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PhD in Computer Science

ANNARIINA KOIVU

Key Challenges in the Current TB & HIV Information System in South Africa

A Case Study in Khayelitsha, Western Cape

A THESIS SUBMITTED TO THE

UNIVERSITY OF DUBLIN, TRINITY COLLEGE

FOR THE DEGREE OF

DOCTOR OF PHILOSOPHY

2015

Declaration

I declare that the work described in this dissertation is, except where otherwise stated, entirely my own work, and has not been submitted as an exercise for a degree at this or any other university. I further declare that this research has been carried out in full compliance with the ethical research requirements of the School of Computer Science and Statistics.

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Abstract

South Africa has one of the most serious human immunodeficiency virus (HIV) / and tuberculosis (TB) epidemics in the world, with high incidence, prevalence and co-infection rates. Information is at the heart of managing the TB and HIV epidemics, both inside and outside healthcare facilities. All stakeholders including the general public, patients, health professionals and policy-makers need access to valid, complete and up-to-date information in order to make choices and decisions (HIQA, 2013). Yet, this goal is not often met in developed countries and almost never in developing ones.

This research, conducted by means of a qualitative case study, aims to understand the key challenges in the current collection, reporting and use of TB and HIV information in under-privileged settings in South Africa, because a holistic and in-depth understanding of key issues is a prerequisite for addressing and improving them. The findings of the study suggest that there are serious interrelated challenges in 1) the quality of data produced by the South African TB and HIV information system, 2) the manner the information system functions to produce that data, and 3) the utilisation of that data. However, this study also identifies positive, well-functioning characteristics in the South African TB and HIV information system. Furthermore, the findings highlight the importance of seeing the health information system as an integral part of the health system.

This study provides unique insights into the TB and HIV information system in resource-restricted settings thereby contributing to a growing literature of health information systems in low- and middle-income countries (LMIC).

Acknowledgements

I would like to thank my supervisors Prof. Jane Grimson and Prof. Lucy Hederman (Trinity College, Ireland) for agreeing to supervise my research, for their unflagging support and insightful contributions. I also wish to thank Adjunct Prof. Mikko Korpela, (University of Eastern Finland, UEF) for his feedback, encouragement and practical advice. Furthermore, I would like to thank all my colleagues and fellow students in our international network of universities: the INDIGO Programme and Centre for Global Health and School of Computer Science and Statistics (SCSS) in Trinity College, Ireland; Cape Peninsula University of Technology (CPUT) and Human Sciences Research Council (HSRC) in South Africa; and Holistic Information Systems Development Approach for Societal Development (ISD4D) project partner institutions.

I wish to thank my African colleagues, Prof. Retha de la Harpe and her group at CPUT: you all have encouraged me during this process and have been an important resource for me to incorporate the genuine African perspective in the research, and realising the interviews in Africa. Specifically, I wish to thank Dr. David Makola and his wife, Dr. Lyn Hanmer, Dr. Pren Naidoo, Mr. Danver Roman, Prof. Karl Peltzer, Dr. Julia S. Louw and her family, Ms. Doreen Mugendi and Prof. Andy Bytheway and his family. Many of you have not only opened doors in terms of research and accessing the right people but also the doors of your homes, making the time in South Africa unforgettable for my husband and me.

While the names are to numerous to mention, I am are truly appreciative for the assistance and feedback particularly during the early development of the this doctoral thesis from Prof. Malcolm "Mac" MacLachlan, Dr. Ogenna Uduma, INDIGO peers and the staff at the Global Health Centre in Dublin.

I feel that some of closest supporters of this research process particularly towards the end of project have been the researchers of the Daisy group: Tuija, Vilma, Marilla, Marika, Irmeli, Pauliina and Susanna. My heartfelt thanks!

Sincere thanks for Brian Conry, José Martinez, Bridget Kane and everybody else who have helped me with my English during the years.

The research data was gathered from several healthcare or health governance related organisations in the Western Cape: my sincere thanks go to the study participants for their valuable time and insights.

The opportunity to reduce my workload at home enabled me to complete the thesis writing and is gratefully acknowledged. Special thanks to all of you who have supported us spiritually, financially, and by taking care of our daughter. Specifically, I wish to mention my family, my grandmother and Mika's family. Katri, Reetta, 'Olkun likat' and MIG teammates have provided much needed distraction. My mother, father, brother and Elisa have all commented on the research draft but also supported us in many other ways. Last but not least, I doubt that I will ever be able to convey my appreciation fully, but I owe my husband Mika my sincere gratitude.

Finally, I wish to thank the following organisations for the financial assistance towards this research: Tampere Tuberculosis Foundation (Tampereen tuberkuloosisäätiö), Instrumentarium Science Foundation, City of Tampere's Science Foundation (Tampereen kaupungin tiederahasto), The Finnish Concordia Fund, as well as the ISD4D project.

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List of Abbreviations

AIDS	Acquired Immune Deficiency Syndrome
APP	Annual Performance Plan (Can refer to either the National Department of Health or Western Cape Department of Health document)
ART	Antiretroviral Therapy/Treatment
ARV	Antiretroviral
CD4	Cluster of Differentiation 4 (A CD4 count is an indicator of how well an immune system is working)
CoCT	City of Cape Town
DAISY	Development of human Activity and Information SYstems
DHIS	District Health Information System
DHMIS	District Health Management Information System
DOH	Department of Health
DOTS	Directly Observed Treatment, Short-Course
GAVI	Global Alliance for Vaccines and Immunisation
HAST	HIV and AIDS, STI and TB
HCT	HIV Counselling and Testing
HIS	Health Information System
HISP	Health Information System Programme
HISR	Health Information Systems Research
HIV	Human Immunodeficiency Virus
HMIS	Health Management Information System

HPSR	Health Policy and Systems Research
HR	Human Resources
HSRC	Human Sciences Research Council
ICT	Information and Communication Technology
ICT4D	Information and Communication Technology for Development
IS	Information System
ISD	Information Systems Development
ISR	Information Systems Research
IT	Information Technology
LMIC	Low- and Middle-Income Countries
M&E	Monitoring & Evaluation
MCH	Maternal and Child Health
MDG	Millennium Development Goals
MDR-TB	Multidrug-Resistant Tuberculosis
MOU	Maternal Obstetrics Unit
MSF	Médecins Sans Frontières
NDOH	National Department of Health
NGO	Non-Governmental Organisation
NHLS	National Health Laboratory Service
NIDS	National Indicator Data Set
NIM-ART	Nurse Initiated Management of Antiretroviral Treatment
PEPFAR	U.S. President's Emergency Plan for AIDS Relief
PHC	Primary Health Care

PHCIS	Primary Health Care Information System
PLWHA	People Living With HIV/AIDS
PMTCT	Prevention of Mother-to-Child Transmission of HIV
PREHMIS	Patient Record and Health Management Information System
RHIS	Routine Health Information System
RMR	Routine Monthly Report/Reporting
SANAC	South African National AIDS Council
SOP	Standard Operating Procedure
STI	Sexually Transmitted Infection
TB	Tuberculosis
UCT	University of Cape Town
UN	United Nations
UNAIDS	Joint United Nations Programme on HIV/AIDS
UNFPA	United Nations Population Fund
UNGASS	United Nations General Assembly Special Session Declaration of Commitment on HIV/AIDS
VCT	Voluntary Counselling and Testing
WCDOH	The Western Cape Department of Health
WHO	World Health Organization
XDR-TB	Extensively Drug-Resistant Tuberculosis

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Chapter 1 Introduction

1.1 OVERVIEW

Healthcare is an information-intensive domain where data is needed every day. Yet, the quality of any decision, whether it concerns allocating resources for health or the care of an individual patient, depends largely on the quality of the data that the decision is based on. Hence, healthcare data needs to meet several quality criteria, including accuracy, timeliness and completeness. However, since most health systems have limited human and other resources, it is crucial to investigate that the way the health information system functions to produce that data is purposeful and efficient. Finally, the collected data should not stay in files, registers, computers or statistics - it is valuable only when it is utilised in a meaningful way in decision-making. **The need for reliable and high-quality data produced by an efficiently functioning health information system (HIS) is particularly important with diseases that are global priorities, such as tuberculosis (TB) and human immunodeficiency virus (HIV) infection.** This chapter provides an introduction to the area, as well as to the thesis. First, this chapter sets out the rationale for the study in section 1.2 "Background and motivation". In section 1.3, the scope of the study is defined, and within that scope, the research question and research objectives are stated for the reasons outlined in the motivation. Then, the manner by which the research question is investigated is explained (1.4). Next, the outcomes and contributions of the study are proposed (1.5). Finally, section 1.6 provides an outline of the remainder of the thesis.

1.2 BACKGROUND AND MOTIVATION

Every day, various kinds of data are acquired at different levels of any health system. The data is collected so that numerous actors within the health system and beyond can use it for various purposes. Healthcare professionals generate, collect and utilise information in the context of clinical decisions and patient care; at manager-level data is required to increase efficiency and effectiveness; those whose job is to plan services consult statistics for operational decisions; and policymakers on local, national and international levels rely on information for setting priorities and allocating resources (Abou-Zahr et al., 2007). The Ebola outbreak in several West African countries provides a recent example of the importance of adequate, accurate and timely data to detect and respond to infectious diseases. Moreover, comprehensive information is needed for epidemiological estimates and modelling, to monitor performance and progress towards goals, such as the Millennium Development Goals (MDGs), to enhance transparency and accountability, and to create a better understanding of what works and what does not: how many lives were saved by health interventions and at what cost? (WHO, 2014f; Boerma and Abou-Zahr, 2007).

However, the data coming from African countries do not truly reflect the situation in Africa; information is generally not always available, and even when it is, it often fails to be comprehensive, complete or up to date (Sewankambo and Katamba, 2009; WHO's Regional Office for Africa, 2002; Ndira et al., 2008). Research in resource-limited settings indicates that the quality of data is inconsistent (Ndabarora et al., 2014; Monda et al., 2012; Forster et al., 2008; Okonjo-Iweala and Osafo-Kwaako, 2007), often leading to limited use of the collected data (Ndabarora et al., 2014; Braa et al., 2012; Wolvaardt et al., 2014). Compared to the rest of Sub-Saharan Africa, South Africa is in many respects at a more advanced stage in health data production (for instance in civil registration and mortality statistics, Kabudula et al., 2014) than many other countries. Nevertheless, research has identified gaps, data quality issues and other deficiencies in various South African information systems relating to TB and HIV (see for instance Auld et al., 2013; Heunis et al., 2011; Garrib et al., 2008; Mphatswe et al., 2012).

Having high-quality systems that produce accurate data is particularly important in South Africa, since the country is plagued by an HIV epidemic that is arguably one of the most severe in the world. While the epidemic does not hit the headlines in the Western world in the way it did in the 1980s and 1990s (Cullen, 2003), it is still an incurable disease that claims more than 200,000 South African lives per year (UNAIDS, 2014a). In 2012, an estimated 12.2% of the population (6.4 million people) were HIV positive with extremely high infection rates in some population groups, such as 36% in 30-34 year old women (Shisana et al., 2014). As a result of patients being more susceptible to TB when their immune system is weakened by HIV, South Africa is also undergoing *"an extraordinary TB epidemic"* (Heunis et al., 2011). Indeed, South Africa is one of the countries with the highest burden of TB (WHO, 2013b). As the volume of patients has grown, it has become crucial that both they and their information are managed as effectively as possible. Any deficiencies in the collection, use and reporting of this data are magnified with such exceptional patient loads. Much of the manual collection and reporting of data at the facility level is assigned to the health professionals (including doctors and nurses), who are expected to do it alongside their care work. However, the South African public health system is lacking an estimated 83,000 health professionals (PEPFAR, 2012a) due to the medical 'brain drain', making the health system buckle under the high disease burden combined with other challenges that have emerged as a legacy of the apartheid era. Therefore, it is paramount that the resources available are used in the best possible way.

The obtaining, management and use of data on TB-HIV co-infection requires special attention. While South Africa has 0.7 percent of the world's population, it has an estimated 28 percent of the world's TB-HIV co-infected individuals (USAID, 2010). HIV and TB interact synergistically: HIV advances a latent TB to progress into an active disease, which is in turn associated with increased HIV viral load, consequently increasing the risk of acquired immune deficiency syndrome (AIDS) and death (Uyei et al., 2011). Additionally, multi-drug resistant tuberculosis (MDR-TB) has emerged from the intersection of TB and HIV (Kerschberger et al., 2012) further worsening patient outcomes. There are interventions, such as early initiation of antiretroviral treatment in TB-HIV co-

infected patients and isoniazid preventive treatment for TB prevention in HIV positive people which improve survival (Stockdale et al., 2013; Abdool Karim et al., 2011; Blanc et al., 2011; Havlir et al., 2011; Golub et al., 2015; Rangaka et al., 2014) but for various reasons they remain under-utilised resulting in missed opportunities (Mayosi et al., 2012; Kerschberger, et al., 2012). Hence, the efficient processing and managing of TB-HIV data in connection with each other and its availability for intended users is extremely important at both facility and population level. Unfortunately, in South Africa, as is the case in many other countries in the developing world, health services are largely organised in a disease or programme specific vertical manner (Uyei et al., 2014) which may result in patients being seen by different services and health staff (Coetzee et al., 2004). The reporting follows a largely similar vertical pattern, resulting in parallel data flows and duplication of work in a situation where resources are already thinly spread.

1.3 THE SCOPE OF THE STUDY, THE RESEARCH QUESTION AND THE OBJECTIVES

Taking into consideration the issues summarised above, this research aims to **identify and analyse the key challenges in the current TB and HIV information system in South Africa** through the lens of a case study. In order to understand that system, the study examines a number of data flows, which are defined as

1. being TB or HIV related

2. originating from one public health clinic in Khayelitsha, which is a part of the City of Cape Town, in Cape Town Metropolitan District of the Western Cape Province in South Africa.

Khayelitsha is a poor, under-privileged and densely populated township in the outskirts of Cape Town. In South Africa, a township refers to an urban residential area created for non-whites including black Africans, Coloureds and Indians (Statistics South Africa, 2004) and the majority of the black population still lives in them. Khayelitsha can be viewed as representative of a South African

township in that many of the challenges, such as poverty, crime and ill-health which the residents experience are also prevalent in other South African informal urban areas. Khayelitsha is also greatly affected by TB and HIV epidemics with higher estimated prevalence rates than the national average. A more detailed description of Khayelitsha is provided in section 2.6.

The research follows how the data flows in various ways from the facility level via sub-district and district level to provincial level as described in Chapter 5. While the data flows up to the national and international level, due to the scope of this research, they are only followed to the provincial level (for more about scope, see section 4.4.1).

So, in order to define the scope of the research, the study is conducted around these particular kinds of data flows originating from one particular place and followed until a particular level is reached. However, in the context of the data flows, **TB and HIV related data is collected, captured in various paper-based and electronic TB and HIV related health information systems, reported, used and fed back.** This entity may be called a **health information system (HIS)**. Health information system(s), as well as many other concepts used in this study have different interpretations and require a clarification in terms of what they mean in this study. The terms are elaborated in section 3.2. It should be noted that the researcher follows an approach where an information system is seen as *"a socio-technical system of managing information within an organization; a purposeful systemic entity which consists of people, processes, information and technologies (manual and computer-based ones)"* (Tiihonen et al., 2010). In other words, the focus of this study is not limited to certain electronic and computer-based systems; various systems can be viewed as an entity ("the South African TB and HIV information system"); and the local health workers contributing to data collection, reporting and use are seen as an integral part of the HIS.

Within the context of South Africa, the research question is as follows:

What are the key challenges in the current TB and HIV information system in an underprivileged community?

In order to address the research question, the following research objectives have been derived:

A. To research relevant academic and grey literature that supports identifying and analysing key challenges and good practice in health information systems in under-privileged settings.

B. To examine how TB and HIV related information is collected, reported and used currently in Khayelitsha in the Western Cape Province in South Africa.

C. To identify the key challenges in systems and practices as perceived by the local health professionals.

D. To analyse and categorise these challenges in order to identify where systemic improvements are needed.

The findings produced by meeting these objectives should improve the understanding of key challenges of the TB and HIV information system and their impacts in the context of an under-privileged setting. Besides the aforementioned research objectives, this study also aims to identify and highlight some of the good experiences. In addition, building on the literature and the identified examples of good practice, the study wishes to examine what kind of approach might be appropriate in attempting to address the challenges. Finally, this study aims to assess the extent to which the findings of this case study can be applied beyond the case study setting.

1.4 METHODOLOGY

The study employs empirical qualitative research principles through the use of **interviews**, obtaining relevant **documents** and **observation** to collect data. More specifically, the interview data was obtained from 28 informants, who worked at each level (clinic, sub-district, district and provincial level) of the health system in various roles ranging from clinical to clerical, and from

monitoring and evaluation (M&E) to health governance and management. The interviews resulted in 410 pages of data (150,923 words). Alongside the observations and documents, interviews were interpreted by means of thematic analysis in order to reach the findings to address the research problem. The research design uses a case study. The full explanation of the research methodology can be found in Chapter 4.

1.5 OUTCOMES AND CONTRIBUTION OF THE RESEARCH

The main outcome of this research is an improved understanding of the key issues in the South African TB and HIV information system and how the challenges are experienced in practice by the local stakeholders who are part of that system. A characteristic that sets this research apart from previous published studies on South African health information systems and landscape, and one of the key contributions of this study, is that it attempts to examine all the data flows in one thematic area (TB and HIV related)[1]. Studies from different viewpoints of particular TB or HIV related information systems have been published in the developing country context before (Ledikwe et al., 2014; Amoroso et al., 2010; Hedt-Gauthier et al., 2012; Saeed et al., 2013 to name but a few). A number of studies have examined one disease specific HIS in South Africa (including Heidebrecht et al., 2011; Osler et al., 2014, Kawonga et al., 2013; 2012) or the District Health Information System (DHIS) (Braa et al., 2007; Jacucci et al., 2006; Shaw, 2005) or data related to a specific health programme (for instance Mphatswe et al., 2012). In addition, Auld et al. (2013) and Heunis et al. (2011) looked at certain aspects of TB and HIV information systems together. However, to the researcher's knowledge, precisely the kind of approach that has been applied in the current thesis has not been taken before. While this approach comes with certain challenges, it is a novel way to describe in detail the health information system barriers regarding the multiple data collection and reporting activities that have been built around priority diseases. In other words,

[1] Excluding data flows that are mentioned in section 4.4.1.

by analysing all the data flows together, this study highlights the whole burden of reporting responsibilities assigned to the health work force, points out more explicitly avoidable duplicative work and identifies important gaps in the health information system. The outcomes of this project are also aimed at contributing to several research domains, which are discussed in the final chapter of this thesis (section 9.6).

1.6 THESIS OUTLINE AND RESEARCH OBJECTIVES REVISITED

This thesis comprises nine chapters. In section 1.3, several research objectives were introduced (listed as A to D). The objectives are reflected in the chapters of this thesis as illustrated in Table 1-1. The third column of Table 1-1 provides an overview of the chapters.

Table 1-1. The chapters of the thesis, the research objectives and an overview of the chapters.

Chapters of the thesis	Research Objectives	Overview of the chapters
CHAPTER 1 Introduction	---	Chapter 1 introduces the reader to the problem area, the research question and objectives, methodology, as well as expected outcomes and contributions. The structure of the thesis is presented.
CHAPTER 2 Background	A. To research relevant academic and grey literature that supports identifying and analysing key challenges and good practice in health information systems in under-privileged settings.	In Chapter 2, the South African healthcare landscape is explored in terms of its historical roots and their impact on the current situation. The burden of HIV, TB and co-infection is described both globally and in the South African context. The case study setting, Khayelitsha, is introduced in order to contextualise the findings. Relevant developments and paradigm shifts in global health and with reference to South Africa, such as the human resource crisis in health, prioritisation of key diseases, vertical health care delivery model, and the opposing paradigm that emphasises comprehensive approach in health and integration of programmes and activities, are discussed.
CHAPTER 3 Literature Review	A. To research relevant academic and grey literature that supports identifying and	Chapter 3 provides an overview of current relevant literature. It reviews different ways to classify health information systems and concludes with the view applied in this study. Moreover, it explains why information is important in healthcare and identifies

	analysing key challenges and good practice in health information systems in under-privileged settings.	the issues contributing to challenges in data quality, HIS functioning and utilisation of data in low- and middle-income countries. The review also covers key aspects of current thinking relating to the reporting of priority diseases. Finally, the review introduces relevant studies conducted in South Africa within the subject area of the current study.
CHAPTER 4 Methodology	---	Chapter 4 specifies the research design in terms of the research approach and philosophy of the researcher, and the research process that is followed. In addition, the research methods, ethical considerations, as well as special challenges that the researcher encountered when entering a specific local context as a foreigner, are detailed.
CHAPTER 5 Empirical Findings: Description of TB and HIV related data flows.	B. To examine how TB and HIV related information is collected, reported and used currently in Khayelitsha in the Western Cape Province in South Africa.	Chapter 5 presents the empirical findings of the research. The data flows originating from the case study clinic are described in detail, and they are followed up to the provincial health authority. This supports a holistic analysis of the key challenges relating to the data flows, which is the topic of the succeeding chapters.
CHAPTERS 6-8 Analysis of Findings	C. To identify the key challenges in systems and practices as perceived by the local health professionals. D. To analyse and categorise these challenges in order to identify where systemic improvements are needed.	Chapters 6 to 8 provide an analysis and presentation of the case study findings. Specifically: • Chapter 6 focuses on the data quality of the South African TB and HIV information system • Chapter 7 concentrates on the functioning of the South African TB and HIV information system and • Chapter 8 focuses on the utilisation of the data produced by the system.
CHAPTER 9 Discussion and Conclusions	---	Chapter 9 concludes this research project. It revisits the research question and presents core findings, discussion and conclusions. It discusses the generalisability of the findings, study limitations and contributions of the study and makes suggestions for future work.

Throughout the thesis, several verbatim quotations and little vignettes titled *"A Case Study Within the Case Study"* are provided. They are presented to illustrate themes emerging from the analysis, deepen understanding about specific issues, enhance readability and to reinforce the underlying idea of this study that the informants' voices should be heard. In other words, this case study attempts to understand some of the key challenges in the TB and HIV information *system as perceived by the local stakeholders within the system.* However, the quotations and the local stakeholders' personal opinions and perceptions are accompanied by the researcher's analysis and commentary that is informed by the academic literature.

Chapter 2 Background

2.1 OVERVIEW

The purpose of this chapter is to provide a general context and a historical background to the research topic; this will help the reader to appreciate the need for and importance of this study. Moreover, the socio-economic, epidemiological and health system related issues covered in this section will aid in understanding the key issues examined in the literature review (Chapter 3), as well as place the findings of Chapters 6-8 into perspective. The researcher's aim has not been to thoroughly cover every topic that relates to the research question, but map the key concepts underpinning the research area.

First, in order to contextualise the South African HIV and TB situation, the basic information on the epidemics on the global level is provided (in section 2.3). Second, HIV, TB and co-infection in South African context are examined, as the magnitude of the epidemics underscores the importance of this study (2.4). Third, the human resource crisis in the health sector is briefly reviewed, because when a country has limited resources, it is important that they are used as efficiently as possible (section 2.5). Fourth, leaving global and national levels, section 2.6 zooms into Khayelitsha to show that some of the challenges, which are very severe on a national scale, are even worse in the township that this case study focuses on. Fifth, the concepts of global health priority setting, vertical systems and integration are introduced in section 2.7, since global development in these areas is a major cause that has led to the South African TB and HIV reporting system becoming what it is. Finally, the focus is placed on the prioritisation, vertical systems and integration efforts in South Africa (2.8). By reviewing these topics, this study addresses the research objective A: *"To research relevant academic and grey literature that supports identifying and analysing key challenges and good practice in health information systems in under-privileged settings."*

2.2 INTRODUCTION: THE WORLD SOUTH AFRICANS LIVE IN

According to a World Bank classification, South Africa is a middle-income country (World Bank, 2013a). However, that world looks very different depending on who you are and where in South Africa you live your everyday life. The significance of socioeconomic determinants of ill-health, such as poverty, social exclusion and poor living conditions as key drivers of an unequal society is well illustrated in South African society, where social inequalities were structural and state motivated for decades (Sewankambo and Katamba, 2009). Undeniably, the country's history is saturated with discrimination based on race and gender (Coovadia et al., 2009).

Unfortunately, income surveys suggest that no real progress towards income equality has been made since the end of apartheid (OECD, 2013). In fact, white-headed households on average earn more than 5.5 times the income of the average black African-headed household (Statistics South Africa, 2012). In 2013, South Africa's Gini coefficient was 0.63[2] (World Bank, 2013b), placing it amongst the most unequal societies in the world. According to a calculation by a recent Oxfam report, the two richest people in South Africa have the same amount of wealth as the bottom half of the population, making South Africa significantly more unequal than it was at the end of Apartheid (Seery and Arendar, 2014).

Moreover, unemployment remains excessively high in South Africa (33.4% in 2012), exacerbating an array of social problems and tensions. Whilst unemployment figures in underdeveloped settings are not always directly comparable to those of developed settings, the OECD report argues that the unemployment is involuntary, very few of the unemployed receive any unemployment insurance benefits, and most of them have never held a job. Indeed, while the government has used the tax and benefit system to help to alleviate inequality, there is large number of South Africans who have no labour

[2] Gini coefficient is a widely used measure of the deviation of the distribution of income among individuals or households within a country from a (hypothetical) perfectly equal distribution. A value of 0 represents absolute equality, and value of one (or 100) absolute inequality. Scandinavian countries experience typically a high income equality as indicated by a low 0.25-0.27 Gini coefficient, whereas the Russian Federation and the United States can be seen as more unequal (Gini coefficient 0.40-0.41). Only few countries have a Gini coefficient higher than 0.60 indicating extreme inequality. (Source for the figures: World Bank, 2013b).

earnings, income assets, social benefits or other transfers, and who survive solely with support from their family (OECD, 2013).

In addition to poverty and unemployment, financial mismanagement and disaffection with local government contribute to social problems connected with very high levels of violence in South African society (Human Rights Watch, 2014). Interpersonal violence has been ranked fifth among the leading causes of death and the second leading cause in men in South Africa (Norman et al., 2006[3]). Moreover, estimations of homicide rates have placed SA among the most violent countries in the world (Norman et al., 2007) making the chances of dying violently in South Africa approximately 30% higher than elsewhere in the World Health Organization's (WHO) AFRO region (Corrigall and Matzopoulos, 2013). In conclusion, colonial and apartheid heritage, discrimination, poverty, crime, migrant labour system and destruction of family life have all shaped South Africa's past, as well as influenced the health system and health of its citizens (Coovadia et al., 2009). Indeed, they make it very difficult for the citizens to realise their economic and social rights and even their fundamental human rights, including those that have to do with health.

In the apartheid era, until 1994, the health system was highly privatised and very much distorted towards the hospital needs of urban whites (Baker, 2010). When apartheid ended, the health system was faced with massive challenges. Coovadia et al. (2009) consider the following as "**roots of a dysfunctional health system**":

- The persistence of economic inequalities between races, since the macroeconomic policies advanced growth rather than redistribution.
- Failures in stewardship and weak management, which have often led to insufficient implementation of otherwise well-functioning policies, albeit

[3] This figure is from the website of Medical Research Council updated in 2014, suggesting that it is considered the latest available data on the issue. The figure is based on the Revised Burden of Disease estimates for the Comparative Risk Factor Assessment for South Africa, 2000 by Norman et al. (2006). While Statistics South Africa reports 10,3 % of deaths of unnatural reasons in 2013, their data is from death notifications and does not include ranking for non-natural causes of death (Statistics South Africa, 2014). Therefore, the researcher considers the Medical Research Council's findings more indicative of the levels of violence in the community.

that this happens in the context of a public health system which has been improved into a more integrated, comprehensive national service.

- Critical deficiencies in the primary health care.
- Serious human resource crisis in the health sector.

All these, the authors argue, have contributed to the collision of the epidemics of communicable and non-communicable diseases in South Africa.

Many of these root causes have contributed to **further challenges**. In the 2009 Lancet Health in South Africa Series, a group of national and international experts identified several key issues (discussed next). The series of articles coincided with a newly elected Health Minister and a new administration, which was particularly welcome after the damage caused by President Mbeki's and his Health Minister's AIDS denialism (Coovadia et al., 2009). It may feel untimely to discuss issues that were identified in 2009, but they are presented here for three reasons: first, the article series was *widely quoted* by academics, policy commentators, and senior staff in the provincial and national Health Ministries (Mayosi et al., 2012). Hence, the call for action by the various experts prompted health policy changes and progress that took place at the time when the researcher was collecting her data in South Africa in 2012. In other words, the health policies and practices that were being implemented at the case study setting (as well as everywhere else in South Africa) when the researcher investigated it, were informed and influenced by the article series, as there had arisen a need to address the identified challenges. Second, the challenges identified in 2009 *still persisted* to a large extent in 2012 as witnessed by the researcher and the literature (Mayosi et al., 2012). Third, to a certain degree, they *still remain*. The key messages of the article series are summarised in Table 2-1.

Table 2-1. Key messages from 2009 Lancet Health in South Africa Series (Coovadia et al., 2009; Chopra et al., 2009a; Abdool Karim et al., 2009; Mayosi et al., 2009; Seedat et al., 2009; Chopra et al., 2009b in Mayosi et al., 2012).

• Four colliding epidemics
  ○ **HIV and tuberculosis (TB)**
  ○ a high burden of chronic illness and mental health disorders
  ○ deaths related to injury and violence
  ○ a silent epidemic of maternal, neonatal and child mortality.

• Supportive policies meant moderate spending on health, but health outcomes were deteriorating, particularly due to HIV and TB.
• The **health system was under pressure** to cope with the high burden of disease, especially at the district level. Three **priorities** were emphasised: 1. **Prevention of infections (notably HIV and tuberculosis)**; non-communicable diseases; injury; and maternal, neonatal and child health (especially Prevention of Mother-to-Child Transmission of HIV (PMTCT) and improved neonatal health). 2. **Integrated,** effective primary health care, with strong management and capable use of **data**. 3. Widespread scale-up of successful innovations and relevant and rigorous clinical research.
• South Africa was not on track for the Millennium Development Goals, but had the potential to be. Other epidemics could have been decreased with strategic investment, implementation, leadership and accountability.

Table 2-1 is modified from Mayosi et al. (2012). Emphasis (bold text) is by the researcher. All of the bullet points of the table have an important connection to this research, but some of the most relevant topics, (emphasised in bold), are discussed separately in the following sections: HIV and TB in sections 2.3 and 2.4. Moreover, in accordance to Coovadia et al's (2009) observation on health system being under pressure due to the human resource (HR) crisis in the public health sector, that issue is revisited in section 2.5. TB and HIV are particularly pressing challenges at the case study setting of Khayelitsha, which is the topic of section 2.6. Priorities and integration are key topics of sections 2.7 and 2.8. The final emphasised word in Table 2-1, *"data"*, is examined from various angles in the Literature Review (Chapter 3). The purpose of connecting this thesis to the findings of an expert panel (i.e. Table 2-1) is to illustrate that this study is not

undertaken in isolation, but builds on earlier evidence and many of the challenges identified years ago have unfortunately remained unsolved.

2.3 HIV, TB AND CO-INFECTION GLOBALLY

At the end of 2012[4], the World Health Organization estimated that more than 35 million people were living with HIV/AIDS (as indicated in Summary Table 2-2).

Table 2-2. HIV in 2012, summary.

HIV, globally, in 2012	
Incidence	2.3 million
Prevalence	35.3 million (0.8%[5])
Mortality	1.6 million

Since the beginning of the epidemic, almost 75 million people have been infected with the HIV virus and about 36 million people have died of it (WHO, 2014a). However, the burden of the disease varies significantly between countries and regions. Sub-Saharan Africa remains the most severely affected, as illustrated in Figure 2-1.

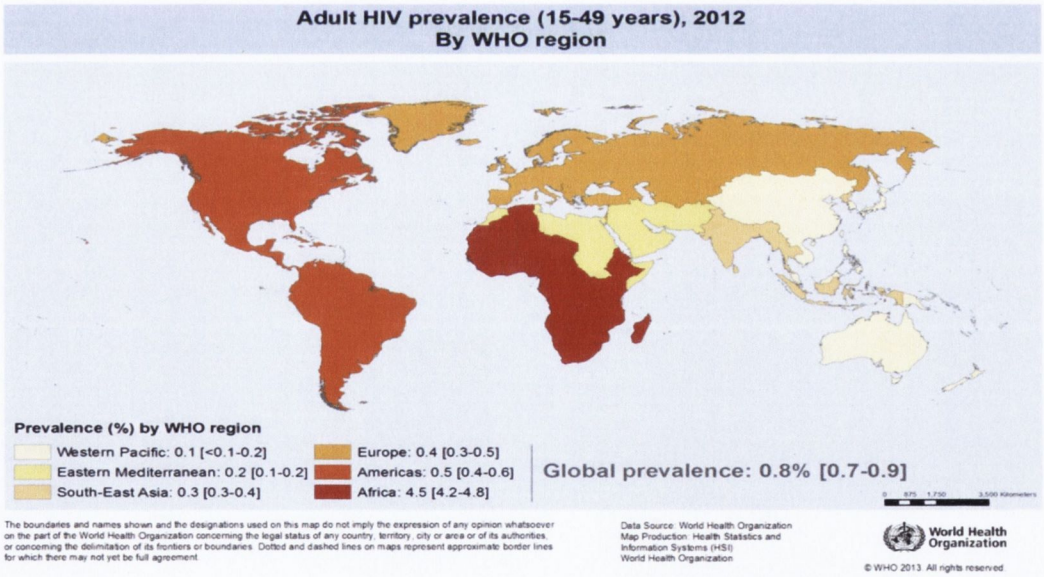


Figure 2-1. Adult HIV prevalence (15-49 years) in 2012 by WHO region. (WHO, 2014a).

[4] 2012 is the most recent year of which data is publically available both nationally and internationally with regard to all the aspects that the researcher wishes to report on.

[5] Of adults between 15-49 years.

More than 70 per cent of all people living with HIV (PLWHA) reside in this region, meaning that 1 in every 20 adults is living with HIV (WHO, 2014a).

However, as Figure 2-2 shows, it is largely the Sub-Saharan Africa and particularly the highest-burden countries (Swaziland, Lesotho, Botswana, South Africa and Zimbabwe) that remain most affected.

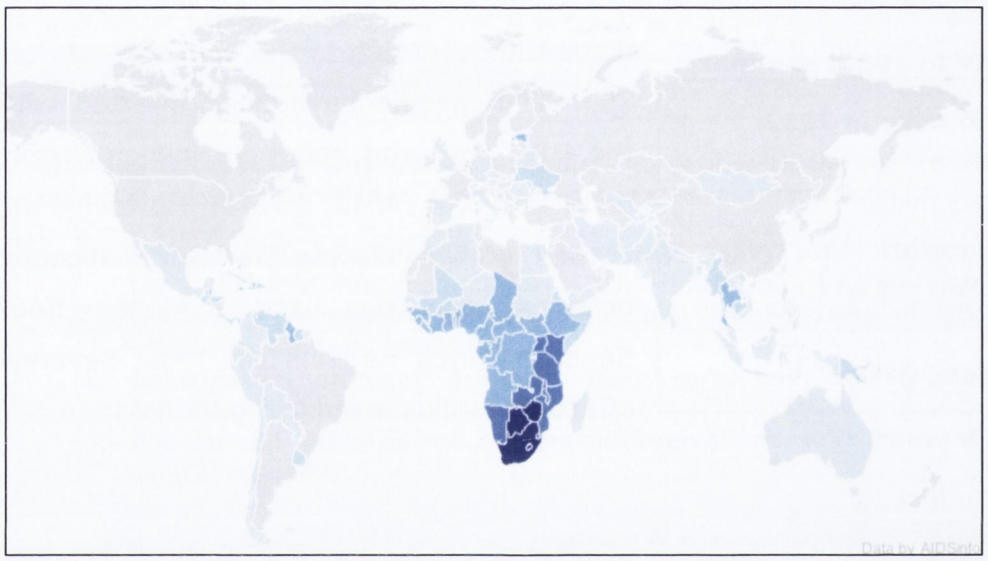


Figure 2-2. Adult HIV prevalence in 2012 by country. (UNAIDS, 2014d).

Globally, there were 2.3 million new HIV infections in 2012. The trend is declining, indicating that prevention efforts continue to bear fruit (UNAIDS, 2013a, c). In that year, there were approximately 9.7 million people on life-saving antiretroviral treatment (ART) (WHO, 2013a). As illustrated in Figure 2-3, the scale-up has been enormous from the 300,000 people who were receiving ART in low- and middle-income countries in 2002.

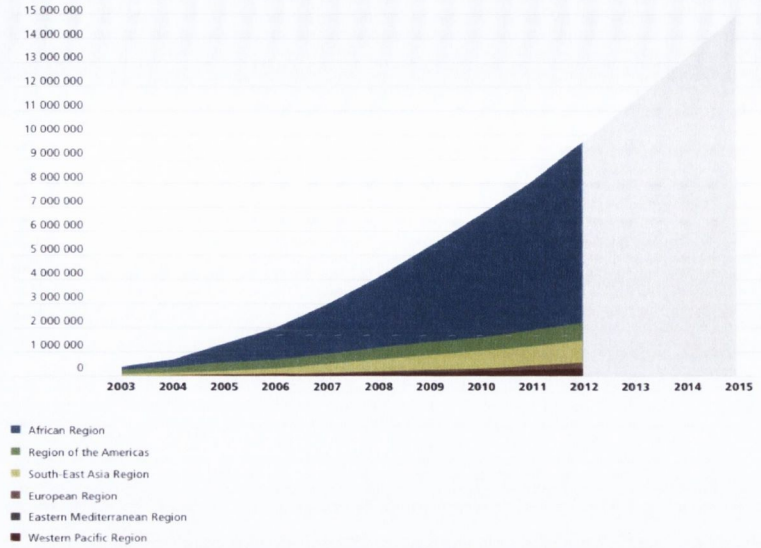


Figure 2-3. Actual and projected numbers of people receiving antiretroviral therapy in low- and middle-income countries, and by WHO Region, 2003–2015. (WHO, 2013a).

HIV-positive mothers may pass HIV to their babies during pregnancy, labour, delivery or breastfeeding. Globally, over 900,000 women were receiving ART in order to prevent mother-to-child infections in 2012 (WHO, 2013a). While there exists effective treatment for HIV, there is no cure for HIV infection. In 2012 it remained the leading cause of death from a single infectious agent and the second leading cause of death after lower respiratory infections in low-income countries (WHO, 2014b).

Almost 20 years after the WHO declaration of TB as a global public health emergency, it remains a major health problem worldwide. Table 2-3 shows that an estimated 8.6 million people developed TB in 2012 (WHO, 2013b).

Table 2-3. TB in 2012, summary.

TB, globally, in 2012	
Incidence	8.6 million (122 cases / 100,000 population)
Prevalence	12 million[6]
Mortality	940,000[7] / (320,000[8])

Globally, the incidence rate of TB is slowly declining, but there is substantial variation between regions both in the number of new cases and how the epidemic is developing, as can been seen from Figure 2-4. In 2012, 940,000 people died from TB. The number of TB deaths is unacceptably high given that most TB deaths could be prevented if people had access to healthcare for a timely

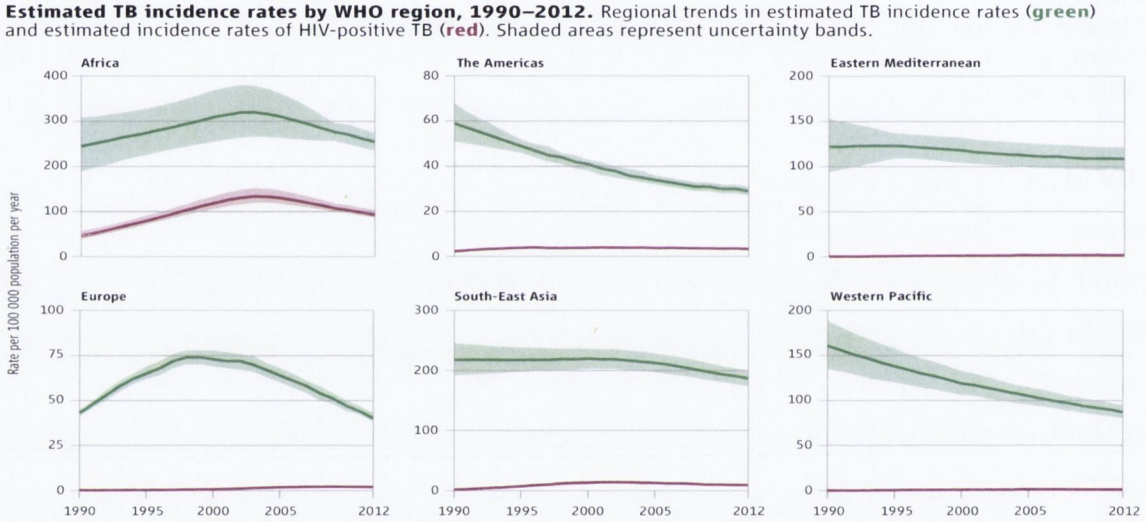


Figure 2-4. Estimated TB incidence rates by WHO region 1990-2012 (WHO, 2013b).

diagnosis and the right treatment were provided (WHO, 2013b). It ranks as the second leading cause of death from a single infectious agent after HIV. TB is often considered a disease of poverty: over 95% of TB deaths occur in low- and middle-income countries (WHO 2014c). Nevertheless, access to TB care has

[6] Source: WHO (2014d). The data on TB prevalence should be interpreted with caution. While there has been an increase in the number of measurements of TB prevalence from nationwide population-based surveys, the new data becoming available usually affects global TB estimates for the current year and retrospectively (WHO, 2014d).

[7] Excluding HIV positive TB mortality.

[8] HIV positive TB mortality.

increased substantially since the mid-1990s. According to WHO, 22 million lives has been saved between 1995 and 2012 since 56 million people were successfully treated for TB in countries that had adopted the WHO TB strategy (2013c).

TB most often affects the lungs, but there are also extra-pulmonary types of TB that may affect, for instance, the lymph nodes. Moreover, there exist TB organisms that are resistant to the antibiotics used in TB treatment. Drug resistance emerges as a result of inadequate treatment and once resistance has been acquired, TB organisms can spread from person to person in the same way as drug-sensitive TB. Multidrug-resistant forms of TB (MDR-TB)[9] do not respond to the standard six-month treatment with first-line anti-TB drugs and their treatment can take two or more years with drugs that are less effective, more toxic and more expensive.

Table 2-4. MDR-TB in 2012, summary.

MDR-TB, globally, in 2012	
Incidence	450,000
Prevalence	N/A
Mortality	170,000

As the Summary Table shows, in 2012, an estimated 450,000 people developed MDR-TB, and approximately 170,000 people died of it (WHO, 2013d). While prevalence figures as such are not available, drug resistance surveys and surveillance among notified TB cases suggest that approximately 3.6% of newly diagnosed TB cases and 20% of those previously treated for TB have MDR-TB (WHO, 2013b).

HIV and TB are highly interconnected and they interact synergistically: HIV advances latent tuberculosis infection to progress into an active disease, which is in turn associated with growing HIV viral load (Uyei et al., 2011). TB is

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[9] While this study uses multidrug-resistant TB (MDR-TB) as an overall term, specifically there exists:

a) MDR-TB, resistant to at least the two most effective anti-TB drugs, isoniazid and rifampicin.

b) Extensively drug-resistant TB (XDR-TB), resistant to isoniazid and rifampicin (i.e. MDR-TB), as well as any fluoroquinolone and any of the second-line anti-TB injectable drugs.

c) Rifampicin-resistant TB, resistant to rifampicin, with or without resistance to other drugs. (WHO, 2013d)

the most common presenting illness among people living with HIV, including those taking ART. At least one-third of the approximately 35 million people living with HIV worldwide are infected with latent TB. Indeed, PLWHA are approximately 30 times more likely to develop active TB than persons without HIV (WHO, 2013f). As indicated in the Summary Table, there were an estimated 1.1 million HIV positive new TB cases worldwide in 2012. Around 75% of these people live in the African Region. TB is also a leading killer among people living with HIV: at least one in five deaths among people living with HIV can be attributed to TB. In 2012, about 320,000 people died of HIV-associated TB. Moreover, PLWHA are facing the emerging threat of drug-resistant forms of TB (WHO, 2013f). Due to an increased attention towards collaborative activities, joint TB and HIV interventions have been implemented worldwide. WHO estimates that they saved more than 400,000 lives in 2011 alone (2013a). However, toxic effects and pharmacokinetic interactions of TB treatment and ART can severely complicate the treatment of HIV-positive patients with recently diagnosed TB (Mfinanga et al., 2014; Marks et al., 2009; McIlleron et al., 2007).

Table 2-5. TB-HIV globally in 2012, summary.

TB-HIV, globally, in 2012	
Incidence	1.1 million[10]
Prevalence	N/A
Mortality	320,000

To conclude, HIV and TB are undeniably major health issues causing human suffering every day and almost everywhere in the world, which makes this study important.

2.4 HIV, TB AND CO-INFECTION IN SOUTH AFRICA.

While HIV and TB are undoubtedly major health issues globally, it is justifiable to argue that South Africa suffers from one of the world's severest, if not the

[10] Particularly: HIV positive new TB cases in 2012.

severest, HIV epidemics in the world. According to the most recent (from 2012) South African national HIV survey by the Human Sciences Research Council, (Shisana et al., 2014) it was estimated that in 2012, more than 12% of the population (6.4 million people) were HIV positive, which is 1.2 million more people living with HIV than in 2008. In other words, almost every fifth HIV-positive person in the world is South African.

Table 2-6. HIV in SA in 2012, summary.

HIV in South Africa in 2012	
Incidence	469,000[11]
Prevalence	6.4 million (12.2%)[12]
Mortality	240,000

There is significant variation with respect to sex and age: Women aged 30-34 and men aged 35-39 had the highest infection rates: 36% of females and 28.8% of males in these respective age groups had contracted HIV[13], as Figure 2-5 shows. To put it another way, while the prevalence is lower in younger and older people, more than

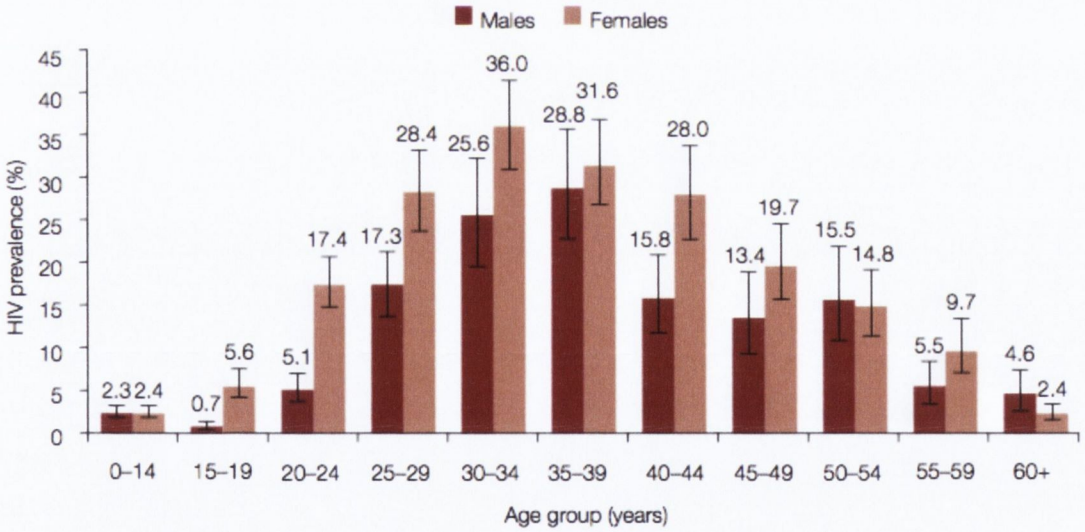


Figure 2-5: HIV prevalence by sex and age, South Africa (Shisana et al., 2014).

every third woman and almost every third man in certain age groups is HIV-positive.

