



UNIVERSITY of the  
WESTERN CAPE

*Community participation in collaborative tuberculosis and HIV activities including prevention of mother- to- child- transmission (PMTCT): development and evaluation of an intervention to enhance integration of TB/HIV/PMTCT services in a rural area of South Africa*

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**School of Public Health - University of the Western Cape**

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South Africa**

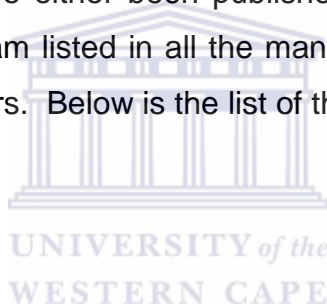
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University of the Western Cape, South Africa**

## DECLARATION

I declare that “Community participation in collaborative tuberculosis and HIV activities including prevention of mother-to-child transmission (PMTCT): development and evaluation of an intervention to enhance integration of TB/HIV/PMTCT services in a rural area of South Africa” is my own work, that it has not been submitted before for any degree or examination at any other university, and that all the sources I have used or quoted have been indicated and acknowledged as complete references.

This thesis is written in monograph format with Chapter 4 Results written in the form of five manuscripts which have either been published or submitted for publication. This serves to confirm that I am listed in all the manuscripts as the first author and my supervisors were co-authors. Below is the list of the papers:



### **Paper I**

Uwimana J, Jackson D and Zarowsky C (2012). Health care providers' and patients' perspectives on provision of TB/ HIV services including prevention of mother-to-child transmission (PMTCT) in a rural district, South Africa. *BMC - Health Research Services*, submitted in June 2012. *Accepted*

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### **Paper III**

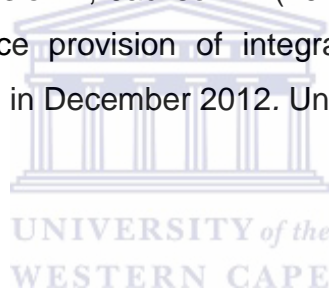
Uwimana J, Jackson D, Hausler H, Zarowsky C (2012). Engagement of Non-government Organisations (NGOs) and Community Care Workers (CCWs) in collaborative TB/HIV activities including prevention of mother to child transmission (PMTCT) in a rural district of KwaZulu-Natal, South Africa: Opportunities and Challenges". *BMC Health Services Research*; **12**:233. doi:10.1186/1472-6963-12-233 .

#### **Paper IV**

Uwimana J, Zarowsky C, Hausler H and Jackson D (2012). Training community care workers to provide comprehensive TB/HIV/PMTCT integrated care in KwaZulu-Natal : lessons learnt. *Tropical Medicine and International Health*; **17**(4):488–496

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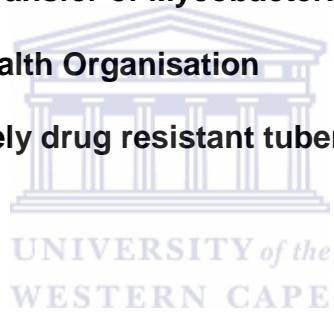
My God, my heavenly father, you have been always there for me, you carried me through this journey, my pillar of strength. I am indebted to you, Thank You so much.

## **ABBREVIATIONS AND ACRONYMS**

<b>AIDS</b>	<b>Acquired Immune Deficiency Syndrome</b>
<b>ANC</b>	<b>Antenatal care</b>
<b>ART</b>	<b>Antiretroviral therapy</b>
<b>ARVs</b>	<b>Antiretroviral drugs</b>
<b>CPT</b>	<b>Cotrimoxazole preventive therapy</b>
<b>CHW</b>	<b>Community health worker</b>
<b>CCW</b>	<b>Community care worker</b>
<b>DOH</b>	<b>Department of Health</b>
<b>DOTS</b>	<b>Directly observed treatment short-course strategy</b>
<b>FGD</b>	<b>Focus group discussion</b>
<b>HBC</b>	<b>Home-based carer</b>
<b>HCT</b>	<b>HIV counselling and testing</b>
<b>HB-HCT</b>	<b>Home-based HIV counselling and testing</b>
<b>HH</b>	<b>Household</b>
<b>HCBC</b>	<b>Home and community-based care programme</b>
<b>HIV</b>	<b>Human immunodeficiency virus</b>
<b>HR</b>	<b>Human resources</b>
<b>HRH</b>	<b>Human resources for health</b>
<b>IPT</b>	<b>Isoniazid preventive therapy</b>
<b>KII</b>	<b>Key informant interview</b>
<b>KZN</b>	<b>KwaZulu-Natal province</b>
<b>MDGs</b>	<b>Millennium development goals</b>
<b>MDR-TB</b>	<b>Multi drug resistant tuberculosis</b>
<b>NGO</b>	<b>Non-governmental organisation</b>



<b>NVP</b>	<b>Nevirapine</b>
<b>OIs</b>	<b>Opportunistic infections</b>
<b>PLHIV</b>	<b>People living with HIV and AIDS</b>
<b>PMTCT</b>	<b>Prevention of mother-to-child transmission</b>
<b>PHC</b>	<b>Primary health care</b>
<b>TB</b>	<b>Tuberculosis</b>
<b>STI</b>	<b>Sexually transmitted infection</b>
<b>SA</b>	<b>South Africa</b>
<b>SSA</b>	<b>Sub-Saharan Africa</b>
<b>VTRTB</b>	<b>Vertical transfer of Mycobacterium tuberculosis</b>
<b>WHO</b>	<b>World Health Organisation</b>
<b>XDR-TB</b>	<b>Extensively drug resistant tuberculosis</b>



## ABSTRACT

**Background:** The epidemiological interconnectedness of tuberculosis (TB) and human immunodeficiency virus (HIV) epidemics is well documented. Although international agencies such as the World Health Organisation (WHO) have been advocating for the implementation of collaborative TB/HIV activities at all levels in order to mitigate the impact of the dual epidemic on communities, health care delivery and programme management, its implementation has been very slow, particularly in countries highly burdened with TB/HIV infection, such as South Africa. Provision of integrated TB/HIV services has been partial and sub-optimal at community level. This requires innovative interventions that go beyond health facility boundaries such as engaging community care workers (CCWs). This thesis presents ways of engaging community members such as CCWs in collaborative TB/HIV activities including prevention of mother-to-child transmission of HIV (PMTCT).

**Methods:** Both action research and health systems strengthening research were used as theoretical frameworks. The study was conducted in three phases which consisted of: a situational analysis; design and implementation of the intervention; and evaluation of the intervention. Mixed method research using both quantitative and qualitative research methods in one study was conducted, and various research designs were used depending on the research questions and the study phases.

**Results:** The findings of *Phase I* of this study highlight partial integration of TB/HIV/PMTCT services at facility and community levels, and sub-optimal provision of integrated services, particularly at community level where only 10% of TB and HIV patients needing care at community level were supported by CCWs. Most TB-HIV co-infected patients were managed at the primary health care (PHC) clinic level of care, compared to other levels ( $p < 0.05$ ), and less than 50% of PHC clinic staff were trained in TB and HIV management. This phase also indicates poor linkage between facility and CCWs through the nongovernmental organizations (NGOs) managing CCWs. In addition, it identifies various health systems barriers that impede the implementation of collaborative TB/HIV/PMTCT activities and involvement of CCWs in the mainstream of the primary health care system. The findings of *Phase II* and *III* show that integrating different CCW cadres into one cadre and expanding their scope of practice to provide a comprehensive package of care for TB/HIV/PMTCT is

a feasible and an effective intervention to accelerate the implementation of collaborative TB/HIV activities, including PMTCT, at community level. In addition, the findings suggest that up-skilled CCWs contribute significantly to bridging the current service delivery gaps in vertical TB, HIV and PMTCT services by increasing coverage for case finding of TB (38%) and sexually transmitted infections (STIs) (40%), PMTCT services (infant feeding, referral for PCR and AZT adherence support) (30%), and TB and antiretroviral treatment (ART) adherence (30%, 28%). The increase in uptake of TB/HIV/PMTCT services was statistically significant ( $p < 0.05$ ). Provision of home-based HIV counseling and testing by CCWs proved to be acceptable and feasible. Of 684 people offered home based HCT, 634 (82%) accepted to be tested and 45 (7%) tested HIV positive. However, other PHC care services such as integrated management of childhood illnesses (IMCI) and referrals to social welfare were poorly provided. **Conclusion and Recommendations:** The findings indicated that up-skilling CCWs resulted in improvement of CCW's performance in provision of integrated TB/HIV/PMTCT services, particularly for TB and STI symptom screening, HCT, infant feeding counselling and AZT treatment support for PMTCT, and treatment adherence support for TB and ART. However, this study emphasised the need for addressing contextual and health systems issues such as structural, organisational and managerial constraints. There is a need to reorganise the PHC system to ensure that CCWs are integrated as part of the PHC system. Systematic skills building and consistent CCW supervision, with reliable referral and monitoring and evaluation (M&E) systems are required for efficiency and sustainability of any community based intervention. It is also necessary to ensure that other PHC activities, such as referral for social welfare and IMCI, are not compromised when additional activities are added to the CCW care package.

**Keywords:** Tuberculosis, HIV, PMTCT, community participation, community health workers, integration, up-skilling, evaluation, rural district, South Africa.

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## DEFINITION OF TERMS

Integration: refers to an attempt to provide all elements of care in a seamless continuum of care (Thaldorf & Liberman 2007). Although there are a variety of models of integration, for this study, integration of TB/HIV/PMTCT services or collaborative TB/HIV activities, including PMTCT, will be viewed at the level of “service delivery” and “management”.

Community participation: refers to the participation of individuals, groups and the community to varying degrees in planning, monitoring, evaluation, implementation and management of different health and social needs and problems. For this study, community participation refers to participation of CCWs employed and managed by non-governmental organisations.

Non-governmental organisation (NGO): refers to non-governmental organisation or community-based organisation providing various activities related to TB and HIV and other health-related activities at community level including health promotion, community based care, treatment and support services at home, and which are also mandated by the government to manage CCW programme implementation.

Community care workers: refers to “any health worker carrying out functions related to health care delivery; trained in some way in the context of the intervention; and having no formal professional or paraprofessional certification or a degree from tertiary education” (Levin *et al.* 2005). The use of the term “community care workers” in this thesis is used to denote all categories of “non-professional” health workers such as community health workers (CHWs) and home-based carers (HBCs). These CCWs are funded by government and NGOs, and managed by the NGOs.

# CHAPTER 1

## INTRODUCTION

### 1.1 Introduction

An extensive body of scientific literature documents the many interactions between human immunodeficiency virus (HIV) and tuberculosis (TB) infection and disease. TB has however received relatively little attention compared with HIV, and the serious implications for women and new-borns of the interactions between HIV and TB are even more neglected. HIV is fuelling the TB epidemic, particularly in sub-Saharan Africa (SSA). South Africa (SA) is one of the SSA countries heavily burdened with both TB and HIV infection, and has the third highest annual number of new TB cases of the 22 high TB burden countries worldwide (WHO 2011). The World Health Organisation (WHO) global report on high burden country profiles indicates that in SA the incidence of TB was estimated at 981 per 100,000 population per year (including TB in HIV patients), with an estimated 490,000 incident cases of TB and 9,200 cases of multi-drug-resistant TB (MDR). As for the burden of the HIV epidemic in SA, the 2011 report from the Joint United Nations Programme on HIV/AIDS (UNAIDS) indicates that in 2010 HIV prevalence in the general population was estimated at 17.9%, and the number of people living with HIV (PLHIV) was estimated at 5.6 million (the highest number of PLHIV in the world). Although there are indications of a decrease by a third in HIV incidence from 2001 to 2009 (2.4% to 1.5%), the HIV incidence in SA is still high (UNAIDS 2011).

In some parts of the country, such as KwaZulu-Natal (KZN) province where the study took place, HIV prevalence in the general population is estimated at 24.9%, with HIV antenatal prevalence at 39.5%, and high variation (31.1-42.3%) across its 11 districts (DOH 2011).

KZN province is one of the most populated and rural of the nine provinces in SA, and is the epicentre of HIV and TB infection. The TB/HIV co-infection rate ranges between 75-80% in some settings (DOH-KZN 2011; Perumal, Padayatchi & Stiefvater 2009), and in the same the province an outbreak of MDR-TB and extensively drug-resistant TB (XDR-TB) occurred in 2006 (Ghandi *et al.* 2006). Since the outbreak of MDR and XDR-TB in KZN, the number of cases has increased, with an HIV co-infection rate estimated at 90%. As result, the mortality rate continues to rise in the province and countrywide (Ghandi *et al.* 2009).

With such high TB and HIV infection rates in SA, pregnant women are at high risk of contracting and transmitting the infection to their infants. Women account for more than 45% of all smear positive cases, compared to 36% of smear positive TB cases globally (Perumal *et al.* 2009; WHO 2010a). Patients co-infected with HIV have a greater incidence of extra-pulmonary TB and a higher risk for vertical transmission of TB to infants, yet provision of key services for TB prevention and care for pregnant women is still inadequate (Kali *et al.* 2006).

With this epidemiological profile of TB and HIV in SA, fostering the implementation of collaborative TB and HIV activities is important, since the provision of integrated TB/HIV services aims to improve quality of care, and ensure continuity and sustainability of prevention and care of both TB and HIV.

The risk of vertical transmission of TB (VTRTB) from pregnant women to their babies, and the toll of maternal and infants deaths caused by TB, calls for implementation of collaborative TB/HIV activities to include prevention of mother-to-child transmission (PMTCT). However, the implementation process of collaborative activities has been problematic in SSA countries, particularly in SA, due to lack of political commitment and denial of the HIV epidemic, as well as health systems issues rooted in historical ways of running TB and HIV programmes in silos (Friedland, Harries & Coetzee 2007; Abdool Karim *et al.* 2009).

In 2004, the Global TB/HIV working group developed an interim policy (WHO 2004a) to assist countries in implementing and monitoring collaborative TB/HIV activities, in order to lessen the burden of TB among PLHIV and equally lessen the HIV burden in TB clients. The 2004 interim policy was later updated in 2012 (WHO 2012). The WHO and other international agencies, such as UNAIDS and the President's Emergency Plan for AIDS Relief (PEPFAR), have recommended that TB and HIV disease control programmes should incorporate testing, diagnosis, treatment and care for both diseases. TB patients should be offered HIV counselling and testing (HCT) and cotrimoxazole preventive therapy (CPT) if found HIV positive; while HIV patients should be offered TB screening if asymptomatic and isoniazid preventive therapy (IPT) (WHO 2004a; WHO, PEPFAR & UNAIDS 2009; WHO 2012).

Wang *et al.* (2007) argue that for countries such as SA, with high HIV prevalence and a large number of HIV-related TB cases, TB prevention and care services should be considered as an integral dimension of HIV control.

The WHO policy on collaborative TB/HIV activities has been embraced worldwide, however the pace of the implementation of the policy has been very slow, including in SSA countries where the co-infection rate of TB/HIV is above 70% (Gunneberg, Reid & Williams 2008; Perumal *et al.* 2009; WHO 2009).

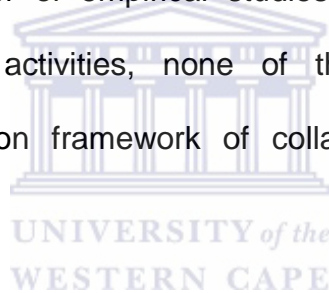
Due to the complexity of the health systems and the inherited culture of running TB and HIV programmes in silos, policy makers and health care providers are faced with complex choices on how best to integrate these programmes at all levels of health care, including community level. Most of the TB/HIV collaborative activities have been implemented at facility level (Eang & Chheng 2007; Friedland *et al.* 2007; Laserson 2007; Getahun & Gunneberg 2010) and not at community level.

Where TB and HIV related activities have been implemented at community level, these have typically been single disease based and in silos rather than comprehensive (Dudley *et al.* 2003; Lewin *et al.* 2005; Clarke, Dick & Lewin 2008; Mulogo *et al.* 2011). In the light of persistent barriers to access and utilisation of health facilities, interventions beyond health facility boundaries are vital to hasten the implementation of collaborative TB/HIV activities and improve coverage, access and treatment outcomes. These will require community participation in collaborative TB/HIV activities including PMTCT.

Several studies in the literature have highlighted the impact of community participation in health care, including an increase in health services coverage, efficiency, effectiveness, equity, access and self-reliance (Lewin *et al.* 2005; Haines *et al.* 2007; Lewin & Glenton, 2007; Hermann *et al.* 2009).

Based on the potential benefits listed above, involvement of community care workers (CCWs) and community groups is likely to enhance the implementation of collaborative TB/HIV activities, including PMTCT. Additionally, the huge burden of the TB and HIV epidemics has overstretched the health system in SA and other SSA countries, particularly in rural areas where most of the health facilities are understaffed. Hence, this study explores possible ways of involving CCWs in the implementation of collaborative TB/HIV/PMTCT activities and assessed their impact on providing TB/HIV/PMTCT integrated services at community level and strengthening the primary health care (PHC) system as whole.

Although there are a number of empirical studies reported in the literature on collaborative TB and HIV activities, none of the studies included PMTCT programmes in the evaluation framework of collaborative TB/HIV activities or integration.



The substantive originality of this study is twofold: the inclusion of PMTCT programmes in the collaborative framework recommended by the WHO policy (WHO 2012) and focusing on community engagement. Furthermore, most published studies have been based on a positivist paradigm, yet the complexity of the health systems requires theories that consider social and dynamic aspects of health systems. This study thus also addresses methodological and theoretical gaps in the literature on evaluating interventions for TB/HIV integration, through its grounding in an interpretive paradigm which engages stakeholders as active collaborators in identifying problems, and designing and implementing effective interventions aimed at bringing about change within the health system.

## 1.2 Overview of the burden of TB and HIV epidemics worldwide

The recent UNAIDS 2011 epidemiological report estimates 33.4 million [31.6–35.2 million] PLHIV by the end of 2010, with an increase of 17% worldwide from 1999. The same report estimates 2.7 million [2.4–2.9 million] new HIV infections in 2010, including 390,000 [340,000–450,000] infections among children. It is also estimated that there was a decrease of 15% from 2001, and a 21% decrease from the number of new infections in 1997 (UNAIDS 2011). However, SSA remains the region most affected by the HIV epidemic: 68% of PLHIV were from the SSA region and it accounted for 70% of new HIV infections by the end of 2010 (UNAIDS 2011). In the same year, a total of 22.9 million [21.6–24.1 million] PLHIV were estimated to live in SSA, while the numbers of new infections was estimated at 1.9 million [1.7-2.1 million]. The estimates from the UNAIDS 2011 report show an annual decrease in HIV incidence in South Africa from 2.4% [2.1%–2.6%] to 1.5% [1.3%–1.8%] between 2001 and 2009 (UNAIDS 2011). The decrease in HIV infection in SSA could be explained, among other factors, by the expansion of access to antiretroviral therapy (ART), with a 20% increase in ART coverage in one year (from 2009-2010) (UNAIDS 2011).

Some countries such as Botswana, Namibia and Rwanda have achieved universal access to ART treatment (80% or more). This may have contributed to a reduction in the estimated number of HIV related deaths (UNAIDS 2011).

With regards to HIV related mortality, the UNAIDS report shows that in 2010, SSA accounted for 72% of global HIV related deaths, while 20% of PLHIV died of AIDS-related causes (UNAIDS 2011).

The same report estimates that AIDS related deaths have fallen to 1.2 million [1.1-1.4million] deaths in 2010, from 1.4 million [1.3-1.6 million] in 2001. Furthermore, the estimates for AIDS related mortality in children under the age of 15 years also declined by 19% in 2010 from 1997 (UNAIDS 2011). In addition, the number of HIV positive children born to mothers living with HIV is estimated at 370,000, with 54% of those women receiving antiretroviral medication for PMTCT in 2010 (UNAIDS 2011).

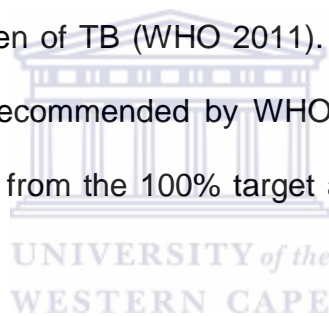
The decline in deaths related to AIDS illnesses in children reflects the expansion of PMTCT, and to a certain extent increased access to ART for children (UNAIDS 2011). However, more efforts are required to accelerate access to ART among children and adults, particularly in rural areas where infrastructure and a shortage of health care workers remain the main challenges. In contrast to the decrease in HIV new infections and mortality related to AIDS worldwide particularly in SSA discussed above, the incidence of TB continues to rise in most SSA countries, and TB remains the main opportunistic infection (OI) and cause of death among PLHIV (Corbett *et al.* 2007; Date *et al.* 2010; WHO 2010a).

Research studies have shown that PLHIV have a 20–30 times higher risk of developing active TB in their lifetime, compared with people without HIV (Corbett *et al.* 2007; UNAIDS & WHO 2011). In 2010, PLHIV accounted for about 13% of all new TB cases worldwide, and about 360,000 people died from HIV related TB (WHO 2011). The rise in incident cases of TB has led to a dual burden of TB and HIV that is of serious public health concern. The 2011 WHO global TB report indicates that in 2010, there was an estimate of 8.8 million incident cases of TB (equivalent to 128 cases per 100,000 population) globally, compared to 9.4 million incident cases of TB in 2009 (WHO 2011; WHO 2010a).



With regards to mortality related to TB, the WHO 2011 report estimates over one million deaths (range 0.9–1.2 million) among HIV negative cases of TB, and less than half a million (0.35 million) TB deaths related to HIV (WHO 2011). The same report indicates that the TB-HIV co-infection rate was estimated at 13% worldwide, with the African region accounting for 82% of these cases. Yet the uptake of HIV testing among TB patients was estimated at 59%, and the co-infection rate was estimated at 44% by the end of 2010 in Africa.

It is striking that in less than two years there has been a tremendous increase of the uptake of HIV testing (> 75%) among TB patients in the African region, particularly in 68 countries with a high burden of TB (WHO 2011). However, management of TB-HIV co-infected patients as recommended by WHO (WHO 2012), which includes CPT, ART and IPT, is still far from the 100% target as stated in the Global Plan to Stop TB (WHO 2010b).

