 million people currently living with HIV in the country with new infections estimated to be about 1500 per day. The distribution of HIV is disproportionately skewed towards women as 55% of those infected are female, most of who are in the reproductive age group of 15-49 years. In the 15-24 year age group, HIV prevalence is up to four times higher amongst females than males of the same ages.

Nationally, HIV prevalence amongst women attending public antenatal care (ANC) clinics in 2006 was 29.1%, a slight reduction from 30.2% in 2005. The 2006 UNAIDS report puts this into perspective by stating that 1 in 3 pregnant women attending a public ANC clinic in 2005 was HIV positive. Without any intervention, children born to these mothers face a 20-45% chance of mother to child transmission of HIV (MTCT), which can occur in-utero (during pregnancy), intra-partum (at birth) or postpartum (after birth) through breast feeding.

Recognition of this risk led to the formulation of interventions to prevent mother to child transmission of HIV (PMTCT). In resource rich countries where PMTCT entails antiretroviral prophylaxis, elective caesarean section and complete avoidance of breast feeding, MTCT of HIV has been reduced to below 2%. South Africa’s efforts to curb mother to child transmission saw the introduction of the first PMTCT interventions to ANC clinics in 2001. This entailed administering nevirapine (NVP) to the mother at onset of labour, and to the infant after delivery followed by exclusive breast feeding or exclusive formula feeding. This approach reduced MTCT to as low as 5%.

In February of 2008, the Department of Health introduced a new PMTCT policy which expanded the medication given to both the mother and child from mono therapy with
nevirapine (NVP) to dual therapy (NVP at onset on labour and Zidovudine-AZT, from, 28 weeks gestation). In April 2010, the PMTCT policy was updated such that the treatment initiation threshold was raised to a CD4 count of 350 or below, women with CD4 counts above 350 received AZT from 14 weeks gestation. This is followed by Single dose NVP at onset of labour, 3 hourly AZT during labour and single dose Tenofovir (TDF) + Emtracitabine (FTC) after delivery. The infant receives a daily weight adjusted does of NVP from the time of birth until it is 6 weeks. These measures together with appropriate obstetric and infant feeding practices should further reduce MTCT of HIV.

Thus with the adoption of the new PMTCT policy, more children will be protected from MTCT, however, the health and wellbeing of pregnant women still needs to be given due attention. HIV positive pregnant women whose CD4 count is at 200 or less or when their clinical presentation places them at stage 3 or 4 of HIV disease progression still require initiation of ART. Without treatment, their health can deteriorate rapidly to the extent that their children are orphaned and vulnerable at a young age.

Integration of PMTCT into ANC care supported by access to antiretroviral treatment (ART), nutrition counselling, peer counselling, and social grants presents an opportunity to avert some of these deaths. The 2001 and 2008 PMTCT guidelines and the National Strategic Plan of HIV/AIDS and STI for 2007-2011 stipulate an approach where PMTCT interventions also serve as opportunities for HIV positive pregnant women to access follow on services they may be in need of.

This research investigated the uptake of ART and other services such as CD4 count monitoring, psychosocial support, nutrition counselling, HIV & AIDS education and treatment of opportunistic infections, all of which fall under what has for purposes of this study been called Wellness services by women referred there from ANC clinics where

\[\text{Data for this study were collected when the threshold CD4 count was at 200, thus all reference to CD4 counts will be at 200}\]
the Perinatal HIV Research Unit (PHRU) provides PMTCT services. This study was conducted at primary heath care facilities in Soweto.

1.1.2. **PMTCT Services Provided by PHRU**

In South Africa PMTCT is primarily offered through ANC clinics. Pregnant women are offered VCT at their initial ANC clinic visit for a given pregnancy. Those testing positive are given NVP to be taken at onset of labour, a weight-adjusted dose is given to the baby at birth. Those testing positive also have CD4 counts done, the result is used to guide referrals to ART clinics.

The women are informed through a group discussion of the standard HIV testing procedure. The group talks include general education on HIV and the benefits of knowing their status both for their own health and for that of their unborn children. After the general talk, all women then receive individual, private, pre and post test counselling. Women who choose not to test for HIV opt out during the individual counselling. The result of the HIV test is given to the women as part of the post test counselling.

PHRU supports provision of PMTCT services at thirteen ANC clinics in Soweto by placing a full time midwife and a team of lay counsellors to assist staff at the health facilities. This ensures dedicated leadership and a smaller counsellor to patient ratio, all PHRU staff are trained annually on various aspects of PMTCT including counselling, infant feeding, prevention of opportunistic infections, disclosure and partner violence. PHRU also provides infant formula for HIV positive mothers who choose to exclusively formula feed (EFF).

Twelve of the thirteen clinics are located at primary health care (PHC) facilities and one at Chris Hani Baragwaneth Hospital. All thirteen clinics also offer Wellness services, and five of the thirteen clinics offer ART services.

Referral of HIV positive women to ART is primarily based on CD4 counts:

- CD4 < 200: referred to an ART clinic for immediate commencement of treatment. If ART clinic is located on the same premises, a member of the PHRU team escorts the pregnant woman to the ART clinic and hands over her referral documentation to the
person registering patients. If no onsite ART clinic women are out referred to the nearest ART clinic, these women are given a referral form to take with them.

- > 200 CD4 < 350: referral to a Wellness clinic and monthly support group, repeat CD4s every three months\(^8\).
- CD4 > 350: referral to Wellness and support groups with repeat CD4 counts every six months\(^*\)

All the women who test HIV positive at the PHRU PMTCT sites are also given NVP and instructed when to take it, they have blood samples sent to labs for CD4 counts to be done. These women were also referred to TB screening points within the clinics where they accessed PMTCT.

HIV positive women are instructed to return to the ANC clinic on a given date (usually after 2 weeks) for their CD4 count result. When the women return to the PMTCT clinics for their CD4 count result, their names and CD4 results are captured in a CD4 results book.\(^††\) If the CD4 count is 200 or less, the women are then referred to the ART clinic at the appropriate ART facility. A note that the women have been referred to ART is made against their names in the PMTCT register. The specific ART clinic a women can be referred to is determined by proximity of the women’s home to the ART facility. Women typically access ANC at clinics close to where they live, thus the ART clinics to which they would be referred are likely to be close to where they accessed ANC.

\[1.1.3. \quad \text{Statement of the Problem}\]

Anecdotal evidence suggests that a significant proportion of women who are referred from PMTCT clinics to ART and Wellness may not be accessing the services to which they are referred. Thus the question was asked “To what extent do women referred from PMTCT clinics to ART and Wellness clinics take up the service to which they are referred?”

\(^8\) Government run PMTCT facilities use a CD4 range of 200 < CD4 > 500 for six monthly repeat CD4 monitoring.

\(^*\) It is recommended that repeat CD4 counts carried out every six months in government run PMTCT facilities.

\(^††\) The CD4 results books were not used as data sources for this study as only women who went back for their CD4 results were captured in the book.
1.1.4. Justification of the Study

PHRU provides PMTCT services based on national PMTCT policy guidelines. According to this policy, women who test HIV positive should when eligible be referred to ART treatment clinic and should be given information on and be referred to support services and positive living support groups. In keeping with these guidelines, HIV positive women are referred to ART or Wellness services depending on their CD4 count and clinical presentation. However, it is not known what proportion of these women access the services to which they are referred, more so if the service to which they are referred is not available on the same premises as the ANC clinic. Review of the literature did not yield information on uptake of these services by pregnant women. Thus there is need to review the linkages between these services and to determine the levels to which services are taken up, and in so doing suggest measures to improve linkages between these services.

1.1.5. Literature Review

Every year an estimated 3.28 million HIV positive women give birth and over 700 000 children become infected with HIV, most in developing countries. Projections made by Dorrington and colleagues (2006) estimate that in South Africa, in 2005, 38 000 children were infected at birth and 26 000 more were later infected through breast feeding. Application of PMTCT interventions such as ART, elective caesarean section and either complete avoidance of breastfeeding or exclusive breastfeeding for six months followed by abrupt weaning should help reduce intra and post partum MTCT levels. The success of these interventions is influenced by a multitude of factors including maternal stage of disease, viral load, presence of STIs, obstetric practices, use of ART and infant feeding practices. Application of these measures in different countries has reduced MTCT from highs of 20-45% to ranges of between 2% - 15% depending on specific interventions adopted. In South Africa, MTCT transmission rates were reduced to below 5% using NVP to both the mother and child, elective caesarean section when possible and either avoidance of breastfeeding or exclusive breast feeding.

In February 2008, South Africa adopted a new PMTCT policy which prescribes the use of dual therapy for both the mother and child. The 2008 policy entails the use of AZT
(Zidovudine) from 28 weeks gestation in combination with NVP at the onset of labour. This policy was further updated in April 2010 stipulating that women begin AZT at 14 weeks. Post delivery, the infant is given a single dose of NVP plus AZT for seven days (if the mother commenced AZT at 28 weeks) or AZT for 28 days to the infant (if the mother had less than 4 weeks of AZT or ART or she only received NVP). The 2010 policy calls for infants to receive NVP for 6 weeks after birth. Like the 2008 policy, the updated 2010 policy calls for initiation of appropriate ART for women whose CD4 count reaches the prescribed threshold level; and for all HIV positive women to have access to micronutrient supplementation; management of opportunistic infections; and provision of ongoing psychosocial support. In addition, the policy gives direction on safe infant feeding options, either exclusive breast feeding or exclusive formula feeding depending on the social, economic and cultural conditions within which the mother lives. All these measures should help to further reduce MTCT.

Despite varying levels of success, PMTCT programmes are ensuring that fewer children become infected with HIV through MTCT, more attention should be paid to the effects of HIV on maternal health. HIV/AIDS is increasingly cited as a causal factor in maternal deaths in South Africa as well as in other resource constrained countries. The 2008 report on Confidential Inquiries into Maternal Deaths for South Africa shows a steady increase in deaths from non pregnancy related causes (mostly HIV infection and AIDS) from 31.4% for the period 1999-2001, to 37.8 % for the periods 2002-2004 and finally to 43.7% for the period 2005-2007. The report further states that 17%, 20.1% and 23.1% of maternal deaths were specifically linked to AIDS for the aforementioned time periods respectively. Similar increases in maternal deaths due to HIV/AIDS have been noted in countries such as Zambia and Tanzania. Studies have shown that there is a greater likelihood of poor health and increased death amongst infants and children whose mothers die early in their lives. Children whose mothers frequently battle opportunistic infections due to HIV or whose mothers die as a result of AIDS may not receive adequate care in infancy and childhood. As a result they too suffer from ill health and can easily die in childhood. HIV positive pregnant women whose CD4 count is at level where they are eligible to begin ART should therefore be
initiated onto treatment to help them remain healthy, those with CD4 above the initiation threshold should have access to other services which can help them maintain their well being made available to them.

The focus of PMTCT programmes should therefore not only be to prevent the MTCT but also to ensure that PMTCT facilitates access to other life saving services for HIV positive pregnant women. Access to ART for those who are eligible to initiate treatment reduces their morbidity and helps them live longer, access to support groups helps the women come to terms with their HIV status, access to nutritional counselling helps them know how best to feed themselves and their family. Thus pregnant women should be given holistic care as stipulated in the Comprehensive Care Management and Treatment (CCMT) policy addressing their physical, emotional and mental wellbeing. This care should begin at they time they are diagnosed at ANC and carry on to the post partum period where they should be supported through infant feeding and child care.

PMTCT service points should therefore be viewed places where HIV pregnant women can access facilities to protect their children from HIV but also as locations where they can access other services to help them maintain their health. One such service is initiation of antiretroviral treatment at the recommended threshold levels i.e. CD4 of 200 or less or WHO stage 3 or 4 of HIV disease progression. It has been found that delays in treatment initiation for up to 6 months can result in the deaths of as many of 22% of those waiting to begin treatment. Delayed treatment has also been associated higher chances of mortality soon after (usually within six months) initiation of treatment. It is therefore essential that PMTCT programmes offer comprehensive services which can include: clinical monitoring, ART, education and counselling, adherence support, family planning, social and psychosocial support to the mother and other members of her family.

PMTCT services should therefore provide opportunities for HIV positive pregnant women to access services which not only prevent MTCT but also help them to receive

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‡‡ As of April 2010, all HIV positive pregnant women in South African begin ART when their CD4 count at 350 or below.
holistic care which can meet all spheres of need such as physical, emotional, psychosocial and spiritual needs. In South Africa, access to comprehensive care is referred to as the Comprehensive Care Management and Treatment approach and is applied to management of HIV positive patients. According to this approach, both clinic and non clinical needs of HIV positive clients should be addressed, with PMTCT service points serving as access points to other services which the women may be in need of.

The integration of access to other services into PMTCT has been echoed in the 2008 and 2010 PMTCT Policies and in the 2007-2011 South Africa’s National Strategic Plan (NSP) for HIV/AIDS and STI. These policy documents also call for the involvement of men so as to facilitate partner disclosure and support, and for the implementation of referral systems that link PMTCT to other relevant services such as family planning, Wellness and ART. However, accessing required health services at has been found to be influence by factors around the women who are intended users and by the manner in which the services are organised and managed.

