

**Patients' perspectives on the  
provision of tuberculosis and HIV integrated services in  
Sisonke district, KwaZulu Natal.**

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A mini-thesis submitted in partial fulfilment of the requirements for the award of the degree of Masters in Public Health (MPH) at the School of Public Health, University  
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WESTERN CAPE

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## ABSTRACT

Viewing the provision of TB-HIV integrated services from the perspectives of TB/HIV clients can help to identify ways to enhance the provision of these services. The aim of this study was to assess the provision of TB/HIV services including PMTCT from clients perspectives in order to make recommendations on ways to enhance the provision of TB/HIV/PMTCT services at facility and community level. **Method:** Secondary data analysis was undertaken on a survey that was part of a cross-sectional study conducted in 2008 in Sisonke district, a rural district of KwaZulu Natal province, South Africa. Exit interviews were completed by 274 clients accessing TB, HIV and PMTCT services in 10 selected facilities in Sisonke district. A questionnaire that had both closed and open-ended questions was used for exit interviews. Ethical clearance of the study was originally obtained from the Ethics Committee of the University of the Western Cape. The researcher sought permission from the custodian/owner (primary researcher) of the data. The researcher also adhered to maintaining data integrity including the confidentiality procedures as defined in the primary study. In analysing the data it was checked completeness and internal consistency. The quantitative part of the data was stratified, cleaned and coded. The qualitative part of the data was reviewed repeatedly and clustered. The measures of central tendency like frequency, means, median and standard deviation were used for continuous data while categorical data were analysed with frequency and proportions. The Chi-square test was used to assess the association between depend and independent variables.

### Results

The results of this study show that the respondents preferred accessing integrated TB-HIV / PMTCT services. Most of the respondents, especially a majority of younger respondents comprising of PMTCT (66.7%), HIV (29.8%) and TB (30.8%) categories reported that they were educated on HIV

matters. Also, most of the younger respondents (18 – 30 years) among the PMTCT category (74.3%) and most of the older respondents (older than 30 years) of the pre ART & ART category (71.2%) reported that they were educated about TB matters.

In general, the majority ( 90 %) of the respondents preferred TB/HIV/PMTCT services to be provided at the same place but a small majority (42%) of the respondents preferred to be seen the same clinicians. Most (68%) of the PMTCT younger (18-30 years) respondents preferred to receive TB-HIV integrated care at their homes while 70% and 68% of HIV and TB older respondents (>30 years) preferred to receive TB and HIV services at their homes. Viewing the advantages, disadvantages and barriers for accessing TB/HIV/PMTCT integrated services, there is a proportionate distribution in the responses amid the categories though the female respondents comparatively take the lead in reporting about their experiences in accessing TB/HIV/PMTCT integrated services. In this study, majority of the respondents demonstrated that they access good integrated TB-HIV / PMTCT services both at the facilities level and at home. Providing integrated TB-HIV / PMTCT services is widely accepted. Majority of the respondents especially the younger females preferred to continue receiving TB-HIV integrated care at their homes in comparison with older respondents.

## **Conclusion**

Most of the respondents comprised of females aged less than 30 years. These respondents like the services provided by the TB-HIV integrated services and want it sustained. They prefer the facilities to be in the same location. However, they prefer to consult different clinicians for the two different health conditions. The respondents also preferred to have HIV test at the same facility and to be visited at home by community health workers in support of the provision of TB/HIV/PMTCT care.

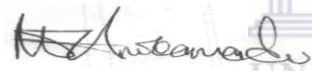
## DECLARATION

I declare that Patients' perspectives on the provision of tuberculosis and HIV integrated services in Sisonke district, KwaZulu Natal is my own work. That it has not been submitted for any degree or examination in any other university, and that all the sources I have used or quoted have been indicated and acknowledged by complete references.

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Date: 30<sup>th</sup> November 2012.

Signed.....



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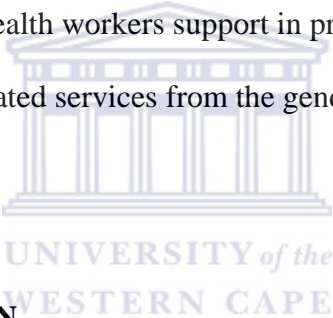
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## LIST OF ACRONYMS

ART:	Anti Retroviral Therapy
ARV:	Antiretroviral
CHW:	Community Health Worker
DOH:	Department of Health
HCW:	Health Care Worker
HIV:	Human Immunodeficiency Virus
IPT:	Isoniazid Preventive Therapy
KZN:	KwaZulu Natal
MDG:	Millennium Development Goal
NSP:	National Strategic Plan of South Africa
PLWHA:	People living with HIV & AIDS
PMTCT:	Prevention of Mother to Child Transmission
ProTEST	The World Health Organisation's-coordinated initiative to encourage testing for HIV by using VCT as an entry point to a variety of HIV/TB/STI prevention and care interventions
SA:	South Africa
SAPIT:	Starting Antiretroviral therapy at three Points in Tuberculosis therapy
TB:	Tuberculosis
WHO:	World Health Organisation
XDR-TB:	Extremely Drug Resistant Tuberculosis



## DEFINITION OF TERMS

- TB-HIV integration or collaboration: A process by which TB and HIV services are offered to end users simultaneously from the same facility or facilities within close range, in order to maximise treatment outcomes.
- Defaulter: A situation in which a TB client interrupts treatment for 8 consecutive weeks or more after the date of the last attendance while undergoing treatment.
- Directly Observed Treatment Short-course (DOTS): This is a strategy of treating tuberculosis that was recommended by the World Health Organisation. DOTS applicability relies on a combination of five strategies of fighting tuberculosis which include government / policy-level commitment, TB case detection, directly observed standardised treatment regimen by HCWs, constant drug supply and a standardised recording & reporting system
- Extremely drug resistant tuberculosis (XDR-TB): This is a situation that arises when someone suffering from tuberculosis is also resistant to three or more of the six classes of second-line drugs usually used in treating the condition.
- Isoniazid Preventive Therapy (IPT): This is a drug used to treat latent TB infection in HIV-positive clients likely to, or also are having M. tuberculosis infection
- Mother to child transmission: This is the transmission of HIV from infected mothers to unborn or newly delivered babies, which may occur during pregnancy, delivery or after delivery during breastfeeding.
- Multi-drug-resistant tuberculosis (MDR-TB): This situation arises when there is resistance to the two most effective first-line TB drugs known as rifampicin and isoniazid.

- Voluntary counselling and testing (VCT): This is a situation in which an individual undergoes counselling to enable her / him make an informed decision about being tested for HIV, assess their personal risk for HIV and develop a risk reduction strategy in this process.



## CHAPTER 1 INTRODUCTION

### 1.0 Introduction

### 1.1 Background

The co-infection of tuberculosis (TB) and human immunodeficiency (HIV) epidemics globally and particularly sub-Saharan Africa has led to dramatic increases in morbidity and mortality associated with both infections (Gandhi, Moll, Lalloo, Pawinski, Zeller, Moodley *et al.*,2009). Tuberculosis infection is currently the main cause of morbidity and mortality among HIV-infected clients (Mukadi, Maher & Harries, 2001). Although there have been successful programmes related to TB prevention and treatment, there has been a comparatively high mortality rate of HIV due to TB co-infection ranging between 25% - 40% prior to the establishment of antiretroviral therapy (ART) (Mukadi *et al.*,2001). However, there are improvements in providing ARTs resulting in declining mortality rates of up to 55% among TB-HIV co-infected patients with early initiation of ARVs in TB coinfecting patients as compared with sequential therapy, as demonstrated by the SAPIT study (SAPIT, 2008). . It was projected that in the year 2007, just prior to the study in which the survey reported here was conducted, 5.27 million people in South Africa were infected with HIV/AIDS (UNAIDS, 2008; Department of Health, 2008). KwaZulu Natal (KZN) is one of the provinces in South Africa (SA) with the highest rate of TB-HIV co-infection with two-thirds of new TB clients testing positive to HIV (UNAIDS, 2010).

Table 1 TB-HIV related profile of KZN

TB-HIV co-infection rate in KZN	> 70%
HIV prevalence rate	37.4%
HIV incidence rate	2.63%
Current number of PLHIV in the province	1,622,870 (i.e. 15.8%) of the total population
Estimate for patients in need of ART	486,861
Leading cause of death in the province	HIV and AIDS related illnesses
Second leading cause of death in the province	TB
Current diagnosed TB cases	118,000 (as at 2009, as reported by DOH Annual Report, 2010)
KZN TB caseload	1,156 cases per 100 000 population
Contributors to the high prevalence of HIV	Poverty, underdevelopment, very low male medical circumcision prevalence, concurrent sexual partnerships, transactional sex and late marriage further contribute (SANAC, 2011)
Budget allocated to ART	55%
Medical male circumcision (MMC) attainment	20%

Source: Office of the Premier, (2011).

Based on the lessons learned from ProTEST study and the increasing burden of TB-HIV co-infection worldwide particularly in sub-Saharan Africa, the World Health organisation (WHO) and other international bodies advocated for the implementation of collaborative TB/HIV activities (WHO, 2004). The WHO developed a policy on collaborative TB/HIV activities that has 3 main components as described below:

Table 2 The WHO policy on collaborative TB/HIV activities

<p><b>A. Establish the mechanisms for collaboration</b></p> <ul style="list-style-type: none"><li>- Set up a coordinating body for TB/HIV activities effective at all levels</li><li>- Conduct surveillance of HIV prevalence among people with TB</li><li>- Carry out joint TB/HIV planning</li><li>- Conduct monitoring and evaluation</li></ul>
<p><b>B. Decrease the burden of TB among people living with HIV</b></p> <ul style="list-style-type: none"><li>- Establish intensified TB case-finding</li><li>- Introduce isoniazid preventive therapy</li><li>- Ensure TB infection control in health care and congregate settings</li></ul>
<p><b>C. Decrease the burden of HIV among people with TB</b></p> <ul style="list-style-type: none"><li>- Provide HIV testing and counselling</li><li>- Introduce HIV prevention methods</li><li>- Introduce co-trimoxazole preventive therapy</li><li>- Ensure HIV care and support</li><li>- Introduce antiretroviral therapy</li></ul>

Source: World Health Organisation, (2004).

A viable means of providing integrated TB and HIV services involves a comprehensive worldwide approach that links prevention to education and treatment of TB and HIV/AIDS's continuum of care (adherence) in order to enhance treatment outcomes. With respect to the prevention and control of the co-infection of TB and HIV, the goal of integration of TB and HIV programmes is to improve the quality of the services, ensure the continuity / sustainability of

care, as well as prevent and decrease the burdens of the two epidemics on the patients and the society (WHO, 2004). Studies have shown that providing antiretroviral therapy (ART) significantly leads to over 80% improvement in TB treatment outcomes and survival rates amongst TB-HIV co-infected clients (Manosuthi, Chottanapand, Thongyen, Chaovavanich & Sungkanuparph, 2006). Integration of TB/HIV programmes has been found to be cost-effective for the effectual management of patients co-infected with TB/HIV (Buthelezi, 2008). However, despite the milestones made, at the time of this research progress had slowed in the implementation of collaborative TB-HIV activities because of a lack of commitment, requisite tools and systems to capture monitoring and evaluation data necessary to monitor the progress or where applicable, address the gaps (Gunnerberg *et al.* 2008).

Globally, there are 14 million people with TB and HIV co-infection (Gunnerberg *et al.*, 2008 ; USAID, 2009). A study conducted in KZN suggests that the effect of TB/HIV co-infection in pregnant women and their infants is important, as there is a 32-fold chance of mortality associated with being pregnant and TB-HIV co-infection (Khan, Pillay, Moodley & Connolly, 2001). Similarly, the consequence of maternal TB and HIV-1 co-infection on foetal acquisition of HIV-1 associated with high viral burden and CD4 suppression results to a higher overall vertical transmission of HIV-1 and greater risk of rapidly progressive in utero and infant HIV infection (Pillay, Sturm, Khan, Adhikari, Moodley *et al.* 2004).

## **1.2 Problem statement**

The risk of developing active TB in HIV positive people is ten times higher than in HIV-uninfected individuals, with possible drug interaction-related challenges (Datiko, Yassin, Chekol, Kabeto, & Lindtjørn, 2008).

Accessing and adhering to treatment poses particular challenges to such patients. Providing successful TB/HIV care ought therefore to consider the needs and views of the clients accessing the services, both within and outside the health facilities. Considering these needs involve viewing TB/HIV/PMTCT services from the eyes of the clients, which is not the norm. This is the gap that this study sought to address, in order to enhance treatment outcomes and improve service delivery of TB/HIV/PMTCT care to suit the needs of the patients, who are the primary stakeholders.

### **1.3 Study rationale**

The benefit of this study is to contribute to the enhancement of the survival of TB-HIV co-infected people undergoing simultaneous TB-HIV treatment, by viewing the services these people receive from their eyes (Ryan, 2008). Viewing the provision of TB-HIV integrated services from the perspectives of TB/HIV clients helps to assess the delivery mechanism of TB/HIV services, in order to identify factors that could contribute to enhanced performance of facilities in relation to implementation of the policy on collaborative TB/HIV activities. The enhanced performance of TB-HIV facilities will extend to improved treatment outcomes and quality of life to the end users. However, health facilities have few mechanisms established to minimise the challenges faced by patients accessing TB and HIV services (Sanou, Dembele, Theobald & Macq, 2004). Patients experience three layers of challenges in accessing TB-HIV integrated services. These include accessing the facility, regular attendance and experiences they had while in the health facility (Sanou, Dembele, Theobald & Macq, 2004). Moreover, pregnant women face a more complex situation as they contend with perinatal challenges and challenges associated with the dual infections of TB and HIV. Without adequate care, pregnant women co-infected with TB and HIV risk giving birth to co-infected babies with

resultant mortality and morbidity (Chintu & Mwaba, 2005). In this respect, integration of TB prevention and care into PMTCT program is paramount. Hence, the need for assessing the provision of TB/HIV/PMTCT services from patients' perspective as well as to explore means of enhancing the delivery of TB/HIV/PMTCT integrated services and ultimately improve treatment outcomes. To date there are limited studies conducted to assess the provision of TB/HIV/PMTCT services from patients' perspective particularly in rural areas with dual burden of TB and HIV. Hence the need for conducting this study in a rural district in KwaZulu Natal, namely Sisonke district.





## **CHAPTER 2            LITERATURE REVIEW**

### **2.1     Introduction**

This chapter reviews literature associated with the study, which

- assessed whether patients actually got what they were supposed to get, and
- what patients thought about the quality of care that they got, in integrated TB/HIV/PMTCT services in Sisonke District, KwaZulu Natal.

The literature review begins with the epidemiological, policy and programme foundations that led to the elements of integrated care assessed from patients' perspectives in this study. It reviews the burden of TB and HIV epidemics worldwide, in sub-Saharan Africa and in South Africa, including the necessity for including PMTCT as a part of the provision of TB and HIV integrated care. It outlines the policies, measures and strategies adopted to address the issues related to the implementation of the policy on collaborative TB/HIV activities from the upstream level and discuss the spill over effects to the individual end-users downstream. The focus is ultimately on the challenges faced by and the perspectives of the end users of TB and HIV integrated services including PMTCT (prevention of mother-to-child transmission). Finally, it reviews literature focusing on the perceptions of patients/clients on healthcare services in general.

#### **2.2.1 Global TB -HIV infection epidemiology**

HIV/AIDS and tuberculosis dominate the global burden of communicable diseases (Bonita, Beaglehole, & Kjellstrom, 2006). When combined with HIV/AIDS, TB is a major contributor to the global burden of disease (Corbett, Marston, Churchyard & De Cock, 2006). The HIV pandemic interplays with TB epidemic by promoting disease progression and mortality among TB-HIV co-infected people (Lawn, Bekker, Middelkoop, Myer & Wood, 2006).