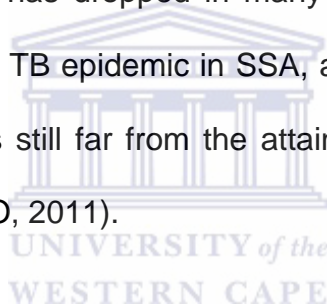


The 2011 WHO report indicates that from 2009 to 2010, more than 0.3 million TB co-infected patients were enrolled on CPT globally. South East Asia and African regions achieved a higher coverage of CPT (87% and 76%) compared to other regions. Although there has been an improvement in CPT coverage in the African region, more efforts are required to reach the global target set by the Global Plan to Stop TB (WHO 2010b).

The uptake of ART among TB-HIV co-infected patients has been somewhat slow in most high burden countries. However, from 2004 to 2010 there has been a steady improvement in ART uptake, with an estimate of 200,000 (46% of the people needing ART) TB-HIV co-infected patients (WHO 2011).

Regarding the uptake of IPT in 2010, a total of 278,000 PLHIV (12%) without active TB were on IPT compared to 80,000 PLHIV (0.8%) in 2009 (WHO 2010a; WHO 2011). Although this figure shows an increase from previous years, the use of IPT among PLHIV worldwide is still inadequate (WHO 2011). This indicates very slow progress of the roll out of IPT, yet the use of IPT is essential for a comprehensive HIV care package, particularly in countries where the prevalence of latent TB (LTB) is above 30% (Date *et al.* 2010).

It is important to note that in recent years there has been great improvement in HIV and TB prevention and control globally, especially in SSA. The HIV epidemic has stabilised, and HIV incidence has dropped in many SSA countries. However, HIV remains the main driver of the TB epidemic in SSA, and the clinical management of TB-HIV co-infected patients is still far from the attainment of the targets set in the Global Plan to STOP TB (WHO, 2011).



There is still much to do in order to enhance provision of essential HIV care, such as CPT and ART, despite the benefits of CPT in PLHIV on morbidity and mortality in HIV-infected TB patients (Mulenga *et al.* 2007; Nunn *et al.* 2007; Date *et al.* 2010).

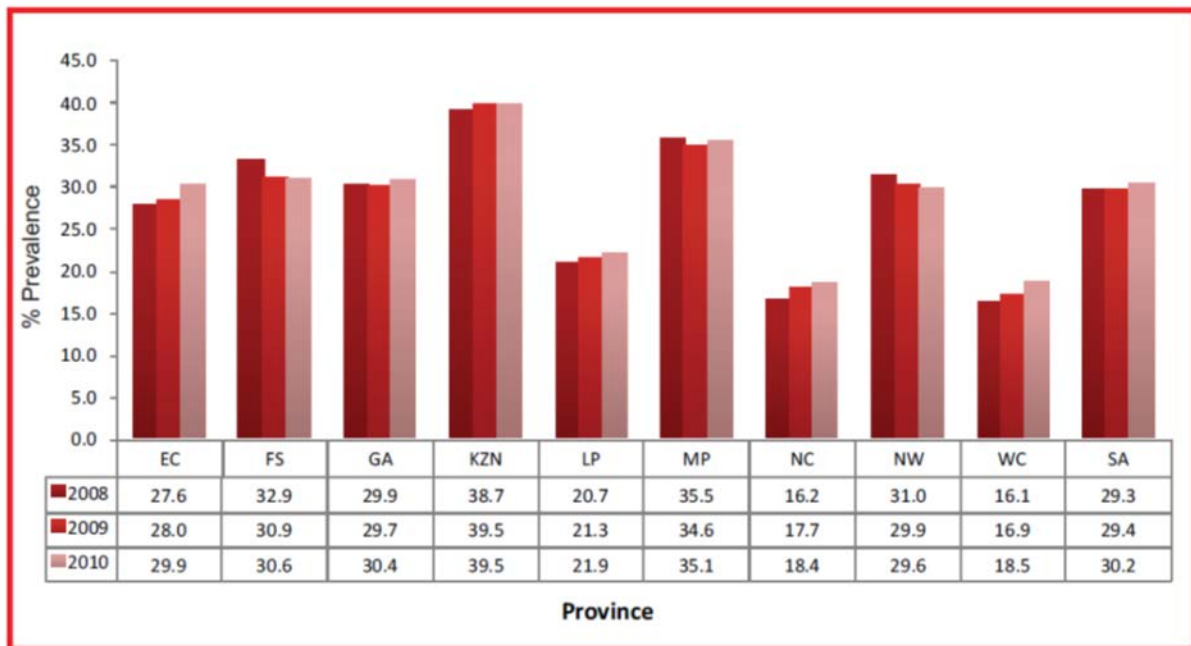
ART reduces the incidence of TB and mortality by 80% in endemic areas with TB and HIV (Badri, Wilson & Wood 2002; Corbett *et al.* 2006). This calls for devising means to intensify provision of ART among PLHIV to reduce TB incidence, and both CPT and ART to reduce mortality among those co-infected with TB. Hence integration of TB/HIV care at all points of care is important to reduce the impact of the dual epidemics, particularly in high burden countries such as South Africa.

### 1.2.1 Overview of the burden of TB and HIV in South Africa

South Africa is one of the SSA countries heavily affected by the dual epidemic of HIV and TB, with an estimated 60% of TB patients co-infected with HIV (WHO 2011). The co-infection rate of TB/HIV has been measured to be between 75% and 80% in some settings in KZN province (Abdool Karim *et al.* 2009; Perumal *et al.* 2009).

South Africa has the largest number of PLHIV in the world. The 2011 UNAIDS report estimates that in 2010, HIV prevalence in the general population was estimated at 17.9%, and there were approximately 5.6 million PLHIV in SA. Of these, 3 million were women (15 years and above) and 518,000 were children below 15 years (UNAIDS 2011). The 2010 national antenatal sentinel HIV and syphilis prevalence survey indicates a great variation according to gender, age and provinces (DOH 2011). The HIV prevalence among antenatal women was estimated at 30.2% [29.39-30.9%] at country level. KZN province was the province with the highest HIV antenatal prevalence [39.5%] and Northern Cape was the province with the lowest HIV prevalence [18.4%] (DOH 2011) (Figure 1). Women continue to sustain higher levels of HIV infection compared to men, with the HIV prevalence among women aged 15–19 years 2.7 times higher than that of men (DOH 2011).

In addition, HIV prevalence is much higher in pregnant women aged 30 years and above (42.6%) compared to age group 15-19 years (14%).



**Figure 1: HIV Antenatal prevalence trends by province from 2008-2010**

Although there has been a slight increase in HIV prevalence among pregnant women in South Africa, it is important to note that there was great improvement regarding HIV prevention from mother to child transmission in 2010 compared to other countries in the southern Africa region (Goga, Dinh & Jackson 2012; UNAIDS 2011).

The WHO estimates that HIV and AIDS account for 41% of the burden of disease (measured in DALYs or Disability Adjusted Life Years) in South Africa (WHO 2009), and in 2010 annual AIDS deaths were estimated at 282,578 deaths (WHO 2011).

Studies in the literature have indicated the great impact of ART in the reduction of mortality among PLHIV (Hogg et al., 1998; Palella et al. 1998; Badri et al. 2002). In SA in 2010, the total number of PLHIV needing ART was estimated at 1,711,561 including children (UNAIDS 2011).

The 2011 UNAIDS report indicates that there had been an increase of 20% by the end of 2010 in the number of PLHIV needing ART who are on ART (UNAIDS 2011). Although ART coverage in SA falls into the range of 40-50%, according to the recent UNAIDS report (UNAIDS 2011), there is still a need to intensify efforts to achieve universal access to ART (defined as 80%) (UNAIDS & WHO 2011).

It is also important to note even if there has been a decrease of HIV incidence by a third from 2001 to 2009 (2.4% to 1.5%), the HIV incidence in SA is still high, and contributes to the high burden of TB. In 2010, TB incidence including HIV patients was estimated at 981 cases per 100,000 population per year, and the case detection rate was estimated as 72% for all forms of TB (WHO 2011).

The HIV co-infection rate was estimated at 60%, and the HIV uptake among TB patients improved from 40% in 2009 to 54% by the end 2010. Of the 128,457 TB patients co-infected with HIV, 9,505 of them (74%) were started on CPT, and 54% were initiated on ART in 2010 (WHO 2011), compared to 67% on CPT and 35% on ART in 2009 (WHO 2010a). In view of this low uptake of CPT and ART among TB co-infected patients, there is a need for further advocacy for provision of TB/HIV integrated care.

### *1.2.2 The burden of TB and HIV infections among women and children*

Studies nationally and worldwide have shown that women bear a large burden of the dual epidemics of TB and HIV, particularly in the childbearing age (15-49 years), which increases mortality in this age group (Adhikari 2009; UNAIDS 2011; WHO 2011).

The WHO Global TB report (2011) indicates that women account for an estimated 3.2 million TB cases, and approximately 900,000 women of reproductive age are infected with TB. In 2009, women accounted for more than 45% of all smear positive pulmonary TB cases in South Africa (WHO 2009; WHO 2010a).

Tuberculosis is often linked to HIV infection and is the third leading cause of death among women of reproductive age (15–44 years) in developing countries, while it ranks fifth worldwide among women aged 20–59 years (WHO 2010a). Women have a higher rate of progression from infection to disease due to various factors, including immunological and hormonal differences, as well as socio-economic and cultural contexts of the disease (Marais *et al.* 2010a). Furthermore, Khilnani (2004) argues that patients co-infected with HIV have a greater incidence of extra-pulmonary TB and a greater risk for vertical transmission of TB to infants.

Studies conducted in KZN province indicate that 774/100,000 HIV infected pregnant women have active TB, representing nearly 10 times the rate in HIV uninfected women (Pillay *et al.* 2004). Kali and colleagues (2006), in their study in Soweto, Gauteng province found that the prevalence of TB among HIV infected women was 2.16%.

Chintu and Mwaba (2005) argue that TB is the most common cause of morbidity and mortality in Zambian children co-infected with HIV. Jeena and colleagues (2002) also argue that children with TB-HIV co-infection have a six-fold higher mortality rate compared to co-infected adults.

In children, the risk for progression of TB disease after diagnosis with TB infection is 24% in children under five years and 43% in children less than a year (Adhikari 2009). Hence, intensified TB case finding in pregnant women and children is vital.

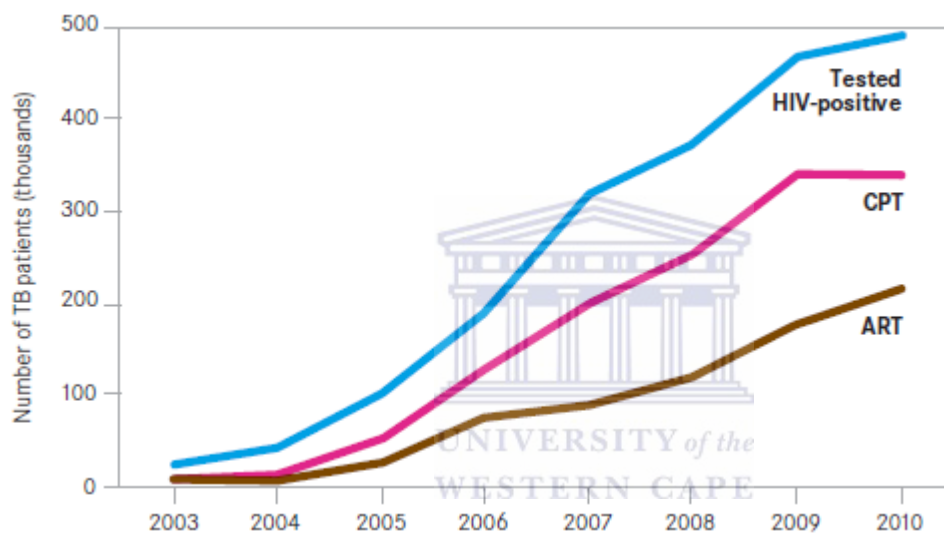
The PMTCT programme should be an opportunity for TB symptom screening, diagnosis and treatment among pregnant women. However, a recent study conducted in KZN indicates that only 57% of interviewed pregnant women reported that they were screened for TB symptoms by a health care worker on the day of their visit, while the facility routine PMTCT programme data shows that out of 542 HIV positive pregnant women, 298 (55%) were screened for TB symptoms (Uwimana *et al.* 2010).

The findings discussed above show that key services related to TB prevention and care, such as TB symptom screening, IPT and TB treatment for women during their antenatal care and post-natal care, have been inadequate, particularly for those who are HIV positive and thus at higher risk of vertical transmission of TB. This calls for policy makers and service providers to design and implement effective interventions tailored for integration of TB/HIV/PMTCT services.

### **1.3 Progress on the implementation of collaborative TB/HIV activities including PMTCT**

Although there has been some progress in implementing collaborative TB/HIV activities; many countries heavily burdened by both TB and HIV still struggle to implement effectively collaborative activities.

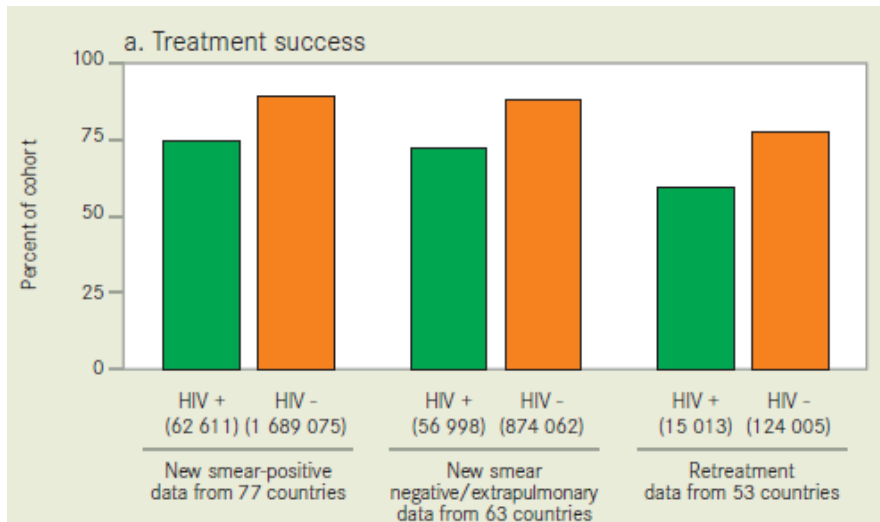
Most of the high burden countries are still far from achieving the targets set by the Stop TB strategy for collaborative TB/HIV activities (Gunneberg *et al.* 2008; WHO 2010b). Less than a third of PLHIV co-infected with TB sought treatment by the end of 2010, 77% of PLHIV co-infected with TB were on CPT while only 46% of PLHIV co-infected with TB were initiated on ART worldwide (WHO 2011). Figure 2 illustrates the number of TB patients tested HIV positive in HIV care from 2003 to 2010 (WHO 2011).



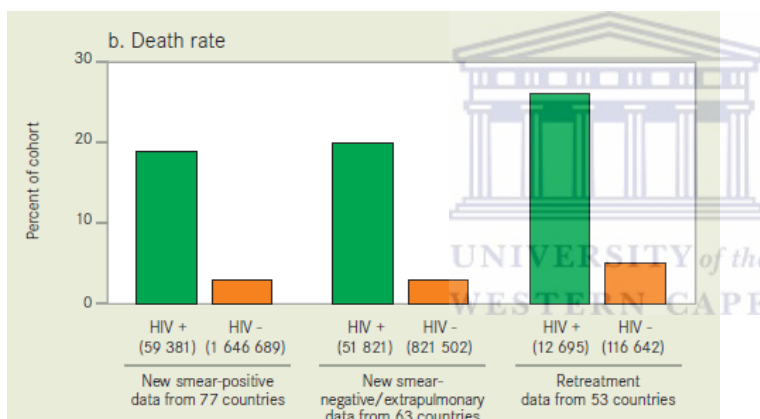
**Figure 2: Co-trimoxazole preventive therapy (CPT) and antiretroviral therapy (ART) for HIV positive TB patients, 2003–2010**

With regards to treatment success and death rates among PLHIV co-infected with TB, 81 countries reported on TB treatment outcomes, less than half of which were from the high burden countries. The estimate for treatment success and death rates in PLHIV co-infected in 2009 were 72% and 20%, compared to 88% and 3% in non HIV positive TB cases (WHO 2011). This shows a high death rate among PLHIV. Hence the need to improve CPT and ART coverage for co-infected patients. Figures 3a and 3b show treatment outcomes among TB/HIV co-infected patients and HIV negative TB patients (WHO 2011).





**Figure 3a: Treatment outcomes for HIV positive and HIV negative TB patients, 2009. (Numbers under bars indicate the number of patients in each cohort)**



**Figure 3b: Death rates**

In 2010, 2.3 million PLHIV were screened for TB compared to 1.7 million in 2009, and 178,000 of those without active TB were enrolled on IPT (12%) compared to 80,000 in 2009 (WHO 2009; WHO 2011).

Intensified efforts are needed to approach the target of providing IPT to all those without active TB, and 100% of HIV positive TB patients on both CPT and ART by 2015, as stipulated in the Stop TB strategy (WHO 2010b). These targets should be also be incorporated into maternal and child health (MCH) services because TB remains a life threatening disease for women and children in TB endemic areas.

This was substantiated by Havlir *et al.* (2008) and Ngadaya *et al.* (2009), who argue that in order to reduce the burden of TB for HIV care and treatment programmes, TB prevention, diagnosis and treatment should be incorporated into paediatric and adult ART clinics as well maternal health programmes.

Although the WHO report on global TB control highlights the burden of TB among women and children (WHO 2011), the progress on integration of TB prevention and care activities into maternal and child health programmes globally is still unknown. There have been some studies conducted in South Africa on the integration of TB prevention and treatment care activities into PMTCT programmes, which indicate the inadequate roll out of TB symptom screening and IPT among PMTCT clients (Kali *et al.* 2006; DeLuca *et al.* 2009; Uwimana *et al.* 2010). This suggests an immediate need for expanding collaborative TB/HIV activities into the MCH programme, and monitoring the progress of this integration. Moreover, international policies stress the importance of integrating TB with HIV services, including PMTCT (WHO 2010c; WHO 2012).

In addition, the establishment of surveillance and a proper reporting and recording system that monitors the progress of integration of TB/HIV/PMTCT services is required since most countries do not have such systems in place.

### *1.3.1 Progress in the implementation of collaborative TB/HIV activities in South Africa*

The progress on the implementation of collaborative TB/HIV activities in achieving the global targets has been very slow worldwide particularly in countries highly

burden such as South Africa.

South Africa was involved in the early steps of TB and HIV strategy development with the implementation of the WHO ProTEST initiative in four districts in 1997 (WHO 2004b). Based on the success of the TB/HIV Pilot Districts, the national Department of Health (DOH) developed a joint strategy for HIV&AIDS, sexually transmitted infections (STIs) and TB control in 2001, and provinces committed to implement the lessons learned from the TB/HIV Pilot Districts (DOH 2007). However, Grimwood and colleagues (2006) argue that despite the establishment of structures such as the HIV&AIDS, STI and TB (HAST) units, only 16% of HIV positive clients were screened for TB, and the proportion of HIV positive clients with confirmed TB was estimated at 44%, while 30% of them were assessed for ART eligibility in 2006.

A later study conducted in Cape Town assessing the integration of TB/HIV/STIs showed that the level of integration was variable but promising (generally over 65%) across the programmes. Screening of HCT clients for TB and STIs was 70% and 68% respectively; screening of HIV clients for TB and STIs was 51% and 79% respectively; and 71% of STI clients and 94% of TB clients were offered HCT (Scott *et al.* 2010).

In South Africa, the adoption and wide implementation of the WHO guidelines on TB screening and IPT among PLHIV occurred in 2010. This contributed to more than a fivefold increase in the uptake of IPT among PLHIV from 23,583 in 2009 to 124,049 in 2010 (WHO 2010a; WHO 2011). Table 1 illustrates the implementation of collaborative TB/HIV activities in 2010.

**Table 1:** Progress of collaborative TB/HIV activities in South Africa, 2010

TB patients with known HIV status	213, 006
% of TB patients with known HIV status	54
TB patients that are HIV positive	128,457
% of tested TB patients that are HIV positive	60
% HIV positive TB patients started on CPT	74
% HIV positive TB patients started on ART	54
HIV positive screened for TB	758, 837
HIV positive people provided with IPT	124, 049

Source: WHO (2011)

Regarding provision of TB prevention and care services to pregnant women, some studies indicate the same trends in the general population whereby less than 60% of pregnant women known to be HIV positive are screened for TB symptoms (Kali *et al.* 2006; DeLuca *et al.* 2009; Uwimana *et al.* 2010). Furthermore, less than 30% of all pregnant women (irrespective of their HIV status) were screened for TB symptoms, and the uptake of IPT was not even recorded (Uwimana *et al.* 2010).

Grimwood *et al.* (2006) argue that the assessment of collaborative TB/HIV activities in SA has been very problematic due to poor design and the lack of a standardised recording and reporting system for TB/HIV programmes that includes key indicators to monitor integration, as recommended by the WHO policy on collaborative TB/HIV activities.

If PMTCT coverage in SA has reached beyond 80% (UNAIDS 2011; Goga *et al.* 2012), while TB screening among PMTCT clients is less than 60%, it is clear that there is an urgent need to intensify efforts to strengthen integration of TB/HIV/PMTCT services. Moreover, in the context of South Africa's highly uneven distribution of both disease burden and health system resources, the provincial and

district epidemiological profiles of TB and HIV must also be considered.

It is also important to note that there has been steady progress in the implementation of collaborative TB/HIV activities in South Africa since 2008, due to new political leadership (Abdool Karim *et al.* 2009). On World AIDS Day 2009, President Jacob Zuma confirmed that TB/HIV integration was government policy by saying that TB and HIV should be treated under one roof (South African Government of Information, 2009). Additionally, the National Strategic Plan on HIV, STIs and TB 2012-2016, which was launched on World AIDS Day 2011, clearly promotes integrated TB/HIV services (DOH 2012). However, more efforts are still required to achieve the global targets set by Stop TB strategy and the millennium development goals (MDGs).

#### **1.4 Need for accelerating and monitoring efforts for collaborative TB/HIV/PMTCT activities**

According to Gunneberg *et al.*'s (2008) global report on monitoring of collaborative TB/HIV activities, most countries are failing to report on collaborating activities, due to poor recording and reporting systems. The report shows that of 72% national TB programmes surveyed, only 56% reported that they have revised their monitoring and evaluation systems to include TB/HIV activities.

Moreover, Uwimana *et al.* (2010) in their study in KZN also found that PMTCT recording and reporting tools do not have key indicators on screening for IPT and TB treatment outcomes.