Some factors related to the intended users which have been found to influence service utilisation, particularly ART, include perceived stigma from health workers; cost of medication; cost of transportation; cost of supplementary food; difficulty of sustaining treatment; unwillingness to disclose status to family members; lack of access of health facilities; interruptions in drug supply; and difficulty in adhering to treatment requirements.

Weakness in the manner in which the health systems is organised such as large amounts of funding poured into stand alone programmes targeting specific diseases has also come into play. Targeted programmes may help quickly address the disease area of interest however, this encourages fragmentation as such services are rarely integrated with other health services, it also pulls staff away from regular health services since such programmes tend to pay better salaries. Other health system factors which can influence ART uptake include poor case management, drug stock outs and impractical dispensing procedures. All these factors erode confidence of potential users and decrease the likelihood of the services being used. These health system factors coupled with personal
factors and possibly mortality before or soon after treatment initiation all contribute to low uptake and client attrition that is observed in ART programmes. 31, 32

Though much has been written about what constrains access of ART services, there is limited documentation on HIV positive pregnant women’s access to other services which such as treatment of opportunist infections, psychosocial support and nutrition counselling. Furthermore, there is limited documentation on the linkages between PMTCT and services to which women testing HIV positive at ANC clinics are referred, or the extent to which accessing of these services is influenced by the afore mentioned factors. Available data shows varying degrees of success in health systems referrals and levels of collaboration between facilities. 41, 42 Given these gaps, this study set out to determine the level of uptake of ART and Wellness services, thereby assessing the linkages between PMTCT, ART and Wellness services.

1.2 Study Objectives

Study Aim:

This study sought to describe uptake of ART and Wellness services by pregnant women referred to these services from PMTCT clinics at selected clinics in Soweto so as to determine the linkages between PMTCT, ART and Wellness services.

Specific Objectives:

The specific objectives of this study were to determine:

• The proportion of all pregnant women being tested for HIV at selected PMTCT sites in Soweto between January to March 2008.
• The proportion of pregnant women referred to ART and Wellness services over a period of January to March from the selected PMTCT sites in Soweto.
• The uptake of Wellness and ART by women referred to these services from the selected PMTCT sites in Soweto.
• Health worker perceptions of possible barriers to service uptake at the selected PMTCT, ART and Wellness clinics in Soweto.
• The standard referral procedures in place at selected PMTCT, ART and Wellness clinics in Soweto.
Chapter 2: Methodology

2.1. Methodology

This chapter presents the approach taken to guide data collection and analysis. It also details how health facilities where data collection took place and study participants were selected for inclusion.

2.1.1. Study Design

This study was a descriptive cross sectional study i.e. taking a snapshot in time. The collected data to some degree describes the levels to which pregnant women that undergo the PMTCT process access follow-on services to which they are referred.

2.1.2. Study Population

The study population was composed of pregnant women who accessed PMTCT services for the first time for that pregnancy, and received a positive HIV test result at sampled clinics over the period January to March 2008.

The study population also included staff members at the sampled clinics who are involved in the provision of PMTCT, ART and VCT services.

2.1.3. Sampling Frame

PHRU facilitates the provision of PMTCT services at 12 Primary Health Care clinics in Soweto, 4 of these clinics also provide on-site ART services. The remaining 8 facilities which do not have on-site ART services refer clients who need to begin ART to one of the 4 clinics which do. For purposes of this study, clinics which offer on-site ART services are referred to as Type 1 clinics and those which do not provide ART services are referred to as Type 2 clinics.

Referral of clients from a Type 2 clinic to a specific Type 1 clinic for ART services is guided by proximity between the two types of clinics and ease of access to the Type 1 clinic for the client. PHRU has assigned specific Type 2 clinics to Type 1 clinics with the
Type 1 clinics’ usually falling within the Type 2 clinics’ catchment area. The total number of clinics and the services they provide are depicted on Error! Reference source not found.

Table 1: Clinics by Type of Services Rendered

<table>
<thead>
<tr>
<th>Type of Clinic</th>
<th>Services offered</th>
<th>Number of clinics offering services</th>
</tr>
</thead>
<tbody>
<tr>
<td></td>
<td>PMTCT</td>
<td>WELLNESS</td>
</tr>
<tr>
<td>Type 1</td>
<td>X</td>
<td>X</td>
</tr>
<tr>
<td>Type 2</td>
<td>X</td>
<td>X</td>
</tr>
<tr>
<td>Total Clinics</td>
<td></td>
<td></td>
</tr>
</tbody>
</table>

The sampling frame was therefore comprised of: all the Type 1 and Type 2 clinics where PHRU supports provision of PMTCT, the records of pregnant women who had accepted to test for HIV at these clinics and staff involved in the provision of PMTCT, ART and Wellness services.

The ANC clinic at Chris Hani Baragwanath hospital was excluded because the women accessing the tertiary institutional services tend to be in need of higher level of care and are therefore be more likely to access services to which they are referred.

**Patient Records Inclusion criteria:**

- Records of all pregnant women who initiated ANC visits at the sampled clinics in the selected months for that current pregnancy and underwent the PMTCT process;
- Records of all women who accessed the ART services for the time period under review, as shown in the ART clinic register;

**Patient Records Exclusion criteria:**

- Records of women referred to the sampled facilities from other non sampled clinics.
- Records of women whose CD4 count results are not written down in the PMTCT registers.

Staff involved in service provision were approached by the principle researcher to take part in key informant interviews. Selection was based on their level of involvement in the provision of PMTCT, ART and Wellness services. Participation was entirely
voluntary and they were informed that they could terminate the interview at any time without negative repercussions.

**Key Informant Inclusion criteria:**

- All staff involved in day to day provision of PMTCT and ART services, who have been working in that area for more than six months.

**Key Informant Exclusion criteria:**

- Clinic staff who do not provide core services such as the cleaners and those who have been employed at the clinics less than three months.

Interview notes were captured by the principle researcher as the conversations took place. A total of eight (8) key informants were interviewed, the different cadres of health workers interviewed are shown on Table 2 below.

**Table 2: Cadres of Key Informants Interviewed**

<table>
<thead>
<tr>
<th>Cadre of Key Informants</th>
<th>Clinic 1</th>
<th>Clinic 2</th>
<th>Total</th>
</tr>
</thead>
<tbody>
<tr>
<td>PMTCT coordinator (nurse)</td>
<td>X</td>
<td>X</td>
<td>2</td>
</tr>
<tr>
<td>ART coordinator (nurse)</td>
<td>X</td>
<td></td>
<td>1</td>
</tr>
<tr>
<td>ANC nurse</td>
<td>X</td>
<td>X</td>
<td>2</td>
</tr>
<tr>
<td>Lay counsellor at ANC</td>
<td>X</td>
<td>X</td>
<td>2</td>
</tr>
<tr>
<td>Lay counsellor at general VCT</td>
<td>X</td>
<td></td>
<td>1</td>
</tr>
<tr>
<td><strong>Total number of Key Informants Interviewed</strong></td>
<td><strong>5</strong></td>
<td><strong>3</strong></td>
<td><strong>8</strong></td>
</tr>
</tbody>
</table>

**2.1.4. Study Sampling**

Simple random sampling was used to select the Type 1 and Type 2 clinics where data were collected

i. A Type 1 clinic was randomly selected from the list of four.

ii. A Type 2 clinic which refers clients to the sampled Type 1 clinic was then selected from those assigned to refer clients to that particular clinic.

iii. PMTCT registers at the sampled clinics were reviewed for the period January to March 2008. The register from the ART clinic was reviewed for the period January to August 2008. The ART register was reviewed for a longer period of time to allow for possible delays in accessing the service by pregnant women.
iv. Key informants were purposively sampled based on inclusion and exclusion criteria.

2.1.5. Data collection

Data Source
Data were collected from routine statistics maintained at PMTCT service points (the PMTCT registers) at ANC clinics using record review tool ( ), as well as from the patient register maintained at the ART clinic using record review tool (Error! Reference source not found.).

Procedure for Data Collection
The PMTCT registers were reviewed for the period January to March 2008. The review solicited information on HIV testing, the result of the test, CD4 count and status of referral for those women whose CD4 count was 200 or less. According to current national guidelines on treatment of HIV, all HIV positive patients should be referred to an ART centre for initiation of treatment when their CD4 count is 200 or less, or when their symptomatic presentation places them at Stage 3 or 4 of the WHO clinical staging guide.43 44 The register at the ART clinic was therefore reviewed to trace women who based on their CD4 results should have been referred to the service from PMTCT. The ART register was reviewed for the period January to August 2008 to allow extra time for those women who may have delayed accessing the ART services.

Key informant interviews (KII) were also conducted by the principle investigator at the ANC, PMTCT and ART clinics with members of staff whose daily work contributes to the provision of PMTCT and ART. A staff member from the service point where voluntary counselling and testing is offered to the general public was also interviewed. The KIIs were conducted in private to ensure confidentiality and openness of responses.

A questionnaire on referral systems in place was administered to the key informants at the PMTCT, ART and VCT service points to determine referral and feedback systems in place. Thus both quantitative and qualitative data collection methods were used to gather data for this study. All data were collected between September and October 2008.
2.1.6. **Quantitative Data**

Quantitative data were collected using standard tools (Annexure 1 and Annexure 2) from the clinic register used for the counselling and testing pregnant women during the PMTCT process at the selected ANC clinics, and from the client register used to monitor client visits at the ART clinic. The PMTCT registers were reviewed to determine which clients, based on their CD4 counts, required immediate ART initiation. The ART register was then reviewed to determine which of these women had accessed ART at that service point. It was not possible to review records for women who required Wellness services as there was no documentation at the PMTCT service point of which wellness service they could have been referred to. A standard questionnaire on referral systems was administered to key informants, each key informant was given a brief background of the study and requested to give informed consent.

2.1.7. **Qualitative Data**

Qualitative data were obtained through key informant interviews with staff who work at the PMTCT, ART and VCT service points in the sampled health facilities. The questions asked of the Key informants were framed along the tenants of Appreciative Inquiry (AI) a research methodology which seeks to bring out the best of what happens.

AI was chosen as the approach for structuring the key informant interviews because unlike traditional research and evaluation, AI seeks to identify and highlight positive aspects of programme implementation by enquiring into the best of people, their organisations and their work.45 This approach enabled key informants to voice their opinions on what made their programmes work well.

KIIIs were conducted using a structured interview guide which sought to bring out information on the interviewees work, what they think works best and how they think they can achieve better results. The KII guide, information sheet and consent form are attached as Annexure 3, Annexure 4, and Annexure 5, The KII on referral systems tool (Annexure 6) was adapted from a guide on baseline
assesssment tools for PMTCT that was developed by Family Health International in 2003.46

The key informant interviews provided valuable insight into how the PMTCT programme is functioning and also provided a forum for staff working on the programme to voice their opinions on what makes their programme work well and what can be done to improve service delivery.

2.1.8. Measurement

The variables under consideration are:

- **HIV positive status**: those women who were found to be HIV positive.
- **CD4 Count**: Pregnant women whose CD4 count result was 200 or below which made them eligible for initiation of ART.
- **Referral**: an indication in the PMTCT registers of whether or not women required ART as indicated by their CD4 count or clinical staging had been sent from PMTCT to the ART service point where they could begin treatment.
- **Service Uptake**: Utilisation of ART or Wellness services by pregnant women who had been referred there from the PMTCT service point.

2.2. Pilot Study

All the tools were pre-tested at Zola clinic in Soweto. This clinic provides ANC, PMTCT, Voluntary Counselling and Testing, and ART. The pre-testing resulted in modification to the tools and approach for the study. Changes made include

- Elimination of social economic data from the PMTCT and ART clinic register tools. This information is not captured in the PMTCT registers but in the client ANC cards, these are not left at the clinic but rather taken home by the women.
- Addition of project number column to the PMTCT tool as each client who tests positive at the ANC clinic is assigned a project number by PHRU.
- Client names and CD4 counts were used to follow up clients from PMTCT to ART as clinic codes or patient identifiers given to pregnant women at the ANC clinic were not used at the ART clinic.
• The PMTCT registers were reviewed for a longer period of time as a follow up of clients from a two week period would have yielded a very small sample of HIV positive women with a CD4 count of 200 or less who could then be followed up at the ART clinics. Thus PMTCT registers were reviewed for the period January through March 2008. The ART registers were reviewed from January through August 2008.

2.3. Limitations of the Study

The study has a number of limitations which result primarily from lack of resources to carry out more in depth data collection activities. The specific limitations faced are:

- Time and resource constraints made it impossible to speak to women who had utilised PMTCT, ART and Wellness services thus underlying casual factors to their health seeking behaviour could not be established.

- Pressure of work and lack of time resulted in some key informants requesting that the interviews be cut short midway and not all questions were addressed.

- Infant feeding, though a key determinant of PMTCT outcomes was not explicitly discussed with key informants as it was beyond the limited scope of this study.

- Information captured from Key Informant Interviews was all captured by hand during the interview and thus discussion points were not captured word for word.

- PHRU supported PMTCT clinics are atypical of government run PMTCT services as staffing levels tend to be higher. Each service point has a dedicated midwife to provide support and coordinate PMTCT services, each site also has several lay counsellors. Thus the PHRU PMTCT services may not be generalisable to other health facilities.