In the year 2007, there were 33.2 million HIV prevalent and 2.5 million HIV incident cases recorded globally (WHO, 2009b). Similarly, there were approximately 30.8 million adults and 2.5 million children were living with HIV at the end of 2009 (UNAIDS, 2010). The HIV prevalence has resulted to increased incidence of TB (WHO, 2005). This situation made the World Health Organisation to declare TB as an emergency requiring immediate and extraordinary action in the African continent (WHO, 2005; Grimwood, Almeleh, Hausler, Hassan, 2006).

TB is the commonest infectious agent for global human disability and mortality, since the history of man (Zumla, Malon & Henderson, 2001). One-quarter of TB-caused deaths occurred in people living with HIV, as TB-HIV deaths was 456,000 in 2007 (WHO, 2009b). This situation has improved because of the progress made in scaling up ART provision with Africa accounting for 79% of the world's 9.27 million incident TB cases, of which 1.37 million (14.8%) were HIV-positive (WHO, 2009b). WHO (2009b) estimated that there were 13.7 million prevalent TB cases and 9.27 million new TB cases with 4.1 million (44%) cases of smear positivity in the year 2007.

### **2.2.2 TB and HIV epidemiology in South Africa**

In the recent past across sub-Saharan Africa as a whole, a quarter of HIV positive people had TB co-infection (De Cock & Chaisson, 1999). This TB and HIV co-infection poses various challenges in terms of resistance to drugs, diagnosis, treatment and burdens on the health system (Kassu, Mengistu, Ayele, Diro, Mekonnen et. al., 2007).

South Africa has the highest number of people living with HIV/AIDS worldwide. The national antenatal clinic HIV prevalence was 30.2% in 2010 (National Department of Health, (2010).

Similarly, the WHO/UNAIDS model projects that the overall HIV prevalence in South Africa was 17.3% (UNAIDS, 2012)). This is still the highest in the world. South Africa had the worst TB-HIV co-infection prevalence rate worldwide. In 2011, the figure was 768 per 100,000 population. South Africa also had 650 incident rate per 100,000 population in 2011. South Africa also recorded 230 /100,000 TB-related deaths in 2007, ranking South Africa as the nation with the highest TB mortality rate in addition to higher cases of Multiple Drug Resistant TB (MDRT-TB) estimated to be 16,000 cases, including cases of extremely drug resistant TB (X-DRTB) (WHO, 2009). South Africa also accounts for an estimated 28% of the global populace living with TB-HIV co-infection (WHO, 2009b).

### **2.2.3 TB and HIV epidemiology in Kwa Zulu Natal (KZN)**

TB-HIV co-infection rate in KZN is estimated at 80% in some settings (Gandhi et al, 2009). The HIV prevalence rate for KZN was 37.4% in the year 2007 (DOH, 2008). This figure has improved as the HIV prevalence among ANC clients tested was 28.3 (District Health Barometer, 2010). KZN's HIV prevalence was 39.5% in the year 2010 (National Department of Health, 2010). Also in Sisonke district of KZN, the HIV testing rate for those attending antenatal clinic was 74.7% while the rate of HIV testing in the community was 2.6% (Sisonke District Report, 2006). There is a marked improvement in this figure as the proportion of antenatal care clients tested for HIV was 79.6 (District Health Barometer, 2010). Sisonke, a part of KZN has a HIV prevalence rate of 37.2% in 2010 according to antenatal survey (National Department of Health, 2010). Based on the recent WHO global progress report on TB, South Africa has been ranked as country with the 3<sup>rd</sup> highest burden of TB (WHO 2009). KZN province is one of the provinces in South Africa with highest co-infection rate of TB and

HIV (UNAIDS, 2010). This has led to the establishment of the TB Crisis Management Plan by the WHO/AFRO African Health Ministers (DOH, 2006).

#### **2.4 TB-HIV integration and PMTCT**

The epidemiological situation of TB and HIV epidemics in South Africa also encompasses PMTCT. PMTCT in South Africa forms part of the component of integrated care as HIV/AIDS is the leading cause of mortality amongst children of less than five years across all provinces of South Africa, because of the vertical transmission of HIV perinatally (Bradshaw, Nannan, Laubscher, Groenewald & Joubert, 2004). It is estimated that 40,000 children in South Africa get infected with HIV annually because of inadequate PMTCT measures. (Statistics South Africa, 2010). Despite the global improvements in perinatal mortality, around 30% of pregnant women in South Africa were HIV positive (National Antenatal Survey, 2009). This situation underscored the need for South Africa to deliver effective PMTCT programmes (DOH, 2010). To lessen the transmission of HIV to infant from HIV-positive mothers especially through breastfeeding, PMTCT got prioritised in South Africa (HST, 2003). PMTCT runs simultaneously with VCT and ARVs prophylaxis in public-owned health facilities (HST, 2003). South Africa's PMTCT programme aims to raise the general standard of PLWH mothers and protecting infants from being HIV infected (HST, 2003). While South Africa's PMTCT programme is breastfeeding-friendly, at the time of the study, it provided free infant feeding formula to mothers that opt to replace-feed their infants (DOH, 2007c). The relationship of PMTCT with TB-HIV integrated care addresses the gap associated with studies suggesting that children with TB-HIV co-infection have a 6-fold higher mortality rate in comparison to adults with related health conditions (Jeena, Pillay,

Pillay, Coovadia, 2002). Generally, TB is the commonest cause of morbidity and mortality in children co-infected with HIV (Chintu & Mwaba, 2005).

Viewing the provision of TB-HIV and PMTCT integrated services from the clients' point of view aims at ensuring that the integrated services enhance treatment outcomes (Sanou, Dembele, Theobald & Macq, 2004).

Figure 1. South Africa's National HIV prevalence

Indicator	UNAIDS <sup>1</sup> 2008	UNAIDS <sup>2</sup> 2009	UNAIDS 2010
Total HIV population (Adults & children)	5 570 000	5 630 000	5 575 096
HIV+ Adults(15+)	5 240 000	5 300 000	5 056 294
Adult (15 -49) prevalence(%)	17.9	17.8	17.9
Adult HIV+female population(15+)	3 230 000	3 270 000	2 945 686
HIV population (children <15)	325 000	334 000	518 802
Total annual AIDS deaths	330 000	314 000	282 578
AIDS orphans	1 850 000	1 950 900	2 138 909
Adult AIDS deaths (15+)	297 000	284 000	252 348
Adult New HIV infections (15+)	352 000	344 000	332 512
New infections (children<15)	49 800	42 700	48 088
Need for ART among adults (15+)	1 475 000	1 584 000	1 407 026
Need for ART(children)	156 800	158 600	304 535
Infected mothers needing PMTCT	218 700	213 800	260 280

Source: National Department of Health, (2010).

## 2.5 Progress on the Implementation of collaborative TB/HIV activities worldwide

### 2.5.1. Progress of implementation of collaborative TB/HIV activities in South Africa

The objective of implementing collaborative TB and HIV activities according to the WHO is to lessen TB burden in HIV positive people and equally lessen the HIV burden in TB clients through provision on TB/HIV integrated care (WHO, 2004). The motivation for integrating TB and HIV activities is to ensure that TB-HIV co-infected clients receive optimal treatment and care.

### 2.5.2 The ProTEST initiative

South Africa is an active participant in an initiative called ProTEST. ProTEST was initiated in 1997 by WHO. It is an initiative established to stimulate a more articulate response to TB in areas with high HIV prevalence, through integrating TB and HIV control programmes, starting with HIV counselling / testing, and including a portfolio of prevention, care and support services (WHO, 2004). ProTEST's strategy is to lessen the burden of HIV-linked TB, with the merging of TB and HIV programmes (Faussett, Maher, Makadi, Nunn, Perriens & Raviglione, 2002). The ProTEST initiative also enhanced the provision of TB-HIV and PMTCT integrated services in South Africa, with the establishment of TB/HIV pilot districts. These pilot districts executed and appraised a comprehensive TB/HIV prevention package that targeted pregnant women. The stakeholders, because of the TB-HIV Pilot Districts Initiative gained several levels of benefits. Amongst these benefits were home-based carers that received trainings on TB, with DOTS supporters trained on TB. Other benefits that resulted from the initiative were that TB-HIV clients started benefiting from an enhanced service as it relates to HIV care and the staffs of the health facilities were empowered to provide enhanced TB-HIV care, amongst others (Hausler, Similela, Vilakazi, Mvusi, Naidoo, Penrose *et al.*,2004). Some of the lessons learned from the proTEST strategy include that there is:

- a high demand of TB-HIV services with high degree of cross-referral between the two services;
- a TB service targeting the attainment of an 85% cure rate amongst smear-positive patients;
- a well-established and highly standardized TB service;
- an HIV service with a more holistic approach to the patient with HIV;

The other side is that there are:

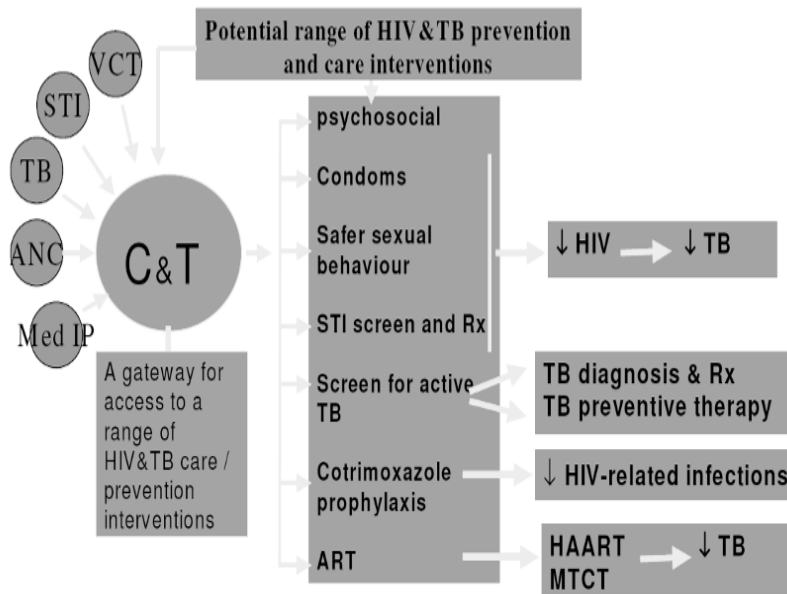
- overlapping of activities;
- staff under-utilisation.
- TB-HIV-related services duplication;

The result is that there are missed opportunities for TB and HIV prevention, diagnosis and management despite the benefits to integrating HIV and TB services (Coetzee, Hilderbrand, Goemaere, Matthys & Boelaert, 2004).

Another lesson learnt was that it was possible to establish and sustain a successful integration of TB and HIV services in resource-constrained settings characterised by programmatic, infrastructural, and staffing challenges. This is to ensure that persons co-infected with TB and HIV are the beneficiaries of the best possible treatment outcomes involving the introduction of VCT, Isoniasid preventive therapy and ART (Howard & El-Sadr, 2010).

Based on the lessons learned from ProTEST study, the WHO developed an interim policy for collaborative TB/HIV activities as a policy guide for country to address the dual burden of TB and HIV from National, provincial, district and community levels. The policy was enacted globally, regionally and locally in support of integrative TB-HIV activities (Grimwood *et al.*, 2006). Figure 2 shows the links between TB and HIV activities, as outlined in the ProTEST work. Figure 2 depicts the opportunity of accessing TB and HIV integrated care through a range of related clinical services including sexually transmitted infection services for TB care. The figure also represents the range of accessible TB and HIV integrated care available for patients. They include psychosocial care; screening for HIV, TB & STIs, treatment and condom distribution.

Figure 2. Operationalising the link between TB and HIV activities



Source: WHO / ProTEST, (2004).

## 2.6 Progress of South Africa in implementing TB-HIV integrated activities in South Africa

In consonance with WHO recommendations and the National Strategic Plans of South Africa, South Africa administers isoniazid preventive treatment (IPT) prior to starting other treatment regimens for TB-HIV co-infected people routinely, as studies elsewhere suggest that it is effective and economical (Foster, Godfrey-Faussett, & Porter 1997). Some of the progresses made in TB-HIV integrated activities in South Africa as reported by TB-HIV care (2011) include:

- Strengthening of the link between communities and facilities via funded facility-based community team leaders coordinating community care workers.
- Prioritisation of ART roll out in TB facilities;
- Improved health systems management;
- Implementation of policy changes that rationalise the use of health facilities
- Economical means of tracing TB contacts;



- Decentralisation of MDRTB treatment;
- A comprehensive TB-HIV care, from diagnosis to treatment;

In addition, there are efforts to scale up TB-HIV integrated activities throughout South Africa (WHO, 2009b). These efforts are geared towards improved case finding and overall improved treatment outcomes.

## **2.7 The PMTCT linkage to TB-HIV integrated activities in South Africa**

Around the time of this study, children born with HIV in South Africa annually were around 70,000, reflecting an inadequate PMTCT strategy against HIV/AIDS (WHO, 2009a). Exacerbated by the HIV epidemic, studies also show that there is a resurgence of TB amongst pregnant women (Margono, Mroueh, Garely, White, Duerr, *et al.*, 1994). This scenario has made PMTCT strategic in TB-HIV collaboration, which in turn complements the National Strategic Plan (NSP) of South Africa on HIV/AIDS and STIs (DOH, 2007). In this context, the NSP, aimed at reducing the incidence rate of HIV in children below 5 years, through prevention of HIV infection, as well as providing treatment, care and support for eligible clients. From a global perspective, the National Strategic Plan of South Africa on HIV/AIDS and STIs complements international policies and guidelines on PMTCT (de Paoli, Manongi & Klepp, 2002). Similarly, South Africa's revised PMTCT guidelines reflect the objectives of WHO recommendations. According to the DOH (2010), the said PMTCT guidelines advise that:

- all pregnant women that are HIV-positive should start receiving treatment at 14 weeks instead of in the last term of pregnancy;
- HIV-positive pregnant women should start treatment when their CD4 count drops below 350 cells/mm<sup>3</sup>;

- HIV-positive women should receive antiretroviral therapy postpartum.

On a general note, the challenges related to access to TB, HIV and PMTCT services reflect other challenges earlier discussed above including those within the facilities like programmatic, infrastructural, and staffing challenges (Howard & El-Sadr, 2010). Other barriers occur both within the facilities and beyond. These are related to stigma and discrimination of those that are co-infected with TB and HIV (NACA, 2003).

Figure 3. HIV prevalence amongst antenatal women in KZN by District, 2008 to 2010.