In addition, reporting tools for PMTCT programmes or maternal and child care in general are not yet revised to include key data for TB prevention and care (Uwimana *et al.* 2010; Loveday & Zweigenthal 2011). This calls for strengthening of M&E

systems for all three programmes (TB/HIV/PMTCT).

Studies in other parts of the African continent have stressed the importance of establishing proper recording, reporting, and communication systems in health facilities where referral and partial integration models exist (Wandwalo *et al.* 2005; Harries *et al.* 2006; Friedland *et al.* 2007).

## **1.5 Community participation in TB and HIV collaborative activities**

Community participation, through encouraging people in the community to engage in activities that are related to TB and HIV prevention, treatment and control, is vital to reach the large number of people who are affected, and to reduce the burden of TB and HIV infection on people who are dually infected.

Community interventions can hasten universal access to TB and HIV care, and could also be considered as one of the avenues to address the human resource (HR) crisis and strengthen the health system to address the dual burden of the TB and HIV epidemics.

Evidence from the literature shows that the success and effectiveness of TB directly observed treatment short course (DOTS) and ART adherence were enhanced through the greater participation of CCWs and other community groups (Abaasa *et al.* 2008; Friedman *et al.* 2007; Friedland *et al.* 2007).

Community participation is one of the pillars of primary health care (PHC) as described in the Alma Ata declaration (WHO 1978). The WHO campaign for Health for All by the Year 2000 had at its core community participation. This has led many countries to adopt this concept, through which important health problems can be addressed and access to care can be enhanced, particularly in remote, rural areas.

However, most countries in SSA, including South Africa, are currently considering re-vitalising the PHC concept with a focus on integration of CCWs into their health systems.

Integrating CCWs in the health care chain for the provision of integrated TB/HIV/PMTCT care will require task-shifting/sharing and up-skilling of CCWs to provide comprehensive care.

The WHO defines community participation as the process by which the members of the community either individually or collectively, and with varying levels of commitment: (a) develop the capability to assume greater responsibility for assessing their health needs and problems; (b) plan and then act to implement their solutions; (c) create and maintain organizations in support of these efforts; and (d) evaluate the effects and bring about necessary adjustment in goals and programmes on an on-going basis (WHO 1989). For this study, “community participation” refers to involvement of CCWs in provision of health services at community level.

The role of the community in the fight against HIV and TB is increasingly acknowledged in the literature. Mukherjee and Eustache (2007), in their study in Haiti, give an indication of the potential of community health workers (CHWs) for fostering the integration of HIV and PHC by improving access to care, ART adherence, promotion of HIV testing and TB prevention, as well uptake of PHC services such as nutrition for children. Another study in Malawi by Zachariah *et al.* (2004) showed the significant contribution of community involvement in the improvement of TB and HIV control.

The findings of the study indicated that 41% of HIV tests in HCT centres were performed by lay counsellors, 39% of HIV patients were at WHO clinical stage III or IV, 100% of whom were on CPT, 45% on ART and 60% of HIV patients with TB received care and support from CHWs (Zachariah *et al.* 2004).

There is longstanding and substantial consensus in the literature and global advocacy for developing countries, particularly in SSA where most countries are severely affected by HIV, to mobilise the community to harness health workers to *overcome* the human resources for health (HRH) crisis by allowing well trained CCWs to deliver core health functions (Chen *et al.* 2004).

Studies have shown that CCWs act as the first line of contact with the health system in most low and middle income countries (Hongoro & McPake 2004), and services such as home based care and HIV counselling are mostly provided by CCWs (Schneider & Lehmann 2010).

Moreover, a review by Lehmann and Sanders (2000) of studies from Gambia, South Africa, Zambia, Madagascar, and Ghana suggests that CCWs enhance the performance of community health programmes with some evidence of cost-effectiveness.

Despite the evidence of community participation in health care highlighted in the literature, in most settings community resources are often under-exploited (Zachariah *et al.* 2004). Therefore, participation of the community in health care at the community level could be seen as a strategy that could enhance HRH and be integrated in the healthcare system particularly in Africa.



Through extending the reach of HRH by involving CCWs in the delivery of integrated TB and HIV services, community participation could also increase the accessibility of prevention, case finding, care and treatment in the community.

## **1.6 Conclusion**

This chapter has described the many interconnections between TB, HIV, pregnancy, and maternal, child, and general health outcomes. In high TB/HIV prevalence countries, none of these major health problems can be effectively addressed without addressing each of the others, at clinical, facility, management and policy levels. Collaboration and integration of TB, HIV and PMTCT activities is essential.

However, for communities that live out of reach of health facilities, activities for both HIV and TB, such as HCT and TB case finding and treatment adherence, do not exist. Therefore, joint TB and HIV prevention activities should go beyond health facilities, and this will require community involvement with CCWs. This is likely to be one of the ways of accelerating the implementation of collaborative TB/HIV/PMTCT activities, based on the lessons learned from community participation in health (Parry & Wright 2003; Preston *et al.* 2009; Viswanathan *et al.* 2009).

In view of the background presented above, this study seeks to explore ways in which community participation, by integrating CCWs into the mainstream of PHC systems, could hasten the delivery of integrated TB/HIV/PMTCT services.

## CHAPTER 2

### LITERATURE REVIEW

This chapter presents and discusses the literature review in relation to the concept of integration and collaboration and its application within the health system with focus on service delivery. This chapter also presents the framework for implementation of collaborative TB/HIV activities as recommended by WHO recent policy on collaborative activities, and discusses further the inclusion of PMTCT services in the framework. The benefits and constraints for implementation of collaborative TB/HIV activities are also discussed. This chapter further discusses the engagement of community or community participation in collaborative TB/HIV/PMTCT activities and identifies the gaps in the literature in relation to community engagement in collaborative TB/HIV/PMTCT activities. Finally, this chapter presents the study rationale, the overall aim and objectives of the study as well as the research questions.

#### **2.1 The concept of integration versus collaboration**

Despite the growing interest and amount of literature on the topics of integration and/or collaboration in healthcare provision, there appears to be little consistency in the definitions and the clarity of the goal for these concepts. Some scholars in the literature argue that integration and collaboration are two distinct terms that have a common goal of working together for the good of the patients (Boon *et al.* 2009).

Friedland and colleagues (2007), in their study on the assessment of implementation of collaborative TB/HIV activities, used the term integration when referring to co-location of TB and HIV services, whereas the term collaboration referred to the co-

ordination of TB and HIV programmes.

In contrast, Sobczak (2002) argues that there is no difference in meaning between integration and collaboration, although the terms are different and often used interchangeably.

The WHO defines integrated health care as the organisation and management of health services so that people get the care they need, when they need it, in ways that are user-friendly, achieve the desired results and provide value for money (WHO 1996). According to the WHO definition, the emphasis is on the patient as the centre of all clinical and administrative processes. Sobczak (2002) also supports the WHO definition, stating that integration in health care is oriented to patients' needs, but also to extending or improving professional skills, and creating mechanisms and technology that enhance health gains.

Although these two concepts (integration and collaboration) differ somewhat (Boon *et al.* 2009), there seems to be no one single definition of the concept of integration (Boon *et al.* 2009; Loveday & Zweigenthal 2011; Sobczak 2002). The lack of precise definitions contributes to divergences over aims, goals, means of integration/collaboration, and evaluation of programmes using these concepts.

Furthermore, the way policymakers and managers define and understand both terms underpins the design of policies and implementation. This is substantiated by Oliff *et al.* (2003) in their study in Tanzania on integration of reproductive health services in health sector reform. The findings show that the understanding of the term integration and how to implement it varied widely, and thus has led to difficulties in the implementation process.

Lush and colleagues (1999) further argue that the ideology and the myth around the concept of integration have influenced the way services are integrated in practice. This suggests that these terms must be defined at the outset to avoid confusion in discussions on policymaking, programme implementation and evaluation.

Moreover, for successful outcomes of integrated care, policy makers, programme managers and health managers need to have a common understanding of the concept, and implement what is appropriate in the setting.

For the purpose of this study “integration” and “collaboration” refer to the same thing. Although the researcher considers integration and collaboration as one concept, it is also important to recognise the many possible steps in the process of applying these two concepts in the health system to achieve a common goal. People could work together across organisation/structural boundaries and provide a seamless continuum of care to achieve better patients’ outcomes.

In this study, the concept of integration will be looked at through the lens of Thaldorf and Liberman (2007). They define integration in health care as an attempt to provide all elements of care in a seamless continuum of care.

Although there are a variety of models of integration described by Dudley and Garner (2011), in this study integration of TB/HIV/PMTCT services or collaborative TB/HIV activities, including PMTCT, will be viewed at the level of “service delivery” and “management”.

By” integration at service delivery level”, we refer to the provision of TB/HIV/PMTCT at one point of care and by the same health care worker (HCW) or community care worker (CCW).

By” integration at management level”, we refer to planning and operationalisation of these services as one programme, M&E systems, and training and supervision of HCWs as well as CCWs.

Although this study looked at integration of TB/HIV/PMTCT services into the broader spectrum of the health system (as discussed in Paper II), the overall aim of this study was to address issues related to service delivery at community level. Hence, the point of emphasis reflects the study context, where the training of CCWs was based on the disease (TB or HIV) and their scope of practice. Additionally, the supervision of the CCWs was done by different people and through different mechanisms. Needless to say, for this study “integration” we also refer to integration of different cadres of CCWs into one cadre.

### *2.1.1 Significance of the application of the integration approach in health care/systems*

In the literature, the comprehensive integrated approach has been widely advocated since the Alma-Ata Declaration in 1978, with the emphasis on health care provision seen through the lens of provision of comprehensive primary health care as strategy for a broader political and economic development agenda (WHO 1978).

From the late 70s and early 80s, advocacy with a comprehensive rather than selective approach in provision of health care has been widely embraced. However, problems arise in the details of the implementation of the approach, particularly

where the TB and HIV epidemics have further exacerbated the situation in developing countries.

The basic purpose of promoting integration in health care systems or provision of comprehensive care is the quest for equity, effectiveness, efficiency, quality and sustainability (Lush *et al.* 1999; Feenstra & Vissechedijk 2002; Autun *et al.* 2008). Sobczak (2002) contends that the need for integration could also be due to the complexity and the diversity of the health care systems.

The current epidemiological profile of TB and HIV diseases and high rates of maternal and infant mortality in SSA have also led to the need for an integrated approach. As a result, several studies in the literature and international bodies such as WHO have been advocating for the integration of TB and HIV services at all levels, including PMTCT services (Corbett *et al.* 2007; Nunn *et al.* 2007; WHO, PEPFAR & UNAIDS 2009; WHO 2012) planning and evaluation (Gunneberg *et al.* 2008), provision of training, service delivery (Friedland *et al.* 2007; Havlir *et al.* 2008) and research (WHO 2010c). However, the approach for “integration” of programmes and services can be viewed from different perspectives and can also serve as a mechanism to achieve several goals.

### *2.1.2 Domains of application for integration approach*

According to the literature, there are two domains into which integration can be classified, namely vertical and horizontal integration. Sobczak (2002) and Feenstra and Vissechedijk (2002) define vertical integration as the ability of one provider system to provide at all levels and intensities of services to patients and health care consumers based on specific health problems. Horizontal integration refers to one

provider providing a similar range of services to patients for the broad spectrum of common health problems.

Freenstra and Vissechedijk (2002) further argue that integration does not exclude specialised services, but that they fall within the general health system/service. Dudley and Garner (2011) further argue that vertical and comprehensive (integrated health care services) approaches are not mutually exclusive but they are complementary approaches within a continuum of care.

Although integration approaches may differ (vertical or horizontal), the main outcomes of the approach include economies of scale, cost-effectiveness and efficiency, increased health care staff and resources flexibility, better service convenience for patients and quality services/care (WHO 1996; Feenstra & Vissechedijk 2002; Sobczak 2002; Cruz, Kurowski & Mills 2003; WHO 2007a).

Evidence in the literature regarding the impact of the integration approach in health care includes effectiveness and efficiency (Sobczak 2002; Thaldorf & Liberman 2007), and improved access and delivery of health care (Dudley & Garner 2011).

However, Dudley and Garner (2011), in their review on strategies for integrating PHC services in middle- and low-income countries at the point of delivery, indicate little or no evidence that fuller integration of PHC services improved people's health status. This was attributed to two main factors which included poor design of monitoring and evaluation systems for integrated services; and lack of capacity within the health systems to implement strategies, to provide necessary support to local managers, and to coordinate/document all the required inputs (Magtymova 2007).

Hence, there is a need for further studies with sound study designs to measure the impact of the strategy.

### *2.1.3 Challenges to integration of health care services*

Integration of health care has been promoted by international bodies such as WHO to achieve Health for All, and most low-income countries have it on their agenda as part of health care system reform (Freenstra & Vissechedijk 2002).

While the concept of integration is well advocated in the health care setting, there are challenges to the implementation of integration of health care/health systems. Freenstra and Vissechedijk (2002) argue that the integration process has been hampered by various factors, which include factors related to lack of commitment, poor planning and inadequate implementation. Lack of commitment implies resistance to change among various groups at different levels of the health care system. Poor planning and implementation refer to lack of careful planning of the process of integration, and of inadequate skills and supervision support to achieve integration.

From Sobczak's (2002) perspective, based on Poland's experience on integration of health services, challenges related to the integration of health care systems were attributable to lack of standardisation of clinical or information systems and lack of procedures aimed toward integration of services and financing systems. The latter was also echoed by Lush *et al.* (1999), stating that the implementation of the integration approach has been hampered by logistical and financial dilemmas of the health systems.



Other factors cited in the literature include:

- Cultural dimension (Scott *et al.* 2003): underlying beliefs, values, norms and behaviours of the system, which either support or inhibit clinical integration work.
- Technical dimension (Freenstra & Vissechedijk 2002; Corbett *et al.* 2006; Wang *et al.* 2007; Boon *et al.* 2009): extent to which people have necessary training and skills to achieve integration.
- Structural dimension (Wang *et al.* 2007): overall organisational structure of the system to support integration efforts.
- Health care consumers/patients dimension (Levin *et al.* 2006; Friedland *et al.* 2007): lack of knowledge, perceptions of services and stigma from patients.

Although the integration approach is deemed to be essential for strengthening the PHC system, it is important to consider, in the context of the health systems at large and changes over time, where both vertical and horizontal approaches could play a significant role in responding to health needs and expanding access to health care.

## **2.2 Framework for implementation of collaborative TB/HIV activities, including PMTCT**

To ensure proper implementation and monitoring of TB/HIV collaborative activities, in 2004 the WHO global TB/HIV working group developed an interim policy for collaborative TB/HIV activities as a guideline for countries to implement the policy (WHO 2004a), which was updated in 2012 (WHO 2012). This policy was developed based on the lessons learned from the ProTEST study conducted by the WHO in 1997 in three countries in southern Africa, including South Africa (WHO 2004b).

The ProTEST study was conducted in order to establish a comprehensive response to TB prevention, care and support in settings with high HIV prevalence. The key findings of the ProTEST study highlighted the feasibility of joint TB/HIV activities with high uptake of HCT, TB case finding and provision of IPT. The results of this study resulted in the formulation of strategies and structures for joint TB/HIV activities by participating countries and the WHO.

In SA, the ProTEST study led to the establishment of a national TB/HIV unit to coordinate and promote implementation of collaborative TB/HIV activities by the DOH, while at provincial and district level, HAST (HIV/AIDS/STI/TB) coordinators were recruited to foster the integration process (WHO 2004b; Grimwood *et al.* 2006).

Although there is limited literature on policy or guidelines for collaborative TB/HIV activities that include PMTCT or MCH programmes, some studies suggest provision of key activities such as TB case finding, diagnosis and care, and provision of IPT for MCH/PMTCT services (Kali *et al.* 2006; DeLuca *et al.* 2009; Uwimana *et al.* 2010).

One could argue that all the core activities provided for collaborative TB/HIV activities should also be applicable to MCH/PMTCT programmes. Table 2 below summarises the core components recommended by the WHO policy on collaborative TB/HIV activities (WHO, 2012).

**Table 2:** Core components recommended by the policy on collaborative TB/HIV activities

Components for integration or collaboration	Activities
<b>Establish mechanisms for collaboration</b>	<ul style="list-style-type: none"> <li>• Set up a coordinating body for TB/HIV activities</li> <li>• Surveillance of HIV prevalence among TB patients and TB prevalence in HIV patients</li> <li>• Joint TB/HIV planning</li> <li>• Conduct monitoring and evaluation</li> </ul>
<b>Decrease the burden of TB in people with HIV</b>	<ul style="list-style-type: none"> <li>• Establish intensified TB case finding</li> <li>• Introduce IPT</li> <li>• Ensure TB infection control in health care and congregate settings</li> </ul>
<b>Decrease the burden of HIV in TB patients</b>	<ul style="list-style-type: none"> <li>• Provide HIV testing and counselling</li> <li>• Introduce HIV prevention methods</li> <li>• Introduce CPT</li> <li>• Ensure HIV care and support</li> <li>• Introduce antiretroviral therapy</li> </ul>

Source: WHO (2012)

Although TB and HIV programmes have over decades often pursued separate paths, they share mutual concerns: TB prevention, case finding and case holding should be a priority for HIV programmes; and HIV prevention, testing and treatment should be a priority for TB control programmes (Maher *et al.* 2005a; Corbett *et al.* 2007). In addition, the emerging evidence of the impact of TB on MCH and PMTCT calls for integration of TB prevention and care into MCH as well as PMTCT. Therefore, for effective collaborative TB/HIV/PMTCT activities, policymakers and programme managers should ensure that core components of TB and HIV collaborative activities, as recommended by WHO with the incorporation of the MCH programme, should be implemented and monitored in any model of integration/collaboration.

Where TB and HIV programmes as well MCH/PMTCT are still being delivered separately, this requires considerable effort to ensure that programmes are able to work effectively together, particularly at facility and community level (Wang *et al.* 2007; Abdool Karim *et al.* 2009).

Coordinating bodies at national and local levels should also ensure that all stakeholders at all levels, including communities, meet regularly to plan jointly, implement, and monitor collaborative activities. The latter has been substantiated by several studies evidencing parallel and uncoordinated systems for monitoring collaborative TB and HIV activities (Corbett *et al.* 2006; Wang *et al.* 2007; Gunneberg *et al.* 2008; Loveday & Zweigenthal 2011).

Although there are considerable benefits to integrating TB/HIV programmes as well as PMTCT into the PHC system, there are also enormous health systems constraints and barriers to implementation of collaborative TB/HIV/PMTCT activities. This is due to historical ways that these programmes have been running as vertical programmes, and having different philosophies of care. Furthermore, health systems are social structures that have other agendas and interests beyond the technical or medical goals. It is important to note that beneficiaries of health care services (patients) are often not considered in the health systems frameworks such as the WHO framework on health systems (WHO, 2000) and other conceptual frameworks for analysis of integration of health interventions into health systems (Cairncross 1997; Atun *et al.* 2010a).

Yet beneficiaries' perspective could be considered as another health systems building block that could help improve or alter the integration of services.

This was substantiated by Peltzer (2009) who stated that provision and utilization of health services is dependent on the interaction between the health care provider and patients. Hence in this study, patients' perspectives were considered in the assessment of the implementation of collaborative TB/HIV/PMTCT activities as discussed in Paper I: "*Health care providers and patients perspectives' on provision of TB/ HIV services including prevention of mother-to-child transmission (PMTCT) in a rural district, South Africa*". and Paper II: "*Health systems barriers to implementation of collaborative TB/HIV activities including prevention of mother-to-child transmission in South Africa*".

## **2.3 Benefits and constraints regarding implementation of integration of TB/HIV/PMTCT programmes**

### *2.3.1 Benefits for integration of TB/HIV/PMTCT programmes*

The ProTEST study and several other studies have proven the feasibility of implementation of collaborative TB and HIV activities (WHO 2004b). There is also a growing body of knowledge on the importance and benefits of integrating TB/HIV/PMTCT programmes and services at all levels, from managerial to operational level (Coetzee & Hilderbrand 2004; Wandwalo *et al.* 2004; Corbett *et al.* 2006; Nunn *et al.* 2007; Wang *et al.* 2007), individual level (TB and HIV patients) (Levin *et al.* 2006; Kigozi *et al.* 2011) and community level (Zachariah *et al.* 2004; Harries *et al.* 2005).

Perumal *et al.* (2009) argue that the integration of TB and HIV programmes is better than the sum of the verticalisation of TB and HIV services. There are suggested benefits regarding integration of TB/HIV/PMTCT documented in the literature.

The most common documented benefits of integration of TB and HIV programmes, as well as PMTCT services are described below:

- Increased access to comprehensive care (Corbett *et al.* 2007; Nunn *et al.* 2007; Ghebreyesus *et al.* 2010)
- Reduction of TB incidence and other related infections by HAART (Badri *et al.* 2002; Lawn *et al.* 2005; Corbett *et al.* 2006; Date *et al.* 2010)
- Increase in TB case notification and early case detection (Zachariah *et al.* 2004)
- Prevention of latent TB among PLHIV (Churchyard *et al.* 2007; Date *et al.* 2010)
- Scaling-up delivery of ART (Harries *et al.* 2005; Corbett *et al.* 2006)
- Prevention of VTRTB from HIV pregnant women to their unborn child (Pillay *et al.* 2004; Grange *et al.* 2010)
- Contribute to the establishment of new networks of organisations (Zachariah *et al.* 2004; Corbett *et al.* 2006)
- Increase in TB case notification (Zachariah *et al.* 2004; WHO, 2004b; Harries *et al.* 2006)
- Improving performance of TB and HIV programmes (Friedland *et al.* 2007; Scott *et al.* 2010; WHO 2010a)
- Help to strengthen the health system (Wang *et al.* 2007; Atun *et al.* 2010a; Atun *et al.* 2010b)

### 2.3.2 Constraints in implementation of integration of TB/HIV/PMTCT activities

In view of the need and the evidence of the benefits of integration of TB and HIV programmes, as well as PMTCT, the integration process is still lagging behind to achieve the MDGs goals, as well as the international targets set by the STOP TB Partnership strategy on collaborative TB/HIV activities (Nunn *et al.* 2007; Gunneberg *et al.* 2008; Getahun & Gunneberg 2010).

The slow progress of implementation of the integration of TB/HIV/PMTCT services, or the policy in general, is due to various factors that are not necessarily specific to TB and HIV programmes, but to the realities of the integration process as an approach. This has been supported by Boon *et al.* (2009) stating that the complexity of health care systems in general, the epidemiological dimensions, as well as the human dynamics, influence the integration process and make it very difficult to achieve and sustain.

There is an emerging consensus in the literature that indicates that the major constraints/challenges for implementation of collaborative TB/HIV activities, including PMTCT, are related to health systems factors discussed below.