- Socio-economic data such as marital and employment status are not captured in the PMTCT registers and therefore it was not possible to correlate these factors against the variables under consideration.

- Use of different data capturing systems at PMTCT and ART service points made it difficult to trace some of the women who had been referred from PMTCT to ART.

- Data capturing systems in use at the PMTCT service point did not give an indication of which Wellness services HIV positive pregnant women may have been referred to.
Despite these challenges, the study was able to describe the linkages between the services and the extent to which they were utilised by women who had been referred there from PMTCT.

### 2.4. Data Processing Methods and Data Analysis

Quantitative data gathered from record reviews were captured onto an Ms Excel worksheet and exported to SPSS version 17 for cleaning and generation of descriptive statistics using frequency tables and cross tabulations. The quantitative analysis sought to determine which of the pregnant women whose CD4 count indicated need for ART initiation had began treatment. Identifiers from the PMTCT registers for women who required treatment were compared against those in the ART register to determine how many of them had accessed ART services. OpenEpi was used to calculate p-value at 0.05 to compare between Type 1 and Type 2 clinic in receiving a CD4 count result and accessing ART services. A 95% confidence interval is calculated for the estimates. The analytical assessment on comparing two groups on ART utilisation is done using odds ratio with p-value of 0.05 for significant testing.

Qualitative data from key informant interviews were thematically analysed using Atlas TI version 5.2.0. The qualitative data have been incorporated into the study results to add depth to the findings. Quotes from the interviews have been included as part of the results.

### 2.5. Ethical Considerations

Ethical clearance to conduct the study was obtained from the Witwatersrand Committee for Research on Human Subjects-Medical (Annexure 7) and the Gauteng Province, Department of Health - Directorate for Policy Planning and Research (Annexure 8). Permission to access health facilities was also sought from the Health Facility Managers (Annexure 9 and Annexure 10).

Confidentiality of PMTCT client records was maintained by capturing all data into excel and keeping it password protected. Personal identifications details such as names of clients and dates of birth have not been included in the report, these were used to link the
client records from the different registers reviewed. However, once matched, the identifiers were removed and unique identification numbers assigned to each record.

Informed consent was sought from key informants before the interviews were held. It was made clear to them that participation was voluntary and that declining to participate did not bear any negative repercussions for them. Names of the sampled clinics and key informants spoken to have not been included in the report. The results of the key informant interviews are presented in such a way that it’s not possible to distinguish who the key informants were or at which facility they work.
Chapter 3: Utilisation of Services

3.1. Presentation of Results

This chapter presents the results of the record reviews and key informant interviews.

3.1.1. Utilisation of PMTCT Services

Review of PMTCT registers for the period January to March 2008 showed that a total of 1350 women accessed ANC services at for the first time for that given pregnancy at the sampled clinics. All these women were offered an HIV test as part of ANC, only one (1) declined the test. Thus a total of 1349 (99.92%) women underwent HIV counselling and testing which are offered as part of PMTCT services.

Three hundred and eighty-eight (388 or 29%) of the 1349 women tested positive for HIV, of these 77 (20%) had a CD4 count of 200 or less and were therefore eligible for referral to ART. Eighteen (18 or 23%) of the 77 ART eligible women were found to have accessed the service. The PMTCT registers further showed that 144 (37%) of the 388 HIV positive women did not return to their respective ANC clinics for their CD4 results, 24 (31%) of these were amongst the 77 women who were eligible for initiation of ART. Figure 1 illustrates the number of women at each level of the PMTCT cascade.

No referrals to Wellness services were indicated in the PMTCT registers thus no women could be traced from PMTCT to Wellness service points. No registers were reviewed at any of the service points which fall under wellness services as there was no indication of pregnant women having been referred there from PMTCT.
The proportion of women who tested for HIV; who did and did not return for their CD4 results; who were referred to ART and Wellness as well as those who accessed the service to which they were referred is detailed in Table 1. This flow of clients is diagrammatically depicted later in this report in Figure 3. At the time of data collection, PHRU was in the process of instituting a short messaging system which would be used to follow up on clients who did not return for their CD4 results.
Table 3: PMTCT Linkages to ART and Wellness

<table>
<thead>
<tr>
<th>Category/ Sub-Category</th>
<th>Numerator (n)</th>
<th>Denominator (N)</th>
<th>Percentage</th>
<th>95% Confidence Interval</th>
</tr>
</thead>
<tbody>
<tr>
<td><strong>HIV Testing</strong></td>
<td></td>
<td></td>
<td></td>
<td></td>
</tr>
<tr>
<td>- Proportion of Women who tested negative for HIV</td>
<td>961</td>
<td>1349</td>
<td>71%</td>
<td>69 - 74</td>
</tr>
<tr>
<td>- Proportion of Women who tested positive for HIV</td>
<td>388</td>
<td>1349</td>
<td>29%</td>
<td>26 - 31</td>
</tr>
<tr>
<td>- Proportion of Women eligible for ART (CD4count ≤ 200) amongst those who tested for HIV</td>
<td>77</td>
<td>1349</td>
<td>6%</td>
<td>5 - 7</td>
</tr>
<tr>
<td><strong>Eligibility of ART</strong></td>
<td></td>
<td></td>
<td></td>
<td></td>
</tr>
<tr>
<td>- Proportion of Women Eligible for ART Referral among HIV positive pregnant women (CD4 count ≤ 200)</td>
<td>77</td>
<td>388</td>
<td>20%</td>
<td>16 - 24</td>
</tr>
<tr>
<td>- Proportion of Eligible women who returned for their CD4 results</td>
<td>53</td>
<td>77</td>
<td>69%</td>
<td>58 - 78</td>
</tr>
<tr>
<td>- Proportion of Eligible women who did not return for their CD4 results</td>
<td>24</td>
<td>77</td>
<td>31%</td>
<td>22 - 42</td>
</tr>
<tr>
<td><strong>Referral to ART among those who returned for their results</strong></td>
<td></td>
<td></td>
<td></td>
<td></td>
</tr>
<tr>
<td>- Proportion of Eligible women with indication of referral to ART</td>
<td>33</td>
<td>53</td>
<td>62%</td>
<td>49 - 75</td>
</tr>
<tr>
<td>- Proportion of Eligible women with no indication of referral to ART</td>
<td>18</td>
<td>53</td>
<td>34%</td>
<td>22 - 47</td>
</tr>
<tr>
<td>- Proportion of Eligible women already on ART</td>
<td>2</td>
<td>53</td>
<td>4%</td>
<td>0.63 - 12</td>
</tr>
<tr>
<td><strong>Linking PMTCT to ART</strong></td>
<td></td>
<td></td>
<td></td>
<td></td>
</tr>
<tr>
<td>- Proportion of Eligible women with indication of referral to ART traced at ART clinic</td>
<td>13</td>
<td>33</td>
<td>37%</td>
<td>24 - 57</td>
</tr>
<tr>
<td>- Proportion of Eligible women with no indication of referral traced at ART clinic</td>
<td>4</td>
<td>18</td>
<td>22%</td>
<td>7 - 45</td>
</tr>
<tr>
<td>- Proportion of Eligible women already on ART traced at ART clinic</td>
<td>1</td>
<td>2</td>
<td>50%</td>
<td>3 - 98</td>
</tr>
<tr>
<td><strong>Proportion of ART eligible women who returned for their CD4 results and were traced to ART</strong></td>
<td>18</td>
<td>53</td>
<td>34%</td>
<td>22 - 47</td>
</tr>
<tr>
<td><strong>Proportion of all ART eligible women traced to ART</strong></td>
<td>18</td>
<td>77</td>
<td>23%</td>
<td>15 - 34</td>
</tr>
<tr>
<td><strong>Linkages to Wellness Services</strong></td>
<td></td>
<td></td>
<td></td>
<td></td>
</tr>
<tr>
<td>- Women eligible for Wellness services (CD4 ≥ 200)</td>
<td>311</td>
<td>388</td>
<td>80%</td>
<td>76 - 84</td>
</tr>
<tr>
<td>- Women referred to Wellness</td>
<td>0</td>
<td>388</td>
<td>0%</td>
<td>--</td>
</tr>
</tbody>
</table>

Of the 1349 women who tested for HIV, 901 (67%) accessed the service at a Type 1 clinic and the remaining 488 at the Type 2 clinic. The break down of HIV and CD4 test results as well as utilisation of services by type of facility are presented in Table 4.
Table 4: PMTCT to ART Linkages by type of clinic

<table>
<thead>
<tr>
<th>Activity</th>
<th>Type 1 Clinic</th>
<th>Type 2 Clinic</th>
<th>Total</th>
</tr>
</thead>
<tbody>
<tr>
<td>Testing for HIV at first ANC visit for a given pregnancy</td>
<td></td>
<td></td>
<td></td>
</tr>
<tr>
<td>- Opted out of HIV testing at PMTCT service point</td>
<td>1</td>
<td>0</td>
<td>1</td>
</tr>
<tr>
<td>- Tested for HIV at PMTCT service point</td>
<td>901</td>
<td>448</td>
<td>1349</td>
</tr>
<tr>
<td><strong>Total number of women at ANC first visit</strong></td>
<td><strong>902</strong></td>
<td><strong>448</strong></td>
<td><strong>1350</strong></td>
</tr>
<tr>
<td>Results of HIV tests</td>
<td></td>
<td></td>
<td></td>
</tr>
<tr>
<td>- Positive HIV test result</td>
<td>277</td>
<td>111</td>
<td>388</td>
</tr>
<tr>
<td>- Negative HIV test result</td>
<td>624</td>
<td>337</td>
<td>961</td>
</tr>
<tr>
<td><strong>Total number of women tested</strong></td>
<td><strong>901</strong></td>
<td><strong>448</strong></td>
<td><strong>1349</strong></td>
</tr>
<tr>
<td>Return to clinic for CD4 test results by the positive women</td>
<td></td>
<td></td>
<td></td>
</tr>
<tr>
<td>- Women who <strong>returned</strong> for CD4 count results</td>
<td>165</td>
<td>79</td>
<td>244</td>
</tr>
<tr>
<td>- Women who <strong>did not</strong> return for CD4 results</td>
<td>112</td>
<td>32</td>
<td>144</td>
</tr>
<tr>
<td><strong>Total number of CD4 Count test done</strong></td>
<td><strong>277</strong></td>
<td><strong>111</strong></td>
<td><strong>388</strong></td>
</tr>
<tr>
<td>CD4 Results for HIV positive women which were above 200</td>
<td></td>
<td></td>
<td></td>
</tr>
<tr>
<td>- Women who <strong>returned</strong> for CD4 result</td>
<td>131</td>
<td>57</td>
<td>188</td>
</tr>
<tr>
<td>- Women who <strong>did not</strong> return for CD4 result</td>
<td>97</td>
<td>23</td>
<td>120</td>
</tr>
<tr>
<td><strong>Total Number of Women with CD4 above 200</strong></td>
<td><strong>228</strong></td>
<td><strong>80</strong></td>
<td><strong>308</strong></td>
</tr>
<tr>
<td>CD4 Results for HIV positive women which were equal to or below 200</td>
<td></td>
<td></td>
<td></td>
</tr>
<tr>
<td>- Women who <strong>returned</strong> for CD4 result</td>
<td>32</td>
<td>21</td>
<td>53</td>
</tr>
<tr>
<td>- Women who <strong>did not</strong> return for CD4 result</td>
<td>15</td>
<td>9</td>
<td>24</td>
</tr>
<tr>
<td><strong>Total Number of women with CD4 below equal to or below 200 therefore eligible for referral to ART</strong></td>
<td><strong>47</strong></td>
<td><strong>30</strong></td>
<td><strong>77</strong></td>
</tr>
<tr>
<td>CD4 Results Not Recorded in PMTCT Register for</td>
<td></td>
<td></td>
<td></td>
</tr>
<tr>
<td>- Women who returned for their CD4 results</td>
<td>2</td>
<td>1</td>
<td>3**§§</td>
</tr>
<tr>
<td>- Women who did not return for their CD4 results</td>
<td>13</td>
<td>0</td>
<td>13</td>
</tr>
<tr>
<td><strong>Total women with NO CD4 result recorded</strong></td>
<td><strong>15</strong></td>
<td><strong>1</strong></td>
<td><strong>16</strong></td>
</tr>
<tr>
<td>Indication of Referral of ART Services in PMTCT Register for Women who returned for their CD4 Result and were Eligible to begin Treatment (53 Women)</td>
<td></td>
<td></td>
<td></td>
</tr>
<tr>
<td>- HIV positive women eligible for ART with indication of referral to service</td>
<td>20</td>
<td>13</td>
<td>33</td>
</tr>
<tr>
<td>- HIV positive women eligible for ART with no indication of referral to service</td>
<td>13</td>
<td>6</td>
<td>19</td>
</tr>
<tr>
<td>- HIV positive women eligible for ART with indication they were already on treatment</td>
<td>4</td>
<td>4</td>
<td>8</td>
</tr>
<tr>
<td><strong>Total ART eligible women Traced to ART</strong></td>
<td><strong>13</strong></td>
<td><strong>5</strong></td>
<td><strong>18</strong></td>
</tr>
<tr>
<td>Women Traced to Wellness</td>
<td></td>
<td></td>
<td></td>
</tr>
<tr>
<td>- Women eligible for Wellness***</td>
<td>230</td>
<td>81</td>
<td>311</td>
</tr>
<tr>
<td>- Women eligible for ART who were referred and traced to Wellness services</td>
<td>0</td>
<td>0</td>
<td>0</td>
</tr>
</tbody>
</table>

**§§ 2 of these women were on treatment, one was on dual therapy, therefore they are all assumed to have received their CD4 results.**

*** These would be women whose CD4 count was higher than 200 and who were not already on ART.
This retention of women within the PMTCT cascade by the type of facility where they accessed ANC is graphically illustrated in Figure 2.