YEAR	2008			2009			2010		
	N	% HIV +	95% CI	N	% HIV +	95% CI	N	% HIV +	95% CI
<b>KZN Province</b>	<b>6 963</b>	<b>38.7</b>	<b>37.2 – 40.1</b>	<b>6 744</b>	<b>39.5</b>	<b>38.1 – 41.0</b>	<b>6 887</b>	<b>39.5</b>	<b>38.0 – 41.0</b>
Amajuba	420	34.7	29.2 – 40.7	410	37.3	33.3 – 41.6	407	39.5	30.5 – 41.6
Sisonke	343	35.8	31.6 – 40.3	324	35.2	29.3 – 41.6	325	37.2	31.6 – 43.2
Ugu	507	40.6	36.9 – 44.3	435	40.2	36.0 – 44.6	453	41.1	35.5 – 46.9
UMkhanyakude	413	39.9	34.8 – 45.3	396	39.7	33.1 – 46.6	389	41.9	35.6 – 48.5
UMzinyathi	339	29.2	23.7 – 35.2	340	28.2	22.2 – 35.1	334	31.1	24.9 – 38.1
UThukela	450	38.6	32.6 – 45.0	444	46.4	41.1 – 51.8	450	36.7	30.6 – 43.2
Uthungulu	641	36.1	31.4 – 41.2	597	37.7	33.0 – 42.6	712	36.9	32.8 – 41.3
Zululand	587	36.1	31.8 – 40.5	586	36.7	30.4 – 43.5	583	39.8	34.2 – 45.6
eThekweni	2 153	40.3	37.6 – 43.0	2 140	41.5	38.9 – 44.0	2 144	41.1	38.3 – 43.9
ILembe	424	35.8	30.7 – 41.3	421	40.6	36.5 – 44.9	416	42.3	37.5 – 47.3
uMgungundlovu	686	45.7	42.1 – 49.4	651	40.9	36.2 – 45.7	674	42.3	39.0 – 45.7

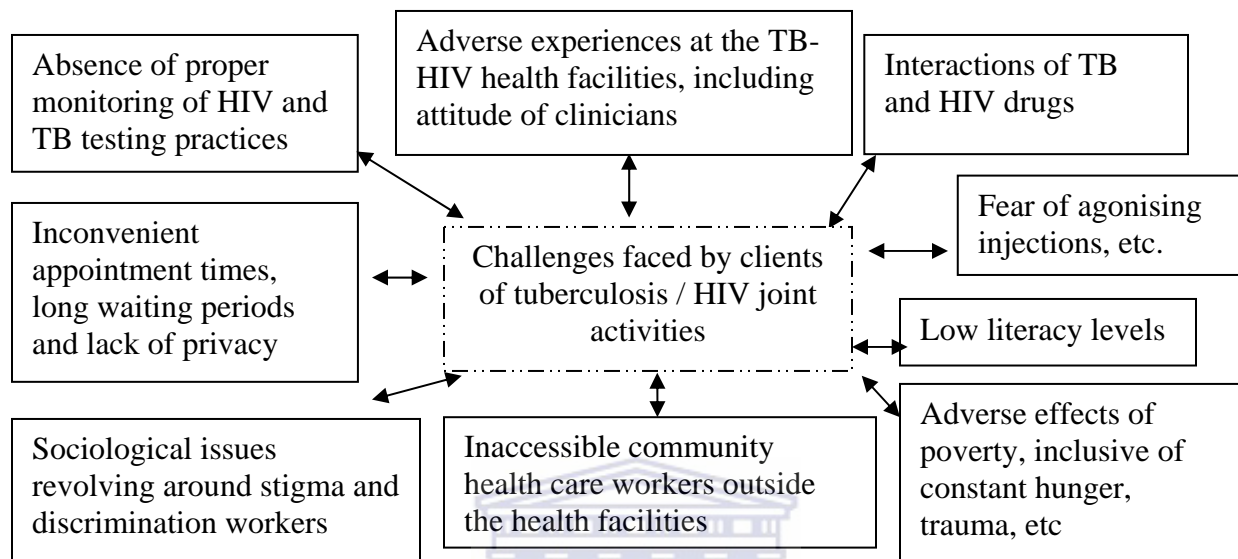
Source: National Department of Health, (2010).

## 2.8 Perception of patients on provision of TB/HIV/PMTCT integrated services

### 2.8.1 Issues associated with implementing integrated TB/HIV activities and action taken to address these gaps

Patients face a range of issues in accessing and adhering to TB/HIV services. These are outlined in Figure 4 below, and discussed in the following section.

Figure 4. Problem analysis diagram portraying challenges faced by clients of Tuberculosis and HIV integrated services including PMTCT.



The provision of comprehensive care to people co-infected with HIV and TB is a general strategy of attending to these peoples' needs by different disciplines ranging from medical care to social support (Narain, Chela & vanPraag, 2000). Clients' choices in taking treatment are framed by the disease's structural and psychological impacts and the society's cultural systems (Tulsky, Hahn, Long, Chambers, Robertson *et al.*, 2004). Inadequate human resources, poor health systems, insufficient clinical / laboratory infrastructure compound the situation in the face of TB-HIV co-infection, in addition to scant training programmes for integrated TB-HIV care (Corbett *et al.*, 2006).

The actions taken to address these gaps associated with the experiences of HIV positive people taking TB treatment or simultaneously undergoing treatment for both diseases include:

- Resolutions on how to implement HIV testing in TB patients by understanding issues surrounding HIV screening among TB patients as viewed from the local stakeholders' perspectives (WHO, 2005);
- Studies on HIV testing in relation to other diseases exclusive of TB, which indicated that knowledge, fear and access might provide significant challenges to HIV testing (Lee, Cheung, Kwong, Wan & Lee 2005).

### **2.8.2 Issues associated with TB-HIV integrated services at the national level**

Studies on this subject show that at the national level, there is underemployment of personnel, overlapping of activities and duplication of services for both TB and HIV (Coetzee *et al.*, 2004). Similarly, the ProTEST intervention's lessons gathered from some pilot sites in South Africa reported that uptake of, and adherence to Isoniazid Preventive Therapy (IPT) was low after HIV counselling and testing. The low IPT adherence reflected on the proportion of patients completing 6 months of IPT ranging from 24% to 59% at the 6 pilot sites (WHO, 2004).

### **2.8.3 Strategies used to address the issues associated with TB-HIV integrated services at the national level**

The strategies used to remedy the situations included:

- The introduction of the clinical record incorporating screening questionnaire at the Nelson Mandela Bay Clinic in Eastern Cape South, Africa. This led to a marked increase in the number of people coming for TB-HIV services. The purpose of introducing the clinical record was to check the bottlenecks associated with the tedious ritual of screening for TB every time the client attended follow-up care. This is constraining in facilities serving numerous people or in resource-constrained

environments (Wessels, Verkuijl, Reed, et al.2009). This can affect the clients in the form of long waiting times and unprofessional treatment from the clinicians because of work pressure.

- In the case of the ProTEST intervention's issues discussed above, the report stated that addressing this gap involved:
  - encouraging clients to attend clinic support groups by the clients,
  - empathic and non-discriminatory clinic services by the clinicians, and
  - support from family members and the community.
- ○ At a workplace HIV prevention and care program for miners, the intervention was successful as IPT uptake for eligible persons with HIV infection or AIDS that initiating IPT was successfully as high as 82%. On the other hand,, it was challenging to monitor treatment adherence (Charalambous, Grant, Day, *et al.*, 2004). Factors that added to the intervention's acceptability included:
  - attention paid to confidentiality issues,
  - efforts to minimise stigma,
  - the use of lay counsellors,

Addressing the difficulties of monitoring treatment adherence involved connecting IPT implementation at the HIV care and treatment settings to routine TB case finding activities.

## **2.9 Viewing TB-HIV integrated services from the perspective of the end users**

Adhering to integrated TB- HIV care relies on several psychosocial factors. A study (Daar, Cohen, Remien, Sherer & Smith, 2003) listed these psychosocial factors to include:

- the knowledge of the clients of TB-HIV co-infection about the condition,

- rationale for adherence to TB-HIV integrated chemotherapy,
- attitudes,
- cultural / health beliefs,
- coping skills,
- level of motivation
- confidence in the integrated therapy, and
- confidence in the health care workers (HCWs)

Related to this is that South Africans acquaintance with HCWs especially in terms of speaking the same language enhances adherence to drug regimens (Orell, Bangsberg, Badri & Wood, 2003). This suggests that relative familiarity with the HCWs by the clients accessing TB-HIV/PMTCT integrated services cushions the bottlenecks faced by these clients.

Finally, clients of TB-HIV integrated services might encounter abuse of their rights within and outside TB-HIV integrated facilities (Office of the Premier, 2006). These rights of the clients include the rights to care, dignity, information, choice, confidentiality, justice and security (World Care Council, 2006). The strategy adopted to address rights-based issues involved proper monitoring of HIV and TB testing practice, which is essential to guarantee and enforce such rights-related policies in agreement with international guidelines on human rights and HIV/AIDS (Gruskin, 2004). The reason for this is that the rights of PLWHs are the same with the rights of others who are HIV negative.

The discourse above indicates that the existence of cordial interpersonal relationships between patients of TB-HIV integrated care, the clinicians and the society is extremely vital to improved treatment outcomes.

## **2.10 Patients/clients perceptions on healthcare services**

Studies discussing patients' perceptions of healthcare delivery seek to find out what their opinion is on the service they receive and viewing their general experience while accessing services in the health facilities from their perspective, rather than from the perspective of planners, researchers, or providers. Patients' perceptions and anticipations are not simply linked because medical, clinical and health services are not technically inclusive (Priporas, Laspa and Kamenidou, 2008). Research accessed for this part of the literature review considers that healthcare services fall within the category of the service industry, and the field of services marketing. In recent years, there has been increased demand for better healthcare-based service delivery, because of continually evolving trends in societies' demographics and psychographics (Daniels, 1993; Lamb, Hair, McDaniel, Boshoff & Terblanche, 2004). Healthcare providers strive to meet these changing trends of the patients' needs and expectations by looking at the services they provide from the perceptions of these patients, who are increasingly more educated and informed about options and accordingly, more demanding (Grönroos, 2000).

## **2.11 Findings on patients' perceptions on healthcare services**

Studies suggest that the perceptions of patients on the quality of service they are likely to receive influence their degree of satisfaction positively, with resultant influences on the patient's choice in choosing a specific healthcare provider (Andaleeb, 2001). The plan of the healthcare industry is thus to ensure that these patients are satisfied with the services that they receive, as the industry considers that patient satisfaction is a key product of care (Lin and Kelly, 1995). Similarly, patient satisfaction boosts a health facility's image, with a resultant increased service use and patronage (Andaleeb, 1988). While much of this healthcare industry research is based in developed countries, it is relevant to this study because there are differences in the way people

undergoing HIV therapy including those of TB-HIV integration view the services they receive. This affects their attitudes towards treatment adherence and eventually treatment outcomes (Davis-Michaud, Yurk , Lansky, Asch, & Wu, 2004). On the other hand, prioritising patients' views makes it possible to address issues related to treatment defaults within and outside facilities offering TB-HIV integrated services and leads to improved treatment outcomes (Peltzer, 2009).

As described by Jackson, Chamberlin & Kroenke, (2001), evaluating patient satisfaction serves several purposes related to improving health care. Some of these are:

- to assess the quality of care
- to identify which aspects of a service need to be modified to enhance patient satisfaction and
- to assist health facilities in identifying beneficiaries that are likely to default or 'disenroll'

Another study found out that patient satisfaction with services received from health facilities depends on interpersonal relationship between the patient and the clinician like caring, empathy, reliability and responsiveness (Tucker, 2002). Furthermore, findings about patients perceptions on health services extends to other factors including core services provided at the health facilities like professional credibility, competence and communication skills on the part of the clinicians (Alrubaiee & Alkaa'ida, 2011). Generally human involvement in the service situation by the clinicians with display of empathy to the patient/client leads to positive patient outcomes such as pain relief, life saving and dealing with bitterness or disappointment with life after medical interventions (Bowers, Swan & Koehler, 1994).

Patients' perspectives on the provision of tuberculosis and HIV integrated services in Sisonke district, KwaZulu Natal therefore is an integral part of assessing healthcare service delivery in



relation to what the services are meant to provide, as well as addressing client satisfaction as described in the literature on patients' perceptions of healthcare services.

## **2.12 Research questions**

Based on the literature about TB/HIV integration, client satisfaction, and the importance of patient perspectives in assessing and improving services, this study asked a number of questions:

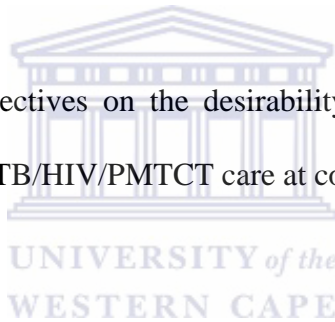
- i. How do the patients experience the provision of TB, HIV /PMTCT integrated care?
- ii. Do the patients' perceptions on provision of TB/ HIV/ PMTCT care reflect what guidelines and the literature suggest should be provided at facility level?
- iii. What are the constraints related to accessing TB/HIV/PMTCT services when viewed from patients' perspectives?
- iv. What are the patients' perspectives on the advantages of accessing integrated TB/HIV/PMTCT services?
- v. What are the patients' perspectives on the desirability of community health workers support in the provision of TB/HIV/PMTCT care at community level?

### **2.13 Aim**

The aim of this study was to assess the provision of integrated TB/HIV/PMTCT services from patients' perspectives.

### **2.14 Objectives**

1. To explore patients' perceptions on provision of TB/ HIV/ PMTCT care at the facility level.
2. To identify constraints related to accessing TB/HIV/PMTCT services from patients' perspectives.
3. To understand patients' perspectives on the desirability of provision of integrated TB/HIV/PMTCT services.
4. To explore patients' perspectives on the desirability of community health workers support in the provision of TB/HIV/PMTCT care at community level.



## CHAPTER 3

## METHODOLOGY

### 3.1 Introduction

This chapter discusses the research method for this secondary analysis as well as for the source study. This includes the study design, setting, population, sample size and procedure. It also discusses the data collection, processing, analysis, validity and reliability. Other topics discussed in this chapter are the study's generalisability, limitations and ethical considerations.

This study relies on a secondary analysis of data earlier collected from a larger ongoing project conducted in Sisonke district on TB and HIV integrated activities including PMTCT. The data was collected using exit interviews with patients accessing TB, HIV (pre-ART and ART) and PMTCT services in 10 selected facilities. This study reports on the analysis of interview data, conducted by the researcher.

### 3.2 Source Study and project study design

This study used a cross-sectional exploratory survey design. The use of the cross-sectional design was adopted because it was convenient and cost-effective for an exploratory study. The survey took in Sisonke district, KwaZulu Natal from August to September 2008. The overall research method used for this study consisted of a mixed methods research approach using both quantitative and qualitative methods. A mixed methods research approach as defined by Onwuegbuzie & Leech (2006) is a third research method paradigm that makes use of both quantitative and qualitative methods concurrently or sequentially. An ideal mixed methods study integrates the research objectives with both qualitative and quantitative approaches and methods (Tashakkori & Creswell, 2007; Johnson & Onwuegbuzie, 2004). The mixed methods research method enhances quantitative-based research outcomes as the collection, analysis, and interpretation of qualitative data can aid the interpretation of statistically and

practically significant findings. In the same vein, quantitative data collection, analysis and interpretation add more meaning to qualitative findings, hence the choice of mixed methods research. As it relates to this study, the use of mixed methods research is to ensure that the findings are exhaustive.

The instruments used for the exit interviews consisted of both closed and open ended question. The open ended questions were referring to perception on provision of and challenges related to provision of integrated TB/HIV/PMTCT services while closed ended questions were referring to kind of services TB, HIV and PMTCT patients received on the day of the visit at the facility. While the analysis is mostly quantitative, open ended questions were analysed qualitative by identifying categories and themes, then analysed quantitatively. The present sub-study focus more on quantitative analysis rather than a full mixed-methods study.

### **3.3 Study setting**

Sisonke District in KZN Province, South Africa was the site of the research. KZN is among the five provinces of South Africa with the highest TB-HIV co-infection rates (UNAIDS, 2008). Sisonke district has a geographic area of 11,128 km<sup>2</sup>, divided into five municipalities. These include Greater Kokstad, Ingwe, KwaSani, Ubuhlebezwe and UMzimkhulu. With a population of 500,000, the district has 13.6% urbanisation, 79% unemployment and 71% poverty rates (Sisonke District Report, 2008). The literacy level is low with farming as the predominant occupation. The district is poor in infrastructure with understaffed and poorly equipped community health centres. The setting is characterised by poor transportation systems with attendant restricted access to health facilities. Government-run health facilities and some Non Governmental Organisations (NGOs) provide community and home based TB and HIV services activities in Sisonke.