- *Lack of political commitment and governance factors*

Although countries pledged their commitment to implement the WHO interim policy for collaborative TB/HIV activities, most countries in Africa were still struggling with the impact of HIV, with no or little political will to support the implementation of the policy. As a result, only 50-60% of the high-burden countries appointed a TB/HIV focal point in the National Tuberculosis Programme (NTP) and developed a context-based policy and guidelines for the implementation of joint TB/HIV activities, and less than 50% of the countries had a policy on IPT (Gunneberg *et al.* 2008; WHO 2010a).

In South Africa, after the ProTEST study (WHO 2004b), there were policies and structures established from national to district level. However, due to the long denial of the impact of the HIV epidemic in the country, there was little political will for implementation of collaborative TB/HIV activities (Abdool Karim *et al.* 2009; Perumal *et al.* 2009).

This contributed to the slow progress of implementation of joint TB/HIV/PMTCT activities until recently in 2010. However, the Zuma-led government brought radical changes in political will to foster the implementation of collaborative TB/HIV activities (Loveday & Zweigenthal 2011) that influenced the governance of TB and HIV programmes, by injecting funding to support the implementation process. As a result, there has been an increase in access to ART services, HIV testing and use of IPT for both TB and HIV patients requiring these services (UNAIDS 2011; WHO 2011). This suggests that increased political will together with good governance is required to hasten the progress of collaborative TB/HIV/PMTCT activities and towards attainment of MDGs.

- *Financing of collaborative TB/HIV activities*

Due to the historical management of TB and HIV programmes as vertical programmes, the financing of these programmes has been uneven. The HIV/AIDS programme receives funding from multiple external donors, compared to the TB and MCH-PMTCT programmes, which are mainly funded by government (Loveday & Zweigenthal 2011).

Unequal funding of these programmes has contributed to a lack of interest in implementation of collaborative activities, since there is no separate budget or money allocated to joint TB/HIV/PMTCT activities.

The 2010 WHO report highlights that the funding available for TB control in the 22 high burden countries (HBCs) has increased each year since 2002, and was expected to reach US\$2.6 billion in 2010 (WHO 2010a).



However, less than US\$1.5 million was allocated for collaborative TB/HIV activities (Agarwal 2009). This shows a very small amount of money allocated to joint TB and HIV activities, which contributes to the slow progress of collaborative activities and undermines the performance of TB/HIV units at national and local level, as reported elsewhere in the literature (Maher *et al.* 2005a; Wandwalo *et al.* 2006; Wang *et al.* 2007). In addition, the 2009 Treatment Action Group (TAG) report highlighted that funding of TB research and development remained under-resourced, compared to funding initiatives to fight HIV/AIDS (Agarwal 2009). This suggests that unequal funding between TB and HIV/AIDS programmes as separate programmes, and the small amount allocated for collaborative activities, will undermine the attainment of global targets for collaborative TB/HIV activities as indicated in the Stop TB strategy.

Even though some increased funding for TB and HIV has occurred through the Global Fund and PEPFAR, the flow of external funding remains inequitable (Agarwal 2009). This calls for international funding agencies and countries to advocate and mobilise for more resources for collaborative TB/HIV/PMTCT services.

- Organisational and structural factors

The appropriate configuration of health system structures can ensure a clear delineation of responsibilities and accountabilities inside an organisation and shape the performance of the organisation or programmes.

In line with organisational factors, it is well noted in the literature that the organisational culture of a health system determines the performance of the system and is linked to performance of programmes and outcomes (Davies 2002).

Scott *et al.* (2003) argue that shared beliefs, values, attitudes and behaviour shape the organisation or system in defining what is legitimate and acceptable; and somewhat predict the organisation's performance and the outcomes of a programme.

Nearly a decade later, the inherited organisational culture of TB and HIV programmes as vertical programmes, with different philosophies of care management, continue to resonate with the experience of managers at all levels. This calls for policymakers and implementers to look closely at the "soft" issues related to organisational culture, since they affect programme performance and outcomes.

The lack of a common understanding of the concept of "integration" among policymakers and implementers creates irregularities or variability in the implementation process. This was substantiated by Sobczak (2002) and Boon *et al.* (2009) who stated that lack of precise definitions of the concept contributes to divergences over aims, goals and means of integration.

This observation echoes the findings of a study in South Africa assessing the implementation of collaborative TB/HIV activities (Friedland *et al.* 2007) and in Tanzania by Ollif *et al.* (2003) on the integration of family planning into reproductive health. These studies found that the lack of a common understanding of the concept of integration among managers and health providers was identified as a barrier that contributed to the poor quality of services. Hence, it is imperative for policymakers and implementers to forge a common understanding on the meaning of integration or collaborative TB/HIV activities.

There are several studies that show that the lack of proper structures to support the implementation of joint TB/HIV/PMTCT services are at programmatic or operational level (Wang *et al.* 2007; Perumal *et al.* 2009). Furthermore, the legacy of decades of running TB and HIV programmes vertically and separately has affected the integration process.

Nonetheless, structural changes and lack of clarity in managerial roles create tension among TB, HIV and MCH-PMTCT programme managers and co-ordinators. These have been cited as barriers to the implementation of joint TB/HIV/PMTCT activities (Chono, Mugisha & Adatu. 2009; Loveday & Zweigenthal 2011). Hence, in order to enhance the implementation process of joint TB/HIV/PMTCT services, a clear delineation of responsibilities and accountabilities is required at all levels of the health system.

At facility level, the separate location of TB and HIV services, and limited space at facilities to allocate TB and HIV services under one roof, are constraints in provision of integrated services. Where TB, HIV and PMTCT/MCH services are separate, patients become lost in the process of referral from one point of care to the other (Friedland *et al.* 2007; Chono *et al.* 2009).

Due to this loss of patients in the referral process, and poor quality of care related to miss opportunities, there is consensus in the literature in favour of providing TB/HIV/PMTCT services by the same clinicians (Coetzee & Hildebrand 2004; Friedland *et al.* 2007; Havlir *et al.* 2008). However, this requires appropriate infection control to avoid nosocomial infections, particularly in facilities with limited space (Loveday & Zweigenthal 2011).

- Human resources

The magnitude of the dual TB/HIV burden with high caseloads adds to the strain on the existing overstretched health care systems, and contributes to demand for HRH, particularly in rural areas where there is a high turnover of skilled clinicians. Studies that evaluated TB and HIV joint activities acknowledge HRH as a challenge to enhancing integration of TB and HIV services (Harries *et al.* 2005; Vassal & Compennolle 2006; Wang *et al.* 2007).

Due to the complexity in management of co-infection of TB and HIV in both children and adults, skilled health care providers are essential in delivering quality care (Corbett *et al.* 2007; Zachariah *et al.* 2009); yet most facilities are crippled by deficiencies in human resources.

Scott *et al.* (2010), in their study on the assessment of the integration of TB/HIV/STIs in Cape Town, found inadequate levels of staff training across the cluster of HIV/TB/STI. Only 30% of clinical staff (professional nurses and doctors) were trained in HCT, 40% in general HIV care, and 42% in syndromic management of STIs.

In the same study Scott *et al.* (2010) highlight that despite the fact that all the facilities that participated in the study had a dedicated TB nurse, only 57% of HIV positive clients were staged according to WHO criteria, and, 68% of these were appropriately referred for ART initiation. Out of the 24% of HCT clients who tested HIV positive and received a follow-up medical assessment, 61% of HIV positive clients (pre-ART) had on-going HIV management plans recorded. This clearly indicates poor quality of care, which is associated with lack of training of clinicians.

A study in Cambodia highlighted that availability of routine HCT in TB clinics was dependent on staff capacity to perform the test (Eang & Chheng 2007). These findings suggest the need to strengthen the human development plans in building the capacity of clinicians (Harries *et al.* 2005; Vassal & Compernelle 2006), and setting up strategies for staff retention in the public health sector, particularly in rural areas with high staff turnover (Zachariah *et al.* 2009).

There is also a growing body of argument in the literature for countries in SSA to include task-shifting in their strategies for addressing the HRH crisis (Callaghan, Ford & Schneider 2010; Zachariah *et al.* 2009), and this could entail the expansion of the scope of practice of CCWs in performing core health services such as HIV testing (Marais *et al.* 2010b; Mutale *et al.* 2010).

- Monitoring and evaluation (M&E) of joint TB/HIV/PMTCT activities

Lack of a comprehensive M&E system for both TB and HIV programmes has led to difficulties in the assessment of collaborative TB/HIV activities globally, particularly in high-burden countries.

Gunneberg *et al.* (2008) in their report on global monitoring of collaborative TB/HIV activities indicate that in 2005, out of 63 countries, 53 were able to report on the progress of the implementation of joint TB/HIV activities.

Lack of integrated M&E systems for TB/HIV, as well PMTCT programmes, makes it difficult to measure the impact of the integration approach (Grimwood *et al.* 2006; Gunneberg *et al.* 2008; Chono *et al.* 2009), and to link programme performance to treatment outcomes and health outcomes.

- Community and individual norms

Other challenges related to provision of integrated TB/HIV/PMTCT services include community and individual dimensions, such as norms and beliefs, and stigma (Levin *et al.* 2006; Kigozi *et al.* 2011). Thus, in line with barriers listed above that impede the successful implementation of collaborative TB/HIV activities, including PMTCT, innovative strategies and interventions that consider the context in which the policy and the guidelines are being implemented are vital.

These strategies must be geared toward local and individual changes in practice and organisational culture for the entrenched effects of vertical programming to be transcended and integration to succeed. This is substantiated by Blamey and Mackenzie (2007), Mackenzie *et al.* (2007), and Wang *et al.* (2007), who assert that contextual issues such as political, organisational, epidemiological, social and individual dimensions should be considered in the formulation of policy and its implementation. Due to weak and overstretched health systems, and to the existing burden of the HIV epidemic, particularly in rural areas where health facilities lack appropriate structures and qualified staff to deliver quality care beyond the borders of the facilities, this will require involvement of the community in delivering selected core health activities.

#### **2.4 Community participation in health and TB and HIV programmes, including PMTCT**

Community participation in health is a complex issue that has been extensively examined in the literature (Oakley 1989; Rifkin 1990; Rifkin 1996; Zakus & Lysack 1998) and has been a critical part of health programmes since the adoption of the Alma Ata declaration in 1978 (WHO 1978).

The origin of the concept of community participation in health lies in the attempt to improve health, social and economic conditions (WHO 1989). So far in the literature, according to Rifkin (1996) community participation in disease control programmes has referred mostly to CHWs, although the nomenclature could be different depending on each setting (Lehmann & Sanders 2000; Lewin *et al.* 2005).

Community participation in health programmes continues to be of great interest globally, particularly in developing countries due to the HRH crisis and the high burden of the TB and HIV epidemics.

Several studies have highlighted the impact of community participation in health care, including an increase in health service coverage, efficiency, effectiveness, equity, access and self-reliance (Lewin *et al.* 2005; Lewin & Glenton 2007; Haines *et al.* 2007; Hermann *et al.* 2009).

In addition, the WHO interim policy on implementation of collaborative TB/HIV activities, and other scholars from TB and HIV/AIDS communities, recommend community participation as an integral part of the implementation of collaborative TB/HIV activities, that will result in the enhanced provision of TB/HIV integrated care at community level (Farmer *et al.* 2001; Maher *et al.* 2005b; Zachariah *et al.* 2006).

A study in KZN on the feasibility of integration of TB/HIV services in an MDR and XDR-TB hospital shows that engagement of CHWs as DOT supporters improved adherence levels and treatment outcomes of both TB and HIV patients (Gandhi *et al.* 2009).

WHO reports and studies in SSA suggest that community involvement in TB prevention and control is one of the mechanisms to expand access to care and to improve awareness and understanding of the disease (Maher *et al.* 2005a; Maher *et al.* 2005b; WHO 2004a; WHO 2012).

Although CCWs have great potential for expanding primary health care (PHC) at community level and addressing the HRH crisis, in most settings CCWs are under-utilised (Zachariah *et al.* 2009). Kahssay and Baum (1996) argue that community participation is mostly unrecognised in district health systems. Therefore, it is important to identify effective ways to maximise the involvement of CCWs in the implementation of collaborative TB/HIV/PMTCT activities.

Involvement of CCWs in collaborative TB/HIV/PMTCT activities could entail provision of several interventions to prevent, find and treat TB and HIV, such as screening of TB symptoms, home-based HIV counselling and testing (HBHCT), TB and ART adherence support, education on PMTCT feeding options, home-based care, advocacy and community mobilisation. This has been done by using a single cadre of CCWs or multiple cadres of CCWs. The latter has been practised in many African countries, where CCWs are trained only as TB directly observed treatment (DOT) supporters, health promoters or home-based carers (HBC) dealing with HIV patients.

In South Africa, community members such as CCWs, traditional healers and other individuals have been involved in HIV prevention and care, advocacy, support and counselling, in efforts to level off HIV infection and mitigate its impact (Friedman 2005; Friedman *et al.* 2007; Schneider *et al.* 2008).



There are many cadres of CCWs (CHWs, HBCs, TB DOT supporter, etc) that have been trained on a single disease or a particular programme of interest. This has created CCWs who are specialised rather than comprehensive or generalist, which has resulted in TB and HIV services being provided separately by different cadres of CCWs in the household. This has created conflicts among CCWs, and discomfort to the household member who has to be visited by more than one CCW (Clarke *et al.* 2008). It is imperative to explore ways of integrating different types of CCWs involved in TB and HIV programmes, including PMTCT, as one cadre of CCW to provide comprehensive care and bridge the gaps in service delivery of TB and HIV as well as PMTCT care as vertical services than comprehensive.

#### 2.4.1 *Involvement of community care workers in health in South Africa*

In South Africa, the government estimates there are over 65,000 CCWs, the majority of whom are involved in HIV and TB care, and whose numbers are greater than front line PHC health care workers, such as professional nurses (Schneider & Lehman 2010).

The high number of CCWs is due to various factors, such as interest by the government to engage NGOs and job creation, but most importantly the dual burden of TB and HIV, and the HRH crisis (Clarke *et al.* 2008; Schneider *et al.* 2008; Schneider & Lehmann 2010). This has led to a large number of NGOs involved in both HIV and TB programmes, and the creation of many cadres of CCWs, such as HIV lay counsellors (providing HIV counselling and testing), CHWs (generalist but focusing more on health promotion), HBCs (focusing on nursing care or terminal care for HIV/AIDS clients), TB DOT supporters, and others.

It also opened opportunities for job creation (addressing unemployment levels) to a certain degree (Friedman *et al.* 2007). However, these multiple cadres of CCWs have been trained in a single disease or a particular programme of interest to a programme manager or a funder. This has created specialised CCWs rather than comprehensive or generalist CCWs, as was intended by the national policy framework on CHWs programme (Schneider *et al.* 2008).

Schneider and colleagues further argue that due to the high number of CCWs that are involved specifically in TB and HIV activities; the national CHW programme in South Africa has been shaped by these two epidemics (Schneider *et al.* 2008).

Recently in SA, there has been an increased interest in fostering the CHW programme through the re-engineering of the PHC system. The integration of all cadres of CCWs into one cadre, and the integration of CCWs into the PHC system is also high on the political agenda (Pillay & Barron 2011), as there are enormous benefits for strengthening health systems and addressing the HRH crisis. Nonetheless, the CHW programme is still crippled by various health system challenges that hamper the successful involvement of CCWs (Friedman *et al.* 2007; Schneider *et al.* 2008). These studies identified a lack of proper training, poor remuneration of CCWs, lack of good supervision of CCWs, and lack of supportive structures at facility level for CCWs, as some key challenges facing the CHW programme in SA. Lack of funding for the CHWs, including supplies, and other factors such as stigma at individual and community level, also impede CHW performance. These constraints are not unique to SA and have been reported elsewhere (Celletti *et al.* 2010; Wringe *et al.* 2010).

Achieving community participation through CCWs in health service delivery in resource-limited settings with a high disease burden of TB and HIV and other competing interests is not a simple task. Furthermore, health systems constraints related to implementation of collaborative TB/HIV activities, as discussed above, plays a role in the manner CCWs are engaged in these activities.

## **2.5 Rationale for the study**

At the time of this study (2008), there was no research in SA that had identified health system constraints related to implementation of TB and HIV collaborative activities, including PMTCT. Only feasibility and acceptability studies were conducted in pilot sites (ProTEST study: WHO 2004b).

Additionally, studies have highlighted the potential role that the community plays in the fight against HIV and TB (Zachariah *et al.* 2006, Wandwalo *et al.* 2006). However, little is known about the impact of community participation with regard to the integration of TB and HIV programmes, particularly at PHC level.

Hence, the rationale for conducting this study was to document the process of engaging CCWs in collaborative TB/HIV/PMTCT activities, and inform policymakers, district managers and programme managers on effective mechanisms to strengthen the provision of integrated TB/HIV/PMTCT services, by involving community members in a rural setting.

## **2.6 Aim of the study**

The overall aim of the study was to develop and evaluate a community-based intervention that will strengthen the district health system's capacity to improve the provision of integrated TB/HIV/PMTCT care in Sisonke district, KwaZulu-Natal.

## 2.7 Study questions

Although there are benefits for involving CCWs in collaborative TB/HIV/PMTCT activities, little is known how TB and HIV services, including PMTCT, are provided in the community as integrated services, and how effective they are in contributing to TB/HIV/PMTCT outcomes.

It is against this background and the knowledge gaps highlighted in the literature that the present study attempted to answer the following questions:

1. To what extent is integration of TB/HIV/PMTCT being implemented in Sisonke district?
2. What are the constraints to implementing integration of TB/HIV/PMTCT in Sisonke district?
3. To what extent does the community participate in the provision of integrated TB/HIV/PMTCT care in Sisonke district?
4. What is the impact of community participation on delivering integrated TB/HIV/PMTCT services in Sisonke district?

## 2.8 Study objectives

The study was conducted in three phases with the following specific objectives:

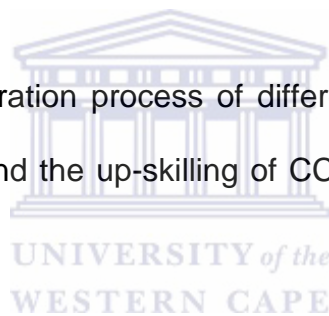
### **PHASE I:** *Situation analysis of the integration of TB/HIV/PMTCT programmes*

1. To determine the extent to which TB and HIV programmes, including PMTCT, are integrated in Sisonke district

2. To identify barriers to implementation of integration of TB/HIV/PMTCT services at facility and community levels
3. To explore ways in which the community could participate in the implementation of joint TB/HIV/PMTCT activities

**PHASE II:** *Design and implementation of an intervention on TB/HIV/PMTCT integrated services*

4. To design a community-based model that enhances the provision of integrated TB/HIV/PMTCT services
5. To implement a community-based integration model for TB/HIV/PMTCT services
6. To document the integration process of different cadres of CCWs to create one cadre of CCWs, and the up-skilling of CCWs to provide TB/HIV/PMTCT comprehensive care



**PHASE III:** *Evaluation of the community-based intervention on TB/HIV/PMTCT integrated services*

7. To evaluate the impact of the community-based intervention on provision of TB/HIV/PMTCT integrated services

## CHAPTER 3

### METHODOLOGY

#### 3.1 Research setting

The study was conducted in Sisonke district in KwaZulu-Natal (KZN), the province in South Africa with the highest prevalence of TB and HIV (Abdool Karim *et al.* 2009; DOH 2011). The district has a geographic area of 11,128 km<sup>2</sup> and is divided into five municipalities, namely: Ingwe, KwaSani, Greater Kokstad, Ubuhlebezwe and Umzimkulu (Sisonke District Health Information System – DHIS 2008).

The district has a population of 501,872 with 79% unemployment, 71% of the population is considered to be poor and 13.6% urbanisation (Sisonke DHIS 2011). The population consists mainly of subsistence farmers, and the level of education is quite low. The district has poor infrastructure, with understaffed health facilities that are not well equipped. It is mostly rural, with poor roads that lead to transportation difficulties and limited access to health facilities (see map Appendix 1).

HIV prevalence in the general population of Sisonke was estimated at 27% (Sisonke DHIS 2011), while the antenatal HIV prevalence was estimated at 35%, based on the recent national antenatal surveillance of HIV and syphilis prevalence survey report (DOH 2011). With regards to the TB profile, the district reported 933/100,000 incident TB cases per year with 813/100,000 (87%) pulmonary TB cases, 75% of which were HIV co-infected (DOH-KZN 2011).

In 2008, the district had 32 NGOs managing HBCs, 26 of which were DOH funded. These NGOs managed a total of 414 HBCs, while one large independent NGO managed 402 CHWs, giving access to a total of 816 CCWs. In addition, the district had 63 community development workers employed by the DOH through the Extended Public Works Programme (EPWP), and 17 youth ambassadors who are TB DOT supporters.

These CCWs had different scopes of practice, whereby CHWs were more involved in health promotion while HBCs were more involved in providing home-based or palliative care to terminally ill HIV patients. Although the scope of practice of these two different cadres of CCWs varied, at times some were providing similar services based on their level of training. The implementation of Phase I of this study was conducted in the entire district (see Papers I, II and III), while the rest of the research (Phases II and III) was conducted in four sub-districts where a total 89 CCWs (both CHWs and HBCs) were included in the study, as described in Papers IV and V.

Since 2007, the district has been supported by the School of Public Health, University of the Western Cape (UWC) and an NGO called TB/HIV Care Association (THCA), and by the President's Emergency Plan for AIDS Relief (PEPFAR) through the Centres for Disease Control and Prevention (CDC) South Africa, to enhance the integration of TB/HIV programmes in the district with a focus at facility level. Through the CDC funding, UWC facilitated the review of the recording and reporting tools for TB, HIV and PMTCT programmes, and developed an M&E system for the ART programme in the district, which was later adopted provincially.

Based on the UWC facility TB/HIV integration project and a research grant from SATBAT - a South African / US research-training collaboration - funded by the Fogarty International Center (grant: 1U2RTW007370-01A1), formative research was conducted by the researcher to assess the implementation of collaborative TB/HIV activities including PMTCT. Although the formative research was led by the researcher, the conceptualisation of the research was done in collaboration with provincial and district officials of the Department of Health. Based on the findings of the formative research, the current research was conceived in collaboration between UWC, THCA and DOH.