A total of 18 women, representing 23% of all eligible women accessed ART services. Utilisation of Wellness services could not be determined ad no referrals to services comprising Wellness were recorded in the PMTCT registers.
3.1.2. **Referral of Pregnant Women from PMTCT to ART and Wellness**

Reviewing the PMTCT registers showed that referral systems were not well structured or documented. Only 9% (33 out of 388) of the HIV positive pregnant women had an indication of referral to a follow on service against their record in the PMTCT registers, all of which were to ART. Referrals to services which are part of Wellness services were not documented. The PMTCT and ART registers further showed that of the 77 women who were eligible for ART only 23% (18 out of 77) accessed the service. This flow of clients through the PMTCT cascade and retention to ART has been illustrated in Figure 3.

Women who tested HIV positive at the sampled facilities and were in need of Wellness services were reportedly referred to the appropriate service. None of the women who are referred to follow-on Wellness services are given a referral letters, furthermore, it was not documented in the PMTCT registers which other services pregnant women may have been referred to. Wellness services could therefore not be traced from the PMTCT service points. At the time of data collection, only the Type 1 facility had a functional support group which is one of the recommended Wellness services through which HIV positive pregnant women can access psychosocial support. Support group members met once a week for discussions and general talks. The support group at the Type 2 facility had been shut down due to lack of funding over the time period for which data for this study were collected. The Type 2 clinic has since resumed activities for its support group. Attendance registers of support group meetings are not maintained.
1350 women attending ANC at the sampled clinics

1349 women agreed to test for HIV

388 Women tested positive and had blood samples sent for CD4 counts

981 women who tested negative for HIV

244 women returned to the clinic for their CD4 results and therefore had the opportunity to access PMTCT related services.

144 women did not return to their respective clinics for their CD4 counts and therefore did not access PMTCT services at these clinics.

188 women had CD4 counts above 200 and were not eligible for ART but could be referred for Wellness. 3 had no CD4 recorded

53 women had CD4 counts of 200 or less and were eligible for referral to ART services.

107 of the women who did not return for CD4 results had counts above 200 and were not eligible for ART but could have been referred to Wellness. 13 had no CD4 recorded

24 of the women who did not return for CD4 results had counts of 200 or less and were therefore eligible for ART referral.

Records show that 33 women were referred to the ART clinic.

No record of referral to ART for 18 eligible women.

Records show that 2 eligible women were already on ART.

20 women who were referred to ART were not traced to the sampled facility.

14 eligible women with no record of referral to ART were not traced to the ART clinic at the sampled facility.

1 woman on ART was not traced to the ART clinic at the sampled facility.

13 women accessed ART at the sampled facility.

4 women with no record of referral to ART were traced to the ART clinic at the sampled facility.

1 woman on ART was traced to the ART clinic at the sampled facility.

A total of 18 women accessed ART at the ART clinic to which they had been referred.

961 women who tested negative for HIV
3.1.3. **Uptake of ART Services by Pregnant Women**

The PMTCT registers documented referral to ART services for 33 of the 77 women who were eligible. The registers at the ART clinics were reviewed to determine what proportion of the 77 women eligible to initiate treatment had accessed the service. The ART register showed that:

- 13 of the 33 women who are noted in the PMTCT register as having been referred to ART accessed the service
- An additional 4 women accessed the service despite the referral to ART not being recorded against their names in the PMTCT registers
- Records for one of the two women who informed PMTCT staff that they were already on ART were found in the ART register.
- No record of the women who did not return for their CD4 counts were found in the ART register.

Thus 34% (n = 18, N = 53) of eligible women who returned for their CD4 results were referred to and accessed ART services. This proportion is an even lower 23% (n = 18, N = 77) when all 77 eligible women, including those who did not return for their CD4 results are taken into consideration.

It was also found that some clients were captured more than once in the PMTCT register, with each subsequent visit being recorded as a new visit. Such duplicate records were discovered during data cleaning in both PMTCT and ART registers, all duplicate records whose first visit fell outside the period under review were excluded from the study.
Table 5: The uptake of ART among HIV positive pregnant women of first ANC visit from January to March 2008 at selected clinics in SOWETO, Gauteng

<table>
<thead>
<tr>
<th>CD4≤200</th>
<th>Utilised services</th>
<th>Did not utilise services</th>
<th>Total</th>
</tr>
</thead>
<tbody>
<tr>
<td>Eligible and know their eligibility to ART</td>
<td>18</td>
<td>35</td>
<td>53 (69%)</td>
</tr>
<tr>
<td>Eligible but did not know their eligibility to ART</td>
<td>0</td>
<td>24</td>
<td>24 (31%)</td>
</tr>
<tr>
<td>Total</td>
<td>18 (23%)</td>
<td>59 (77%)</td>
<td>77 (100%)</td>
</tr>
</tbody>
</table>

P Value = 0.0003

Sixty-nine percent (69%) of women were aware of the need to initiate treatment, however, only 23% accessed ART at the sampled health facility. All of the women utilised ART were among those who had returned to their clinics for their CD4 results indicating a close link between awareness of need and initiation of treatment (p value = 0.0003).

When comparing the two groups of women (those who returned for CD4 and those who did not); the OR = 2.6 (p-value = 0.0003) indicates that utilisation of ART services is significantly linked to knowledge of eligibility for ART. Thus women who knew that they needed to initiate ART were 3 times more likely to use the service.

Seventeen percent of women eligible for ART were seen at the Type 1 clinic whereas 27% were seen at the Type 2 clinic. The proportion of eligible women from the Type 1 clinic who accessed ART is 28% (95% confidence interval [CI] 13-22%) compared to only 17% (95% CI 20 – 36%) of eligible women from the Type 2 facility. Thus the Type 2 clinic saw more HIV positive pregnant women who were in need of ART initiation but fewer of them accessed ART.
<table>
<thead>
<tr>
<th>Client description</th>
<th>Type 1 Clinic</th>
<th>Type 2 Clinic</th>
</tr>
</thead>
<tbody>
<tr>
<td></td>
<td>Numerator (n)</td>
<td>Numerator (n)</td>
</tr>
<tr>
<td>Proportion of women eligible for ART</td>
<td>47</td>
<td>30</td>
</tr>
<tr>
<td>Proportion of women who did not return for CD4 results</td>
<td>15</td>
<td>9</td>
</tr>
<tr>
<td>Proportion of women with referral to ART stated in register</td>
<td>20</td>
<td>13</td>
</tr>
<tr>
<td>Proportion of women who accessed ART services</td>
<td>13</td>
<td>5</td>
</tr>
</tbody>
</table>

### 3.2. Standard Referral Procedures

Referral procedures were for the most part standard, however, the data management systems used to track referral to ART and Wellness services as well as feedback systems to the out referral clinics are not well developed. Indication of referral to follow on services were made for 9% (33 out of 388) of all the women who tested HIV positive, all of them were to ART. Referral systems at a Type 1 clinic are such that HIV positive women whose CD4 count indicates the need to initiate ART were escorted to the ART clinic by one of the PMTCT lay counsellors. The counsellors then leave the women in the ART registration room, for where their details to be captured in an ART register. At the Type 2 clinic, women who required ART initiation were given a referral letter and instructed to present it to PMTCT staff at the Type 1 ANC clinic to which they were referred. These women were then escorted to the ART registration room by a PMTCT lay counsellor.

At the time of data collection, PHRU had introduced a new referral letter to the Type 2 clinic, the new form had a return slip which was supposed to be returned to the out referral clinic by the client after they had accessed the service. Prior to submission of this report, the primary investigator enquired with the Type 2 clinic if the referral letters were being returned by the clients and was informed that only two had been retuned over a twelve month period. To keep track of women who accessed ART, the PMTCT
coordinator had co-opted the ANC nurses to assist with follow-up. Client who should have accessed PMTCT were asked if they had done so at each ANC visit, this information was then passed on to the PMTCT staff.

At the time of data collection, an indication was made in the PMTCT registers against the names of all women referred to the ART clinic. However, the review of the PMTCT registers and the results of the trace to the ART register shows that referral to ART is not always documented in the PMTCT registers. 77 women had CD4 counts of 200 or less, therefore all 77 women should have been referred to ART, however 24 of these women did not return to the PMTCT service points for their CD4 counts and therefore were unaware of the need to initiate treatment. This lack of documentation is illustrated in the table below.

<table>
<thead>
<tr>
<th>CD4 Count</th>
<th>Register showed referral to ART</th>
<th>Register showed no referral to ART</th>
<th>Did not return for CD4 result and referral Not Stated</th>
<th>Returned for CD4 result BUT referral Not Stated</th>
<th>Register shows client already on ART</th>
<th>Total</th>
</tr>
</thead>
<tbody>
<tr>
<td>0 – 100</td>
<td>15 (47%)</td>
<td>0 (0%)</td>
<td>5 (16%)</td>
<td>11 (34%)</td>
<td>1 (3%)</td>
<td>32 (100%)</td>
</tr>
<tr>
<td>101 – 200</td>
<td>18 (40%)</td>
<td>0 (0%)</td>
<td>19 (42%)</td>
<td>7 (16%)</td>
<td>1 (2%)</td>
<td>45 (100%)</td>
</tr>
<tr>
<td>201 – 300</td>
<td>0 (0%)</td>
<td>46 (58%)</td>
<td>34 (43%)</td>
<td>0 (0%)</td>
<td>0 (0%)</td>
<td>80 (100%)</td>
</tr>
<tr>
<td>301 – 400</td>
<td>0 (0%)</td>
<td>47 (57%)</td>
<td>35 (43%)</td>
<td>0 (0%)</td>
<td>0 (0%)</td>
<td>82 (100%)</td>
</tr>
<tr>
<td>401 – 500</td>
<td>0 (0%)</td>
<td>29 (67%)</td>
<td>13 (30%)</td>
<td>0 (0%)</td>
<td>1 (2%)</td>
<td>43 (100%)</td>
</tr>
<tr>
<td>501 +</td>
<td>0 (0%)</td>
<td>62 (69%)</td>
<td>25 (28%)</td>
<td>0 (0%)</td>
<td>3 (3%)</td>
<td>90 (100%)</td>
</tr>
<tr>
<td>CD4 Not stated</td>
<td>0 (0%)</td>
<td>0 (0%)</td>
<td>13 (81%)</td>
<td>1 (6%)</td>
<td>2 (13%)</td>
<td>16 (100%)</td>
</tr>
<tr>
<td>Total</td>
<td>33 (9%)</td>
<td>184 (47%)</td>
<td>144 (37%)</td>
<td>19 (5%)</td>
<td>8 (2%)</td>
<td>388 (100%)</td>
</tr>
</tbody>
</table>

There were no structured feedback systems between PMTCT and ART services as statistics on number of pregnant women referred from PMTCT to ART as well as number of PMTCT clients sent at ART were not regularly exchanged between the two service points.
3.3. **Health Worker Perceptions on PMTCT Service.**

Key informants were asked to share their views on PMTCT service provision and referral systems. Several opinions were voiced by the key informants on why they thought their service was widely accessed, what made their service work well and they thought were barriers to service utilisation. The interviewees were also asked to suggest what could be done to improve both PMTCT uptake and referral systems.

In response to these questions key informants stated that services were utilised because they were close to the people for whom they were meant, services are free and of good quality. They however acknowledge that some women were not able to fully utilise the services for various reasons including poor staff attitudes, fear of disclosing their status to family, the cost of travelling to the health facilities. The key informants also suggested some measures which could help improve service uptake including better communication between departments; higher staffing levels, and raising awareness of available services in the community. Discussion from the key informant interviews are presented in this section of the report.

3.3.1. **Why Services were utilised**

Several of the key informants cited the close proximity of the PMTCT services to client’s neighbourhoods and the lack of user fees as contributory factors to why the service was widely utilised. Others stated that clients were well received and provided with good quality counselling which encouraged utilisation.

“Patients are given individual counselling but they are made to understand that the result of their test will be subject to shared confidentiality as other health workers who will treat them may need to know their status...It’s due to the good quality of counselling, counsellors listen to what the mothers have to say. Mothers also get free infant formula which gives them the option for safe infant feeding”. KII *1*

“The clinic is also close to where the people are so it’s convenient and there are no long queues at the clinic so they patients don’t have to wait long to be seen. … Clients like the service we provide some come from others areas instead of using their clinic. KII *7*
The manner in which activities are carried out was also cited as a possible reason why the service is utilised. On some mornings, light physical exercises are facilitated by an ANC nurse, educational group discussions are also held. All PMTCT staff and activities are supported by PHRU, whilst ANC activities such as foetal growth monitoring and ART services are facilitated by government nurses.