TB/HIV Care Association is one of the NGOs providing support to the provincial Ministry of Health in Sisonke and has been supporting provision and integration of TB/HIV/PMTCT services in selected facilities across the district since 2007. All of the facilities where data collection took place for this study were supported by TB/HIV Care Association. The ten facilities were purposively selected at sub-district level by considering the three levels of care and the existence of an antiretroviral treatment clinic at the three levels of care.

Hence, a total of 4 district hospitals, 1 Community Health Centre and 4 Primary Health Care clinics were selected out of the 45 facilities in the district.

### **3.4 Study population**

The study was conducted from August-September 2008. The study population comprised of antenatal-PMTCT and HIV (pre-ART & ART) and TB patients attending the 10 selected facilities in the district as contained in Appendix 1. The inclusion criteria included all registered TB, HIV and PMTCT clients between the period of January-June 2008 attending the selected facilities aged 18 years and above..

### **3.5 Sample size and sampling procedure**

The sample size was calculated based on the number of respondents that could be interviewed by field workers. Based on the pilot of the questionnaire, one field worker could interview up to 18 clients on a day. The maximum number of clients that could be interviewed by two field workers in ten facilities over 20 days yielded a sample of 360 clients. The numbers of clients for each category was drawn proportionately from the total number of registered clients from January –June 2008 in each facility. Each facility had a quota of clients to interview as illustrated in appendix I. The sample size was not intended to be statistically generalizable to all patients, but to capture a broad range of perspectives that were likely to reflect a substantial

part of the overall experience of the TB,HIV and PMTCT clients attending the selected facilities.

### **3.6 Sampling strategy and procedure**

The sampling frame used at district level consisted of a selection of facilities based on the level of care (i.e. district hospital, Community health centre and PHC clinic) and the existence of an antiretroviral therapy clinic at each level of care. The sampling frame used at patient level was based on all PMTCT, HIV and TB patients registered at the 10 selected facilities between January-June 2008 aged 18 years and above as illustrated in Appendix I.

The facilities were selected purposively based on the criterion listed above and a convenience sample of 360 patients was drawn proportionately from the total number of registered clients of each category (i.e. ANC-PMTCT, HIV and TB) in 10 selected facilities. The actual selection of individual study participants followed a systematic sampling approach. Systematic sampling considers selecting elements from an ordered sampling frame. Systematic sample units are consistently distributed over the population provided the said population is logically homogeneous. The feature of this approach is that it gives every element of the population under study a known and equal probability of selection in an ordered sampling frame (Black, 2004). An ideally random sampling that is representative of the general population is not usually possible within a clinical environment except if there are other sources of ensuring that the clinic population is truly representative of the general population. Ensuring true representativeness is therefore usually unrealisable, though it is possible to get a properly representative random sample of the population of patients who have access to, and use these facilities. This adds to the choice of adopting systematic sampling to minimise such gaps. The advantage of using systematic sampling is that it is easy,

quick and less expensive. In this scenario, it is necessary to select a part of the general population under study (Denise, Cheryl, & Hungler, 2001). A systematic sampling approach was used whereby at each point of service every second client exiting the consultation room was approached for the interview. Hence, the recruitment of the respondents was done on a daily basis, based on their attendance at the facilities.

### **3.7 Data collection and processing**

The data collection method used in this study consisted of an exit interview using a questionnaire. Trained data collectors interviewed the respondents as they were leaving the consulting rooms of the health workers at the TB/HIV/PMTCT units in the facilities. Invitation of these respondents to participate in the study was followed by requesting individual informed consent from the respondents before the interview. Participants' information sheet and informed consent forms are included in Appendix II and III.

The questionnaire was designed in English by the principal investigator of the project. A professional translator translated this into isiZulu language and back again into English. The content of the questionnaire elicited the following information:

- the services provided by the healthcare worker (HCW) on the day the visit to the health facility;
- challenges faced by the respondents in accessing TB, HIV and ANC-PMTCT services;
- opinion of the respondents on the involvement of community health workers (CHWs) in providing TB/HIV/PMTCT services at household level.

The questionnaires used in the study are in appendices IV and V respectively.

### 3.8 Data analysis

This study reports on a secondary analysis of data earlier collected from a larger ongoing project conducted in Sisonke district on integration of TB and HIV programmes including PMTCT. First, the data were checked to ensure completeness and internal consistency. The quantitative data was stratified, with subsequent cleaning and coding for analysis. The coding of the answers depended on the nature of the responses to the questions, which were either ordinal or nominal. Coding the questions with multiple responses according to the frequency of the responses took place. In this regard, it involved number-assignment of the commonest responses while other less common responses were clustered. The close-ended questions were classified as binary variables. These are:

- sex – female / male;
- age - 18-30 years / 31 years or older;
- respondents category - PMTCT / pre-ART & ART / TB.
- Other close-ended questions included 'Education about CD4 test', 'Underwent CD4 test', 'Education about ARVs', 'Education on adherence Support', 'Education about TB', choice of location of TB/HIV/PMTCT services facility, choice of provision of TB/HIV/PMTCT services by the same or different clinician and option of home visit by a community health care worker.

The responses contained in the qualitative part of the questionnaire used for the study were reviewed repeatedly and clustered into major subgroups prior to assigning a name to each of the emerging broad themes. These theme keywords were then used cluster comparable responses into subcategories by checking whether the theme keyword adequately captured



each response. These clustered responses were subjected to extra assessment and consideration, looking for subthemes and subcategories within the major subgroups.

The responses that appeared to cluster together under a subtheme were compiled to form a common category. The resultant categories were also inspected for similarities before compiling a final shortlist of comparatively mutually exclusive categories. This process of reviewing, coding and grouping responses into thematic categories and subcategories was the qualitative part of the analysis. Each of these was coded with a keyword label, and the numbers of responses per keyword were analysed quantitatively along with the responses to the closed-ended questions. The Statistical Package for Social Sciences (SPSS) version 19 was used to capture and analyse the data using descriptive statistics. The measures of central tendency such as frequency, means, median and standard deviation were used for continuous data while categorical data were analysed using frequency and proportions. A Chi-square test was used to assess the association between depend and independent variables. A Chi-square test with a p-value of 0.05 was considered as statistically significant.

### **3.9 Validity**

The extent to which an instrument measures what it originally aims to measure is validity (Denise, Cheryl, & Hungler, 2001). isiZulu is the main language spoken in Sisonke, a professional translator from Medical Research Centre (Durban Centre) translated the questionnaires from English to isiZulu and re-translation of the questionnaires from isiZulu back to English in order to ensure validity there after. A pilot study was conducted to ascertain if the respondents easily understood the contents of the questionnaire and if these questions were clear and unambiguous. Based on the results of the pilot, the questionnaire was modified accordingly.

### **3.10 Reliability**

Reliability implies the extent or degree of similarity of information got with the repetition of the study or measurement in question on the same respondents. It considers if the information will be the same or will change anytime it is measured and the extent to which such information will change (Katzenellenbogen, Joubert & Abdool Karim, 1997).

The same sets of questionnaires were used in all the health facilities or clinics during the data collection. All the subparts of the questionnaires had the same measurements using similar characteristics. For uniformity and consistency especially with respect to antenatal-PMTCT clients as well as HIV and TB clients most of the questions were similar with the exception of some as indicated in appendices 4 and 5. The fieldworkers were trained and were supervised during the collection of data. The analysis of these data was done by the researcher with support from a statistician and from the supervisors.

### **3.11 Generalisability**

Generalisability implies that the sample taken for the study can be generalised for the whole population. In quantitative research, generalizability usually means statistical generalizability, which requires a random sample and that other statistical assumptions are met. Because this was not a random sample of the facilities or the whole population, the study results are not statistically generalizable. However because the sample was quite large and was purposively selected to capture a wide range of facilities and programmes across the whole district, it is probably a good reflection of what is going on across the facilities supported by TB/HIV Care Association and, in respect of general constraints and views on accessing care, is probably generalizable to the population of the district. This study asked about experiences and perceptions on services provided by particular programmes and facilities and reflects the

services actually provided. Therefore the results are not generalizable to other facilities, where services may be better or worse or different. However this study, especially when added to the findings of other parts of the Source study, can be said to be relevant for theoretical generalisability – its findings can help to interpret and be applied to similar questions in similar settings.

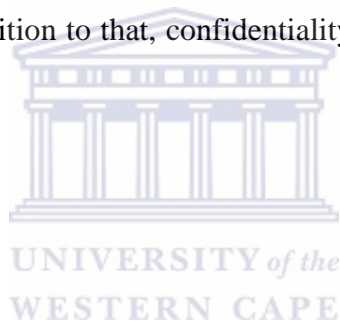
### **3.12 Limitations for this study**

This study is not free of limitation. The fact that the researcher did not participate in the design and data collection poses a limitation as it restricts the researcher from probing deeper into the responses given by the respondents, with the possibility of biases being introduced into the study. Another study limitation is that data on services received are based on patients' self reports, rather than direct observation of patient-provider encounters or medical record data. This could bias results in either direction. Patients could under-report because they forgot (recall bias) or did not understand, or they could over-report because of social desirability bias.

### **3.13 Ethical considerations**

The researcher sought permission from the custodian/owner (primary researcher) of the data. The researcher also adhered to maintaining data integrity including the confidentiality procedures as defined in the primary study. As this is an integrated study, the primary researcher earlier sought ethical clearance of the project. The letter of the approval of the major project/study is as contained in Appendix 8. Other activities executed by the primary researchers include that the ethical clearance for “Community participation in tuberculosis and HIV integrated activities, constraints and costs for enhancing the integration of tuberculosis and HIV programmes in a rural area of South Africa”, project number: CHHD 08-4 14 March

2008, was obtained from the Ethics Committee of the University of the Western Cape. The consent form and information sheets used in this project are appendices 6 and 7 respectively hereunder. In addition, the KZN Department of Health (Research unit), the District Manager of Sisonke and the facility managers of the selected health facilities gave permission for the study to take place. In order to maintain anonymity, there were no records taken of any participant's name on the questionnaires. The informed consent and interviews were in the preferred language of the participant either in English or in isiZulu. The information sheet approved by the Ethics Committee was translated into isiZulu. All participants were free to withdraw at any point devoid of any adverse consequences, even after granting their prior consent to the interviewers. In addition to that, confidentiality was maintained throughout the study.



## **CHAPTER 4            RESULTS**

### **4.1     Introduction**

This chapter presents the findings of this study based on the study questions and objectives.

The findings are categorised into three divisions comprising PMTCT Clients; TB clients and HIV or pre-ART & ART clients. These pre-ART & ART clients consist of those that are about to start receiving antiretroviral therapy (pre-ART) and those already receiving antiretroviral therapy (ART). The reason for differentiating between the respondents is that in these TB-HIV integrated clinics or facilities, the access point for some of the clients is via PMTCT clinics. Others access treatment as (antiretroviral therapy) ART clients while others undergo therapy as TB clients. The differentiation will enable the study to determine whether clients accessing TB-HIV services through these three different gateways have different experiences of provision of integrated care. The response rate was 76% (274 out of 360). Out of the 360 clients recruited, 274 clients agreed to be interviewed during the data collection period and this gave a response rate of 76%.

#### **4.2.1 Demographic characteristics of the respondents**

The demographic characteristics of the respondents included gender and age. As presented in Table 4.1 below, all PMTCT clients are of course women; however women were also the majority of both HIV and TB clients, with the TB clients coming closest to an equal gender distribution. On the average, the PMTCT respondents were younger than the HIV and TB respondents were. Similarly, looking at the CD4 count results, the table suggests that PMTCT clients are the healthiest, while the TB and HIV clients are sicker. The median CD4 counts are high for the PMTCT programme and comparatively low for the HIV and TB programmes, which suggest that many clients are still accessing TB/HIV/PMTCT integrated care late, when

they are quite sick but that some are doing very well on treatment. It can be suggested that these CD4 counts are much better than what was obtainable a few years ago, when single and double digit counts were extremely common.

Table 4.1 Demographic characteristics and the CD4 count of the respondents

Characteristics		Patients category		
		PMTCT	HIV (ART & pre ART)	TB
Age				
Mean		25.9	36.9	36.7
SD		5.9	10.5	11.5
Range (Age)				
Lowest		18	19	18
Highest		46	75	70
CD4 Count				
Median		298.5	177	94
Percentiles (IQR)	25	198.75	94.00	54.00
	50	298.50	177.00	94.00
	75	467.45	341.00	171.00
Gender N (%)				
Female		137 (100)	95 (77.9)	31 (46.3)
Male		0 (0.0)	19.6 (22.1)	36 (53.7)

#### **4.2.2 Distribution of participants by age groups**

The ages of the respondents were divided into two groups, as preliminary analysis with a larger number of age categories yielded cell sizes that were too small to analyse. The age groups chosen were:

- 18-30 years
- > 30 years (consisted of those that were 31 years old and older)

This classification was chosen because it was felt that differences in treatment experience and perceptions around the study questions would probably be different for younger adults (18-30) than for older adults, over 30 years, who have different overall roles and status in the community.

The PMTCT category consisted of 105 (76.6%) respondents aged 18-30 years and 32 (23.4%) respondents aged > 30 years. The pre-ART & ART respondents consisted of 36 (29.5%) respondents aged 18-30 years and 86 (70.5%) respondents aged > 30 years. The TB category consisted of 22 (32.8%) respondents aged 18-30 years and 45 (67.2%) respondents aged > 30 years. The older respondents outnumbered the younger ones, but for the PMTCT programme. See table 4.1 for details of the age groups.

#### **4.3 Themes and codes emerging from qualitative questions**

Before analysing the distribution of the answers to the open-ended questions, responses were read, re-read, and clustered into major and minor thematic groups. These are presented below, with the total frequency counts of the final code keywords. Details of these are as contained in tables 4.2 to 4.5 below. Responses that occurred twice or less than two times were coded as “other” and reflected diverse reasons, individual personal concerns and issues. While many

responses clustered in themes, there was considerable individual variability. While some of the “Other”/individual reasons were somewhat related to the major themes, they were left as “other” in order to avoid imposing homogeneity on a diverse issue.





Table 4.2 Advantages of having services for TB and HIV in the same clinic

		Category of Respondents					
		PMTCT		HIV		TB	
		N	(%)	N	(%)	N	(%)
1	Accessibility	40	17.6	42	23.2	29	27.9
2	Ensure Privacy/confidentiality	57	25.1	68	37.6	37	35.6
3	Save money/ Minimise transport costs	41	18.1	29	16.0	14	13.5
4	Time saving	58	25.6	29	16.0	15	14.4
5	Reduce stigma	3	1.3	1	.6	9	8.7
6	Diverse features/Other	28	12.3	12	6.6	29	27.9

Table 4.3 Disadvantages of having services for TB and HIV in the same place

		Category of Respondents					
		PMTCT		HIV		TB	
		N	(%)	N	(%)	N	(%)
1	Lack of privacy	17	41.5	8	44.4	0	0.00

2	Enhance stigma	6	14.6	0	0.00	0	0.00
3	Poor care given/non-comprehensive care	8	19.5	9	50.0	0	0.00
4	Lost in referral process	10	24.4	1	5.6	1	100
5	Lack of privacy	17	41.5	0	0.00	0	0.00
6	Other disadvantages / other	0	0.00	0	0.00	0	0.00

Table 4.4 Obstacles associated with TB/HIV/PMTCT Integrated services

		Category of Respondents					
		PMTCT		HIV		TB	
		N	(%)	N	(%)	N	(%)
1	Inconvenient	53	39.3	59	51.8	12	17.6
2	Enhance stigma	16	11.9	8	7.0	6	8.8
3	Poor care given/non-comprehensive care	19	14.1	9	7.9	1	1.5
4	Lost in referral process	22	16.3	0	0.00	18	26.5
5	Not getting medication on time/defaulting	23	17.0	21	18.4	31	45.6
6	Assorted personal issues / other	2	1.5	17	14.9	0	0.00

#### **4.4 Summary of the findings**

The following tables hereunder present the summary results of the descriptive analysis, disaggregated by the programme of access (PMTCT, HIV, and TB). The first few rows up to “education on adherence support” document patients’ reports on whether or not they received key elements of integrated TB/HIV care. The remaining items document what patients report as the advantages, disadvantages, challenges and preferences regarding accessing integrated services.