Since 2008, THCA has been supporting the district through its funding from PEPFAR through a cooperative agreement with CDC South Africa. THCA's aim is to decrease the burden of TB and HIV by increasing access to TB and HIV prevention, diagnosis, treatment and adherence support. The CDC PEPFAR funding was for 'Project Integrate' which included support for mobile counselling and HIV testing, linked with screening for TB and STIs, a clinical mentorship programme to improve the quality of TB/HIV clinical care, and support for community care workers to provide a comprehensive package of TB/HIV prevention, screening and adherence support.

This research was conceived to design, implement and evaluate the community component of Project Integrate in Sisonke district. THCA consulted with the Sisonke District Health Management Team (DMT) to determine what support the district required to strengthen their response to TB and HIV. The model of support that evolved from this consultation was that a nurse mentor was employed to provide clinical mentorship and support to four facilities in each sub-district.



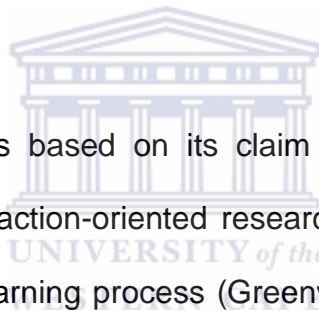
Community health facilitators (CHFs) were employed to provide supervisory support to CCWs in the catchment areas of the supported facilities. Data capturers were employed in each supported facility to update relevant registers (HCT, TB suspect, TB, pre-ART, ART and PMTCT). Nurse mentors supervised both CHFs and data capturers. Project Integrate specifically funded the up-skilling and supervisory support of CCWs on HCT, TB/STI screening, TB/ART adherence support and PMTCT, as well as the payment of stipends so that all CCWs were paid the same stipend after being trained in a comprehensive TB/HIV/PMTCT package.

### **3.2 Theoretical framework for the study**

There is growing evidence of effective community-based interventions related to TB and HIV programmes, such as TB DOT support, antiretroviral therapy (ART) adherence support, promoting HIV counselling and testing (HCT), home-based HCT, and education and counselling on infant feeding for PMTCT (Zachariah *et al.* 2004; Lewin *et al.* 2005; Friedman *et al.* 2007; Hermann *et al.* 2009; Parsa *et al.* 2009; Simon *et al.* 2009; Celletti *et al.* 2010).

Global initiatives such as the Global Fund and PEPFAR have included support for interventions to enhance TB and HIV prevention, treatment and care (Samb 2009). However, most of these initiatives have been implemented in a selective approach, with little consideration of their applicability within the framework of PHC as a comprehensive approach. Thus Remme and colleagues (2010) argue that there have been a number of global initiatives to support the implementation of priority health problems such as TB, HIV and maternal and child health, however most of these initiatives have been selective rather than comprehensive.

Most TB and HIV research studies have been grounded in a positivist paradigm, which often does not consider the complexity of health systems or their links with social aspects. Hence, it is vital to use theories that consider social aspects related to health systems, with recognition of the role of the interpretive paradigm, by engaging stakeholders as active collaborators in identifying problems, designing and implementing effective interventions aimed at bringing change within the health system. It is against this background and the research questions of this study, that both Action Research (AR) and Health Systems Strengthening Research (HSSR) were used as theoretical frameworks for this research, with “mixed methods research” or “third paradigm” research providing the specific methodological grounding.



The rationale for using AR is based on its claim as a process of collaborative knowledge development and action-oriented research, involving local stakeholders as full partners in a mutual learning process (Greenwood & Levin 2007). Although the researcher acknowledges that many schools of thought, particularly in social sciences, define AR as a research method grounded in an interpretive paradigm, for this study AR is considered as a style of research that incorporates three main concepts: participation, democratic impulse and action that simultaneously contribute to change, as indicated by Meyer (2000).

Meyer further argues that due to the relevance of AR in health care settings, AR is increasingly being used as an appropriate approach for identifying problems in clinical practice and helping develop potential solutions in order to improve practices. Hence, the process of this study followed the cyclic frame of AR described by Meyer (2000) which has five steps, listed below:

1. Problem identification
2. Design and implementation of an intervention with practical solutions
3. Systematic monitoring of the intervention
4. Reflection on the process
5. Evaluation of the intervention based on outcome change

Relevant stakeholders such as provincial and district managers, programme coordinators, facility managers, NGOs involved in TB and HIV programmes, lay health workers such as CHWs and HBCs and beneficiaries (patients) of the facility and services, were involved in each step of the three phases of the study, as reflected in all five papers of this research. A comprehensive AR approach was mainly used to answer research questions 2-4 (see Papers I, II, III and IV).

HSSR, also known as Applied Health Research, is defined as a research approach that is participatory in nature and aimed at strengthening the health system (Remme *et al.* 2010). Although there are many definitions and frameworks in the literature regarding HSSR (WHO 2007a; Mills *et al.* 2008), Remme and colleagues (2010) have recently released a simple framework that allows us to better understand and apply the HSSR approach at one or more levels of health systems. This framework categorises HSSR into three main research approaches or domains which include operational research, implementation research and health systems research (HSR), which primarily engage health care providers, programme managers, and health system managers or policy makers, respectively.

The direct “utility” or applicability of findings similarly ranges from the more local to the more global. In this framework, each domain of research is considered to draw on a range of theoretical and methodological approaches or tools. This study drew on all three domains, but is aimed primarily at the HSR domain. The WHO and the Alliance for Health Policy and Systems Research and other scholars define HSR as people, institutions, and activities that aim through research to generate sound knowledge that can be used to promote, restore, and/or maintain the health status of populations (WHO 2007a; WHO 2007b; Mills *et al.* 2008).

Although it is disease led (TB and HIV), the broader aim of this study was to inform policy on service delivery mechanisms that strengthen the health systems and ultimately improve health outcomes. WHO (2007a) and Remme *et al.* (2010) argue that HSR addresses health systems and policy questions that might not be necessarily disease-specific but deal with problems such as service delivery mechanisms, human resources and financing, that have repercussions for the performance of health systems as a whole. This approach was mainly used to answer research question 4.

Because of its grounding in AR and HSSR, this study required an iterative and developmental process of design, protocol development, and implementation of each phase and component of work. Each phase and activity had to be developed and implemented in relation to the priorities and practical realities of the health system and community stakeholders.

While an overall approach and design was developed and approved by scientific and ethical review committees in advance of the project, the implementation and the evaluation of this study was subjected to changes based on the dynamism of the stakeholders at district level and the district research committee (described in Paper IV). The latter was established by the researcher and the district management team to ensure full participation and ownership of the study. Hence, it would be inaccurate to characterise the study in purely epidemiological terms.

Broadly, this was a mixed methods pre-post intervention study, comprising formative research in a comprehensive situation analysis, participatory development of an intervention informed by the findings of the situation analysis, and quasi-experimental implementation with process and outcome evaluation.

However, each phase and objective required design, development and implementation, and the ultimate designs and methods included a spectrum of approaches, from facility audits and in-depth qualitative key informant interviews, to a phased implementation of the CCW intervention, and pre and post household surveys for the evaluation of the intervention, developed and implemented in Phase II and evaluated in Phase III. The complexity of this “real world” approach to AR and HSSR led the researcher to engage much more seriously with “mixed methods research” in order to have a broader view of issues related to development, implementation and evaluation of a community based intervention that would enhance collaborative TB/HIV/PMTCT activities and strengthen the primary health system as whole. Hence, the complexity of the study and research methods applied for this study was imbedded in health systems research rather than a pure ethnographic or epidemiological study (Meyer 2000).

### 3.2.1 *Set up of the district research committee*

Based on the three concepts and the cycle frame of the AR approach described above, the researcher in collaboration with the District Management Team (DMT) established a district research committee (DRSC), and terms of reference for the DRSC and its sub-committees were developed.

The committee was initially chaired by a deputy district manager and co-chaired by the researcher. In order to enhance the capacity of the DRSC team in research matters, the researcher provided basic training on HSSR. The DRSC team consisted of district managers, programme coordinators, representatives from the funding NGO (THCA), and other local NGOs involved in community based activities, plus other research institutions such as the Medical Research Council (MRC) involved in the district, and representatives of health institutions.

Due to various research projects that were conducted in the district, a sub-committee (SC) was established as a technical and working group of the DRSC to design, implement and evaluate this study which was denoted: *“the up-skilling of CCW project”*. The SC was led by the district programme co-ordinator of HIV and the home and care programmes (HCBC). The latter was in charge of reporting back to the DRSC team on the progress of the project on a quarterly basis. The role of the researcher was to provide technical guidance with regard to the design and implementation of the intervention, and to conduct the formative and summative evaluations.

### **3.3 Research methodology: Mixed methods or “third paradigm” research**

In addition to AR and HSSR as overall frameworks for the research, this study sought to engage the theoretical and methodological literature on mixed methods research, going beyond multi-method research.

Mixed methods research is a research method also called ‘third paradigm’ that uses both qualitative and quantitative methods either sequentially or concurrently in one study (Creswell & Miller 2003; Dures *et.al.* 2010), and that carefully documents how and when the various methods are used for data collection, analysis and interpretation. Mixed methods research has increasingly been viewed as a useful alternative to either qualitative or quantitative methods alone, which balances the strengths and weaknesses of both methods by providing more informative and useful results (Leech & Ownuegbuzie 2007; Dures *et al.* 2010).

O’Cathian, Murphy and Nicholl (2007) further argue that the mixed methods approach is anchored in the applied nature of HSR, emanating from a need to engage with the real world and address the complexity of health care, from studying a disease to the implementation of an intervention, as well as the research environment in which the intervention was conducted. Similarly, Glenton, Lewis and Scheel (2011) argue that the contribution of qualitative methods is increasingly being recognised in the development and evaluation of complex interventions and trials.

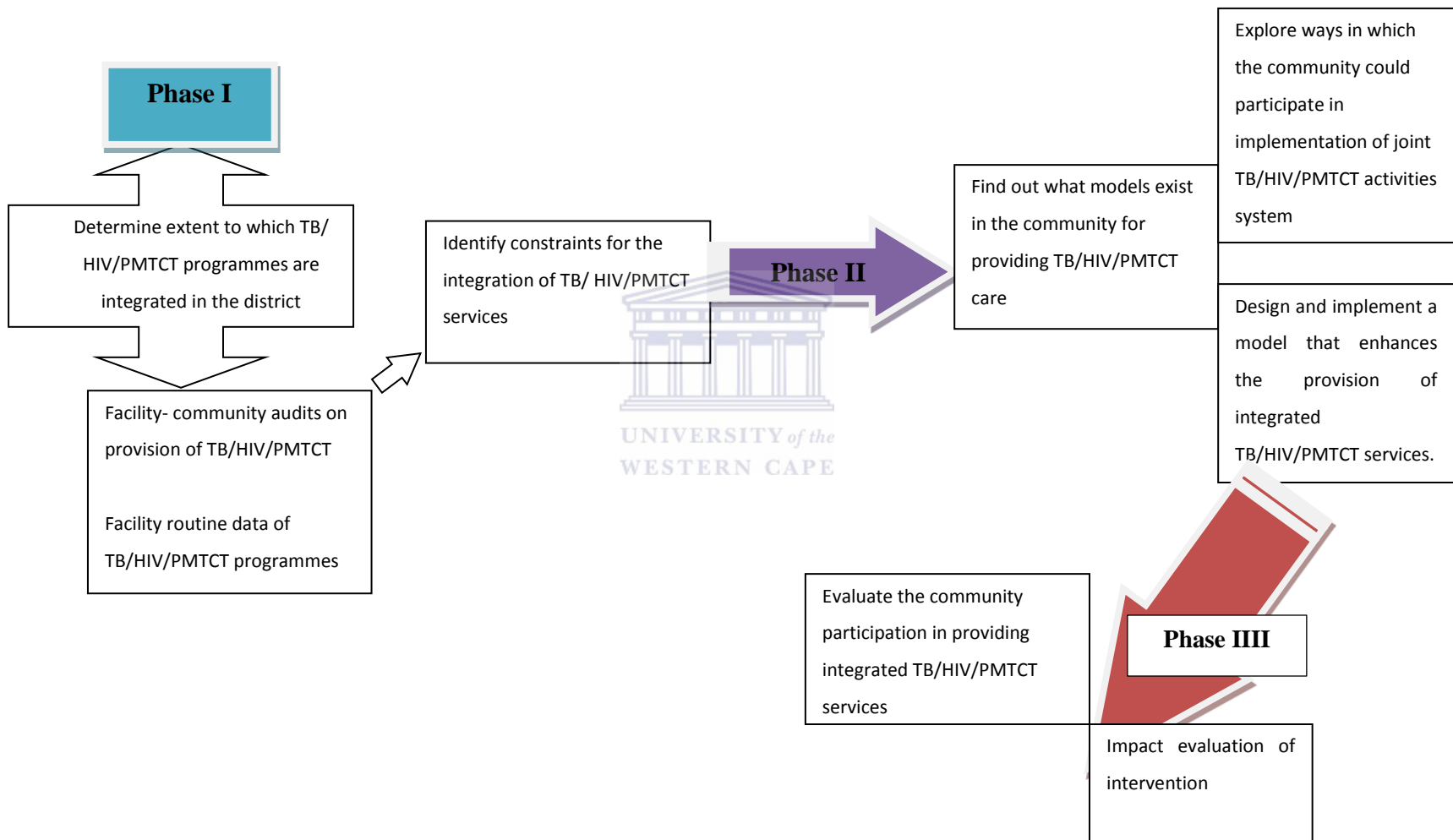
The rationale for using a mixed methods paradigm was based on four main considerations. Firstly, this theoretical framework was employed in the study in order to address the research questions, secondly to design and evaluate the

interventions, thirdly for comprehensiveness of the study and its impact on practice, and lastly the researcher's epistemological stance on the complexity of health systems which should be looked at from more than one perspective. In cognisance of the complexity of health systems, and the importance of addressing various factors impeding the health system in implementation of collaborative TB/HIV/PMCT activities, this study focused on addressing issues related to provision of integrated TB/HIV/PMTCT services at community level.

The study objectives were divided into three phases, and different study designs were used in each phase. The study framework for research activities is based on these three phases as outlined in Figure 4 below.

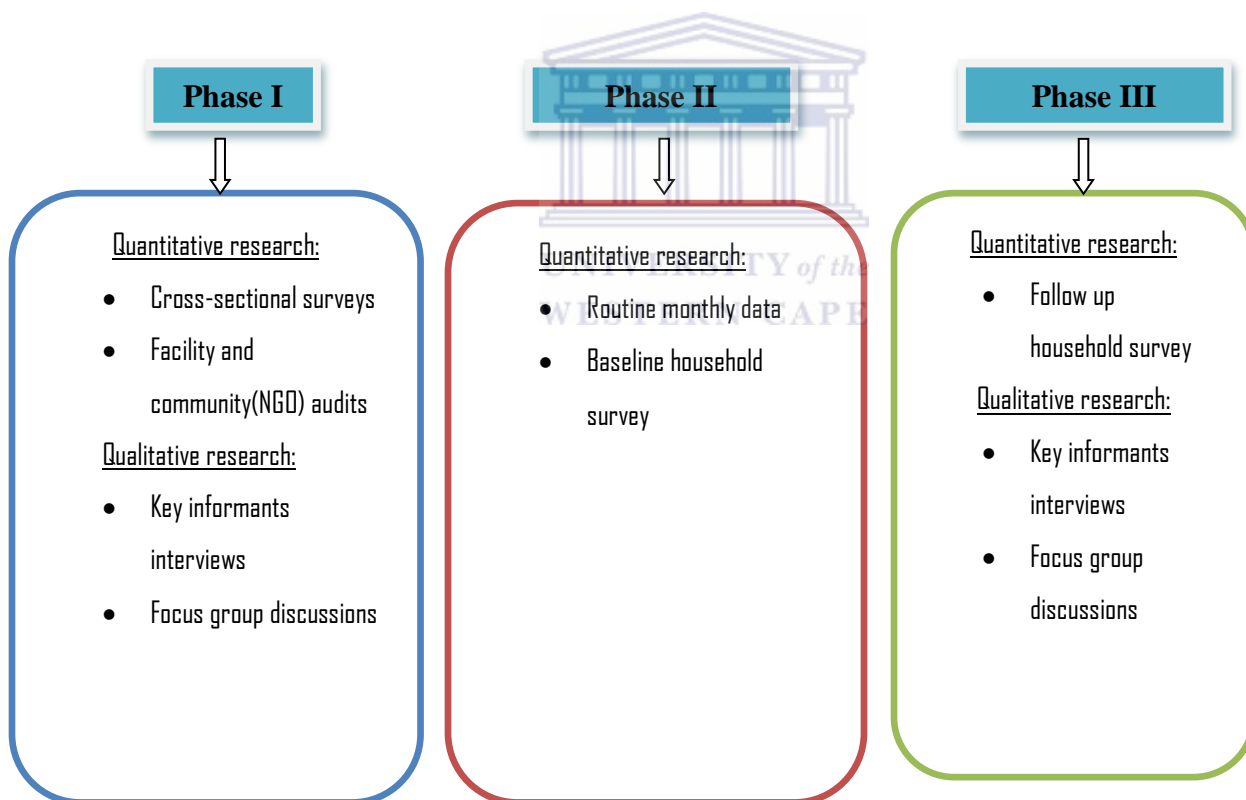






**Figure 4 : The conceptual framework of research activities**

The discussion of research methods below includes an overview of the whole study, a brief outline of the design and methods used for each phase and objective, and then a detailed description of each phase and step in the research in terms of the data sources, sequence, and relative weighting of qualitative and quantitative methods. Papers I-V each contains a summary of the methods relevant to the focus of the specific paper. The overall design of this study was a pre and post intervention study imbedded in mixed methods research. Figure 5 presents a description of methodology used for each phase.



**Figure 5: Description of the methods used for each phase of the study**

A detailed discussion on the design and research methods used for each phase is presented below:

3.3.1 *Phase I: Situation analysis of the implementation of collaborative TB and HIV activities including PMTCT*

This phase consisted of establishing a clear picture of current implementation of collaborative TB/HIV activities from provincial, district, facility and community levels. Three main objectives were set, as defined in Chapter 2. The following table summarises the methods used throughout this phase.

**Table 3:** Methods for Phase I

Research design	Type of mixed method design	Description
Mixed methods research	Fully mixed concurrent dominant status <b>(Objective 1)</b>	Cross-sectional surveys of HCWs and patients
		Facility audit including review of facility routine data and interviews with facility managers
		NGO audit which consisted of records review and interviews with managers
	Sequential explanatory <b>(Objective 2 and 3)</b>	Qualitative in-depth interviews of key informants

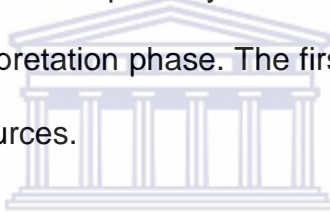
**Objective 1**

To determine the extent to which TB and HIV programmes, including PMTCT, are integrated in the district. Two steps of data collection were undertaken.

The first step consisted of determining the level of provision of TB/HIV/PMTCT integrated services at facility level, based on health care providers' and patients' perspectives.

A fully mixed concurrent equal status design was used. Leech and Onwuegbuzie (2007) define fully mixed concurrent equal status design as a study design that mixes quantitative and qualitative research methods within one or more components of a single research study (the research objectives, type of data and operations, type of analysis and inferences). For the first step both quantitative and qualitative methods had the same weight, and two different data sources were considered.

For the second step, only quantitative methods were used to collect data. The data for this step was analysed separately and integrated with the analysis of data from Step 1 in the interpretation phase. The first step consisted of collection of data from two different sources.



Data source 1: A cross-sectional survey of health care workers (HCWs) was conducted in May 2008. A questionnaire with closed and open-ended questions was developed to assess the capacity of HCWs to provide TB/HIV/PMTCT integrated care, by looking at training received, patient loads, mechanism of service delivery and referrals, perceptions of HCWs on provision of TB/HIV/PMTCT services at their facilities, and identification of constraints related to the provision of TB/HIV/PMTCT integrated services, and ways of enhancing the provision of integrated services at facility and community level. The study population consisted of HCWs, specifically nurses and medical doctors who were working in the TB, HIV and PMTCT services in the selected health facilities in the district.

Health facilities were purposively selected to ensure that three levels of care were included: district hospital, community health centre (CHC) and ART clinics at PHC facilities in each sub-district.

A limited number of HCWs cover each shift at each facility (on average five staff per shift at CHC and ART clinics, and 15 at the hospitals). As the situation analysis sought to maximize breadth of coverage across the district, a convenience sample was drawn from among the staff working at the selected facilities on the day the research team visited. Data collection was to occur over 20 days, hence an estimated sample size of 200 HCWs was proposed. There were 142 HCWs who completed self-administered questionnaires.

Prior to data collection, the questionnaire was piloted in a facility that had not been selected for the study. The final, revised questionnaire is included in Appendix 2.

Data source 2: A cross-sectional survey of patients' experience and perspectives on the provision of integrated TB/HIV/PMTCT services was undertaken from August-October 2008, using exit interviews with patients attending TB, HIV or PMTCT clinics at the facilities where the HCWs' survey was conducted. Three questionnaires were developed by the researcher (PMTCT clients, TB patients, and HIV clients, including pre-ART and ART clients). Both closed and open-ended questions were used.

Questions were translated into isiZulu and translated back into English by two research assistants conversant in both isiZulu and English. The first research assistant translated the questionnaire from English to isiZulu, and the second researcher translated the same questionnaire from isiZulu back to English. Questionnaires were piloted in one of the facilities that was not part of the selected facilities. The final questionnaires were revised, based on the outcomes of the pilot (Appendix 3).

The study population comprised ANC/PMTCT, HIV and TB clients. The inclusion criteria of clients included all registered ANC/PMTCT, HIV and TB clients attending the selected facilities aged 18 years and above. Based on the pilot, one data collector could interview up to 18 clients in a day. The maximum number of clients that could be interviewed in a day by two data collectors in ten sites over 20 days yielded a proposed sample of 360 clients. The numbers and category of clients to be interviewed was drawn proportionately, based on the total number of clients registered in each service (TB, HIV, and PMTCT) at each facility. A table that illustrates the total number of clients required for each facility and category of clients (ANC/PMTCT, HIV & TB) is attached (Appendix 4).

Recruitment of the participants was on a daily basis, based on their attendance at the facilities. A systematic sampling approach was used for the study, whereby every other client coming from the consulting room was approached for the interview.