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[11] In the population 2 years and older.

[12] This is the prevalence of in the whole population, not the adult prevalence, as in Table 2-2.

[13] Race is not considered in this figure.

Moreover, as Table 2-7 indicates, black Africans have the highest HIV prevalence compared to other race groups, followed by Coloureds.

Table 2-7: Overall HIV prevalence by sex, all age groups, race and locality, South Africa, 2012 (Shisana et al., 2014).

Variable	n	%	95% CI
Sex			
Male	12,896	9.9	8.9–11.0
Female	15,794	14.4	13.3–15.6
Age group (years)			
0–14	8,039	2.4	1.9–2.9
15–24	5,890	7.1	6.2–8.1
25–49	8,830	25.2	23.2–27.3
50+	5,986	7.6	6.5–8.8
15–49	14,720	18.8	17.5–20.3
Race			
Black African	18,629	15.0	14.0–15.9
White	1,733	0.3	0.1–0.8
Coloured	5,625	3.1	2.2–4.2
Indian or Asian	2,626	0.8	0.5–1.4
Locality type			
Urban formal	14,821	10.1	8.8–11.7
Urban informal	3,329	19.9	17.4–22.7
Rural informal	7,801	13.4	12.2–14.7
Rural formal	3,046	10.4	7.4–14.4
Total	**28,997**	**12.2**	**11.4–13.1**

As Table 2-7 suggests, locality type also matters. HIV prevalence is highest in informal urban areas[14] (19.9%), such as Khayelitsha. Indeed, in attempt to explain the possible reasons for differential racial HIV prevalence, the survey report points out that black Africans are less likely than other races to live in formal urban areas and informal urban areas tend to be under-resourced and lack some of the basic necessities, including access to preventive health services (Shisana et al., 2014). Finally, the survey shows that there is considerable

[14] Fast-paced urbanisation and insufficient capability to cope with the housing needs of people in urban areas have contributed to the development of informal settlements. The definition of informal settlements is context-specific (WHO, 2003). In South Africa informal urban area refers often to a township, as explained in Introduction. Section 2.6 provides more insight about Khayelitsha.

variation between the provinces, KwaZulu-Natal having the highest HIV prevalence (16.9%) and the Western Cape the lowest (5%). Nevertheless, based on her observations, the researcher is inclined to think that the township resident status is prone to effectively outweigh many of the benefits that otherwise come with residing in a better-off province. Moreover, amongst the metropolitan areas, the City of Cape Town (alongside the City of Johannesburg) recorded large increases of HIV prevalence ($\geqslant$ 75%) between 2008 and 2012 (Shisana et al., 2014).

The number of new HIV infections is also important. The survey reported just under 470,000 new HIV infections in South Africa in 2012, making the country rank first in HIV incidence in the world. With an HIV-incidence rate of 4.5%, black African females aged 20–34 years recorded the highest HIV incidence among the analysed population groups (Shisana et al., 2014). This is an extremely high figure. More than 2 million South Africans were on ART in 2012, making it by far the world's largest ART programme (Venter, 2013). In other words, among all the people living with HIV, approximately one third were exposed to ART. While all the people who would be eligible still cannot access the treatment, the exposure almost doubled between the 2008 and 2012 from 16.6% to 31.2% (Shisana et al., 2014). There were an estimated 240,000 deaths due to HIV/AIDS in 2012 (UNAIDS, 2014a), although the mortality has declined substantially from 2010, as illustrated in Figure 2-6. However, mortality remains high among HIV-positive adults who are not receiving ART (Republic of South Africa, 2013).

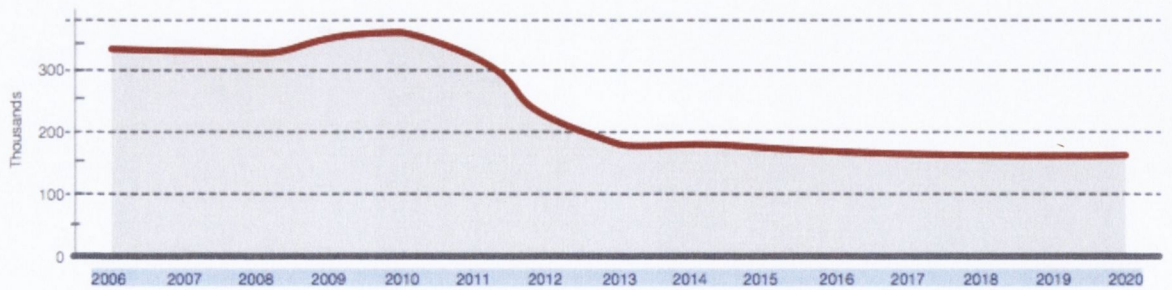


Figure 2-6. South Africa Annual AIDS Deaths, 2012. (Republic of South Africa, 2013).

The TB situation of South Africa is not very favourable either. South Africa is one of the countries with the highest burden of TB, with an estimated incidence of 530,000 in 2012 (WHO, 2013b) as summarised in Table 2-8. In other words,

Table 2-8. TB in SA in 2012, summary.

TB in South Africa in 2012	
Incidence	530,000
Prevalence	450,000
Mortality	31,000[15] / (88,000[16])

roughly 1% of the population develop active TB each year. With India and China, South African TB incidence is amongst the highest in the world (WHO, 2013b). Moreover, an estimated 80% of the population of South Africa is infected with latent [17] TB. The highest estimated prevalence of latent TB, (88%) occurs in the 30-39 age group residing in townships and informal settlements (South African Tuberculosis Association, 2013), i.e. in very similar settings to the case study area. As Table 2-8 indicates, 450,000 people had active TB in 2012.

South Africa's HIV and tuberculosis epidemics are inextricably linked; 330,000 of the country's 530,000 new TB cases in 2012 were also living with HIV (WHO, 2013b). South African Department of Health reports that 73% of TB patients are HIV positive (2012a). In other words, the burden of co-infection is extremely high. TB also remains the leading cause of death for people infected with HIV in South Africa (UNAIDS, 2013a). Finally, fuelled by the size of the TB and HIV epidemics, South Africa's MDR-TB situation is amongst the gravest world-wide. The

Table 2-9. TB-HIV in SA in 2012, summary.

TB-HIV in South Africa in 2012	
Incidence	330,000
Prevalence	73%[18]
Mortality	88,000[19]

[15] Excludes HIV positive TB mortality.

[16] HIV positive TB mortality.

[17] A person with latent TB infection does not have symptoms, feel sick or spread TB infection to others. However, he/she is infected with TB bacteria, and usually has a positive reaction to the tuberculin skin test or TB blood test. Without treatment, approximately 5-10% of infected persons will develop an active TB disease at some point in their lives. For people with HIV infection, the risk of developing TB disease is significantly higher than for those with normal immune systems (Centers for Disease Control and Prevention, 2011).

[18] Percentage of TB patients who are HIV positive. The estimates are different depending whether one is looking the proportion of PLWHA in TB patients or the proportion of PLWHA who have TB.

[19] HIV positive TB mortality.

country's TB challenge is exacerbated by the high caseload of MDR-TB and XDR-TB. An estimated 8100 MDR-TB cases were notified among pulmonary tuberculosis cases in South Africa in 2012. However, WHO argues that this estimation is too conservative and that there are deficiencies in the quality of this data (WHO, 2013b). Moreover, the WHO estimates that up to two thirds of the TB patients

Table 2-10. MDR-TB in SA in 2012, summary.

MDR-TB in South Africa in 2012	
Incidence	8100[20]
Prevalence	N/A
Mortality	55%[21]

who are estimated to have MDR-TB, remain undetected in high-burden countries. Four out of five patients were enrolled in the treatment in 2012 (WHO, 2013b). Finally, among MDR-TB patients started on treatment in 2011, only 45% had a successful outcome (WHO, 2014d).

In conclusion, the combined burden of TB and HIV in South Africa may be the worst in the world. Moreover, the pandemics hit the most dis-advantaged groups hardest (Loveday and Zweigenthal, 2011). Hence, it is appropriate and justifiable to conduct this kind of study in South Africa (versus other places). Moreover, any insights gained may be particularly helpful in South Africa.

2.5 HUMAN RESOURCE CRISIS IN HEALTHCARE

The health workforce is at the heart of every health system. There is ample evidence that the numbers and quality of health workers correlate with health outcomes in various fields from child survival to cardiovascular diseases (WHO, 2006). However, several studies reveal a flow of healthcare workers from low-

[20] The number of MDR-TB cases among notified pulmonary TB cases, including the new cases and cases in re-treatment.

[21] This figure can be considered illustrative of the situation. However, it is based on the notion that the treatment success rate rifampicin-resistant tuberculosis / MDR-TB cases started on second-line treatment in 2011 was 45% (WHO, 2014d) and therefore it does not take into account that some patients may have defaulted the treatment but are still alive. Definitions for treatment outcomes in global MDR data have caused some challenges and they were simplified in 2013 (WHO, 2013b).

and middle-income countries to high-income countries (Aluttis et al., 2014; Kasper and Bajunirwe, 2012; Stilwell et al., 2004) and the migration of doctors and nurses from Africa has raised concern of an African medical brain drain (Clemens and Pettersson, 2008; Kasper and Bajunirwe, 2012). Indeed, Africa bears 25% of the global disease burden but only 3% of the whole global health workforce (Kasper and Bajunirwe, 2012).

South Africa is amongst the countries (with Zimbabwe, Nigeria, Ghana and Zambia), which have already stressed health systems and which experience a net outflow of healthcare workers (Aluttis et al., 2014; Clemens and Pettersson, 2008). Indeed, the critical shortage of key health workers is a significant barrier in the delivery, implementation and sustainability of health services in South Africa (Dookie and Singh, 2012). In their analysis, George et al. (2013) show how the loss of trained health workers has been compromising the provision of health care in South Africa over the past 20 years. The situation is exacerbated by the fact that the South African health system includes a strong private sector, serving less than 20% of the population but employing 70% of medical doctors and 54% of professional nurses (George et al., 2013; Lehmann, 2008; Day and Gray, 2008; Chabikuli et al., 2005). A workforce model developed by South Africa's Department of Health in 2008 and scheduled for updating in 2012, suggests that in 2011 there were 83,043 fewer professionals than needed. This represents a shortage of 19,805 staff nurses, 22,352 professional nurses and 14,651 community health workers (PEPFAR, 2012a), rural areas remaining the most understaffed (George et al., 2012; Mills et al., 2008).

In light of the sharp rise in HIV and TB detailed in the previous section, it can be seen that the shortage of skilled health care workers is a major cause for South African health system being under severe pressure, as highlighted in Table 1-2. To conclude, when the human resources in health are already stretched to the extreme, it is vital that their skills and time is used in the best possible manner, which is one of the areas that this study focuses on.

2.6 KHAYELITSHA

The previous sections have set the scene for the research by describing some of the issues affecting people's lives and the functioning of the health system in South Africa. This section zooms into Khayelitsha, where much of the data obtained for the study was collected. Khayelitsha is the research setting in the sense that the case study clinic and the sub-district office are located there, as well as most of the users of the health services provided by the case study clinic. It is also the source of the studied TB and HIV related data flows, albeit that the flows are followed to the district and provincial level (and actors operating on those levels form also an important part of this study). Khayelitsha is a township. The term 'township' has a different meanings depending on the context, but as mentioned in Chapter 1, in South Africa, it refers to an urban residential area created for non-whites including black Africans, Coloureds and Indians (Statistics South Africa, 2004). Millions of black Africans still live in townships. Life in a township can be hard, and Khayelitsha is a very difficult place to live, work and provide health services. Vignette 2-1 provides more detail on the key aspects of the case study setting.

A CASE STUDY WITHIN A CASE STUDY

Khayelitsha

Khayelitsha is a high population density township located on the outskirts of Cape Town in the Western Cape Province. Estimates of the population range from approximately 400,000 to more than 500,000 inhabitants (Department of Social Services and Poverty Alleviation of the Western Cape, 2006; Strategic Development Information and Geographic Information System (hereinafter: SDI&GIS) Department of City of Cape Town, 2013, Cox et al., 2010). The population is predominantly black African - 99% in 2011 (SDI&GIS, 2013[22]). A little more than a third (36%) of adults aged 20 years or older have completed Grade 12 or higher. An estimated 62% of the labour force is employed, indicating a higher unemployment rate than the South African average (38% vs 33%). Approximately 3 out of 4 households have a monthly income of ZAR 3200 or less which roughly corresponds to EUR 230. Housing is both formal and informal: 55% of

[22] City of Cape Town 2011 Suburb Census, information compiled together by SDI&GIS, 2013.

households live in informal dwellings (SDI&GIS, 2013). Khayelitsha's crime statistics remain high, exceeding South Africa's national averages in murders, sexual crimes and assaults with intent to commit grievous bodily harm. Khayelitsha's three police stations reported 354 murders in 2012/2013 (O'Regan-Pikoli Commission of Inquiry into policing in Khayelitsha, 2014). A recent example includes the murder of a doctor who was shot when he left the Khayelitsha hospital to buy food after a work shift: an incident that has left health professionals fearing for their safety when working in the township (Oneale, 2014).

The majority of residents were not born in the township but have moved there, primarily from the Eastern Cape, to search for employment and a better life. While poverty makes people vulnerable, migrants are often in an even more vulnerable position, as they try to adapt to the urban settings of the Cape Town without the safety networks they had at home (Poswa and Levy, 2006). Therefore, many residents of Khayelitsha are particularly disadvantaged when facing additional challenges, such as TB or HIV.

Eight primary health clinics, three community health centres and a recently opened district hospital serve the healthcare needs of Khayelitsha residents (Green et al., 2014). Khayelitsha's HIV burden is one of the largest in the country, with an antenatal HIV prevalence of 34%. As a comparison, the antenatal HIV prevalence was 20% in the City, 18% in the Western Cape province and 30% nationally[23] in 2012. The TB incidence is a *"massive"* 1,165/100,000 population, compared to Cape Town 706 per 100,000 population (which is also considered an extremely high figure) and with the national figure of approximately 500 per 100,000 (City of Cape Town, 2013). In 2005 an estimated 76% of patients with TB were co-infected with HIV[24] (Friedland et al., 2007). The following factors have been identified as fuelling HIV/AIDS in Cape Town: suboptimal use of condoms and practising safer sex; high levels of other STIs; social norms which accept or encourage high numbers of sexual partners and sexual concordance as well as so-called "sugar daddies"; gender inequality; sexual violence and rape; poverty and

[23] Because other (reliable) data sources have been lacking, antenatal HIV surveillance has been used to estimate the HIV epidemic in many countries since the late 1980s (UNAIDS, 2005). In the absence of reliable data on general HIV prevalence in Khayelitsha, also this research cites *antenatal* HIV prevalence and compares it to local, regional and national *antenatal* prevalence (instead of the general prevalence figures which have been presented earlier.) The national antenatal prevalence is from 2011, since 2012 figures were not yet released, but the researcher considers it indicative. All the figures are rounded to nearest full digit by the researcher and they are all from the City of Cape Town's HIV and TB Plan 2013/2014 (City of Cap Town, 2013).

[24] More recent Khayelitsha specific figures were not available. One clinic in Khayelitsha (not the case study clinic) states that 70% of their TB patients have HIV (Médecins Sans Frontières, 2011).

unemployment; informal settlements with insufficient services; commercial sex work including child prostitution; stigma and discrimination relating to HIV; migrant labour; and substance abuse. TB is also associated with several fuelling factors: poverty; urbanisation with consequential overcrowding; damp, poorly ventilated houses and shacks; high HIV burden; clients presenting or being identified late in the course of the disease who therefore infect many others before treatment; treatment defaulters; substance abuse and smoking (City of Cape Town, 2013). All these factors are very much present in Khayelitsha.

Some of the matters described in this Vignette have been illustrative of the negative issues relating to Khayelitsha and health. One positive aspect that is worth mentioning is that there *are* health services available and many new interventions have begun there or became available there at a relatively early stage. For instance, the first routine PMTCT programme in South Africa was initiated at the two health centres in Khayelitsha that provide maternity services in 1999 (Abdullah et al., 2001; Coetzee et al., 2004). Three HIV/AIDS clinics began to offer free ART in Khayelitsha in 2001 (Coetzee et al., 2004), whereas the government's public ART programme did not become available until three years later (Venter, 2013). It is also one of the first places where integration of TB and HIV services began as a pilot project in one local clinic in 2003 (Friedland et al., 2007). Finally, Khayelitsha is one of the places where the nurse initiated and managed ART (NIM-ART) began around 2011 (Green et al., 2014).

Vignette 2-1: Khayelitsha.

To conclude, Khayelitsha is in many respects similar to other townships in South Africa, and it probably shares a lot of characteristics with other informal urban areas around the globe. What may be common to these kind of places around the world is population density and presence of ill-health, poverty and unemployment and safety-issues, as well as vulnerability of people to sink deeper into difficulties if any disaster, personal or other, strikes. What may be different to other townships in South African and elsewhere is the magnitude of certain challenges. South Africa is one of the countries most severely affected by HIV and TB, and since Khayelitsha is even more severely affected by the epidemics, it can be viewed as a true global hotspot for TB, HIV and co-infection. Moreover, the degree of violent crime that the people continue to experience and witness in Khayelitsha is high in comparison to many under-privileged, yet safer, areas. The issue of safety is elaborated in Vignette 4-1, as it was a concern regarding the research process, and revisited in 7.5.6 since it also featured in the

research data in connection with the health information system functioning, which may be surprising.

2.7 HEALTH PRIORITIES, VERTICAL SYSTEMS AND INTEGRATION GLOBALLY

Table 2-1 emphasised the importance of identified health *priorities* in order to address various health system related challenges in South Africa. This section will be an essential building block in an attempt to explain how global priority setting has a connection to the TB and HIV information system in South Africa. On the global level, there has always been tension between acute and deadly pandemics versus social conditions and chronic diseases that kill many more people, albeit in less dramatic ways. Yet, the global efforts to control infectious disease have dominated and shaped global health policies, agendas and budgets, often at the expense of the chronic maladies (Markel, 2014). This applies also to South Africa to a certain extent: while TB is the most common natural cause of death, and HIV is third, diabetes and cerebrovascular diseases each kill almost as many people as HIV, and non-natural causes, such as accidents and violence kill more people than TB (Statistics South Africa, 2014).

Since 1990, major changes have been seen in global health architecture. Lidén (2014) has analysed three key indicators (funding, global health initiatives and health outcomes) in connection with global health priority setting indicating roughly similar trends. As explained below, these trends illustrate stagnation/slow growth 1990 to 1997; a fast change/expansion in 1998 to 2009 and uncertainty from 2010 onwards.

- **Funding for health**. Official development assistance and non-governmental funding for health increased by 49% from 1990 to 1997, from 5.74 billion to 8.54 billion US dollars and then rocketed from 1998 to 2010 to 28.2 billion with the growth rate of 230% (Lidén, 2014). As noted by Atun et al. (2012), funding has grown particularly for HIV, TB and malaria. After 2010 total health related assistance has remained steady with certain shifts in sources of

financing, despite the economic crisis (Institute for Health Metrics and Evaluation, 2014).

- **Global health initiatives**. Correspondingly, there were only a handful of new global health initiatives between 1990 and 1997. However, the period from 1998 to 2008, which has been called the *"grand decade for global health"*, as well as the following two years until 2010 witnessed the birth of several dozen partnerships, initiatives, foundations and institutions dedicated to financing, coordinating or implementing global health programmes, or to achieve global health goals. Amongst these were the U.S. President's Emergency Plan for AIDS Relief (PEPFAR) and the Global Fund to Fight AIDS, Tuberculosis and Malaria, as well as the United Nations Millennium Development Goals (MDGs). Post 2010, however, has been marked with uncertainty in terms of many global health initiatives (Lidén, 2014).

- **Health outcomes.** The rapid spread and acceleration of the HIV pandemic from 8.9 million PLWHA in 1990 to 23.1 million in 1997 marked the 1990s. TB incidence increased only slowly but TB-HIV co-infection aroused concern, as did some other global health priorities, such as malaria and stagnant immunisation coverage figures. Positive results in various key areas began to emerge especially from 2004 onwards as a result of global efforts (Lidén, 2014).

What does this have to do with priorities? Lidén argues that funding and health outcomes have become a central driver of global health priorities (2014). Since partnerships and health initiatives cannot cover everything, they tend to focus on certain specific battles for various particular reasons, often far beyond epidemiological reasons. A whole debate exists on why some health topics receive the attention and funding and some do not, but this debate is beyond the scope of this study. Moreover, while there are institutions that are in a position to promote primary healthcare and health for all, such as WHO, Lidén's analysis shows how the increased funding has largely been channelled outside of it. Indeed, during the *"grand decade for global health"* all sources of funding for any health intervention, except the Global Fund, were dwarfed by the PEPFAR. Moreover, the Bill and Melinda Gates Foundation became the single largest non-

governmental funder of health research, as well as a major funder of Global Alliance for Vaccines and Immunisation (GAVI), the Global Fund and a number of health advocacy initiatives and partnerships. Due to its money and increasing expertise in health it became a powerful authority in shaping policies and setting global health priorities (Lidén, 2014).

Globally, much of the funding that became available was connected to a vertical healthcare delivery. In other words, health care service delivery was organised to address specific health problems, in line with the approach that became popular in the 1950s and 1960s (Uyei et al., 2014). In first contact care in low- and middle-income countries, *"this approach plays out in its most extreme form as series of 'vertical' programmes with resources, staff and activities contained within each silo, such as in family planning, malaria control, tuberculosis control, HIV prevention and treatment, and delivery of vaccines to prevent common childhood illnesses"* as explained in a Cochrane Review on healthcare integration strategies (Dudley and Garner, 2011).

This approach has advantages and disadvantages. Particularly in countries where the public healthcare system is comparatively weak (Atun et al., 2008), it is believed that vertical programmes allow specialisation, larger resources, central technical supervision and direct monitoring and evaluation to safeguard performance. Hence, the vertical approach ensures the delivery of care in priority areas (Dudley and Garner, 2011; Briggs and Garner, 2006). Moreover, large global health initiatives connected to vertical care delivery are argued to have contributed in the rapidity of scale-ups (Biesma et al., 2009; Atun et al., 2008), increased coverage of targeted interventions (Kawonga et al., 2013), improved linkage from inputs to performance, enhanced channelling of funds to non-governmental stakeholders (Biesma et al., 2009) and better opportunities to wider stakeholder participation (Biesma et al., 2009; Spicer et al., 2010). Finally, large vertical programmes and the challenges that may emerge when delivering programmes in disease-specific silos can sometimes provide a rare opening to harness funding for general health system strengthening (Pfeiffer et al., 2010; Maeseneer et al., 2008; Kim et al., 2006).

On the other hand, the vertical approach can prove to be extremely inefficient, with service duplication and fragmentation (Dudley and Garner, 2011; Briggs and Garner, 2006; Kawonga et al., 2013; Biesma et al., 2009; Atun et al., 2008; McKinsey 2005; Chilundo and Aanestad, 2003) which in turn leads to a waste of resources (Hutton, 2002; Chilundo and Aanestad, 2003). Duplication may occur in areas such as training, supervision, drug supplies and reporting systems (Kawonga et al., 2013; Dudley and Garner, 2011). At the patient level there may be confusion: patients may be confronted with a range of different publicly funded activities occurring at different times and in various ways (Dudley and Garner, 2011). For instance, it is still common in Africa to see a new, well-staffed HIV clinic side by side with crumbling primary care facility, with very limited integration and few linkages between them (Pfeiffer et al., 2010).

Furthermore, disease specific programmes may employ people with better conditions of service than in government services, causing within-country brain drain, as has happened in many countries, for instance in Mozambique (Dudley and Garner, 2011; Mussa et al., 2013). The work itself in a disease-specific system may be characterised by dreariness, since the staff members encounter only certain kinds of patients (Mutemwa et al., 2013). With regard to training, the healthcare workforce may prefer the training seminars organised to improve the performance of the specific vertical programme as these may involve per diems and financial support for travel and lodging, over other training opportunities (Chilundo and Aanestad, 2003).

Finally, vertical programmes do not always facilitate transparency, or comprehensive and long-term planning (Hutton, 2002; Chilundo and Aanestad, 2003). The donors' performance requirements may limit the scope for national decision making and planning (Chilundo and Aanestad, 2003), and result in the prioritisation of these programmes by the governments (Dudley and Garner, 2011). Furthermore, the outside pressure by funders may instigate shifts in management and resources in a way that favours vertical programmes at the expense of routine services (Dudley and Garner, 2011), other urgent health priorities (Pfeiffer et al., 2010) or coordinated efforts to strengthen health systems and re-verticalisation of planning, management and monitoring and evaluation systems (Biesma et al., 2009).

As a response to the critique towards fragmentation resulting from over verticalised health systems in middle- to low-income countries, integration has been proposed (Oliveira-Cruz et al. 2003; Atun et al. 2008; World Health Organization 2008a; Dudley and Garner 2011 in Uyei et al., 2014). As a conceptual backbone for her study, the researcher wishes to use Uyei et al.'s framework for integration (2014) albeit earlier work has also informed the researcher's thoughts, such as a review on strategies for integrating primary health services in middle- and low-income countries (Briggs and Garner, 2006).

The researcher considers Uyei et al.'s framework helpful as it is recent, it has been used in measuring the degree of integrated tuberculosis and HIV service delivery in Cape Town (Uyei et al., 2014) and it is based on earlier evidence on TB and HIV service integration (Uyei et al., 2011), as well as other relevant literature (Gillies et al., 1993; Shortell et al., 1994; VanDeusen Lukas and Desai, 1999; VanDeusen Lukas et al., 2002). Echoing others (for instance Loveday and Zweigenthal, 2011; Uwimana et al., 2012) in that integration is a multidimensional concept with no singular definition, Uyei et al. (2014) have created a definition on the basis of approximately ten previous sources[25].

> integrated service delivery = *"joining inputs, management, organization and distribution of health services related to diagnostics, treatment, care, rehabilitation and health promotion as a means of improving health status, access, quality and continuity of care, consumer satisfaction and efficiency."*
>
> (Uyei et al., 2014)

Hence, it means more than just the integration of vertical programmes with the general health system, or the interaction of two or more such programmes with each other (such as HIV and reproductive health) (Briggs et al., 2002).

According to the framework, there are three domains where integration can happen: functional, organisational and clinical integration.

1. Functional integration = the extent to which central financial and administrative operations and activities can be combined at the

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[25] For the source definitions, see Uyei et al., 2014.

managerial and policy level

- Includes strategic planning, budgeting and operational guidelines.
- Is considered to support organisational and clinical integration but not automatically required for organisational and clinical integration to take place.

2. Organisational integration = the extent to which non-clinical programme components are incorporated at the point of care

- Includes co-location of services, combined patient records, information management and joint training.

3. Clinical integration = the extent to which clinical programme components are concurrently or synchronically delivered to the patient.

- Includes diagnostic, treatment, care, rehabilitation and health promotion

Uyei et al., 2014.

As illustrated by the Figure 2-7, integrated service delivery is inclined to influence both output and impact.

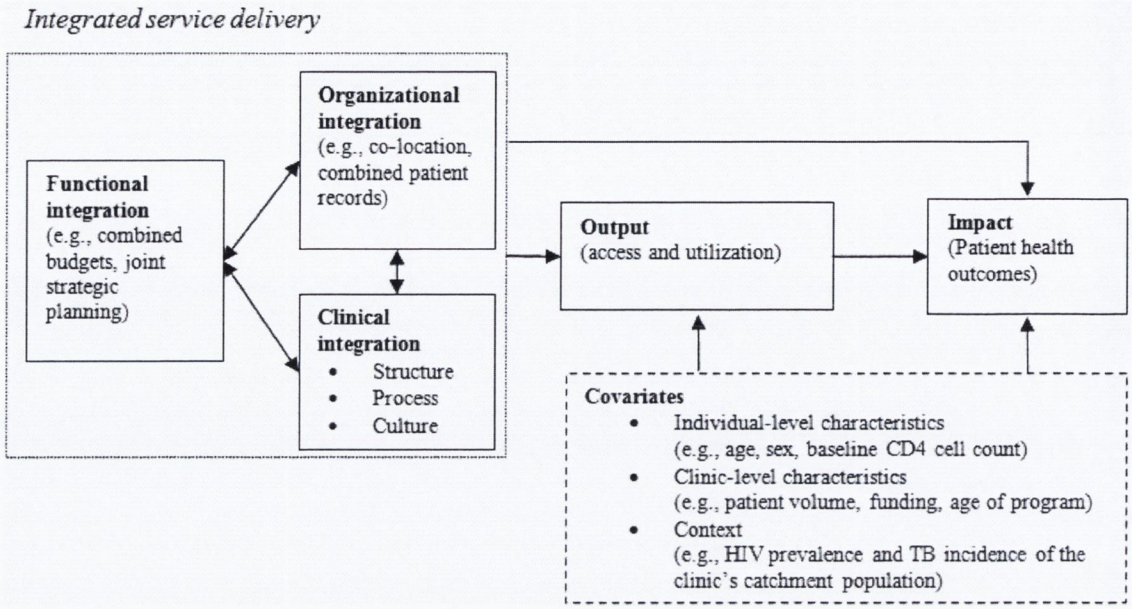


Figure 2-7. Integrated service delivery by Uyei et al., 2014.

The framework suggests that barriers to integration can be found in various areas of the health system. These should be identified and addressed in order to achieve better outcomes in TB and HIV morbidity and mortality.

Mutemwa et al. (2013) have studied what they call operational integration, and what it means at a practical level in Kenya. They differentiate between:

- provider-level integrated facilities, where patients are provided more than one service in the same room
- unit-level integrated facilities, where clients receive integrated services within specialist units under different rooves but within the same facility and
- a blend of the two above, which means more one service per patient but in different rooms.

The researcher considers the findings of Uyei et al. (2014) and Mutemwa et al. (2013) helpful in analysing her findings in Chapters 6-8.

Integration of services is believed to ensure more efficient management of services, more equal access to them, more satisfying service for the patients,

and ultimately, better health outcomes (Uyei et al., 2011; Briggs and Garner, 2006). Whilst there is very limited evidence from controlled studies of the actual impact of integration (Scott and Sanders, 2013; Briggs and Garner, 2006), the evidence base suggesting that there are benefits of delivering integrated services, is increasing (Hoke et al., 2014). A systematic review of integrated TB-HIV services found that integration increases the coverage of essential services (Legido-Quigley et al., 2013). Intensified TB case-finding and treatment in Prevention of Mother-to-Child Transmission of HIV (PMTCT) has been shown to prevent mortality (Nachega et al., 2003) and HIV testing of TB patients has improved co-infected patients' access to antiretrovirals, (Lawn et al., 2011b). It has been argued that the integration of ART into primary health care increases the uptake of HIV counselling and testing (HCT), places more patients on ART more quickly and reduces loss-to-follow-up (Pfeiffer et al., 2010). On the basis of their findings in South Africa, Scott and Sanders (2013) state that co-location of TB and HIV services has the potential to improve access across the HIV-TB-STI[26] cluster of services. Elsewhere in Africa, positive results have been found in the context of connecting HCT and family planning (Stephenson, 2011) and reproductive health and ART (Andia et al., 2009). With regard to the close connection of TB and HIV, joint care may also improve management of clinical complications deriving from drug interactions, toxic effects and immune reconstitution inflammatory syndrome (Uyei et al., 2011). However, others believe that if health services are integrated, health care professionals may become overburdened or they may not have the specialised skills required to diagnose and manage specific diseases. This can lead to poor quality services and poor health outcomes (Briggs and Garner, 2006; Friedland et al., 2007). With reference to South Africa, Friedland and colleagues also propose that separate TB and HIV cultures and traditions may be a potential barrier to successful integrated TB-HIV care.

To conclude, at the time of the researcher's data collection in South Africa (2012), there had been roughly a decade where large sums of money had become available for health globally. Several international goals and targets had

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[26] Sexually Transmitted Infections (STI)

been set, of which many had to do with key diseases, including TB and HIV. Thus, a majority of the funds could only be used in the areas that had been selected as priorities. Moreover, there had emerged a number of powerful actors who gave and used that funding for the selected key purposes. Furthermore, the course of HIV and TB epidemics gave a reason to target these diseases albeit that there is always a multitude of political, economic and other reasons that contribute to the global health agenda setting. Finally, a lot of healthcare was delivered in a vertical manner to tackle the prioritised health challenges. However, there has been growing criticism of this approach.

2.8 HEALTH PRIORITIES, VERTICAL SYSTEMS AND INTEGRATION IN SOUTH AFRICA

The previous section has largely looked back in time and cited the vertical healthcare model as part of the past. However, even currently, the organisation and delivery of TB and HIV services in sub-Saharan Africa at national and local levels "*largely remain disconnected with each programme continuing to operate as vertical disease-specific programmes*" (Uyei et al., 2014). This applies also to South Africa.

In essence, South Africa's case can be considered particularly consistent with the kind of development characterised in the previous section in terms of health challenges, health priority setting, funding and care delivery. First, with regard to TB and HIV epidemics combined with the high co-infection rate, the situation is extremely challenging, as detailed in section 2.4. Second, while health needs are unlimited, resources are always limited, hence priorities need to be set. As indicated in Table 2-1, at the time of the data collection and currently, South Africa is focusing on four colliding epidemics, and of those, notably on HIV and TB. Third, the extent of the HIV epidemic in particular has contributed to South Africa becoming a focus of donors and the international public health community (Venter, 2013, Mayosi et al., 2012). The country-wide roll-out of probably the world's most ambitious ART programme (at substantial expense) has attracted even further attention (Venter, 2013; Hecht et al., 2010). Hence, also funding has been available, though South Africa has more of its own

resources to tackle TB and HIV compared to many other high-burden countries. As shown in Table 2-11, the PEPFAR bilateral funding for HIV in South Africa was approximately 3.2 billion US dollars between 2004 and 2011 (PEPFAR, 2014). The Global Fund disbursed almost USD 500 million for HIV/AIDS between 2003 and 2014 (Global Fund, 2014).

Table 2-11. HIV/AIDS funding for South Africa by PEPFAR and the Global Fund.

Global Health Actor	Time period	TB and HIV/AIDS (including TB-HIV) funding for South Africa, USD in millions
PEPFAR	2004-2011	3234
Global Fund	2003-2014	491
	Total:	3725

Recently, South Africa's government has stepped up domestic financing and funds approximately three quarters of the national HIV/AIDS response with PEPFAR providing about 20% and other donors providing between 5 - 10% of annual funding. For instance, the HIV funding from the National Treasury allocated to each provincial government (termed the Conditional Grant for HIV and AIDS) was around ZAR 11 billion (USD 1.25 billion) in 2012, (PEPFAR, 2012b). Since most HIV funding is allocated through the Conditional Grant, which is different to regular funding in that it is given through the provincial health budget, there exists a vertical disease-specific funding structure (Kawonga et al., 2013) with its own accountability arrangements within the national system even when excluding foreign donor funds.

In contrast to HIV historically attracting funding from multiple external donors, the TB programme has mainly been government funded and at a lower level. Traditionally the financing of these programmes has been very uneven, and has not allowed collaborative activities as the HIV funds have been 'ring-fenced' - i.e. protected and earmarked for HIV/AIDS (Loveday and Zweigenthal, 2011; Uwimana et al., 2012). Currently, the balance may still be uneven, as Figure 2-8 indicates. An analysis of the Global Fund grants suggests that there is greater direction towards integration but it is difficult to see if the earmarked

funds would really allow collaborative activities in areas such as PMTCT, chronic diseases or nutrition.

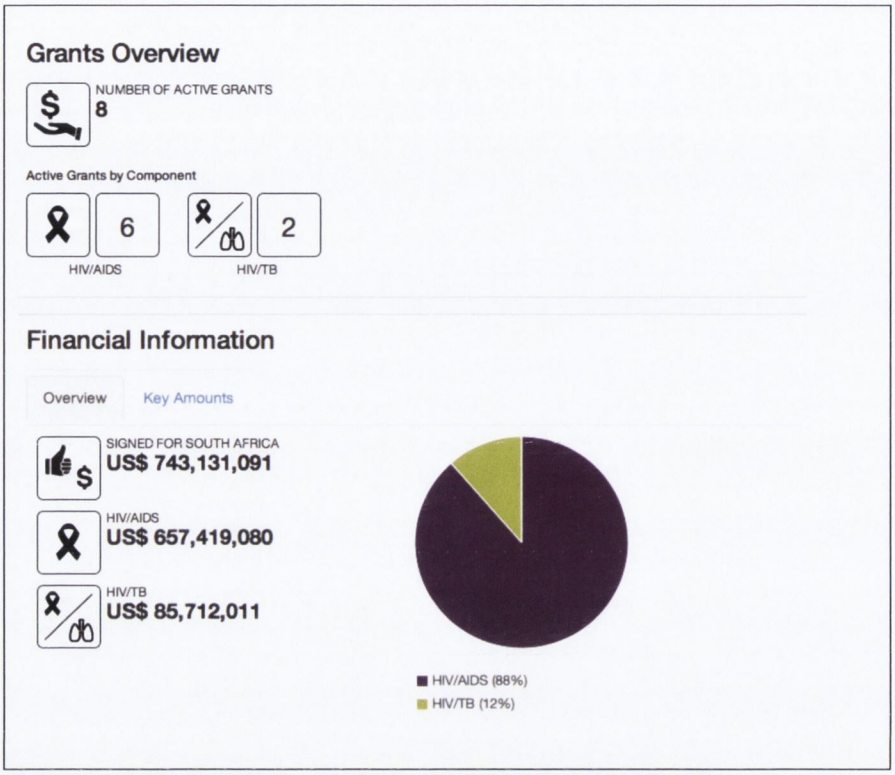


Figure 2-8. Grant Overview. (Global Fund, 2014)

The funding has allowed various national health policy initiatives to address the HIV and TB epidemics in South Africa. Amongst these is the adoption of the 2012-2016 National Strategic Plan for HIV, STIs and TB. The goals of the plan are:

- *Reduce new HIV infections by at least 50%, using combination prevention approaches*

- *Initiate at least 80% of eligible patients on antiretroviral treatment (ART), with 70% alive and on treatment five years after initiation*

- *Reduce the number of new TB infections, as well as the number of TB deaths by 50%*

- *Ensure an enabling and accessible legal framework that protects and promotes human rights in order to support implementation of the plan*

- *Reduce self-reported stigma related to HIV and TB by at least 50%*

(South African National AIDS Council, SANAC, 2011)

In order to achieve these and other national targets several health policy actions have been taken. Amongst these are:

- **The National HIV Counselling and Testing Campaign**. During the campaign more than 20 million South Africans were tested for HIV over the course of 20 months, plus a further 9 million between April 2012 and March 2013.
- **The raising of the treatment threshold**. The starting of HIV treatment (ART) is determined by immunological criteria, measured by the CD4 count. The treatment threshold was raised from 200 to 350 cells/ul for all in 2012. Moreover, pregnant women and anyone with TB are given ART irrespective of CD4 count.
- **Rapid scale up of ART.** Fast scale up of ART services resulted in a four-fold increase in the number of patients receiving ART between 2009 and 2012.
- **Acceleration of Prevention of Mother-to-Child Transmission (PMTCT) services.** Despite the substantial disease burden, South Africa did not implement a PMTCT programme until 2002. In that year an estimated quarter of pregnant women were HIV-positive. In 2008, the national PMTCT accelerated plan (A-plan) was launched to reduce mother-to-child transmission of HIV from 12% to less than 5% by 2011. One of the achievements of the A-plan is that pregnant women are now routinely tested for HIV, whereas in 2005 less than half of the mothers were tested.
- **The rollout of Gene-Xpert**. Traditionally, TB has been diagnosed with sputum smear microscopy. However, it may not detect the illness of smear-negative TB patients and it cannot test for drug resistance. The rollout of Gene-Xpert improved testing for susceptibility to first and second-line anti-TB drugs and shortened test result turn-around times.

- **Integration efforts.** The aforementioned 2012-2016 National Strategic Plan for HIV, STIs and TB and other policy documents outline integration of services as a national goal. Several steps have been taken in that direction, as detailed next.

(Department of Health, 2014b; Venter, 2013; Barron et al., 2013; Evans, 2011).

So far, it has been stated that South Africa's case can be considered particularly consistent with global development in terms of health challenges, health priority setting and funding. In addition, much of care delivery around HIV and TB has been organised vertically in South Africa for a long time (Uwimana et al., 2012; Kawonga et al., 2012; Auld et al., 2013; Friedland et al., 2007), similarly to many other low- and middle-income countries. However, recently there has been significant direction towards greater integration. A Joint Review of the HIV, TB and PMTCT Programmes (hereinafter: Joint Review), commissioned by the National Department of Health (DoH, 2014b), was conducted in 2013. According to the review, the Department of Health has made integration of services *"an overarching policy both in the context of transformation of the health system and primary health care re-engineering"*. In 2009, TB was integrated into the mandate of SANAC alongside HIV as the National Strategic Plan was developed. To foster cooperation, HIV/AIDS, sexually transmitted infections (STI) and TB (HAST) unit was established at provincial and district level (Uwimana et al., 2012). The recruitment of TB-HIV coordinators and the development of integrated clinical guidelines also suggest integration (Scott et al., 2010). Moreover, the Joint Review reports *"successful, functional integration of HIV, TB and PMTCT services, particularly at primary care level"* (Joint Review, 2014). This is consistent with the issue also being emphasised in Table 2-1.

While HIV, TB and PMTCT are located in the same branch of the National Department of Health, this is not the case at the lower levels. Some provinces have a single HAST unit, whereas others separate their TB and HIV units and most provinces have the PMTCT programme within Maternal and Child Health (MCH). However, all provinces prioritise HIV, TB and MCH services, implement national policies and align activities according to the national plans. In addition,

HAST business plans linked to the Conditional Grant are prioritised by provinces (Joint Review, 2014). At the district level, according to the Joint Review, HAST and MCH coordinators manage and supervise programme activities. Finally, the Department of Health argues that functional delivery of integrated TB, HIV and PMTCT services take place in most primary healthcare facilities at the facility level (ibid.). Table 2-12 illustrates the fact that there are various components of health service, which can be integrated. However, it also shows that the extent to which the policies are implemented in practice varies throughout different settings.

Table 2-12. Integrated health service components.

Integrated service component	**How it is applied**	**Source of data**
HIV counselling and testing (HCT) for all patients	HCT *should* be offered by health providers on any patient's visit to any health facility for any ailment.	Department of Health, 2010.
	However, the researcher argues that the DoH guideline was **not fully implemented** in practice at the time of the study, since A) only 8% patients were offered HIV tests in 2011 B) in general, 95% of primary healthcare facilities are able to offer HCT and C) HCT is not offered to all high risk patients, such as those with TB.	A) Pillay et al., 2012 B) Health Systems Trust, 2012 C) See next row
HCT for TB clients	HCT is offered to *"most"* TB clients	Joint Review, 2014
	HCT is offered to 87%-92% TB clients.	Scott and Sanders, 2013
HCT for pregnant women	HCT is offered to *"most"* antenatal care clients.	Joint Review, 2014
Symptomatic TB screening for HCT clients and PLWHA (HCT, pre-ART, ART)	This policy is *"generally well implemented"* / TB screening is offered to *"most"* HCT clients and PLWHA, including pregnant women.	Joint Review, 2014
	Approximately 90% of HCT patients screened for TB, but the rates are much lower in HIV positive patients not yet receiving ART and those on ART, varying	Scott and Sanders, 2013

	from 52% to 62%.	
	76% of patients with newly diagnosed with HIV infection were screened for TB.	Chehab et al., 2013.
ART (Antiretroviral Treatment) initiation in TB patients	ART is being initiated *"in most facilities"* immediately after the first two weeks of TB treatment.	Joint Review, 2014.
	Less than a quarter of eligible newly registered TB patients newly diagnosed with HIV were initiated on ART.	Chehab et al., 2013.
Sexually Transmitted Infection (STI) screening	Up to 90% of HCT patients are screened for STIs in rural settings.	Scott and Sanders, 2013.
	STI screening is not done in general (except for ART clients).	Joint Review, 2014.
Clinical staging (Patients gain access to ART through an eligibility evaluation based on their CD4 count / clinical stage)	In urban settings only 50% of HCT clients are adequately assessed; usually they have CD4 count performed but lack staging.	Scott and Sanders, 2013.
Isoniazid preventive therapy (IPT) for PLWHA. (IPT for HIV positive people reduces the likelihood of TB)	Pregnant women were systematically screened for TB and provided IPT.	Joint Review, 2014.
	IPT was offered by 71% of sites surveyed and was the least available TB service.	Chehab et al., 2013.
	73% of ART patients who were eligible for IPT did not receive it.	Kufa et al., 2014.
Additional information: The list of healthcare components that can be integrated (left column) is not exhaustive. There is no current and comprehensive data on the extent to which integrated service is delivered in South Africa. About the sources: The Joint Review: A total of 21 districts and about 100 health facilities were visited throughout the country. Scott and Sanders (2013): 26 rural and 146 urban primary healthcare facilities were evaluated. Kufa et al. (2014): 597 participants were interviewed at two primary healthcare facilities. Chehab et al. (2013): TB and HIV focal persons were surveyed from 49 public medical facilities in the high HIV prevalence districts throughout South Africa, and data was verified with the help of facility registers.		

It is not the purpose, or within the scope of this study to conduct a comprehensive analysis of the degree of clinical integration in South Africa. The researcher concludes that as indicated in Table 2-12, some components of integrated care delivery, such as HIV testing of people in high-risk groups, seem to work well, whereas other components, such as providing IPT for PLWHA may be seen as an under-utilised opportunity.

This variation is reflected in the academic literature on the topic. Uwimana et al. (2012) argue that the South African health system is *"comprehensive"* (Lush et al. 1999), with integrated TB and HIV programmes involving Prevention of Mother-to-Child Transmission of HIV (PMTCT). However, they also point out that these programmes are not yet *"fully integrated"* into the health system as defined in conceptual frameworks for analysis of integration of health interventions into health systems (Cairncross 1997; Atun et al. 2010a) or the WHO framework on health systems (WHO, 2000). Besides the sources listed in Table 2-12, several studies have examined to what extent HIV, TB and PMTCT programmes are integrated with each other or with the primary healthcare structure or how the integrated programmes are implemented in South Africa (Uwimana et al., 2012; Loveday and Zweigenthal, 2011; Uebel et al., 2013a; Uebel et al., 2013b; Horwood et al., 2010) Metropolitan District of Cape Town (Scott et al., 2010) or in Khayelitsha (Kerschberger et al., 2012; Brown et al., 2011; Friedland et al., 2007). They further support the fact that the degree of integration and extent of integrated service provision received by HCT, HIV positive (and in-care but not yet receiving ART), ART and TB patients varies substantially across settings. One of the most integrated models is described by Kerschberger and colleagues (Kerschberger et al., 2012; Brown et al., 2011). They depict a *"one stop shop"* model in Khayelitsha where the provision of TB and HIV services takes place in the same structure, by the same staff, at the same time, and with integrated patient files. According to them, the full clinical implementation of the model has been rolling out in City Health Khayelitsha clinics since 2008, but as this study will show, the full implementation of the model has not been reached by the time of the researcher's data collection in 2012. Moreover, another study shows that with co-infected patients whose TB is diagnosed in hospital, 80% of patients were referred to two separate clinics, one

for TB and one for HIV care (Voss De Lima, et al., 2013) indicating poor integration.