##### **4.4.1 Analysis of patients’ perspectives by gender and age in the three programmes**

This is a presentation of a combination of the descriptive results involving who reported receiving what services and expressing what perspectives), as well as analyses comparing age and gender groups across the 3 categories of programme. Also, the result suggests that there appears to be differences and trends, but that on the whole these are not statistically significant.

###### **4.4.1.1 Comparing responses between younger and older clients**

The result suggests that a majority of the respondents across the three categories were educated about the necessity of CD4 testing. While a greater proportion of younger respondents reported so in the PMTCT category, the older respondents did in the HIV and TB categories respectively. The trend continued in their reportages about undergoing CD4 testing, education about ARVs, education about TB, adherence support. In terms of the advantages, disadvantages and barriers to accessing TB/HIV/PMTCT integrated services, there seemed to be a proportionate distribution in the responses amongst the three categories though the younger respondents comparatively take the lead in reporting about their experiences in accessing TB/HIV/PMTCT integrated services. All the *p-values* suggest that the individual results across the three categories were predominantly not statistically significant. That is to say that 'Education about CD4 test',

'Underwent CD4 test', 'Education about ARVs', 'Education on adherence Support', 'Education about TB', 'Advantages/positive experiences reported', 'Disadvantages/negative experiences' and 'Challenges to access' were all not statistically significant and associated with the age groups of the respondents.



Table 4.5.1.1 Analysis of patients' perspectives on TB and HIV services provided with age group in the three programmes

Variable	Response	PMTCT Category				HIV (ART & pre ART Category)				TB Category					
		18 to 30 year-olds		> 30 years		18 to 30 year-olds		> 30 years		18 to 30 year-olds		> 30 years		p-value	
		n	%	n	%	n	%	n	%	n	%	n	%		
Education about CD4 test	Yes	25	67.6	12	32.4	35	29.2	85	70.8	.505	13	32.5	27	67.5	1.000
	No	0	0	0	0	1	50.1	1	50.1		0	0	2	100	
Underwent CD4 test	Yes	21	63.6	12	36.4	35	29.9	82	70.1	1.000	12	31.6	26	68.4	1.000
	No	4	100	0	0	1	20.0	4	80.0		1	25.0	3	75.0	
Education about ARVs	Yes	24	66.7	12	33.3	34	29.8	80	70.2	1.000	12	30.8	27	69.2	0.325
	No	1	100	0	0	2	25.0	6	75.0		1	100	0	0	
Education on adherence Support	Yes	17	65.4	9	34.6	20	25.0	60	75.0	1.000	9	31.0	20	69.0	0.704
	No	8	72.7	3	27.3	16	38.1	26	61.9		4	40.0	6	60.0	
Education about TB	Yes	75	74.3	26	25.7	30	28.9	74	71.2	0.360	6	23.1	20	76.9	0.281
	No	30	83.3	6	16.7	6	33.3	12	66.7		6	42.9	8	57.1	

Table 4.5.1.2 Analysis of advantages and disadvantages of services provided with age group in the three programmes

Variable	Response	PMTCT Category				p-value	HIV (ART & pre ART Category)				p-value	TB Category				
		18 to 30 year-olds		> 30 years			18 to 30 year-olds		> 30 years			18 to 30 year-olds		> 30 years		
		n	%	n	%		n	%	n	%		n	%	n	%	
	No	30	83.3	6	16.7		6	33.3	12	66.7		6	42.9	8	57.1	
Advantages/positive experiences reported	Accessibility	26	65.0	14	35.0	0.221	18	42.9	24	57.1	.209	10	45.5	19	46.3	0.463
	Ensure Privacy/confidentiality	43	75.4	14	24.6		15	22.1	53	77.9		11	50.0	26	63.4	
	Save money/Minimise transport costs	30	73.2	11	26.8		8	27.6	21	72.4		5	22.7	9	22.0	
	Time-saving	48	82.8	10	17.2		10	34.5	19	65.5		6	27.3	9	22.0	

	Reduce stigma	2	66.7	1	33.3		0	.0	1	100.0		0	0	0	0
	Diverse features	22	78.6	6	21.4		2	16.7	10	83.3		2	9.1	7	17.1
Disadvantages/ negative experiences	Lack of privacy	14	82.4	3	17.6	0.458	4	50.0	4	50.0	.107	0	0	0	0
	Enhance stigma	6	100	0	0		0	0	0	0		0	0	0	
	Poor care given/non-comprehensive care	7	87.5	1	12.5		1	11.1	8	88.9		0	0	0	0
	Lost in referral process	8	80.0	2	20.0		1	100	0	0.00		1	100	0	0

Table 4.5.1.3 Analysis of challenges associated with providing TB-HIV integrated services with age group in the three programmes

Variable	Response	PMTCT Category				p-value	HIV (ART & pre ART Category)				p-value	TB Category				
		18 to 30 year-olds		> 30 years			18 to 30 year-olds		> 30 years			18 to 30 year-olds		> 30 years		
		n	%	n	%		n	%	n	%		n	%	n	%	
Challenges to access	Inconvenient	43	81.1	10	18.9	0.955	23	39.0	36	61.0	.578	2	11.8	9	23.7	0.222
	Enhance stigma	13	81.3	3	18.8		2	25.0	6	75.0		0	.0	5	13.2	
	Poor care given/non-comprehensive care	16	84.2	3	15.8		3	33.3	6	66.7		1	5.9	0	.0	
	Lost in referral process	15	68.2	7	31.8		0	0	0	0		8	47.1	10	26.3	
	Not getting	19	82.6	4	17.4		6	28.6	15	71.4		10	58.8	21	55.3	



	medication on time/defaulting														
	Assorted personal issues	1	50.0	1	50.0		3	17.6	14	82.4		0	0	0	0

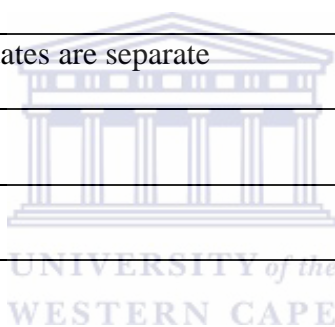


The assorted personal issues as presented in Table 4.5.1.3 above are presented hereunder as reported verbatim by the respondents are as presented in table 4.5.2.1 below.

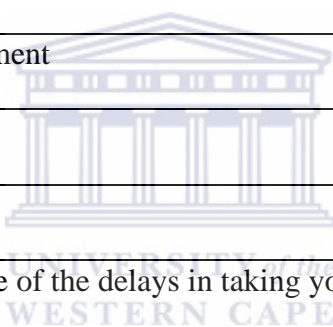
Table 4.5.2.1 Assorted personal issues or difficulties associated with accessing TB/HIV/PMTCT Integrated services

Bad service
Be on labour
Confusion
Delay
Different queues
Disclosing to different people
Distance
Far
Fear
Files will get mixed up
Hungry
I like getting my treatment in one place, going to different facilities will inconvenient me
I'm working
Insufficient medication
It will be intimidating
Its strenuous when you're ill
Lack of facilities in the nearest clinic

Laziness
Lazy
Long distance
Long queues
Lost
Male
Medical records in different places
Might not receive treatment in time
Money
No difficulties if the appointment dates are separate
Not Cared for
Not recognized
Nurses might not be there
Queues
Risk of getting ARV treatment in time
Risk of not getting your treatment in time
Senior professional; nurse not available
Service
Stigma
Swollen feet
The new people might be unfriendly to you
The risk of not receiving your treatment in time



The risk of not taking medication in time
They might conceive on the way
They will need details all the time
Time
Timid
Tiring
Transport
Walking
Weather conditions
Won't make it to different appointment
Won't make it to TB clinic
Work
Your condition will worsen because of the delays in taking your treatment



#### **4.5.1.1.2 Choice of clinician and location of TB/HIV/PMTCT integrated services from the age group angle**

The result suggests that a greater proportion (> 50 %) of the respondents preferred different clinicians. However, the younger respondents in the PMTCT category (82.7%) preferred the same clinician unlike the younger respondents of the HIV (26.3%) and TB (44.4%) categories. Most of the respondents reported that they preferred TB/HIV/PMTCT facilities to be located in the same place. All the *p-values* imply that the individual results across the three categories were not statistically significant.



Table 4.5.3 Perception on preferences on provision of TB/HIV/PMTCT integrated services from the age group angle

Variable	Response	PMTCT Category				HIV (ART & pre ART Category)				TB Category					
		18 to 30 year-olds		> 30 years		18 to 30 year-olds		> 30 years		18 to 30 year-olds		> 30 years		p-value	
		n	%	n	%	n	%	n	%	n	%	n	%		
Choice of clinician	Same	43	82.7	9	17.3	10	26.3	28	73.7	.672	12	44.4	15	55.6	0.122
	Different	62	72.9	23	27.1	26	31.0	58	69.0		10	25.6	29	74.4	
Choice of location	Same	95	75.4	31	24.6	33	29.2	80	70.8	0.722	22	33.3	44	66.7	1.000
	Different	10	90.9	1	9.1	3	33.3	6	66.7		0	0	1	100	

#### **4.5.1.1.3 Choice of community health workers support in providing TB/HIV/PMTCT integrated services from the age group angle**

Table 4.5.4 below illustrates that many (43.7%) of the respondents preferred community health workers (CHW) assistance in continuation of TB/HIV/PMTCT integrated services beyond the facilities. A majority (67.7%) of younger clients in the PMTCT category wanted CHWs support while a greater proportion of HIV and TB respondents preferred CHWs support. All the *p-values* suggest that the individual results across the three categories were not statistically significant.



Table 4.5.4 Choice of community health workers support in providing TB/HIV/PMTCT integrated services from the age group angle

Variable	Response	PMTCT Category				p-value	HIV (ART & pre ART Category)				p-value	TB Category				p-value
		18 to 30 year-olds		> 30 years			18 to 30 year-olds		> 30 years			18 to 30 year-olds		> 30 years		
		n	%	n	%		n	%	n	%		n	%	n	%	
Desire for community health workers support	Yes	21	67.7	10	32.3	0.344	31	30.1	72	69.9	1.000	12	33.3	24	66.7	0.539
	No	0	0	1	100		1	33.3	2	66.7		0	0	3	100	



#### **4.5.1.2 Provision of TB and HIV services based on gender**

Considering the provision of TB and HIV services based on the respondents' gender, the findings of the study indicate that a significant proportion of female HIV (pre ART & ART) (94.7%) of respondents and all (100%) female TB respondents reported on being provided services on HIV, especially on the provision of ARVs. Similarly, most female ART & pre ART respondents (83.2%) and female (72.2%) of TB respondents also reported that they received education related to the provision of TB services in the facilities. The trend continued in their reportages about undergoing CD4 testing, education about ARVs, education about TB, adherence support.

Most of the p-values, except for cross tabulating 'Education on adherence Support' with gender for the TB category suggest that the individual results across the three categories of respondents were not statistically significant. That is to say that 'Education about CD4 test', 'Underwent CD4 test', and 'Education about ARVs' 'Education about TB', were all not statistically significant and associated with the gender of the respondents.

Table 4.5.5.1 Analysis of patients' perspectives on TB and HIV services provided with gender in the three programmes

Variable	Response	HIV (ART & pre ART Category)				TB Category					
		Females		Males		p-value	Females		Males		p-value
		n	%	n	%		n	%	n	%	
Education about CD4 test	Yes	93	97.9	27	100.0	1.000	18	94.7	22	95.7	1.000
	No	2	2.1	0	.0		1	5.3	1	4.3	
Underwent CD4 test	Yes	91	95.8	26	96.3	1.000	18	94.7	20	87.0	0.613
	No	4	4.2	1	3.7		1	5.3	3	13.0	
Education about ARVs	Yes	90	94.7	24	88.9	0.373	19	100.0	20	95.2	1.000
	No	5	5.3	3	11.1		0	.0	1	4.8	
Education on adherence Support	Yes	60	63.2	20	74.1	0.362	17	94.4	12	57.1	0.011
	No	35	36.8	7	25.9		1	5.6	9	42.9	
Education about TB	Yes	79	83.2	25	92.6	0.357	13	72.2	13	59.1	0.510
	No	16	16.8	2	7.4		5	27.8	9	40.9	

The advantages and disadvantages to accessing TB/HIV integrated services, as presented in table 4.5.5.2 hereunder suggests there was a proportionate distribution in the responses amongst the two categories though the female respondents comparatively take the lead in reporting about their experiences in accessing TB/HIV integrated services.

'Advantages/positive experiences reported' and 'Disadvantages/negative experiences' were all not statistically significant and associated with the gender of the respondents.



Table 4.5.5.2 Analysis of advantages and disadvantages of services provided with gender in the three programmes

Variable	Response	HIV (ART & pre ART Category)				TB Category					
		Females		Males		p-value	Females		Males		p-value
		n	%	N	%		n	%	n	%	
Advantages/positive experiences reported	Accessibility	37	42.0	5	20.0	0.242	10	45.5	19	46.3	0.903
	Ensure Privacy/confidentiality	52	59.1	16	64.0		11	50.0	26	63.4	
	Save money/ Minimise transport costs	20	22.7	9	36.0		5	22.7	9	22.0	
	Time-saving	24	27.3	5	20.0						
	Reduce stigma	1	1.1	0	.0		0	0	0	0	
	Diverse features	6	6.8	6	24.0		6	27.3	9	22.0	
	Disadvantages/negati	Lack of privacy	8	57.1	0		.0	0.198	0	0	

ve experiences	Poor care given/non-comprehensive care	6	42.9	3	100.0		0	0	0	0
	Lost in referral process	1	7.1	0	.0		1	100	0	0



As presented in Table 4.5.5.3 under, there was a proportionate distribution in the responses amongst the two categories though the female respondents comparatively take the lead in reporting about their experiences in accessing TB/HIV integrated services as it relates to barriers to accessing TB/HIV integrated services, Also, 'Challenges to access' of TB-HIV integrated services is not statistically significant and associated with the gender of the respondents



Table 4.5.5.3 Analysis of challenges associated with providing TB-HIV integrated services with age group in the three programmes

Variable	Response	HIV (ART & pre ART Category)				TB Category				p-value
		Females		Males		Females		Males		
		n	%	N	%	n	%	n	%	
Challenges to access	Inconvenient	14	53.8	7	87.5	2	11.8	9	23.7	0.393
	Enhance stigma					0	0	5	13.2	
	Poor care given/non-comprehensive care	1	3.8	0	.0	1	5.9	0	.0	
	Not getting medication on time/defaulting	6	23.1	1	12.5	10	58.8	21	55.3	
	Lost in referral process	0	0	0	0	8	47.1	10	26.3	
	Assorted personal issues	5	19.2	1	12.5	0	0	0	0	

#### 4.5.1.2.1 Choice of clinician and location of TB/HIV integrated services from the gender angle

The result suggests that a most of the respondents comprising of females (69.5%) and males (66.7%) of the HIV category preferred different clinicians. Among the TB category, females (58.1%) and males (60%) preferred different clinicians. This suggests that there is no statistical difference. In the choice of location of the TB-HIV integrated facilities most of the females an all the males in the HIV and TB categories preferred the facilities to be located in the same locale, All the *p-values* suggest that the individual results across the three categories were not statistically significant.