### Data analysis:

All closed questions from data source 1 and 2 were entered into Microsoft Excel™ and analysed using STATA version 10. Variables were classified as continuous and binary variables. Descriptive statistics such as measures of central tendency were used. In order to measure the differences in services provided by level of care, patients seen per month, patients referred to CCWs per month, preference of service delivery mechanism (same or different place) and preference of health care provider (seen by same or different clinician); bivariate analysis was used, and the Pearson Chi-square test was used for categorical data with a 95% confidence interval (95%CI), and P-values less than 0.05 were considered as statistically significant. For multi-variate analysis, odds ratio (OR) was used to determine predicting factors such as patients' category, age, gender, TB symptom screening, HIV testing, CD4 test count and preferences on provision of TB/HIV/PMTCT services as described in Paper I.

For open-ended questions, post-coding content analysis (Elo & Kyngas 2008) was used to analyse the data. In respect of each open-ended question, codes were created by the research assistant in collaboration with the researcher.

After careful consideration and comparison, similar subcategories were combined to form a generic category. The resulting categories were further scrutinised for similarities before compiling a final shortlist of mutually exclusive categories. A frequency for each of the established categories was calculated using STATA 10.

Categories with very low frequencies were combined to form the category 'other'. Facility registers and DHIS were analysed using frequency and proportions. Details on the methodology used for objective 1 are discussed in Paper I. The second step of data collection consisted of two data sources.

Data source 3: Facility data from TB, pre-ART and ART and ANC/PMTCT registers of quarter 1 to quarter 4, 2008-2009 were reviewed and extracted from the registers and DHIS, and were captured using Microsoft Excel™. The extracted data was validated with respective facilities to ensure accuracy of the data.

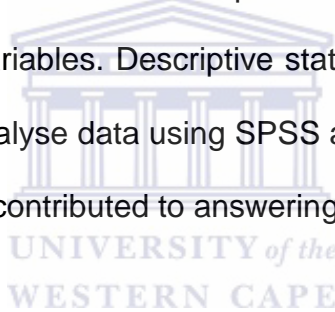
Data source 4: A facility NGO audit was conducted in all health facilities (42 facilities including the 10 selected sites) in the district, one provincial NGO managing CHWs, and 32 NGOs managing HBCs in the district. The questionnaires were designed by the researcher, and were presented to the district research sub-committee. Later the questionnaire and the plan for the audit were presented to the district research committee (DRC) in order to monitor the overall process of this research and other research activities taking place in the district. Amendments to the audit tools (Appendix 5) were made based on the feedback from the DRC. An independent NGO, TADSA, was contracted by THCA to conduct the audit in collaboration with the researcher.



The purpose of the audit was to determine the burden of disease managed by the facilities, linkages between facilities and NGOs in the provision of care and support related to TB/HIV/PMTCT, and training level of CCWs. Self-administered questionnaires were provided to hospital and operational managers of 42 health facilities and the 33 NGOs mentioned above. This step was conducted to respond to Objectives 1 (degree of integration) and 2 (barriers to integration).

Data analysis:

For the facility NGO audit, the data was captured using Microsoft Excel™ and classified into categorical variables. Descriptive statistics such as frequency and proportions were used to analyse data using SPSS as described in Paper III. The analysis of this data source contributed to answering Objective 2.



**Objectives 2 and 3**

Objective 2 sought to document and contextualise experiences of programme managers at all levels (province, district, facility and community NGO) on the extent of and barriers to the implementation of collaborative TB/HIV activities and provision of TB/HIV/PMTCT integrated services at facility and community levels.

Objective 3 explored possible ways in which the community (specifically, NGOs and CCWs) could participate in the implementation of joint TB/HIV/PMTCT activities and be integrated into the patient management chain.

A sequential explanatory mixed method design (Leech & Ownuegbuzie 2007) was used. Qualitative data was used to explain and interpret the primary quantitative study described above, and these two methods were integrated during the interpretation phase (Creswell & Miller 2003). In addition, this sub-study explored ways of engaging both NGOs and CCWs in provision of integrated TB/HIV/PMTCT services at community level. This component of the overall study is described in Papers II and III.

The findings of Phase I were shared with district and provincial stakeholders as part of the AR approach at a meeting that took place in February 2009. In addition, the outcomes from Papers II and III informed the second phase, which was the design and implementation of an intervention.



3.3.2 *Phase II: Design and implementation of a community-based intervention on TB/ HIV/PMTCT integrated care*

This phase consisted of two steps which included firstly, the design of the intervention based on the outcomes of Phase I, and secondly, the implementation and monitoring of an intervention for the provision of a comprehensive package for TB/HIV/PMTCT care. Table 4 illustrates the methods used in Phase II.

**Table 4:** Methods for Phase II

Research design	Type of Mixed method design	Description
Mixed methods research	Sequential explanatory  <b>(Objective 4-6)</b>	Qualitative in-depth interviews of key informants
		Household survey before the intervention
		Routine programme data

As noted above, the findings from Phase I were shared with stakeholders in the district. The feedback from the stakeholders' meeting was considered in the design of the intervention, whereby the stakeholders recommended the core activities to be implemented by CCWs in the community in order to provide TB/HIV/PMTCT comprehensive care. These included the following activities:

- Define a package of care to be provided by CCWs at community level
- Selection of implementation sites
- Training of CCWs
- Evaluation of the intervention

At a later stage, the outcomes from the district stakeholders' meeting were also shared at provincial level. Through a formative approach, consultations and feedback meetings with relevant stakeholders in the district were conducted during the design and implementation phase. Trochim (2006) argues that the formative approach provides information that feeds the cyclic learning process in the design and development trajectory of an intervention, contributing to the improvement of the intervention by examining the delivery of the programme, the

quality of its implementation, and the assessment of the feasibility of the intervention through organisational context, personnel, procedures and inputs. The active participation of key stakeholders was critical, as the intervention proposed significant changes to current practices.

### 3.3.2.1 *Description of the intervention and the implementation process*

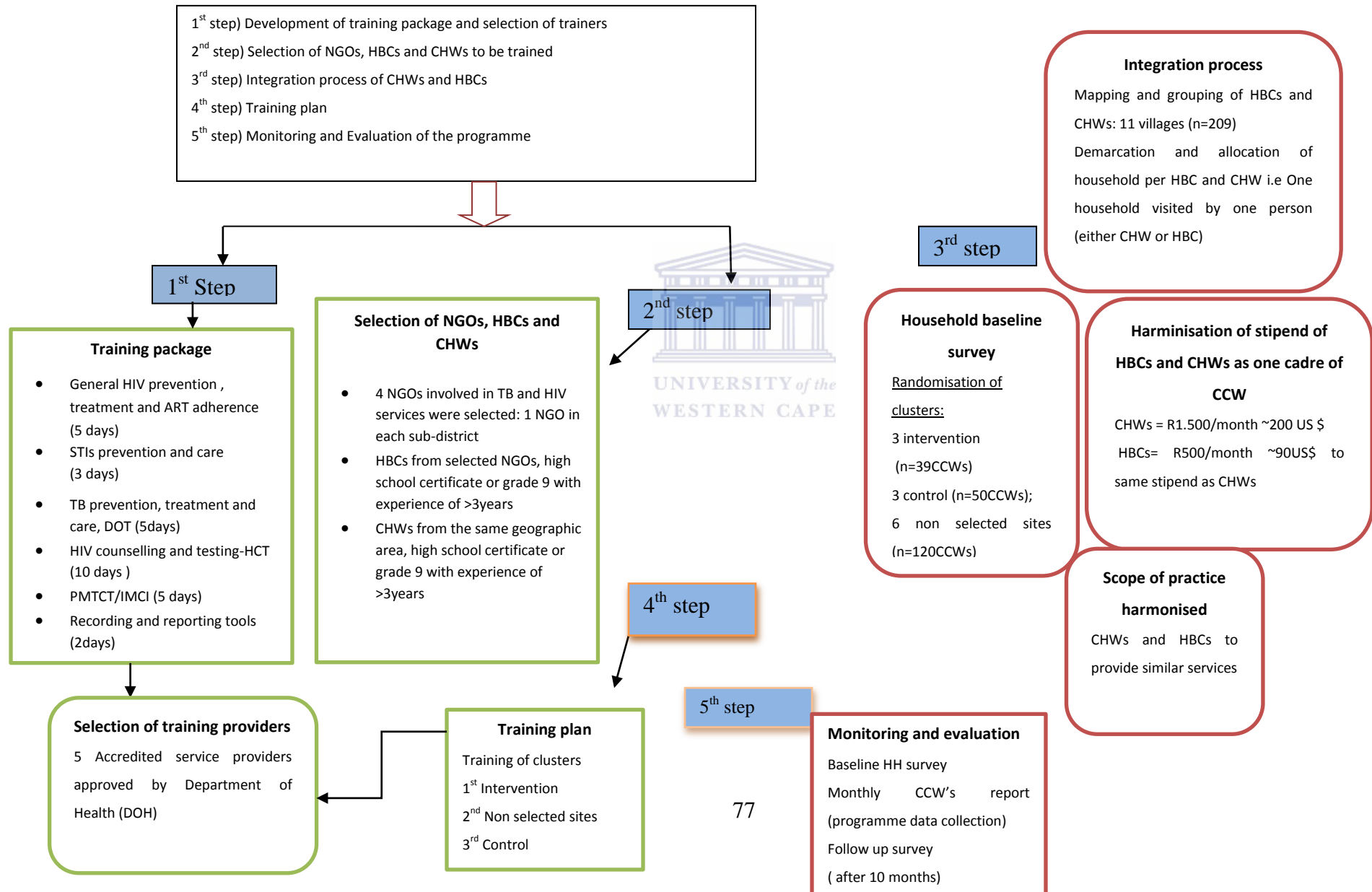
The intervention consisted of three steps which included firstly, the selection of NGOs and mapping of CCWs to be up-skilled/trained as discussed in Paper V. Secondly, the scope of practice of CHWs and HBCs was harmonised, whereby CHWs and HBCs were providing the same services in the community and the stipends were also made equivalent by THCA. In the areas where both CHWs and HBCs existed, a demarcation of households was done in such a way that one household (HH) was only visited by either a CHW or HBC, not by both, as desired by the stakeholders including beneficiaries of the CCW's services. The latter was done to avoid multiple visits. Thirdly, prior to the training of CCWs, a baseline HH survey was conducted in September 2009 in 11 villages in the four sub-districts.

Six of the 11 villages surveyed were matched, based on demographic and socio-demographic characteristics, and access to health facilities (distance kms). These six villages were randomly assigned a number (even and uneven numbers) for those who would be trained first (three intervention clusters) and last (three control clusters).

The remaining five villages were too different to match, and were classified as non-selected sites. The design and the implementation of the study are illustrated in figure 6, and the findings of the HH surveys are discussed in Papers IV and Paper V.



**Figure 6: Framework for the development and implementation of the CCW's up-skilling programme for provision of integrated TB/HIV/PMTCT services**



A training plan was developed and CCWs were trained in a phased approach, whereby CCWs from the intervention clusters were trained first, followed by non-selected sites and lastly, the control clusters. The training plan consisted of the design of training manual/content, and the duration and selection of service providers of the training. The training of CCWs was based on the core activities to be performed by CCWs in relation to the provision of comprehensive care for TB/HIV/PMTCT, after assessing the level of involvement of CCWs in provision of TB/HIV/PMTCT services, and from the recommendations from the stakeholders (discussed in Paper III). The core activities to be performed by CCWs are illustrated in Table 5.

**Table 5:** Core activities related to collaborative TB/HIV/PMTCT activities provided by community care workers in Sisonke district

Activities	Description
Health education: TB prevention and care; HIV prevention and care; sexually transmitted diseases (STIs) and other issues such as hygiene and environmental health.	Health education was given as a talk to householder members during household visits and campaigns or community events
General home-based care	Provision of nursing care (bathing, feeding, etc.) to HIV terminally ill patients
TB symptoms screening, treatment adherence and tracing of defaulters	Screening of household members for TB symptoms and refer TB suspects to the clinic for further care Providing treatment adherence support to household members diagnosed with TB Tracing TB contacts and TB defaulters
STI symptoms screening	Screening of household members for TB symptoms and refer TB suspect to the clinic for further care
Home-based HIV counselling and testing	Provision of HIV counselling and testing in homes (HIV pre-counselling, HIV testing using rapid test and post-test counselling) and on-going counselling
Treatment adherence support for ART and tracing of ART defaulters	Provide ART adherence support and tracing of ART defaulters
Treatment adherence support to PMTCT clients (AZT), counselling on infant feeding for HIV positive pregnant clients and refer pregnant women for antenatal care (ANC) visits (within 14 days)	Provision of adherence on dual therapy, education and counselling of pregnant women on infant feeding options and encouraging pregnant women to attend ANC visits particularly the 1 <sup>st</sup> ANC visit at 14 days

After training, community mobilisation events were organised in the three intervention clusters, prior to the provision of the comprehensive package of care for TB/HIV/PMTCT at HH level, in order to raise awareness of the services to be provided by CCWs and the purpose of the study. Monthly routine data was collected in both intervention and control clusters to monitor the progress of the intervention. A detailed description of the design and the implementation process of the intervention is described in Paper IV.

### 3.3.3 Phase III: Evaluation of the intervention on TB/HIV/PMTCT integrated services

This phase was undertaken to evaluate the implementation of the intervention (process evaluation) and to determine the impact of the intervention on enhancing collaborative TB/HIV/PMTCT activities and the health system as a whole. Table 6 presents the methods used for Phase III.

**Table 6:** Methods for Phase III

Research design	Type of Mixed method design	Description
Mixed methods research	Fully mixed sequential dominant status	Follow up household survey after the intervention
	<b>(Objective 7)</b>	Qualitative in-depth interviews of key informants

The mixed methods approach was used in order to gain a better understanding of the outcomes of the intervention, in view of the context in which the study was conducted, and make recommendations on the implications of the study for practice.



A fully mixed sequential dominant status design (Leech & Ownuegbuzzie 2007) was used, whereby a quantitative study was conducted first, followed by a qualitative study. The quantitative study was given priority compared to the qualitative study since the qualitative study was used to shed light on the findings of the summative evaluation, by looking for processes and other factors that could help explain homogeneity or heterogeneity of the outcomes. In addition, it also helped to understand the context and other factors that could have contributed to the outcomes of the interventions, with emphasis on exploring replicability of the study on a large scale (district and provincial wide) and strengthening the PHC system.

The quantitative component of this phase consisted of two household (HH) surveys. A baseline HH survey (September 2009) was conducted to complete a household listing and obtain baseline HH information in proposed wards/clusters, in preparation for the implementation and monitoring of the intervention. This was followed in April 2011 by a follow-up HH survey to assess the effectiveness of the intervention and its impact on collaborative TB/HIV activities, as well as on other programmes and the health system more broadly.

A phased approach was used for the implementation of the intervention (training clusters in a phased manner as described in Figure 6). Before and after design was used to evaluate the intervention. Sequential cross-sectional HH surveys were used to collect data at two points in time.

### 3.3.3.1 *Methodological description of the household surveys for the evaluation of the intervention*

The intervention was considered as a pilot study to be implemented in a few selected sites for learning purposes and monitoring, and for possible scale-up if it proved successful. A phased implementation approach was used, where by at the end of the intervention, all CCWs from the selected communities (intervention and control clusters) will receive training, although the order in which communities received the intervention was random (Figure 7): intervention clusters started the training first followed by non-selected sites. The control clusters were trained last.

The intervention was conducted over a period of ten months, and the follow up HH survey was conducted prior to the training of control clusters. However, all clusters were exposed to harmonised scopes of practice and stipends and reallocation of households before the training started. The phased implementation approach used was an optimal design to use for the logistical implementation of the intervention and for ensuring that by the end of the project time-line all the CCWs were going to be trained.

#### **a) Sample size**

A sample size calculation was done for the primary outcome, prevalence of HIV counselling and testing (HCT). The inter-cluster correlation coefficient (ICC) was assumed at 0.0034. To detect an increase in this HCT uptake from 32% to 40% post intervention, with a total of six clusters (three per arm), 80% power and an alpha of 0.05. We needed approximately 500 households per cluster, making a sample size of 1500 households per arm (intervention and control clusters).

These were obtained by sampling three clusters with 500 subjects each in the intervention arm, and three clusters with 500 subjects each in the control arm to achieve 80% power to detect a difference between the group proportions of 0.0800. The proportion for the control arm was 0.3200. The intervention arm was assumed to be 0.3200 under the null hypothesis and 0.4000 under the alternative hypothesis. The statistic test used was the two-sided Z test (un-pooled). The estimate was conservative since the intervention was new and has never been rigorously assessed in South Africa. Although the intervention was mainly focused on provision of comprehensive/integrated TB/HIV/PMTCT care by CCWs including HIV testing, the use of HIV counselling and testing as a primary outcome for sample size calculation was based on the fact that HIV testing (uptake of HIV testing) was a suitable outcome to use for the community under study. In addition, the small number (six) of selected clusters is explained by the fact from the baseline household survey, we couldn't get more than six clusters that could match based on socio-economic status factors, HIV testing rate, and accessibility to health care facilities.

#### **b) Baseline household survey**

The aim of this initial baseline household survey was to complete a household listing and obtain baseline household information in proposed wards/clusters in preparation for the intervention. The objectives were:

1. To complete a household listing of all households (STATSSA master listing)
2. To obtain a census of all household members older than 17 years
3. To obtain baseline socio-demographic information by household
4. To obtain numbers of infant deaths (< 1 year old) in the last year (12 months)
5. To obtain numbers of TB deaths and HIV/AIDS deaths in the last year

6. To obtain estimates of the number of current pregnancies and births in the last year (12 months)
7. To obtain estimates of the number of current TB cases
8. To estimate numbers of HIV positive individuals in selected households
9. To obtain estimates of the number of household members on TB treatment, ART and IPT
10. To obtain estimates of CCW contacts in each household (services provided by CCWs)

*i) Training of field workers*

For the baseline HH survey, a total of 33 CCWs were selected as field researchers, meaning both HBCs from the selected NGOs and CHWs from the same geographic areas with HBCs. The researcher trained them to conduct a household interview, and how to use the cell phone data collection system for this project.

*ii) Data collection procedure and management*

The data collection process of the baseline HH survey consisted of interviews using a basic cell phone and the Clyral Research console. Households with adults of 18 years old or above were eligible for the HH interview. The questionnaires for both baseline and follow-up surveys (Appendix 6 and 7) were developed by the researcher. The questionnaires were programmed into the cell phones in collaboration with the service provider Clyral ([www.clyral.com](http://www.clyral.com)).

Logical, range, missing data and other checks were also programmed to minimise data entry error by field workers. A one-day pilot study was conducted in one of the selected sites (Umzimkulu sub-district) prior to data collection, in order to test technical issues related to use of cell phones and the content of the questionnaire.

The data was collected by trained CCWs and data collection took a maximum of ten days. The data was exported cell-phone web system into Microsoft Excel™. The data cleaning done in Excel by a researcher assistant, then transferred into STATA version 10 for analysis.

*iii) Data analysis*

Categorical data was analysed using frequencies, cross-tabulations with Chi-square and 95% confidence intervals (CI) for odds ratios and p-values less than 0.05 were considered as statistically significant. Continuous data was analysed using means and variance, and comparison of mean differences and 95% CI around the mean difference. The details of the baseline survey are described in Papers IV and V. The analysis of the baseline survey focused on determining the level of burden of TB and HIV in the communities surveyed, uptake of HIV testing (HCT) and services provided by CCWs.



**c) Follow up household survey**

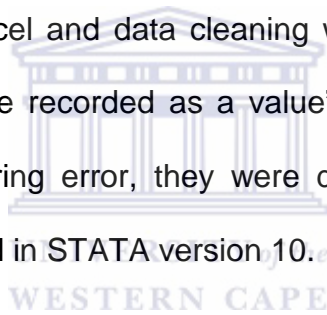
The follow up HH survey was conducted in the six randomised clusters listed above. The aim of the follow up survey was to assess the effectiveness of the intervention, based on the training provided to up-skill CCWs from the intervention clusters to provide integrated TB/HIV/PMTCT services, compared to the control clusters where CCWs did not receive the training prior to the survey. The questionnaire was developed by the researcher (Appendix 7) and the same procedures for data collection of baseline HH were used (use of cell phones).

*i) Training of field workers*

A total of 24 field workers who were not CCWs were recruited and trained by the researcher on how to conduct a HH survey, procedures for data collection and referrals of cases in homes that required medical attention. Five days of training for field workers was conducted. This included practical sessions (field work), to familiarise them with the nature of the survey and to test cell-phones.

*ii) Data collection and management*

Prior to data collection, a pilot study was conducted and amendments were made based on problems encountered in data entry and sequencing of the questionnaire/interview. Data collection took 20 days. The data was exported from cell phones into Microsoft Excel and data cleaning was undertaken by a research assistant. Missing values were recorded as a value "99" and were never duplicated were observed due to capturing error, they were deleted. After data cleaning in excel, the data was transferred in STATA version 10.0.



*iii) Data analysis*

The analysis was conducted by the researcher with the assistance of the Medical research council, Biostatistics Unit. Categorical data was analysed using frequencies, cross-tabulations with Chi-square and 95% CI. Bivariate and multivariate analyses were used using odds ratios and 95% CI. Continuous data was analysed using means and variance. In order to adjust for clustering and household effects, a survey data analysis was performed by setting for cluster groups and households and using logistic regression analysis for survey data (linearized standard error). Using a logistic regression model, primary outcomes and social demographic factors were included in the model.

Primary outcomes included health education, HIV counselling, TB and STIs screening, sputum collection, treatment adherence, counselling on infant feeding and referral for PCR whereas secondary outcomes included treatment outcomes, IMCI and referrals for others services. Independent predictors for the performance of CCWs were identified using odds ratio (OR), 95% CI and p-values less than 0.05 were considered statistically significant. The details of the follow-up survey and statistics used are described in Paper V.

**d) Qualitative component**

The follow-up survey was followed by a qualitative study, in order to understand the context in which the study took place (implementation process), and attach meaning to the outcomes of the quantitative study, as well as to document the perceived impact of study on practice in order to inform policy.

A research assistant was employed to conduct individual interviews with key informants (KIs), and focus group discussions (FGDs) with beneficiaries, CCWs and community health facilitators (CHFs). Interview guides and FGDs guides were developed by the researcher in English (Appendices 8 and 9). The FDG guides were translated and conducted in isiZulu by the same research assistant.

*i) Data collection*

An interview schedule was developed and data collection was conducted from June-July 2011 and field notes were taken. Interviews and FGDs were recorded using a digital recorder, and transcribed verbatim into English by the research assistant. A purposive sampling approach was used in order to capture participants' experiences during the implementation of the intervention. Table 7 below describes the study population and sample of the qualitative study.