Another reason cited for utilisation was the non discriminatory manner in which pregnant women are treated as PMTCT services are provided in such a way that it is not possible to distinguish the HIV status of the pregnant women. For instance, universal precautions are applied by the nurses the ANC nurses when they attend to all the women, i.e. gloves worn for all instances of pricking, sharps disposal in one designated bin. This helps facilitate utilisation of the service as HIV positive clients do not feel conspicuous.

> “HIV positive pregnant women are not given any special treatment for example nutrition talks are given to all, the only difference is if they have abnormal weight i.e. very low then they are referred for further investigation.” KII

### 3.3.2. Possible barriers to service utilisation

All the key informants were aware that some pregnant women shy away from ANC clinics and by so doing do not have the opportunity to make use of the PMTCT services. Possible explanations for this were suggested by the key informants, they include: dislike of frequent visits to the ANC clinic despite the possibility of complications arising during the course of the pregnancy; lack of awareness of the need to attend ANC, for instance, first time moms may use the service less often or not at all as they do not know what to expect.

The lack of funds was also suggested as a possible barrier to service utilization as some women may need to take public transport to travel to the clinic. Also suggested were fear of knowing one’s status and ignorance about HIV.

> Testing for HIV it is one of their fears, some women want to terminate the pregnancy when learn of their status, they think that when they terminate the pregnancy the HIV will go, this is due to ignorance. Group education in the mornings tries to minimise this. ~ KII

0707048E 36
Some people don’t believe in western medicine they won’t come to the clinic when they are pregnant, rather they will go inyanga (traditional healer), also they don’t believe in HIV, so they deliver at home or as unbooked patients at Bara. – KII *6

Poor staff attitudes were also mentioned as a possible barrier to service utilization as those clients who in the past had negative experiences may decide not to use the service again.

Nurses attitude because they have this shouting attitude. If staff attitudes are not good then the patients may not return on their next pregnancy. – KII *2

This may be linked to past experiences where health workers were mean. This meanness happens even today, patients are not given a chance to explain themselves if they are late in booking the visit. We need to support and listen to them – KII # 8

With regard to barriers for utilisation of ART services, it was suggested that some clients referred to the ART clinic opt to delay accessing the service until after they have delivered. Some of these women still do not access the service even after the birth of their children.

“Some patients don’t make use of ART because they would like to wait until after they have delivered their babies. Others don’t use the facilities because they don’t return to the ART clinic after they have delivered. Typically patients first undergo 3 sessions on adherence counselling, one per week, they only start treatment after the 3rd visit which means to 3 weeks of coming to the clinic.” KII # 4

Other clients reportedly sought treatment in areas where they do not live due to fear that members of their communities would learn their status. Reluctance to disclose their status was also suggested as a possible reason why Wellness services such as support groups were not highly utilised.

3.3.3. Suggested measures to improve PMTCT service utilisation

When asked what they thought could be done to improve service utilisation the responses given ranged from increased funding to need for more staff, to change in attitudes towards patients; and increased community education on the importance of ANC and PMTCT.
Increased staffing to facilitate proper patient management was raised across all service points. For instance, repeat testing after the 3 month window period for women who test negative at the first visit was not being done due to high patient load.

"More staff are needed, currently have to look at first visits and subsequent visits therefore there are high patient loads. Staff need to check if patient is on AZT, if patients tested negative, they need to retest if the 3 month window period has closed, but this is not done i.e. follow up of patients is not done due to high current patient load.” KII 6

It was also suggested that low salaries should be addressed as better incentives would help improve staff attitudes and cascade to improved quality of services given to clients. Another suggestion was for increased media coverage on the importance of PMTCT. It was mentioned that there was a lot of general information on HIV and AIDS, PMTCT messaging should be an integral part of these awareness campaigns.

"Government should improve salaries which will in turn improve staff attitudes. Currently staff are overloaded and short staffed which results in poor attitudes towards patients, there is no time for dedicated one on one education, counselling and management. ~ KII 3

"More staff are needed this improves attitudes. One can’t be a good listener because of being overworked. With more staff we can then have or do better health education talks, these are at times not done due to lack of time. ~ KII 7

"There is a lot of information and talk on general HIV but they leave women and children out. If they include messages on women and children then clients are likely to be more psychologically ready to accept a positive result. ~ KII 4

The need for greater cooperation and better linkages between ANC, PMTCT and ART facilities was also stressed. Each service point needs to be aware of what is happening at the other points so as to facilitate a unified approach to dealing with clients. For instance, hospitals and health facilities in South Africa are moving towards adopting baby friendly practices where exclusive breast feeding is the preferred choice for the first six months of a child’s life.
In the context of HIV and AIDS women are advised to either exclusively breast feed or exclusively formula feed their children for the first six months based their social, economic and cultural circumstances. Factors such as disclosure to partners, parents and other family members, availability of clean drinking water and fuel or energy to heat water and reliable supply of milk formula are some of the factors considered clients are advised to consider as they choose a feeding option. Both the WHO and the South African Department of Health advise that when women are counselled on exclusive formula feeding they should look at the Acceptability and Feasibility of the decision, the Availability of milk formula as well as the Safety and Sustainability (AFASS) of the decision. Women whose social, economic and cultural environment does not allow them to meet all AFASS criteria are advised to exclusively breast feed whilst those who can meet the criteria are advised to exclusively formula feed.

The poor communication between departments was mentioned as a possible reason why some women were unclear on what feeding choice to opt for and they resorted to mix feeding their children. Joint meetings were suggested as a means of fostering a unified approach and facilitating information exchange.

“There is fragmentation within the same departments, there should be a system of feedback, the departments can do different things but they must report back to each other. At the moment, one department does not know what the other is doing. It is also difficult to get statistics from the other departments.” ~ KII #4

When the mothers come back for the six week check up, the baby’s don’t want to feed from the bottle, when you ask the mothers to put the baby to the breast, the baby’s attach immediately like the are used to breast feeding. ~ KII #1

Other points raised were that suggestions for improvements should come from the bottom up, starting with clients who use the service via a suggestion box and include staff who work hands on at the different service points.

3.3.4. Improvements Suggested for ART Services

It was reported that some of the women who present to the ART clinic state that they are not aware why they should be going to an ART clinic since they were there for ANC. Thus clients should be better prepared before they are sent to the ART clinic. In aid of
this, it was suggested that adherence counselling could be started at PMTCT service points so that clients are better prepared mentally and emotionally before they present to ART. This could also reduce the time lag between first visit to the ART clinic and initiation of treatment. At the time of data collection, those referred to ART first had to undergo three adherence counselling sessions over a three week period before initiation of treatment. This translates to three separate visits to the ART clinics which the women may struggle with both financially and in terms of time.

Turn around time for CD4 count results should be shortened to cut down on the number of clients who do not return for their results because of the waiting period which is generally about two (2) weeks. Shorter resulting time is especially important for women who may wish to move closer to their families when they fall pregnant. Thus women need to know as soon as possible if they require ART for their health or prophylaxis for PMTCT purposes only.

Some patient stay out of town and they are only here for a short period of time then they go back where they came from. The need to return home may be greater for women when they fall pregnant, thus faster resulting and follow on action can mean the difference in a child’s life.

KII #6

3.3.5. Suggestions for Wellness Services

Wellness services were the least well established at both clinics. It was suggested that clients should be encouraged to have repeat CD4 counts either at the general VCT section††† (if they have delivered) or at ANC. Women with CD4 counts which were border line should be encouraged to have repeat CD4 counts done just before delivery. Boarder line CD4 counts was the term used by key informant to refer to CD4 counts which were above 200 but only just, for instance, some women may have had CD4 counts below 250 but were not referred to ART due to the tight enrolment criteria. Key informants stressed the importance of such women having repeat CD4 counts done as pregnant women’s CD4 status could deteriorate over the course of the pregnancy.

††† The general VCT section refer to the service point at all clinics where HIV counselling and testing are offered to all members of the public interested in knowing their HIV status. This is unlike the ANC where only pregnant women are tested.
Encouragingly, it was reported that some clients come back of their own accord to have repeat CD4 counts done.

*The patients don’t return because at the time they are still healthy. They should be given information and taught that if they don’t comeback the virus keeps destroying their bodies, it doesn’t stop.* ~ KII # 5

“Need to have dedicated staff to follow up on patients with high CD4s within ANC as this promotes uniformity of messages compared to what they get from the general side. This relates to content of counselling for those who have high CD4 but need to keep track.” KII # 7

Setting up and sustaining support groups was also suggested as a measure which should also be encouraged for Wellness services as support groups

- aid patient education for instance appropriate infant feeding
- expose members to available treatment options
- provide opportunities HIV positive patients to share experiences with those in similar circumstances and seek clarity, for example, condom use with partners.

It was further suggested that the support groups should be split by age group with one for young adults and another for older clients.

*Support group are there on Thursday but not every week, if we could improve support group and categorise into different age groups one for adolescents, one for older women and women grannies and have age specific activities for the different age groups.” KII # 2

One of the key informant stated that there is a need for a designated Wellness clinic as it could help clients plan their pregnancies, monitor their CD4 count and nutrition and overall to remain healthy. It was also mentioned that there was need to follow up with clients post delivery and to have additional services such as social workers and nutritionists included in the Wellness services.

### 3.3.6. **Suggestions to Improve Referral Systems**

Key informants highlighted the need to improve communication and feedback systems between the different service points through the use of telephones and messengers to carry documents back and forth. At the time of data collection, return slips attached to referral forms were not being taken back to the out referral clinics. A suggestion was
made to facilitate movement of clients from one clinic to another through the provision of transport from a Type 2 clinic to a Type 1 clinic for clients who referred to Type 1 clinics for ART.

They should possibly provide transport to take patients to the ART clinic along with communication such as telephone call to alert the ART sister that a patient has been referred so that she can receive the patient. At present sending patients to the PMTCT sisters who then ask a counsellor to physically escort the patients to the ART clinic and sign them into their books. Then they leave the patient there to wait in a queue to be seen. ~ KII 6

Clients referred from a Type 2 clinic to a Type 1 clinic for ART can only present themselves at the Type 1 PMTCT clinic on Fridays. It was suggested that this restriction should be changed so that services can be accessed any day. Related to this is the need to revise the booking system. At the time of data collection, women who presented at ANC clinics for the first time for that pregnancy did not get the ANC evaluation, which includes PMTCT, on that day. Rather they were given a date when they should return. The clients should be permitted to access PMTCT at that first presentation even though they will not receive other ANC services on that day.

Interviewees also suggested better linkages between the services such that women who present to ANC with problems relating to ART can be seen to even though it is not the prescribed ART day for pregnant women.

When patients come to ANC when not well and it’s not a day when the ART clinic is seeing pregnant women, the patients are told to go home and return when clinic is open. They should be seen to any day that come. ~ KII 6

A further suggestion was that Wellness services should be integrated into the ANC and well baby clinic so that the set up is similar to that which is at the ART clinics.
Chapter 4: Discussion of Results

4.1. Discussion

HIV testing acceptance to for the 1350 women who accessed ANC for the first time for that given pregnancy was close to 100% as only one (1) woman opted out of the test. Acceptance by the greater majority indicates that universal testing for HIV can be achieved and with it opportunities for HIV positive pregnant women to protect their unborn children from MTCT of HIV. The focus of this study was to assess the extent to which women who tested HIV positive accessed follow on services to which they had been referred from the PMTCT service points. This section of the report uses the study findings and other existing literature to explain the observed service uptake levels and the implications thereof. By so doing the linkages between the different service points will be illustrated.

4.1.1. PMTCT Linkages to ART Services

Twenty-nine percent (29%) of 1349 women who agreed to test for HIV as part of PMTCT at the sampled facilities were found to be HIV positive. Among these 20% (n=77, N = 388) were eligible to begin ART.

It is of concern that 37% (n = 144, N = 388) of the women who tested HIV positive did not return to their respective clinics for their CD4 results. It is not known if they went on to access required PMTCT services at other PHC facilities. These women also missed out on opportunities to receive emotional support from other women who were in a similar position to them. Even more concerning is the fact that 17% (n = 24, N = 144) of the women who did not return for their CD4 results had CD4 counts equal to or below 200 and therefore required immediate referral to ART for treatment initiation.

The women who required ART initiation missed opportunities to do as much as possible to protect their children from MTCT and safeguard their own health for the benefit of their unborn children and other family. With CD4 counts below 200, these women were
easily susceptible to opportunistic infections and at risk of developing full blown AIDS. The increased disease burden faced by these women means that they may not be able to adequately care for their unborn children as well as other children they may already have. In addition, the chances of maternal mortality are significantly higher for women who develop AIDS related illness. As a result children born to women who do not initiate ART when required face increased risks of being orphaned which in turn increases their risks of dying in infancy or childhood.\textsuperscript{34} Should they survive infant and childhood mortality, their increased vulnerability from lack of a mother places them at greater risk of abuse and domestic instability compared to children with a living mother. PMTCT should therefore facilitate access services which help women remain healthy both for their sake and that of their children.