Finally, while operational research suggests that integration is desirable (Scott and Sanders, 2013; Kerschberger et al., 2012), in South Africa there remain challenges in terms of the physical infrastructure (Uebel et al., 2013a); medical issues (Friedland et al., 2007; Loveday and Zweigenthal, 2011); structure, organisational culture, attitudes, management, planning and power issues (Loveday and Zweigenthal, 2011; Uwimana et al., 2012; Uebel et al., 2013a); unequal financing (Uwimana et al., 2012; Loveday and Zweigenthal, 2011); human resources (Friedland et al., 2007; Uwimana et al., 2012; Loveday and Zweigenthal, 2011; Uebel et al., 2013a); scale-up (Friedland et al., 2007); regulatory problems (Loveday and Zweigenthal, 2011; Uwimana et al., 2012) as well as conflicting principles underlying different programmes (Loveday and Zweigenthal, 2011). These issues may complicate integration efforts.

To summarise, South Africa's development is consistent with (if not a prime example of) the kind of development that has taken place in global health policy. In particular, HIV has attracted a lot of funding, but the funding has not been very flexible or even. Several health policy actions have been taken to curb the dual epidemics. Whilst the programmes have operated in disease specific silos for a long time, integration efforts have been made more recently with varying degrees of success. The results of this study will shed further light on the extent of the process and on what it means at a practical level and with respect to data and reporting. Finally, global and South African health policy changes and the organisation of health services around priority diseases influence TB and HIV related data collection, use and reporting practices. This is one of the topics of the next chapter.

2.9 SUMMARY OF CHAPTER 2

This chapter has provided a general context and a historical background to the research topic. TB and HIV remain global health threats, and South Africa has one of the world's worst TB, HIV and co-infection epidemics. Historical injustices

together with current health system challenges make addressing the disease burden very difficult. Under-privileged settings, such as the township of Khayelitsha (i.e. the case study setting), are particularly affected. Like many low- and middle-income countries, South Africa has established dedicated disease specific health programmes to respond to TB and HIV/AIDS. However, this approach has been criticised, and the local and global focus has shifted towards integration of services.

Chapter 3 Literature Review

3.1 OVERVIEW

The main aim of this chapter is to review what is written on some of the key issues relating to the research topic and thereby continue addressing the research objective A: *"To research relevant academic and grey literature that supports identifying and analysing key challenges and good practice in health information systems in under-privileged settings."* There are many ways to conduct a literature review, and it is important to choose a method that is appropriate for this particular study. For example, systematic literature reviews with explicit inclusion and exclusion criteria and using a comprehensive approach, *"for identifying, evaluating, and synthesizing the existing body of completed and recorded work produced by researchers, scholars, and practitioners"* (Fink, 2005) have been widely used in health sciences and have been proposed as a suitable approach for IS research (Okoli and Schabram, 2010). However, scoping reviews are an increasingly accepted methodology for reviewing health research evidence (Levac et al., 2010) and they have been successfully applied in a variety of fields relevant to this study, such as assessing the impacts of e-health programmes in low- and middle-income countries (Piette et al., 2012). Scoping reviews generally refer to *"mapping, a process of summarizing a range of evidence in order to convey the breadth and depth of a field"* (Levac et al., 2010) which seems particularly fitting for this study. Additionally, there are further characteristics of scoping reviews that support choosing this approach: the scoping process benefits from analytical reinterpretation of the literature, while it does not usually require assessing the quality of included studies and it may be especially relevant in clarifying complex concepts and in disciplines with emerging evidence. Furthermore, scoping reviews allow the incorporation of a variety of evidence and study designs in published and grey literature, and they help to address a wide range of questions beyond the 'traditional' ones (such as those strictly related to intervention effectiveness etc. (Levac et al., 2010)) - indeed, this technique may not be suitable for addressing a very narrow and specific research question (Arksey and O'Malley, 2005). Scoping reviews may also produce novel findings (Levac et al., 2010).

For these reasons, the researcher has chosen this approach for reviewing literature relating to key challenges in TB and HIV reporting systems with the aim of the review being *"a hermeneutic understanding process"* as proposed by (Boell and Cecez-Kecmanovic, 2014). This means that developing interpretation and understanding form an inherent part of the review process.

Specifically, subsequent to the Overview (section 3.1), the following areas are discussed: first, this chapter defines what is meant by health information systems in this study and briefly reviews some of the most relevant ways they can be categorised for this study (in section 3.2). Section 3.3 continues by making more explicit the underlying assumption of the study - that it is important that different actors at varying levels of any health system have good quality data for making decisions. Then, this chapter examines some key aspects of health information systems (HIS) in low-resource settings (sections 3.4-3.6). These include data quality, the overall functioning of the HIS and utilisation of data. Section 3.7 discusses how increasing information needs on global health priorities have affected their reporting, particularly in low-resource settings. Finally, this chapter reviews what has been written on South African TB and HIV related information systems (section 3.8) because that is needed to understand and contextualise the findings of this study.

3.2 HEALTH INFORMATION SYSTEMS

Many of the concepts used in this research have different interpretations and require clarification in terms of what they mean in this study. This section considers the different perspectives and concludes with the view adopted in this research. The South African system for reporting TB information consists of a paper-based register and a national Electronic TB Register (ETR.net), which was introduced in 2003 (De Azevedo and Caldwell, 2004). Data is collected at the facility level, captured on computer at the sub-district office, reported onwards all the way to national and international level and used at various points of the chain. This system will serve as an example around which the discussion is organised.

According to the World Health Organization, the purpose of a **health information system** is to ensure "*the production, analysis, dissemination and use of reliable and timely information on health determinants, health systems performance and health status*" (WHO, 2007). The Health Metrics Network has defined the health information system as consisting of 6 components in their Framework and Standards for Country Health Information Systems. The components are

- *health information system resources*
- *indicators*
- *data sources*
- *data management*
- *information products*
- *dissemination and use*

(Health Metrics Network, 2008a)

The system around TB information in South Africa can be seen as a HIS. For instance, Heunis et al. (2011) who have compared facility-level and provincial-level TB data in South Africa, call the entity as TB-HIV Information System (part of their study focuses on HIV as well).

Hotchkiss et al. (2012) have explored the role of **routine health information systems (RHIS)** in improving health system functioning in resource-limited settings. Drawing from earlier research (Aqil et al., 2009) they define RHIS as systems that "*provide information at regular intervals of a year or less through mechanisms designed to meet predictable information needs*". Furthermore, for them a wide array of routine systems can be considered RHIS, such as:

- surveillance systems;
- individual paper-based or electronic medical records that can be used by doctors, nurses, or other health workers to improve the quality of care delivered to individuals;
- facility-based paper-based or electronic systems that can be used by district- and facility-level officials to track the delivery of health care

and related support systems, such as equipment, supplies, finance, payment, infrastructure and human resources (HR).

(Hotchkiss et al., 2012)

The South African tuberculosis information system fills these criteria, so it could be called RHIS. Complexity arises when considering Hotchkiss and colleagues' notion that RHIS are receiving growing attention as a *"sustainable strategy towards country-owned, integrated national systems that reduce reliance on parallel, vertical systems"* because not all systems that comply with the RHIS definition necessarily support that.

Hotchkiss et al. (2012) count surveillance systems as RHIS. Surveillance can be defined as follows:

> *"Public health surveillance is the continuous, systematic collection, analysis and interpretation of health-related data needed for the planning, implementation, and evaluation of public health practice."*
>
> (World Health Organization, 2011b)

Heidebrecht et al. (2011) evaluating the functioning of ETR.net in South Africa, do it from the point of view of a **surveillance system** and refer to it as such. Moreover, Nadol et al. (2008) comparing three different TB information systems, including the South African one, in different resource-limited settings, use the term **recording and reporting system**. This term is used in a similar context also by others (such as Norval et al., 2008; Huang et al., 2014) without an explanation how recording and reporting differs from surveillance or why the term HIS or RHIS is not used.

Facility and district level **health management information systems** (HMIS) are considered as belonging to the group of 'RHIS' by Hotchkiss et al. (2012) but they point out that, confusingly, they are also sometimes used as synonyms. One such system also discussed in this study is the District Health Management Information System (DHMIS)[27] of South Africa. According to the

[27] Specifically, the actual electronic database used to collect, store and analyse information is often referred to as DHIS (District Health Information System) and the provincial equivalent for that is called Sinjani.

Government's DHMIS policy, the purpose of the system is to derive a combination of health statistics from several sources to track health service delivery in sub-districts, districts, provinces and nationally (Department of Health, 2011a). Because the South African DHMIS differs from ETR.Net in that it is for aggregated routine health service data across different fields of medicine whereas ETR.Net is built around one disease, the researcher does not view ETR.Net as a HMIS per se.

Monitoring and evaluation (M&E) is an essential component of managing a health programme (Sánchez et al., 2010). According to WHO, monitoring and evaluation can be defined as follows.

> Monitoring: *"Routine tracking and reporting of priority information about a program / project, its inputs and intended outputs, outcomes and impacts."*
>
> Evaluation: *"The rigorous, scientifically-based collection of information about program / intervention activities, characteristics, and outcomes that determine the merit or worth of the program/ intervention."*
>
> (World Health Organization, 2009)

Strong monitoring and evaluation (M&E) systems can generate the information needed to evaluate progress, produce data for programme management, and advance replication and scale up of successful interventions by offering evidence on health outcomes (Reynolds and Sutherland, 2013) much like a 'health information system'. Whilst monitoring is often considered an ongoing activity and evaluation post hoc (Reynolds and Sutherland, 2013), Porter et al. (2012) point out that in global health, M&E usually refers to the umbrella of efforts that are used to inform programmes, such as surveillance systems and population-based surveys, various health information systems, evaluation and research. While they state this in the context of HIV, it applies to TB as well. Hence, it possible to see the South African TB information system as an M&E system, in a way various health information systems have been viewed in connection with TB, HIV and so on (see for instance Peersman et al., 2009).

It has also been proposed that M&E data and patient care data should be essentially one, rather than M&E processes existing as a separate layer from the clinical process (Douglas et al., 2010). This applies to South African ETR.Net in the sense that the database includes identifiable patient information and the whole database is routinely sent to the provincial level, as elaborated in section 7.3.5. However, because of the reporting focus and since the ETR.Net is comprised standardised pulmonary TB related care data (rather than a comprehensive patient history) the researcher does not consider the South African TB system a **medical record** per se.

Finally, the paper registers and the ETR.net in South Africa do not exist in a vacuum but there are people whose job is to collect, capture, analyse and use the information. Indeed, the system would not function, benefit anybody or even exist without the human actor. Hence, the researcher's primary interest is to view information systems in organisations as **socio-technical systems**: people working together and using technologies for a purpose (Korpela et al., 2013; Berg, 1999; Alter, 2008). In other words, for the researcher, an information system is *"a socio-technical system of managing information within an organization; a purposeful systemic entity which consists of people, processes, information and technologies (manual and computer-based ones)"* (Tiihonen et al., 2010). This line of thinking is revisited in Methodology (section 4.2). What adds complexity is that the health information systems operate in **health systems** which include *"(i) all the activities whose primary purpose is to promote, restore and/or maintain health; (ii) the people, institutions and resources, arranged together in accordance with established policies, to improve the health of the population they serve, while responding to people's legitimate expectations and protecting them against the cost of ill-health through a variety of activities whose primary intent is to improve health"* (WHO, 2011c). Therefore, the boundaries between a HIS (seen as a socio-technical entity) and a health system (as defined by WHO) are blurry but in this study HISs are seen as a part of health systems.

To conclude, for the purpose of this study, the researcher calls the various paper-based and electronic systems that are used to collect, process and report TB and HIV related data in South Africa a health information system (HIS) as suggested in the Introduction. The researcher

acknowledges that for others in academia or praxis, HIS may refer to a number of systems ranging from mHealth devices to medical imaging. Despite the fact that the observed South African health information systems are used routinely (contrary to, for instance, surveys which can also be used for M&E) and some of them include management related information, the researcher chooses not to call them RHIS or HMIS. Similarly, the researcher agrees that they can be used and are used for reporting, recording, surveillance and M&E. Furthermore, while some of them include patient information, the researcher does not view them as medical records per se. That being said, patient files are also sometimes discussed in this study. Finally, the researcher sees people and processes in organisations as part of the system. Hence, she chooses to discuss, for example, integration as a socio-technical issue, rather than a question of semantic standards and technical interfaces. It also means that the different TB and HIV related systems can be viewed as an entity: **a TB and HIV information system**, functioning in the South African health system.

3.3 SIGNIFICANCE OF INFORMATION IN HEALTH CARE

Good quality and timely data from health information systems is the basis and foundation of all health systems (Nutley and Reynolds, 2013; Chen et al., 2014; Mutale et al., 2013). That argument underpins this study, with a few conditions: A) health information systems are understood in their socio-technical meaning and B) the system needs to function in an adequate way (i.e. the resources invested in the system should be proportionate to the quality of data that is produced by the system) and C) the *existence* of good quality data somewhere in the system is not quite enough - the data should be actually utilised.

High-quality data is essential in healthcare because it is required basically at every corner of the health system. The Health Information and Quality Authority (HIQA) of Ireland point out that a substantial amount of data is collected on a regular basis about health services. This data is used for various fundamental purposes, including decision making, monitoring of diseases, planning of services, informing policy-making, for global reporting purposes and ultimately, improving population health (HIQA, 2013). Each of these purposes

can be further divided into more specific and mutually interconnected targets: for instance, *"monitoring of diseases"* may refer to assessing TB or HIV burden and epidemiological trends and processes; monitoring unusual occurrences; evaluating impacts; identifying high risk, vulnerable or underserved populations; demonstrating feasibility and scalability of HIV or TB care and treatment services, and so on (Nishikiori et al., 2013; Porter et al., 2012). Similarly, consulting appropriate information in *"policy-making"* can relate to a variety of things including performance-based resource allocation, evidence-based decision-making or transparency requirements.

The significance of information in health care is also well recognized by major global health actors. The World Health Organization's framework for health systems strengthening identifies six building blocks of a health system (WHO, 2007). *"Health information"* is one of the building blocks but *"production, analysis, dissemination and use of reliable and timely information"* also informs decision making in each of the other building blocks, namely health workforce, health services, health financing, governance and leadership, and medical products, vaccines and technologies (WHO, 2007).

Although information is such an essential part of the health system, many countries experience challenges with it in a manner that erodes the benefits that the information is supposed to generate. While the focus of the current study is the developing countries, next, some examples from the developed world are presented. This is done to show that fragmented and even failed HIS projects and environments are by no means a third world problem only. The HIQA has undertaken an international review of the approaches taken by several countries in their national health and social care data collections efforts in order to identify good practice and develop guidelines. Their report argues that as in many other countries, Ireland's national data collections have evolved over the years in a largely uncoordinated manner leading to a fragmented health information infrastructure with substantial variation in quality, duplication, data completeness issues, access problems, and growing costs which all undermine the quality and safety of services. The researcher considers Ireland's situation typical for many developed countries. Indeed, research has found substantial challenges with significant numbers of different kinds of HISs in healthcare (Heeks, 2006) ranging from *"turbulent, painful and troublesome"* implementations of the

electronic health records (Takian et al., 2012) to deficiencies contributing to patient safety issues in hospital information systems (Farley et al., 2013). For instance in Canada, a relatively comprehensive and integrated national health information system has been developed (HIQA, 2014). However, its development over the years has required that various challenges have been identified and addressed, including unmet information needs, lack of comparable data, lack of inventory of data holdings, their location and the technical documentation on their source, concepts, definitions, coverage and quality assessment (National Health Information Council, 1991). Similarly, a review on health indicators in European countries highlights an urgent need to develop harmonised methods for collecting and disseminating representative health data (Kilpeläinen et al., 2012). Peute et al. (2010) describe a range of human, social and organisational issues that cumulatively led to a failure of a computerised physician order entry system project in the Netherlands. In England, a national audit found that nurses and doctors spend a significant amount of time per week on bureaucracy. Whilst technology was considered helpful, if paper and electronic systems were not successfully integrated with each other, and without smarter application of processes, staff spent even more time managing multiple systems, inputting to and transcribing from paper (HSCIC, 2014). Finally, in Finland, nearly one third of working-age Finnish doctors feel that their currently used electronic health record systems do not adequately support their daily work and clinical tasks (Kushniruk et al., 2014). Difficulties in feedback when developing HISs have been identified as a potential contributor for the deficiencies (Martikainen et al., 2014). Cross-organisational health information exchange has been developed in Finland for years to address information gaps and fragmentation and to enhance the efficiency and continuity of care but national legislation and local interpretations of data protection may be a barrier for its successful utilisation (Hyppönen et al., 2014). As illustrated by these examples, high-income countries often encounter barriers to reaping the benefits relating to health information. In resource-limited settings, challenges are likely to be more aggravated, albeit that there may not be many legacy HISs.

In conclusion, **the quality and success of any operation at any level**, beginning from an individual doctor's choice about the care of an individual

patient to the high-level decisions concerning national and international health agenda setting and resource allocation, **depends in large measure on the quality of the information used in making those decisions**. Hence, to make any improvements, it is necessary to identify the gaps and deficiencies in the content, management and use of that information, as has been attempted in this study within the particular context of TB and HIV data in public health in South Africa.

3.4 THE QUALITY OF DATA PRODUCED BY HEALTH INFORMATION SYSTEMS IN UNDER-PRIVILEGED SETTINGS

The previous section explained how high quality data is the prerequisite for better decision-making and improved population health (Chen et al., 2014; Mutale et al., 2013) virtually in all health systems. This section, similarly to sections 3.5 and 3.6, focuses on **under-privileged settings** that are prevalent in many low- and middle-income countries (LMIC). These sections, looking into **data quality, HIS functioning and data utilisation**, are organised in a way that they discuss the topic in question A) at a general level B) with reference to TB and C) with reference to HIV, as depicted in Table 3-1.

Table 3-1. The organisation of sections 3.4-3.6.

Section	Organisation of the section	
3.4 The quality of data produced by HISs in under-privileged settings	The quality of public health data **generally** in under-privileged settings	
	The quality of **TB** data in under-privileged settings	
	The quality of **HIV** data in under-privileged settings	
3.5 The functioning of HISs in under-privileged settings	The functioning of HISs **generally** in under-privileged settings	FRAMEWORK INTRODUCED
	The functioning of **TB** information systems in under-privileged settings	FRAMEWORK USED
	The functioning of **HIV** information systems in under-privileged settings	FRAMEWORK USED
3.6 The utilisation of HIS's data in under-privileged settings	The utilisation of public health data **generally** in under-privileged settings	
	The utilisation of **TB** data in under-privileged settings	
	The utilisation of **HIV** data in under-privileged settings	

As illustrated in Table 3-1, the literature focusing on HIS functioning is reviewed with the help of a relevant framework (Ledikwe et al., 2014).

In general, the quality of public health data in under-privileged settings varies considerably. Several studies have raised concerns regarding data quality related shortcomings in the routine HISs in the LMIC context (Simba, 2004; Ndabarora et al., 2014; Braa et al., 2012; Bosch-Capblanch et al., 2009; Wilkins et al., 2008; Mesfin et al., 2012). These shortcomings have been found in various countries and in data relating to practically any health issue. For instance, a 27-country study focusing on immunization data quality in LMICs reported that *all* countries had weaknesses in their monitoring systems leading to inconsistencies in immunization data (Ronveaux et al., 2005). Among other data elements, age data in developing countries may be questionable since preference for age ending with numbers '0' and '5' has been found (Denic et al., 2004;

Mabaera et al; 2008). Additionally, a report from Tanzania raises an interesting, but not that often discussed, concern that data, even when it is of doubtful quality, may be considered truthful once it is entered in the computer and disseminated through the Internet (Simba, 2004). Indeed, research has found that the data coming from African countries does not truly reflect the situation in Africa; information is not always available, and even when it is, it often fails to be comprehensive, complete or up to date (Sewankambo and Katamba, 2009; WHO's Regional Office for Africa, 2002; Ndira et al., 2008).

There are several approaches to evaluating HISs and the quality of the data they generate, although often the approaches are somewhat intertwined. For instance, one can examine 'purely' the various quality dimensions of data. According to a recent review of data quality assessment methods in public health, completeness, accuracy and timeliness are the three most-assessed attributes of data quality (Chen et al., 2014). However, research has identified almost 50 attributes of the quality of data (ibid). This kind of research can been done, for example, by comparing clinic registers to monthly reports or to the data in a HIS (see for instance Mate et al., 2009; Lambdin et al., 2012). A systematic review (Ndabarora et al., 2014) on the quality of the data collected in health facilities in LMIC found several studies reporting (amongst other issues) on incompleteness of data (Harper et al., 2011; Odhiambo-Otieno, 2005; Mate et al., 2009[28]) and inaccuracies in data (Bosch-Capblanch et al., 2009; Mate et al., 2009). Early evidence from a five-country study found timeliness as a major challenge in five out of the six information systems examined (Wilkins et al., 2008). Braa et al. (2012) report less than optimal baseline timeliness, correctness, consistency and completeness of data in Tanzania while the study itself looks into the use of data. Furthermore, a study from Ethiopia indicates that insufficient supervision and feedback, coupled with inadequate investments in human resource capacity and infrastructure contribute to unreliable, incomplete and late health reporting (Mesfin et al., 2012). However, there is also evidence suggesting progress in the area. A data quality assessment from Rwanda indicates high and increasing completeness of reporting and internal consistency in the national HMIS

[28] This is a South African study, and it is further discussed in section 3.8.

(Nisingizwe et al., 2014). The study attributes the improvement to data quality interventions implemented in the country by the government and non-governmental organisations. Likewise, data audits and standardisation of data collection tools have contributed to improvements in accuracy, timeliness, validity and completeness of data in Botswana (Mpofu et al., 2014).

The quality of TB data in under-privileged settings is variable. However, establishing that can be difficult, since TB information systems, their functioning, data quality and data use are under-researched areas. This study has cited two current large reviews on data quality in public health information systems: Chen et al. (2014) and Ndabarora et al. (2014), the latter focusing specifically on LMICs. Of the 39 publications reviewed by Chen et al., two were related to TB. One concentrated on England and is excluded from this study; the other one is an Afghan study, which is discussed later. Ndabarora et al. reviewed 38 studies and identified one TB study, which is from South Africa (Heunis et al., 2011). This is in concordance with Hoa et al.'s (2012) observation that an *"extensive evaluation of the experience with an electronic tuberculosis surveillance system in a low-income country"* has been published very rarely. Nevertheless, one African review regarding TB data quality has been conducted by Nturibi (2010). Excluding the results regarding the private sector and laboratory systems, he found four studies indicating varying data quality in TB registers and information systems in Africa. In Kenya, TB registration records were incomplete with no outcome data available for 25% of cases studied (Chakaya et al., 2002). Meijnen et al. (2002) and Harries et al. (2000) identified poor data quality and inaccurate registration in Malawi. The South African TB information system has been assessed and this will be discussed in section 3.8. The implementation of the same electronic system in Botswana has been described by Vranken and colleagues (2002). Their experience was that although the accuracy and completeness of the TB register improved after implementation of the electronic programme, it did not improve the timeliness of reporting to the central TB unit. Additionally, the two national TB surveillance systems in Afghanistan have recently been evaluated (Saeed, 2013). The data quality of both systems was considered *"average"* with the government-supported system

associated with timely reporting and the non-government-supported system with poor timeliness (Saeed et al., 2013).

TB-HIV integration has brought up new types of data quality issues relating to HIV elements in TB systems and vice versa. Research has identified completeness related challenges in the national TB records in Kenya and Kazakhstan in terms of missing HIV data, but the situation has improved after enhanced integration (Klinkenberg et al., 2012). Similarly, a study in Ghana calls for more research and training to address data completeness and accuracy issues in HIV related data in TB case registers (Ansa et al., 2014). Brouwer et al. (2013) found that the TB register in Mozambique was accurate on ART-use in 73% of co-infected cases and complete in 74%. In addition, the reporting on ART-use at the end of the TB case finding quarter was complete in only 56% of the cases. Waiting for the TB treatment outcome results (12 months after the start of TB treatment) would increase the completeness of the ART-use data to 75%, but this obviously decreases the timely availability of the information. The researchers point out, that the HIV patient record seems a much better source for the data elements studied. These findings undermine the perceived benefits of collecting TB elements in HIV registers and vice versa.

Regarding **the quality of HIV data in under-privileged settings**, a 15-country study found that the quality of the collected data is unsatisfactory for many sites involved in the scale-up of ART (Forster et al., 2008). There is further evidence suggesting that HIV related data quality challenges existed at that time. For instance, data quality limitations were identified in one third of the 59 HIV related Global Fund grants. Peersman et al. (2009) argue that this compromised the effectiveness of the performance-based disbursements, and possibly resulted in misdirected decision-making.

HIV related data quality seems to depend largely on which country and which data element is looked at. Reports from Malawi (Makombe et al., 2008; Lowrance et al., 2007; Douglas et al., 2010) and Uganda (Castelnuovo et al., 2012, Kiragga et al., 2011) indicate gaps and accuracy related data quality issues (but also progress in the area), whereas in Mozambique completeness and reliability of the HIS used in HIV care was assessed to be high for most variables except for height and weight (Lambdin et al., 2012). In Brazil, the national

HIV/AIDS database was found to suffer from completeness problems (Miranda, et al., 2009). Furthermore, there are studies (from Kenya, Rwanda and Malawi) that look into the quality of care but which also found data quality problems including gaps in data (such as missing CD4 results or missing addresses that complicate follow-up) (Oluoch et al. *in press*; Lowrance et al., 2009; Mandala et al., 2012). HIV related data has also been evaluated as part of routine primary care HIS data quality assessment in Mozambique (Gimbel et al., 2011). In this study, the data concordance from facility clinical registries to monthly facility reports was 72% in terms of an HIV testing related indicator. The PMTCT programme requires timely HIV testing and medication related data about HIV-infected mothers and children. A multi-country study conducted on ART response of children in West Africa found that more than half of the medical records of children in care lacked information on PMTCT exposure (Ndondoki et al., 2014). The data had to be traced on hand-written maternal medical records and was not electronically recorded. This had negative consequences for the care of the children and the use of data for research. As this is often the case elsewhere in sub-Saharan Africa, the authors call for improved linkage between children's and maternal records and better data quality in the sub-Saharan HIV programmes.

Nevertheless, an implementation of data quality tools has yielded positive results in some African countries. A robust tool uncovered thousands of records with data integrity problems in Kenya (Monda et al., 2012) and another decreased systematic errors by 92% in Rwanda (Amoroso et al., 2010). Finally, a Malawian study, while reporting high data quality, questioned the system put in place, as well as the large amount of time required to conduct the exhaustive record review and subsequent data cleaning (Hedt-Gauthier, 2012). This is an important question, since it raises the discussion to another level: it is not only about quality, but also about the level of resources that can be dedicated into data cleaning and checking to achieve an accepted level of quality.

In conclusion, the data quality in HISs in low resource settings remains a challenge, as exemplified here with TB and HIV information systems.

3.5 THE FUNCTIONING OF HEALTH INFORMATION SYSTEMS IN UNDER-PRIVILEGED SETTINGS

Inspecting the content of registers and databases indicating gaps and errors may not be that fruitful. Hence, many studies focus either on deficiencies in data collection and processing[29] or explain or complement their data quality findings by examining their causes, these causes often stemming from the structural challenges in the functioning of the health information system. **In general, research has identified various shortcomings in the functioning of different health information systems in under-privileged settings**. For instance, additionally to the quality issues in the content of the data, the previously mentioned systematic review (Ndabarora et al., 2014) found inconsistencies in data collection and processing (Bosch-Capblanch et al., 2009; Heunis et al., 2011[30]; Harper et al., 2011). Furthermore, it identified poor utilisation of standard data collection tools, data duplication, multiple registers (Garrib et al., 2008[31]; Bosch-Capblanch et al., 2009), low and irregular data quality checking procedures, lack of guidelines and inconsistencies in the use of denominators to estimate coverage (Bosch-Capblanch et al., 2009). Similar shortcomings have been experienced elsewhere (see for instance Braa et al., 2012; Kimaro et al., 2008; Aiga et al., 2008). Simplification of paper registries, data element harmonisation and protocol standardisation, coupled with other support mechanisms have improved data quality and HIS functioning in Ghana, Mozambique, Rwanda, Tanzania and Zambia (Mutale et al., 2013).

Ndabarora et al. (2014) understand inconsistencies in data collection and processing quite narrowly and closely related to the actual acts of collecting and reporting data. The researcher of the current study chooses to see the issue somewhat more widely by also identifying system-level deficiencies, for which there is an appropriate framework. Ledikwe and colleagues have recently conducted an assessment of data management and reporting systems in Botswana (2014). It is presented here because A) it focuses on a HIS in a LMIC

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[29] That is also sometimes considered as "data quality" issue, such as in Ndabarora et al., 2014.

[30] This is a South African study, and hence it is further discussed in 3.8.

[31] This is a South African study, and hence it is further discussed in 3.8.

and B) it provides a framework to examine not only their findings, but the findings of others as well. Moreover, many of their findings concur with the results of the Ndabarora et al. (2014) review suggesting that the findings are not unique to Botswana, or to their particular HIS. According to Ledikwe et al., challenges in health information systems may be found in the following areas: i) M&E structures, functions and capabilities ii) indicator definitions and reporting guidelines iii) data collection and reporting forms and tools iv) data management processes and v) links with the national reporting system. The functioning of TB and HIV related HISs with respect to these categories is discussed next.

Aligned with the finding that TB related HISs in general are not widely researched, also **the functioning of TB information systems** remains an under-researched area. Applying the categories by Ledikwe et al. (2014) shows that most of the evidence concerns the area of:

i) M&E structures, functions and capabilities. An early Botswana study (Vranken et al., 2002) reported high user acceptance provided that the on-going training needs are addressed. Yet, similarly to Tanzania (Nadol et al., 2008), delays and challenges in the physical transfer of data to central level hampered TB information system functioning when the electronic TB register is not networked (Vranken et al., 2002) – as is the case in South Africa more than a decade later. An interesting study has been conducted in Cambodia and Viet Nam to assist the shift towards electronic TB reporting. Hoa et al. (2012) measured the data entry time required to complete and double-enter TB records of more than 11,000 patients, and estimated the time for the correction of errors in the captured information from TB case registers. The mean data entry times per record were 97.5 seconds in Cambodia and 66.2 in Viet Nam. Data capturing time was inversely associated with error frequency (6% and 39%), suggesting that 'saved' time was likely lost in revisiting more records for corrections. The authors estimated that approximately 118 person-hours were required to produce 1,000 validated TB records (Hoa et al., 2012). Although the study has some limitations, it underlines the centrality of the human actor in TB information systems.

Nadol et al. (2008) have compared electronic and paper-based TB information implemented in various resource-limited settings. Their key findings in terms of pros and cons for both types of systems are presented in Table 3-2 below.

Table 3-2. Comparison of the advantages and disadvantages of paper vs. electronic TB surveillance systems. (Nadol et al., 2008).

TB System	Advantages	Disadvantages
Paper-based	• Well-established, standardised system of data collection and reporting • Relatively low technology threshold required for implementation • Can be easily implemented at all levels of health care • Low costs to implement and maintain	• Difficult to rapidly detect variation in the quality of reporting between quarters and among administrative levels • Time-consuming manual entry, compilation, transfer and analysis of TB data • Restricted 'real-time' quality control and validation of data for supervision • Limited options for securing data to maintain patient confidentiality and prevent data loss
Electronic	• Time-saving (record reviews, patient follow-up) • Real-time report generation capability (standardised and ad hoc) • Allows for complex analyses • Increased accuracy and confidentiality controls • Safer data maintenance (i.e., patient confidentiality and integrity)	• Dependent on a well-established paper-based system • Increased infrastructure needs (e.g., computers, regular electricity supply) • Specialised human resource requirements • Specialised training and support requirements • Higher implementation and maintenance costs

Many of the 'disadvantages' they identify can be associated with possible deficiencies in TB data collection and processing and in particular with structures, functions and capabilities. For instance, "*specialised human resource requirements*" may translate into lack of skills in data collection and processing. Echoing earlier research (Vranken et al., 2002), Nadol et al. underscore the essentiality of a well-established paper-based system before attempting to move into an electronic system. The same notion – addressing any structural deficiencies in TB data collection and processing prior to attempting technological advantages – can also be found in a recent review on web-based tools for

managing and monitoring TB (Chapman et al., 2013)[32]. The researchers emphasise that particularly in resource-poor settings, infrastructure-related, practical and financial challenges at a national level need to be addressed if the potential of new developments is to be maximised.

ii) Indicator definitions and reporting guidelines: None of the evidence reviewed directly concerns this area. This is surprising, since there have often been changes and revisions in standard definitions and guidelines. For instance, section 2.8 introduced the WHO-approved rapid diagnostic tool called Gene-Xpert, used in South Africa. Yet, the results from the rapid diagnostic tools do not always fit with the previous case definitions and treatment outcomes as envisaged by the WHO for paper-based reporting (WHO, 2013g). The language of the definitions has also been revised (the terms *"defaulter"* and *"TB suspect"* have been replaced by *"lost to follow-up"* and *"presumptive TB"*). Finally, MDR-TB patients who are in treatment for a long time do not always fit into outcome categories of *"cured"* and *"treatment failed"*, which has instigated a need for further revisions (ibid). Against this backdrop, the researcher would have anticipated articles citing challenges in indicator definitions and global reporting guidelines as a contributor to deficiencies in HIS functioning.

iii) Data collection and reporting forms and tools: Nadol et al. (2008) and Nturibi (2010) point out that paper-based TB systems, prevalent in many of their research countries, are labour-intensive, time-consuming and prone to errors, particularly if they require that the standard reports must be calculated by hand. A few other studies provide anecdotal evidence of particular deficiencies in reporting forms, such as a missing column for a date in the TB transfer register (Meijnen, et al., 2002). A study from Afghanistan describes more difficult settings (Seddiq et al., 2014). They argue that during the post-conflict period the TB data collection forms were not always available, and the programme staff had to prepare forms by hand and then fill them with the appropriate information. Vranken et al. (2002) points out with reference to Botswana, that ETR.net is

[32] This article is not discussed here extensively since it is not limited LMICs and it focuses on a wide variety of web tools ranging from those used for diagnosis to those used for TB research.

available only in English[33], which may be a challenge for a non-native speaker. The same applies to South Africa. Finally, a study in Kenya reports that TB section of an integrated reporting tool by the Ministry of Health was considered too difficult by the users to use, and this has led to shortcomings in data quality (Mbondo et al., 2013).

iv) Data management processes: Electronic systems provide improved data security measures (such as passwords) compared to paper-based records (Nadol, et al., 2008).

v) Links with the national reporting system: Norval et al. (2008), advise that TB systems should complement the national health information systems without duplication. An Afghan study claims that information sharing between the national TB programme and the international donors has worked well and contributed in avoiding duplication of effort and waste of resources (Seddiq et al., 2014). This can be contrasted with another Afghan study (Saeed et al., 2013) pointing out that the two information systems used for TB surveillance in the country are duplicative and neither covers private healthcare.

Next, this section continues with **deficiencies in HIV related health information systems functioning**. It should be noted that the previously mentioned assessment of data management and reporting systems in Botswana by Ledikwe and colleagues (2014) focuses on programmes related to HIV/AIDS (including HCT, ART, PMTCT and condom distribution amongst others), making it particularly suitable for this discussion.

i) M&E structures, functions and capabilities: Limited computer–literacy, insufficiently trained personnel or inadequate numbers of trained personnel who are able to collect, process or analyse data have been identified as barriers to the optimal functioning of HIV related HISs by Ledikwe et al., 2014; Peersman et al., 2009; Forster et al., 2008; Siika et al., 2005; Makombe et al., 2008; Castelnuovo et al., 2012; Mbondo et al., 2013 and Halpern et al., 2010.

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[33] Specifically, ETR.Net is currently available in English, French, Portuguese and Spanish but Botswana and South Africa use the English versions since French, Portuguese and Spanish are not among the official languages of the two countries.

Moreover, Ledikwe et al. (2014) point out that the M&E-related tasks were generally not clearly assigned at the facility level, leading often to a lack of ownership of reporting responsibilities in Botswana. However, they propose that task shifting of reporting duties at the facility level to paraprofessional cadres, including data clerks, may be a good strategy to improve HIS functioning and data quality. Another study in Botswana suggests that lay counsellors perform better in documentation for programme M&E than other cadres of health workers (Ledikwe et al., 2013). Others have shown that the more clerk-hours per ART patient, the better the data quality (Forster et al., 2008) suggesting similarity with the previously mentioned findings in TB (Hoa et al., 2012). In addition, supervision has been emphasised by Makombe et al. (2008) and Libamba et al. (2006). Research also recognises insufficient physical infrastructure and low organisational capacity as a limitation for M&E of HIV/AIDS (Porter et al., 2012). For example, inadequate information technology support was reported in Botswana (Ledikwe et al., 2014). Interestingly, poverty has been identified as a barrier for an optimally functioning HIV M&E system: the proportion of the population living on less than US$ 1 per day was positively associated with missing data in Forster et al.'s multi-country study (2008). It becomes clear from the literature that HIS functioning and data quality are very much inter-connected.

ii) Indicator definitions and reporting guidelines: Ledikwe et al. document a varied existence and availability of indicator definitions whereas reporting guidelines appear to be widely known in Botswana (2014). This can be contrasted with Mbondo et al. (2013) who report on the lack of written guidelines and standard operating procedures (SOPs) concerning data validation and routine data quality audits in Kenya. Whilst several authors highlight the need for indicator definition harmonisation in HIV reporting (see for instance Porter et al., 2012; Peersman et al., 2009; Wolf et al., 2004), besides Ledikwe et al. and Mbondo et al., there seem to be no case studies of how the availability or clarity (or lack of them) of indicator definitions and reporting guidelines have contributed to HIV related HIS functioning in the LMIC context.

iii) Data collection and reporting forms and tools: Standard tools for HIV reporting are generally available in Botswana, however some of tools are

frequently changed, making it difficult to be sure that the up-to-date version is being used (Ledikwe et al., 2014). Contrariwise, Mbondo et al. (2013) cite the unavailability of the recommended standard tools, which has resulted in the development of duplicate tools by some stakeholders. In Kenya and Guyana, presentation of data from the voluntary counselling and testing (VCT) and treatment sites has been complicated by the use of different data collection tools (Otwombe et al., 2007; Halpern et al., 2010). On the other hand, particularly with paper-based tools, too much simplicity may pose limitations as the volume of patients rises (Lowrance et al., 2007). Finally, non-availability of tools for *collaborative* routine TB-HIV data collection and reporting in HIV settings has also been recognised as a barrier (Okot-Chono, 2009).

iv) Data management processes: Ledikwe et al. (2014) report that there was little evidence of clear guidance on procedures for collection, aggregation and manipulation of the data in Botswana, including guidelines for cleaning, editing and documenting changes to source documents, raw data or reports. Additionally, there are no mechanisms for addressing data quality issues. Indeed, Kiragga et al. (2011) note that the quality of HIV related data collection can only be demonstrated through detailed and arduous review of medical notes, which tend to be unorganised, illegible or missing. Regarding timeliness of HIV data, there is seldom a data tracking system to pinpoint where delays occur (Otwombe et al., 2007). Ledikwe et al. (2014), Mbondo et al. (2013) and Siika et al. (2005) also report on the lack of standard practices for backing-up the data, maintaining and storing source documents, or for safeguarding confidentiality.

v) Links with the national reporting system: Porter et al. (2012) note that some countries have been known to have too many indicators regarding HIV M&E and little harmonization of the indicators within and across countries. In line with that finding, several studies (Mbondo et al., 2013; Nash et al., 2009; Moon et al., 2010; Ledikwe et al., 2014) document multiple reporting of a single data element, as well as extensive reporting. For instance, a particular summary form, which is completed by all public health facilities (over 600 facilities in Botswana), contains almost 300 data elements. Moreover, electronic HISs exist but they are not usually integrated across health programmes or networked across health facilities and therefore tend not to eliminate the need for paper-based forms, but rather occur in parallel (Ledikwe et al., 2014). Also Mbondo and colleagues

consider the lack of coordination among all the numerous subsystems and implementing partners as their greatest challenge at the provincial level.

To conclude, the functioning of a HIS may be sub-optimal in the LMIC context. Research has identified deficiencies in several areas, as discussed here with reference to TB and HIV systems. Much of the evidence is not disease specific: for example, manual calculation for standard TB compilation reports was argued to be labour-intensive and prone to errors. This certainly applies to any paper-based HIS that requires manual aggregation of figures for reporting. Similarly, lack of skilled human resources, discussed here with reference to HIV, will impede the functioning of any HIS.

3.6 THE UTILISATION OF HEALTH INFORMATION SYSTEMS' DATA IN UNDER-PRIVILEGED SETTINGS

Previous sections have so far focused on the various quality aspects, such as reliability of the data content, as well as examined different aspects relating to how well TB and HIV information systems work in generating that data. However, neither of these things matters, unless the data produced by the systems is utilised in a meaningful way. Health data utilisation in this research refers to making health information available to intended users through feedback and sharing of the information, as well as using it for meaningful purposes (Ndabarora et al., 2014).

In general, challenges have been experienced in data utilisation in under-privileged settings. Ndabarora et al.'s review (2014) identifies several studies that report on the varied degree and kind of utilisation of health information in LMICs in terms of health information use for decisions and planning, feedback initiatives and health information use for research. The use of health information for decisions and planning has been studied by Booman et al., 2000; Merrell et al., 2004; Siika et al., 2005; Rahimi and Vimarlund 2007; Guy et al., 2009; Farias et al., 2010; Were et al., 2010; feedback initiatives have been documented by Garrib et al., 2008; Mate et al., 2009; Harper et al., 2011;

Taylor and Shimp, 2010; van der Veer et al., 2010; Heunis et al., 2011; and health information use for research by Martin et al., 2002; Diero et al., 2006.[34]

Health information has been used in different LMIC contexts in various ways including public health interventions planning, impact assessment, risk identification, programme evaluation, in the context of medical data sharing, and for improving patient management (Ndabarora et al., 2014).[35] However, the review also revealed that challenges outweighed the good practice in delivering reliable health information for improved decision-making and planning. In general, besides the review by Ndabarora et al., *poor* use of data in low-resource settings has often been reported (for instance in Braa et al., 2012; Sæbø et al., 2011; Wilkins et al., 2008; Kimaro et al., 2008; Plaza et al., 2012; Simba 2004; Mesfin et al., 2012; Hanna and Kangolle, 2010; Mliga, 2003). Wilkins et al.'s study (2008) provides early evidence on six surveillance and M&E related HISs in five LMICs. They found that data from the HISs was not perceived to be useful by decision-makers in any of the six systems, either because it was not disseminated sufficiently or did not meet the needs of the intended target audiences. In Ethiopia, decision-making and discussion based on routine HMIS data took place only in 35% of the facilities (Mesfin et al., 2012).

Low data quality may be the most quoted reason for limited utilisation. It is a vicious circle, as argued by Braa et al: data whose quality is poor will not be used, and since it is not used, the data will remain of low quality (2012). This finding is present also in earlier research such as Wilkins et al. (2008). In four of the six systems they examined, lack of confidence in data quality was a contributing factor in its non-utilisation. Equally, the development of a skilled M&E cadre at the district level contributed positively to data quality and consequently to increased use of data for surveillance, operational research and planning purposes (Mpofu et al., 2014). Sæbø et al. (2011) found in their four country study that in all countries, fragmentation of health information in various

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[34] The evidence from South African studies is discussed in 3.8 which zooms in on HISs in the South African context.

[35] International health funders require data from aid recipient countries to track performance and guarantee accountability. This can be viewed as use of data, too. Ndabarora et al. (2014) do not focus on this kind of utilisation of data, and it is not discussed in this section, either. However, section 3.7 returns to this topic.

and partly overlapping subsystems run by different vertical health programmes represented a major barrier to the use of information. Furthermore, Hotchkiss et al. (2010) have proposed a lack of information culture as an underlying factor that might influence information use in low-resource settings. Finally, potential users' inadequate skills and competencies to use the data have been found as a reason for poor use of data in LMICs (Wilkins et al., 2008). Research, therefore, suggests that HIS functioning is closely connected with, not only data quality but also data utilisation.

Feedback is another focus of the Ndabarora et al.'s review. Overall, the studies reviewed associated the following factors with effective feedback: improved data quality, motivation and expectations of the health professionals, and the availability of necessary equipment to enforce quality enhancement (Ndabarora et al., 2014). Moreover, another systematic review concludes that feedback can positively affect both the process and the quality of care (van der Veer et al., 2010). Unfortunately, limited feedback seems to be a customary challenge in various areas of health and across a number of LMICs. This is reflected in Ndabarora et al's review, which shows poor evidence of feedback practices. Correspondingly, several other studies have either identified it as a challenge or otherwise recommended fortification of the feedback system (Otwombe et al., 2007; Mavimbe, 2005; Mutale et al., 2013; Ledikwe et al., 2014; Wilkins, 2008). Studies from Africa (Mesfin et al., 2012 and Ledikwe et al., 2014) connect insufficient feedback to lower data quality and lower use. Deficiencies in the communication infrastructure may a barrier to providing timely feedback, however, if such challenges can be overcome, feedback can improve timeliness of routine reporting (Mpofu et al., 2014). Henceforth, strengthening feedback mechanisms is a relatively inexpensive way to strengthen the HIS and the whole health system.

The academic evidence on the specific issue of **utilisation of tuberculosis data** produced by a routine TB data system, including the use of TB data for feedback, is extremely scanty. WHO routine reports that can be automatically generated from the electronic TB register, have been proposed to be useful and to provide important management tools by Vranken et al. (2002). Similarly, Nadol et al. (2008) point out that an electronic TB system can

accelerate data analysis, report generation and supervisory feedback, as well as increase ownership and access to TB data at the sub-national level. These are issues that generally enhance data use. A Chinese evaluation has looked into the functioning of the national communicable disease surveillance systems (including TB) at province and country level. Six of the nine county level TB centres had not received any feedback from the upper-level during the last calendar year (Xiong et al., 2010). The researchers argue that the quality and the performance of infectious disease surveillance activities may be compromised by the lack of clear feedback from the health administration to lower levels. Seddiq et al. (2014) argue that extensive sharing of information within the Afghan TB programme has contributed positively to the functioning of the TB information system. Another Afghan study points out that feedback in a government supported TB information system is working well (Saeed et al., 2013). Finally, regarding collaborative TB-HIV services, Okot-Chono et al. (2009) identify non-use of data as a barrier to successful implementation of the services. A full utilisation of fit-for-purpose data is particularly critical for the M&E of integrated service delivery management because of the comparative scantiness of the existing evidence base (Reynolds and Sutherland, 2013).