**Table 7:** Description of methodology used for qualitative study

Category of participants	Research tools	Estimated sample
District programme coordinators Primary health care (PHC) supervisors/nurse mentors Operational managers of clinics	Individual interviews (IDI)	12 participants
Community health facilitators (CHF)	Focus group discussions (FGDs)	3 FGDs
CCWs and HBCs involved in the study	FGDs	5 FGDs
Beneficiaries (TB and HIV patients) served by CCWs participated in the study	FGDs	4 FGDs

*ii) Data analysis*

Interviews were analysed using the five stages of the framework approach as described by Pope and Mays (2000). The framework was chosen as it allows the researcher not only to focus on the pre-set questions, but also to consider other themes emerging from the analysis (O’Cathain *et al.* 2007).

An analytical grid of key themes was developed based on the study aims and familiarisation with the first few transcripts, and then applied to the rest of the transcripts. The data was captured and coded using ATLAS.ti (Muhr & Friese 2004).

A constant comparison process was used during analysis, where all relevant data for each category of participants was identified, examined and compared with the rest of the data, to identify dominant themes occurring in all groups. The non-dominant themes were also grouped separately and compared across categories of participants to identify similarities and inconsistencies.



The analysis was conducted by the researcher and reviewed by the sub-district committee and the findings were presented to the district research committee for member checking validation. Thereafter the findings of the qualitative research were triangulated with the quantitative findings to explaining key factors affecting the intervention. The details of the qualitative study are discussed in Paper V.

### **3.4 Validity and reliability of the study**

The concepts of validity and reliability of the study will be applied to the quantitative data, while credibility and trustworthiness will be used for the qualitative data. Validity is an indication of the extent to which an instrument measures what we think it is supposed to be measuring (Sarantakos 1998). Hence, for all phases, questionnaires, interviews and FGDs, guides were designed in English first then translated in isiZulu, and thereafter they were translated back into English for verification of the content.

A pilot study with people who were similar to the intended study participants as described in Section 3.3 was conducted to ensure content and construct validity.

Reliability refers to dependability or the way a tool such as a questionnaire will produce similar results in different circumstances if nothing changes (Sarantakos 1998). Reliability was assured by training interviewers on questionnaires and checking that they conducted interviews in a consistently similar way.

A triangulation approach for analysis of both qualitative and quantitative data reduces the possibility of bias, and produces results that are more reliable with complementary strengths (Rees & Bath 2001). To ensure trustworthiness and credibility of qualitative data, procedures described by Mays and Pope (2000) were employed, such as:

- Prolonged engagement with the participants and persistent observations – the same participants and research assistants were involved throughout all phases of the study. This gave the researcher the opportunity to observe their interaction over a long period. The participants could then develop a sense of ownership and involvement in the outcome of the research, which strengthened the quality of their engagement with the issues. Additionally, engaging participants such as key stakeholders, CHFs and CCWs in the process of designing, piloting the tools, evaluating the intervention and data analysis added value regarding the credibility and validity of the study (respondent validation).
  - Triangulation as described by Roberts and Priest (2006) refers to another way of enhancing the trustworthiness of qualitative research by combining two or more data sources, methods, theories etc.
- The analysis of individual interviews, FGDs, and observations were compared and contrasted in order to achieve as rich a picture of the situation as possible and to increase credibility.

### **3.5 Generalisability**

For the quantitative components of Phase I and III, participants interviewed (HCWs, CCWs and patients) were representative of HCWs based on the level of care; CCWs were representative of other CCWs since they were working under similar conditions (similar settings/villages) with other CCWs; and patients involved in the study represented the clinic's population as a whole and the community.

However, one could argue that the level of engagement of stakeholders and dynamics at community level may limit the generalizability of this study at sub-district and provincial levels.

### **3.6 Limitations of the study**

Studies such as this are prone to limitations due to various factors that are out of the control of the researcher, since the study was conducted in a typical health system environment.

Although the study was tailored into cluster randomised design, it was difficult to control other activities related to TB and HIV programmes that could have affected the results (contamination) of this study. Many changes occurred in the study setting (campaigns on HCT, community outreach activities for home-based TB screening, adoption of the integration model for CCWs after six months of the implementation of the intervention. Also structural and HR adjustments such as placement of CHF's at clinic level to supervise CCWs and holding CCWs' monthly reporting meetings have contributed positively to the performance of CCWS in the intervention clusters as indicated in the qualitative findings (discussed in Paper V).

Since the researcher did not conduct most of the interviews due to a language barrier (isiZulu was not her first language), field notes and reflections during data collection were provided by the research assistant. This limited the researcher from having adequate interaction with participants, or reflecting on the data collection process.

Another limitation of this study was the few numbers of clusters (six) involved in the study against the recommended number of clusters (at least eight clusters per arm) required for a cluster randomised trial. In addition, to adjust for clustering and household effects a survey data analysis method (linearized standard error) was performed using logistic regression analysis for survey data instead of multilevel modelling method using variance, fixed effect or random effects. This was due to smaller number of cluster groups (6) than 20-50 clusters as recommended by Maas and Hox (2005) for a design where individuals are nested within groups/clusters.

Finally, this study focused more on addressing health systems factors related to provision of integrated TB/HIV/PMTCT services at community level, with the involvement of CCWs by using mixed methods, rather than exploring in depth all health systems issues related to implementation of collaborative activities (Meyer 2000; Pope *et al.* 2000). As a result, the findings emanating from each research method employed were not reported in depth, instead the researcher was more interested in reporting on broader health systems issues that would influence practice. Hence this study should not be considered as either ethnographic or epidemiological, but as health systems research that combines both methodologies to address the overall study aim.

### **3.7 Ethical clearance**

Permission was obtained from the Senate Research Committee of the University of the Western Cape. Secondly, permission from the KZN-DOH was also sought. Thirdly, permission was sought from the Sisonke district manager and the facility managers of health facilities involved in the study to have access to the patients'

records and other related data. Finally, an information sheet explaining the purpose of the study, its benefits and the risks, was read out by the research assistant, in order for participants to understand what the study entailed prior to the signing of the written consent form by the participants (Appendices 10 and 11).

Consent was obtained from the participants, and they were assured of respect, confidentiality and anonymity. Participation in the study was voluntary and participants were free to withdraw from the study at any time. As some of the subjects interviewed were HIV or TB positive, the researchers recognised the sensitivity surrounding these conditions and took utmost care to protect the confidentiality of the subjects' HIV and TB status to avoid inadvertent disclosure of sensitive subject information.



## CHAPTER 4

### FINDINGS

#### 4.1 Introduction

This chapter presents the findings of the study by summarising the findings of the five papers emanating from this study. Each paper was structured on the study phase and objective presented below, and the complete papers are included after the summary. For clarity we begin by identifying the Phase and Objectives related to each paper.

**Paper I:** Uwimana J, Jackson D & Zarowsky C (2012). Health care providers' and patients' perspectives on provision of TB/HIV services, including prevention of mother to child transmission (PMTCT) in a rural district, South Africa. *BMC- Health Research Services*, 2012. Accepted.

Phase I: This paper emanates from Phase I of the study that involved conducting a situation analysis of the implementation of collaborative TB and HIV activities, including PMTCT, in the district.

Objectives:

- To determine the extent to which TB and HIV programmes, including PMTCT, are integrated in Sisonke district
- To identify barriers to implementation of integration of TB/HIV/PMTCT services at facility and community levels

**Paper II:** Uwimana J, Jackson D, Hausler H, Zarowsky C (2012). Health systems barriers to implementation of collaborative TB/HIV activities, including prevention of to-mother-to-child transmission in South Africa. *Tropical Journal of Medicine and International Health*; **17**(5):658-665.

Phase I: This paper consisted of identifying and understanding of health systems barriers related to implementation of collaborative TB/HIV activities including PMTCT in order to devise an intervention that will enhance collaborative activities in the district.

Objective:

- To identify barriers to the implementation of integration of TB/HIV/PMTCT services at facility and community levels.

**Paper III:** Uwimana J, Jackson D, Hausler H and Zarowsky C (2012). Engagement of Non-government Organisations (NGOs) and Community Care Workers (CCWs) in collaborative TB/HIV activities including prevention of mother to child transmission (PMTCT) in a rural district of KwaZulu-Natal, South Africa: Opportunities and Challenges". *BMC Health Services Research*; **12**:233. doi:10.1186/1472-6963-12-233 .



Phase I and II: This paper emanated from two phases. Phase I: Situation analysis of the implementation of collaborative TB and HIV activities including PMTCT. Phase II: Design and implementation of an intervention on TB/HIV/PMTCT integrated services

Objectives:

- To identify barriers to the implementation of integration of TB/HIV/PMTCT services at community levels
- To explore ways in which the community could participate in the implementation of joint TB/HIV/PMTCT activities
- To design a model that enhances the provision of integrated TB/HIV/PMTCT services

**Paper IV:** Uwimana J, Zarowsky C, Hausler H & Jackson D (2012). Training community care workers to provide comprehensive TB/HIV/PMTCT integrated care in KwaZulu-Natal: lessons learnt. *Tropical Medicine and International Health*; **17**(4):488–496

Phase II: This paper emanates from Phase II which consisted of designing and implementing an intervention on TB/HIV/PMTCT integrated services.

Objectives:

- To implement an integration model for TB/HIV/PMTCT services
- To document the integration process of different cadres of CCWs to create one cadre of CCWs and the up-skilling of CCWs to provide TB/HIV/PMTCT comprehensive care



**Paper V:** Uwimana J, Zarowsky C, Hausler H and Jackson D (2012). Evaluation of a community based intervention to enhance provision of integrated TB/HIV/PMTCT services, South Africa. *AIDS 2012, submitted.*

Phase III: This paper emanates from Phase III which consisted of evaluating the impact of the intervention.

Objective:

- To evaluate the impact of the intervention for provision of TB/HIV/PMTCT integrated services



## 4.2 Summary of findings

For Paper I, a cross-sectional study was conducted to explore health care providers' and TB, HIV, and antenatal/PMTCT patients' perspectives of integrated provision of TB, HIV and PMTCT services in Sisonke district, in order to inform the design of an intervention to enhance provision of integrated services. A total of 144 health care providers (physicians and nurses) completed a self-administered questionnaire and 311 patients completed exit interviews. Respondents were selected proportionately to staff/patient numbers from a purposive sample of ten facilities covering TB, HIV and antenatal/PMTCT programmes, and three levels of care (five PHC clinics, one community health centre, and four district hospitals) provided the sampling frame for a convenience sample of health care providers (physicians and nurses) and patients drawn proportionately from each facility and programme type, respectively. The findings of this study shows that HIV patients were significantly more likely to be offered TB services such as education on TB prevention (OR=2.6, 95%CI=0.05-4.04, p=0.03) and TB screening (OR=14.3, 95%CI =5.46-37.46, p=0.00) compared to PMTCT patients. Both TB and HIV patients were significantly less likely to be educated on STIs and family planning (HIV patients: OR=0.42, 95%CI=0.42-0.82, p=0.01; TB patients: OR=0.25, 95%CI=0.11-0.56, p=0.000). The majority of the patients (84%) across all 3 programmes preferred to have TB, HIV, and PMTCT services available at the same place. While most TB-HIV co-infected patients are managed by nurses, less than 50% of PHC clinic staff was trained on general HIV management and co-infection of TB/HIV. Patient level barriers identified included lack of money for transport to attend services provided on separate days, time wasted in queues, and fear to disclose HIV status to more than one HCP and stigma.

HCPs identified shortage of staff and space; lack of training in TB/HIV/PMTCT, lack of functional referral systems at community level for continuum of care and lack of resources as barriers to provision of integrated services. In conclusion, the findings of Paper I suggest that TB/HIV/PMTCT services were partially integrated, provision of these services was mainly related to patients' category, HCP's category and level of care. Mechanism to ensure continuum of care at community was reported to be weak. Strategies to enhance integration of TB/HIV/PMTCT services should address providers' and patients' perspectives as well as systems-level barriers.

In Paper II, an interpretive approach was used to identify and understand health systems barriers related to the implementation of collaborative TB/HIV activities, including prevention of mother-to-child transmission of HIV (PMTCT), with a focus on managers' and community care workers' perceptions. Twenty-nine in-depth interviews were conducted with health managers at provincial, district and facility level, and with managers of NGOs involved in TB and HIV care, as well as six focus group discussions (FGDs) with community care workers (CCWs). Thematic analysis of transcripts revealed a convergence of perspectives on the process and the level of implementation of policy directives on collaborative TB and HIV activities across all categories of respondents (province, district, facility and organisations). The findings of this study indicate that the majority of participants felt that the implementation of the policy was insufficiently consultative, and that leadership and political will were lacking. The predominant themes related to health systems barriers included challenges related to structure and organisational culture; management, planning, and power issues; unequal financing; and human resource capacity and regulatory problems notably relating to the scope of practice of nurses and CCWs.

This study concluded by suggesting the need for political will and leadership to address these health systems barriers, in order to enhance and accelerate the implementation of collaborative TB/HIV activities including PMTCT.

In Paper III, we report on the assessment the extent of engagement of NGOs and CCWs in the implementation of collaborative TB/HIV/PMTCT activities, and constraints and opportunities to enhance effective participation of NGOs and CCWs. A mixed research method approach was used. Facility and NGO audits, a household survey (n=3867), 33 key informant interviews with provincial, district and facility managers, and NGO managers, as well as six CCW focus group discussions were conducted to assess the level of engagement of NGOs and CCWs, constraints and explore ways of involving CCWs in provision of integrated TB/HIV/PMTCT services at community level. This paper shows that most contracted NGOs were providing TB or HIV support and care with little support for PMTCT. Only 11% of TB and HIV patients needing care and support at the community level were receiving support from CCWs, while 2% of pregnant women were counselled by CCWs on infant feeding options and HIV testing. Most facilities (83%) did not have referral mechanisms or any linkage with NGOs. Interestingly enough, the constraints identified at this level of enquiry were also systems based, as found in Papers I and II. The major constraints identified were system-related: structural, organisational and managerial constraints; inadequate CCW training and supervision; limited scope of CCW practice; inadequate funding; and inconsistency in supplies and equipment. Individual and community factors, such as lack of disclosure and stigma related to HIV, and cultural beliefs, were also identified as constraints.

This paper also concluded that there was sub-optimal NGO/CCW engagement in the implementation of collaborative TB/HIV/PMTCT activities, despite the potential benefits to enhance provision of integrated TB/HIV/PMTCT services at community level. Therefore, effective interventions that address contextual and health systems challenges are required, and these interventions should combine systematic skills-building and consistent CCW supervision with a reliable referral and M&E system. Policy reviews to harmonise and expand the scope of CCW practice with task-shifting to include home-based HIV counseling and testing were considered vital. Based on the findings of the three papers presented above, an intervention was designed and implemented.

Paper IV present the findings of the implementation and monitoring and evaluation process of the community based intervention. This paper focuses on up-skilling (training) of CCWs to provide comprehensive TB/HIV/PMTCT services at community level. The full description of the design, the implementation and the evaluation process is provided in Paper IV. For the evaluation process, a baseline household (HH) survey was conducted in 11 villages, and only six villages were able to be matched based on SES and access to health facilities. Routine monthly data from CCWs were collected from March–December 2010. The data was subjected to bivariate tests. For the implementation process, a training package was developed, and a phased approach was used to implement the intervention. The six villages were randomly selected into the intervention and control clusters. Training was provided first to CCWs from the intervention cluster (IC), followed by the control cluster (CC). A total of 89 CCWs were trained.

The findings of this study show that from the baseline HH survey 3,012 HH members were visited by CCWs in 2008, 21% were screened for TB symptoms, 7% were visited for TB adherence support, 2% for ART adherence, and 1.5% were counselled on infant feeding options. Based on monthly routine programme data collected in the six clusters after training of the three ICs, the data shows that during the study period (10 months) in IC, 684 adults were offered HCT by CCWs, 92% accepted HCT and tested, and 7% tested HIV positive and were referred to the clinic for further care. Of 3,556 adults served in IC, 44% were screened for TB symptoms, 32% for symptoms of sexually transmitted infections (STIs), and 37% of children were traced as TB contacts. Out of 6, 226 adults served in CC, 10% were screened for TB symptoms and 7% for STI symptoms. The differences in uptake of services between IC and CC were statistically significant ( $p < 0.05$ ). The findings of this study highlighted a higher uptake of TB and STI symptoms screening, TB contact tracing and home-based HCT in the intervention clusters. Hence, up-skilling CCWs could be considered as one avenue to enhance TB/HIV case finding, TB contact tracing and linkages to care.

Finally the last paper of this study (Paper V) reports on impact assessment of an intervention tailored to enhance the provision of TB/HIV/PMTCT integrated services at community level. This paper built on Paper IV findings discussed above, by conducting a follow up household survey (after 10 months of intervention) prior to training of CCWs in CCs. The survey was conducted in April-May 2011 in both clusters and trained field workers collected data using a cell-phone based system. A qualitative study followed after the survey (June 2011). The latter included different categories of study participants: patients, CCWs, CCWs supervisors, facility managers and district managers.

This mixed method design was used to assess the intervention and get an in-depth understanding of the implementation process and the impact of the intervention at district and community levels. Findings from both quantitative and qualitative studies were triangulated, after analysis of each study separately. The details of the methodology used for this paper are presented in Paper V.

The findings from the household (HH) survey show that a total of 3,584 HH members aged 18 years and above were interviewed, 1,976(55%) HH members were from the IC and 1,608 (45%) in the CC. The mean age of the respondents was 42 years with a range of 18-98 years and SD 17. The majority of the respondents were females in both clusters (IC=78%; CC=68%) and the remainder were males (IC=22%; CC=32%). Most of the respondents (44%) were single and 35% were married. Across both clusters, most of respondents were unmarried but the difference in marital status between clusters was statistically significant ( $p<0.001$ ). With regards to education level, less than 50% of the respondents had a primary level or high school level and this is across both clusters. However, the IC has a higher proportion (53%) of respondents who never attended school compared to CC (37%) and the difference in education level was statistically significant ( $p<0.001$ ).

Most of the respondents (32%) reported a household income of a range of R1001-R2000 (125USD-250USD) and only 2% of the respondents had an income of more than R3000 (375USD) a month. At participant level, 33% of respondents reported earnings of R1001-R2000 (125USD-250USD) per month and only 1% of respondents earned more than R3000 (375USD) per month. However, among the two arms (clusters) there was a slight variability of income at HH and participant levels and the difference was statistically significant ( $p<0.001$ ).

Most of the respondents (31%) in the IC had a HH income of R501-R1000 (62USD) and 32% of the same income at participant level. While in the CC, most of the respondents (34%) had a HH income of R1001-R2000 (125USD-250USD) and 35% of the same income at participant level. The difference in income level at HH and participant level was statistically significant ( $p < 0.001$ ).

The up-skilling of CCWs (intervention) was found to significantly increase the uptake of HIV testing in both clusters. The uptake of HIV testing increased from 56% at baseline to 75% after the intervention. There was a high statistical significance in the uptake of HIV testing between clusters, in IC 78% of respondents were counselled and tested for HIV compared to 71% in CC ( $p < 0.001$ ). The inter-cluster correlation coefficient (ICC) was less than 0.0001. In addition, a total of 489(25%) respondents in IC received home based HCT. This resulted in 14% increase in the overall uptake of home based HCT considering the fact that home based HCT was not provided by CCWs in the CC.

Out of 106 respondents (those who received home based HCT) who were willing to disclose their HIV status, 7(7%) were HIV positive and 99(93%) were negative. The lower level of disclosure of the HIV status could be explained by the level field workers/data collectors were people residing in the same community not CCWs and issues around confidentiality of field workers. Although field workers were trained on issues around confidentiality and other ethical matters related to the study, the lack of disclosure could be also an indicative of level of stigma in the communities.

Bivariate and multivariate analyses highlight that the CCWs from the IC clusters performed better in TB/HIV/PMTCT services compared to the ones in CCs and the difference in performance was statistically significant ( $p < 0.05$ ). For health education (92%, OR=2.7; 95%CI=2.20-3.34), TB and STIs symptoms screening (63%, OR=4.7, 95%CI=4.07-5.50; 52%, OR=4.29, 95%CI=3.67-5.02) TB and HIV treatment adherence including dual therapy for HIV pregnant women (31%, OR=10.26, 95%CI=8.05-13.08; 28%, OR=8.86, 95%CI=6.98-11.25; 23%, OR=6.68, 95%CI=5.20-8.58), counselling on infant feeding options for HIV pregnant women (81%, OR=1.5, 95%CI=1.25-1.73) and some aspects of infant care such as referral for weighing and immunization (29%, OR=2.16, 95%CI=1.81-2.58). However, CCWs from the CC performed better in provision of education on IMCI (85%), referral for vital documents (83%) and referral for social grants (86%) compared to those in IC. The difference in performance was statistically significant ( $p < 0.05$ ). CCWs from IC were less likely to provide: education on IMCI (66%, OR=0.36, 95%CI=0.31-0.43), referred for vital documents (60%, OR=0.30, 95%CI=0.26-0.36) and referred for social grants (OR=0.25, 95%CI=0.21-0.30). Details findings are displayed in table 3 and 4 in paper V.

Survey data analysis method was used using logistic regression analysis instead of multilevel modelling to adjust for clustering and household effects. This was due to the fact the number of cluster groups were less (6) than 15 clusters. After adjusting for cluster and household effects, health education, HIV counselling, TB and STIs symptoms screening, treatment adherence, counselling for infant feedings options for PMTCT and referral for weighing and immunisation remained statistically significant ( $p < 0.05$ ).



Social-demographics factors such as age, gender, household income, marital status and level of education remained statistical significant ( $p < 0.05$ ) in the models. Details of the findings are provided in Table 5&6 in paper V. Overall the intervention indicates a significant increase for TB, STI and HIV case finding (38%, 40%, 25%), TB and ART treatment adherence support (30% and 28%), and PMTCT services (30%).

The qualitative findings show that the district managers and programme coordinators, facility managers and health care providers felt that the intervention strengthened the PHC system in improving supervision of CCWs, facility-community interface and coordination of activities. In addition, CCWs indicated that the intervention enhanced their performance, and built their confidence and image in the community. In conclusion, the study suggests that the intervention was effective in enhancing collaborative TB/HIV activities including PMTCT, particularly for TB/STI/HIV case finding, treatment adherence and PMTCT services. Attention to other PHC services is required to ensure that all key PHC services are attended to at community level.