Only 23\% (n=18, N = 77) of the 77 of women who required ART initiation utilised the service. Forty-five percent (n=24, N=53) of those who did not access the service were unaware that they needed to begin treatment as they did not return for their CD4 results, Several reasons for the low utilisation levels and non return for results were suggested by key informants and have been postulated in other studies. These possible explanations can be broadly categorised as patient related; health worker related, quality of services and health system factors. The study did not seek information from patients themselves thus the patient related factors discussed are those suggested by key informants and existing literature.

**Patient Related Factors that Influence Services Utilisation**

Women attend ANC clinics in the knowledge that they will be assisted with managing their pregnancy, unfortunately some are them informed that not only are they HIV positive and, but they may also need to initiate ART. Thus they may not be mentally or emotionally prepared to accept the change in their lives. The emotional jolt that inevitably comes with learning that they are HIV positive may therefore be a contributory factor to them not returning to the clinic for their CD4 counts. It was suggested by some key informants that reluctance to accept an HIV positive status at times drove women to access PMTCT at other health facilities in the hope that they would test negative for HIV. Similar findings of patients not returning for the CD4 results and taking HIV tests at
other health facilities have been noted in other studies where women went for initial testing and received results but then went on to test at other facilities and therefore did not present for follow on PMTCT services where they initially tested.\textsuperscript{40, 47, 48}

Seeking alternative diagnosis therefore contributes to the number of women who miss opportunities to begin timely PMTCT prophylaxis and to access follow on PMTCT services at the health facilities where they initially tested for HIV. The 2010 PMTCT guidelines recommend that AZT prophylaxis for PMTCT should begin at 14 weeks gestation and that women who need ART for life commence treatment when their CD4 counts at 350 or less. Thus timely initiation of the required intervention may be hampered by delays resulting from testing at other health facilities.

Key informants suggested that non access of PMTCT services was due to low knowledge of these services by the HIV positive pregnant women. Similar low knowledge levels of PMTCT were found in a study on PMTCT service utilisation in Kenya where 52.4\% of women stated that they first received information on PMTCT at the health facility when they presented for ANC.\textsuperscript{49} Another study in Nigeria found that only 68\% of 164 pregnant women interviewed were aware of MTCT.\textsuperscript{50} This limited exposure to PMTCT messaging indicates need for more pre and post test counselling to orient expectant mothers to the options available for PMTCT. The perceived low levels of exposure to PMTCT messaging could also have contributed to the 37\% (n=144, N=388) CD4 result non return rate noted in the study as the women may not have been sufficiently prepared and informed of services available to them during the information and counselling sessions.

Preference for traditional medicines as opposed to conventional allopathic medicine was another explanation put forward by a key informant for low service utilisation. It was said that some women would rather consult traditional healers than go to a clinic. Stigmatisation from community members was another contributory factor cited. This fear of stigmatisation has been noted in other studies and tends to limit the level of disclosure to both partners and family members as the women fear violence and ostracisation.\textsuperscript{49, 28} These factors can limit level of utilisation for PMTCT related services.
and can influence ability to adopt an infant feeding practices which best protect babies. For instance, family members to whom the status has not been disclosed may frown upon formula feeding, children may therefore end up being mixed fed as opposed to being either exclusively breast fed or exclusively formula fed.

Though infant feeding was not expressly investigated in this study as part of the key informant interviews, it emerged as one of the PMTCT areas which requires strengthening. A key informant mentioned that, from the manner in which children refused to bottle feed during clinic visits and instead comfortably latched onto the mother’s breast suggested mixed feeding as opposed to either exclusively breastfeeding or exclusively formula feeding. This practice increases the chances of MTCT of HIV from breast milk.

A possible solution to these patient related factors that may influence service uptake suggested by key informants was to incorporate messaging on PMTCT and related services into information, communication and education material what is currently used for HIV/AIDS campaigns. Similar measures were suggested by Torpey et al. from their study on scale up of PMTCT in Zambia. Their results show that not addressing PMTCT information gaps and misinformation could lead to discrimination, stigmatisation and low service uptake. Their study also calls for involvement of male partners and traditional healers to mobilise communities to utilise PMTCT services.

The financial costs associated with ART initiation such as travel (bus fare and personal time) to and from clinics can also contribute to low utilisation of ART services by pregnant women. Each woman is required to attend three adherence counselling sessions at the ART clinic spread over a period of three weeks before treatment can be initiated. Thus women need to set aside extra time and money for these trips which are an addition to the required once monthly ANC clinic visits. Other studies have also found that the opportunity cost of time lost and the monetary costs associated with travel to clinics for treatment have been barriers to access of health care services. Consequently, it can be said that some of the factors which contributed to the low ART utilisation levels are patient related in that they have a direct effect on the patient and stem from perceptions.
and preferences that patients have. For instance, financial and time costs associated with clinic visits, and fear of stigmatisation from community members.

**Quality of Services Provided**

Key informants spoken to put forward some possible explanations why women do not make use of ART services. It was suggested that the quality of counselling given to the women does not sufficiently prepare them for this new aspect of their lives.

>*The quality of counselling is poor. The women don’t know why they are coming to ART. They say they were told to come there (ART clinic) but they came to the clinic for ANC. The women are not well prepared.* ~ KII 4

Poor quality of counselling was highlighted by Coovadia H in his review of current issues in PMTCT (2009) as one of the many inadequacies in PMTCT programmes in Africa today. 54 Key informants further suggested that the manner in which health services are delivered could also contribute to low service utilisation. For instance, the supposed poor mental preparation of women for ART initiation at PMTCT service points coupled with non-prioritised registration of women at the ART service points could lead to clients not returning to the relevant health facility to commence ART. Similar factors were identified by Nguyen et al. when they investigated barriers to PMTCT uptake in well resourced settings. Some of their findings were that poor quality of counselling, poor staff attitudes and inadequate follow through of assessments required for comprehensive PMTCT service provision contributed to low PMTCT coverage rates. 40

**Health Worker Factors that Influence Service Utilisation**

Low utilisation can also be partially attributed to the manner in which pregnant women are treated at the PMTCT and ART clinics. Poor staff attitudes towards patients was raised as a possible explanation for low service utilisation by key informants. Previous studies have shown that poor staff attitudes have contributed to low service utilisation with clients opting to either use a different service point where their status is not known or in the case of pregnant women to deliver at home. 28, 55, 40 Some studies have linked ill
treatment of patients to low morale amongst health workers resulting from low remuneration coupled with high patient load. Low remuneration was cited as a possible explanation for low staff morale by one of the key informants despite the occupation specific dispensation which was introduced for nurses in 2008 and other health workers in 2009.

High patient load was also cited as a possible barrier to service utilisation as staff were said to be overworked and demoralised. These statements are echoed in the findings of a study by Schneider et al. where the South African public health sector had an overall vacancy rate of 31.1%. The Schneider study also highlights the low salaries and low staff morale in other countries as having contributed to poor treatment of patients. Key informants interviewed for this study also pointed out poor treatment of patients as being a contributory factor to low service utilisation. According to key informants, reported low salaries and under staffing, as well as low morale have contributed to poor treatment of patients. There is need for policy makers to review recommend staffing norms at such service points to facilitate optimal quality of care to patients which is likely to encourage service utilisation.

Health System Factors that Influence Service Utilisation

The set up of ART services is another factor which could have contributed to the low utilisation levels. South Africa uses a medical model which relies heavily on doctors to prescribe ART and as such treatment is administered at dedicated ART clinics. ART clinics are structurally and operationally separate from other services at health facilities, such that ART can only be accessed from the specific service points. The heavy reliance on doctors to prescribe ART slows down the rate at which new clients can be initiated onto treatment, whilst the structural separation promotes fragmentation of services and impedes communication between service points. Countries such as Malawi and Lesotho have scaled up ART access by empowering nurses to administer ART.

Adopting such practices can help to speed up patient initiation onto ART as the nurses at ANC clinics could also initiate pregnant women onto ART, eliminating some delays in initiation of treatment and ultimately increase service utilisation and patient follow up.
This need to initiate treatment at PMTCT service points is particularly pertinent for women who access PMTCT at a Type 2 facility as they have to be referred to a Type 1 facility to ART initiation. Only 16% of women from the PMTCT clinic at the Type 2 facility who required ART initiation accessed the service compared to 27% from the Type 1 facility. This difference points to higher missed opportunities for access to required health services when services are not located on the same premises.

**Comparison between a Type 1 and Type 2 Facility**

When results from the two health facilities are compared, the Type 1 clinic, which is larger than the Type 2 clinic had a greater proportion of women who did not return for their CD4 results i.e. 40% compared to 29%. The Type 1 facility also had much higher patient loads than the Type 2 facility as 71% of all the HIV positive women accessed PMTCT at this facility. As such counsellors at the Type 1 facility may have spent less time counselling clients compared to staff at the Type 2 facility. This study did not specifically look at recommended staffing norms and patient load, however, it is likely that the higher patient load at the Type 1 facility has a bearing on the amount of time spent with individual clients and the overall quality of counselling. Though not highly statistically significant, a chi square test on patients returning for CD4 results by Type of clinic yielded a point estimate value of 0.032 indicative of some relationship between the Type of clinic where PMTCT was accessed and the return for CD4 count results.

<table>
<thead>
<tr>
<th>Women who...</th>
<th>Type 1 Clinic</th>
<th>Type 2 Clinic</th>
<th>Total</th>
</tr>
</thead>
<tbody>
<tr>
<td>Returned for CD4 Result</td>
<td>165 (60%)</td>
<td>79 (71%)</td>
<td>244 (83%)</td>
</tr>
<tr>
<td>Did not Return for CD4 result</td>
<td>112 (40%)</td>
<td>32 (29%)</td>
<td>144 (37%)</td>
</tr>
<tr>
<td>Total</td>
<td>277 (71%)</td>
<td>111 (29%)</td>
<td>388 (100%)</td>
</tr>
</tbody>
</table>

P-value = 0.032

Neither the Type 1 nor Type 2 facility had an active follow up system for women who did not return for their CD4 counts or for those who had been referred to ART to ensure that they initiated treatment. Pregnant women were expected to return to the facilities for follow on ANC visits, however ANC was provided by different staff from those who provided PMTCT thus patient follow up for PMTCT related services was not actively
done during these monthly ANC check ups. This indicates lack of communication between the different service points and a disconnect between ANC and PMTCT which could have contributed to the observed low service uptake levels. Greater efforts retain to patients in care are required from all service points.

PMTCT can be the point of entry into care for HIV positive pregnant women, more so for those who need to initiate ART. Women who may not return to the PMTCT service point for their CD4 results are likely to return for further pregnancy related care at ANC. Therefore, collaboration between PMTCT and ANC staff can help to follow up on women who do not return for their CD4 results and by so doing increase ART and Wellness service utilisation. Such collaboration would be help retain patients in care more so at Type 2 facilities where clients referred to ART have to access the services at a different facility. Differences between Type 1 and Type 2 facilities should be given due consideration by policy makers to ensure that health systems are structured in a manner which facilitates service utilisation and client retention.

4.1.2. **PMTCT Linkages to Wellness**

Wellness services available to HIV positive pregnant women are mostly limited to support groups (if operational), CD4 count monitoring and referral to treatment of opportunistic infections. Neither one of the two facilities where data were collected recorded referrals to Wellness services in the PMTCT register. Therefore it was not possible to assess linkages to Wellness. This is a significant shortcoming in the data management systems at the facilities as it compromises their ability to track all services rendered to clients.

Some women were referred to and made use of a support group that was operational at one of the clinics, however, these referrals were not recorded in the PMTCT register, neither was there an attendance register for the support group. The absence of structured support groups deprives women of the psychosocial support which they are often in dire need off. The pronouncement of an HIV positive result is for anyone an emotional event, women have been known to suffer emotional distress as a result of learning their HIV
positive status.\textsuperscript{47} Thus it is important that such support services are available to clients to ensure they receive holistic care.

Though difficult to comprehend or appreciate, pregnant women who are told that they are HIV positive undoubtedly go through a range of emotions from disappointment, to rage to despair, to hope, fear, acceptance and back again through the kaleidoscope of emotions. In all this, they not only think of themselves but also of their partners, their family, other children they may already have as well as the children they are carrying. The importance of psychosocial support for these women can not be over emphasised. The absence of adequate support groups at the sampled facilities is a significant failure in attempts to provide holistic care to HIV positive pregnant women and may be one of the reasons why some women did not return for their CD4 count results or access ART services.

In addition to support groups, a Wellness service which is available to all HIV positive pregnant women is a repeat CD4 count. The women are advised to have repeat CD4 counts done either before delivery at the PMTCT centres or post delivery at the general VCT sections. Neither the PMTCT nor general VCT teams make a note of those clients who come back for repeat CD4 counts. Furthermore, those clients who opt to have repeat CD4 counts done after they have delivered, are advised to do so not at the ANC section they are familiar with but rather at the section where counselling and testing is offered to members of the general public. This is a potential systematic barrier to service utilisation as the women may not be comfortable presenting themselves to the general section.