Table 4.5.6 Perception on preferences on provision of TB/HIV integrated services from the gender angle

Variable	Response	HIV (ART & pre ART Category)				TB Category				p-value
		Females		Males		Females		Males		
		n	%	n	%	n	%	n	%	
Choice of clinician	Same	29	30.5	9	33.3	13	41.9	14	40.0	1.000
	Different	66	69.5	18	66.7	18	58.1	21	60.0	
Choice of location	Same	86	90.5	27	100.0	30	96.8	36	100.0	0.463
	Different	9	9.5	0	.0	1	3.2	0	.0	

#### 4.5.1.2.2 Choice of community health workers support in providing TB/HIV integrated services from the gender angle

The result as detailed in table 4.5.7 below indicates that females (100%) and males (87%) of the HIV category as well as females (100%) and males (85%) of the TB category of respondents preferred community health workers (CHW)'s assistance in continuation of TB/HIV integrated services beyond the facilities. The *p-value* for the 'Desire for community health workers support' for the HIV category suggests that it is statistically significant.



Table 4.5.7 Perception on preferences of community health workers support from the gender angle

Variable	Response	HIV (ART & pre ART Category)				p-value	TB Category				p-value
		Females		Males			Females		Males		
		n	%	n	%		n	%	n	%	
Desire for community health workers support	Yes	83	100.0	20	87.0	0.009	19	100.0	17	85.0	0.231
	No	0	.0	3	13.0		0	.0	3	15.0	

#### 4.6 Conclusion

The results as presented above indicate that the respondents, especially the females aged 30 years and below:

- Prefer to be attended by different clinicians rather than the same clinician in the course of accessing TB-HIV integrated services;
- Have appropriate access to TB/HIV integrated care that is in line with guidelines; and are adequately enlightened about the likes of CD4 test, ARVs, adherence Support, TB-HIV care, healthcare beyond the health facilities, etc;
- Associate TB/HIV integrated care with such features like ‘Accessibility’, ‘Ensure Privacy/confidentiality’, ‘Save money/ Minimise transport costs’, ‘Time-saving’, ‘Reduce stigma’, etc;
- Relate TB/HIV integrated care with such challenges like ‘Lack of privacy’, ‘Enhance stigma’, ‘Poor care given/non-comprehensive care’, ‘Lost in referral process’. Others are ‘Inconvenient, ‘Enhance stigma’, ‘Poor care given/non-comprehensive care’, ‘Lost in referral process’, ‘Not getting medication on time/defaulting’, etc.
- Prefer accessing TB-HIV integrated facilities and services in the same place rather than in different locations. This especially applies to those aged 30 years and above;

## **CHAPTER 5           DISCUSSION**

### **5.1 Discussion**

The purpose of this study was to assess the provision of TB and HIV integrated care from clients' perspective. This is in order to make recommendations on ways to enhance the management of TB-HIV co-infected clients and treatment outcomes in Sisonke district, reflecting the understanding that the basic link of HIV/AIDS to several other health issues makes TB-HIV integration a priority (Sweeney, Carol, Obure, Maier, Greener, Dehne & Vassall, 2012). There is equally a general agreement that TB-HIV integration can enhance the quality and continuity of care for PLWHAs and extend HIV services to those who would likely not have access to them, especially PMTCT clients (World Bank, 2009). Generally, there is a wide range of public health and clinical benefits associated with TB-HIV integration (The African Union Commission, 2006).

#### **5.1.2 Insights on TB/ HIV/ PMTCT services at the facility level**

The purpose of implementing collaborative TB and HIV activities is to lessen TB burden in HIV positive people and equally lessen the HIV burden in TB clients (WHO, 2004). This is achievable by viewing TB-HIV / TB integrated services from the eyes of those accessing the service. In this context, the respondents agreed that the services that they receive regarding the provision of integrated TB/ HIV/ PMTCT care at the facility level from health workers were optimal. This is in agreement with efforts made to scale up TB-HIV integrated activities throughout South Africa (WHO, 2009b). In a related development, the establishment of TB/HIV pilot districts in collaboration with the WHO's ProTEST initiative enhanced the provision of TB-HIV and PMTCT integrated services in South Africa (Hausler et al.2004). In relation to this study and on discussions on the specific services the respondents received in the TB-HIV collaborating facilities, majority of the respondents affirmed that these services were adequate. This considers the

frequency of the responses according to their categories, devoid of breaking them down further into age groups or gender. Broken down according to the responses as follows:

- ARVs education: Most of the respondents, as presented in Chapter 4 above reported that they had enlightenment on ARVs. Seen from the age group angle, these were PMTCT category <31 years (67.6%) and those > 30 years (32.4%). ART & pre ART respondents <31 years (29.2%) and those > 30 years (70.8%). TB respondents <31 years (32.5%) and those that are > 30 years (67.5%). Unlike PMTCT respondents, older ART pre ART and TB respondents report more about being enlightened about ARVs. ARVs are available and administered to registered attendants as a component of providing integrated TB and HIV/AIDS support, care and prevention. This is in consonance with the necessity for TB- HIV integrated services, which is to advance the quality of the services, guarantee the continuity / sustainability of care, as well as preventing and decreasing the burdens of TB and HIV on the clients and the society (WHO, 2004). On the contrary, the minute number of those that reported that they did not learn about ARVs is disputable as the administration of ARVs is an integral part of HIV-TB integrated services for those that are eligible. On a general note, it is a standard practice for PLWHAs to be educated about, and to have *pro bono* ARVs as part of the TB-HIV integrated treatment process if they are eligible.
- Support on TB-HIV adherence: Seen also from the age groups angle, most of the PMTCT (65.4%) of < 31-year olds and 34% of > 30-year olds, pre ART & ART (25%) of < 31-year olds and 70% of > 30-year olds, as well as TB (31%) of < 31-year olds and 69% of > 30-year olds respondents respectively reported enlightenment on TB-HIV adherence support. Treatment adherence support is an attribute of integrated TB-HIV/ PMTCT services. Even in the TB-HIV Pilot

Districts Initiative, one of the several benefits gained by the stakeholders were that the home-based carers received trainings on TB, with DOTS supporters trained on TB (Hausler et al., 2004). Some of the features of treatment adherence support are that it enhances the confidence of the clients of TB-HIV integrated services in the treatment that they undergo, increases these clients' motivational levels and promotes their coping skills (Daar, Cohen, Remien, Sherer & Smith, 2003). Treatment adherence support also helps the clients of TB-HIV integrated services to cope with the various challenges associated with taking TB-HIV integrated medicines including the long duration of taking such drugs and the phobia associated with the likes of agonising injections. Treatment adherence support equally helps these clients to cope effectively with effects of drug interactions and toxicities of TB-HIV dual therapy medicines (WHO, 2002). There is therefore the need to empower HCWs more by training them on the various components of TB-HIV/PMTCT integrated care. With proper monitoring and feedback mechanisms, the trainings they receive will enhance managing TB-HIV / PMTCT clients.

In a similar fashion, most of the respondents reported that they went for CD4 test after the advice of the healthcare worker on the day of the visit. This is a prerequisite to taking ARVs if one is HIV positive. When viewed from the angle of age groups, 63.6% of those younger than 31 years and 36.4% of the respondents older than 30 years reported that they underwent CD4 testing amongst PMTCT category. Similarly, 29.9% and 70.1% respectively of pre-ART & ART respondents reportedly underwent CD4 testing. Also amongst the TB categories, 31.6% and 68.4% respectively of those younger than 31 years versus those older than 30 years reported that they underwent CD4 testing.

Seen from the angles of age groups and gender, most of the respondents reported that they had optimal services in the course of their accessing TB-HIV/PMTCT integrated services. This is as contained in the tables in Chapter 4 above, as earlier mentioned.

#### **5.1.3.1 Education on the availability of TB services for HIV patients**

Education on availability of TB services for PMTCT and ART & pre-ART clients as an integral part of the TB/HIV/PMTCT services directly involved the PMTCT and ART & pre-ART clients. In terms of gender, most of the female respondents in the pre ART & ART and TB categories reported more that they had education on the availability of TB services in the facilities. Similarly, when viewed from the age group angle, the results show that the older respondents especially among the females know about the availability of TB services in the facility.

#### **5.1.3.2 Education on HIV services availability for TB patients**

Education on availability of HIV services for TB patients in the facilities is also an integral part of the TB/HIV/PMTCT services. The reason for this is that not all TB patients might be HIV positive. Similarly, not all HIV positive clients might be suffering from TB though they have a higher chance of contracting TB as a result of their being immune-compromised. As earlier reported above in Chapter 4, almost all the female HIV (ART & pre ART) and female TB respondents reported that they received education related to the provision of HIV services in the facilities. Majority of the male respondents in both categories also reported receiving education related to the provision of HIV services in the facilities. Most of these respondents for both categories also reported that they were educated about undergoing CD4 testing, about ARVs and on adherence support.

#### **5.1.4 Issues associated with accessing TB/HIV/PMTCT services**

The respondents reported on the issues that they associate with accessing TB-HIV and PMTCT integrated services. Age group and gender of the respondents, according to their categories separate this.

These issues include the following:

- Lack of privacy
- Poor care given/non-comprehensive care
- Lost in referral process

Other issues associated with TB/HIV/PMTCT integrated services and recorded as challenges are:

- Inconvenient
- Enhance stigma
- Poor care given/non-comprehensive care
- Not getting medication on time/defaulting
- Lost in referral process
- Assorted personal issues



The assorted personal issues as part of the items listed above seem to be in agreement with global trends as reflected in the literature review and in the conceptual framework of this study (Levin, Irving, Dikgang, Punwasi, Isaacs & Myer, 2006).

##### **5.1.4.1 Issues associated with accessing TB/HIV/PMTCT services from a broad perspective**

Clients of TB-HIV integrated services might not have access to proper nutrition due to sociological factors. Directly linked to malnutrition is the negative effects of poverty on families and communities, which is also daunting. Poverty may be characterised by constant hunger, trauma, and issues of family food insecurity including meeting up to the

infant's dietary needs as it specifically relates to PMTCT (Rose-Jacobs, Black, Casey, Cook, *et al.*, 2008). Also from the client's perspective generally and specifically in terms of PMTCT, the difficulties that are encountered include the constraints of adhering to infant feeding recommendations, (Stringer, Chi, Chintu, Creek, Ekouevi, Coetzee, *et al.*, 2008). Studies also indicate that HIV-related maternal depression may be part of the problems faced by PMTCT-HIV-positive mothers (Murphy, Austin, & Greenwell, 2006). Another difficulty relates to the maternal level of literacy (Eickmann, Lima, Guerra, Lima, Lira, 2003). This is because the level of literacy of the woman might determine her predisposition to optimal maternal care including observance of environmental issues like proper sanitation and ventilation (Rahman, Harrington & Bunn, 2002).

#### **5.1.4.2 Issues from the age group perspective**

The trend suggests that younger respondents' associate issues with accessing TB-HIV integrated care when compared with the younger respondents among the PMTCT respondents. On the other hand, older pre ART & ART regard accessing TB-HIV integrated care as daunting. There is a near-proportionate reportage among TB respondents of both age ranges with respect to associating TB-HIV integrated care with banes.

#### **5.1.4.3 Issues from the gender perspective**

The female respondents especially among the ART & pre ART category seemed to associate TB/HIV/PMTCT integrated care with issues. These issues discussed above coincide with constraints reported in other studies and include:

- Confidentiality, stigma and refusal to treat the clients by the staff of TB-HIV integrated services at the health facilities (Pool, Nyanzi & Whitworth; 2001).
- Non-convenient appointment times, long waiting periods and lack of privacy (Greene, 2004; Munro *et al.*, 2007).

- Difficulties associated with taking medications, lengthy period of treatment and sometimes the fear of agonising injections (Munro *et al.*, 2007) and the constraints associated with concurrent usage of ARVs and TB-treating drugs like medicine toxicities, threats of immune reconstitution events, interaction of drugs, etc (WHO, 2002).
- The challenges especially faced by PMTCT-HIV-positive mothers, like HIV-related maternal depression (Murphy, Austin, & Greenwell, 2006).
- The challenges faced outside the facilities including stigma, discrimination and threats to established interpersonal relationships (Ilyasu, Kabir, Galadanci, Abubakar, & Aliyu, 2005).

These issues associated with attending TB/HIV/PMTCT integrated services as discussed above shows that despite the achievements, there is the need to address some gaps to achieve effective service delivery of TB/HIV/PMTCT care.

### **5.1.5 Options linked with TB/HIV/PMTCT integrated services**

People accessing TB and HIV integrated services have an overwhelming desire for the sustainability of the services and for the facilities to be in the same location rather than in different sites. However, if given choices, they prefer to consult different clinicians for the two entirely different health conditions rather than one clinician.

#### **5.1.5.1 Choice of location of TB/HIV/PMTCT integrated facilities**

There is an overwhelming preference for the TB/HIV/PMTCT integrated services to be located in the same place. When viewed from the gender and age group perspective, there was no much difference in the responses. The overall result suggests that most of the older respondents preferred TB/HIV/PMTCT facilities to be located in the same place.



### **5.1.5.2 Choice of clinician within TB/HIV/PMTCT integrated facilities**

The choice of preferring same or different clinicians was viewed from both the age group and gender perspectives.

#### **5.1.5.2.1 Choice of clinician within TB/HIV/PMTCT integrated facilities from the age group perspective**

The choice of clinician within TB/HIV/PMTCT integrated facilities from the age group perspective shows that among the PMTCT clients, the younger ones prefer consulting different clinicians for both health conditions. Though the difference is not much, older respondents of TB category reportedly prefer different clinicians for both health conditions. The reason for this cannot easily be deduced and might merit further research.

#### **5.1.5.2.2 Choice of clinician within TB/HIV/PMTCT integrated facilities from the gender perspective**

Though not detailed here but as presented in Chapter 4, the outcome of the analysis shows that the female respondents preferred different clinicians attending to them, rather than by the same clinician while accessing TB-HIV and PMTCT integrated services.

The desire for people preferring TB-HIV and PMTCT integrated services is to take advantage of the worldwide aim to lessen TB burden in HIV positive people and equally lessen the HIV burden in TB clients (WHO, 2004). It will also help to ensure that the beneficiaries of TB-HIV integrated services undergo optimal treatment mechanisms. Also, the respondents that preferred different clinicians at the same facility might be because of the unprofessional attitudes of the available staff to the clients of TB/HIV/PMTCT services at the health facilities (Pool, Nyanzi & Whitworth; 2001). It might also be because the available staffs are not from the locale of the clients and as a result would not be effectively communicating with them in the same language (Orell, Bangsberg, Badri & Wood, 2003). This discussion on the

choice of clinician within TB/HIV/PMTCT integrated facilities from the gender perspective relies on hypothesis based on the literature reviewed earlier in this study.

#### **5.1.6 Option of community health workers support in extending TB/HIV/PMTCT care at community level**

A significant number of respondents were interested in continuing TB/HIV/PMTCT integrated care in their homes, with the assistance of the CHWs. Most of the respondents' preferred home visits by community health workers in continuation of their treatment. When viewed from the gender and age group perspective, there is not much difference in the responses. Significantly, the younger respondents embraced home visits more than the older ones. Specifically seen from the age group angle, the PMTCT respondents that preferred home visit by CHWS were 67.7% of the younger respondents and 32.3% of the older respondents. The pre ART & ART respondents that preferred home visit by CHWS were 30.1% of the younger respondents and 69.9% of the older respondents. The TB respondents that preferred home visit by CHWS were 33.3% of the younger respondents and 66.7% of the older respondents. It appears that apart from the PMTCT respondents, older ART & pre ART and TB respondents embrace the option of community health workers support in extending TB/HIV/PMTCT care at community level through home visits. The minority of the respondents that declined visits at home in continuation of their treatment might be because of issues revolving around stigma. Stigma and the so-called 'disclosure to other people' are the most frequently reported issues. It is likely one of the major reasons for respondents refusing visits at home in continuation of TB/HIV/PMTCT integrated care.