Despite being under-reported in academia, the researcher does not think that TB (or TB-HIV) data is particularly under-utilised. Rather, information on data use in low-resource setting regarding other health conditions (including HIV) may provide some indication of how TB data is or is not utilised. However, different diseases have different dynamics and additionally, there are likely to be large differences between contexts. Consequently, careful consideration of whether the evidence is really generalisable, is required. Thus, it is important to gain knowledge via new studies that report utilisation of data in a country-specific context as in this study.

In terms of **utilising HIV related data** for meaningful purposes, including feedback, a survey has been conducted in almost hundred countries on data use in HIV/AIDS programme planning and implementation. About half of the countries rated their data use as above average whereas approximately one in five countries in the Caribbean, Eastern Europe, Central Asia and South and Southeast Asia rated themselves below average (Peersman et al., 2009). According to the authors, the self-ratings suggest that there is significant room

for improvement in the utilisation of HIV related information. This finding is echoed in some of the country-specific studies discussed here (such as Moon et al., 2010). For instance, Mbondo et al. (2013) argue that particularly at the facility level HIV data dissemination and use is viewed as merely a *"forwarding exercise".* Peersman et al. (2009) emphasise the importance of a better understanding of the barriers and facilitators for data use in HIV control. Some of these barriers may have been identified by a UNAIDS report arguing that bureaucratic pressures and inertia may work against the termination or revision of particular strategies or programmes, even when evidence obtained indicates that they are unlikely to work (UNAIDS, 2008). The report further maintains that in some countries the allocation of HIV prevention resources at national level is sometimes severely at odds with the picture of the epidemic generated by national surveillance systems. In addition, routinely reported M&E data often ends up in district, provincial, national and international databases, notwithstanding the fact that implementation of health services usually takes place at the local level. Similarly, the data is habitually targeted to meet donors and national level decision-makers' needs, rather than facility- and district-level implementers (Nash et al., 2009).

However, Guy et al. (2009) have reviewed 38 public health interventions where routinely collected data from VCT (voluntary counselling and testing) sites has been used. They conclude that such data is useful for various health interventions in under-developed settings. Also a number of studies reviewed here (such as Amoroso et al., 2010 and Halpern et al., 2010) indicate that routine HIV related information is used for various purposes including clinical decision-making, identifying and tracing defaulting patients, outreach, resource allocation, following programme performance, pin-pointing gaps in service and so on.

In line with the experiences of the challenges in HIV data utilisation, a lack of timely feedback of useful data to managers and decision-makers at all levels in a position to improve HIV related programmes has been suggested as a common weak link of M&E systems by Nash et al. (2009). According to Mbondo et al. (2013) the lack of even minimal written feedback about supervisory visits and on the HIV data submitted from the facilities to the national level contributes

to under-appreciation of the collected data and uncertainty about whether the required follow-up occurs. On the positive side, feedback was also considered a key factor in the success of networked HIV HIS in Nigeria (Chaplin et al., 2015). A good lesson for improved data utilisation and feedback may be found from Ledikwe and colleagues (2014). They emphasise *"building recognition"* for the importance and different uses of HIV related data for evidence-based decision-making through M&E-specific workshops. In the workshops, the actual data relevant to the participants is discussed and the importance of capturing data accurately is exemplified in terms of its impact on higher-level analysis if the facility-level data is wrong or missing, or what kind of wrong conclusion can be drawn from it. Since participants' successes, challenges and future plans are also discussed, the researcher of the current study assumes that the workshops are negotiative two-way processes, rather than naming and blaming sessions.

To summarise and conclude the key messages of this and the two previous sections, the quality of HISs can be assessed at least in three different ways. First, the quality of data produced by these systems can be evaluated. Unfortunately, the lack of reliable and good-quality data is a major obstacle in many developing countries (Okonjo-Iweala & Osafo-Kwaako, 2007) and it seems TB and HIV related data sets, registers and information systems are no exception. Amongst other challenges, research has identified completeness, accuracy and timeliness issues. Second, issues that hinder the optimal functioning of health information systems can be examined. Following the assessment by Ledikwe et al. (2014) the researcher of the current study identified several studies reporting weaknesses in different TB and HIV systems in LMICs in terms of i) M&E structures, functions and capabilities; ii) indicator definitions and reporting guidelines; iii) data collection and reporting forms and tools; iv) data management processes; and v) links with the national reporting system. Nevertheless, it does not matter how sophisticated and well-functioning a system there is, or how accurate the data it produces, if that data is not utilised in a meaningful manner. This review has indicated a varied use of data in low-resource settings. It is important to understand that these issues are inter-related. Moon et al (2010) report difficulties in utilising HIV data in Mozambique because programme documentation tools have been developed in a vertical process with very limited integration of HIV related data across the services. This

serves as an example of how a) there are challenges regarding the **use** of data but b) it stems from **deficiencies in relating to functioning of the HIS.** While data quality is not covered in Moon's study, it may be argued in line with Braa et al. (2012) that this may result in **limited data-quality**, which again may turn into a barrier to data use. Finally, this example also underlines the idea that structural mechanisms, such as the vertical organisation of care delivery, may have an impact on reporting of TB and HIV information. This will be one of the topics of the next section.

3.7 MONITORING & EVALUATION OF GLOBAL HEALTH PRIORITIES

As discussed in section 3.2, information plays a crucial role in managing the HIV and TB epidemics, inside and outside the clinics. As a result of the enhanced global priority setting and increased funding, particularly during the *"grand decade for global health"* (Lidén, 2014), the need to monitor and evaluate (M&E)[36] various TB and HIV programmes around the world has increased. In other words, global funding has been accompanied by a growing demand for more and better statistics to track performance and accountability (Boerma and Stansfield, 2007; Chan et al., 2010). Building on what was previously argued of the significance of information in health care, data is not required just for decision-making and similar purposes: as pointed out by Boerma and Abou-Zahr (2007) *"big diseases mean big money".* In other words, disease programmes may also use health data to build government commitment and advocate their case to sustain programme funding.

A need for health data is not a new phenomenon. In the Lancet Series dedicated to Health Statistics, Boerma and Stansfield (2007) recall that the adoption of the Health for All initiative at the 1977 World Health Assembly was followed by the monitoring requirements of 20 health indicators. The Millennium Development Goals (MDGs) generated further pressure for high-quality and

[36] As pointed out in section 3.2, M&E usually refers to the umbrella of efforts that are used to inform health programmes and those who provide funding for them. This is not something separate of HISs is LMICs, merely a different angle. Routine reporting by HISs can be used (amongst other things) for addressing M&E needs.

timely data on country progress as the MDGs' reporting is based on 48 indicators, of which 17 concern health. Moreover, the UN agencies have their own rigorous country reporting requirements. Finally, the generation of indicators in disease-specific programme areas has been even more noticeable. At the time of the Lancet Series, at least 75 indicators regarding TB were required from any country to monitor their TB programmes and more than 140 indicators were expected from HIV/AIDS programmes (Boerma and Stansfield, 2007).

However, at the country level, increased monitoring efforts led to a situation where there are *"thousands of indicators recommended but few measured well"* (Murray, 2007) and the escalation in the demand for data soon exposed major challenges in the supply of health statistics (Boerma and Stansfield, 2007). The international health community was forced to acknowledge that particularly under-privileged countries have limitations that impede the production of timely quality data, including input, output, outcome and impact indicators (Chan et al., 2010; Porter et al., 2012) as elaborated in detail in the three previous section.

As a result, the global health community has had to concentrate its efforts on improving measurement of a smaller number of priority areas (Murray, 2007) and strive towards larger investments and greater efficiency in the area. In 2010, eight major agencies working in global health (Bill & Melinda Gates Foundation, GAVI, Global Fund to Fight AIDS, Tuberculosis & Malaria, UNAIDS, UNFPA, UNICEF, World Bank and WHO) pledged to

- *Enhance investments in country data sources and strengthen information systems through global health partnerships and special disease initiatives as part of current funding and through new efforts. A commonly used figure, by, for instance, the Global Fund to Fight AIDS, Tuberculosis and Malaria, is that 5% to 10% of program funds should be invested in data collection, monitoring, evaluation, and operational research;*

- *Improve the efficiency of health information investments by closer collaboration between partners in support of one strong country*

M&E plan that covers all major disease and health programs and all data sources.

(Chan et al., 2010)

Chapter 2 illustrated how a lot of healthcare delivery in LMICs has been organised separately to address specific health problems. When the monitoring follows that approach, this may have negative consequences. Research has identified the following: First, a vertical approach in M&E may result in excessive, duplicative and parallel monitoring efforts (Porter et al., 2012; Boerma and Stansfield, 2007; Ledikwe et al., 2014; Chen et al., 2014; Sæbø et al., 2011; UNAIDS, 2010; Nash et al., 2009; Otwombe, 2007; Chilundo and Aanestad, 2003) including multiple M&E reports, with different formats and deadlines (Sæbø et al., 2011; Biesma et al., 2009; Moon et al., 2010; McKinsey 2005; WHO, 2005). Second, there may be requirements for additional indicators that are not part of countries' own systems or are too elaborate for them (Nash, et al., 2009; McKinsey 2005). Third, if there are several independent vertical programmes, the lack of shared standards for data collection may mean that additionally to duplicate reporting activities, gaps emerge where essential data does not get reported (Sæbø et al., 2011; Braa et al., 2007). Fourth, a vertical approach in monitoring may lead to a general undermining of national programmes' M&E system (Biesma et al., 2009; Gimbel, 2011; Peersman et al., 2009), as well as poor data quality (Chen et al., 2014) in particular if the amount of data required is large (Loveday and Zweigenthal, 2011; Shaw, 2005). Fifth, a single sector M&E system makes planning and reporting of *collaborative* activities difficult (Uwimana et al., 2012; Auld et al., 2013), may not reflect a country's own priorities (Reynolds and Sutherland, 2013; Wilkins et al., 2008) and has very limited flexibility to meet information needs beyond that disease (Hotchkiss, et al., 2012). Sixth, since the data is seldom shared across vertical programmes, this approach does not allow for productive utilisation of collected data to guide future policy decisions (Moon et al., 2010; Xiong et al., 2010; Sæbø et al., 2011). Seventh, fragmentation and lack of coordination often connected with vertical systems (Ledikwe et al., 2014; Nash et al., 2009; Garrib et al., 2008; Otwombe, 2007; Kawonga et al., 2012; Mahundi et al., 2011; Sæbø et al., 2011) and insistence by international agencies on maintaining their own single sector

systems impedes the creation of strong HISs in general (Braa et al., 2012). Finally, a vertical approach in M&E may have human and financial resource implications (Reynolds and Sutherland, 2013; Ledikwe et al., 2014) and pose an added burden and confusion for the site level staff, responsible for collection and reporting of the data (Nash et al., 2009; Moon et al., 2010; Xiong et al., 2010). Hence, alongside the appeals to strengthen health systems and exploring ways of maximising positive synergies between single-disease programmes and health systems (Kawonga et al., 2012), the growing knowledge about deficiencies in the vertical approach in M&E has prompted calls for better collaboration in tracking the programmes' progress. Indeed, the latest available versions of many major international plans and guidelines that are M&E related and have a TB or HIV focus have moved towards the direction of harmonisation, closer collaboration or inter-linking, as detailed in Appendix A.

However, there are also concerns about integrating or interlinking monitoring of health conditions. This area is not discussed extensively in the literature, probably because of a lack of evidence to date. The process of integration, however, is not easy and it requires a holistic consideration of the HISs across the health sector (Mahundi et al., 2011). Sæbø et al. (2011) emphasise that integration happens at several levels simultaneously, ranging from the purely technical to the organisational. Consequently, it is the interplay of these levels throughout the process that determines a suitable approach and strategy. If there is a general reporting system that is not highly valued or (consequently) the reported information is of low quality (such as incomplete or unreliable), or there is not a strong culture for using the data it produces, the fragmented information systems need to be *"upgraded"* before any integration efforts (Chilundo and Aanestad, 2003). Such an upgrading is not a trivial activity, as it demands resources and skills which are not always available in low-resource settings (ibid). Consistent with this line of thinking, there have been concerns that the integration of TB recording and reporting into a multi-disease HIS would probably lead to deterioration in the quality of routinely collected TB data, if the process was not carefully managed (Heunis et al., 2011; WHO, 2008b).

Furthermore, challenges remain, with or without integration. First, despite streamlining efforts, M&E continues to be an **inherently complex activity** as suggested by the number of guidelines. The ones presented in Appendix A are

not the only ones, as many large international funders have their own guidance for reporting and monitoring. For instance, WHO's guidelines for second-generation HIV surveillance (2013h) list another 20 UN/WHO publications on guidance on surveillance and monitoring of HIV/AIDS.

Second, regardless of the global efforts to harmonise data collection efforts, **there still exist a lot of indicators.** According to the WHO Regional Office for Europe, WHO still uses largely the 50 TB indicators listed in the 2004 Compendium of Indicators for Monitoring and Evaluating National Tuberculosis Programs (personal communication, 2014). Moreover, there exists a minimum set of indicators for the programmatic management of MDR-TB in national tuberculosis control programmes (WHO, 2010), excluded from the Appendix A, consisting of another 19 indicators. The number of recommended HIV/AIDS indicators seems to be even larger than the number of TB indicators[37]. Furthermore, besides routinely reported 'basic' HIV/AIDS related indicators, new indicators have been introduced. For instance, countries were requested in 2010 to report on the implementation of the United Nations General Assembly Special Session Declaration of Commitment on HIV/AIDS (UNGASS) resulting in 58 indicators[38]. Likewise, the UNAIDS guidelines on the global AIDS response progress (2014c) invite countries to submit their monitoring data (38 indicators) regarding ten targets set in the 2011 United Nations Political Declaration on HIV and AIDS. These are not all different indicators, however. In particular the indicators listed in publications on linked monitoring (in Appendix A) are already largely part of other programme-specific indicator sets (Three Interlinked Patient Monitoring Systems for HIV Care / ART, Maternal and Child Health / PMTCT ->17 indicators, A Guide to Monitoring and Evaluation for Collaborative TB/HIV activities ->13 indicators).

Nevertheless, it is important to acknowledge that all data needs or data collection recommendations will not end up as data elements in routine monthly

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[37] Despite consulting various guiding documents, as well the UNAIDS and WHO information offices, the number of routinely recommended HIV/AIDS related indicators could not be established.

[38] Including both health sector and UNGASS indicators.

or quarterly clinic level reporting in all countries. Countries have a choice as to what they think that they are capable of reporting; they can obtain information, for instance, by surveys or from sentinel sites, some data is only provided by focus countries, and some data is collected only annually or even less frequently.

Third, harmonisation of data collection efforts at a global level is very much a **work in progress.** The researcher suspects that the proliferation of harmonisation guidance may not always translate into fully streamlined and efficient reporting activities.

Fourth, **new information needs are emerging** and this development is likely to continue for at least 5 different reasons, analysed below by the researcher as from A to E. Again, all of the new information needs will not automatically mean an increase in routine reporting; however some of the following changes in the global M&E scene may in the long term be reflected in particular countries' reporting requirements.

A) As epidemics mature and epidemiological situations change, new needs will arise.

The emergence of MDR, and how it has resulted in an established data collection, use and reporting procedures, serves as an example. However, as the HIV/AIDS epidemic has matured, it has become evident that HIV also has the ability to mutate itself. Following the first global report on HIV drug resistance WHO recommended that countries implement HIV drug resistance prevention and surveillance activities in national routine surveillance and M&E programmes. Moreover, as more HIV-positive people are accessing ART, and in many places they are living longer due to it, new challenges appear. For instance, WHO advocates that countries would implement viral load monitoring (WHO, 2014e) and toxicity surveillance (WHO 2014f) within HIV programmes to diagnose ART failure and establish the frequency and clinical relevance of and specific types of toxicities associated with ARV drugs (WHO 2014e,f). Finally, with older people living with HIV, there is now more need for information on HIV and chronic diseases (such as hypertension and cardiovascular disease). These developments require new data to be collected, further adding to the reporting burden.

B) The paradigm shift towards integration and joint activities may produce new kind of M&E needs.

This concerns not only TB-HIV co-infection or inter-linking HIV care/ART, MCH/PMTCT and TB/HIV (as in publication number 7 in Appendix A). For example, the WHO HIV programme is increasing its focus on viral hepatitis and HIV *co-*infection in 2014–2015, as well as *dual* elimination of mother-to-child HIV transmission and congenital syphilis. Also cross-cutting issues, such as gender violence as part of HIV control programme may be receiving more attention in the future (WHO, 2014f).

C) Accumulating knowledge and new innovations are inclined to gradually change the M&E scene.

When a novel pandemic emerges, initially there is not much information available, and countries and international organisations try to establish crude estimates of the basic figures, such as incidence, prevalence and mortality. When knowledge gradually accumulates, the attention shifts to lower level issues. WHO's Indicator C.2.1 *"Number of TB facilities where free condom distribution is practised and condoms are available, expressed as a proportion of all TB facilities"*[39] serves as an example. In addition, innovation in prevention, treatment and care of HIV and TB ranging from male circumcision to new diagnostics, vaccines and medicines have altered and will likely alter the M&E focus.

D) Changes in the global health agenda may result in changes in M&E needs.

For instance, in 2006 Global Plan to Stop TB case detection rate indicator was included in the DOTS component whereas in 2011 Plan it was not. This is because beginning from the mid-1990s, great attention was given to monitoring the case detection rate as two major targets set for TB control at that time were to detect 70% of the new cases of smear-positive TB, and of those, to successfully treat 85%. These targets were initially set for the year 2000, and

[39] This is currently an optional indicator (UNAIDS, 2014b).

later reset to 2005. As the target year 2005 passed, the focus has changed to measuring progress against impact, i.e. targets for decreases in the burden of disease (measured in incidence, prevalence and mortality) (WHO, 2011a). Whilst this example is on leaving something out rather than including something new, some of the earlier examples regarding HIV seemed to indicate that a new declaration usually corresponds to new measuring requirements.

E) Finally, major paradigm shifts in the global health agenda may produce new information needs.

As discussed earlier, while health generally has remained a priority globally, the priorities within health have changed over time and not simply as a result of epidemiological considerations. The debate on vertical versus an integrated or comprehensive approach has been going at least for 50 years in different forms. Hence, the current situation is not an end point, but at a point in time in a continuum of gradual change. Since the major paradigms in global health usually come with increased information needs towards the 'new' approach, country reporting requirements are likely to reflect that development.

In conclusion, 'what should we measure' and 'how should we measure it' are constantly changing. These processes are also profit-driven: there are profits to be made in a variety of areas including patents, diagnostics, programme management, information systems, consultancy fees and so on, albeit that it may be about accessing (public) funds, not only corporate profit-making.

In summary, at the time of the data collection of this study in South Africa, there had been a period, which had been marked globally by a proliferation of initiatives for monitoring and evaluation. However, the demand for high-quality data proved to be greater than the supply. Furthermore, a single-disease approach to reporting, particularly in resource-limited settings, has a number of weakness. In order to tackle the deficiencies, the global health community has increasingly aimed towards harmonisation and collaborative activities in M&E, as evidenced by the paradigm shift at least on a discursive level in the major plans and guidance documents in Appendix A. However, integrated M&E (for which there is not yet a common definition and which therefore is a very context-specific term) may have equal weaknesses. Finally, integration or no integration, M&E remains an inherently complex and unceasingly changing area with

continuously emerging new data needs. Money is probably amongt the key drivers behind the increase in information needs. The global development in this area has affected and will probably also continue to affect South Africa's M&E landscape.

3.8 THE TB AND HIV INFORMATION SYSTEM IN SOUTH AFRICA – WHAT IS KNOWN?

This study introduced the reader to some key challenges in the South African health system in Table 2-1. Several issues were further accentuated by emphasising them with bold text. The last emphasised word on Table 2-1 was 'data'. Unfortunately, in South Africa, the word 'data' may be coupled with the word 'fragmentation'. The fragmentation of HISs originates essentially from the apartheid era. With 14 departments of health at the central level (one National and separate administrations "White," "Coloured", "Asians" and "Black" Homeland administrations) the apartheid health governance led to a situation in which there were numerous forms for reporting data but no agreed health data standards (Sæbø et al., 2011). Therefore, the HISs depicted in the studies reviewed at the end of this section should be examined and understood against the background of the apartheid legacy. However, before reviewing studies of particular electronic or paper-based systems in South Africa, this section discusses what is known about the South African HIS landscape in general.

The previous chapter described the global development regarding monitoring of priority diseases during the *"grand decade for global health"* (Lidén, 2014). The development of the South African TB and HIV information system is consistent with this global development, if not an archetypal example, in that the development of information systems has been more abundant there than in many other African countries in which lack of infrastructure, higher levels of poverty or other issues such as wars may have steered the attention and aid flows in other directions. In other words, in addition to TB and HIV care delivery, **information systems for M&E of the two diseases have been developed and implemented as vertical programmes** and have historically tracked the epidemics independently (Auld et al., 2013).

There are reasons for the vertical reporting structures. In addition to the donors whose funds tend to come with monitoring requirements, South Africa's own health-funding system has contributed to reporting becoming and remaining programme-specific. As described earlier, the comprehensive Health AIDS grant forms the main funding channel for HIV and AIDS in the health sector, accounting for 90% of the total health HIV and AIDS allocations (Ndlovu, et al., 2013). Since the Conditional Grant reporting is different to that required for other health funding, provinces need to submit HIV data as well as narrative and financial reports to the National Treasury separately from other health reporting (Kawonga et al., 2012). Furthermore, South Africa's performance based disbursement system which rely on certain performance indicators creates reporting needs for the various public health programmes to demonstrate their productivity (Bhana, 2010). Hence, there exist *internal* governance and finance structures in South Africa that influence the health information system, in conjunction with the structure relating to foreign funding.

The complexity of health reporting is well recognised in South Africa. In 2011, the national Department of Health stated that both local and international institutions "*generate health statistics for key health outcome indicators, often using different methods and techniques, with results that are variable, if not contradictory, at times*" in the report of Health Data Advisory and Co-ordinating Committee (hereinafter: HDACC) which was established to address the challenge. Specifically, the HDACC's aim is to

- *improve the quality and integrity of data on health outcomes*
- *establish consensus on indicators and indicator values and identify reliable data sources to be used to monitor these indicators, as well as mechanisms to improve data systems*
- *advise on baseline values and targets for the negotiated service delivery agreement for the 2010–2014 period.*

(HDACC Report, 2011)

While the HDACC Report indicates that considerable progress in these areas was achieved, it also acknowledges that reliable data on South Africa's key health outcomes remains a challenge. Indeed, Mayosi et al. (2012) describe South Africa as "*data rich but information poor, because the data systems might not*

provide nationally representative, good-quality information in a timely manner". This is particularly problematic in terms of understanding and managing TB-HIV co-infection both at the level of the individual patient and of the population as a whole. Yet, it is essential since South Africa remains the epicentre of TB and HIV co-infection (Churchyard, 2014). Even though research has found that early ART initiation in TB-HIV co-infected patients improves survival (Abdool Karim et al., 2010) in particular in patients with a low CD4 count (Stockdale et al., 2013; Abdool Karim et al., 2011; Blanc et al., 2011; Havlir et al., 2011) — about half of the patients with TB are not aware of their HIV status (Mayosi et al., 2012) or even when they are, significant delays - up to 116 days – may occur in ART initiation (Lawn et al. 2011a). Information related causes, including prolonged referral times in moving between vertically organised TB and ART services, have been stated as a major reason for delays (Lawn et al. 2011a; Kerschberger et al., 2012). Furthermore, South Africa has probably the largest programme of isoniazid treatment for tuberculosis prevention in the world with 372,994 people starting the treatment in 2011. However, more than 80% of eligible HIV positive people have not received this treatment (Mayosi et al., 2012) although it can improve survival (Golub et al., 2015; Rangaka et al., 2014). This further emphasises the importance of relevant, good-quality data that is a prerequisite for treating co-infected patients in an optimal way and on a higher level for developing better understanding of what works, what it costs, where the gaps are and so on.

The topic of this section is collection, reporting and use of TB and HIV information (i.e. the TB and HIV information system as an entity) in South Africa. The researcher is not the first one to examine this area: there are several studies related to the various electronic and paper-based HISs that include TB or HIV related data in the South African context. The most relevant ones are reviewed next. Studies solely on hospital information systems in South Africa (such as the one by Cline and Luiz, 2013 or Hanmer, 2009) and the referral challenges regarding TB or HIV information between PHC facilities and hospitals (Edginton, et al., 2005; Voss De Lima et al., 2013) are beyond the scope of this research. However, they, as well as other studies have been analysed and incorporated

into this study as secondary sources of information, either earlier in this chapter or in the analysis of the findings (chapters 6-8).

To begin, the **TB information system** in South Africa has been evaluated recently:

A) against guidelines on surveillance systems and from the user perception viewpoint (Heidebrecht et al., 2011, in Cape Town)

B) from the data quality viewpoint in Cape Town (Dunbar et al., 2011), Western Cape (Du Preez, 2011) and elsewhere in South Africa (Heunis et al., 2011).

Heunis et al. (2011) note that the quality of TB monitoring was originally very weak because investments in TB reporting lagged behind the investments made in routine data recording of HIV monitoring. While a lot has improved since the early days of TB data collection, studies examining different aspects of the quality of TB data, such as accuracy and completeness, have identified several gaps. Dunbar et al. found a high number of bacteriologically confirmed cases from the laboratory databases that were not recorded in the TB registers at the clinic level (2011). Comparing facility and provincial level data, Heunis et al. (2011) found inconsistencies in approximately one fifth of the data entries. The highest discrepancy was observed in the TB treatment start date (44%). Du Preez and colleagues, also looking at the provincial level data, found that 38% of children who were hospitalised with TB were never registered in the provincial electronic TB register and so did not appear in national or international TB data (2011). Moreover, earlier research has identified inaccuracies and other deficiencies in TB case registration at the clinic level in adults (Botha, 2008) and in children (Marais et al., 2006).

However, in terms of the current functioning of South African TB data collection and processing, Heidebrecht and colleagues have assessed the TB information system as 'strong'. Moreover, they found that users were very accepting of the system, although there were also concerns regarding the system's rigidity. Nevertheless, the integration of TB and HIV data left a lot to be desired, as did the multidrug-resistant TB (MDR-TB) surveillance (Heidebrecht et al., 2011). Staff shortages were found to be the most important challenge in the

daily operation of the South African TB information system (Heunis et al., 2011) in concordance with what is globally considered as a key deficiency regarding HIV related information systems.

Regarding TB data utilisation, in the study by Heunis and colleagues, almost all of the respondents (19 out of 20 nurses) argued that they indeed considered the data useful for planning purposes, including using it for feedback to managers, staff and the community. However, some nurses felt they would need more frequent feedback from their supervisors.

The **HIV** programme was introduced in South Africa soon after the formation of the first democratic government in 1994, with public sector antiretroviral therapy (ART) services introduced in 2004 (Kawonga et al., 2012). The initial National Department of Health (NDoH) reporting procedure consisted of a multi-page questionnaire built on WHO recommendations on a per-patient basis. This became so arduous that it was soon abandoned by sites. There was a plethora of local 'registers', with sporadic and inaccurate reporting to the National Government. For a long time only sites that were research-supported or where donors had invested in expensive M&E systems were capable of outcome reporting (Venter, 2013). A more comprehensive HIV M&E system was established following the NDoH's Operational Plan for Comprehensive HIV and AIDS Care, Management and Treatment for South Africa and expanded after the adoption of HIV & AIDS and STI Strategic Plan 2007-2011 (Kawonga et al., 2012).

In contrast to TB, the data quality and the functioning and the utilisation of the HIV information system in the public health sector in South Africa has not been evaluated to any great extent (Kawonga et al., 2012). The current three-tier framework for ART monitoring is described by Osler et al. (2014). Kawonga and colleagues appear to be the only ones who have assessed it in a more analytical sense (2012, 2013). While Osler et al. view the system as an efficient approach to safeguarding system-wide harmonisation and accurate monitoring of service delivery, Kawonga et al. identify several challenges including availability of data and duplication of work. However, the main challenge for Kawonga et al. is the nature of the system: it can be described as a top-down, over-sized

vertical system, which consumes a substantial amount of energy and resources to primarily generate ART indicators. HIV prevention data is captured in the district health information system (DHIS), but the production of ART indicators bypasses the DHIS, fuelled by a lack of confidence in the capacity of DHIS, amongst other reasons (Kawonga et al., 2012). Kawonga and colleagues have also attempted to assess the degree to which general health service (horizontal) managers exercise authority over the HIV programme's M&E function, namely HIV data collection, collation, analysis and use (2013). They found that relative to vertical managers i.e. managers working in a disease-specific (HIV) position, horizontal managers had lower HIV M&E knowledge, and were more likely to produce HIV data but less likely to use it. Moreover, vertical managers are inclined to use HIV data in sub-programme silos, further indicating that South African HIV M&E coordination is generally not administratively integrated (Kawonga et al., 2013).

Monitoring of TB-HIV co-infected patients in the Western Cape has been covered by Auld et al. (2013) and Heunis et al. (2011). Auld and colleagues examined various paper and electronic stages of the TB and ART reporting flow to determine the completeness and concordance of data. Demographic data proved to be highly complete and concordant across the TB and HIV systems, whereas TB variables in the HIV systems and HIV variables in the TB systems were of lower quality (Auld et al., 2013). In line with much of the evidence from other countries (as discussed in 3.4 and 3.5), they associate data quality issues with structural weaknesses in the collection and processing of data. They conclude that independent recording and reporting systems are among the factors that have impeded integrated care and surveillance for co-infected patients. Data reflecting co-infection is particularly susceptible to error, especially if patients receive their TB and HIV care at separate facilities that use different forms (Auld et al., 2013). Heunis et al. (2011) argue that the considerable burden of the co-epidemic overwhelms the nurses "*possibly causing them to consider collecting and entering data a lesser priority*".

The **District Health Information System (DHIS),** which includes general medicine data and services data but also TB, HIV and PMTCT data, has been examined by Garrib et al. (2008) and Braa and colleagues (Braa et al., 2007; Jacucci et al., 2006; Shaw, 2005). Shaw (2005) and Braa et al. (2007)

describe the creation of an essential data set at district level as a response to the myriad of data collection efforts, whereas Jacucci and colleagues (2006) use South Africa as a case study to argue for sustainability and standardisation of HIS in resource-limited settings.

Regarding data quality in DHIS, Garrib et al. (2008) have found missing data (mean of 2.5%), validation rule violations and data (25%) that was outside the minimum and maximum values specified for the facilities. However, the more interesting findings relate to the deficiencies in the collection, processing and use of that information. Amongst other issues, Garrib et al. report duplication of data collection in all the study clinics (10), high perceived work load and data collation tools that were not used as intended. Moreover, although there was good understanding of the data collation process, very little analysis, interpretation or use of data occurred. Data were not discussed in staff meetings nor analysed or used to inform targets or monitor plans at the clinic level. Finally, there was no feedback, so that most respondents were not aware of their facilities' performance relative to other facilities or to national targets (Garrib et al., 2008).

Jacucci and colleagues (2006) relate data quality to sustainability of HIS i.e. the quality of data needs to be sufficient to sustain the system. They propose that the best strategy for achieving data quality is ensuring that the data is used at the level of its collection. Considering Garrib et al's findings, DHIS may not be sustainable unless there have been considerable improvements since the time of that study.

Based on earlier research, Jacucci and colleagues (2006) identify other barriers for sustainability of IS in under-privileged settings:

- Time constraints in financial support by donors
- Insufficient focus on local expertise
- HIS interventions may not take into account that a parallel reform of the health sector would also be required
- Technical bias of projects (limited focus on Human Resource development)
- Orientation towards pilot projects

The quality of **PMTCT data**, which also ends up in the DHIS, has been examined by Mphatswe et al., 2012; Mate et al., 2009 and Mlambo et al., 2014. Comparing source data from health facility registers to PMTCT data in DHIS all three studies found substantial data completeness and accuracy problems. The oldest study reported hugely inadequate data quality in DHIS (Mate et al., 2009): Surveyed data elements were reported only 50.3% of the time and were 'accurate' (i.e. within 10% of reconstructed values) 12.8% of the time. Mphatswe et al. (2012) found that after an intervention consisting of training, review and audit, the quality of data improved. However the percentage of data that was considered accurate according to the study protocol was still only 65%. A more recent study, while not focusing on the PMTCT data but the quality of care, has cited as key challenges deficiencies in the quality of data, lack of understanding of key indicators and lack of feedback and monitoring linked to action (Bhardwaj et al., 2014). The PMTCT related data quality challenges in the DHIS has resulted in many non-governmental organisations, academic institutions and other development partners in South Africa adopting parallel data collection systems to track programme's performance (Mphatswe et al., 2012).

In summary, previous research has identified considerable challenges around the information systems that are used to collect and report TB and HIV related data in South Africa. First, there are several quality issues with the data. De la Harpe, looking at data quality in the South African context has pointed out that all the stakeholders need to understand the significance of data quality in order to align a stable network around it (2009). The under-appreciation of the importance of data is also noted in some of the studies reviewed here.

Second, the process of collection and reporting of the data, and the overall functioning of the system is sub-optimal. However, with the exception of Kawonga et al., (2012, 2013) and some of the work of Braa and colleagues, the studies have focused on certain specific aspects of that system, rather than attempt to holistically understand the information system in its unique political, economic and social context. Hence, the approach of this study is a valuable addition to the area.

Finally, in particular earlier evidence reports very limited use of the data. According to Byskov and Ohlson (cited in Garrib et al., 2008 and in Heunis et al.,

2011), there has been a universal *"culture of reporting"* instead of a *"culture of using"* data at the district level, and this finding is present also in more recent evidence (Wolvaardt et al., 2014). The findings of this study will also contribute to that discussion.

In summary, the reporting requirements of the key diseases in South Africa are very much in line with global health policy development, resulting in independently functioning monitoring systems and contributing to a *"data rich but information poor"* (Mayosi et al., 2012) health system. In addition to donor funding, country's own funding structures are inclined to maintain a vertical approach to monitoring. There has been progress in various areas including indicator streamlining and integrity of data as indicated by the HDACC report, yet data quality, HIS functioning and data utilisation seem to be challenges, as suggested by the research done in South Africa.

3.9 SUMMARY OF CHAPTER 3

This chapter has reviewed what is written on some of the key issues relating to the research topic, beginning with the basics: what is meant by 'HIS' and why information is important in healthcare. However, in an LMIC context, the benefits of the information collected are often undermined by challenges in data quality, HIS functioning or utilisation of data, as demonstrated by examples in TB, HIV and other public health data in sections 3.4 to 3.6. Globally, information needs have increased due to the changes in international health policy. However, a vertical approach to M&E, customary in South Africa and in many LMICs, tends to provide a number of challenges. The South African TB and HIV information system may be considered as a prime example of this approach, as evidenced by the studies reviewed in section 3.8 focusing on the different paper-based and electronic systems used for reporting TB and HIV related data in South Africa. Therefore, a detailed analysis of the current situation is a worthwhile idea.

Chapter 4 Methodology

4.1 OVERVIEW

While the previous chapter was largely based on other researchers' findings regarding different aspects of the South African TB and HIV health information system, the focus is now on this particular study, and more specifically, *how* the researcher has chosen to approach it. In this chapter, an account of the **research methodology** is given. First, this chapter outlines the conceptual and ontological premises that the research is built on, i.e. it explains the **research approach** applied in the study (in section 4.2). Second, this chapter introduces the **case study methodology** and its key aspects with reference to this particular study (4.3). Third, this chapter describes the **research process** in section 4.4. This includes a number of topics, including explanation on what the 'case' of this case study is, an overview of the research steps that were followed to complete the research and a detailed account of data collection and analysis methods. The research process is also described graphically in Figure 4-3. Finally, a **summary of central aspects** relating to the research methodology is provided (4.5).

4.2 RESEARCH APPROACH

In academia, it is considered helpful to disclose the philosophical paradigms behind the research. These philosophical assumptions on the nature of reality and knowledge, and their connection to how the research is carried out, can be called a research approach. This study could be considered multidisciplinary, since it draws on knowledge from different disciplines (Choi and Pak, 2006) including global health and information systems research. More precisely, it may be defined as falling under the category of **health policy and systems research (HPSR)** and, in particular, **health information systems research (HISR)**, which can be seen as an area of the former. Both of these fields have been connected to various knowledge paradigms, which are discussed next.

According to Gilson (2012), HPSR is seldom based on purely a positivist approach (in contrast with medical or epidemiological research) but draws largely

on social science perspectives, embracing the critical realist and the relativist paradigms. Also interpretivism and social constructionism may be seen as approaches that are close to the relativist paradigm of knowledge in HSPR as shown in Table 4-1.

Table 4-1. Key elements of knowledge paradigms as applied in HPSR. Modified from Gilson (2012).

Knowledge paradigm	**Positivism**	**Critical Realism**	**Relativism (interpretivism / social constructionism)**
Types of questions addressed	Is the policy or intervention (cost)-effective?	What works for whom under which conditions?	How do actors experience and understand different types of interventions or policies? What are the social processes, including power relations, influencing actors' understandings and experiences?
Related disciplinary perspectives	Epidemiology, welfare economics, political science	Policy analysis, organisational studies	Anthropology, sociology, political science
Key research approaches and methods	Deductive: Hypothesis driven Measurement through surveys, use of archival / other data records Statistical analysis Qualitative data collected through, for instance, semi-structured interviewing procedures	Deductive and inductive (theory testing and building) Multiple data collection methods including review of documents, range of interviewing methods, observation	Inductive (may be theory building and/or testing) Multiple data collection methods including in-depth interviewing (individuals and groups), documentary review but also participant observation or life histories, for example.

Without going into a very deep discussion about what kind of research questions or methods are innate for each knowledge paradigm, it can be stated in a very general and simplistic sense that according to the positivist and critical realist

view of world, the world exists independently of those observing it (Bhaskarar, 1975)[40]. In the field of social sciences, however, it is often believed that the phenomenon being investigated is *produced through interaction* among social actors. Such phenomenon does not, thus, exist independently of these actors but is constructed through the way the actors make meaning of their experience, these interpretations changing over time (Gilson, 2012). While critical realism takes a less interpretive stance than relativism or interpretivism, it nevertheless perceives that the *pre-existing structures and processes of society affect, and are affected by, actors*. Likewise, human action is influenced by various individual, group, organisational and societal processes and structures. Consequently, critical realists do not accept that cause and effect mechanisms hold across different contexts and times, but argue that between cause and effect there are a range of mediating mechanisms, including those linked to actors and contexts (Gilson, 2012). This makes sense in the field of HPSR, where it is common that a health policy or a health delivery programme that is successful in one place may not be that in another.

Leaving HPSR and focusing on the information systems research (ISR), in the past, much of ISR has been largely based on positivist research approaches (Mingers, 2003; Kabanda, 2009; Kekwaletswe, 2007 in Mlitwa and Van Belle, 2010). This applies particularly to Sub-Saharan Africa: Mbarika et al. (2005), who searched for publications concerning Sub-Saharan Africa in three top-ranking journals dedicated to ISR (MISQ, ISR and JMIS), found that almost half the articles adopted a positivist research approach. However, as pointed out in a South African conference paper on ICT and E-Commerce research in low-resource settings, the positivist approach fails to give full recognition of the complexities that cannot be tackled by reductionism and the *meanings* that we as humans attach to the world around us (Kabanda, 2009).

There has been a growing interest in various disciplines including ISR in critical realism (Mingers et al., 2013). In response to the statement that there is a lack of examples of how critical realism might be applied in practice within ISR

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[40] Bhaskar actually critiques the traditional, positivist conception of science (Fox, 2009) but due to the limited scope of this research, the ontological and epistemological distinctions in different philosophies are not discussed here further.

(Fox, 2009; Vaujany, 2008), there have recently been a few cases where critical realism has been applied or has informed studies in the field of IT and ISR (see, for instance, Williams and Karahanna, 2013 or Volkoff and Strong, 2013). It has been argued that critical realism should be applied to research concerned with information and communication technologies to increase understanding of causal mechanisms and contexts that are needed in order to achieve outcomes from actions (Fox, 2009).

However, currently also interpretive research is a well-established part of the information systems field (Walsham, 2006). Moreover, qualitative ISR can be performed following a paradigm of pragmatism, which is usually associated with action, intervention and constructive knowledge (Goldkuhl, 2012). In action research the aim is to *"contribute both to the practical concerns of people in an immediate problematic situation and to the goals of social science by joint collaboration"* (Rapoport, 1970). In practice, this may refer to variety of different type of projects where the purpose can be to design, develop or implement an information system, build software, capacity or infrastructure, or to create links between different units engaging in similar development efforts (see, for instance, Aanestad et al., 2014).

Specifically, the theoretical work on health information systems' (HISs) success and failure has generally tended towards an interpretivist approach (Hanmer, 2009). This is plausible, since these type of studies aim to develop an understanding of the social and other factors which contribute to the implementation and operation of HISs in different social environments (Hanmer, 2009).

In this study, the **interpretive research approach** is taken, following the lead by Hanmer (2009) and Uwimana et al. (2012). According to the interpretivist approach, the aim is to deepen the understanding of the relationships between *an organisation* (in this study the case study organisations as listed in 4.4.1), *the people in that organisation* and *the information system* (the TB & HIV collection and reporting system in this study) (Hanmer, 2009). Similarly to Hanmer study, which concerned hospital information systems in South Africa, the researcher does not seek to test an outside view about the

interaction between these elements but gain an understanding of the environment from the perspective of those within it.

In addition, the researcher also recognises a critical realism underpinning her interpretive research in that she is happy to accept the ontological position of critical realism (Mingers, 2004; Walsham, 2006) that there is an objective reality. While interpretive and critical research are philosophically distinct, in the practice of research the distinction is not clear (Myers, 1997). Moreover, in practice, it is not always possible to classify an entire study as only either interpretive or critical (Luukkonen, 2012; Myers, 1997).

The researcher's views on the nature of reality are not the only thing that has an impact on the choice of methodological approach. The broad framework for the research approach used in this study stems from the recognition of the complexity of the issue that is being addressed. As introduced in Chapter 1, the researcher understands information systems as **socio-technical,** along the lines of the definition by Tiihonen et al. (2010): *"a socio-technical system of managing information within an organization; a purposeful systemic entity which consists of people, processes, information and technologies (manual and computer-based ones)".* Moreover, contrary to *"a-contextualized and de-temporalized approaches"*, the socio-technical approach is based on the embedding of information systems into *"the more complex world of situated action: a world that is tightly tied to the characteristics of where the actions occur"* (Sawyer and Jarrahi, 2013). According to Sawyer and Jarrahi, the socio-technical approach focuses on situating work and seeks to investigate all contextual factors, including those with limited influence (2013). However, while the researcher has chosen this type of investigation, she does not think that it is possible or sensible to attempt to scrutinise *all* the contextual factors. Nevertheless, the way she interprets the socio-technical approach is that it is interested in and examines contextual factors in a more profound way than 'traditional' ISR approaches. Korpela, Tiihonen and colleagues have conducted long term research on *how* to analyse and address contextual factors, building on their experiences from Finland, China, South Africa, Nigeria and Mozambique. They propose a holistic information systems development (ISD) approach for developing IS-supported healthcare services (Korpela et al., 2013) of which one part is a LACASA model for context analysis (Tiihonen, 2011). The proposed holistic information systems

development (ISD) approach is called DAISY (Development of human Activity and Information Systems) and it provides integrated methodologies for *"(1) understanding the contexts of healthcare providers, healthcare "consumers" and technology providers; (2) understanding the needs arising from the everyday life activities of healthcare "consumers" in communities; (3) understanding the needs arising from the work activities of healthcare professionals; (4) defining architectural level requirements for information-technological solutions that address the needs; and (5) co-designing the interaction and usefulness requirements of the required solutions"* (Korpela et al., 2013). These areas can be viewed as the 'petals' of the daisy, as illustrated in Figure 4-1.

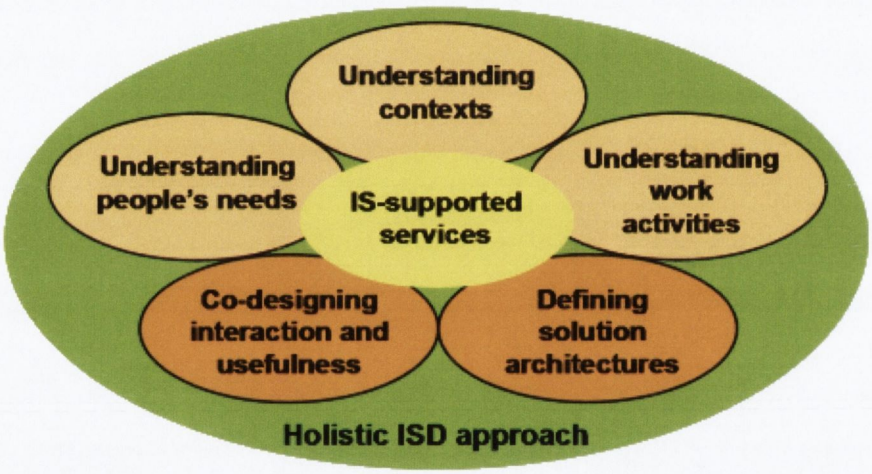


Figure 4-1. The 'petals' of a holistic approach for developing IS-supported services (Korpela et al., 2013).

Since the purpose of this study is not to implement information-technological solutions, the researcher finds the three top 'petals' more relevant than the two bottom 'petals'. Specifically, the LACASA model for context analysis is a helpful tool to examine HISs in a socio-technical manner. LACASA differentiates between the Levels of Analysis, Categories of Analysis and Scopes of Analysis. At each level, the model identifies major categories of contextual factors – technological (infrastructure), human (people), socio-political etc. The factors arise from various scopes, such as natural environment, human cultures, historical developments and immediate surroundings (Tiihonen, 2011). While the researcher did not consider it purposeful to attempt to apply each part of the

LACASA or DAISY models to her data, the models informed her research decisions, in particular in terms of appreciating the holistic nature of the socio-technical approach.

Finally, an accepted distinction of research methods for HPSR, HISR, as well as for many other disciplines is quantitative, qualitative (and mixed). Interpretivism is often associated with qualitative research while sciences applying positivist approaches tend to employ a largely quantitative repertoire. This study follows the traditions of qualitative research, which the researcher undertook in the form of a case study. Typical features in qualitative social research include non-numerical data, inductive logic, a focus on meaning and appreciation for contexts (Robson, 2011), which all support the aims of this study.

4.3 CASE STUDY AS A RESEARCH METHOD

Case studies have been used widely in a range of disciplines, including public health (Gerring, 2006), as well as in various research fields of relevance to HPSR (Gilson, 2012). Case studies have also gained acceptance over the past decade in IS research tradition (De la Harpe, 2009; Dubé and Paré, 2003) and are an accepted method for examining HIS implementations (for instance in Hanmer, 2009; Mohd Yusof et al., 2008; Aarts et al., 2004). Moreover, the interpretive case study approach has also been used to gain understanding on not-easily-quantifiable values like 'local sustainability' in the context of a HIS study in South Africa (Jacucci et al., 2006). The distinctive need for using case study as a research method arises out of desire to *understand complex social phenomena* (Yin, 2009). Case study as a research method (as opposed to case studies in teaching) has been defined as follows:

> *"Development of detailed, intensive knowledge about a single 'case', or a small number of related 'cases'"* (Robson, 2011)

or

> *"an empirical inquiry that*

- *investigates a contemporary phenomenon in depth and within its real-life context, especially when*
- *the boundaries between phenomenon and context are not clearly evident."*

(Yin, 2009)

Typically, case study research involves a **selection** of a single case or small number of related cases of a situation, individual, or group of interest, **study** of the case in its context, and **collection of information** via a range of data collection methods including observation, interview and documentary analysis, producing usually, but not always, qualitative data (Robson, 2011).