This was touched on by a key informant who stated that Wellness services should be integrated into ANC such that women could access services they needed at the service point they were familiar with. Referrals from PMTCT to other Wellness services such as treatment for opportunistic infections, or to social workers were reportedly made but again could to be ascertained as no record of such referrals are made against the client names in the PMTCT register. Protocols for referral of clients to Wellness need to be reaffirmed amongst PMTCT staff so that clients are referred to appropriate services as required.
4.1.3. **Referral Systems and Data Management Practices**

Staff at all the service points where data were collected indicated awareness of services to which clients could be referred if they were not offered at that particular service point. However, referral to such services was rarely recorded. For instance, of the 53 women who returned for their CD4 results and were eligible for ART initiation, only 33 were noted as having been referred in the PMTCT register. Of the 18 women who were found to have accessed ART, 4 women did not have a record of referral to ART services in the PMTCT registers. This indicates that though referrals are not always documented, women who are in need of ART are likely referred to the service. Lack of documentation makes it difficult to track such referrals, more importantly patient follow up to ensure they received relevant services is compromised by incomplete documentation.

Sixteen of the 388 HIV positive women did not have their CD4 count recorded in the PMTCT registers, 13 of these were among the 144 women who did not return for their CD4 results, 2 were already on ART and 1 received prophylaxis for PMTCT. This demonstrates incomplete documentation at the PMTCT service points, more so at the Type 1 facility as 15 of the 16 women accessed PMTCT at the larger clinic. This again points to the link between patient load and level of documentation. The Type 1 facility attended to more clients, had more incomplete patient records, and had higher non return rates for CD4 results compared to the Type 2 facility, indicating greater need for improvement at the Type 1 facility than at the Type 2 facility.

Data management practices at the PMTCT clinics can therefore compromise comprehensive monitoring of services to pregnant women. Referrals to ART were not always documented in the PMTCT register, none were recorded for Wellness and some client records were duplicated. This inability to consistently capture data for women against their first entry in the PMTCT registers compromises the ability of staff to track services rendered to clients over the course of their pregnancies. More so with the advent of dual therapy as it is necessary to monitor the administration of AZT at the specified periods over the course of an HIV positive woman’s pregnancy. Incomplete documentation can also hinder efforts to retain patients in care, for instance, in cases where the CD4 result was not captured in the PMTCT register, it would not be possible to
know whether these women required ART or Wellness. The quality of care given the patients is therefore affected by the data management practices employed by health workers at the various service points.

Despite the awareness and ongoing practice of referring clients to services they need such as treatment of opportunistic infections, only the PMTCT clinic at the Type 2 facility had a standard referral form that was given to clients. The form was limited to use with clients who are referred to the Type 1 facility for ART initiation. Review of the PMTCT registers at both the Type 1 and Type 2 clinics revealed that the only referral service which was at times recorded in the registers was to the ART clinic. No standard referral forms were used when clients were referred to Wellness services. In addition, the client identification numbers assigned to women at as part of the registration process at the ANC clinic before they access PMTCT were not used at the ART clinic even when the clients were from within the same facility. This exclusion of client identifiers further makes it difficult for clients to be tracked through the system should the clinics wish to do so at a later date.

Feedback mechanisms between the Type 1 and Type 2 facilities as well as those within facilities were not well structured nor were they utilised. Between facilities, the Type 2 clinic did not notify the Type 1 clinic of patients to expect for ART initiation, neither did the Type 1 facility communicate to the Type 2 clinic how many women who had been referred there had initiated treatment. Within the Type 1 facility similar communication between the PMTCT and ART service point was not part of routine feedback. This absence of regular feedback and communication between facilities and service points further compromises the health system's ability to retain patients within care.

**4.1.4. Potential Implications Resulting from Poor Linkages and Service Utilisation**

Ease of access to ART and Wellness services is a means through which the health and well-being of HIV positive mothers can be safeguarded. With these services, women are
given the opportunity to live healthy lives such that they are well enough to properly care for their children and families.

The availability of ART services was made known to women as was the need for them to initiate treatment, however uptake of the service at 23% (18 out of 77) was very low. Women who do not access treatment when needed face the possibility of declining health status increased morbidity, reduced quality of life and reduced capability to care for their unborn children. Access to ART coupled with good adherence has been shown to reduce health care costs mostly as a result of improved health status which translates to reduced outpatient visits and reduced hospitalisation. The non utilisation of ART services that was noted in this study may contribute to both the high levels of maternal mortality in South Africa (up to 43.7% were attributed to AIDS related causes) as well as to overall health care costs in the country.

Wellness services were therefore found to be fragmented and not well structured. Data management systems in use at the time of data collection did not attempt to track referrals to and utilisation of Wellness services. There was no way of knowing which wellness services women had been referred to and whether or not they had accessed the services. The different services which can be assessed under the Wellness umbrella are equally important. They include: social workers; treatment of opportunistic infections; nutrition counselling; and psychosocial support, however, only the latter would be an immediate need for all women. Facilitating access to psychosocial support is key to assisting the women to adjust to the discovery that they are HIV positive and the long term implications for their health and that of their children which come with an HIV positive status.

Also included in Wellness is CD4 monitoring such that treatment can be commenced immediately when needed. Ultimately, poorly developed Wellness services deprive women of opportunities to access services which can help them maintain optimum health. The observed poor linkages between PMTCT and Wellness services therefore creates barriers for HIV positive pregnant women to access services that can help them maintain both physical and emotional health.
The observed weak data management practices and client monitoring systems such as absence of feedback mechanisms between service points, non documentation of referrals, duplication of records, non utilisation of clinic patient numbers for internal tracking contribute weak linkages between service points and ultimately low service utilisation.

The vertical set up of services and lack of integration and communication may be limiting the flow of information which could be used to improve linkages between the service points as well as service provision and utilisation of facilities. For instance the fact that only 23% of women eligible to ART accessed the service could be used to flag the existence of barriers to service utilisation, which could then be addressed by the facilities and if required policy makers. Internal communication between service points coupled with use of internal systems such as clinic numbers, referral letters and feedback forms could also be used to facilitate patient follow up at all stages of the PMTCT cascade.

The low service utilisation levels noted in this study can have the following implications

- Continued deterioration of health status and progression to AIDS
- Increased risk of maternal mortality
- Increased risk of vulnerability and orphanhood for children born to these women
- Increased chances of infant and/or childhood morbidity and mortality for children who lose their mothers to AIDS related causes
- Increased patient loads in clinics from sick mothers and children
- Breakdown of family structures due to absence of maternal control
- Increased financial strain on families due to hospital bills and loss of income where mothers are not able to work
Chapter 5: Conclusions and Recommendations

5.1. Conclusion

This study was aimed at describing the linkages between PMTCT, ART and Wellness services and has to some extent described these linkages and referral systems well as staff opinions on what works and what can be improved.

The study results show that linkages between PMTCT, ART and Wellness services do exist, however these linkages are poorly developed such that women who could potentially benefit from these services are slipping through the cracks and missing opportunities to access required services. The majority of women (77%) who required ART services did not access the service. Linkages to Wellness services were weakest as the data management systems at PMTCT did not facilitate patient tracking to Wellness services.

HIV testing rate at ANC was close to 100% as only one out of 1350 opted out of testing, thus 99.99% of women went through the first step of PMTCT and therefore had the opportunity to access follow on services. Of the 388 women who tested HIV positive, 37% (n=144, N=388) did not return for their CD4 count results. This was the first loss to follow up in the PMTCT cascade as these women were not followed up by facility staff to ensure they accessed required PMTCT services at the facilities where they tested for HIV.

Of the 388 HIV positive women, 20% (n=77, N=388) had CD4 results which indicated need to initiate ART, however 24 of these women were among those who did not return for their CD4 results thus only 53 women were aware of the need to initiate ART. Thirty-five percent (n=18, N=53) of the women who were aware of need to initiate treatment were traced to the ART service point, however, only 23% (n=18, N=77) of all ART eligible women accessed the service showing significant under utilisation and missed opportunities for improved health for the women who did not make use of the ART services.
Though available, it could not be determined if women were referred to or made use of Wellness services such as repeat CD4 counts, psychosocial services (including support groups), social service and treatment for opportunistic infections as the only referrals captured in PMTCT registers were to ART.

Thus, data management practices as well as referral and feedback systems in place at the PMTCT, ART and Wellness service points did not facilitate accurate tracking of services rendered to individual clients or follow on services to which the clients may have been referred. Only 9% (n=33, N=388) of all the women who tested HIV positive had an indication of referral, all of which were to ART. Referral and feedback systems within and between health facilities will therefore need to be strengthened so that clients can be tracked as they move from one service point to another, which will also facilitate efforts to retain patients in care. The growing culture of monitoring and evaluation, and accountability that is taking place in South Africa, requires that data management systems provide reliable and good quality data to aid decision making. Thus the data management systems in use at the facilities will also need to be addressed.

The study further showed that staff working at the service points were aware of the suboptimal service utilisation levels and had ideas of measures to improve utilisation. These include: improved interdepartmental communication, improved staffing, improved salaries, integration of Wellness services into PMTCT service points and inclusion of PMTCT messaging in HIV/AIDS education campaigns. The issue of low staff morale will also need to be addressed as it can affect quality of services rendered to clients.

It can therefore be concluded that linkages between PMTCT, ART and Wellness services exist, however the linkages are not well developed, are under utilised and in need of strengthening to maximise the benefit to intended users. In describing the linkages between PMTCT ART and Wellness services, this study raised questions which require further investigation:

- Why did the greater proportion (77%) of HIV positive women who are eligible for ART not access the service and what can be done to improve utilisation?
- Why are Wellness services not well developed at the selected clinics?
5.2. Recommendations

Based on the results of this study and the input for key informants, the following measures are suggested to improve linkages between PMTCT, ART and Wellness services.

Short Term Improvements

The short term recommendations require little financial input to implement and can be instituted fairly easily if there is buy in from management and staff at all levels.

- Reorganisation of existing linkages between PMTCT and ART services through:
  - Improved registration processes for pregnant women referred to ART.
  - Active follow up of women who do not return for their CD4 results.
  - Active follow up with staff at ART service points to check status of women referred there by PMTCT staff.
  - Improved feedback mechanisms between service points.
- Inclusion of adherence counselling into PMTCT for those who require ART initiation.
- Improved inter service (departmental) communication.
- Improved supervision and communication between management and staff on what required improvements.
- Improved referral mechanism between service points, including documentation of referrals and follow up on referred clients.
- Consistent and correct documentation of client information and verification of reported numbers.
- Use of data collection, collation and reporting tools that facilitate monitoring of services rendered to individual clients.
- Provision of opportunities for clients to rate the quality of services they are given and what improvements they would like to see.
- Formation of linkages with grassroots (community based) HIV advocacy organisations for community education and awareness-raising activities.
**Long Term Improvements**

These recommendations will require budgetary input, technical support and commitment from management, they include:

- Improved staffing compliments at all service points.
- Expansion of available services to improve integration of Wellness into ANC.
- Strengthening protocols for referral to Wellness services.
- Introduction or integration of Wellness services into well baby clinics so that families can be attended to during well baby clinic visits.
- Improved data management systems at all service points to include consistent and correct documentation of client information and verification of reported numbers. This can include provision of computers and staff training.

It is also recommended that further research into causal factors behind client’s non-utilisation of services be carried out so that improvements made address these factors.
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### Annexures

**Annexure 1: Record Review Tool for PMTCT Clinics**

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<tr>
<th>Q. No</th>
<th>Question</th>
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<td>No..................................................................................2</td>
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<td>8</td>
<td>Received individual confidential post-test Counselling</td>
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<td>Yes..................................................................................1</td>
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<td>No..................................................................................2</td>
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<td>Received HIV test results</td>
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<td>Yes..................................................................................1</td>
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<td>CD4 results obtained</td>
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<td>Yes..................................................................................1</td>
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<td>11</td>
<td>Date of receiving CD4 results</td>
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<td>Period of time between testing and receiving CD4 result</td>
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<td>Three weeks .............3</td>
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<td>Referred to wellness clinic</td>
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<td>Yes..................................................................................1</td>
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<tr>
<td>14</td>
<td>Date referred to Wellness</td>
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<tr>
<td>15</td>
<td>Location of Wellness</td>
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<td>Onsite...............................................................................1</td>
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<td>16</td>
<td>Name of Clinic to which referred for Wellness</td>
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<td></td>
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<td>17</td>
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<td><strong>If No go to Q. 25</strong></td>
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<td>18</td>
<td>Date referred to ART</td>
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<td>Location of clinic to which referred to for ART</td>
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<td>Onsite.....................................................................1</td>
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<td>20</td>
<td>Name of Clinic to which referred for ART</td>
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<td>..........................................................................................</td>
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<td>Referral to service other than ART or Wellness?</td>
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<td>Yes.........................................................................1</td>
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<tr>
<td>No.........................................................................2</td>
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<td><strong>If No End</strong></td>
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<td>Alternative service(s) to which referred</td>
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<td>Service 1.................................................................</td>
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<td>Service 2.................................................................</td>
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<tr>
<td>Service 3.................................................................</td>
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<tr>
<td>23</td>
<td>Date of referral</td>
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<td>Location of the service(s)</td>
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<td>Service 2:</td>
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<tr>
<td>Service 3:</td>
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<tr>
<td>Onsite.................................................................1</td>
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Annexure 2: Record Review Tool for Wellness and ART Clinics

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<td>2</td>
<td>Type of Service offered</td>
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<td>Wellness……………………………………………………2</td>
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<tr>
<td>3</td>
<td>Date of first visit to service</td>
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<td><strong><strong>/</strong></strong>/2006</td>
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<td>4</td>
<td>Client CD4 count.</td>
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<td>5</td>
<td>Name of clinic from which referred</td>
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<td></td>
<td>Onsite…………………………………………………………………….1</td>
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<td>Clinic A……………………………………………………………………2</td>
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<td></td>
<td>Clinic B……………………………………………………………………3</td>
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<td>6</td>
<td>Service from which referred</td>
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<td>ANC……………………………………………………………………………….1</td>
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<td>Wellness………………………………………………………………………2</td>
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<td>Service accessed</td>
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<td>ART……………………………………………………………………………….1</td>
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<td>Nutrition………………………………………………………………………3</td>
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<td>Support group…………………………………………………………………4</td>
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<td>8</td>
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<td>If No End.</td>
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<td>No………………………………………………………………………………2</td>
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<td>9</td>
<td>Service to which referred</td>
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<td>ART……………………………………………………………………………….1</td>
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<td></td>
<td>Other……………………………………………………………………………...</td>
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<td>10</td>
<td>Location of onward referral service</td>
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<td>Onsite…………………………………………………………………………1</td>
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<tr>
<td></td>
<td>Offsite………………………………………………………………………..2</td>
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</tbody>
</table>
Annexure 3: Participant Information Sheet

Hello, my name is Annette Ching’andu, I am student in the School of Public Health at the University of the Witwatersrand. I am conducting a study on how prevention of mother to child transmission of HIV services are linked to referral services such as ART and Wellness. This information will hopefully be used to improve the PMTCT programme.