Some of the features of needing TB/HIV/PMTCT care outside the health facilities and subsequently at the homes of the clients are that:

- It makes it possible for people accessing TB/HIV/PMTCT care to have a positive mindset about their condition and be able to accept counselling by HCWs as it relates to living positively with their conditions (Zandile, 2004).
- Accessing TB/HIV/PMTCT care makes it possible for the adequate training of HCWs in counselling and interpersonal communication skills. This capacity building invariably extends to the primary beneficiaries and leads to improved quality of TB/HIV/PMTCT care (MOHSS, 2004).

Effective home service-delivery of TB/HIV/PMTCT care is an inalienable complement to the health facilities-based integrated services. A very important advantage of extending TB/HIV/PMTCT to the home of the clients is that it will underplay the 'death sentence' associated with HIV diagnosis, which is regarded as being equivalent to a death sentence if the result turns out to be positive (Bradford, 2004). It is therefore vital to extend TB/HIV/PMTCT integrated services beyond the health facilities, especially as it is possible and effective both within the health facilities and at the homes of the clients (Friedland, Harries & Coetzee, 2007b).

## CHAPTER 6 CONCLUSION AND RECOMMENDATIONS

### 6.1 Conclusion

This study assessed the provision of TB and HIV integrated care including PMTCT in Sisonke district, KwaZulu Natal from the perspective of the clients. This was in order to make recommendations on possible ways to enhance the management of TB-HIV co-infected clients and treatment outcomes. Viewing TB-HIV and PMTCT integrated services from the perspective of the beneficiaries was a strategy used to achieve this aim.

Topics under consideration included perceptions of respondents on the services offered by health workers on the day of the visit; the study showed that the respondents were happy with the TB/HIV/PMTCT integrated services they received from the health workers despite the existence of some gaps. Other issues that were studied included education and provision of CD4 test, ARVs, TB drugs and availability of treatment adherence support by health worker. It was also determined that most of the respondents have access to these services as an integral part of the TB-HIV and PMTCT integrated services. The issues faced by clients while accessing TB/HIV/PMTCT services were cross tabulated with gender and age groups; it was ascertained that most of the people that access these services were females and that most of them were younger people. On the preference of respondents on provision of TB/HIV/PMTCT care, the study found out that this is widely accepted. The study found out that most of the respondents especially the older ones preferred receiving treatment at the same place. The respondents also registered their preferences to have an HIV test at the same facility and their preference for home visit by community health workers in support of the provision of TB/HIV/PMTCT care, but not to undergo treatment by the same clinician for TB/HIV/PMTCT care.

Contrary to expectations, clients that are accessing TB/HIV/PMTCT care are pleased with the services and prefer accessing TB/HIV/PMTCT services, despite the drawbacks

associated with HIV and TB. Another point worth mentioning is that contrary to expectations, younger respondents preferred to continue receiving TB-HIV integrated care at their homes in comparison with older respondents.

## **6.2 Recommendations**

1. There is the need to replicate, establish and continue promoting integrated TB-HIV and PMTCT services.
2. There is the need for the recruitment and training of more HCWs in delivering TB-HIV and PMTCT integrated services.
3. It is suggested that integrated TB-HIV and/PMTCT services should focus on clients satisfaction in order to enhance its delivery.
4. The challenges associated with integrated TB-HIV and/PMTCT services especially as it relates to staff shortages, stigma and confidentiality issues should be addressed with adequate policies entrenched to safeguard the interests of the clients.
5. It is suggested that the community should be more enlightened and made to be actively involved in integrated TB-HIV and/PMTCT services. This will help to reduce the stigma associated with TB, HIV and AIDS. It will also enhance HIV-related health promotion within the society.
6. There is the need to promote interventions that should actively involve more males in TB/HIV/PMTCT integrated services. This will amongst others remove the labelling of HIV as an all-female affair and effectively involve more stakeholders in the fight against the HIV pandemic.
7. It is recommended that more research on ways to promote the satisfaction of clients accessing integrated TB-HIV and/PMTCT services needs to be done.

8. It is of utmost importance to extend integrated TB-HIV / PMTCT services to other health facilities that are not yet offering such services.



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## APPENDICES

### Appendix 1: Table containing sample size for the exit interview.

Sample size for exit interviews (data collection grid)

Name of sub-district	ANC	TB	Pre-ART & ART	Total
Egum	32	12	17	61
Kokstad TLC	16	5	8	29
CTK	3	13	32	48
Jolivet	6	8	10	24
Reitvlei	16	2	23	41
Riverside	15	8	11	34
SAH	12	13	19	44
Pholela	9	8	5	22
Underberg	26	3	10	39
Kilmun	6	5	7	18
Row Total	141	77	142	<b>360</b>

## **Appendix 2. Participant information sheet.**

**Study title: Assessment of clients' perspective on provision of TB and HIV integrated services including PMTCT in Sisonke district, KZN- South Africa.**

Dear participant

I would like to invite you to participate in this study. Your involvement will take about 30-45 minutes. Your participation in this study is completely voluntary. Before agreeing to participate, it is important that you read and understand the purpose of the study and the procedure. This information sheet is to help you decide if you would like to participate.

Permit me at this point to introduce myself. I am Anikamadu, Michael. A Masters in Public Health student of the University of the Western Cape. This is an academic research being conducted for mini-thesis purposes. I am in the process of collecting information on the assessment of clients' perspective on provision of TB and HIV integrated services including PMTCT in Sisonke district, KZN- South Africa.

If you have any questions, do not hesitate to ask the researcher. You are at liberty to participate or not to participate in this research. If you agree to participate in the study, you are still free to withdraw from the study at any stage and this will not be held against you in any way. You may also decline to answer and / or discuss particular question(s) should you wish to do so. If you decide to take part in this study, you will be requested to sign the consent form to confirm that you understand the study and agree to take part. Equally, you will be given a copy of the said consent form to keep.

### **Purpose of the study**

The researcher aims to assess the provision of TB and HIV integrated care from clients' perspective in order to make recommendations on ways to enhance the management of TB-HIV co-infected clients and treatment outcomes in Sisonke district. This study will therefore

assist in enhancing the provision of TB-HIV integrated services as it will be seen from the eyes of the clients.

### **Risks and Benefits**

There are no probable risks involved in participating in this study. The information gained will not be used for any other purpose other than the study.

The benefit of the study on the other hand is to identify the likely gaps in the delivery of integrated TB and HIV activities by viewing it for the clients' perspective and to subsequently make appropriate suggestions.

### **Confidentiality**

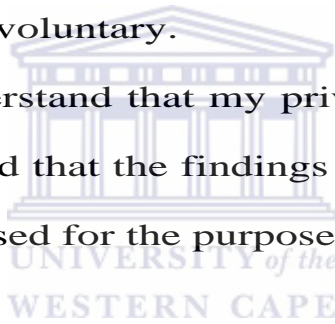
All information provided by you will be kept strictly confidential and will only used by the researcher. Data that may be reported in the research report will not include any information that identifies you as a participant in this study. The names in the informed consent and other personal information during the course of the study will also be kept confidential. In order to ensure that you remain anonymous, after the study is completed any form of identity relating to you will be removed to ensure you remain anonymous.

### Appendix 3: Informed Consent to the participant

#### Informed consent

I have been informed about the intention of the study. I have equally been told about what my participation involves. I also understand that I can leave from the study at any time, without having to give an explanation. I also understand that this study is completely voluntary.

I as well understand that my privacy will be maintained and that the findings of the study will only be used for the purposes research.



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Participant's signature of

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Date

**Appendix 4: The questions as contained in the questionnaire for the exit interview with TB and HIV clients**

1. Can you tell me how you experienced your visit today at the clinic/hospital?

2. For TB clients


2.1	Did a health worker talk to you about TB directly observed treatment or DOT support?	Yes	No
2.2	If yes, who is your DOT supporter?	Husband Family member Community health worker Home based carer Community volunteer Nurse at the clinic	
2.3	Did a health worker talk to you about the signs and symptoms of sexually transmitted infections?	Yes	No
2.4	Did a health worker talk to you about the importance of using condoms for HIV prevention?	Yes	No
2.5	Did a health worker talk to you about the HIV testing?	Yes	No
2.6	Have you been tested for HIV? If yes, go to 2.8	Yes	No
2.7	If no, can you tell me why you have decided not to have HIV test		
2.8	If yes, where did you get tested?	TB clinic Referred to VCT ARV clinic Others (specify)	
2.9	If tested, did you get your test results	Yes	No
2.10	If you feel comfortable telling me, what was the result of your test?	Positive Negative Don't know Chooses not to disclose	
2.11	Did a health worker talk to you about sharing your test results with your partner or family?	Yes	No
2.12	Did a health worker talk to you about a CD4 test?	Yes	No
2.13	Have you had a CD4 test?	Yes	No
2.14	If yes, where?	TB clinic ARV clinic	
2.15	What is your CD4 result?	CD4 count:	Don't know
2.16	Did a health worker talk to you about drugs called antiretrovirals (ARVs) that are available to treat people living with HIV?	Yes	No

2.17	If (CD4 is less than 200), have you been referred to an antiretroviral (ARV) clinic?	Yes	No
2.18	Are you on both TB medications and ARVs?	Yes	No
2.19	Did a health worker refer you to a community supporter for adherence support?	Yes	No
2.20	Does your DOT supporter (see 2.2) also support you for antiretroviral (ARV) treatment?	Yes	No
2.21	If no, who is your supporter in the community?	Husband Family member Friend HCW Home based carer Mother to mothers Nurse Others (specify)	
2.22	Would you prefer to have the same person supporting you for TB treatment and antiretroviral (ARV) treatment?	Yes	No

### 3. For HIV positive clients

3.1	Did a health worker talk to you about a CD4 test?	Yes	No
3.2	Have you had a CD4 test?	Yes	No
3.3	What is your CD4 result?	CD4 count:	Don't know
3.4	Did a health worker talk to you about drugs called antiretrovirals (ARVs) that are available to treat people living with HIV?	Yes	No
3.5	(If CD4 is less than 200), are you on antiretroviral (ARV) treatment?	Yes	No
3.6	Did a health worker talk to you about antiretroviral adherence support available in the community?	Yes	No
3.7	Did a health worker refer you to a community supporter for adherence support?	Yes	No
3.8	If yes, who is your supporter in the community?	Husband Family member Friend HCW Home based carer Mother to mothers Nurse Others (specify)	
3.9	Did a health worker talk to you about family planning options?	Yes	No
3.10	Did a health worker tell you what are the signs and symptoms of TB?	Yes	No
3.11	What are the signs and symptoms of TB? (Tick all that are mentioned)	Cough for a month Coughing up blood Night sweats Weight loss	



		Loss of appetite Chest pain Enlarged lymph nodes Weakness	
3.12	Did a health worker ask you if you are coughing?	Yes	No
3.13	If you are coughing, did a health worker ask you for sputum for TB test?	Yes	No
3.14	If yes, is your TB test positive?	Yes	No
3.15	If yes, were you referred to a TB clinic to start TB treatment?	Yes	No
3.16	If no, did you start your TB treatment at the same clinic?	Yes	No
3.17	Did a health worker talk to you about adherence support available in the community?	Yes	No
3.18	Did a health worker refer you to a community supporter for adherence support?	Yes	No
3.19	Does your DOT supporter also support you for antiretroviral (ARV) treatment?	Yes	No
3.20	If no, who is your supporter in the community?	 Husband Family member Friend HCW Home based carer Mothers to mothers Nurse Others (specify)	
3.21	Would you prefer to have the same person supporting you for TB treatment and antiretroviral (ARV) treatment?	Yes	No

4. General knowledge on HIV and TB

4.1	Is a person living with HIV more likely to have TB than an HIV negative person?	Yes	No	I don't know
4.2	Can TB be cured in people living with HIV?	Yes	No	I don't know
4.3	Do you know that all pregnant women should have an HIV test?	Yes	No	I don't know
4.4	Can HIV be transmitted through breastfeeding?	Yes	No	I don't know
4.5	If an HIV-positive mother breastfeeds and formula feeds, is she more likely to transmit HIV than if she exclusively breastfeeds or formula feeds?	Yes	No	I don't know
4.6	Do you think that it is necessary for every baby born from an HIV positive mother to get an HIV test?	Yes	No	I don't know

5. Perceptions on service delivery mechanism

5.1	If you were on TB treatment and you were HIV positive would you prefer to receive treatment for both diseases at the same clinic or in different clinics?	Same	Different
5.2	Would you prefer to be able to be tested for HIV in the antenatal clinic or in a separate place?	Same	Different
5.3	If you were HIV positive, would you prefer to receive treatment for both diseases by the same nurse or by different nurses?	Same	Different

5.4. What are the advantages of having services for TB and HIV in the same clinic? (List at least 3 advantages)

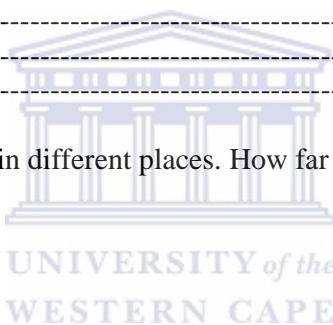
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5.5. What are the disadvantages of having services for TB and HIV in the same clinic? (List at least 3 advantages)

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5.6. VCT/ARV and TB services are in different places. How far away are they from each other?

1. 5 minutes to 10 minutes
2. 10 minutes to 15 minutes
3. 15 minutes to 20 minutes
4. 20 minutes to 25 minutes
5. 25 minutes to 30 minutes
6. I don't know



5.7. VCT/ARV and TB services are in different places, what difficulties would you face in going to both? (List at least 3 difficulties)

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5.8. Would you want to have a HCW visiting you at your household for support during illness?

1. Yes       2. No

5.9. If no, what are the reasons? (List at least 3 reasons)

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5.10. Have you ever been visited by a HCW in your household? 1. Yes  2. No  (if no, go to 5.12)

5.11. If yes, which support did she/he provide?

1. Health education
2. Screen for TB
3. Voluntary counselling & HIV testing

- 4. Support for antiretroviral treatment
- 5. TB directly observed therapy (DOT)
- 6. Others (please specify)

5.12. If you have received support from a community health worker, what did you dislike about the support given? (List at least 3 mostly like)

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5.13. If you have received support from a community health worker, what did you like about the support given? (List at least 3 mostly like)

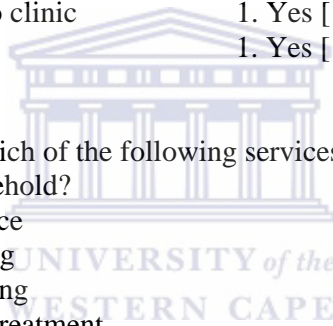
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5.14. If you are living with HIV, which of the following services would you be willing to receive from a HCW and allow him/her to do in your household?

- 1. Support for antiretroviral treatment adherence 1. Yes  2. No
- 2. Screen for TB by asking about TB symptoms 1. Yes  2. No
- 3. Collect sputum to be taken to clinic 1. Yes  2. No
- 4. Support for TB treatment 1. Yes  2. No
- 5. Others (please specify)

5.15. If you are having TB, which of the following services would you be willing to receive from a HCW to do in your household?