In addition to Robson's relatively straightforward definition of case study, and Yin's slightly different take on it, an earlier definition can be considered. According to Schramm (1971), the central tendency among all types of case study is that *"it tries to illuminate a decision or set of decisions; why they were taken, how they were implemented, and with what result"*. While Yin criticises that citing a case study topic is insufficient to establish the definition for case study, there is something in this definition that enlightens the essence of this research. How TB & HIV information is collected, reported and used, as well as the challenges in the system, have resulted from a set of decisions over time and the way those decisions have been implemented within the local context.

Every researcher has to make a decision on which method to choose to investigate the research question, and to be able to argue why the method is appropriate. Equally, in this research, it had to be considered why a case study is the right method over other well-known methods in social science. Surveys, ethnography, grounded theory study or action research might have been used instead. However, they would have required a different kind of approach and resources and would likely have produced a very different kind of study. Looking into the case study definition by Yin (2009) in Table 4-2 provides a way to check if a case study inquiry is appropriate for this study.

Table 4-2: Yin's definition for a case study (2009).

Yin's case study definition	**How it applies to this study:**
A case study *"investigates a contemporary phenomenon in depth and within its real-life context, especially when the boundaries between phenomenon and context are not clearly evident"*	Challenges in data collection, reporting and use is certainly a contemporary issue, which would be very difficult to investigate anywhere else than in its real-life context. Additionally, the boundaries between phenomenon and context are not clear. Indeed, there are fuzzy boundaries on two different levels. First, the researcher sees the South African TB and HIV related information system as a socio-technical entity. The boundaries within and closely around that type of system are not clearly evident. Second, that systemic entity operates in a larger socio-economic context. It is part of a health system and socio-political system which again in themselves have fuzzy boundaries. For instance, if an over-worked data capturer in a busy and understaffed clinic feels that it does not matter that much if he does not get the numbers quite right for the statistics, this challenge causing poor data quality is not just an information system challenge but it is rooted in contextual factors.
A case study *"copes with the technically distinctive situation in which there will be many more variables of interests than data points, and as one result relies on multiple sources of evidence, with data needing to converge in a triangulating fashion, and as another result benefits from the prior development of theoretical propositions to guide data collection and analysis"*	The kind of distinctiveness, complexity and use of various sources of data that Yin describes marks this research profoundly. All of the interview participants had their particular viewpoints, their particular roles, particular responsibilities, attitudes and challenges regarding the TB & HIV HIS. They could not all have been asked the same questions, such as in most surveys, because that would have produced irrelevant, fragmented and insufficient data. The researcher could have surveyed, for example, only a large number of South African M&E professionals but that would have provided much less in-depth data, since the situation varies considerably throughout the country and this approach would have lacked both the decision-making and the field level. Had the researcher interviewed, for instance, only TB nurses nationwide, many challenges in HIV or *co*-infection data would likely not have come out. Hence, since much of the challenges lie within the management of *the whole entity in its context* rather than one disease or one information flow, a holistic case study seems the most, if not the only, suitable method for this research. Moreover, the researcher had anticipated that each encounter with evidence (whether that is an interview, observation or document analysis) might provide an

	abundance of data and alternative directions where to take the research. Thus, cross verification of data from multiple sources was required for validating data. Fundamentally, the data that the researcher obtained formed the essential building blocks to develop further ideas that the researcher was in turn able to use in the subsequent encounters with the evidence. A less flexible method than a case study may have produced limited, even faulty results.

In addition to the definition by Yin, there are reasons why the case study approach is especially relevant to the HSPR. First, health policy and systems experience is particularly influenced by, and is often embedded in, contextual factors that need themselves to become part of the focus of inquiry (Gilson et al., 2011). As discussed, this notion is strongly present also in this research. Second, health system research questions often require study of the complex behaviours and relationships of actors and agencies; and how those relationships affect change. Case study is particularly suitable for such experiences (Thomas, 1998). Third, the case study approach can be used to analyse policy, but it can also generate information for further policy development (Gilson, 2012). That is also an ambition for this research.

Dubé & Paré (2003) have listed reasons why case study research has commanded respect and is particularly well-suited to ISR. Although they are primarily interested in positivist case study research, the following arguments may be applied to all kinds of IS case studies, including this one. First, ISR is often interested in information systems in organisations and the interest has shifted to organisational rather than technical issues (Benbasat et al., 1987). Second, having access to and reporting on real-life IT experiences, case studies provide a window for both academia and practice to have a look in and keep up with the ever-changing IT world. Third, the holistic and flexible approach with mixed data collection methods suits well the need to understand the complex and ubiquitous interactions between organisations, technologies and people. Fourth, comprehensive case investigations support new ideas and new lines of reasoning and pinpoint the challenges and opportunities facing IT professionals and managers. Finally, case study research can be used for exploration,

hypothesis generation and testing, as well as providing explanations (Benbasat et al., 1987; Cavaye, 1996 in Dubé & Paré, 2003 and Yin, 2009), all of which contribute to the development of knowledge in the field of IS (Dubé & Paré, 2003).

There are variations in the academic literature on the extent to which case study findings should or should not be generalisable. Like most current theorists of the field, Yin (2009) argues that it is unhelpful to try to consider a case as a 'sample' or case study results in a way that they could or should be generalised to a known population – i.e. attempt statistical generalisation. However, according to Yin, who takes a rather positivist stance, case studies are generalisable to theoretical propositions. In other words, analytical generalisation is possible and desirable. Consequently, he seems to favour multiple-case studies, and the researcher's endeavour towards developing some broader theory.

Nevertheless, there are other approaches. Thomas (2011) argues that the alleged shortcomings in generalisability of the case study approach do not minimise what case studies can offer, but in fact free them to offer something different and distinctive in social science research. The potential of case study may be realised in what he calls *exemplary knowledge*. According to him, this is something rather more nuanced than generalised knowledge and it draws its legitimacy from phronesis rather than from theory.

Non-theory generating case studies have been applied to various contexts, including public health policy and eHealth. Greenhalgh et al. (2011) apply ideas from Ludwig Wittgenstein's post-analytic philosophy to justify the single-case study methodology. Particularly, they explain why the richness and detail of the case study approach would effectively have informed the policymakers on England's rather unsuccessful USD20.6 billion National Programme for Information Technology, if the policymakers had listened. They argue that detailed analyses of individual programmes, articulated in such a manner as to illuminate the contextualised talk and action of multiple stakeholders, offer unique and important insights. Moreover, those kinds of accounts, which are "*portrayals rather than models*", do not deliver statistical nor theoretical (analytical) generalisation, but "*heuristic generalization*": i.e., to achieve a clearer understanding of what is going on (Greenhalgh et al., 2011). They

conclude that case studies are appropriate in understanding the complexity of contemporary health care, particularly when combined with the multiple stakeholders in large technology initiatives, and the nuanced case study reports enable more productive debate about complex, interdependent socio-technical practices. Hence, it is indeed academics' responsibility to develop ways of drawing judiciously on the richness of case studies to inform and influence health policy (Greenhalgh et al., 2011). Similarly, this research attempts to be engaged and interpretive rather than abstracted and representational. However, it can still provide important insights and identify new lessons that can be applicable locally, nationally and internationally, beyond the immediate surroundings of Khayelitsha.

In conclusion, this research aims to investigate the key challenges in the South African TB and HIV information system through a lens of an in-depth case study. This approach is consistent with the choice of data collection tools, namely interviews, document analysis and observation. As evidenced by the literature (Dubé and Paré, 2003; Gilson, 2012) the case study approach is suitable for ISR and HSPR and it therefore makes an appropriate choice for this study.

4.4 RESEARCH PROCESS

4.4.1 The 'case' in this case study, the scope of the research and an overview of the research steps taken

What is the 'case' of this particular case study? This researcher discusses paper-based and electronic health information systems, data flows, people, organisations and so on – it may be difficult to see what is the 'case' of this study. In general, the 'case' can be an individual, group, neighbourhood, service, innovation, programme or virtually anything (Robson, 2011). In HPSR, cases can be, amongst other things, health system decision-making units or particular healthcare facilities (Gilson, 2012). In line with the research question,

> **What are the key challenges in the current TB and HIV information system in an underprivileged community?**

the whole socio-technical information system of collecting, reporting and using TB & HIV information at the case study setting is the 'case' in this particular case study research. The case study *setting* is a clinic (which can be called 'the case study clinic') in the case study sub-district (Khayelitsha) in the Metropolitan Municipality of the City of Cape Town in the Western Cape Province in South Africa, as illustrated in Figure 4-2.

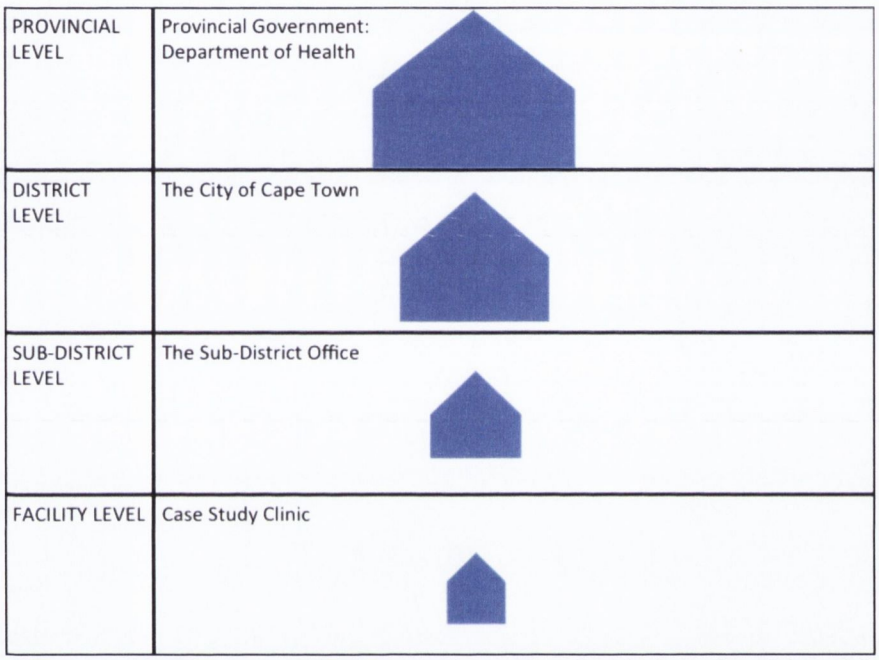


Figure 4-2. The case study setting. The basic levels of health authority in South Africa up to provincial level and the studied health organisations on those levels.

One can also view these as four organisations or four decision-making units: the primary health care facility, the sub-district office, the City Health i.e. the City of Cape Town (CoCT) Health Department and the Provincial Health (via the Metro District Health System of the Western Cape Department of Health) as organisations all have their input on and all draw from the TB & HIV information system, and simultaneously they are a part of that system. It should be noted that these are not the only organisations that are involved with TB & HIV information collection, reporting and use. For instance, sometimes there are provincial and city authorities operating at the same level of the health system. However, there was a very limited amount of information on any organisations other than the 'main' ones described in Figure 4-2. Establishing what these other organisations are in a detailed manner and obtaining access and research

permits to them was beyond the scope of this research. Moreover, as mentioned in the introduction, the data flows do not actually stop at the provincial level but flow all the way to the national, regional (for instance 'Africa' level) and global level. Again, accessing evidence, such as interview information on the national level and beyond would have required extensive permits as well as monetary and time resources that were not available.

Now, the case study setting is defined. The aim of the research is not to investigate everything that goes on in the case study setting. To understand the South African TB and HIV system in the context of an under-privileged setting, the study examines a number of data flows that are defined as

1. being TB or HIV related

2. originating from one public health clinic in Khayelitsha, which is a part of the City of Cape Town, in Cape Town Metropolitan District of the Western Cape Province in South Africa.

This research found 6 TB or HIV related data flows, which are described in detail in the next chapter. However, at the case study clinic other pieces of TB and HIV related information can be found. With pieces, this research means paper documents, spreadsheets, HISs and so on. Some of that information is sent somewhere, so basically it could be viewed as a TB or HIV related data flow. An example of this kind of dataflow is a list concerning HIV clients whose ARV treatment has been initiated by nurses (NIM-ART). However, due to the limited scope of this study, this is excluded as a minor data flow while the decision was taken to focus on the 6 'main' TB and HIV related data flows. There may be more data flows which are 'minor', less frequent, less established or less focused on TB and HIV per se, concerning, for instance, work force or medication stocks but as with NIM-ART data, they are excluded. Moreover, TB is notifiable by law in South Africa and requires infectious diseases notification. The TB notification information flows via various routes depending whether the patient is diagnosed and treated in a public clinic, a hospital, a correctional service or a private clinic. This flow has a slightly different dynamic than the other flows discussed in this

research, so while the preliminary analysis revealed some system-wide challenges regarding duplicative work and sub-optimal data quality in particular with the TB death notification, a decision was made to leave the infectious disease notification data collection and reporting out of the main analysis.

To answer the research question and accomplish the research objectives, the study started with a literature review identifying the key issues relevant to the research topic and establishing appropriate research approaches and underpinning theories to investigate the research topic. Following a pre-research investigation, a suitable clinic was identified. After receiving the required research permits, the data was collected. More specifically, the researcher obtained data by interviewing 28 key informants whose roles varied from top-level authorities to ground-level staff and from M&E and data capturing to clinical and administrative/managerial positions. Moreover, direct observation and official document identification and collection were used to obtain data. Next, the data obtained was transcribed, coded and analysed. Finally, the findings were interpreted to derive the conclusions and identify the contributions.

Figure 4-3 illustrates how the following steps were taken to complete the study: 1. first literature review, 2. formulation of research question, 3. pre-research investigation, 4. ethical and other approvals, 5. data collection, 6. data transcribing 7. data coding and preliminary analysis, 8. second literature review, 9. data analysis and 10. thesis writing. However, in the figure, the research process is portrayed in a simplified manner. In real life, there is more overlap and iteration.

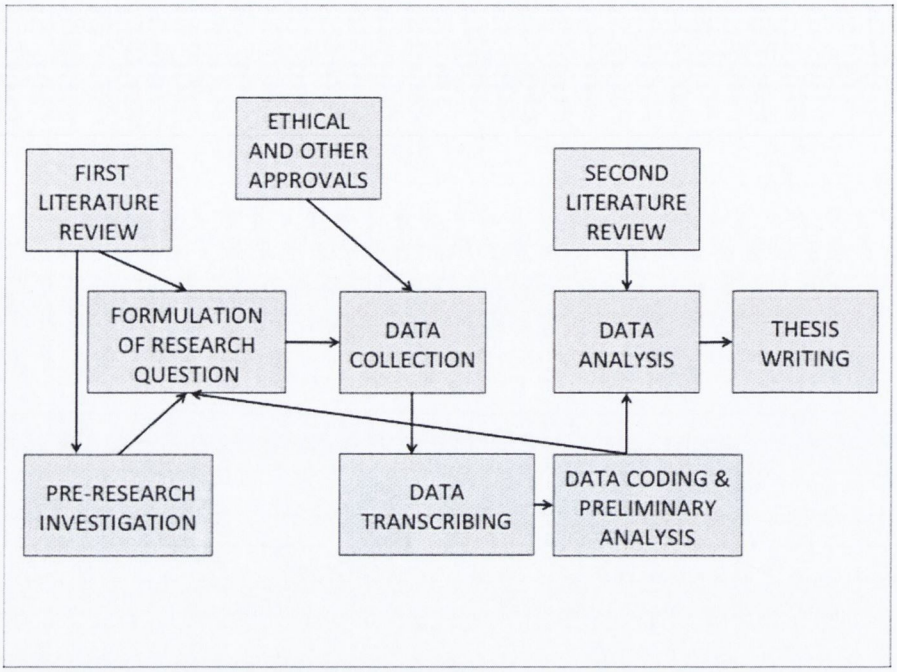


Figure 4-3. Research steps taken.

As Figure 4-3 shows, the first literature review informed the formulation of the research question. Consulting literature continued after the pre-research investigation, as indicated by the second arrow. Finally, the research question was further refined by the preliminary analysis of the collected data, hence the arrow pointing back to the research question.

Some of the research phases are more self-explanatory than others. More information on the approach for literature reviews is provided in Chapter 3 (in 3.1), information on the research question has already been provided and thesis writing does not require further elaboration. Therefore, only the remaining steps are described next, beginning with the pre-research investigation (4.4.2). Following that, this chapter discusses research permits and ethical clearance (4.4.3), data collection in terms of interviews and key informants (4.4.4); identification of the research site and the informants (4.4.5); challenges relating to interview situations (4.4.6); direct observation (4.4.7); and document analysis (4.4.8). Section 4.4.9 provides further information on the research process by describing how the data was transcribed, coded and analysed.

4.4.2 Pre-research investigation

South Africa is a complex country with a history and political system that have also influenced the health system, as described in Chapter 2. A foreign PhD researcher cannot expect that she can just 'waltz in' and successfully request an interview from a health worker or government official. Or, that she will immediately gain the access to or the trust of the stakeholders of the local underprivileged community. On the contrary, achieving these goals will take time and require several meetings. Hence, the researcher spent 3 months in South Africa in 2011, which is here called the pre-research investigation phase. During that time she worked for an academic and a research institution, conducted informal preliminary interviews, familiarised herself with the South African health system, funding and health care delivery, visited 12 clinics in rural and township settings, as well as created a network of preliminary contacts. This should be seen as an integral part of the research process, since it built the foundations for a successful data collection phase, as well as future research endeavours.

4.4.3 Ethical and other approvals

All pertinent ethical issues, including issues of privacy, confidentiality and consent, were addressed. All interview participants were asked to give their informed consent in writing (see Appendix B) and they were given an information sheet about the research, which was available in English, Afrikaans and Xhosa, a local language. Patients were not interviewed and no patient data was collected. The researcher paid special attention not to inflict a significant nor other burden on the participating case organisations, in particular with regard to the busy case study clinic. A variety of approvals needed to be obtained. This process is described in Appendix C.

The following chapters, including the data flow descriptions, mention several health and other professionals, of whom **some** were participants of this study. Rather than identifying specific persons with their exact full occupational title, this study refers to organisational units or roles - particularly in a case that there is i) only one person working in that role or ii) there is something else in that title that would directly reveal the person's identity. This to done to enhance

the study participants' anonymity and to avoid the misconception that any deficiency in any part of the health information system studied might be the fault of a particular identifiable individual. For the same reason, quotes are assigned to:

A) "Informant" when the researcher thinks that further informantion on person's position does not add any value to the quote
B) "Anonymous quote" when the researcher thinks that the quote includes information that makes the informant recognisable if further informantion on his/her position or employer (City/Province) is given or that the quote includes sensitive informantion
C) or when helpful, some further information on person's position or data use is given, but in a way that his/her identity is not revealed. It should be noted that it is additional *contextual* information, and it does not directly refer to Tables 4-6 or 4-7.[41]

4.4.4 Interviews and key informants

To answer the research question and accomplish the research objectives, data was collected in the form of key informant interviews. Interviewing is a widely used method in social research and one of the most important sources of case study information (Yin, 2009). A commonly made distinction is structured, semi-structured and unstructured interview (Robson, 2011). This study used semi-structured interview, largely in a way described by Robson, 2011:

> *"The interviewer has an interview guide that serves as a checklist of topics to be covered and a default wording and order for the questions, but the wording and order are often substantially modified based on the flow of the interview, and additional unplanned questions are asked to follow up on what the interviewee says."*

[41] For instance, the tables indicate that two informants worked in managerial positions with a line-management function over their subordinates. Because this category is so small, the quotes of these informants are not assigned to 'managers' but referred to in a different way.

Precisely, the researcher had a *"shopping list of topics"* (Robson, 2011) for each interview situation, a pre-considered wording for some questions and a plan how to proceed from an introduction and warm-up to the main body of interview and to closure. However, depending on the situation and the time allocated for the interview, the order of questions, their wording and the attention given to different topics altered considerably. If there was something 'tangible' available at the interview situation, such as a computer system or paper files, the researcher was eager to use them as part of the interview for the reasons discussed in section 4.4.8.

The original interview template was piloted, but that had only limited use since each of the interviewees had their own specific occupational role and each of the interview situations was different in terms of the physical, social and contextual surroundings. Table 4-3 shows a sample of interview questions. As it can be seen, they range from very particular to very broad questions.

Table 4-3. Sample interview questions.

Sample interview questions	Intended purpose of the question
What TB and HIV related information are you currently regularly collecting from the public health care units? What information are you involved with? You are involved with A, B and C information? Let's talk about the A first. Why do you collect it? In what form does it come in? Where does it come from? How often do you collect it? What do you do with it? Where do you send it?	To obtain specific information on particular data flows and identifying gaps.
If you consider **your** daily work in the role of X, what are the main challenges? Why?	To obtain information on the key challenges in the health system and the HIS and their root causes, as experienced firsthand by the local stakeholders.
If you had a magic wand and you could change anything in the current collection, reporting and use of TB and HIV information, what would you change? Why? Other people whom I have talked to have brought up the same issue – why do you think it has not been changed yet?	To obtain information on how the local stakeholders perceive the health system and the HIS and the root causes behind the challenges.
Is there anything else that you want to tell me about the register X? Is there anything else I should know?	To give each interviewee an opportunity to discuss areas that they believe to be important.

Naturally, not all informants were asked all / the same questions. Informants who had decision-making power were asked more policy related questions, whereas those who worked at the field level might not be asked that question in the same form. Some questions were dropped as unhelpful after the first couple of interviews, while some new questions were derived from the new knowledge gained from earlier interviews.

There were 22 interviews with 28 informants. The interviews were conducted face-to-face, as 18 individual interviews and 4 group interviews. As indicated in Table 4-4, there were two small group interviews of 2 people and

two small group interviews of 3 people. The small group interviews were chosen when the informants worked in similar roles or otherwise closely together or when it was not possible to interview them separately. The duration of the interviews varied considerably from half an hour to more than two hours. The interviews were conducted over a period of three months in April to June 2012. Interviews were audiorecorded.

Table 4-4. The number of informants and their distribution in individual and group interviews.

Number of informants per interview	Number of interviews of that type	Total number of informants:
1 - Individual interview	18	18
2 - Small group interview	2	4
3 - Small group interview	2	6
Total:	22	28

With one exception, the interviews were conducted at the place of work of each informant. The physical and social environment of each interview situation varied considerably from peaceful offices to busy corridors or a corner of the waiting room full of patients at the case study clinic.

Of the 28 informants, 15 worked for the City and 11 worked for the Province. Additionally, 2 informants were former employees of Provincial Health with a background of cooperation with the City and additionally, they still worked in the field of health and ICTs. They provided predominantly historical data. Table 4-5 below summarises the distribution on informants by their employer.

Table 4-5. Distribution of informants by their employer

	The City of Cape Town Employees	The Western Cape Province Employees	Former employees	Total
Number of Informants	15	11	2	**28**

The researcher interviewed informants at all the levels: clinic level, sub-district level, district level and provincial level. While provincial level employees are employed by the Province, the district, sub-district and the clinic level staff are employed by the City. The researcher could indicate the number of informants working on each level (clinic, sub-district, district and provincial level) but this is not done since it could jeopardise the anonymity of the informants.

Instead, the informants, all connected to South African TB-HIV HIS (understood as a socio-technical entity), are described as follows. Excluding the two former employees, the 26 informants worked in these categories:

- **Director:** 6 worked at director level either for the City or the Province in senior positions with considerable decision-making power and with titles such as Head, Director or Deputy Director.
- **Health Governance, lower:** 5 worked at a slightly lower level of governance either for the City or the Province with less decision-making power than the Director category. While they occupy manager or manager-like positions in their own thematic area, they tend to have no line-management relationship over the people they worked with. A person could still have a medical background although he/she had switched into health governance.
- **Reporting/M&E:** 5 worked in the area of information collection, management reporting and use/M&E in an office-based position either for the City or the Province with very little to occasional interaction with the clinic level.
- **Managers:** 2 worked in managerial positions with a line-management function over their subordinates.

- **Field level:** 8 worked at the ground level i.e. 'field level' at the clinic and/or sub-district level with no sub-ordinates. Positions include a) medical i.e. taking care of patients at the clinic, b) clerical i.e. collecting information and/or entering information c) positions with combination of coordination + information collection, reporting and use. For instance, a medical officer and a nurse are considered here as ground level positions, not in the sense that the position would not require education and skills but because, similarly to other informants in this category, their everyday work is shaped and defined by the demanding reality of the busy township clinic. Below, the distribution of the informants by their occupational role is summarised in Table 4-6.

Table 4-6. Distribution of the informants by their occupational role.

Occupational role	**Number of informants**
'Directors'	6
'Health Governance, lower'	5
'Reporting/M&E'	5
'Managers'	2
'Field level' (including medical/clerical/coordination)	8
Total:	**26**
Former employees	2
Total:	**28**

It should be noted that although there are 5 informants in the reporting / M&E category, all the informants are in one way or another connected to reporting chain of TB and HIV information. Therefore, in Table 4-7, there is further information on their relation to South African TB-HIV HIS.

Table 4-7. Distribution of the informants by their relation to the TB-HIV HIS.

Occupational role	Number of informants	Relation to the TB-HIV HIS
'Directors'	6	Emphasis on data use
'Health Governance, lower'	5	Emphasis on data use
'Reporting/M&E'	5	Emphasis on data management
'Managers'	2	Emphasis on data use / production
'Field level' (including medical/clerical/coordination)	8	Emphasis on data production
Total:	**26**	
Former employees	2	Emphasis on data use / data management.
Total:	**28**	

Finally, the informants included females and males, as well as people of black, coloured and white origin. As a first language, they spoke Xhosa, Afrikaans, English and possibly other languages. The interviews were conducted in English.

4.4.5 Identifying the research site and the informants

The selection of the research site, which cannot be separated from the selection of "case" to be studied, was based on purposive and convenience sampling. The researcher sought to investigate an underprivileged site (the clinic and sub-district) as the purpose was to look into a site where there might be challenges that were caused, accentuated or revealed by the disadvantageous environment (rather than examining a site where everything is working perfectly) and where improvements that might be suggested, could make a difference. However, the

researcher did not wish to choose an area in the very beginning stages of development, but one which would already have an established system to collect TB and HIV data that could actually be examined. Since the Western Cape is more developed than other provinces[42] with many of the information systems actually developed in the area and since the researcher had established connections to the Western Cape and Metropolitan Municipality (the City of Cape Town) these were chosen to be the province and the district where the study would take place. Random selection of cases is not necessary or even preferable in case study research (Eisenhardt, 1989).

While the researcher could decide that it would be feasible and purposeful to conduct the study in the Metropolitan Municipality in the Western Cape, she could not pick just any clinic in any sub-district. As is common in research, negotiations with local authorities had an impact on the final selection. It can be argued that this can cause bias but on the other hand

- this is a case study not requiring a 'representative sample' as discussed in 4.3.
- Inclusion of authorities is inevitable and their local expertise is invaluable.
- In health research, the selection of a research site has to be ethical; choosing an under-staffed clinic under severe pressure to deliver even the most basic care would mean that the research could, albeit temporarily, cause harm to the community. That is unacceptable.

The researcher had to change clinic once but as argued by Walsham whose expertise is in interpretive case study research in information systems, a researcher needs the *"willingness to accept 'no' for an answer but the persistence to try elsewhere"* (Walsham, 2006). The change happened very early on, before the beginning of the data collection. In other words, all the data collection took place at one clinic.

Informants were identified as those collecting, using and/or reporting TB and HIV related information that originates from the case study clinic and is

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[42] This is something that informants routinely argued. Evidence, in terms of human development index (UNDP, 2003) and estimates on poverty, (Human Sciences Research Council, 2014) support the claims.

reported to the sub-district, district and provincial level. A mixture of purposive, snowball and convenience sampling were indicated rather than deviant case or quota. Similarly to the selection of the clinic and sub-district, the knowledge of local authorities and experts was used to identify the key informants. The researcher followed the case logic as described by Robson (2011):

> *"...one starts with a single interview, not knowing how many are going to be sufficient. The choice of the second interviewee will be based on issues arising from the first, perhaps using snowball sampling or some other means to identify a person from a particular background, age or gender. The process is repeated several times until saturation."*

The data collection and the whole study were conducted within certain economical and practical constraints, but the researcher strongly believes that she was able to obtain a sufficient amount of data. The key themes began to emerge already in the first one or two interviews, and the last few interviews provided little new information, suggesting that saturation point had been reached.

4.4.6 Challenges

The researcher was aware that she came as an outsider; a foreigner who did not have the seniority that comes with long experience or local professional and social knowledge on many South African issues. Furthermore, the connotations connected to white skin colour and being a Westerner would be present regardless of what her own attitudes or intentions were.

On the one hand, regarding the approval process and interviewing experts in senior positions, the researcher was kind of an 'underdog'. In other words, she had to be able to justify the importance of the study, answer questions, such as 'what can you tell us that we would not already know' and demonstrate BOTH the understanding that she had already gained of the South African health system, HIV-TB reporting system and the complexity of the socio-political system AND the fact that she was fully aware that she was in very early steps in her

inquiry and did not think that she knew it all. The pre-research investigation phase in the area was essential to overcome that kind of barrier, as well as an open and honest attitude towards informants and authorities. Moreover, adhering to the protocol that was required to obtain the required permissions was important.

On the other hand, at the field level, the researcher had to recognise that there might be other kinds of barriers. The interview situation is not always 'equal' or free of all power relationships, no matter how much the researcher would want that. While some informants were uneasy during the initial stages of the interviews, attempts by the researcher to look for common ground were usually appreciated and a previously mentioned open and honest attitude was helpful. Moreover, the researcher was usually properly introduced by a manager or another person familiar to the informants with whom they already had a good and trusting relationship. In addition, the researcher followed an example described in another PhD study on healthcare & ISs in South Africa (De La Harpe, 2009). According to De La Harpe, the only way that the researcher can understand the multifaceted actions of the actors as they act and relate to each other in that kind of complex healthcare setting is *to immerse herself in the setting* by seeking to understand the environment sufficiently to note the meanings of events and relationships.

Interpretive approaches rely heavily on the common sense, insights, knowledge, intuition, judgment and experience of the researcher to interpret the situation. Events and relationships may not always be a true reflection of the informants' perceptions and ability to interpret their own actions, but may sometimes be the result of a form of power inflicted upon them by other actors (De La Harpe, 2009). The researcher cannot rule out that she may have in some cases been given answers that an interviewee thinks were 'correct' in terms of what she or he assumes that the interviewer wants to hear or in terms of what the interviewee 'should' reply to comply with the managerial or organisational views. It relied then on the researcher's judgement to interpret the answers in their context and use other data sources to validate the information.

Finally, safety issues can be seen as a special challenge concerning this study, in particular with data collection. The next Vignette illustrates the issue,

while simultaneously informs the reader on what it is like to live and work in Khayelitsha, as many of the informants of this study do.

A CASE STUDY WITHIN A CASE STUDY:

Fieldwork in Khayelitsha

The fieldwork in sociological research projects may sometimes take place in difficult or even dangerous circumstances (Nilan, 2002). The researcher knew in advance that South Africa is a violent place to live: for instance, 45 murders take place per day, according to the analysis of the Institute of Security Studies (ISS, 2013). Cape Town is considered safe, however, between April 2011 and March 2012, police recorded more murders in Cape Town than in Johannesburg and Pretoria combined (ISS, 2013). Moreover, of the areas of Cape Town, Nyanga, Khayelitsha, Gugulethu and Harare remain the most murderous in the peninsula, according to an analysis that took population size into account (ISS, 2013). In addition to abnormally high murder rates, attempted murder, rape, robbery, carjacking and assault are prevalent. Whilst most crime happens to the residents of these areas, the researcher had to take caution and plan in advance entering the research site and collecting the data. Precautions included following the news of strikes and protests in the area, planning the driving route ahead, always travelling in daytime and learning a few phrases in the local language. Most importantly, the researcher did not visit the township alone, but with a local colleague, whose knowledge of the area and ability to drive and speak Xhosa was of great assistance.

However, it so happened that a series of vigilante killings took place in Khayelitsha at the time of the data collection, some of them in close proximity to where the researcher had visited and was going to visit. A lack of effective policing was blamed for the rise in vigilante groups who had killed suspected criminals by 'necklacing' i.e. setting them alight with tyres around them. While the researcher would not consider herself to be a likely target of mob violence, after encountering graphic photos of the incidents (which had happened in broad daylight, contrary to what she had expected), distinct qualms about her own personal safety began to register, much as described by other social scientists, who have had to make decisions as to how to address risks in fieldwork (Nilan, 2002; Van Maanen, 1988). What if they drove along the wrong road (there are very few road signs) or just simply happened to be in the wrong place at the wrong time? Earlier, when travelling with another colleague, our car was forced to stop at an intersection and a young man washed the car window although he was specifically told not to. The researcher's colleague refused to pay which led to a heated argument

with a lot of yelling as the young man was trying to prevent us driving forward. It remained unclear to the researcher whether her presence had exacerbated the situation or influenced it at all, and what would have been a viable strategy to get out of the situation, if the young man and his friends had been able to stop the car.

In the end, the researcher was able to carry out the data collection, and fortunately nothing undesirable happened. For the researcher, learning about the incidents served two purposes: first, it provided contextual data about the township as a living and working environment. Second, it gave an opportunity for the researcher to reflect on her position as a researcher, which is influenced by the notions of being white, outsider, Westerner, female, and so on. Lessons can be learnt. First, data collection in under-privileged settings may be risky and have unforeseen consequences. Careful planning is advised, but even then it is possible that due to limited knowledge or purely bad luck, a researcher may find herself in circumstances where she has very little control of the situation. While universities, departments or Ethics Committees have no direct responsibility over what kind of risks a researcher chooses to take, it may be worthwhile to consider if more could be done to acknowledge the risks and ensure the safety of researchers, particularly those with limited field experience.

Vignette 4-1: Fieldwork in Khayelitsha.

4.4.7 Direct observation

Data from direct observation can be used to complement information obtained by virtually any other data collection technique (Robson, 2011) and because a case study takes place in the natural setting of the 'case', that creates a valuable source of evidence (Yin, 2009). In this study, direct, unstructured observation was used as a supportive method to validate, corroborate - or sometimes noticed to contradict the messages from interviews and official document analysis. The observations took place in connection with the interviews. Similarly to the interviews, their duration varied considerably from half an hour to more than two hours and they were conducted over a period of three months in April to June 2012. Observations can be made throughout the field visits (Yin, 2009), and this approach was chosen because of its ability to obtain especially contextual evidence about the case. In other words, in the current study, observations were made during the whole visit to the site as opposed to the interviews, which have more definite starting and ending points. For instance, on her way to the case study clinic, the researcher would already make observations on the case study

community, Khayelitsha, in a casual and unstructured manner. While waiting for an interview to begin, the researcher would observe the surroundings i.e. notice (for instance) that the waiting room of the case study clinic is extremely busy and crowded with patients or that the office of a high-level health official does not differ much from any office in a high-income country. In the actual interview situation, the informants, anything they showed (i.e. documents, computer programmes, information systems), as well as the interview settings (i.e. the case study clinic and the various office environments of the higher level authorities) were observed. The informants were made aware of observation in the informed consent form. Note-taking with pen and paper was used to record observations on-site. Some of the notes were summarised in an electronic document (MS-WORD) subsequent to the field visits. While the researcher recorded data from the observations in written form, she decided that it was not purposeful to code it thematically in the way the interview data was coded. Rather, the researcher used the observational data, alongside the official documents data, to crosscheck and triangulate the interview data.

In the interview situation, if possible, the researcher was keen to ask the informants to show the actual tools they worked with and use them as part of the interview. These tools could be anything from register sheets to computer programs and information systems. Including the tools in the interview served many purposes. First, it was sometimes the only chance for the researcher to see that system or document. Second, 'something tangible' was also helpful in terms of proceeding systematically with the interview and structuring issues around that tool. Third, it ensured that the interviewer and the informant spoke about the same thing, despite any language barriers and the various clinical, occupational and IT related abbreviations. Fourth, challenges and surprising issues relating to the tools emerged, which would not necessarily have come out otherwise. Fifth, it created a better atmosphere: the researcher had a chance to show interest and enthusiasm and the informant could demonstrate her familiarity and expertise in the area. This created a situation in which both were more 'equal' participants than in the traditional question-answer line of inquiry. Sometimes, a researcher was given screen-captures of a system or a paper copy

of an empty information collection sheet to take with her. In these cases, the objects became part of the official document database, discussed next.

4.4.8 Official documents as an object of research

Documentation analysis plays an explicit role in any data collection in case research (Yin, 2009). Also in the current study, analysis of existing printed and electronic documents formed an important source of information. Official documents were identified and obtained prior to, during and after field visits for further analysis. They were mainly text-based, but some included also non-written elements, such as pictures. As detailed in Appendix D, they can be divided under the following headings: A) Tuberculosis, B) HIV-AIDS, C) PMTCT, D) Routine Monthly Reporting, E) Policy Documents, F) Data Flow Descriptions and G) Other. Common approaches to analysing documents in social research are content, thematic and discourse analysis, amongst other more specialised techniques (Robson, 2011). However, the researcher of the current study did not see it purposeful to conduct a systematic quantitative or qualitative content analysis, since they often require sampling and may imply that the 'sample' of documents is representative of some wider entity. Moreover, thematic analysis (as described in 4.4.9) suitable for analysing the interview data, was not an appropriate method for analysing, for instance, an empty sheet of TB register. Finally, a discourse analysis, defined as *"close study of language in use"* (Taylor, 2001) was not suitable either, as the focus of the research is not the language of the documents. Instead, the researcher used the evidence much as described by Yin (2009) with reference to case study methodology:

- verifying correct spellings, titles and names of various people, organisations, information systems or clinical concepts
- obtaining very specific and detailed information on specific information systems or information flows
- identifying corroborative information when compared to the data obtained from interviews or observation
- identifying conflicting information suggesting further inquiry
- making inferences

Therefore, in this study analysing document refers loosely to the use of additional source of data (the documents) with a logic that they may provide clues of 'what is going on' and means to reflect the other two sources of data: the interviews and the observations. The researcher would not take a document, such as a policy circular as 'the truth' but rather would consider who produce it, for what purpose and how current it is. Since some document analysis proceeded during the data collection phase, it could be used as a guide for subsequent interviews and observations.

4.4.9 Data transcribing, coding and analysis

In line with the concept of flexible design research, the researcher began the analysis of the raw data before the end of the data collection phase by listening to the recorded interviews, transcribing the key parts and going through the field notes. This enabled focusing the rest of the inquiry on the emerging key themes. However, at the same time, the researcher also attempted to keep an open mind towards any new emerging issues. After the data collection phase was completed, all the audio-tapes were transcribed in a MS-WORD format resulting in 410 pages of data (150,923 words).

A thematic analysis is a commonly used approach in data analysis in various disciplines of qualitative research, including public health related ones (Vaismoradi et al., 2013; Braun and Clarke, 2006). It is a method for identifying, analysing and reporting patterns within data. At a minimum, it organises and describes the data in detail, but usually it goes further than this by interpreting different aspects of the research topic (Braun and Clarke, 2006; Boyatzis, 1998). Qualitative content analysis and thematic analysis share the same characteristics and have been used interchangeably, but Vaismoradi et al. (2013) propose that the difference lies in the opportunity for quantification of data in content analysis. Braun and Clarke (2006) have compiled guidelines for conducting thematic analysis. Table 4-8 presents these guidelines and how they were applied in this particular research.

Table 4-8. Guidelines for thematic analysis according to Braun and Clarke (2006) and how the guidelines were applied in this study.

Guidelines for thematic analysis (Braun & Clarke, 2006)	How it was applied in this research
1. Familiarise yourself with your data	The audio-tapes were transcribed in MS-WORD format resulting in 410 pages of data (150,923 words). Next, this data was printed. The researcher read through the entire data set. Initial ideas were written down.
2. Generate initial codes	In line with Braun and Clarke's advice to code interesting features of the data in a systematic manner, almost all data was coded, except greetings and the like.
3. Search for themes	Data was collated in themes. While Braun and Clarke separate this from coding, in this research this step took place alongside the generation of codes. In other words, colours and short codes were used to tease out the key themes and to compare passages of text to find out whether they related to the initial themes or were something new. Each passage of text could occur in multiple categories (which the researcher considered roughly the same as Braun and Clarke's 'themes'), such as "TB", "feedback" and "data quality challenge" "timeliness". Computer-assisted tools were considered for this coding and theme identification, but since the ideas for interpretation arise often while coding (and simultaneously interpreting) data and could not have been picked up just by identifying or counting certain words, and because there were resource constraints, the researcher decided to rely on the manual method. Alongside the manual coding and theme identification, the researcher also crosschecked and triangulated interview data with the two other data sources, i.e. the observations and official documents.
4. Review the themes	The researcher checked if the themes worked in relation to the coded passages of texts and the entire data set. Some themes proved to be more relevant than others. Simultaneously, the researcher brought all this data back together in digital form as broader theme documents with copy-pasted quotes. The documents were created • around each data flow (which later informed particularly Chapter 5) • the positives and the challenges in the South African TB and HIV information system (which later informed

	particularly Chapters 6-8) In other words, the passages of text belonging to the theme 'feedback' could be found, for instance, in the TB data flow document (the text relating specifically to TB data feedback) and in the positives and challenges in the South African TB and HIV information system document. Since the broader theme documents contained references to the interviews, it was possible to find out that a challenge (for example relating to data accuracy) was mentioned by informants A, B and C. Moreover, as the data was systematically organised in the broader theme documents, it could be seen that another challenge, which was not the same but a similar or related challenge (for example data incompleteness) is mentioned by informants E and F.
5. Define and name themes	In accordance with Braun and Clarke's advice, the researcher attempted to further refine the themes and analyse the data within them. In other words, the researcher focused on identifying what each theme is about, what was interesting or important about them and what the themes told the researcher overall.
6. Produce the report	Finally, following the second literature review, the data in the form of the broader theme documents was analysed and interpreted to answer the research question. A number of quotes were selected with an attempt to capture the essence of the point that the researcher wishes to demonstrate.

While Table 4-8 may give the impression that the steps need to be completed strictly in order by simply moving from one phase to the next, Braun and Clarke emphasise that analysis is not a linear but recursive process. Similarly, the researcher analysed the data in an iterative manner, moving back and forth between the phases. Some of the defining and final naming of the themes took place while writing up the thesis. In addition, while the first literature review informed data analysis, the preliminary analysis of the data informed the second literature review.

4.5 SUMMARY OF CHAPTER 4

This chapter has described how this research, conducted in the field of health information systems research, was carried out. An interpretive paradigm was used, because the researcher wished to explore and understand a phenomenon in its context. While the researcher accepts that there is an objective reality, she believes that the South African TB and HIV information system is produced through interaction among social actors, as is innate to the interpretive approach. Moreover, she feels that it is important to investigate how the actors make meaning of their experience, as described in section 4.2.

The researcher studied the HIS in its natural setting with the methodology of a qualitative case study. In other words, the HIS, understood as a socio-technical entity, was the 'case'. Data about the case was collected via interviews, direct observation and official document analysis. Specifically, the research process included: conceptualising the research problem with the help of relevant literature; obtaining ethical clearance; pre-research investigation; identification of the research setting and informants; collecting data; recording experiences and transcribing interviews; and analysing and interpreting the collected data according to guidelines for thematic analysis to make sense of it in the light of what the researcher had learnt from academic and grey literature and the pre-research investigation.

The purpose of the process was to develop an in-depth understanding about the key challenges in the South African TB and HIV information system. In addition, the researcher gained insight about the TB and HIV related data flows. These are discussed in the next chapter.

Chapter 5 Empirical findings: Description of TB and HIV related data flows.

5.1 OVERVIEW

The previous chapters have introduced the research area, provided the background information necessary for understanding the South African TB and HIV information system, as well as reviewed what others have found about that system and other similar systems in under-privileged settings. In addition, the previous chapter detailed the manner by which the researcher has chosen to investigate the research question:

> **What are the key challenges in the current TB and HIV information system in an underprivileged community?**

This chapter revisits the research question by addressing the research objective B: *"To examine how TB and HIV related information is collected, reported and used currently in Khayelitsha in the Western Cape Province in South Africa."*

In particular, this chapter depicts the structure of TB and HIV related data flows as described by the key informants and evidenced by observational data and analysis of official documents. In line with the research protocol, data flows were identified as those including TB or HIV related information and originating from the case study clinic. The data flows through several levels of authority, which were illustrated in Figure 4-2 in Methodology with reference to what is meant by *"case study setting"* in this study.

The most significant finding, stemming from the analysis of the research data, is that while enhanced integration is a publicly stated goal by the National Government of South Africa: *"HIV, AIDS and TB services will be completely integrated with PHC services"* (Department of Health, 2014a) and echoed in various documents, such as the National Strategic Plan on HIV, STIs and TB 2012-2016 (SANAC, 2011), **in reality there are a number of parallel TB or HIV related data flows in the Western Cape of South Africa**. One may argue that this is not a very surprising or interesting finding per se, since one can also learn about it without a comprehensive case study and previous

research (for example Kawonga et al., 2012 and Auld et al., 2013) has already suggested it. However, **the amount of multiple data collection and reporting that the data flows inflict and the profoundness of the 'silo logic' that the system reflects, as well as subsequent data quality and other issues** (which are all discussed in the next chapters) are further findings that cannot be fully understood without first closely examining the multiple data flows.

There may have been different ways to identify and categorise data flows but as detailed in section 4.4.1, the researcher decided to follow 6 'major' data flows which A) include TB or HIV information and B) originate from the case study clinic and flow in various ways via sub-district, district and provincial level. Specifically, these are:

- TB-related data flows (relating to Tuberculosis)
- HCT data flow (HIV Counselling and Testing or Voluntary Counselling and Testing hereinafter: HCT)
- ART data flow (Antiretroviral Treatment)
- PMTCT data flow (Prevention of Mother to Child Transmission)
- STI data flow (Sexually Transmitted Diseases)
- RMR data flow (Routine Monthly Report/Reporting)

as presented in a simplified form in Figure 5-2. However, the data does not always flow straightforwardly through all levels, as will be explained later.