This is not an inspection, rather I am trying to learn what is really happening with PMTCT and other related services at health facilities. This facility was selected at random and not for any particular reason. If you choose not to participate there will be no negative consequences for you in any way. At the same time, participating in this study will not give you any advantages. Your participation in this study is entirely voluntary and you can stop the interview at anytime if you decide not to continue.

I will ask you to sign a consent form to show that you have agreed to participate in the study, the consent form will be kept separately from this interview guide and questionnaire. The information you give me will be completely anonymous, your name and the name of the facility you work in will not be used in the report. Please answer questions as honestly and completely as you can. The interview should take about twenty to thirty minutes to complete.

If you have any questions, you can contact Dr Mary Kawonga who is the programme coordinator in the School of Public Health at telephone number 011 717 2575.
Annexure 4: Participant Consent Form

I understand that I am being invited to participate in this study, and that it is my choice whether I agree to be interviewed or not. I also understand that I have the right to stop the interview at any time and can refuse to answer certain questions.

I understand that I will be asked questions regarding the kind of work I do and that my confidentiality will be carefully guarded so that no one besides the researcher will be able to know what I said. I understand that all the answers given by different people will be combined, and so I cannot be identified.

I agree to be interviewed for the project on Linkages between PMTCT, ART and Wellness services in Soweto.

Date ------------------ Participant’s signature ---------------------------------

I have fully explained the procedure to the participant. I have asked whether or not the participant has any questions regarding the interview and have answered the questions to the best of my ability.

Date ----------------- Interviewer’s signature --------------------------------
Annexure 5: Key Informant Interview Guide

Before we begin, I would like you to think about the work that you do and about the services that you and your team members deliver. You help lots of women and through them their families to live healthy lives. With these thoughts in mind ..........

1. What would you say are the key activities which ensure clients utilise your services?

2. How are these activities planned, implemented and supported?

3. What do you think are possible barriers people face when they want to utilise the services you and your team provide?

4. If you were able to do three things to improve utilisation of your services, what would you do?

5. What you think could be done to improve the referral systems between your clinic and other services to which you refer clients?

I will now ask you a few questions specifically relating to how your referral system works.
### Annexure 6: Referral Systems Tool for Key Informants

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<th>No</th>
<th>Question</th>
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<td>PMTCT</td>
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<tr>
<td>1</td>
<td>What are the operating times of your clinic?</td>
<td>Days open Operating hours Mon – Fri …………..……_____ to <strong><strong>hrs Mon – Sat …………..……</strong></strong>_ to <strong><strong>hrs Everyday …………..……</strong></strong>_ to ____hrs</td>
<td></td>
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<tr>
<td></td>
<td>Who draws the blood for any tests that may need to run?</td>
<td>A trained nurse………………………………...1 A lay counsellor………………………………..2 A doctor………………………………………...3 A lab technician………………………………..4 Other……………………………………………..</td>
<td></td>
<td></td>
</tr>
<tr>
<td>3</td>
<td>Who performs the HIV test?</td>
<td>A trained nurse………………………………...1 A lay counsellor………………………………..2 A doctor………………………………………...3 A lab technician………………………………..4 Other……………………………………………..</td>
<td></td>
<td></td>
</tr>
<tr>
<td>9</td>
<td>When do your clients receive their results?</td>
<td>Same day……………………….……….……1 Within a few days……………………….……2 At their next scheduled ANC visit……………………….……3 Other……………………….……….……4</td>
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<td></td>
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<tr>
<td>10</td>
<td>What is the time interval between receiving the sample and the results being available?</td>
<td>______ minutes / hours / days / weeks</td>
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<tr>
<td></td>
<td>Do you conduct CD4 counts as part of your service?</td>
<td>Yes……………………………………………..1 No………………………………………………2</td>
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<tr>
<td></td>
<td>How often are repeat CD4 counts done for the following viral load categories?</td>
<td>CD4 less than 200……………………......... CD4 between 200 and 350………………… CD4 between 200 and 500………………… CD4 over 350……………………………… CD4 over 500………………………………</td>
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<td>14</td>
<td>Where are the CD4 counts done?</td>
<td>Onsite lab………………………………….1 Send to a lab off site………………….2</td>
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<td>REFERRALS</td>
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<td>15</td>
<td>For the following HIV care and support services please say whether you provide the service or refer to the service, or if you don’t know whether the service exists or not</td>
<td>Yes Provide service No service, refer No service no referral</td>
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<td></td>
<td>Treatment of OIs</td>
<td></td>
<td></td>
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<td></td>
<td>Preventive therapy for TB/OIs</td>
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<td></td>
<td>ART’s</td>
<td></td>
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<td></td>
<td>NVP for the mother</td>
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<td></td>
<td>NVP for the baby</td>
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<td></td>
<td>Paediatric AIDS care</td>
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<td></td>
<td>Management of sexually transmitted infections (STIs)</td>
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<td></td>
<td>TB/Chest clinic</td>
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<td></td>
<td>Emotional/psychological support</td>
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<td></td>
<td>Post-test clubs/PLHA support groups</td>
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<td>Spiritual/religious groups</td>
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<td>Family planning services</td>
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<td>Home-based care</td>
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<td></td>
<td>Material/food support</td>
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<td>No</td>
<td>Question</td>
<td>Response</td>
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<td></td>
<td>Income-generating activities (i.e. micro credit)</td>
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<td>Legal services</td>
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<td></td>
<td>OVC support</td>
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<td></td>
<td>Traditional healers</td>
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<tr>
<td>17</td>
<td>Do you feel there are adequate referral services available, particularly for the needs of HIV-positive women?</td>
<td>Yes.................................1</td>
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<td>No.................................2</td>
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<tr>
<td>18</td>
<td>Are there standard forms that need to be filled when a client is referred?</td>
<td>Yes.................................1</td>
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<td></td>
<td></td>
<td>No.................................2</td>
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<tr>
<td>19</td>
<td>Do you keep a copy of this form or letter?</td>
<td>Yes.................................1</td>
<td></td>
<td></td>
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<td></td>
<td>No.................................2</td>
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<tr>
<td>20</td>
<td>Are there any reply forms attached to referral letters you give to clients?</td>
<td>Yes.................................1</td>
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<tr>
<td></td>
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<td>No.................................2</td>
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</table>

We have now come to the end of the interview, than you so much for taking to time to answer my questions.
Annexure 7: Ethical Clearance - Witwatersrand Committee for Research on Human Subjects (Medical)

UNIVERSITY OF THE WITWATERSRAND, JOHANNESBURG
Division of the Deputy Registrar (Research)

HUMAN RESEARCH ETHICS COMMITTEE (MEDICAL)
K14/09 Ching’landu

CLEARANCE CERTIFICATE

PROJECT

PROTOCOL NUMBER M080226
Linkages between PMTCT, ART and Wellness Services: an assessment of uptake of ART & Wellness services....

INVESTIGATORS

Miss AM Ching’landu

DEPARTMENT

School of Public Health

DATE CONSIDERED

08.02.29

DECISION OF THE COMMITTEE*

Approved subject to
Getting permission from relevant clinics

Unless otherwise specified this ethical clearance is valid for 5 years and may be renewed upon application.

DATE

08.06.19

CHAIRPERSON

(Professor P E Clouton Jones)

*Guidelines for written informed consent attached where applicable

cc: Supervisor: Dr KS Tint

DECLARATION OF INVESTIGATOR(S)

To be completed in duplicate and ONE COPY returned to the Secretary at Room 10004, 10th Floor, Senate House, University. I/We fully understand the conditions under which I/We are authorized to carry out the abovementioned research and I/We guarantee to ensure compliance with these conditions. Should any departure to be contemplated from the research procedure as approved I/We undertake to resubmit the protocol to the Committee. I/We agree to a completion of a yearly progress report.

PLEASE QUOTE THE PROTOCOL NUMBER IN ALL ENQUIRIES

[Signature]

[Signature]

0707048E 73
Annexure 8: Ethical Clearance - Gauteng Province, Department of Health - Directorate for Policy Planning and Research

Attention: Annette Ching’andu  
Date: 22 July 2008

APPROVAL FOR RESEARCH CONDUCTED IN GAUTENG

Approval is hereby granted for the data collection within Gauteng Province for the below mentioned study by Annette Ching’andu (Principal investigator) from University of Witwatersrand. The study is titled: Linkages between PMTCT, Wellness and ART CLINICS: An assessment of service uptake by pregnant women referred to those services from ANC clinics in SOWETO

This approval is limited/subject to:

- All ethical principles are observed and complied with during this study.
- Biannual status reports to be submitted to GDoH
- A research report should be submitted electronically to the Provincial Research Unit and the GDoH should be informed of the findings
- Details for publications of the findings to be communicated to the GDoH

Kindly note that it is also compulsory to request permission from the facility managers.

The Evaluator/Reviewer:
Dr V Kelisa

Research and Epidemiology Technical Support
Date: .................. 22/07/2008
Consent Form: Pimville Clinic

I understand that I Annette Ching’andu is requesting permission to access patient registers from the ANC, ART and Wellness service points in Pimville Clinic, for the period 17th-31st March 2008 as part of her data collection exercise. I understand that it is entirely up to my discretion whether or not to allow her access to the facility.

I understand that she will be ask a few members of staff questions regarding the kind of work they do and that their confidentiality will be carefully guarded so that no one besides the researcher will be able to know what they said. I understand that all the answers given by different people will be combined, and such that it will not be possible to identify who the information came from.

I agree to allow Annette Ching’andu access to the Pimville Clinic facility for the project on Linkages between PMTCT, ART and Wellness services in Soweto.

Date: [Signature]

I have fully explained the procedure to the Pimville Clinic facility Manager. I have asked whether or not she has any questions regarding the data collection activities I will conduct at the clinic and have answered the questions to the best of my ability.

Date ---------------- Interviewer’s signature --------------------------
Annexure 10: Permission to Access Lillian Ngoyi Clinic

Consent Form: Lillian Ngoyi Clinic

I understand that I Annette Ching'andu is requesting permission to access patient registers from the ANC, ART and Wellness service points in Lillian Ngoyi Clinic, for the period 17th-31st March 2008 as part of her data collection exercise. I understand that it is entirely up to my discretion whether or not to allow her access to the facility.

I understand that she will be ask a few members of staff questions regarding the kind of work they do and that their confidentiality will be carefully guarded so that no one besides the researcher will be able to know what they said. I understand that all the answers given by different people will be combined, and such that it will not be possible to identify who the information came from.

I agree to allow Annette Ching'andu access to the Lillian Ngoyi Clinic facility for the project on Linkages between PMTCT, ART and Wellness services in Soweto.

Date:
Facility Manager's Name:
Signature:

I have fully explained the procedure to the Lillian Ngoyi Clinic facility Manager. I have asked whether or not she has any questions regarding the data collection activities I will conduct at the clinic and have answered the questions to the best of my ability.

Date -------------- Interviewer's signature -------------------------------
Annexure 11: Services to which referred by level of CD4 Count at Government Run PMTCT Service Points

Pregnant women testing HIV positive are referred to services depending on their CD4 count as follows

- If the CD4 is < 200, the women are referred an ART clinic for treatment.
- If 200 > CD4 < 500, the women are referred to the VCT clinic for wellness where their CD4 count is monitored every six months, they also receive nutrition counselling and attend support groups. Wellness services are offered at the VCT clinics and are open to both men and women.
- Those with CD4 > 500 they are referred to wellness and advised to check their CD4 once a year.

PHRU adheres to the government stipulated CD4 counts to guide referral to ART. It should be noted that the women can also be referred to other services including social welfare, legal aid, STI clinics, and community based organisations depending on individual needs.