- 1. Support for TB treatment adherence 1. Yes  2. No
- 2. Provide counselling on HIV testing 1. Yes  2. No
- 3. Provide counselling and HIV testing 1. Yes  2. No
- 4. Support for antiretroviral (ARV) treatment 1. Yes  2. No
- 5. Screen for TB by asking about TB symptoms to household members 1. Yes  2. No
- 6. Collect sputum to be taken to the clinic 1. Yes  2. No
- 7. Support for HIV care 1. Yes  2. No
- 8. Others (please specify)



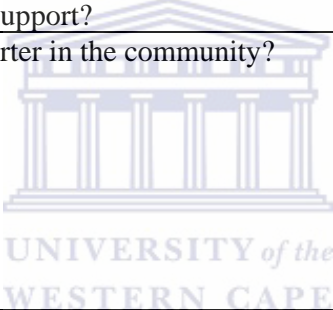
**Appendix 5: The questions as contained in the questionnaire for the exit interview with antenatal PMTC clients or pregnant women at the antenatal clinics.**

1. Can you tell me how you experienced your visit today at the clinic/hospital?

*2. General pregnancy care*

2.1	Did a health worker talk to you about HIV testing?	Yes	No
2.2	Have you been tested for HIV during this pregnancy? If yes, go to 2.4	Yes	No
2.3	If not, can you tell me why you have decided not to have an HIV test (go to question 2.9)		
2.4	If yes, where did you get tested?	ANC clinic Referred to VCT	
2.5	If tested, did you get your test results	Yes	No
2.6	If you feel comfortable telling me, what was the result of your test?	Positive Negative Don't know Chooses not to disclose	
2.7	Did a health worker talk to you about sharing your test results with your partner or family?	Yes	No
2.8	Did a health worker explain to you about the different ways that a baby can get HIV from the mother?	Yes	No
2.9	Did a health worker talk to you about using condoms during pregnancy?	Yes	No
2.10	Did a health worker talk to you about family planning options after the baby is born?	Yes	No
2.11	Did a health worker talk to you about the signs and symptoms of sexually transmitted infections?	Yes	No
2.12	Did a health worker tell you what the signs and symptoms of TB are?	Yes	No
2.13	What are the signs and symptoms of TB? (Tick all that are mentioned)	Cough of more than one month Coughing up blood Night sweats Weight loss Loss of appetite Chest pain Enlarged lymph nodes Weakness	
2.14	Did a health worker ask you if you are coughing?	Yes	No
2.15	If you are coughing, did a health worker ask you for sputum for TB test?	Yes	No
	If yes, is your TB test positive? (If yes, go to 3.15 – 3.17).	Yes	No

3. For HIV positive mothers

3.1	Did a health worker talk to you about a CD4 test?	Yes	No
3.2	Have you had a CD4 test during this pregnancy?	Yes	No
3.3	What is your CD4 result?	CD4 count:	Don't know
3.4	Did a health worker talk to you about drugs called antiretrovirals (ARVs) that are available to treat people living with HIV?	Yes	No
3.5	(If CD4 is less than 200 or doesn't know CD4), have you been referred to an antiretroviral (ARV) clinic?	Yes	No
3.6	Are you taking ARVs?	Yes	No
3.7	Did a health worker talk to you about dual therapy (Nevirapine and AZT) to prevent transmission of HIV to your baby?	Yes	No
3.8	Are you on dual therapy (NVP and AZT)?	Yes	No
3.9	Did a health worker talk to you about adherence support available in the community?	Yes	No
3.10	Did a health worker refer you to a community supporter for adherence support?	Yes	No
3.11	If yes, who is your supporter in the community?	 Husband Family member Friend HCW Home based carer Mother to mothers Nurse Others (specify)	
3.12	Did a health worker talk to you about the importance of using condoms during pregnancy to avoid re-infection?	Yes	No
3.13	Did a health worker talk to you about infant feeding options?	Yes	No
3.14	If you have TB, were you referred to a TB clinic to start TB treatment? (If yes, go to 3.16 and if no, go to 3.15).	Yes	No
3.15	Did you start your TB treatment here?	Yes	No
3.16	Did a health worker talk to you about TB directly observed treatment or DOT support?	Yes	No
3.17	If yes, who is your DOT supporter?	Husband Family member Community health worker Home based carer Community volunteer Nurse at the clinic	

4. *General knowledge on HIV and TB*

4.1	Is a person living with HIV more likely to have TB than an HIV negative person?	Yes	No	I don't know
4.2	Can TB be cured in people living with HIV?	Yes	No	I don't know
4.3	Do you know that all pregnant women should have an HIV test?	Yes	No	I don't know
4.4	Can HIV be transmitted through breastfeeding?	Yes	No	I don't know
4.5	If an HIV-positive mother breastfeeds and formula feeds, is she more likely to transmit HIV than if she exclusively breastfeeds or formula feeds?	Yes	No	I don't know
4.6	Do you think that it is necessary for every baby born from an HIV positive mother to get an HIV test?	Yes	No	I don't know

5. *Perceptions on service delivery mechanism*

5.1	If you were on TB treatment and you were HIV positive would you prefer to receive treatment for both diseases at the same clinic or in different clinics?	Same	Different
5.2	Would you prefer to be able to be tested for HIV in the antenatal clinic or in a separate place?	Same	Different
5.3	If you were HIV positive, would you prefer to receive treatment for both diseases by the same nurse or by different nurses?	Same	Different

5.4. What are the advantages of having services for TB and HIV in the same clinic? (List at least 3 advantages)

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5.5. What are the disadvantages of having services for TB and HIV in the same clinic? (List at least 3 advantages)

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5.6. VCT/ARV and TB services are in different places. How far away are they from each other?

1. 5 minutes to 10 minutes
2. 10 minutes to 15 minutes
3. 15 minutes to 20 minutes
4. 20 minutes to 25 minutes
5. 25 minutes to 30 minutes
6. I don't know

5.7. If antenatal and TB services are in different places, what difficulties would you face in going to both? (List at least 3 difficulties)

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5.8. Would you want to have a HCW visiting you at your household for support during illness?

1. Yes [ ]      2. No [ ]

5.9. If no, what are the reasons? (List at least 3 reasons)

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5.10. Have you ever been visited by a HCW in your household? 1. Yes [ ] 2. No [ ] (if no, go to 5.12)

5.11. If yes, which support did she/he provide?

- |   |     |
|---|-----|
| 1. Health education                     | [ ] |
| 2. Screen for TB                        | [ ] |
| 3. Voluntary counselling & HIV testing  | [ ] |
| 4. Support for antiretroviral treatment | [ ] |
| 5. TB directly observed therapy (DOT)   | [ ] |
| 6. Others (please specify)              | [ ] |

5.12. If you have received support from a community health worker, what did you dislike about the support given? (List at least 3 mostly like)

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5.13. If you have received support from a community health worker, what did you like about the support given? (List at least 3 mostly like)

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5.14. If you are living with HIV, which of the following services would you be willing to receive from a HCW and allow him/her to do in your household?

- |   |            |           |
|---|------------|-----------|
| 1. Support for antiretroviral treatment adherence | 1. Yes [ ] | 2. No [ ] |
| 2. Screen for TB by asking about TB symptoms      | 1. Yes [ ] | 2. No [ ] |
| 3. Collect sputum to be taken to clinic           | 1. Yes [ ] | 2. No [ ] |
| 4. Support for TB treatment                       | 1. Yes [ ] | 2. No [ ] |
| 5. Others (please specify)                        |            |           |

5.15. If you are having TB, which of the following services would you be willing to receive from a HCW to do in your household?

- |   |            |           |
|---|------------|-----------|
| 1. Support for TB treatment adherence                             | 1. Yes [ ] | 2. No [ ] |
| 2. Provide counselling on HIV testing                             | 1. Yes [ ] | 2. No [ ] |
| 3. Provide counselling and HIV testing                            | 1. Yes [ ] | 2. No [ ] |
| 4. Support for antiretroviral (ARV) treatment                     | 1. Yes [ ] | 2. No [ ] |
| 5. Screen for TB by asking about TB symptoms to household members | 1. Yes [ ] | 2. No [ ] |
| 6. Collect sputum to be taken to the clinic                       | 1. Yes [ ] | 2. No [ ] |
| 7. Support for HIV care   | 1. Yes [ ] | 2. No [ ] |
| 8. Others (please specify)  |            |           |

**Appendix 6: CONSENT FORM FOR ALL BENEFICIARIES (TB/HIV/ANC-PMTCT clients)**



## UNIVERSITY OF THE WESTERN CAPE

Private Bag X 17, Bellville 7535, South Africa  
*Tel: +27 21-959, Fax: 27 21-959*

E-mail:

**Title of Research Project:**

**“Community participation in tuberculosis and HIV integrated activities, constraints and costs for enhancing the integration of tuberculosis and HIV programmes in a rural area of South Africa”**

The study has been described to me in language that I understand and I freely and voluntarily agree to participate. My questions about the study have been answered. I understand that my identity will not be disclosed and as a focus group member I need to respect the disclosures of other focus group members. In addition, I may withdraw from the study without giving a reason at any time and this will not negatively affect me in any way.

**Declaration by participant**

By signing below, I..... agree to take part in a research study **“Community participation in the delivery of joint TB and HIV/PMTCT services in Sisonke district, KwaZulu-Natal, South Africa”**

I declare that:

- *I have read or had read to me this information and consent form and it is written in a language with which I am fluent and comfortable.*
- *I have had a chance to ask questions and all my questions have been adequately answered.*
- *I understand that taking part in this study is voluntary and I have not been pressurised to take part.*
- *I understand that the FGDs will be audiotaped*
- *I may choose to leave the study at any time and will not be penalised or prejudiced in any way.*
- *I may be asked to leave the study before it has finished, if the study researcher feels it is in my best interest or if I do not follow the study plan, as agreed to.*

Signed at (place)..... on (date)..... 2008



-----  
Signature of participant

-----  
Signature of witness

**Declaration by investigator /**

I (name )..... Declare that:

- I explained the information in this document to .....
- I encouraged him/her to ask questions and took adequate time to answer them
- I am satisfied that he /she adequately understands all aspects of the research, as discussed above
- I did not use the interpreter

Signed at (place)..... on (date)..... 2008

-----  
Signature of participant

-----  
Signature of witness



Should you have any questions regarding this study or wish to report any problems you have experienced related to the study, please contact the study coordinator:

**Jeannine Uwimana:**  
University of the Western Cape  
Private Bag X17, Belville 7535  
Telephone: (021)959-2513  
Cell: 073-787-1342  
Fax: +27 21 959 2872  
Email: juwimana@uwc.ac.za

## Appendix 7: The Information Sheet



UNIVERSITY OF THE WESTERN CAPE

Private Bag X 17, Bellville 7535, South Africa  
Tel: +27 21-959, Fax: 27 21-959

E-mail:

### INFORMATION SHEET FOR TB, HIV and PMTCT clients

**Project Title: Community participation in tuberculosis and HIV integrated activities, constraints and costs for enhancing the integration of tuberculosis and HIV programmes in a rural area of South Africa.**

#### **What is this study about?**

This is a research project being conducted by the School of Public Health at the University of the Western Cape. We are inviting you to participate in this research project because you are a TB or HIV client or pregnant mother who attends the selected health facility for this project. The purpose of this research is to develop and evaluate a community based intervention that will strengthen the district health system's capacity to improve the provision of integrated TB and HIV care including PMTCT in Sisonke district.

#### **What will I be asked to do if I agree to participate?**

You will be asked to participate in an exit interview and you will be asked to fill a questionnaire that will contain the data below:

- Socio-demographic data (i.e. age, sex, employment status, etc)
- Health status
- Service received
- Perceptions on the service delivery mechanism and the referral system

The exit interview will last approximately 15-30 minutes and we will do our best to keep your personal information confidential. To help protect your confidentiality, your name will not be recorded. If we write a report or article about this research project, your identity will be protected to the maximum extent possible.

#### **What are the risks of this research?**

There are no known risks associated with participating in this research project.

#### **What are the benefits of this research?**

This research is designed to help firstly the researcher and the district health managers to assess the integration of TB and HIV services including PMTCT as well to better understand how the community could participate in the provision of TB and HIV/PMTCT integrated care.

Secondly this research will also help beneficiaries of care such as you to receive a coordinated and cost-effective care at the community level as well at the facility level. Community participation in joint activities is necessary for enhanced provision of integrated care as well improved access to care.

**Do I have to be in this research and may I stop participating at any time?**

Your participation in this research is completely voluntary. You may choose not to take part at all. If you decide to participate in this research, you may stop participating at any time. If you decide not to participate in this study or if you stop participating at any time, you will not be penalized or lose any benefits to which you otherwise qualify. Your decision to participate or not to participate in this research project will not affect your treatment or quality of care that you are receiving from this clinic now and in the future. The data will only be accessed by the principal investigator.

**What if I have questions?**

This research is being conducted by **Jeannine Uwimana**, School of Public Health at the University of the Western Cape. If you have any questions about the research study itself, please contact **Jeannine Uwimana** at the following address:

**Tel: +27 21 959 2513**

**Cell: +27 073 787 1342**

**Fax: +27 21 959 2872**

**Email: juwimana@uwc.ac.za**

Should you have any questions regarding this study and your rights as a research participant or if you wish to report any problems you have experienced related to the study, please contact:

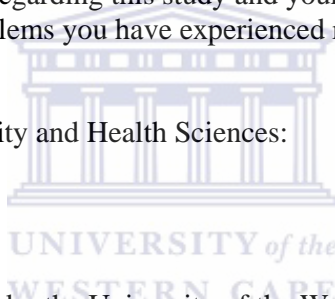
**Head of Department:**

Dean of the Faculty of Community and Health Sciences:

University of the Western Cape

Private Bag X17

Bellville 7535



This research has been approved by the University of the Western Cape's Senate Research Committee and Ethics Committee.

## Appendix 8: Ethical Clearance letter for the major study



UNIVERSITY OF COMMUNITY  
AND HEALTH SCIENCES

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Tel: +27 (0) 21 959 2163  
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E-mail: csjohnson@uwc.ac.za

### HIGHER DEGREES COMMITTEE

19 March 2008

#### TO WHOM IT MAY CONCERN

Dear Sir/Madam

#### **Research Project of MS JEANNINE UWIMANA (Student Number: 2409504)**

This letter confirms that **Ms Uwimana** is a registered student in the Faculty of Community and Health Sciences at the University of the Western Cape.

Her research proposal entitled "*Community participation in tuberculosis and HIV collaborative activities, constraints and costs for enhancing the integration of tuberculosis and HIV programmes in a rural area of South Africa*" submitted in fulfilment of the requirements for the PhD in Public Health, has been examined by the Higher Degrees Committee and found to be of high scientific value, methodologically sound and ethical.

We fully support the research and kindly request that you allow her access to your organization.

Sincerely

A handwritten signature in black ink, appearing to read 'G. Reagon'.

**Dr. GAVIN REAGON**

**Chairperson: Higher Degrees Committee**

## **Appendix 9: World Health Organisation's recommendation for TB-HIV integrated activities.**

To make the integration of TB-HIV activities effective, the World Health Organisation (2004) recommended the following: initiating co-trimoxazole / Isoniazid preventive therapy; initiating of antiretroviral therapy; introduction of HIV prevention methods; making available HIV testing and counselling; minimising the burden of HIV in tuberculosis clients and minimising the burden of tuberculosis in HIV positive people.

Rather than parallel programmes to control both diseases, it is essential that integrative activities should be a part of the continuum of care for clients infected with TB and HIV diseases (WHO, 2004).

To further justify the need for TB-HIV integration, the World Health Organisation, (2002) projected that one third of HIV positive people would eventually develop TB in the course of their lifetime. This is because: HIV increases TB infection; HIV encourages progression to active TB for people recently infected with TB; Increasing TB infection of HIV positive people puts communities at greater risk of acquiring TB; and HIV enhances the possibility of TB recurring. Similarly, HIV positive people are more susceptible to developing TB regardless of their having access to ARVs or otherwise. However, preventing and treating TB results to improved quality and longer life, with the attendant benefits to the families and communities of people living with HIV.