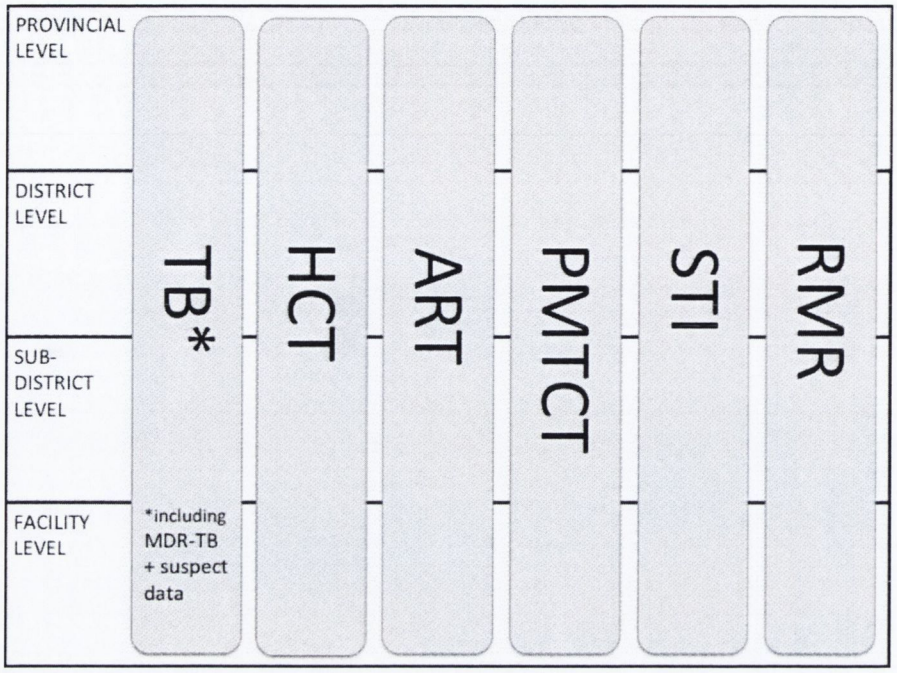


Figure 5-2. The data flows examined in this study. TB or HIV related data flows that originate from the case study clinic and flow through the various levels of health authority.

One should also note, that Figure 5-2 does not take into account the volume or the direction of the data flows, since it is only an introduction to the topic. While the first five are called HAST data flows in accordance with the HAST (HIV and AIDS, STI and TB) programmes, RMR (Routine Monthly Report/Reporting) data flow is not technically one of them. The RMR dataflow, however, additionally to general medicine and service data, includes TB and HIV data components. Thus, it is considered as a TB and HIV related data flow in this study. As Figure 5-2 shows, all TB related data flows (including MDR-TB and suspect TB data) are grouped together for the purpose of this study. Contrariwise, HCT and ART programmes, while both having to do with HIV, are perceived as very much two separate programmes by the South African health authorities. This has to do with the size of programmes: South Africa has the largest ART programme worldwide (Venter, 2013; South African Department of Health, 2007). Hence, they are examined separately in this study and depicted as two flows on Figure 5-2. It is likely that the case study clinic is 'representative' with reference to these 6 data flows, i.e. the same or very similar flows will be found in other City of Cape Town managed clinics.

Figure 4-2 in Methodology provided only an introduction on the health organisations at the case study setting. Figure 5-3 provides more detail on the levels of health authority that the data flows travel through.

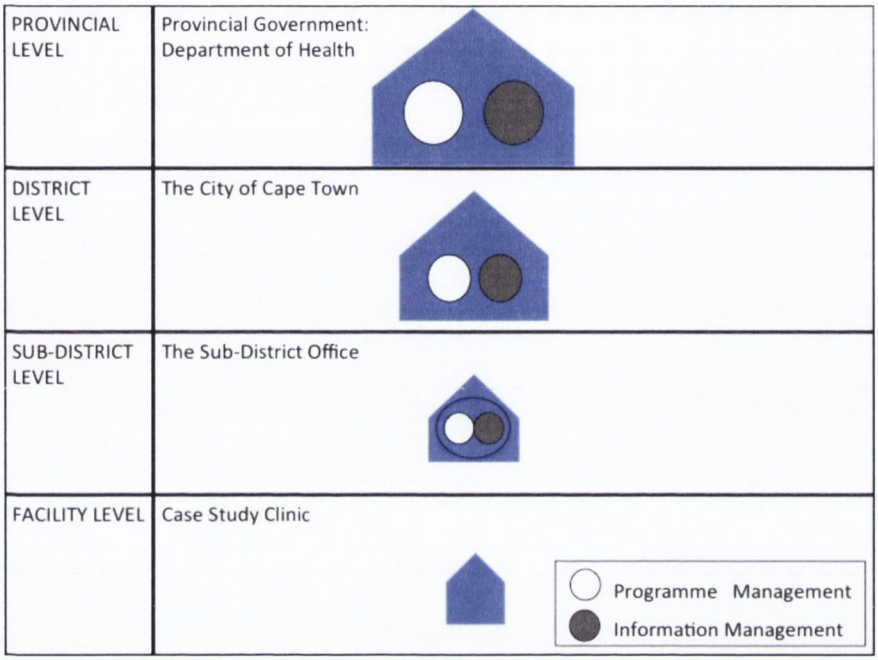


Figure 5-3. The basic levels of health authority in South Africa up to provincial level and certain health organisations and units that are involved with the collection, reporting and use of TB and HIV data in the Metropolitan municipality of the Western Cape.

As can be observed in Figure 5-3, there is a ground level where facilities, including the case study clinic, are situated. Following that, there is the sub-district level, where the sub-district offices operate (one per sub-district). These are managed by the local authority, i.e. the City of Cape Town. Then, there is the district level where the services are again provided by the City of Cape Town (via City Health). Above that, at the provincial level, there is the Western Cape Government's Department of Health. However, while in principle these are the levels, with regard to certain data flows there are actually provincial and city authorities operating at the same level in the health system (as elaborated in 7.4). These provincial authorities have been excluded from this figure, and largely from the following figures due to the reasons covered in section 4.4.1.

In the South African system, there are two groups of people who are involved in the collection, reporting or use of TB and HIV data. The District Health Management Information System (DHMIS) requires different types of HIS staff, who are appointed at different levels of the health system (DoH, 2011a).

Among others, the positions include data capturers (facility level), information officers (sub-district and district level) and health information managers (provicial level). (DoH, 2011a) For the purpose of this study, they are referred to as Information Management[43]. These roles work primarly with the general health data, but that data also includes TB and HIV elements. The second group of people involved in TB and HIV data are those who work with programmes. For the purpose of this study, they are referred to as Programme Management. Confusingly, also the health condition specific programmes include (health condition specific) M&E/HIS roles, as well as coordination roles and high-level health governance roles which may not require hands-on data collection duties but which require utilisation of the data. A close observation of Figure 5-3 reveals that at the sub-district office the people working with general health information (Information Management) and programmes (Programme Management, including coordination) work very closely together. Hence, they are depicted as within one entity, whereas at the higher levels there is more physical and organisational distance between Programme Management and Information Management. Due to the lack of specific data the relationship between Programme Management and Information Management at the facility level is not provided here.

All the data flow descriptions provided here concern the time of the data collection (2012) and there is a degree of uncertainty in them. However, even with possible gaps and minor errors (the researcher cannot exclude this possibility), they can be considered illustrative of how the data flows in a Cape Town administered public health clinic in the Western Cape.

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[43] The informants talk about *"information Management"* and *"Programme Management"*. The researcher believes that this is the division they are referring to.

5.2 TB RELATED DATAFLOWS

5.2.1 Overview

At the case study clinic, there is not one but several data flows comprising TB related information. In addition to the (main) TB data flow, whose purpose is to report confirmed pulmonary TB cases, a TB suspect data flow and a multidrug-resistant (MDR) TB data flow[44] have also been created to address the reporting needs of TB information. The main TB data flow is depicted in a simplified manner in Figure 5-4. The following sections (5.2.2 to 5.2.4) add to the picture by illustrating in detail the TB related data flows and the HISs (manual and electronic) that are used to report the information.

[44] XDR-TB is not separated here as its own category since it is assumed to flow largely alongside the MDR data.

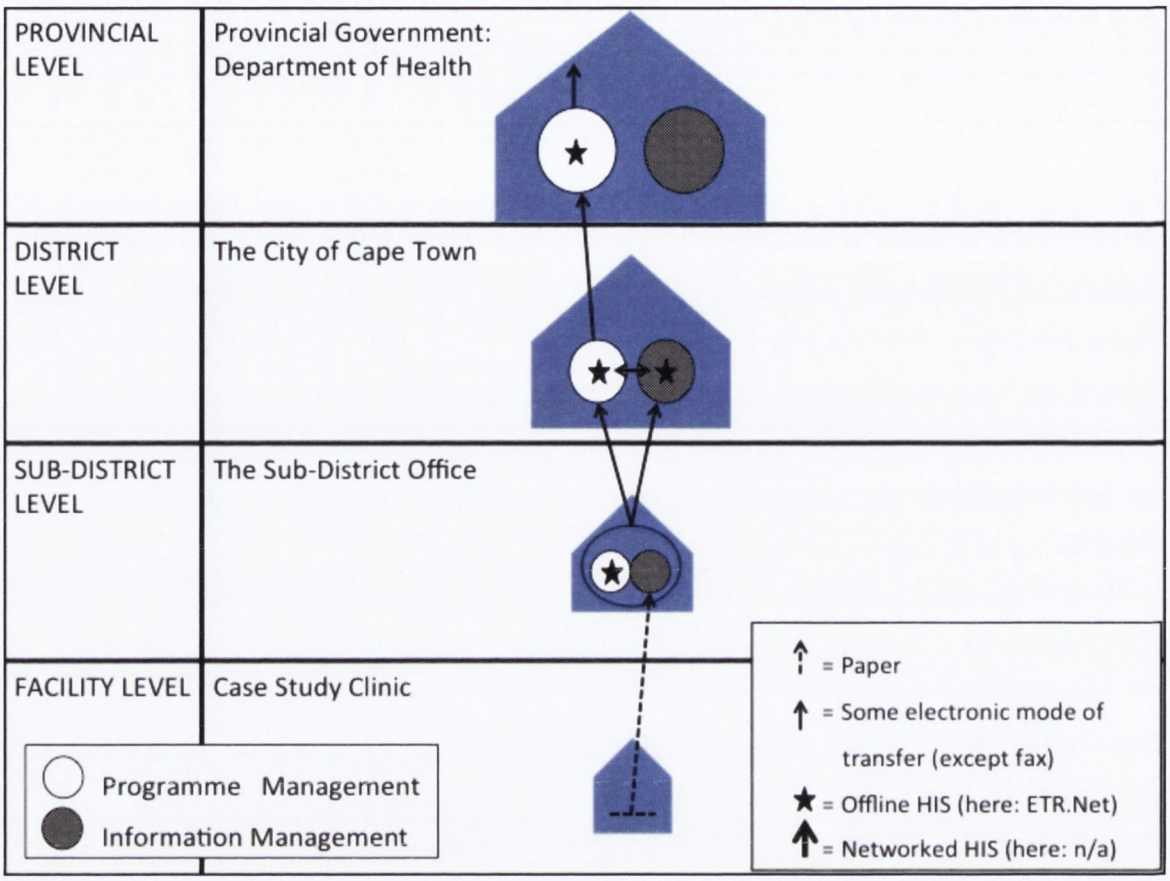


Figure 5-4. Main TB data flow. A simplified representation of the main TB data flow at the case study settings at the time of data collection (2012).

For simplicity, other TB related data flows, further horizontal information distribution at each level, as well as feedback loops have been omitted from Figure 5-4. The ETR.Net information system exists from the sub-district level upwards (as illustrated by star symbols), but since it is not networked, data is transferred via CDs, email attachments etc., which is considered here as 'electronic mode of transfer' and therefore indicated by thin arrows. At the sub-district level, Information Management may also have an access to ETR.Net, but this was not clearly evident in the research data. At the district level, both Information Management and Programme Management receive the TB data and can access the data in ETR.Net. The possible provincial actors (adding, for instance, hospital data) have been omitted from the figure for the reasons stated in 4.4.1. Finally, the provincial Programme Management may also send the TB data to their Information Management, but since there was no mention in the research data, it is not included in this figure.

5.2.2 Main TB data flow

In summary, a TB patient will have his first contact to TB care as a TB patient, or another type of patient showing TB symptoms (such as an HIV patient). Treatment is generally provided by a TB nurse; the doctor or the clinical officer will only see the most complicated cases. A TB patient is seen at a facility level, first of all by the receptionist and the TB clerk who opens/finds a folder for the patient and refers him to the sister (nurse). In South Africa, TB and HIV programmes are closely related and as discussed in 2.8 the national guideline is to offer an HIV test to every patient. Hence, also in the case study clinic the patients are referred to VCT (voluntary counselling & testing of HIV), to give sputum samples for TB or to the enrolled nurse if they seem not to be feeling well. The CD4 counts of HIV positive patients are taken and those with a low count are referred to the ART unit.

The patient folder is completed with the clinical notes from every visit. The TB clerk routinely captures the information from the folder onto the paper-based TB register at the facility level. This is a cohort-based register comprising of different colour pages. The top three forms are printed on carbonised paper so that entries are transferred to underlying pages. The top (pink) sheet is used to define the case finding cohort, the second one (yellow) is for smear conversion data, the third (green) sheet contains information on treatment outcome and the final page, which is white, is retained in the facility register. The carbonat copies of the TB register are torn off and sent up one page at the time to the sub-district office by a courier or they are picked up by the HAST Coordinators. The facility manager validates the TB data before it leaves.

Some of the TB information from the patient folder is captured to the RMR tick sheet by the nursing staff and also entered in to the PREHMIS information system. That information forms part of the RMR information flow that is presented in 5.7.

At the sub-district office, the information goes through approximately 3 different people working in different designated roles. In the case study sub-district office, an official working in the health information role receives the TB information in his/her in-tray (as indicated in Figure 5-4) and checks the data to observe any apparent mistakes or gaps. This role is mainly office-based. In

addition, all the sub-districts have at least one HAST Coordinator, whose job is to give technical support to all the facilities in that area within the HAST programmes. This role has a closer connection to the facilities and field level. While this role is related to programmes rather than general Information Management, validating and checking the data forms a major part of the Coordinator's tasks. The HAST Coordinator or the sub-district office's clerk enters the TB information via the computer into ETR.Net, the National Electronic TB Register. However, since the TB data, similarly to other HAST data, is often moved back and forth at this stage, and the people concerned work physically in the same room, they are depicted as being part of the same entity in Figure 5-4 and no distinction is made as to who sends a CD or email to the next level.

ETR.Net was implemented in South Africa in 2003 (De Azevedo and Caldwell, 2004). It was developed with support from the U.S. President's Emergency Plan for AIDS Relief (PEPFAR) in consultation with a South African partner, WAMTechnology CC and the South African Government (WAMTechnology, 2007). It is implemented in various countries and in all 9 provinces in South Africa (WAMTechnology, 2014a). Specifically, it is a nationally prescribed system, which means that other systems cannot be used for capturing TB information in public health facilities. Despite the name, ETR.Net is not a networked system but a stand-alone system. It is only for confirmed TB cases. At the sub-district office the ETR.net database is dispatched in the form of a memory stick or CD and sent up a to the district level to the City of Cape Town.

At the City of Cape Town, two key officials, working in TB Programme Management and Information Management, are involved in the processing of the TB data. The data from all of the 8 sub-districts is uploaded into one district database. The data is analysed and the standard reports are run. Then, if everything is in order the data will be sent up to the provincial office as a dispatch file.

At the provincial level, there are at least two posts that are directly involved with the data: one in TB Programme Management and the other in TB M&E, which is also a role in provincial Programme Management. Basically, the provincial level is collecting all the indicators from the ETR.Net, TB patients' HIV

indicators as part of those, and separate to that, the case finding indicators. All of these are reported to the national level. The TB M&E official will load the updated district level files onto their database (their version of ETR.Net), run the appropriate reports and the data quality checks. If the M&E official has any queries, he/she will send the whole database back to the district office. If everything is in order, the official will compile the quarterly report for the National Department of Health, as well as sending them a copy of the entire updated database. The National DOH sends out a template specifying the reports they require, because sometimes the posting of the CD to the national office takes too long. That template allows the provincial office to extract the data from their copy of the database, copy-paste the data into the report templates and email the reports, while the local authorities are sorting out the courier issues. Narrative information is required to explain any possible deviations in trend data.

5.2.3 TB suspect data flow

Since the paper-based TB register (and subsequently ETR.Net) can only be used for reporting confirmed cases, a separate paper-based TB suspect register is kept at the facility level. Before a patient is diagnosed with TB, he is called a suspect if he shows symptoms or gives otherwise any reason to be suspected of being infected with TB. These patients are recorded first on the TB suspect sheet and then on the suspect register.

To obtain a diagnosis, the patient gives a sputum sample, and this is sent to the laboratory. The patient will remain in the suspect register until the results come back. The laboratory results are recorded in the suspect register and if the patient is tested positive for TB, his information is also captured into the paper TB register. The clinic sends out community care workers or they attempt to phone the patient, so that they can remind him to come back to begin the treatment. The suspect information is submitted upwards monthly to meet a set deadline.

At the sub-district level, the HAST Coordinators are involved with checking and validating the suspect data, as well as in tracing the data of the patients that seem to have disappeared from the system. The suspect data is entered into an

Excel sheet that is called the suspect register. The sub-district office submits the compiled suspect data forward quarterly to the City of Cape Town. The officials on both Information Management and Programme Management side are involved with the data. The Excel sheet has validation rules to improve the data quality. The data is sent further to the provincial level, which forms its own report, which is again sent to the National Department of Health.

5.2.4 MDR-TB Data Flow

The flow of TB data is further complicated by the fact that MDR-TB is reported as its own separate entity. A patient can have the MDR-TB as a primary infection, or more often, develop the resistance after being a drug susceptible TB patient. The MDR infection can be picked up by the health system via routine testing of TB suspects or during the course of TB patient's treatment if it is noticed that they have developed resistance at that stage.

While the national guidelines originally mandated that treatment of drug resistant TB patients in South Africa should be initiated in specialised hospitals, the growing number of MDR cases has outstripped the bed capacity in these facilities (Brust et al., 2012). As a part of a pilot project implemented to respond to the pressure for beds, many of the Metro area's MDR patients who do not need hospitalisation at the Brooklyn Chest Hospital are being treated at community level, similarly to drug susceptible TB patients. Thus, MDR data is also collected and reported at the case study clinic. The information that is collected during the intensive phase of MDR-TB is written in a yellow folder, and information on the continuation phase is written in a pink one. The aggregated data[45] is compiled by the facility staff in the paper-based MDR register, but it is not self-carbonating in contrast to the 'normal' paper-based TB register at the clinic level. The register has to be submitted quarterly.

[45] Aggregated data means here that it is complied together. The register still holds patient level information.

At the time of the data collection for this study, a new policy had recently been developed; a professional nurse, referred to as the MDR nurse, had been placed in each sub-district to support the facilities in terms of the MDR register and MDR related information and patient management issues. According to an informant whose work is around data and M&E, the idea is that the nurse would visit the clinics with a laptop and Internet connection and capture the information from the clinical register. During the study, the researcher did not meet anybody acting in this role. However, according to another informant, there apparently is one MDR nurse in the case study sub-district and he/she collects and brings or sends the register to the sub-district office. It is unclear if the nurse has a laptop and a network connection at his/her disposal at the clinic level.

Multidrug-resistant tuberculosis has its own electronic tuberculosis register called EDRWeb. Similarly to ETR.Net, it is developed by WAMTechnology which is a PEPFAR prime partner for both projects. According to the developer, EDRWeb automatically downloads drug susceptibility, smear and culture laboratory test results from the National Health Laboratory Services (NHLS) data warehouse on a daily basis. It is implemented in several MDR-TB units throughout the 9 provinces of South Africa (WAMTechnology, 2014b). Unlike ETR.Net, it is networked. Finally, similarly to ETR.Net it is a government endorsed system, which means that other systems cannot be used for capturing MDR-TB information in public health facilities. According to an informant, the process of developing it is at a very early stage: *"it's really a database in development at the moment"*.

The EDRWeb is located at a sub-district office where a clerk, possibly alongside the MDR nurse, captures the MDR information. It seems that the case study's sub-district office enters the data for the all sub-districts regardless where those clients have been treated. The HAST Coordinator removes the MDR patients from the ETR.Net.

At the district level a key official in the City of Cape Town's TB Programme Management works with the MDR data. Since a number of MDR patients are treated at the 3 MDR Units (hospitals) in the Western Cape, these three sites also collect the data. They have their own patient folders, paper registers and data capturers, who enter the data produced at the units into the EDRWeb. Then

they copy the required data and email it in Microsoft Excel format to the official working in the TB M&E at the provincial level, which suggests limited use of the interface provided by the web-based EDRWeb. The provincial TB M&E (a role in Programme Management) checks only if the numbers add up, since it is the hospitals that do the actual compilation of information, and sends the report to the national level.

5.3 HCT (HIV TESTING AND COUNSELLING) DATAFLOW

The case study clinic serves a large number of clients with HIV/AIDS (hereinafter: HIV). Two HIV related data flows originate from the clinic: one concerning HCT data and the other ART data. This section examines the reporting of HCT data.

A patient may be referred to HIV counselling and testing from various places, such as from the TB side (and vice versa). HCT information, including for instance a brief history taken by a nurse, information on blood tests or HCT counsellor's notes, is on a paper form in a patient folder at the facility level. The aggregated[46] HCT information is also in a paper-based register at the facility level. The information is recorded together by the lay counsellors / HCT counsellors at the facility. Similarly to the TB data flow, the HAST coordinators provide support with the HCT information and its collection and recording. Some information on new HIV positive patients is recorded in the RMR data flow and in the case of TB or pregnancy, in TB and PMTCT flows. The facility manager validates the data before it is sent to the sub-district office via fax before the monthly deadline.

At the sub-district office, the HAST coordinator checks the data for discrepancies and sends it forward. At this point, the data moves along two parallel routes, as shown in Figure 5-5.

[46] Aggregated data means here that it is complied together. The register still holds patient level information.

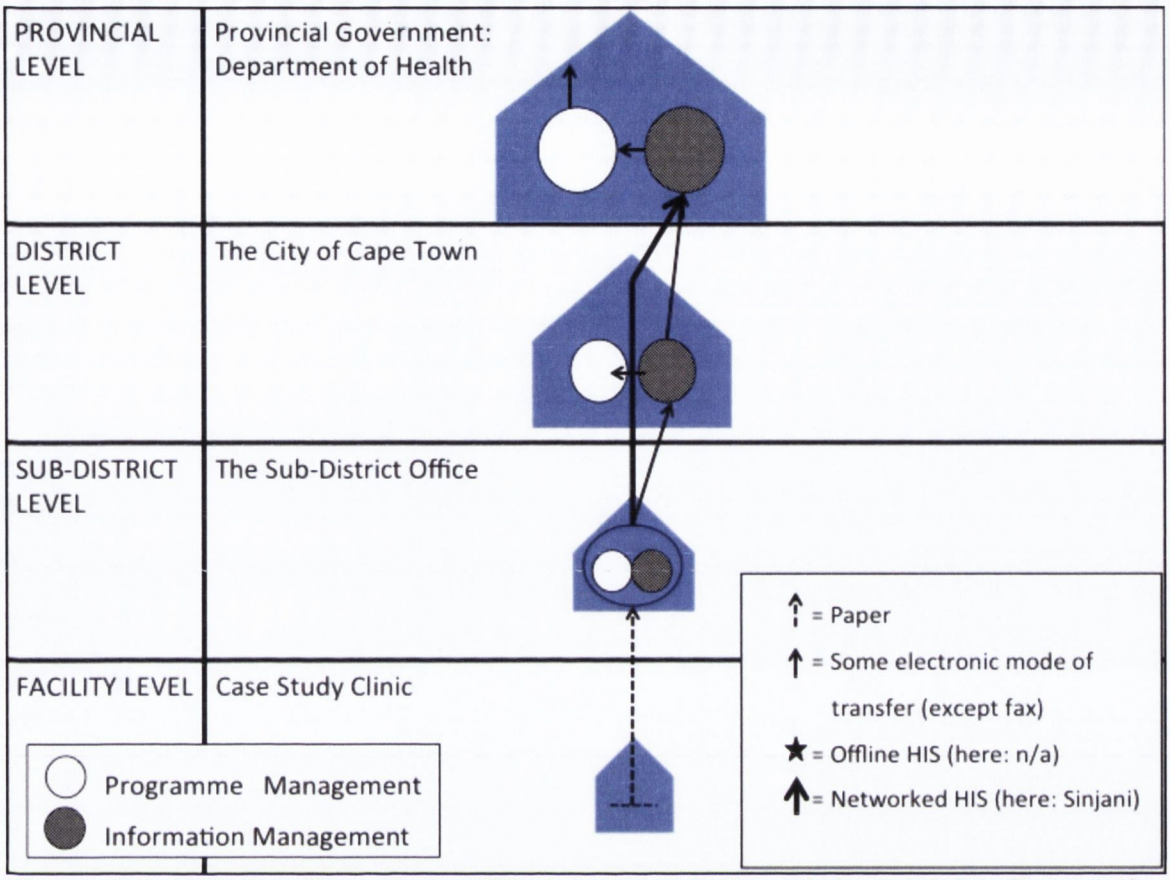


Figure 5-5. HCT Dataflow. A simplified representation of the HCT dataflow at the case study settings at the time of the data collection (2012).

As before for clarity, horizontal information distribution at each level, as well as a feedback loops have been omitted from Figure 5-5. Moreover, the possible provincial actors have been omitted from the figure. The Sinjani information system exists from the sub-district level upwards, as indicated by the thick arrow, but due to transition process the official at the district level Information Management is not accessing it. A parallel flow begins from the sub-district level. Specifically, what happens is: first, the HCT data is compiled on Excel by the HAST Coordinator, copied and sent as an email attachment to Information and Programme Management at the City of Cape Town before a monthly deadline. Second, the HAST Coordinators also capture the HCT information on a web-based HIS called Sinjani. The parallel reporting is due to the on-going transition process. The Sinjani information system is described in section 5.7, and further Sinjani related issues are reported in Vignettes 7-5 and 7-6.

At the district level (in City Health) a key official in Information Management is involved with the HCT data with Programme Management oversight. Although the plan is that Programme and Information Management at

the district level would interact with the sub-district staff and possibly NGOs through Sinjani, at the time of the data collection, Information Management receives the HCT information as an excel sheet, saves it amongst the spread sheets from other sub-districts and copies the totals to a City template. If there is something wrong with the Excel sheets, they are sent back to the sub-district offices to be corrected, which may send them again to the facilities and then all the way back up again. There are several validation rules built into the Excel files to disclose errors and mistakes. After sign-off, the information is sent to the provincial level.

While provincial TB and ART programmes have their own M&E (dedicated roles doing the M&E for the programme) the HIV prevention programme (including HCT, PMTCT and STI) does not, so the programme staff monitor their own programmes. In practice, this means the data flows to provincial Information Management first and then to key officials in Programme Management, whose responsibility is to check the data. The HCT Programme Management receives the HCT data as an Excel format indicator sheet, which is compiled by Information Management once a month for the previous month. If the HCT Programme Management official sees something suspicious, he/she can access Sinjani to view the data but not change it. The official then has to ask Information Management to backtrack back to the district level to find out where the mistake was. The Programme Management reports the information to the higher management levels at the provincial level, as well as the national DoH.

5.4 ART (ANTIRETROVIRAL TREATMENT) DATA FLOW

The HIV positive patients whose CD4 count is 350 cells/mm3 or lower qualify for antiretroviral treatment[47] in South Africa and hence become a part of the ART programme. Generally, the patients are seen first of all by the receptionist and

[47] Other, less common reasons, which make a patient eligible for ART in South Africa, are not listed here, because the focus of this section is not medical.

the ARV clerk[48] who opens/finds a folder for the patient and refers him to the Sister (=nurse) or a doctor. The patient may come to the programme, for instance, from the HCT or TB side and vice versa. The whole HIV treatment is largely provided by a nurse: the doctor or clinical officer will only see the most complicated cases. A nurse may also initiate ARV treatment.

A person initiating the treatment will usually want to know the results of the blood tests before starting treatment. At the ART unit, there are two types of new patients: patients who have not started ART or who have, but in another facility. The researcher's interpretation from the data is that the patient folders do not usually travel with patients from other clinics. Therefore, with both kinds of new patients, the ARV clerk will open the folder, write in personal details and print a sticker on the folder. In the case of a patient whose treatment has not begun, the folder is given to the patient who will go to counsellors, and the folder will stay with the counsellors up until the patient begins treatment. Then the folder will go back to the receptionist for data capturing and filing. In the case of a patient who has already started treatment in another facility, additional information is recorded in the folder. Then the ARV clerk takes the folder to the consultation rooms, the sister sees the patient, records her part on the folder and the patient goes to the pharmacy, receives the medication there and leaves the folder in the pharmacy. The ARV clerk picks up the folders from the pharmacy, captures the information and files the folders.

To summarise, the clinical patient level ART data is in the patient folder. The aggregated[49] ART data can, in principle, be in three different systems in the Western Cape, albeit the same ART data needs to be collected everywhere. Specifically, in South Africa, a three-tier M&E system for ART was adopted by the National Department of Health in late 2010 (Osler et al., 2014). The three tiers are

- A3 paper-based register

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[48] The person is called ARV clerk (instead of ART clerk). Hence, this term is used here, although in general the researcher prefers using ART.

[49] Aggregated data means here that it is complied together. The registers still hold patient level information.

- stand-alone electronic system called Tier.Net (also known as Electronic HIV Register / eRegister)
- networked system by the name of eKapa (also known as Tier-3 solution, or networked electronic medical record solution)

The system is depicted below by Osler et al., 2014 in Figure 5-6.

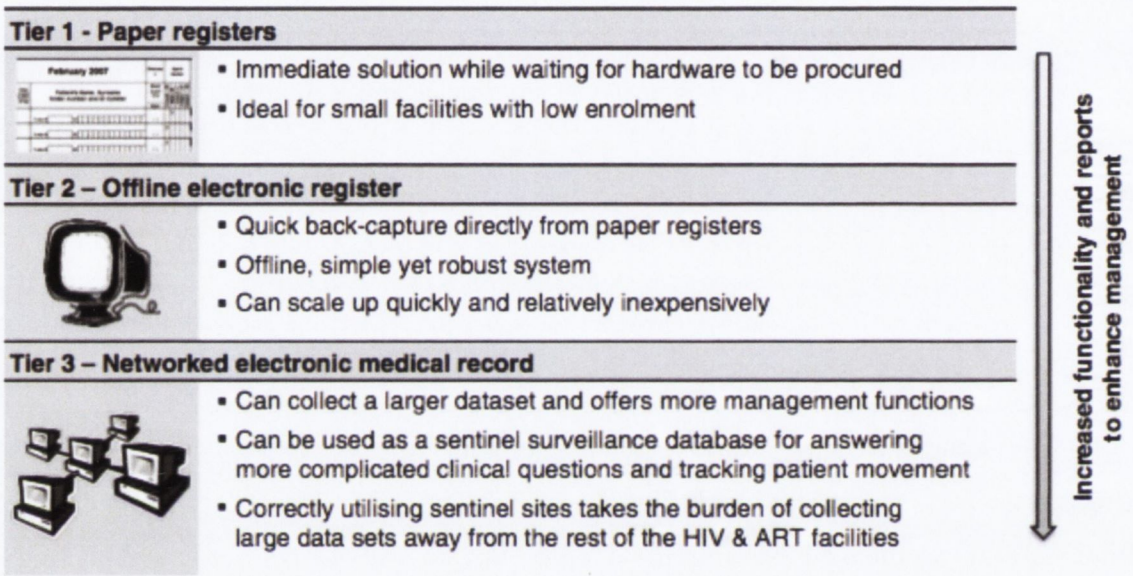


Figure 5-6. A three-tier monitoring and evaluation system capable of working together in a health region (one choice per facility). Figure by Osler et al., 2014.

At the time of the data collection, clinics with less than 500 patients were allowed to use the paper-based system. Tier.Net is at the facility level but it can be shared across all the levels. It may be on two or three computers that are connected to each other, but mostly the programme operates on one stand-alone computer. eKapa, by contrast, is a networked solution piggybacking on the Western Cape provincial networking infrastructure and is linked with the primary health care information system. The estimate in May 2012 was that of 330 facilities in the Province slightly more than 180 offer ART, and of the estimated 180, 6 sites (i.e. 3%) are using eKapa, 85% are using Tier.Net and 12% are using the paper-based system (Informant). The Tier.net software was developed by the University of Cape Town (UCT) in collaboration with WAMtechnoly CC,

National Department of Health, PEPFAR, USAID and the Canadian International Development Agency. Anova Health and Kheth'Impilo (non-governmental organisations) have supported the training of data clerks in Tier.Net and data clean-up at the facility level. USAID funded eKapa was initially developed in partnership with Médecins Sans Frontières (MSF) in Khayelitsha.

At the case study clinic in Khayelithsa, the data is in Tier.Net on a computer at the facility. The facility sends the ART data to the sub-district office as a dispatch file by email on a monthly basis, unless there are technical problems in which case the HAST Coordinators come to pick it up on an USB. Some of the ART information is captured on an RMR tick sheet and in the PREHMIS information system. That information becomes a part of RMR data flow that is described in 5.7. The ART data is also captured in TB and HCT data flows. The facility manager validates the data before it leaves. The HAST Coordinator provides support if necessary.

At the sub-district level, the HAST Coordinator loads the dispatch file onto his/her computer on Tier.Net at the sub-district office in order to compile the monthly and the quarterly reports. The sub-district level requires the data from all their clinics, i.e. they need a copy of the data from each site to draw up the required reports. After compiling the report, the HAST Coordinator will send it to the next level.

The research data is inconclusive as to how the ART data flows through the sub-district and district level, as can be seen in Figure 5-7.

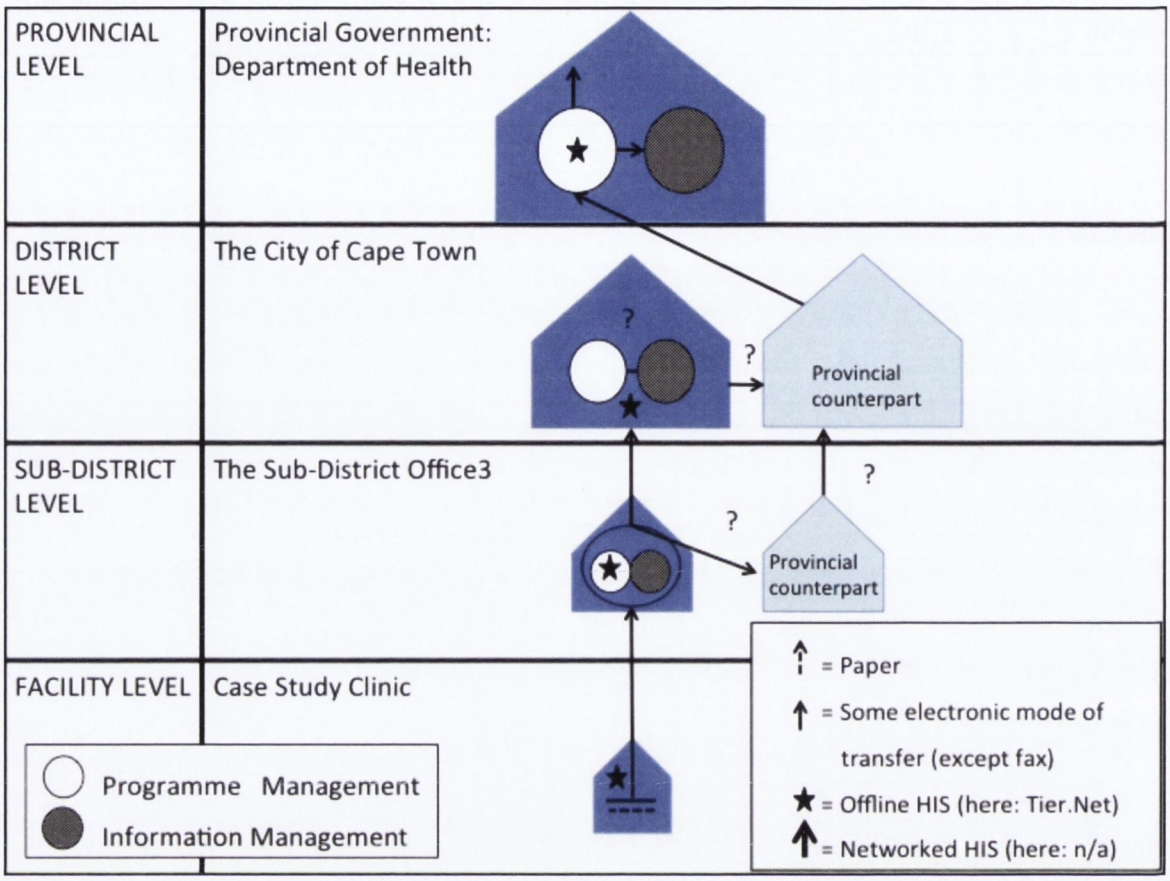


Figure 5-7: ART Dataflow. A simplified representation of the ART dataflow at the case study settings at the time of data collection (2012).

To keep Figure 5-7 legible, further horizontal information distribution at each level, as well as a feedback loop have been omitted from the figure. Tier.Net exists from the facility level upwards (as indicated by stars), but since it is not networked, data is transferred via emails, CDs etc., which is considered here as an 'electronic mode of transfer' as indicated by the thinner arrow.

The exact flow of the ART data at the sub-district and district level could not be conclusively determined from the data. Similarly, questions on who in particular uses Tier.Net in City Health (hence the star within the organisation and not in Information/Programme Management in Figure 5-7), or is it used in provincial offices in district or sub-district level, remain unanswered. This is largely due to the transition that was taking place at the time of the data

collection[50]. It can be argued that it is less important to know how the ART data flowed precisely at the district level at the case study setting at the time of this study. Rather, it is more important to note that HIV and TB data, apparently particularly the ART data, have been flowing quite independently and separately to general health care data, and that the efforts to push them back with the rest of the data can be laborious and confusing, in particular with the co-existence of the two health authorities (City and Province) in one area. This issue is discussed further in the next chapter.

Finally, at the provincial level, the official in ART M&E (a position in Programme Management) collates, interrogates and validates the data under the leadership of programme head. If there are apparent mistakes, the data is sent back to be corrected. The validated data is copied into an import tool and added to the provincial ART database. The database supports some statistical analysis, running reports, manipulation of the data and breaking it down to facility, district and other levels. The most important reports that the provincial M&E official collates is the monthly report and quarterly report to the National DoH. Numerous other reports are also generated at the provincial level but these are not relevant to this research.

5.5 PMTCT (PREVENTION OF MOTHER-TO-CHILD TRANSMISSION) DATA FLOW

In accordance with South African health policy, efforts are being made at the case study clinic to prevent the transmission of HIV from HIV positive mothers to their babies. When a mother and a baby come to the clinic, the sisters (=nurses) divide the patient folders amongst themselves, babies are weighted and mothers

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[50] The ART data used to flow directly from the facility level straight to the provincial level, due to the Province led ART programme. However, since increasing number of sites needed to begin to offer ART as a response to the growing epidemic, it became difficult for the Province to liaise directly with each facility. According to a document called Metro ART data flow, the data would flow through City of Cape Town Information Management, as well as sub-district and district level provincial Information Management, but the informant working in former never mentioned it, while giving a detailed account on the other flows. Furthermore, as stated previously, this study is limited to the City Health operators (by the City of Cape Town) at the district and sub-district level. Therefore, possible provincial actors at those levels were not included in the study. Regarding ART data, the sub-district level argued that the data was sent to the City Health and to another location and the provincial level informant explained, that they received the ART data either from a facility, sub-district or district depending on the situation: *"It is a bit haphazard right now"*.

with their babies are referred to the HCT regardless of the certainty of their HIV exposure. While there are patient files for both the mother and the baby, and there may be information in the folders, it is the researcher's understanding that the nurses mainly obtain information by asking the mother questions. For instance, a nurse trained for Integrated Management of Childhood Illnesses may use this technique to screen the baby for various illnesses or to try to establish the degree of HIV exposure of the mother/baby. The HIV exposed mothers, if they have given birth at a Maternal Obstetrics Unit (MOU) are on Nevirapine. The babies are tested for HIV (PCR test) at 6 weeks and the mothers need to decide whether to breastfeed or formula-feed[51]. The PMTCT nurses largely manage the treatment of the HIV exposed mothers and babies: make sure all the tests and decisions are made, and that the mothers return to the clinic after the test results are ready, the HIV positive children are referred to the doctor and the mothers continue in HCT, ART or other programme. Moreover, formula milk, if wanted, is given, and information regarding that is reported (see Vignette 7-3).

Within the PMTCT programme, the health status of both the mothers and the babies is followed over a period of time and their information is written down on each visit in various paper documents. The aggregated PMTCT register[52] is in a paper form at the facility level. The register follows a yearly cohort of babies born in each month. The left side of the register is for the children's information and the right side of the register (corresponding lines) is for the mothers' information. The PMTCT nurse copies information by hand from the mother's and the baby's patient folders to the register. Moreover, there is another larger register that is called "Stats". It is a monthly record that follows a cohort of PMTCT babies for a year, so it is fairly similar to the PMTCT Baby Register except it is more aggregated. The PMTCT nurse collects the information from the PMTCT Baby register, adding possibly information on blood tests from the computer, to

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[51] This has been a policy change since the time of data collection regarding baby-feeding options.

[52] Aggregated data means here that it is complied together. The registers still hold patient level information.

the "Stats" register. The "Stats" is sent to the sub-district office on a monthly basis after validation by the facility manager.

Next, the "Stats" comes via fax to the sub-district office covering one month's babies' data. The sub-district office checks the data, and if needed, contacts the facility level for corrections or missing PCR results. Finally, the data is sent forward *"electronically",* apparently as an excel attachment by email to the City, specifically to an official in Programme Management.

From this point on it became more difficult to conclude from the data, how the PMTCT data flows in detail. This is again because there was transition process going on at the time of the research and the PMTCT data flow seemed to be a mix of an old and a new system. A document named Current HAST Data Flow (which however was not accurate in all parts), as well as some interviews indicated involvement of a district level provincial actor, who enters the data into the Sinjani information system, as depicted in Figure 5-8.

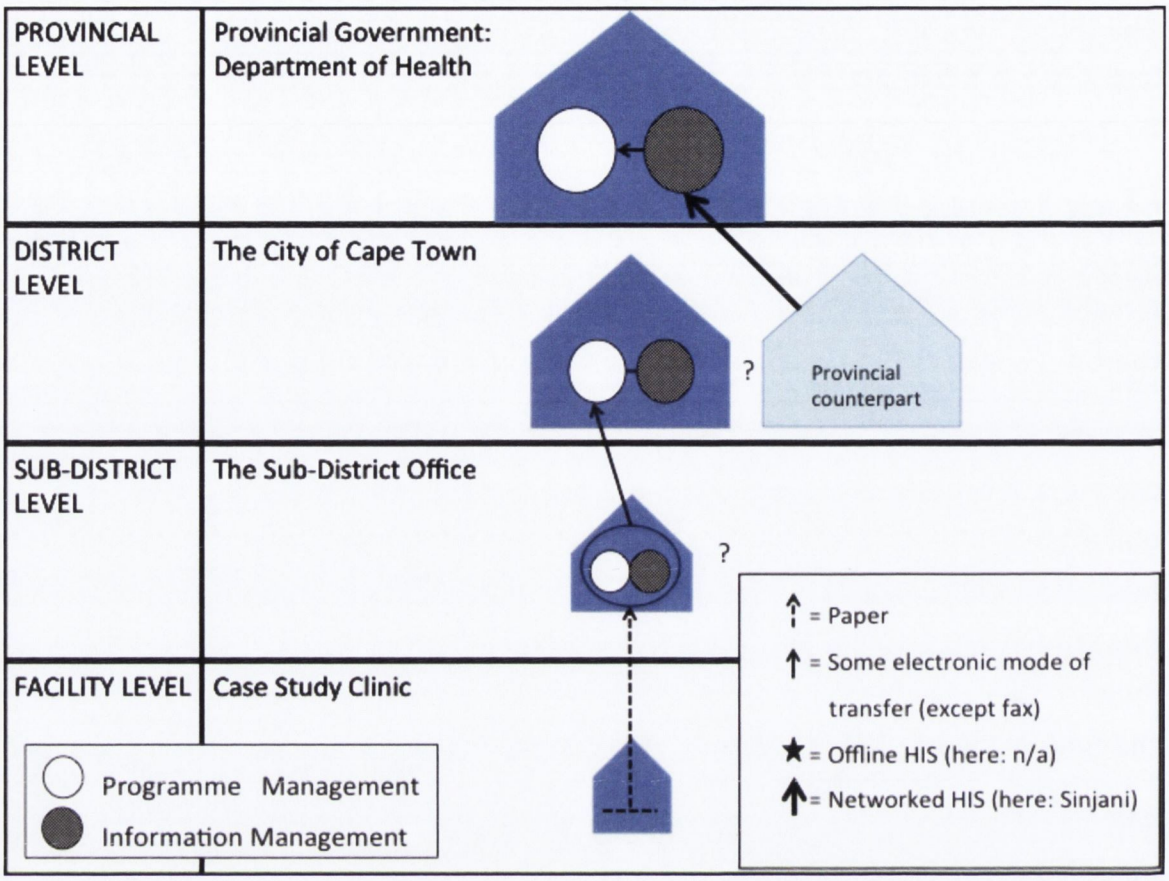


Figure 5-8: PMTCT Dataflow. A simplified representation of the PMTCT dataflow at the case study settings at the time of data collection (2012).

Again, further horizontal information distribution at each level, as well as a feedback loops have been omitted from Figure 5-8. While the Sinjani information system exists from the sub-district level upwards, the research data indicates that the PMTCT data is entered there only at the district level. There is a missing link before the provincial counterpart, due to a gap in the research data and it cannot be stated whether they receive the information through the City of Cape Town or from the sub-district level as indicated with question marks in Figure 5-8.

While the provincial TB and ART programmes have their own M&E staff, the PMTCT programme receives the data from provincial Information Management, who access the data via Sinjani, as indicated in Figure 5-8. Nevertheless, it is the PMTCT Programme Management's responsibility is to check the data for discrepancies. There are 3 provincial registers: antenatal, intrapartum and postnatal and Programme Management receives the information once a month

for the previous month in Excel format. The official in Programme Management sends the validated PMTCT data forward as standard reports.

5.6 STI (SEXUALLY TRANSMITTED INFECTIONS) DATAFLOW

Monitoring of STIs is one component of the HAST programme. However, a very limited amount of information was available for the researcher, perhaps since until fairly recently the data *"hadn't really been allocated to somebody in terms of having overall program oversight"* (Informant). Due to the lack of specific data, a detailed figure of the flow is not provided here. Overall, what can be said is that the STI data is in paper form at the clinic level, some of the STI information is captured also into the RMR dataflow, and it is validated by the facility manager, before it leaves the clinic. Furthermore, the STI data has been largely flowing through Information Management, and it is captured in the Sinjani information system at a certain point. Moreover, the quality of data is problematic; some of the challenges are discussed in Vignette 6-1. At the provincial level, the flow is similar to HCT and PMTCT in that Programme Management receives the data as an Excel form indicator sheet from Information Management, which in turn accesses the data from Sinjani. The data is reported to the national level.

5.7 RMR (ROUTINE MONTHLY REPORT) DATAFLOWS

In addition to programme specific data, all public health clinics are required to report certain monthly statistics called RMR - Routine Monthly Report(ing) or Record. This data is basically general medicine data, including the headcounts and services rendered. Specifically, what is required is

- Basic information
- Headcount information
- Child Health information
- Reproductive health
- Maternal health
- Immunisation
- Nutrition

- STIs
- Mental Health
- Chronic Care
- Oral Health
- **TB**
- **HIV**

This is the offspring of the development of a provincial minimum data set for primary health care, a process started already in 1994, as described by Braa et colleagues, who were an integral part of developing and piloting the system in the Western Cape and elsewhere (Shaw, 2005; Braa et al., 2007; Jacucci et al., 2006). The essential data set is required by the National Department of Health, and it is reported through the sub-district, district and provincial level. Consequently, also the case study clinic collects and reports the RMR data.