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WESTERN CAPE

## CHAPTER 5

### DISCUSSION AND SUMMARY

This study examined the implementation of collaborative TB/HIV activities, including PMTCT, with a focus on exploring ways of engaging community members such as CCWs in collaborative TB/HIV/PMTCT activities in a rural area in South Africa, namely Sisonke district in KZN province. The overall aim of the study was to develop and evaluate an intervention that would strengthen the district health system's capacity to improve the provision of integrated TB/HIV/PMTCT care in Sisonke. This situated the study in a complex health system and policy environment, and the evolving epidemiological context of both the TB and HIV epidemics.

Health systems-strengthening research approaches (Remme *et al.* 2010), action research (Hampshire 2000; McKay & Marshall 2001) and mixed methods or “third paradigm” research (Greene, Caracelli & Graham 1989; Creswell & Tashakkori 2007) provided the theoretical and methodological framework for this study, to address the complex nature of the health system and the intervention. The study sought to answer the following research questions:

- To what extent was the integration of TB and HIV programmes, including PMTCT, being implemented in Sisonke district?
- What were the constraints for implementing the integration of TB and HIV programmes, including PMTCT, in Sisonke district?
- To what extent did the community participate in the provision of integrated TB/HIV/PMTCT care in Sisonke district?

- What was the impact of community participation through CCWs in delivering integrated TB/HIV/PMTCT services in Sisonke district?

A number of studies have been conducted locally (Kironde & Kahirimbanyi 2002; Dudley *et al.* 2003; Heller *et al.* 2010) and internationally (Zachariah *et al.* 2004; Negin *et al.* 2009; Simon *et al.* 2009; Hermann *et al.* 2009; Celletti *et al.* 2010) on community participation in TB and HIV programmes and these studies have highlighted the benefits of using CCWs in the provision of TB and HIV services in the community. However, there are limited studies reported in the literature that focused on an intervention that involved CCWs in the provision of integrated TB/HIV services, including PMTCT.

The study was undertaken in the context of the current discourses and advocacy on the need for accelerating the implementation of collaborative TB/HIV activities, including PMTCT, and the attainment of the MDGs. Most countries in SSA, including South Africa, are currently considering re-vitalising the PHC approach with a focus on integration of CCWs into health systems.

Several studies in the literature document the impact of CCWs in health care, including increases in health service coverage, efficiency, effectiveness, equity, access and self-reliance (Lewin *et al.* 2005; Lewin & Glenton 2007; Hermann *et al.* 2009). There is also a growing body of scientific evidence on the potential of engaging CCWs in the provision of TB and HIV services, such as TB DOT, HIV counselling and testing, and home-based care (Negin *et al.* 2009; Celletti *et al.* 2010; Mutale *et al.* 2010).

The WHO advocates for community participation as an integral part of collaborative TB/HIV activities implementation (WHO 2012), in order to contribute to the successful provision of TB/HIV integrated care at the community level.

In South Africa, interest in engaging CCWs has increased, largely due to the dual TB/HIV burden and human resources challenges (Clarke *et al.* 2008; Schneider *et al.* 2008). The latter have weakened the health system, and most districts are running below staffing norms (Schneider *et al.* 2006), particularly in the rural areas such as Sisonke district, where 66% of the medical officer posts and 45% of professional nurses posts are vacant (Sisonke DHIS 2010). This is evidence of the need for expansion of the health care workforce by considering task-shifting.

The dominant CCW management model in South Africa at the time of this study was for the government to contract with NGOs who employ and deploy CCWs. The increased demand for more and lower-cost health workers has led large numbers of NGOs to be involved in both HIV and TB programmes and the creation of many cadres of CCWs, including: HIV lay counsellors who provide HCT; CHWs who focus more on health promotion; and home-based caregivers (HBCs) who provide palliative care for PLHIV.

However, these multiple cadres of CCWs are each trained in a single disease or a programme dictated by the NGO or funder (Friedman *et al.* 2007). This exacerbates the verticalisation of provision of TB and HIV services at community level, which also leads to multiple visits at a household, creating discomfort among household members as discussed in Papers I & III.

Peltzer (2009) argues that PHC facilities are the only easily accessible health services, and provide basic health care in South Africa. As a result, they carry a large burden and responsibility for providing basic health care, including TB and HIV services. In view of the South African context of the impact of the dual epidemic of TB and HIV and the involvement of CCWs in health care delivery, it is important to develop a comprehensive approach that will strengthen the PHC system, enhancing the implementation of collaborative TB/HIV/PMTCT activities. .

## **5.1 Implementation of collaborative TB/HIV activities including PMTCT**

The findings of this study demonstrate a number of issues related to the implementation of collaborative TB/HIV/PMTCT activities. The implementation of collaborative TB/HIV activities, including PMTCT, was shown to be limited at the time of the situation analysis (2007-2008), with poor performance in key collaborative TB/HIV/PMTCT activities such as TB symptom screening for PLHIV (67%), HIV testing for TB clients (69%), ART uptake among TB patients (10%), and IPT uptake (0.3%). Furthermore, almost two thirds of health care workers (60%) perceived integration of TB/HIV/PMTCT services as partially integrated. This is similar to a study by Conseil *et al.* (2010) in Vietnam showing that both TB and HIV programmes were not fully integrated in health systems dimensions, which contributed to sub-optimal provision of these services.

We noted that the integration of TB prevention and care with antenatal care and PMTCT was particularly weak, despite the high risk for VTRTB to their babies (Khan *et al.* 2001). This has been documented elsewhere (DeLuca *et al.* 2009).

Lack of integration of TB services into PMTCT services could undermine the impact of South Africa's recent efforts at improving PMTCT programmes. Furthermore, South Africa is one of the SSA countries with poor MCH outcomes (Chopra *et al.* 2009). Grange *et al.* (2010) claim that TB in association with HIV is a major non-obstetric cause for maternal and child mortality in SSA. It is therefore important to set up a comprehensive approach that will address this cause.

## **5.2 Health systems barriers to the implementation of collaborative TB/HIV activities including PMTCT**

The slow implementation of collaborative TB/HIV/PMTCT activities and poor performance of health care systems is explained by various health systems barriers emanating from structural, organisational, managerial and financing systems. These factors have been reported in many SSA countries (Eang & Chheng 2007; Friedland *et al.* 2007; Chono *et al.* 2009). Gunneberg *et al.* (2008) in their report on global monitoring of collaborative TB/HIV activities, argue that most SSA countries are far behind the international targets for collaborative TB/HIV activities, due to health systems factors such as those listed above, as well as lack of political will and lack of an integrated M&E system to monitor the progress of collaborative activities. This is also in line with our findings as discussed in Paper II.

Besides health systems barriers, community and individuals factors including cultural practices and norms, beliefs and stigma also affect provision of integrated TB/HIV/PMTCT services, as reflected in quotes such as the following:

*“The main problem in the community is stigma. When you visit a household, they [household members] will hide the person who is sick if they know that he/she is HIV positive or the client will not disclose his/her status ... It's only the family members*

*who know about his/her sickness because they are afraid that they are going to be stigmatised in the community.” (FGD1)<sup>1</sup>*

*“People with HIV don’t disclose their HIV status, they hide themselves. Sometimes when you educate people in their houses to disclose their HIV status they just say I was bewitched I have to go to an Inyanga.” (FGD1)*

These factors have been reported elsewhere (Levin *et al.* 2006; Kigozi *et al.* 2011; Suzan-Monti *et al.* 2011) to affect the uptake of HIV testing and adherence. It is therefore important to devise measures to address these factors, since they influence the health systems performance when looking at the integration of TB/HIV/PMTCT.

It is also striking that in this study, despite the variety of multiple stakeholders (provincial and district managers, facility managers and NGO managers) involved in TB and HIV activities, there was coherence in views regarding health systems barriers to provision of integrated TB/HIV/PMTCT services as discussed in Paper II and III. Besides the inherited nature of the vertical provision of TB/HIV services in South Africa, the uneven funding mechanisms of these programmes, which has been mainly influenced by external funding particularly of the HIV programme, has negatively contributed to the nature and extent of integration of TB/HIV/PMTCT programmes into the district health systems, even at lower levels services as indicated in Papers II and III. This confirms findings of studies conducted in Uganda (Chono *et al.* 2009) and Vietnam (Conseil *et al.* 2010).

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<sup>1</sup> Coding conventions:

FGD with up-skilled CCWs (FGD1); FGD with beneficiaries-patients refers to (FGD2), In-depth interviews with PHC supervisors and nurse mentors refers to (PHC); In-depth interviews with district managers and programs coordinators refers to (DM).



Atun *et al.* (2010a) argue that in most developing countries, requirements imposed on the government by external funding agencies financing HIV/AIDS ring-fence HIV funds for the HIV programme alone - as a result, HIV services are provided in silos. This study calls for both external funders and government to respond comprehensively to the dual epidemic of TB and HIV, by setting up favourable funding mechanisms that enhance integration at all levels. Good policies for collaborative TB/HIV activities and strong leadership are not sufficient to break these silos. Proper fiscal and financing system agreements are pivotal to enhancing the provision of integrated services.

### **5.3 Feasibility and acceptability of the community based intervention to enhance collaborative TB/HIV/PMTCT activities**

This study showed that interventions such as the up-skilling of CCWs to provide comprehensive TB/HIV/PMTCT integrated care, was feasible and effective. Critical to its success was the community participatory approach that involved community leaders at the onset of the intervention.

What we learned from this study was that intensive community mobilisation events that involve community leaders such as the Induna (chief) and aMakhosi (traditional healers) paved the way for the acceptability of the intervention, particularly for services such as home-based HCT (HBHCT).

Chiefs and traditional healers were the first people to go for HIV testing, with TB and STI screening by CCWs who are local people as discussed further in Paper IV. Almost 30% of people who attended the community mobilisation events accepted to be tested by a CCW.

During the implementation phase, a total of 684 clients were offered HBHCT, 92% accepted to be tested and 7% were HIV positive and referred to the clinics for further care.

Despite stigma levels in the community, provision of HBHCT by CCWs proved to be acceptable and feasible. This has been observed in other countries such as Kenya (Negin *et al.* 2009); Uganda (Mulogo *et al.* 2011), and Zambia (Sanjana *et al.* 2009 ; Mutale *et al.* 2010). Home-based HCT by lay workers such as CCWs provide an opportunity for prevention, intensifying HIV case finding and linkage to care. These studies also highlight that HBHCT provides opportunities for high uptake of HIV testing and the expansion of HIV services in communities. Negin and colleagues further argue that HBHCT is an avenue for mitigating HIV related stigma (Negin *et al.* 2009).

#### **5.4 Evaluation of the up-skilling of CCWs to provide comprehensive TB/HIV/PMTCT care**

Currently in South Africa, HBHCT by CCWs is legally allowed and has been promoted in the recent policy documents for National HIV and AIDS and STI strategic plan (2012-2017) (DOH 2012), and the community health worker programme is one of the strategies to enhance HCT and HIV prevention.

Few studies have reported on an integrated approach to provision of TB/HIV services at community level. In Mozambique (Simon *et al.* 2009) and Malawi (Zachariah *et al.* 2004), studies have highlighted the feasibility and effectiveness of lay health workers, such as CCWs, to provide TB/HIV integrated services such as TB symptom screening, TB DOT and ART adherence supports, and other supportive services.

The findings of this study demonstrate that up-skilled CCWs have the potential to bridge gaps in service delivery, increase coverage for TB/HIV/STI case finding, PMTCT services (infant feeding, referral for PCR and AZT adherence support), TB and ART treatment adherence and linkage to care, as presented in Papers 4 and 5. One facility manager expressed this in the quote below:

*“It [the intervention] had an impact on us I want to talk about the CHC although we are not working as the CHC but in general they [CCWs] have been improving our head count” (PHC1)*

This intervention also contributed to the uptake of antenatal care services, as expressed below in one of the FGDs for beneficiaries/patients who received the services from up-skilled CCWs:

*“When they get to the household and find a pregnant woman they ask if she attends the clinic. My daughter used to be afraid of going to the clinic. They came here and encouraged her to go to the clinic and I must also accompany her. I indeed accompanied her to the clinic.” (FGD2)*

CCWs were found to be agents for promoting early booking and utilisation of ANC services. The findings of the HH survey also highlighted that 80% of pregnant women were counselled on infant feeding and received AZT adherence support as presented in Paper V. This shows the acceptability of CCWs to provide infant feeding counselling and adherence support, in contrast to studies conducted in Botswana and Zambia, as reported in Doherty *et al.* (2006), which showed lower levels of treatment compliance among HIV pregnant women on AZT.

This could be an avenue to improve MCH outcomes, particularly for pre- and post-partum HIV prevention. However, a limitation of this study is that we did not measure the treatment outcomes of PMTCT clients who received support from CCWs. This calls for further studies to assess the impact of CCWs on the PMTCT programme.

This study also demonstrated an improved linkage to care through referrals made by CCWs. Patients screened for TB, STIs and tested for HIV were successfully referred to the clinic. This was mainly due to a proper and functional supervisory and referral system. In this study, prior to the up-skilling of CCWs, 10 CHFs (supervisors of CCWs) were recruited and placed in PHC facilities, and a referral system with referral forms was introduced. This echoes findings reported by Simon *et al.* (2009) in Mozambique where most of TB and HIV cases identified in a community by the health care team were successfully referred to the clinics.

It is evident that for any intervention to succeed, a strong supervision and referral system is required. This has been substantiated by several studies (Lewin *et al.* 2005; Friedman *et al.* 2007; Hermann *et al.* 2009).

The findings of this study also show that an integrated approach of combining different cadres of CCWs into one cadre helped in the reduction of multiple visits at household level. This is reflected by a CCW enrolled in the intervention/project:

*“CHWs will go to a household and find a sick patient and she will not touch him/her and call you [HBC] to come and attend to him/her. We now do the same thing comprehensively and there is no longer that rivalry that has been going on. We all educate and do other things like cleaning, etc” (FGD1)*

Although there are no studies in the literature commenting on multiple visits of HHs by CCWs, many of the sub-studies in this research suggest that in the South African context, it is crucial to address the issue of multiple visits and scarce resources, as reported by one of the district managers:

*“...so this one client must establish a rapport with five different categories of CCW coming to the house whereas if it was just one person it would work much better. Even for us as government it’s not cost-effective because we have to pay three different people instead of one.” (DM1)*

This study contributed to the revision of the provincial policy for the home and community based health care (HCBC) programme. Different CCWs are now integrated, have the same scope of practice and the same stipend. However, for this to be effective and sustainable, the study suggests that government should be the sole funder for services, to avoid funding requirements imposed by external donors that focus on a single disease, as has been reported elsewhere (Chono *et al.* 2009).

Although the findings of this study demonstrated good performance of up-skilled CCWs in TB/HIV/STI case finding, PMTCT and treatment adherence support, other PHC services such as education on IMCI and referrals to social welfare were poorly provided.

This could be explained by the fact that the intervention cluster (CCWs who were trained first) focused more on TB/HIV/PMTCT services which somewhat increased workload and time spent on each activity, particularly for HCT and adherence support and infant feeding counseling.

CCWs in the comparison cluster continued to focus more on promotive activities such as health education, awareness, and referrals of clients to other services such as social welfare. There is a need to pay attention to other PHC activities in relation to services related to the dual TB/HIV epidemic, in order to strengthen the PHC system as a whole. This has implication for the workload of CCWs and their performance. Needless to say up-skilling CCWs to provide comprehensive PHC services including TB, HIV and infant care services such monitoring of child growth (weighing and immunization) is appealing; however further research is required.

This study is not free of limitations, although the findings of this study are likely to be generalisable to other similar settings like Sisonke district and KZN province. Mixed research methods were used for data collection and analysis, and the mixed nature of the research lead to somewhat less depth than commonly found in either singular quantitative or qualitative research, as the study was not a purely ethnographic or epidemiological study. The latter is one of the major challenges for evaluation of complex studies like this, as discussed in other similar studies elsewhere (Bradley *et al.* 1999).

Another methodological limitation observed is this study was the smaller number (six clusters) considered for the community randomised trial. However, we could not get more matched clusters due to the context of the study setting with variability in demographic and socio-economic status. Furthermore, there was a limitation in further analysis for multilevel modeling due to the smaller sample size of clusters. Hence we were unable to fully account for factors nested in the intervention.

This study was conducted in the real world of the health systems in a rural setting, although the research was a cluster randomised trial, it was implemented in an operational/action research approach, which made it difficult to control some provincial and district wide programmes that could have had potential unmeasured confounding effects.

While the scope of practice of CHWs and HBCs workers was harmonised, this study did not monitor the impact of the intervention on other services such as home-based care. Therefore, we suggest that further studies are needed to incorporate all components of care rendered by CCWs, in order to inform policymakers on practicalities and implications of rendering such a robust scope of services, and assess the cost effectiveness thereof. It is also important to note that although this study assessed the impact of the intervention on collaborative TB/HIV/PMTCT activities/services, some key treatment outcomes such as mortality and cure rates, were not reported due to the study time frame and the funding for this study.

## CHAPTER 6

### CONCLUSION AND RECOMMENDATIONS

#### 6.1 Conclusion

Enhancing community participation through CCWs in collaborative TB/HIV/PMTCT activities could be seen as an avenue for addressing human resources deficiencies and increasing coverage of health services. However, this requires changes in the scope of practice of CCWs, integrating different cadres of community care workers to one cadre by up-skilling them for the provision of a comprehensive TB, HIV and PMTCT care package at community level, and providing them with adequate supervisory support.

Currently in South Africa, integration of all cadres of CCWs into one cadre and integration of CCWs into the PHC system is high on the political agenda, with enormous potential benefits perceived for strengthening health systems and addressing the human resources needed to address the health crisis.

Community care workers can help bridge significant gaps in integrated TB/HIV/PMTCT service delivery at the community level. This study demonstrated various advantages of up-skilling CCWs to provide comprehensive TB/HIV/PMTCT services. It also identified contextual and health systems challenges to effective CCW engagement that health services elsewhere are likely to face. Effective interventions will need to address structural, organisational and managerial constraints, including inadequate funding for activities.



These interventions should combine systematic skills-building and supervision of CCWs with reliable referral, M&E, and supply systems, key to improving the efficiency of any interventions. Although the findings of this study show good performance of up-skilled CCWs regarding TB/HIV/PMTCT case finding, HBHCT, infant feeding counselling and AZT treatment support (PMTCT), ART and TB treatment adherence; other PHC services such as immunisation, weighing (IMCI) and support for social welfare were not fully attended to. There is a need to pay attention to other PHC activities to strengthen the PHC system as whole.

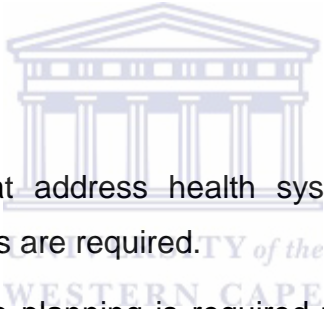
Effective structural arrangements and mechanisms for the supervision of CCWs, transport, fair remuneration of CCWs, and a sustainable supply of commodities and equipment are pivotal elements for efficiency and sustainability of any intervention, and the PHC system as whole.

In conclusion, this study found that up-skilling CCWs resulted in improvement of CCW's performance in provision of integrated TB/HIV/PMTCT services. A conceptual and methodological framework grounded in action-research, health systems strengthening research, and mixed methods research approaches was employed, and revealed that a participatory intervention design and implementation is feasible and can be successful. However, this study emphasised the need to address enduring contextual and health systems issues such as structural, organisational and managerial constraints to ensure that CCWs are integrated into a comprehensive PHC system.

Systematic skills-building and consistent CCW supervision, with a reliable referral and monitoring and evaluation (M&E) systems are required for efficiency and sustainability of any community based intervention.

It is also necessary to ensure that other PHC activities, such as referral for social welfare and IMCI, are not compromised when additional activities are added to the CCW care package. Finally, it is important to note that the findings of this study offer insights that may inform efforts to implement components of a community based programme/intervention that could enhance and accelerate the implementation of collaborative TB/HIV activities including PMTCT. Successful implementation of this community based model requires consideration of the realities that exist on the ground, and the importance of tailoring interventions in a manner that enables the performance of the PHC system and strengthen district health performance.

## 6.2 Recommendations

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- Effective strategies that address health system barriers for collaborative TB/HIV/PMTCT activities are required.
  - Careful and consultative planning is required for mainstreaming of CCWs in the provision of integrated TB/HIV/PMTCT services and integration of different cadres.
  - The scope of CCWs should be expanded to provide core activities to deliver comprehensive TB/HIV/PMTCT services. However, issues around workload should be looked closely.
  - Financing systems for activities and an incentive for CCWs are required. The funding mechanisms should respond to community needs rather than the vertical management of diseases.
  - Interventions that combine systematic skills-building and supervision of CCWs with a reliable referral and M&E system and supply system are needed in order to improve the efficiency of any interventions.

- While a comprehensive package for TB/HIV/PMTCT care is required, attention to other PHC services such as IMCI and referral to social welfare services is also required.
- Although this study has demonstrated the effectiveness of up-skilling of CCWs for provision of comprehensive TB/HIV/PMTCT care at community level, further studies are required to assess cost-effectiveness of such intervention.



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## APPENDIX 1

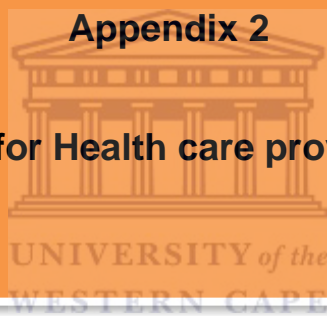
## Map of Sisonke District



Source: Sisonke District Municipality Integrated Development Plan, 2006/07

**Appendix 2**

**Questionnaire for Health care providers – Phase I**



## **Appendix 3**

**Questionnaire for TB, HIV and ANC-PMTCT clients-**

**Phase I**

  
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## **Appendix 4**

**Table for the sample size for TB, HIV and ANC-PMTCT  
clients**

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## **Appendix 5**

### **Questionnaires for Facility and NGO Audit**





**Appendix 6**

**Questionnaire for Baseline Household Survey**

**Phase II**

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**Appendix 7**

**Questionnaire for Follow up Household Survey**

**Phase III**

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## **Appendix 8**

**Interview guides for Individual interviews**

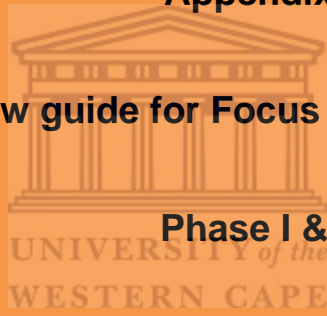
**Phase I & III**

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**Appendix 9**

**Interview guide for Focus group discussions**

**Phase I & III**



**Appendix 10**

**Information sheet**

**Phase I & III**

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## **Appendix 11**

### **Consent form -Phase I & III**



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