At the facility level, data collection is performed manually using paper-based data collection tools, such as tick-sheets and registers. In particular, clinical staff (doctors and nurses) are to check boxes or 'tallies' to record each interaction with patients.

> *"As the professionals deal with the clients, there is a lot of data that gets captured. We've got forms that try to simplify the data collection system whereby you don't have to write that actual services that you provided and the actual issues but you have a form and there is a date and the important issues that we are monitoring, they are all printed out there and you just have to tick on that little block to say this is the service... That is called the Routine Monthly Report or RMR."* (Informant)

At the end of the day, information is collated together by the clerks. The monthly RMR data is compiled together at the facility level RMR sheet and the facility manager validates it.

A Standard Operating Procedure (SOP) was published after the time of the data collection to guide the management of aggregated routine health service based information by the national Department of Health (DoH, 2012b). The SOP provides a routine data reporting flow diagram, which can be seen in Figure 5-9.

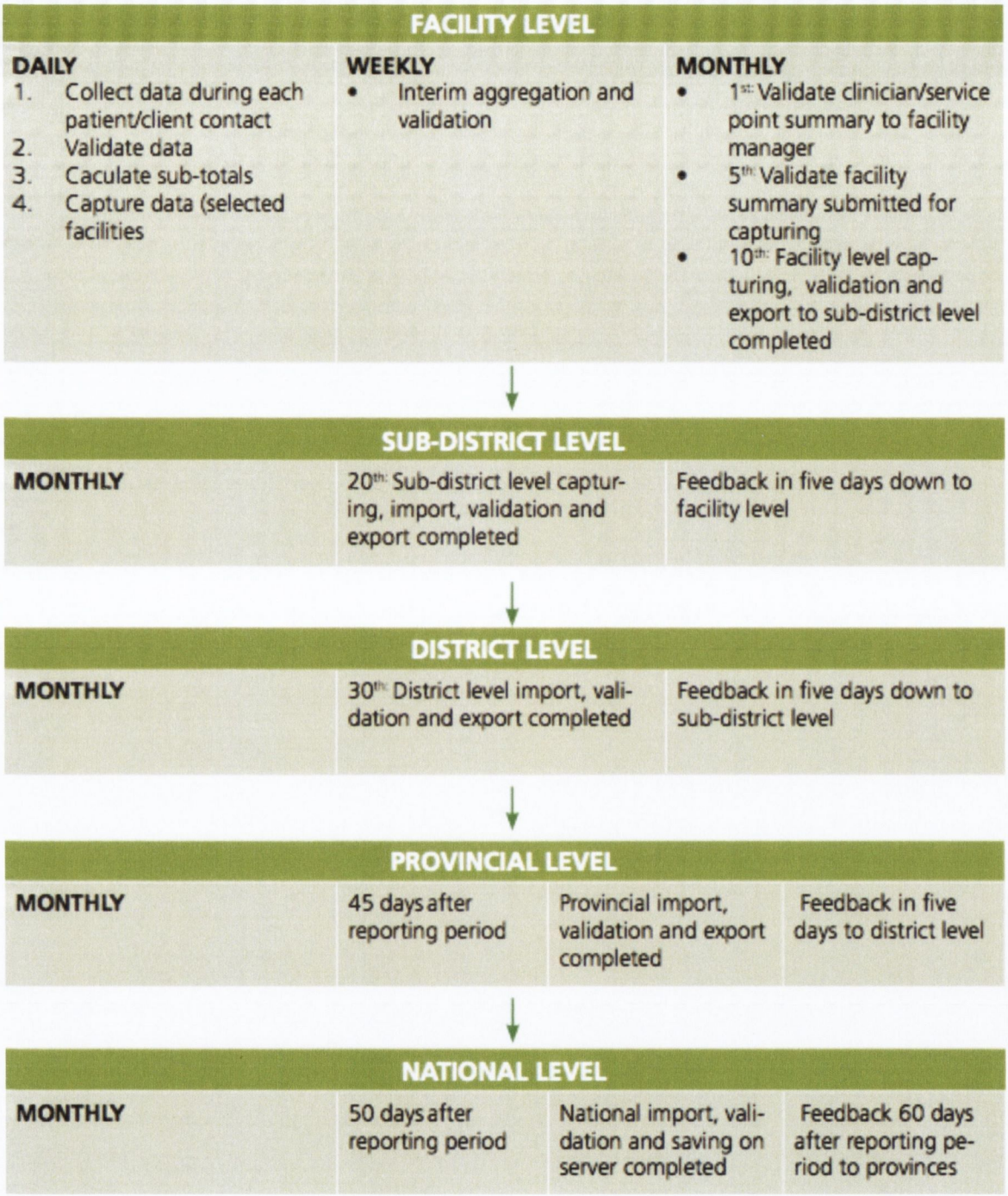


Figure 5-9. Routine data reporting flow diagram as presented in the District Health Management Information System (DHMIS) Standard Operating Procedures: Facility Level. (DoH, 2012b).

Since the SOP was not available for the facility staff or the researcher at the time of the data collection, the researcher cannot confirm whether the data flow was exactly as described in Figure 5-9, particularly in terms of the timelines mentioned and feedback. What is not seen in the routine data flow diagram is that at the case study clinic, some or all of the RMR information is captured in

the PREHMIS information system. This is because the case study clinic is in Cape Town and PREHMIS (Patient Record and Health Management Information System) is a patient based information system used by the City of Cape Town Metropolitan Municipality (WCDoH, 2013a), i.e. the City's electronic patient information management system at the facility level tracking services rendered per patient. It is not a medical record per se, although it was often referred to as 'patient database' in the interviews. It is networked, and used up to the district level. There exists a provincial equivalent, which is used in provincially run facilities.

However, the RMR information is not reported via PREHMIS. Basically, the required information could be extracted from PREHMIS, but work would need to be done first as at the time of the data collection PREHMIS could not provide all of the of information needed and the data would have to be totalled up first (Informant)[53].

RMR data includes the following TB and HIV related data elements:

The TB fields are as follows:

- All sputum samples sent
- Sputum results received in 48 hours
- Suspected TB cases with sputum sent
- Suspected TB case smear positive
- Suspected TB case smear positive, treatment start

The HIV fields are as follows:

- HIV positive new patient started on Cotrimoxazole prophylaxis
- HIV positive new patient started on INH preventative therapy
- Registered ART patient
- Registered ART patient on any adult regimen

Technical reasons are not the only reasons why a system is used or not used in South Africa. There are other policy related reasons, which are discussed in the next chapter.

At the sub-district level, the official working in Information Management reported that they accessed the Routine Monthly Report data in by linking into PREHMIS. However, it is not clear to the researcher how this happens as the RMR data at the facility level is paper-based. In any event, the official enters the RMR data into the Sinjani information system at the sub-district level, as well as compiling the required report and validating the data. Sinjani is a web-based routine system for tracking health service delivery in the public health sector in the Western Cape. Precisely, it is a provincial version of DHIS (District Health Information System). Free and open-source DHIS was adopted as the national standard system for the capture, storage, analysis and reporting of routine data after the first national minimum data set for primary health care was adopted in 1999 (Department of Health, 2011a). The national Department of Health calls the software solution a DHIS and the whole system (including people; policies, procedures) District Health Management Information System (DHMIS) but these are often used synonymously. The Sinjani system has been operational in the Western Cape, including Metro District (the City of Cape Town) from around 2009 (WCDoH, 2009). Since the previously presented data flow diagram does not show by which electronic mean the RMR data is reported, this is shown in Figure 5-10.

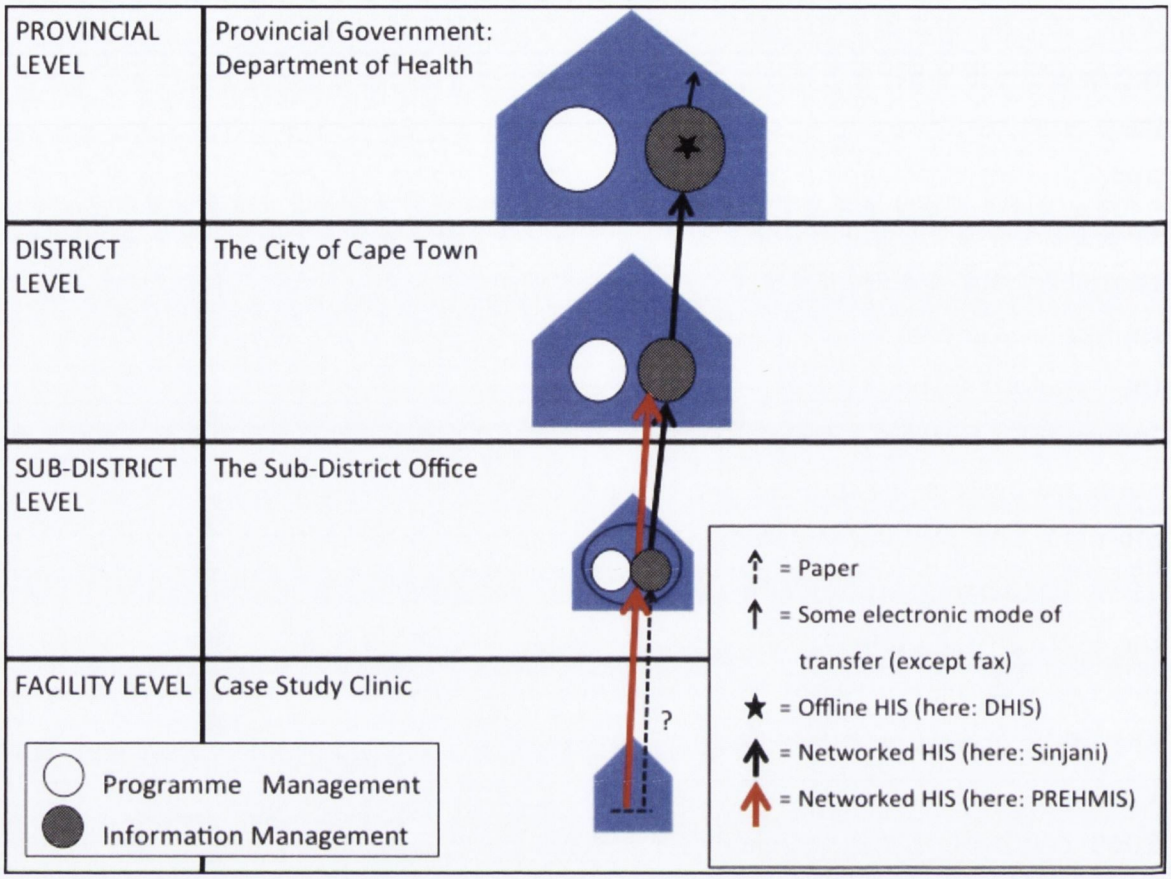


Figure 5-10. RMR Dataflow. A simplified representation of the RMR dataflow at the case study settings at the time of data collection (2012).

As before, further horizontal information distribution at each level, as well as a feedback loops have been omitted from the figure to keep it simple. First, what should be noted is a question mark next to the arrow representing paper flow. This refers to the previously mentioned mixed evidence as to whether the sub-district office accesses all required data through PREHMIS (which exists already at the facility level as illustrated by the thickest (red) arrow) or if the data is sent there also in a paper form. The tool that is used to report RMR data to provincial level, Sinjani, exists from the sub-district level upwards as indicated by a thick black arrow. What looks like a parallel flow from the sub-district to the district level is the co-existence of the Province's Sinjani and the City's PREHMIS. In Sinjani, the data is aggregated whereas in PREHMIS the data is recorded at the level of the individual patients. At the district level PREHMIS is also connected to the Burden of Disease Register, Births, Deaths and Notifiable Diseases. At the district level RMR information needs to be collated from all the sub-districts into

a district database so that the City may compare sub-districts within the district. The district level Information Management has access both to Sinjani and PREHMIS.

Provincial staff can check the data continuously on Sinjani, if they are trained in its use. The data is compared to previous data and is checked for gaps or anomalies. When provincial Information Management needs to report to the national level, they export the data from Sinjani and into DHIS. DHIS is not networked, as indicated by a star in Figure 5-10.

5.8 SUMMARY OF CHAPTER 5

To gain an understanding of the research question this study set out to follow TB and HIV related data flows that originate from the case study clinic. Interviews, supported by data from observations and document analysis, revealed that there are six of them. Figure 5-2 of this chapter displays the 6 data flows, represented as simple grey blocks referring to TB, HCT, ART, PMTCT, STI and RMR data. Figure 5-3 shows the basic health governance structure in the Western Cape and selected organisations at four levels: facility, sub-district, district and provincial level. However, as illustrated in this chapter, the data does not flow in a straightforward way through the organisations. Instead the data is kept in and reported via various different paper form documents such as registers, memory sticks or CDs, Excel sheets and so on. Data is also entered into a number of different electronic health information systems including

- ETR.Net (Tuberculosis)
- EDRWeb (Multidrug-Resistant Tuberculosis)[54]
- Tier.Net (ART data, also known as Electronic HIV Register)
- Sinjani (aggregated HCT, PMTCT, STI, RMR data)
- PREHMIS (Patient Record and Health Management Information System for City of Cape Town clinics)

[54] Not examined in this study in detail.

In addition, in the case study province, eKapa is used to report ART in some clinics (instead of Tier.Net, or the paper-based equivalent), the Primary Health Care Information System (PHCIS) is used instead of PREHMIS in provincially run community health centres, and DHIS is used in place of Sinjani in the rest of the country. This list is not exhaustive as there are various other registers, tools and systems at ground level in different facilities, but these are not directly relevant to this study.

Multiple tools are not the only challenge at the case study setting. What may have already come through the data flow illustrations is that the South African TB and HIV information system consists of parallel and complicated data flows. This kind of system may be seen as a challenge itself, but it may also bring about further problems. This is the broad subject of the next three chapters.

Chapter 6 Analysis of Findings: The data quality in the South African TB and HIV information system

6.1 INTRODUCTION AND OVERVIEW FOR THE ANALYSIS OF THE FINDINGS (CHAPTERS 6-8)

The previous chapter presented the findings obtained from the research by reviewing the TB and HIV related data flows that originate from the case study clinic. This was done deliberately without much interpretation of the meaning or the context of the flows. Figure 6-1 illustrates the focus of Chapters 6, 7 and 8. In them, by contrast, an analytical approach is taken to examine the crosscutting issues regarding the data flows.

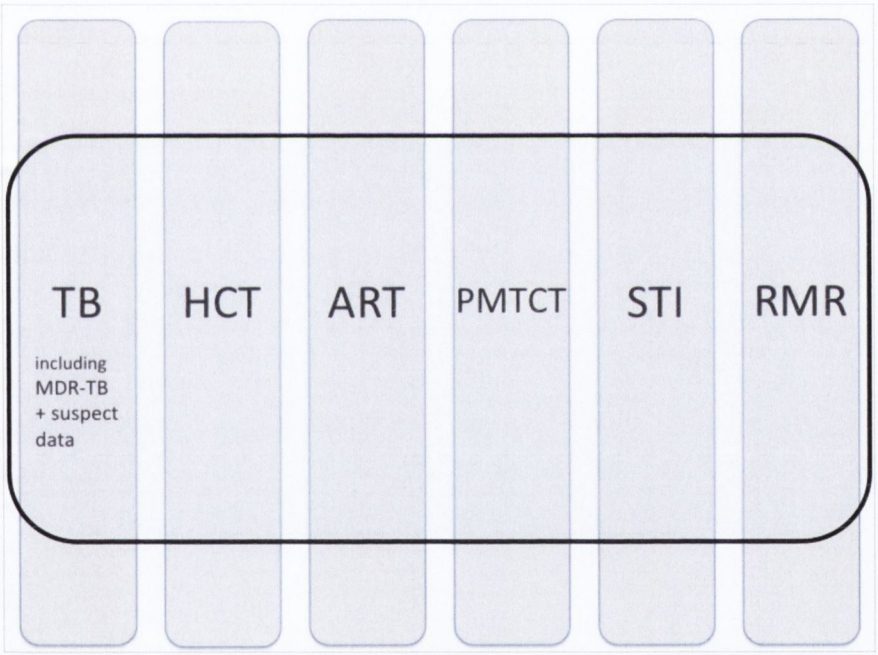


Figure 6-1. The focus on crosscutting issues regarding the examined data flows (Chapters 6-8).

Chapters 6-8 delineate the key findings with respect to the case study methodology adopted in this research. Specifically, they address the research objective C: *"To identify the key challenges in systems and practices as perceived by the local health professionals."* The study is not limited to documenting what the local healthcare and M&E professionals in a variety of different occupational roles report as challenges in the South African TB and HIV

system. Chapters 6-8 also meet research objective D: *"To analyse and categorise these challenges in order to identify where systemic improvements are needed".* The identification, analysis and categorisation of key challenges are conducted by the thematic analysis of the research data (interviews, observations, document analysis) and informed by the literature covered in Chapters 2 and 3. Finally, despite the focus on deficiencies, some aspects of the South African TB and HIV information system which function well are highlighted.

A few more relevant things should be noted about the findings: First, they are highly inter-related. Often, it is different sides of the same phenomenon that are being examined. Second, the findings of Chapters 6-8 are presented according to the same three categories which the researcher used to organise some of the reviewed literature. These categories are:

- The quality of data produced by a HIS
- The functioning of a HIS
- The utilisation of the data produced by a HIS

This approach was chosen to assess the overall quality of a health information system in a holistic, detailed and comprehensive way. In this case, it is the South African TB and HIV information system.

Third, a majority of issues emerging from the research relate to the broad area of the functioning of the health information system, whereas there is less evidence regarding data quality and utilisation of data, as illustrated on the left side of Figure 6-2.

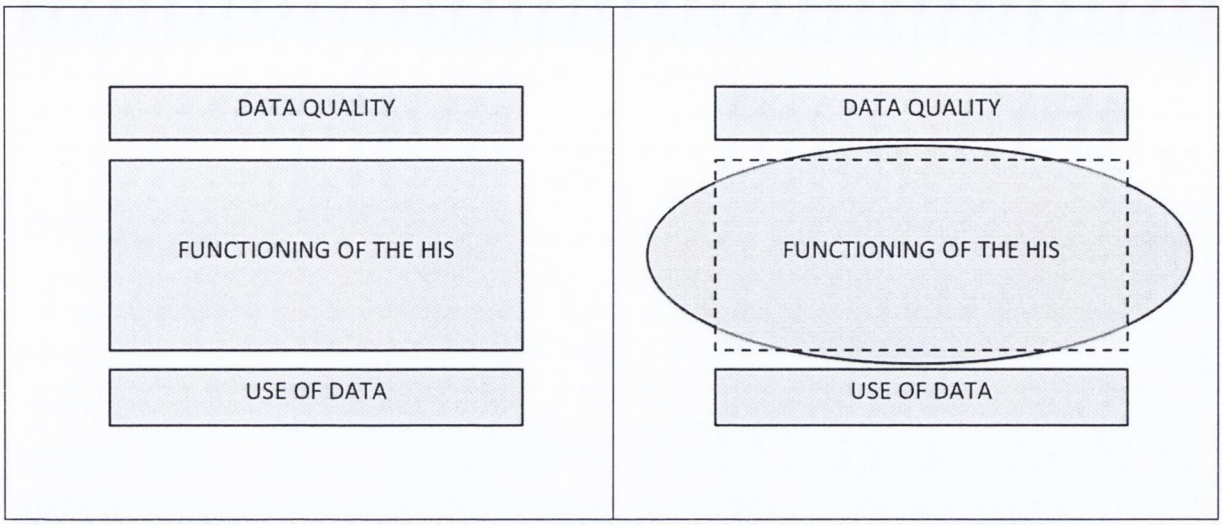


Figure 6-2: The areas, which the findings of this study relate to (left). Illustration of the fact that some of the findings address a broader context than may traditionally be viewed considering HIS functioning (right).

Fourth, as indicated on the right side of Figure 6-2, the findings relating to the functioning the HIS defy categorising and do not neatly fit for instance into Ledikwe, et al.' groupings (M&E structures, functions and capabilities; indicator definitions and reporting guidelines; data collection and reporting forms and tools; data management processes; and links with the national reporting system) (2014). This is mainly because this study addresses wider structural deficiencies, which may be seen as *root causes* for deficiencies. In other words, it would have felt wrong to discuss only, for instance, data reporting forms if the informants themselves have identified two health authorities providing primary health care as a key deficiency in the TB and HIV information system at the case study setting. In other words, the analysis of the findings addresses a broader area that may traditionally be viewed relating to HIS functioning, as illustrated on the right side of Figure 6-2.

Finally, in some studies, the findings are presented separately from the analysis. This is not the case in this study. The qualitative data revealing the complexities of the research topic produces findings that are rich in detail and highly inter-connected. It would be unfruitful to present them without sufficient explanation and commentary and then repeat them again in the analysis section. Therefore, to make it easier for the reader, chapters 6-8 include both findings and their analysis.

In conclusion, this and the two following chapters discuss the quality of the data produced by the South African TB and HIV information system (Chapter 6); the overall functioning that system, including issues that contribute to the functioning of that system (Chapter 7) and utilisation of the data produced by that system (Chapter 8).

6.2 ANALYSIS OF THE FINDINGS: VARYING DATA QUALITY

6.2.1 Data quality - Introduction

As illustrated in the literature review, data coming from African countries does not necessarily truly reflect the situation in Africa (WHO's Regional Office for Africa, 2002; Ndira et al., 2008). Research has identified less-than-optimal data quality in South Africa (for instance in Mphatswe et al., 2012 and Garrib et al., 2008) as well as in other LMICs (for instance in Ndabarora et al., 2014; Braa et al., 2012; Makombe et al., 2008; Forster et al., 2008). Several informants in this study point out that in terms of the quality of data collected, South Africa compares very well with the rest of the continent. This is also indicated to some degree in the literature: in areas such as civil registration and mortality statistics (Kabudula et al., 2014) or education data quality (UNESCO, 2010). Moreover, there is a consensus amongst the informants that both the M&E system and the general data quality are better in the Western Cape than in the other provinces of South Africa.

> *"You know from what I hear from our provincial colleagues that interacted nationally, the ART data set is in a complete mess, the Western Cape is probably the only one, other than some of the other provinces that have had NGOs, that have got on the side with datasets. Very few provinces have anything else other than the number of people that have ever started. They don't have a clue of how many people are still remaining in care."*
> (Informant in decision making / data use position)

The researcher could not find any indication to contradict this claim[55]. However, there is considerable variation in the quality of data **between different (vertical) data flows** at the case study setting, as well as **between different (horizontal) levels of authority** through which the data is moving, which the researcher considers as important findings. Furthermore, the quality depends on **which aspect of data quality** one examines.

The original source of the TB and HIV related information is in the clinical encounter between the patient and the nurse/doctor in the clinic. The researcher did not observe clinical encounters or the original patient documentation to see whether the data had been appropriately transcribed into the reporting system. Hence, a strictly technical IS approach to the concept of data quality was not appropriate. Rather**, data quality is examined through the lens of the informants**.

The informants shared their views on data quality in a very general sense. To structure that conversation, the researcher aimed to organise the discussion around accuracy, completeness, timeliness, comparability and coherence of data, and provide an explanation of each aspect, if required. These aspects were combined from two sources: Irish Guiding Principles for National Health and Social Care Data Collections by The Health Information and Quality Authority (HIQA) (HIQA, 2013) and District Health Management Information System (DHMIS) Policy by South African National Department of Health (Department of Health, 2011a). The former was selected because it incorporates wide national and international evidence in working towards greater consistency in national health data collections. The latter was chosen because it represented a local source that has already considered dimensions of data quality in a way that is suitable for the local context.

A variety of data quality dimensions are presented in both of the documents. However, due to the very limited time that was often available for

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[55] Immigration to the Western Cape, and evidence in the form of a human development index (UNDP, 2003) and estimates on poverty, (Human Sciences Research Council, 2014) as mentioned in 4.4.6, support the claim that the Western Cape is generally more developed than many other provinces in South Africa. Moreover, many of the HISs and pilot projects were originally started there and then scaled up elsewhere. Naturally, neither of this these directly proves that data quality or HIS functioning are better in the Western Cape than elsewhere, but the researcher has no inclination of the opposite, either.

interviews, the researcher had to omit a number of aspects and focus on the ones which seemed to be the most relevant and understandable. Table 6-1 lists the ones that researcher adopted and what is meant by them in this research.

Table 6-1. Description of data quality dimensions. Loosly adapted from Ireland's Guiding Principles for National Health and Social Care Data Collections (HIQA, 2013) and District Health Management Information System Policy by the South African Government (Department of Health, 2011a).

Accuracy	Accuracy refers to correctness - data correctly captures what it was designed to capture.
Completeness	Complete data has all the items required to measure the intended activity or event.
Timeliness	Timeliness refers to notion that there are no significant delays in data collection, conversion into information or data submission.
Coherence and comparability	Coherence of information is the degree to which it can be brought together with other similar information from different sources within a broad analytical framework over time. Comparability of information is the ability to compare data on the same characteristics between different points in time and geographical areas.

In practice, informants had varying ideas as to what they understood as 'accuracy of data' or with other dimensions. Most of the discussion centred on accuracy, completeness and timeliness, which as concepts are easier to comprehend in the field-level day-to-day work context, whereas coherence provoked rather vague comments and was often grouped together with comparability (as it is also in Table 6-1).

The amount of time and attention allocated to data quality discussion depended on the occupational role of the informants. A few informants did not discuss data quality at all. Those who discussed data quality, did it with reference to a specific data flow, HIS, or report that they happened to be involved with or alternatively provided very general statements. Therefore, the strength of the evidence varies: there is more evidence on some flows/some dimensions than others. Table 6-2 illustrates the entity of all data flows and all quality dimensions, i.e. what the researcher wanted to find out.

Table 6-2. The information that the researcher sought to obtain regarding the data flows. From top to bottom: the data flows, from left to right: the dimensions of data quality.

	Accuracy	Completeness	Timeliness	Coherence and comparability
TB Tuberculosis data Note: findings on MDR and suspect data may not correlate with findings on main TB dataflow				
HCT HIV Testing and Counselling data				
ART Antiretroviral Treatment data				
PMTCT Prevention of Mother-to-Child Transmission data				
STI Sexually Transmitted Infections data				
RMR Routine Monthly Report data				

Observations were used to accompany the data from the interviews, while public document analysis provided some additional information. The aspects of data quality are largely intertwined: for instance, due to late reporting at a lower level, an incomplete report may be sent forward resulting in comparability issues at higher levels.

It is important to understand that the following analysis of data quality is based on the informants' perception of it, and the researcher did not conduct an audit or similar formal evaluation.

Sections 6.6.2 and 6.2.3 highlight the **range of variation in quality** without examining all data flows and all aspects. The sections thereinafter, contrariwise, review the **aspects of data quality** with reference to each data flow. Finally, the availability of data is discussed, followed by conclusions and reflections.

6.2.2 Variation in data quality between data flows

The research found that there is **considerable variation in perception of data quality between the different data flows** in the South African TB and HIV information system. While some informants gave positive appraisals of data quality, others held the opposite view:

> *"...there is a lot that needs to happen on our data, most of the data is not actually a true reflection of what is really happening."*
> (Anonymous quote)

Data quality is understood in a very general sense in this section, without separating the different quality dimensions. Overall, several informants argue that the HAST (HIV and AIDS, STI and TB) data sets are acknowledged as being a relatively good reflection of what is actually happening. The informants consider that the TB data is of reasonably good quality, similarly the HCT and ART data (as elaborated later): at least it can be argued that they are of better quality than the STI and the RMR[56] data. The researcher is inclined to agree on the basis of the observational and other evidence. Contrariwise, particularly the STI data flow appears to be of sub-optimal quality. The STI data flow seems to produce partially inaccurate and unreliable information, but the other aspects of data quality are also likely to suffer as a result. Efforts have been made to improve the quality but previously, and possibly even partially currently, lack of ownership may have negatively influenced the quality of STI data.

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[56] RMR is not one of the HAST data flows but is considered as a TB-HIV related data flow in this study as explained in Chapter 5.

> *"...we picked it up in the HAST dataset, actually the STI component that was sitting in fact with Information Management but hadn't really been allocated to somebody in terms of having overall programme oversight. The quality of the common distribution data, especially the STI indicators in terms of number of new STI cases on so on, it was such problematic data that we would've ended up not using it.*[57]*"* (Informant in decision making / data use position)

While this quote informs us about the inadequate quality of STI data, it can also be interpreted as an indication of the governance issues that tend to be amongst the underlying causes for the M&E challenges in the Western Cape (discussed in 7.4). Moreover, the quote echoes Braa et al's notion (2012) that the poor quality of data will be reflected in the low utilisation of the data.

Vignette 6-1 provides an example of insufficient data quality and sheds further light on the multiplicity of reasons that may be behind it.

A CASE STUDY WITHIN A CASE STUDY:

'Cases' and their partners: what is the root cause of inaccurate STI data?

According to several informants, the City and the sub-district level collect STI information as 'cases' and not 'episodes', as prescribed nationally. An informant states that this is mainly due to the fact that many of the patients in the case study area have often a cluster of STIs and one STI easily masks another. Hence, the STIs are not individually diagnosed and treated but the clinics treat the whole syndrome at the same time (i.e. a group of most common STIs without making an individual diagnosis for each STI). Each patient is then counted as one case regardless of the number of STIs. This method is different to the way the national level collects statistics and causes disagreement between the stakeholders. Additionally, since the City and the sub-district level are counting cases instead of episodes, the built in validation rules in the Sinjani information system do not hold. This phenomenon then appears as an error in Sinjani.

To make things more complicated, occasionally there is some inconsistency in issuing Partner Notification Slips. Many of the South African STI patients have more than one partner, and sometimes there may be several. The STI patient is supposed to be

[57] The researcher's interpretation is that the first "it" in the quote refers to the STI data.

given a number of Partner Notification Slips: these slips are supposed to be counted and then how many of the patient's partners came back into the service should also be counted. However, partners may often seek treatment elsewhere. Moreover, there is some inconsistency or ambiguity with the number of slips that are to be issued by the staff, who may underestimate or overestimate the number of partners or deviate from agreed procedure, (for instance, give each patient 4 slips regardless of the number of partners). Nevertheless, apparently this information forms part of the statistics as the National Department of Health's definition for the STI partner notification rate is *"Number of STI partner notification slips issued divided by number of STIs treated, new episode, expressed as a percentage"* (DoH, 2009 in Health Systems Trust, 2014). Considering the inconsistencies in issuing slips, the statistics may not be reliable. Furthermore, if one considers the previous example of the district/sub-district level collecting the STI information as cases and not episodes, this further makes one wonder at the quality of data produced by this specific indicator. Finally, an observation on that particular rate being 154.1% in the Western Cape in 2009 (DoH, 2009 in Health Systems Trust, 2014) raises further questions in regard to the logic, practicality and usability of the indicator.

Vignette 6-1: 'Cases' and their partners: what is the root cause of inaccurate STI data?

The Vignette raises questions: what is the root cause for sub-optimal STI data with reference to this specific indicator (the STI partner notification rate)? Is it merely the different unit of analysis in the statistics (case vs. episode)? Is it the national level's inability to address the local needs or the sub-district and district level's decision to take the path of local flexibility at the expense of disobeying national prescripts? Is it the 'error' in Sinjani, which possibly makes the person requiring the information to use another route to validate the notification rate? Is it lack of supervision or mentoring that may contribute to confusion at the field level with the issuing of the Partner Notification Slips? Or is it the nature of health politics, where the policy, such as 'what we need to know on the STI partner notification and how do we get that information', is developed somewhere at the highest level with very limited room for local flexibility and grass roots level contribution?

In addition to the STI data, the RMR data is not considered to be of very high quality by the informants, and the researcher is inclined to agree. One of the main challenges of the RMR data is the duplication of information with other

registers. For instance, RMR data includes TB and HIV information. However, the TB and HIV related data in the RMR data flow might not be used in local decision-making:

> *"But that information is largely ignored by me... ...Because it's not relevant. It is very incomplete and it doesn't follow the cohort. We've got better sources. We've got registers where the patient's name is in it. And then we follow those patients, those cohorts of patients over a period of time. So if you ask me what is out there that is linked to TB and HIV, I am going to say I would ignore the Routine Monthly Report."* (Informant in decision making / data use position)

Informants argue that the quality of the RMR data has improved significantly over time, and it is now more auditable than it used to be, but it still lags behind in comparison to the HAST data flows. Nevertheless, it is still used in several national and international reports (see, for instance, Republic of South Africa, 2013).

To conclude, while some of the TB and HIV related data flows in the case study setting are of high quality, particularly in the context of South Africa or Africa, variation in quality can be found between the flows. As exemplified with the Vignette 6-1, a question "what causes low quality" cannot be easily answered, because the reasons may be different for different data flows and even for different indicators in one data flow. Finally, a consequence of sub-optimal data quality is that, although that kind of data may be reported, it may not be utilised in decision-making.

6.2.3 Variation in data quality between the levels of authority and data validation mechanisms

The second important observation, complementing the first finding, is that **besides the variation in data quality between the different data flows, there is considerable variation in quality between the levels of authority through which the data travels** in the South African TB and HIV information system. The quality of the TB & HIV related data collected is poorest at the facility level. The assumption may be that if it is poor at the source, it will

inevitably also be poor at the higher levels. However, the situation is in fact quite the opposite. After the efforts of the sub-district staff, the quality of data is improved at the sub-district level, and it further improves at the district level and then again at the provincial level. This is due to the **validation structures** at each level: *"The data... do go through a lot of verification and validation processes"* (Informant). In other words,

> *"it's not supposed to end up; incorrect data should not actually end up, by the time it reaches us. As I explained, we are the last person ...receiving it. But somehow mistakes still slip through."* (Provincial level informant)

Various informants described in detail the systems that have been put in to improve the quality of data. At each round of validation, the errors and gaps detected are also corrected at the lower levels via a feedback loop – at least this is how it is meant to be. The researcher, however, has no means to verify this. Nevertheless, a lot of work is invested in validation and various tools and systems are used to ensure that the data would reflect reality.

> *"I would say that we have got a lot of things in place to pick up any inaccuracy if we need it. So I think we do have a, a quite nice system between us... ...to block that, and you know pick out the inaccuracies. We still have the odd you know here and there, I mean we can't; but we have got systems in place."* (Informant)

The majority, if not all, of the informants who receive and send any pieces of data to the next level, describe it as their duty to validate and check the data for errors before sending it on. In addition to all this, there is a data capturer at the facility, whose responsibility is to perform prescribed data clean-up steps. The facility manager validates the data before it leaves the sub-district office, as do the HAST Coordinators. They may also perform spot checks at the facilities. Furthermore, the provincial level may also do district visits, i.e. randomly select a few districts and visit randomly selected sites there. In total, various *"checks and balances"* are built in the system, particularly on the HAST programme side (Informant). Finally, occasionally even NGOs support the data quality work by

obtaining a copy of the data and having their staff going through it and providing feedback on any shortcomings identified.

There was also evidence suggesting that there is on-going enthusiasm to aim for better data quality which supports the data validation activities: *"all times they're trying to improve on the data"* (Informant, field level). The built-in data quality assurance in the TB and HIV information system at the case study setting can be viewed as one of the well-functioning aspects of the system as perceived by informants and represents good practice on how to improve a HIS. The central aspect of this is that key posts have been made **accountable for the quality** of data. This has, however, not always been the case. **Audits** were also considered helpful and a well-functioning aspect of the Western Cape system. While they are conducted to chiefly audit practice, there are elements of data collection, which are highlighted, including clinical record keeping, data entry into registers and transfer from registers into databases. Nevertheless, it is questionable whether the amount of effort put in is proportionate, and if there are other ways to obtain the same level of quality in data.

Since all aspects of the quality of the data collected improve the higher one goes up the levels of the health authority, one might assume that the data quality is superb at the national level. However, according to the informants, that is not the case. On the contrary, they argue that there used to be a significant data quality challenge, data being *"so rubbish that it means nothing"* (Anonymous quote) and there are still considerable data quality issues.

In conclusion, if one asks what is the level of data quality of register X at the case study setting, one may get a different answer depending on who one asks. A sub-district level staff member may view it as rather poor, since it was originally inaccurate, incomplete or always late and hence gives them a lot of work. Provincial level staff, by contrast, may perceive it as high-quality data (which it may very well be, particularly compared to other provinces), since all the 'middlemen' have already invested in improving it.

6.2.4 Accuracy

The next sections focus on the different dimensions of data quality, namely accuracy, completeness, timeliness, coherence and comparability.

With all the data flows studied, except for the STI and RMR, the accuracy of the data was considered to be from relatively good to very good by the informants. (This is the researcher's interpretation: in the actual interview situation an informant may use an expression, such as *"it is alright you know"*.) Moreover, the informants argue that the accuracy of all data has improved significantly over time. Several informants consider the TB data to be accurate: there have been audits, and one informant reported good compliance in terms of the accuracy of TB information between the individual patient folders and the paper-based register. This is in line with Auld et al's study (2013) but in opposition to Heunis et al's one (2011). While Auld and colleagues report lower concordance across systems (i.e. TB variables in the HIV systems and vice versa) the TB variables they studied in the TB system had high data concordance (Auld et al., 2013). More specifically, the concordance was high with TB specific variables between TB patient file, TB Register and ETR.Net (up to 0.99 as measured with Fleiss' kappa coefficient) with the exception of a TB-HIV related variable[58]. Contrariwise, a fifth of 2800 TB patient data entries had a discrepancy between facility and province level in Heunis et al.'s study (2011). They identified severe resource shortages at the time of their study as a possible reason for their results. The researcher of the current study wonders if her TB data accuracy findings would be more congruent with those of Auld et al. than Heunis et al., because the current study and the one by Auld et al. were conducted in the Western Cape, while the one by Heunis et al. was conducted in the Free State.[59]

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[58] κ values range from 1 to −1, with a value of 1 referring to 100% agreement between sources, a value of 0 indicating no agreement beyond what one would expect by chance, and a value of −1 indicating 100% disagreement. A value of 0.8–1.0 can be considered almost perfect agreement, 0.6–0.8 reflects substantial agreement, 0.4–0.6 moderate agreement, 0.2–0.4 fair agreement, 0–0.2 slight agreement, and <0 reflects poor agreement. The studied TB variables in TB Blue Card + TB Register had values 0.99, 0.97, 0.92, 0.94, in TB Blue Card + ETR.Net 0.98, 0.87, 0.63, 0.93, and in TB Register + ETR.Net 0.99, 0.84, 0.65, 0.92 with the exception on HIV-TB related indicator on cotrimoxazole preventive therapy (used for co-infected patients), where the values were 0.31, 0.20, 0.31 indicating fair agreement (Auld et al., 2013).

[59] The studies of Auld et al. and Heunis et al. are not conducted exactly in the same way and they do not measure exactly the same thing, so they may not be *directly* comparable, but the researcher thinks that there

However, according to the informants, the MDR-TB data and, to some extent, the suspect data have lower data quality. Overall, regarding all data flows, sometimes inaccuracies and mistakes do slip through, but it would mainly be completeness and timeliness of the data that would require additional effort from the people working with data, rather than accuracy per se. Complete fabrication of numbers is not at all common, according to the informants.

HCT data, similarly to ART data, was considered relatively accurate and reliable by many informants who are in position to comment on it. Auld et al's comparison (2013) between the ART file and eRegister (electronic system for the ART data) reflected substantial to almost perfect agreement except for TB data[60], in line with informants' statements. Finally, the researcher's interpretation is that the accuracy of the PMTCT data is more inconsistent than TB, ART and HCT data. However, compared to the earlier findings from Kwazulu-Natal province by Mphatswe et al., 2012 (data from 2008 to 2009) and Mate et al. (2009) on the very low accuracy of PMTCT data in DHIS, the researcher's impression on the basis of her evidence is that the current Western Cape PMTCT data is considerably more accurate than the data reported by Mphatswe, Mate and colleagues.

However, maintaining good accuracy requires continuous work. For instance, with the HCT data the quality comes with a price. Vignette 6-2 describes, how.

A CASE STUDY WITHIN A CASE STUDY:

What does it require to produce good quality HCT data?

The researcher had an opportunity to observe an Excel spreadsheet containing HCT data and discuss it with an informant. The observation revealed that there are plenty of errors

is enough similarity so that a rough comparison is meaningful. Moreover, it should be noted that neither of the studies, nor this study cannot measure accuracy in terms of whether 'what is wrong with the patient and what happened during the clinical encounter' is accurate reflected in the data.

[60] Concordance was measured using Fleiss' kappa coefficient. The values were 0.96, 0.77, 0.70 except for an indicator on cotrimoxazole preventive therapy of which value was 0.08. For more data on the study see two previous footnotes or Auld et al. (2013).

on the Excel sheets and, for instance, validation rules that state that something should add up to 100% could add up to only 99.2%, indicating that there is an error in the original data. According to a district level informant, the district level cannot correct the mistakes, which are due to inaccuracy, or more rarely, a missing value in lower-level data. The Excel sheet is then sent back to the sub-district level and the sub-district office in whose data the mistake occurs needs to go through the data of each facility to spot the origin of the mistake. Three challenges may occur:

First, sometimes, when the district level has asked for clarification for a long time and finally states that the data will submitted as it is now, the clarification suddenly comes at the last minute. In these kind of situations, the district level may wonder whether the sub-district level has actually called the clinic and moreover, whether the person at the bottom end of the chain at the clinic has actually gone through the patient record to check the mistake, or if just a random, right-sounding answer has been given to sub-district level so that the clinic level could continue with their work.

Second, assuming that everybody is truthful and thorough with their endeavours to provide accurate data, sending the Excel sheet back and forth is nevertheless error prone and slow. In other words, due to errors and gaps, one spreadsheet is often sent back and forth several times. In fact, the district level has to keep a log of which version is which and what information has been added, erased or changed. The worst Excel sheet that the researcher observed was version 14. Moreover, it used to be quite possible for one month's data to take 4 months to complete. However, the new policy is to 'lock' the data two months after the submission date. Nevertheless, it is obvious that even if everybody is very careful, there is a risk that something can go wrong when a complex document travels up and down 14 times and multiple people try to work with it. For example, an older version may accidently replace a newer one. Furthermore, occasionally wrong versions may appear in meetings or a high-level person may receive two different versions of the same data. Multiple corrections and hence multiple versions are particularly likely before Plan, Do and Review process[61] since that adds pressure to get timely data.

Third, there are formulas in the Excel spreadsheet and they can sometimes be corrupted. According to an informant, this is in particular if the lower-level members of staff with limited knowledge of Excel try to change them. Indeed, if a facility needs to be

[61] Plan, Do and Review process is discussed in section 8.3.

added on to the Excel sheet, the district level has requested that this is not done at either the sub-district or facility level because of the risk of corrupting the formulas. Hence, this seemingly simple procedure (adding a row to an Excel sheet) requires that the sub-district office sends the Excel to the district level which adds the row and sends it back. More IT training would be helpful, but on the other hand such a scenario could just as well happen in Finland or Ireland.

Finally, the HCT data should actually be reported through Sinjani. However, as mentioned earlier, the district level is reluctant to let go of the Excel sheets due to the perceived inadequacy of Sinjani. Another informant explains: *"So some of the challenges around that is in our Excel versions we had validations built in, but Sinjani when they set it up, they had not set in a validation. So we were reluctant to drop one system until the next system was actually as equipped to deal with those things and for various reasons that haven't happened. So it's hampered, and we've been dragging on too long running a parallel system which is not helpful to anybody. You know it's not efficient, it leads to different data sets coming out... So there has been a little pressure to be able to drop the Excel version, but on the other hand Sinjani hasn't been ready to start doing it."*

Vignette 6-2: What does it require to produce good quality HCT data?

So, the HCT data was said to be fairly accurate, but obviously a lot of time and effort are put in to sustain the desired level of data quality. A question, 'What does it require to produce good quality HCT data?' could be complemented with another question: 'Could the same result be achieved in another way?' Similarly to other issues discussed in these Vignettes, the question of data quality is more complex than it appears at first glance. Training and mentoring at the lower level might reduce mistakes and possibly mistrust and workload elsewhere. The hierarchal top-down nature of the system could be contested. The most pressing question, however, concerns the streamlining of the parallel reporting routes. At the time of the data collection, an error prone and laborious working method was maintained, probably for more than one reason. The researcher does not have enough information on Sinjani to say whether it could have already at that point of time been used to report the required data sufficiently or why the suggested improvements had not been incorporated into it. What can be said is that the researcher can see how working with the Excel sheets can give one a feeling of being in control of the data (and one's programme) and how it is very human to be reluctant to let go of the old tools and take on new ones, in particular if

imposed by other level of authority, and especially if there are deficiencies in the tool. In addition, the use of the tool is entangled with the larger context of the City-Province relationship, which will be discussed in the next chapter. Hence, a seemingly simple issue of dropping one tool and introducing another requires a holistic analysis and approach, since otherwise all sorts of unforeseen side-effects may occur, including a possible drop in the quality of HCT data.

6.2.5 Completeness

In general, informants considered completeness and timeliness more of a challenge than accuracy with most data flows. A large amount of incompleteness at the higher levels of the reporting chain is not very common, since the sub-district level (as well as all levels after that) would highlight the empty space in any sheet or register and the sheet would be taken back to the facility to be completed. With TB, there are not many incompleteness issues, since the standard registers make it difficult to leave a blank space, and in any event, the sub-district level would not accept it. This is not only because they wish to receive a complete data set but also because some electronic information systems, such as ETR.net where the TB data would be entered at the sub-district level, would not accept a blank cell in certain places. These findings are largely in concordance with those of Auld et al. (2013) who note that demographic and clinical TB-related variables are typically complete in the TB sources (up to 100% completeness for certain variables). However, they report incomplete HIV-related variables in the TB sources, which is a finding that does not explicitly come up in the data of this research.

Standard format reporting has probably improved the completeness of other data flows, too. A provincial level informant showed his/her calculations on what percentage of the sites had submitted the ART data required for certain reports by the due date and the result ranged from 95% to 97%.[62] Auld et al's

[62] Completeness is often connected to certain timelines, so this example could be discussed with reference to timeliness, too.

results on data completeness of their selected variables are roughly similar, except for certain TB variables in ART file and eRegister[63]. However, the informant points out that a rigorous follow-up is required to achieve high completeness and there would still always be one or two sites that cannot submit. Nevertheless, the situation has greatly improved from the original 37% completeness of ART data[64]. The HCT information is considered relatively complete, while the PMTCT data was argued to have some interconnected timeliness and completeness issues, as can be seen from the quote below. The quote is about following monthly cohorts of babies and updating their PCR testing information at 6 weeks.

> *"Then monthly they send their stats and monthly they must give us the number of babies according to the cohort of babies. ...And then they must also go back and check those that were done PCR 6 weeks ago and a month ago, they must keep on updating those PCRs and so on. ...If they're not there in say two weeks or three weeks' time they must phone the lab. But what we're saying is that before they give them the stats to us, they must make sure that all the PCRs are being entered. But it is a struggle. ...Now we are expecting to see that babies that were ...born in May ...up to January we want to see the PCR results having been filled. ...Because they must go back every time and check, those PCRs have they been done? If they have done 10 PCRs in April we cannot expect not to have had...not those eh, results by end of June; those results are supposed to be there."* (Informant, field level)

As may be interpreted from the quote, the process seems to be laborious. Consider a baby, who we call "Baby B". The challenge stems from the fact that when a nurse enters Baby B's other information into the register, she cannot write his PCR result, since the test has not been taken yet or the result has not arrived. At this point the nurse should actually remember to check the earlier results i.e. the result from "Baby A", who was entered into the register and tested earlier, and write that in, if it is available. However, when the sub-district

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[63] This is not exactly the same thing: Auld et al., 2013 examine completeness of ART-files and eRegister regarding selected variables whereas the informant looks at how many percent of sites has submitted the data in acceptably complete form. However, they both tell about ART data's relatively good completeness.

[64] "Original" refers to the time when the informant first began to monitor the completeness of the ART data. Unfortunately the researcher does not have a more specific time.

staff require the information, and the coordinators visit the facility, they often find that the results are in the folders but have not been entered in the register. In other words, incomplete information is reported, although availability and timeliness of data can also be seen as issues. Whilst this can be looked at from the point of view of a system flaw, i.e. a HIS that is not designed very well, another informant, however, describes the same phenomenon with the emphasis on the attitude of the data capturing staff:

> *"if they complete in this section, they got the folder here, they complete the section with what's written in the folder. If there is some result that hasn't yet arrived, whenever, they fill the next section. They will not go and check and "oh by the way I did not have this result then, but maybe I got it now, let me see" and you know complete the whole thing. No, they just take it in kind of chunks without looking at the bigger picture, without doing it in a holistic approach. So there are plenty of holes."* (Informant)

This issue is further discussed in section 7.5. Nevertheless, compared to the earlier findings from Kwazulu-Natal province by Mphatswe et al. (2012) (data from 2008 to 2009) and Mate et al. (2009) on the very low completeness of PMTCT data in the DHIS, the researcher's impression on the basis of her evidence is that the current Western Cape PMTCT data is considerably more complete than reported by the earlier research.

Regarding STIs, there was not enough data on the level of completeness of the STI dataflow. Finally, sometimes reported data that appears complete, in that there are no gaps in the report or form, can be based on entirely incomplete information. This may occasionally happen with RMR data, unless the staff who are accountable for it, pick up the gaps, as explained below.

> *"In terms of filling RMR sometimes they're [nursing staff] missing to fill those things, and maybe they see fifteen patients a day, and are filling seven patients a day and what about the eight patients that are nothing? That job it's going down to the drain because if I don't see something that it's not filled in the RMR I ...just assume that there was nothing done to that patient's folder. So that has been a huge problem that we've been dealing with as administrators."* (Informant, field level)

Needless to say, this is not just an administrator's problem but anybody else's who is going to locate resources or make decisions based on that data.

6.2.6 Timeliness

With the main TB data, timeliness is good: staff members adhere to timelines "*by and large*" unless somebody leaves or a crisis interrupts the process (Informant). However, untimely reporting is a feature of the MDR data, which has different dynamics due to the hospitals being part of the chain. Timeliness is also the most pressing challenge with the suspect register: "*Because we sometimes have to really force it out and then that person is not there and then somebody else does it*" (Informant working with TB data). The issue of (South African) TB reporting deadlines are also mentioned by the respondents of Heidebrecht et al. (2011) as they can strain staff resources and take time from other responsibilities. However, when considering the overall system, generally, provinces and even countries have usually 12 months delay in reporting TB treatment outcomes, whereas the Western Cape has only 9 months delay, according to an informant. Also the ART data is largely reported in a timely manner, albeit there are sites that miss the deadline but after follow-up by phone, email and sometimes escalating to managers, the majority of the data will be submitted before the sign-off. Moreover, it is argued that the HCT data is rather timely, but the process depicted in Vignette 6-2 may raise questions on time related issues of the process. Regarding PMTCT, timeliness related issues were reported. The researcher has no specific data on the *timeliness* related issues with STI and RMR, but it does not mean that there would not be any, in particular as in general several informants see it as a substantial challenge and an "*on-going struggle*" to get the staff to submit the data on time.

It is not always the same people who submit late. Moreover, the higher level staff members feel bad pressuring them because A) they may be the ones who usually submit on time B) 'report it or I will tell your manager/supervisor' may not actually help, C) they do not want to spoil the working relationship, D) they have no line management function over them, E) there are often good reasons why they have not submitted the data. For example, the person who is

supposed to submit the data is away or sick, likewise the person to whom the job is delegated (sickness occurs a lot) or the job has not been delegated at all. Also the higher-level informants admit that the timelines are somewhat difficult to stick to. The data has also a hierarchy, it may, for instance, be more important that the quarterly data is submitted on time, rather than the monthly data.

6.2.7 Coherence and comparability

By and large, the coherence and comparability of data seem to be good with TB, HCT and ART and at least reasonable with PMTCT. There is not enough interview data on the coherence and comparability of STI data, but on the basis of other evidence, the researcher suspects that it is questionable. The RMR data was specifically mentioned as lacking comparability. In particular with TB, coherence and comparability is considered very good since everybody speaks and understands the same *"WHO nationally approved TB lingo"* (Informant working with TB data). The same can likely be said with HCT/ART. Moreover, everyone is following the same protocols and guidelines: there are clear internationally defined case definitions and also ETR.Net came with the element definitions. The researcher argues that it is possible that vertical high-priority disease- specific programmes that come with international funding and strict care delivery and M&E guidance may improve data quality, particularly coherence and comparability in certain circumstances, as there is very little room for interpretation and flexibility.

However, there may be some variation in reporting methods at the facility level. One argument is that the variation has to do with the workload and the less busy and small clinics have a tendency to put more effort into cleaning their own data - albeit this comment also refers to accuracy of data. Another informant argues the opposite: *"sometimes it's larger facilities that are complying with what is expected of them, and you find the smaller ones are the ones that are...lethargic ...to do the things as they are supposed to be done"*. Moreover, staff movement may affect the comparability of data because the new staff members may not be filling the registers correctly *"we can see when this report comes in here, then you can see that there's somebody new in that*

particular ...area." (Informant) The researcher believes that it is largely the sub-district office's input that helps even out the differences and improve the coherence and comparability between clinics in terms of data that they produce for the higher levels. Moreover, while comparability is very good between different sites (after the efforts of the sub-district level), and sub-districts within the Western Cape, between districts and provinces the data is less comparable: *"I see sometimes knowing the work and the effort that we put on the ground to achieve sometimes mediocre results and I look at the very good results that are reported by some districts ...I just distrust it."* (Anonymous quote) The quote also highlights the close relationship between accuracy and comparability: if one suspects that the data is not accurate, there is much point in using it in comparisons.

6.2.8 Summary of the data quality of investigated data flows

Table 6-3 combines together what has been discussed regarding the various quality dimensions of TB and HIV related data flows at the case study setting. The table should be considered as an indicative summary of interpretation of various comments rather than results that are directly comparable with each other. Moreover, it should be remembered that a person who first receives a messy handwritten register at the last minute full of gaps would not see its accuracy, completeness, timeliness and other aspects in the same way as the person at the end of the reporting chain after 3 to 5 other people's input on the data's quality.

Table 6-3. The quality of TB and HIV related dataflows as percived by the informants. This is summary of qualitative data, not survey results.

	Accuracy	Completeness	Timeliness	Coherence and comparability
TB Tuberculosis data Note: findings on MDR and suspect data may not correlate with findings on main TB dataflow	Good to Very good	Very good	Fair to good (Good compared to other data flows but fair when compared to other aspects of TB data quality)	Very good
HCT HIV Testing and Counselling data	Good to very good	Good	Fair to good	Good to very good
ART Antiretroviral Treatment data	Good to very good	Good to very good	Fair to good	Good to very good
PMTCT Prevention of Mother-to-Child Transmission data	Fair to good	Fair	Fair (but seen more problematic than accuracy, completeness, coherence & comparability)	Fair
STI Sexually Transmitted Infections data	Poor	No data	No data	Poor
RMR Routine Monthly Report data	Poor	Poor	No data	Poor

6.2.9 Other attributes of data quality: availability

While availability of or accessibility to data was not part of the framework that the researcher used to explore data quality with the informants, the issue did come up. Limited availability of particular data may be due to the notion that the

piece of required data belongs to a different data flow than the person requiring the data (as will be elaborated in Chapter 7). This is consistent with Auld et al's findings on missing TB data in HIV sources and vice versa (2013). However, a clinical officer treating TB may also need information within the same data flow (for instance sputum and culture results from the previous month) that are not available to him. Consequently, the clinical officer needs to phone or to go to the computer and look for the information in another room or phone to somebody to fetch it for him: *"...it's the filing, like the filing system is not working that efficiently. When, if it was already there, it would save me lots of time."* (Informant, field level) In the researcher's opinion, a health system with a highly unfavourable staff-patient ratio, such as in South Africa[65], cannot afford that kind of use of resources. Moreover, the researcher asked somebody at the clinic level whether a Sister treating somebody with TB can see and access the ART folder (or vice versa). The reply was: *"she can do that. She can be able to work on that. She can just phone and ask that I've got this patient..."* That tells the researcher that the principle, as expressed by another informant: *"We believe in one patient, one folder"* is not fully working at the case study clinic. Furthermore, in a general sense, it could be clearly seen from the data that there are at least four places where the patient folder may be located, or it may be lost, and not all have direct and easy access to it.

6.3 CONCLUSIONS, REFLECTIONS, GOOD PRACTICE

To summarise, although a lot of progress has been made, there are still data quality related challenges at the case study setting. The data in the South African TB and HIV information system (as an entity) is not always accurate, complete, timely, coherent, comparable or even there. Nevertheless, while the researcher did not conduct any direct comparison, her interpretation is that the end result is still better than in many other South African provinces or in a majority of the African countries. The data quality achieved is largely a result of the various data **validation mechanisms,** including **audits** and **data accountability**

[65] 0.45 medical practitioners per 1000 patients in the public health care in 2010 (Department of Health, 2011b).

structures in the Western Cape. This represents good practice that could be adopted elsewhere. An important point is that the improvement efforts are continuous. However, a lot of effort is invested in the system in order to maintain a certain level of quality, so the best practice is adaptable only with caution.

Table 6-3 in section 6.2.8 summarised the data quality findings and assessed them in a robust way by giving them values, such as 'good' or 'poor'. The researcher considered evaluating their degree of being 'fit for purpose' instead. However, she concluded that the different quality aspects do not answer the question 'is the quality of the collected data fit for the ultimate purpose: inform decision-makers about the epidemics and ultimately improve health outcomes'. This question is revisited in Chapter 9.

The root causes for the data quality challenges will be described in the next chapters: the amount of collected data, much of it paper-based and duplication of data. For instance, with the HCT information, the sub-district level is looking at the HIV positive patients in terms of whether they have been tested for TB, and with the paper TB register they are checking TB patients to see whether their HIV test has been taken and that the patients whose CD4 count qualify them for ART, receive their medicine. According to the sub-district staff, most of the time the patient has been tested and put on ART but the information is not recorded on the TB register. Hence, the duplication of data, possibly even the knowledge that the same data is being collected as a part of another disease-specific programme may have an effect on the data quality at the ground level. In other words, if treatment is provided, which is the most important thing, and the data is already recorded somewhere, likely at the patient file and to a register specific to that issue, it may not be that high on the agenda to re-record it in another register. On the other hand, it may be that vertical programme-specific reporting (while causing challenges) actually simultaneously improves data quality as discussed further in Chapter 9.

Furthermore, when a large amount of data is routinely required, the data's relevance and usability will be accentuated: *"...If there is anything that you require, it's either servicing two purposes: the epidemiology, oversight and surveillance but also...it must have some utility and be helpful for management*

purposes. Because if it's not both, the quality, the completeness, the timeliness, consistency - all of those things are going to suffer" (Informant in data use position). This issue is further discussed in Chapter 8.

That many of the systems are in transition may also influence the data quality at the case study setting. Moreover, the presence of two health authorities (discussed in section 7.4) makes the situation more complicated and probably has a negative effect on the data quality. That notion is backed up by the fact that in several instances, the informants pointed out different reports or sections in data flows saying that in the Metropolitan municipality (i.e. the City of Cape Town) there may be challenges, whereas in rural areas that particular data is more accurate/timely/complete etc.

Nevertheless, the abovementioned reasons are not the only ones contributing to inconsistent data quality: the next chapter examines the contextual factors that may influence data quality at the case study setting.

Chapter 7 Analysis of Findings: the functioning of the South African TB and HIV information system

7.1 OVERVIEW

The previous chapter provided insight on the quality of data that is produced by the South African TB and HIV information system in the context of this case study. Now, the focus is placed on the *functioning* of that system. In other words, the objective of this chapter is to identify strengths and weaknesses related to the manner in which the TB and HIV information system operates at the case study setting. Often, there is a close connection between the functioning of the health system and the functioning of the health *information* system.

This chapter is related to the previous chapter in the sense that many of the challenges within the HIS (and the health system) are underlying factors that influence data quality. This issue can be examined from another perspective: varying data quality contributes to the sub-optimal functioning of the HIS through a sub-optimal understanding or utilisation of data. The understanding and utilisation of data is discussed within this chapter and particularly in Chapter 8.

Ledikwe et al. (2014) assessed the data management and reporting systems relating to a HIS in Botswana and organised their findings as follows: M&E structures, functions and capabilities; indicator definitions and reporting guidelines; data collection and reporting forms and tools; data management processes; and links with the national reporting system. As stated in section 6.1, the researcher of the current study realised that this would not be the most appropriate way to discuss this study's findings, although there is some overlap. This is because this study addresses phenomena from a wider social context than one strictly centred on data management processes. In section 7.2, a vertical segregation in health governance, delivery and reporting are introduced. Section 7.3 elaborates on the key challenges in the reporting. Section 7.4 discusses parallel structures in health governance, contributing to the complexity in care delivery and reporting. Finally, section 7.5 concludes by looking into further contextual challenges: issues, that could be assigned to 'M&E capabilities', if

using Ledikwe et al's categories. However, this study also highlights factors that can be considered root causes of the challenges. An important thing to note is that these kinds of findings are not independent of each other. In other words, even the 'contributors' are also 'findings'. For instance, limited 'buy-in' towards reporting tasks at the facility level can be considered as an issue contributing towards varying data quality. However, it is also mentioned by informants as a challenge per se within the TB and HIV information system in the case study setting.

7.2 VERTICAL AND PARALLEL NATURE OF SYSTEMS WITHIN THE SOUTH AFRICAN TB AND HIV INFORMATION SYSTEM

7.2.1 Introduction

The first and foremost finding is that both the management of the key health issues (such as TB and HIV) and the reporting connected to them, largely take place in **disease or programme specific parallel silos** in the Western Cape, as indicated by the literature (Uyei et al., 2014). The term 'silo' was picked up from the interviews, although different informants used it in slightly different ways. In this study, the word is used in its broad sense (not the original literal sense). In other words, a 'silo approach' refers to a way of thinking in which departments or organisational entities share goals, tools, information or processes with other entities only in a very limited way. Hence, systems (not only electronic ISs but socio-technical ones including people, practices and procedures) that operate in silos tend to be largely individual and disconnected.

In the Western Cape, most health professionals, from clinical to clerical, from M&E to a person working in governance, seem to have a very specific occupational role tied mainly to a key health programme. For instance, there are roles, such as the TB clerk, PMTCT nurse or HIV Prevention Manager albeit that combination roles also exist, such as the HAST-Coordinator. Despite the endeavours for further integration by the Government, the Western Cape health professionals – both those working for the Province and those working for the City - are still conducting their daily work very much in silos, concentrating on

their own specific areas and their own specific reporting needs. This is recognised by various informants:

> *"...Initially TB and HIV information was a vertical silo process and to be very honest with you it predominantly still is that."* (Informant, Province)

> *"...we tend to work in little silos and- and terribly vertically... I'm sitting here with just my TB and I've got blinkers on and I'm just looking at TB, and I've got doctor [name removed] who's got an ARV, um, focus, and I've got somebody else who's got a different focus."* (Informant, City)

It is important to understand that **it is not just the TB silo and HIV silo**, but as illustrated in Chapter 5, the management of HIV is divided into the pre-ART programme (HIV counselling and testing, HCT) and the medication steered ART programme, which form their own silos under the umbrella of HIV/AIDS. Similarly, PMTCT, STIs and even primary care operate as their own programmes. All of these programmes have their **own agendas, staff and management hierarchies, reporting lines and information systems**. It may be slightly confusing that silos or management structures are often referred to as being '*disease*-specific' by the informants, when they are in fact 'programme-specific'. Also, the literature talks about 'single-*disease* monitoring' approach and so on. Basically, 'disease-specific' and 'programme specific' are considered as referring to the same thing in this study.

The literature review discussed the challenges that are associated with vertical health systems. This section provides insight on what it means in reality in the context of the case study setting in South Africa. The broad issues of verticalness and 'silo mentality' are analysed next further with reference to health governance, care delivery, HISs and reporting.

7.2.2 Vertical segregation in health governance: planning and management 'silos'

A fundamental root cause for many of the key deficiencies in the functioning of the TB and HIV information system in South Africa is the vertical and silo type of approach in much of health governance. In other words, the 'silo approach' can be found in the **planning, organisation** and **management** processes of the health services at the case study setting, in a manner that can probably be found also elsewhere in South Africa, contributing to the fragmentation of the health system and HIS. As presented in the literature review, the consequences of vertical health governance structures are the possibility for **duplicate activities** as discussed in the next section, **inefficiencies**, **gaps**, **costs, impaired long-term planning and skewed prioritisation** (see for example Dudley and Garner, 2011; Biesma et al., 2009; Chilundo and Aanestad, 2003; Hutton, 2002; Pfeiffer et al., 2010; Uwimana et al., 2012). However, a lesser known effect of a vertical health system is what the researcher calls '**plan fatigue**'. What the researcher means is that there are several quality improvement projects going on in the Western Cape to target the challenges within various vertical health programmes, as well as some across them. A lot of data is collected and plans are developed to address the challenges that have been identified. The problem is that:

> *"...those plans are not really implemented. Because there is nobody that keeps track because that's one of the many plans. That would be the TB plan. Then you would have the HIV plan. Then you would have the ARV plan. Then you would have the STI plan. Then you would have the integration plan. So it's difficult, with so much happening to ensure that we turn this information that is available to us into something, that is really useful for action."* (Informant in decision making / data use position)

In other words, vertical planning and management silos may contribute to separate disconnected plans that are difficult to follow through.

Vertical planning and organisation of health services may also result in **missed opportunities**. For instance, when the PMTCT programme was organised in the Western Cape, it did not have any connection with the immunisation schedule, although, for instance, it would have been beneficial for

the babies' 6 week's test and certain obligatory immunisations to take place at the same time. Uwimana et al. (2012) have reported on the lack of joint planning of activities particularly at provincial and district levels, as well as managers focusing on achieving better performance of their own programmes at the cost of paying less attention to joint activities in the province of KwaZulu-Natal. The data from the Western Cape seems to add to that: segregated and parallel health governance structures and the management activities that come with them may be a nationwide challenge. However, this study also found data indicating increased collaboration at the decision-making level. There used to be an HIV policy group meeting at the provincial level, but from the year of the data collection, the group merged with TB, PMTCT and STI programmes, calling it the HAST Policy Meeting. There are also other integration efforts including joint meetings and combined reports. Nevertheless, Uwimana et al. (2012) point out that although the HAST structure exists for coordination, the system lacks a funding mechanism for actual collaborative activities. The scope of this study did not allow an economic analysis, but in a general sense it can be argued that managers and decision-makers at all levels are likely to require sufficient incentive (whether that is monetary or something else) in order to give attention and resources from the daily or 'core' activities to the activities that may not be considered as central.

7.2.3 Managing health conditions vertically: the care delivery silos

As argued in the literature review, a vertical health system is inclined to involve vertical care delivery. This is also the case at the case study setting: vertical health governance structures, including planning and management, are accompanied by a largely silo type of health care delivery at the ground level. This may cause **service duplication** (Dudley and Garner, 2011; Briggs and Garner, 2006; Kawonga et al., 2013; Biesma et al., 2009; Atun et al., 2008; McKinsey, 2005; Chilundo and Aanestad, 2003) such as multiple diagnosing or lab tests. This issue came out clearly from the data, duplication of blood tests being specifically mentioned by several informants.

> *"So if I could have a system where I can see when the last CD4 count was done. ...With this newly notified TB patient, then I don't have to do another CD4 count.... But now, we diagnose the patient's TB, may diagnose the patient's HIV, which was already diagnosed somewhere else, and we do another CD4 count. Because we, we need that for our management of the patient, not knowing that...somebody else is already managing that side of the patient .... We're actually duplicating work and, um, and the same goes for, um, other programmes outside of the TB-HIV."* (Informant in decision making / data use position)

Another example of service duplication, which emerged from the data, is taking a Pap smear multiple times in a short interval when the required piece of information is already there. In other words, the Pap test is required in the PMTCT programme, but it is usually already taken as part of the HIV programme. Obviously, unnecessary interventions are **undesirable for patients** are an additional **burden** on and a **cost** for an already over-burdened health system. Due to the lack of knowledge, the patient may not question why certain interventions are carried out more than once. The researcher had the impression that sometimes the health work force has genuinely and profoundly **internalised** the programme-specific silo in which they work, and this is reflected in how they conceptualise their work, how they conduct it and how they communicate it to the patients. Consequently, patients tend to accept *"...for TB, they gonna do this, for HIV they're gonna do this and, you know...Not getting to the similarities where the patient can say: "Well, I had a Pap smear yesterday.""* (Informant)

A 'silo approach' may cause the care delivery to take place in **multiple locations** as indicated in the literature by Mutemwa et al. (2013). Regarding completely different locations, it was mentioned in an interview that at worst, a co-infected pregnant mother may have to attend three facilities for three different services in one month: the obstetrics maternity unit to book for her antenatal care -> tests HIV positive and requires ART -> needs to go community health centre for antiretrovirals -> is diagnosed with TB -> has to go to a TB clinic. It should be noted, however that this example is not from the case study clinic but from the case study district and has also to do with two health authorities operating in the Western Cape, not just the vertical nature of health service delivery.

However, it is common at the case study clinic that **healthcare packages are provided in different rooms**. Considering that long waiting times have always been a major complaint in all the customer satisfaction surveys in the Western Cape, the 'silo approach' in care delivery causes **missed opportunities** which, in turn may cause significant **harm to the patients** and lead to further **work** that could have been avoided:

> *"There is ...a lot for example ARV staff that is employed to do ARVs they just do ARVs... ...So they have a patient who requires a family planning injection and they will not give it in the consulting room. They will say oh go and wait another I don't know how many hours to get you family planning injection and half the times the women goes and then you find them pregnant. And it turns out that they don't want the baby so then we are doing the pregnancy test and termination of pregnancy or referring them for one."* (Anonymous quote)

This is consistent with what Uwimana et al. (2012) have reported from the province of KwaZulu-Natal: referral of patients from one consulting room to another resulting in the **loss of patients** in the process and the creation of long queues. Moreover, when waiting and several locations are involved, the 'silo approach' induced missed opportunities may cause harm not only for individual patients but to the community, in particular in connection with infectious diseases, such as TB. Thus, it is important not to lose patients from treatment and follow-up in order to avoid further infections and the disease developing into one that is more serious for the patients and more costly to treat.

7.2.4 Collecting, managing and reporting information vertically: the HIS 'silos'

Previous research has identified challenges associated with a single disease HIS or reporting activities (see, for instance, Hotchkiss et al., 2012; Biesma et al., 2009; McKinsley, 2005; Peersman et al., 2009; Auld et al., 2013). Indeed, **parallel information systems** and too many tools at ground level were mentioned as key deficiencies by some informants. For the researcher, a 'silo' approach to health information systems at the case study setting refers to

several issues: first, it means **several stand-alone HISs** within the South African TB and HIV information system. When a vertical health programme is accompanied by a HIS that is forced upon the local level with insufficient or no consultation with local professionals, it may seem as though local capabilities and decision-making power are being undermined. This may cause resentment:

> *"Right up to today I am still perplexed by the fact that ...National at some stage ...committed themselves to a particular company that said that they have a system to collect TB; or they will develop a system to collect TB. They gave them the contract and they did develop a system and then that National decided that, regardless of what anyone in the country says; everyone will use that system. ...To the extent that you couldn't ask them to...'how would you like the data? I can give it you in whichever format you want, I can give it you'. ...They insisted 'no, you will give it to us, you will use this system right down to sub-district level', and if they could they would use it right down to the facility level also. ... And this system ...very much ...was a stand-alone system."* (Anonymous quote)

To put it another way, a top-down process of implementing a vertical HIS without support to try alternative approaches (such as developing a data set to which all parties would commit, regardless of the technical means to report the data) may be perceived as undermining the authority of the local level and for many informants it is likely that it will not be perceived as the best solution.

Moreover, contrary to international guidance (for instance Health Metrics Network, 2008b; WHO, 2004) it appears that there is still a tendency to **create health information systems in a vacuum** as if there were not already several ISs (paper-based or electronic), programmes and registers that could be utilised. The previous quote on the ETR.Net continues on that issue:

> *..."Which meant that everything, other systems that other people might have, will now not run ...it meant a step backwards for many places where they did have systems in place. ...They couldn't use the existing technology or systems and enhance it by connecting maybe to it."* (Anonymous quote)
>
> *"There is a lot of silo approach: when a particular programme comes up with something they don't look to see what's out already that we can build on. They always start as if it was tabula rasa. There's nothing: "Let's come up with monitoring and*

> *evaluation system". They don't see what elements are already being collected and how does that fit in what the other programmes are doing."* (Anonymous quote by a different informant)

Yet, utilising existing structures would be particularly important in South Africa which is not a developing country as such: there are already infrastructure, practices, NGOs, systems and a long funder history. Finally, it is not just systems, HISs, but it is upon existing **practices** and **behaviours** that new systems should be built. Nevertheless, when informants were asked about the 'pros' or the benefits of the current system, it was argued that specific health information systems (Tier.Net and ETR.net, particularly in the rural setting work well on their own, when considered as separate single systems.

Second, for the researcher, a 'silo approach' in relation to a health information system means **parallel data flows** in the TB and HIV information system at the Western Cape. The parallel data flows, however, open up opportunities for **gaps** and situations where the information is **not accessible or available** because it belongs to a different data flow. This may happen to clinical and nursing staff at the clinic level but also to the health authorities at the higher levels who wish to create epidemiological estimates. For instance, regarding the National Health Laboratory Service (NHLS), a practitioner can look up one patient at a time, but not all the results for a particular patient. This may be frustrating for the person delivering care, as well as for those who wish to use it in ther purposes: *"We own the data... but it's not actually accessible to us as easily" (District level informant)*. It can also be argued that this may adversely affect **patient safety** and the **efficacy** of care.

Third, a 'silo approach' in a HIS may mean that the **HISs do not talk to each other** or do it in a limited way. While the researcher has no specific technical data about the issue, it seems that at the time of the study none of the HISs at the case study setting were directly connected to each other. For instance, the previous example on the ETR.Net as a stand-alone system: the system cannot be used for any other purposes beyond reporting and creating statistics on confirmed drug-susceptible TB cases. This has created a need to have a separate suspect TB system, as well as the system for MDR-TB. In

addition, the TB treatment outcome data has a column for treatment failure and it indicates the number of MDR-TBs of the failed cases. Ideally, that information would transfer to EDRWeb. However, these are two completely different programmes with no information transfer between them. In other words, a HIS that is designed to store data on a specific issue or to address specific reporting requirements **may lack sufficient flexibility** to meet varying user information needs (Hotchkiss et al., 2012).

However, there is a Western Cape level **unique patient identifier**, which is considered positive and effective by several informants. The patient identifier is used across the public health system as well as by both the City of Cape Town and the provincial government. This represents good practice and it is an essential pre-requisite for the efforts to connect or integrate different health information systems.

In the absence of integrated information systems, there remain challenges. Both the clinical staff treating individual patients and the health officials who set targets at the population level need **joint information on closely connected diseases**, as well as information on completeness and continuity of care. Vertical systems may not be able to provide that information easily (Uwimana et al., 2012; Auld et al., 2013). The close connection between TB and HIV aggravates the information needs, since these illnesses may advance each other and negatively impact on each other's health outcomes, and the optimal timing of interventions for each disease may require awareness of the other illness and its medication. At the case study setting, the clinical staff have their own means to obtain the required information in connection with individual patients, such as acquiring the appropriate patient folder or making a phone call. The next vignette, Vignette 7-1, on the other hand, details how additional effort is required to estimate the TB-HIV co-infection rate at the higher level of health authority.

A CASE STUDY WITHIN A CASE STUDY

How to combine information from two reporting silos:
Estimating the TB-HIV co-infection rate

South Africa has one of the world's highest co-infection rates (73%)[66] and it is imperative that the health authorities can make national, regional and local estimates for surveillance, planning and intervention purposes. At least three informants gave me (slightly different) accounts on the ways to obtain these figures. The main message seems to be that *"You gotta know from which place to draw which information in order to make sense overall"* (Informant, City).

There are different ways of looking at the co-infection rate and it is not simple: *"we in the...province I would say we need help with this"* (Informant, Province). Because there is no one system where information for TB and HIV would be collected, the authorities have to triangulate data. *"...you take the prevalence of HIV; or you can ...work with the positives, and if you want a co-infection rate for that same period you can look at how many people have gotten TB. But it's not the actual people... ...For example, there are 6,000 new positive patients with HIV, and in the TB programme they usually have about 2,500; which would mean that it's often about 40%. So for our province we know that there's a co-infection rate of TB-HIV of between 40 and 60%. ...Then the other way doing it is that; on the HIV side of the system there are, out of all the people that were tested for HIV, there's an indicator that asks how many of those were tested for TB. But the problem is, from the HIV side we then don't know how many of those were positive for TB. ...so once they're positive they go onto the TB side of the information. So that's...there's a gap; so we don't have a system that says, you're tested for HIV, you're tested for TB and now you're positive in one system."* (Informant, Province)

Another informant from the TB side argues the same: [The way TB data is collected] ..."*serves a purpose for the TB program. ...But it doesn't serve the purpose for wider than the TB program because ... your inclusion criteria is you... must have TB to be.....on the system. And then once you're off the system, we don't have an idea in the general half information system of, of where you are. So we can only track our management of co-infected patients while they are TB patients. ...And that's the actual limitation...*"

As can be seen from this example, estimating the co-infection rate is complicated, may not produce highly accurate results and seems to require considerable effort. The information need is real and may open up a risk of a demand for yet another parallel

[66] Percentage of TB patients who are HIV positive (Department of Health, 2012a). The estimates are different depending whether one is looking the proportion of PLWHA in TB patients or the proportion of PLWHA who have TB.

system, to produce the required information. Excluding this option as undesirable, the question remains whether systems could be integrated in a way that reliable and timely data on the co-infection rate could be produced, or whether surveys could be enough to produce the data.

Vignette 7-1: How to combine information from two reporting silos: Estimating the TB-HIV co-infection rate.

In conclusion: *"The data is still seen as two separate authorities, two separate information systems are used for TB and HIV/AIDS data. ...Although the systems are strong on its own, it's weak as a joint system"* (Informant, different to previous ones). In addition to the challenges concerning 'joint' information on TB and HIV, there is a more profound challenge regarding the need for **holistic information** around patients and their health conditions. Vignette 7-2 provides two examples.

A CASE STUDY WITHIN A CASE STUDY

Information needs beyond the diseases-specific reporting silos

Similarly to other fields of medicine, 'getting the big picture' in maternal health is vital. In the Western Cape, deaths from previously existing diseases that developed during the pregnancy, and which cannot be accounted as direct obstetric causes but physiological effects of pregnancy, have increased (Western Cape DoH, 2013b in Annual Performance Plan 2013/2014 hereinafter: APP) The report suggests that while services to address pregnancy related conditions are improving, services to manage the pregnant women with pre-existing medical conditions could be enhanced. **Considering that nearly half the maternal deaths were preventable as different management interventions might have made a difference to the outcome** (APP, 2013/2014), it is crucial that those who make the clinical decisions have accurate, timely and holistic information beyond the programme-specific silos.

An example can also be found in tuberculosis. Peltzer et al. (2012) have found in their study that in some areas in South Africa more than a fifth of the TB patients are hazardous or harmful alcohol drinkers and almost one in ten male TB patient meets the criteria for probable alcohol dependence. In addition to a higher risk of incidence of TB, there is strong evidence of the negative influence of heavy drinking on the clinical course

of TB, higher relapse rates and suffering from the most destructive forms of TB (Peltzer et al., 2013; Rehm et al., 2009; Lönnroth et al., 2008). However, in the case study settings, where there are reportedly rampant alcohol issues (Wechsberg et al., 2013; Dewing et al., 2013), this research found no evidence that information on patients' alcohol use or abuse is collected, reported or easily available for the staff working with TB at the clinic level. Certainly, the programme managers and other health authorities above the clinic level do not have an indication in their own programme data on whether their patients have alcohol issues. Screening alcohol abuse was not a key issue of this study and the researcher is not arguing that a nurse would not ask a patient about it (in particular if the patient is obviously intoxicated) but it did seem that this is an example of a situation where strict international prescripts on disease-centred care delivery and data collection and reporting may have limitations. In other words, a more holistic approach would certainly be better for the patients that belong to the risk group but possibly also the higher-level authorities might be in better position to plan targeted interventions if they could easily access comprehensive TB data.

Vignette 7-2: Information needs beyond the disease-specific reporting silos.

More than one informant expressed a wish for more holistic information. An ideal information system would include comprehensive data for risk-factors, co-morbidities and beyond:

> *"then we will also know that this TB patient that I'm diagnosing now is pregnant. ...So I must look at the mother, and I must look at the exposure of that infant, and I must look at her HIV and, you know, all of that so it makes it a, a thing.* (Informant in decision making / data use position)

Finally, the parallel reporting flows stemming from a vertical health system are a major cause for Western Cape TB & HIV related **reporting having become burdensome and excessive**, which is discussed in section 7.3.

7.2.5 Conclusions, reflections, good practice

To summarise, the TB and HIV system in the case study setting consists largely of separate silos, where health governance and policy, planning and management and ultimately health care delivery are centred around certain

programmes. Considering the framework for integrated service delivery by Uyei et al., 2014 (Figure 2-7), while further integration of health services is a goal of the national government, that process is very a much work in progress. The framework separates functional, organisational and clinical integration, but at the case study setting, none of these areas can be described as fully integrated. This is acknowledged by the informants: *"So we're in the process of doing all of these things that you're asking. We were in absolute silos, we still between the two*[67]*, because we're in the process of doing."* A **unique patient identifier** in public health represents good practice in the Western Cape, which in the future will help integration efforts and connection of health information systems. Not all less vertical or better-resourced Western health systems have been able to create a comprehensive unique patient identifier, so achieving it in the Western Cape is all the more remarkable.

Vertical governance structures producing largely vertically delivered health care may have negative consequences for the patient, health work force and the health system. Many of the consequences reported in the literature seem to have materialised at the case study setting. A major root cause for the challenges described in this section is funding. It steers the health system towards verticalness through several processes. While those processes are not the main object of this study, the researcher observed one that may be called as the 'internalisation of the verticalness': *"...because they have been employed from the ARV funding they almost feel like they will do just ARVs".* (Anonymous quote)

Finally, it may have seemed odd that this section has discussed vertical health governance and care delivery. However, the argument here is that they are directly connected to the TB and HIV information system. This was already evidenced by examining how the health system silos contribute to disconnected stand-alone systems that are not synchronised with existing systems in the Western Cape. Moreover, vertical and segregated health governance and delivery structures produce separate data flows that make gaps possible and exacerbate challenges in the obtaining complete, joint and holistic information across silo

[67] Researcher's interpretation is that "two" refers to two systems: completely vertical and completely integrated.

borders. Next, the argument is further supported by looking in detail at TB and HIV reporting.

7.3 EXCESSIVE REPORTING STEMMING FROM PARALLEL DATA FLOWS

7.3.1 Introduction

A central though not very surprising finding is that the multiple data flows that are the result of the South African health system including vertical governance and care delivery silos around health priorities, have resulted in a vertical health information system with excessive reporting requirements. In other words, at the case study setting there occurs A) **a lot** of reporting in general and B) more importantly, **multiple reporting**. In this study, multiple reporting refers to *unnecessary replication of information* in the context of TB and HIV related information flows. The next sections (7.3.2) focus first on the amount of reporting as perceived by the informants and then the avoidable repetitive collection and reporting of data (in 7.3.3.). Then, the challenge of large amounts of the data being paper-based is discussed, as well as the practice of reporting an entire database (7.3.4-7.3.5). Finally, the main ideas of this section are further reflected upon in section 7.3.6.

7.3.2 Large volume of reporting

In general, not relating to any specific data flow, the recording and reporting of data is perceived as **time-consuming** and **laborious** by the informants. This finding is reflected in other studies in South Africa (such as Auld et al., 2013). This puts a strain particularly on the facility level staff who do the majority of the manual collecting alongside care delivery. Braa et al. (2007), whose work also focuses on South Africa, have estimated that collecting, collating, capturing, validating and forwarding raw data may take 20% of a health professional's time. The informants interviewed in the current study were reluctant to make exact estimates measured in percentages or minutes but:

> *"...to write all that information ...it takes up lots of valuable time, I would say, that you could've seen more clients."* (Informant, field level)

This is particularly challenging against the background of the inadequate numbers of health professionals and the exceptionally large burden of TB and HIV in the South African health system. The challenge of burdensome reporting practices is recognised by various informants also at the higher level of administration. It is not just the volume of reporting but the combination of volume and lack of simplicity:

> *[How the programme is currently organised] "...makes the data collection very bulky, and also confusing at facility level. Coz often the...professional nurses or the counsellors completing the registers, even though they work with it every single day they've got a hundred things to do. So... you need to make as easy as possible. Some of my registers, there's definitely room for improvement."* (Informant in decision making / data use position)

According to an informant, particularly the reporting requirements that have no direct connection to funding, may often perceived as something *"additional"* on health professionals' plates. The literature review discussed how information needs are likely to increase rather than decrease in the future. However, as new needs arise, so does the amount of information to be collected at the facility level. Informants recognise this:

> *"it's another management component the ...poor people on the ground has to take on... they are clinical people they are so busy with the clinics they don't have much time for this admin."* (Informant)

There are many reasons for this apparently excessive volume of reporting. First and foremost, **each disease-specific programme has its own reporting requirements**, as many of the programmes were established by external funders/stakeholders with specific information needs. Second, **different health authorities at each level** (national, provincial, district, sub-district and clinic) **have their own information needs** and the lower levels usually have to adapt to the requirements, regardless of their own needs. Hence, a request from a

higher level of authority to collect more (or less) data may be contrary to one's own priorities, and may result in feelings of powerlessness or resentment.

> *"So they will take off to suit everyone... They will add to suit everyone. You don't have a say in what you want to collect as a health authority. ...You just have to go with the rest."* (District level informant)

Sub-optimal overall coordination, whether it takes place between authorities or disease-specific programmes, may lead to deficiencies in the reporting system and further increase in the number of required data elements.

> *"we are collecting a lot of data and registers which we don't report on, and then we are not collecting data which we need to report on. So as protocols change, policies change, the registers were adapted, but often things were only added, very seldom were things taken out"* (Provincial level informant)

Sometimes the National Department of Health changes policy in terms of which data to collect as a part of the mandatory data set. For instance, regarding the register for HIV clients whose ARV treatment has been initiated by nurses, the decision to routinely collect this data was first supported and then rejected by the same authorities at the national level, making the situation frustrating for the lower levels. The national DoH may also ask for data outside the national data set.

Finally, **policy changes** regarding on which data elements are to be collected and which not may open up chances for inefficiency in the collection and reporting system. It is possible that these changes increase the volume of collected data in the long run, in particular if there is not a thorough revision of what is already there and whether something could be left out or obtained elsewhere.

This study began with an analysis of the data quality produced by the TB and HIV information system at the case study setting. Research suggests that the larger the number of data elements to be collected and reported upon, the poorer is the quality of the data (Loveday and Zweigenthal, 2011; Shaw, 2005; Stoops and Williamson, 2003). It seems that also at the case study setting

burdensome data collection **may have been one contributor to variable data quality**.

> *"...The problem is that very often the programmes, they want to know this and this and this and that and they think it can be collected in a routine basis. Which of course it can't. What needs to be collected on a routine basis are things that are going to be used routinely by the people, the managers, the staff on the ground. Because if it's not, the quality of the data is of no use."* (Informant in decision making / data use position)

As may be interpreted from the quote, the informant attributes the challenge to the vertical disease-specific programmes, and emphasises not only the quality of data but also the **usability of data**. The volume of the data required is associated with the use of data also in the quote below:

> *"...we've got a mix of data elements that some of them were imposed to us by National, others by Province, others, some of it has got complete buy-in from the City, and others it doesn't. So for the things that we've got buy-in, we do analyse."* (Anonymous quote)

This is in line with what was evidenced in the literature review: an excessive amount of required reporting may lead to sub-optimal use of information. This is further discussed in Chapter 8. However, while the researcher agrees that it is the disproportionate amount of data that may result in its incomplete use, the quote above may also be interpreted as relating also to power relations that will be discussed in 7.4.

7.3.3 Multiple reporting

A key finding is that **multiple reporting** occurs in the Western Cape. In this study, multiple reporting refers to the unnecessary replication of information in the context of TB and HIV related information flows. TB indicators are being collected from HIV patients and vice versa but this is only a small part of the problem. The researcher's observations are in line with those of Loveday and Zweigenthal (2011): even clinics that promote integration use separate stationery for ART and TB care, and with co-infected patients the health

professionals consult at least two sets of notes in order to see the clinical and other history of the patient.

Many patients in Khayelitsha suffer from multiple health conditions. Consequently, their personal details are captured over and over again in several systems. The patient's name and basic information, such as gender, address and telephone number, are captured in PREHMIS. If the patient has TB, this same data is also captured in the TB system. If the patient is then offered an HIV test, which he should be according to policy, the same data is entered into HIV Counselling and Testing Client Records, as well as into the PREHMIS and TB systems. If he is positive and eligible for ART, this information is captured again in the TB system and PREHMIS while his basic information is captured again in the ART system and so on. However, even this is still only one side to the challenge. The detailed approach of this study shows that multiple reporting occurs when there is:

1. REPLICATION OF INFORMATION ACROSS THE *DIFFERENT* DATA FLOWS: The same piece of patient information (for instance a name, address etc., or HIV/TB status) is collected for various disease specific registers/HISs

a) May involve **collecting** the same piece of information from the patient multiple times for the requirements of each data flow.
b) Furthermore, may involve **unnecessary interventions** (such as the Pap smear example discussed previously) in order to produce the information that already exists in other register(s)/HIS(s)/clinical notes.
c) May involve **entering** the data by hand into a paper-based register when it already exists in other register(s)/HIS(s)/clinical notes.
d) May involve **capturing** the data manually into an electronic form/HIS when it already exists in other register(s)/HIS(s)/clinical notes.

2. REPLICATION OF INFORMATION WITHIN THE *SAME* DATA FLOW: information is collected in paper form and then *copied as it is* into other paper form register or electronic format i.e. Excel, other register or HIS.

a) May be 'normal' data being copied from paper to an electronic form i.e. **'digitisation'** of paper-based data.
b) May be **hand-writing** of information in different places due to the poor design of forms. For instance, according to an informant, some of the HIV/ART stationery requires writing a certain piece of information 2-3 different times per patient.
c) May be from **electronic – to paper – to electronic format**. For example, the laboratory results from the National Health Laboratory Service (NHLS) for ART come to facilities as a hard copy and they need to be entered manually into a HIS, while that information is already in electronic format in the NHLS database. An informant sees this as *"hugely inefficient"*.
d) May be **dual capturing** i.e. entering data from paper to two or more different electronic systems. This did not come up at the case study clinic but the interviews confirmed that elsewhere in the case study district there are still clinics that enter the same RMR data both to Sinjani and DHIS, which are basically created for the same purpose, as discussed in Vignette 7-5. Similarly, due to a transition process, HCT information is entered into Excel and into Sinjani at the sub-district office at the time of the data collection, as described in Vignette 6-2.
e) Higher level authorities may request the same information repeatedly in a different format*: "they require the report in an Excel sheet...we plunk it into an Excel. The next one wants [the same] ...in Word* (Informant).

3. AGGREGATION OF DATA WITHIN THE *SAME* DATA FLOW

a) Information in paper form is **aggregated** into weekly or monthly statistics on **paper**. For instance, in the HCT dataflow, aggregation into monthly statistics is made with pen and paper (possibly with a help of a calculator or phone) although the data will need to be entered in electronic form at the next level anyhow).

b) Information in paper form is **aggregated** into weekly or monthly statistics in **electronic** form. (Specifically, this is performing 2a + 3)

One may argue that some of the items on the list above are not 'multiple

reporting' or 'unnecessary replication of information'. For instance, number 2a can be seen as pure digitisation of data, which is indeed necessary. Moreover, aggregation of data (3) is indispensible for any further information use and statistics creation. However, the argument here is that these examples are 'unnecessary replication of information' against the **ideal situation** (for example, if the there was an electronic system at the point of care, 2a + b and 3 could be avoided). The researcher fully recognises that it is impossible to remove all the replication of information, even with the most modern system. The question, however, is to what extent multiple reporting could be decreased and how within the South African local context. Two examples follow in Vignettes 7-3 and 7-4.

A CASE STUDY WITHIN A CASE STUDY

Multiple reporting within one data flow:
formula milk information in the PMTCT programme

At the time of data collection, the PMTCT programme included distribution of free formula milk for infants up to 6 months of age at the case study sub-district if the mother chose formula feeding over breastfeeding. Distribution of the formula requires recording and reporting information in a manner that can be seen as an example of multiple reporting, and specifically as replication and aggregation of information within the same data flow.

First, information on formula feeding is reported on the PMTCT Programme 0-18 Months baby register. It is either the PMTCT baby register or an additional paper where the PMTCT nurse indicates that she has given formula, as well as other information, including the date and month. Second, additionally to this one to two places, she also needs to write it on the Patient Routine Management Report (RMR) Input Sheet. Also the RMR sheet requires at least the date and the amount of the product that the nurse has dispensed. Third, the PMTCT nurse fills weekly the City of Cape Town Clinic Stock Card, which requires aggregated information on the formula and how it compares to the nurse's opening balance of formula in that particular month. Fourth, there is a Control Sheet for PMTCT insp. Products. The monthly control sheet requires at least partially the same information as the other registers: the date, the name, folder number, and how many tins the PMTCT nurse gave the mother on that day. The control sheet also requires both parties signatures to confirm that the formula was really given. Finally, there is

something called Formula Grid, which again requires most of the same information as the control sheet and is sent monthly to the sub-district level.

There is definitely room for streamlining the duplication (or triplication or more) of the hand written formula milk information. As described in connection with data flow descriptions, the PMTCT nurse makes vital clinical decisions regarding her patients and is responsible for managing many aspects of their care delivery in demanding surroundings much like a fully educated and licensed doctor would in the Western context. Hence, hand writing and copying of the formula information takes time and attention away from her other more important tasks. Moreover, managing the data with the Stock sheet and Control sheet requires rather detailed four-digit calculations regarding the opening balance and the tins issued, which, the researcher assumes, are made using pen and paper or possibly a phone by the nurse. Again, this is laborious, time-consuming and error-prone.

A person with a narrow-focused technically centred approach might try to solve the challenges described here by beginning to plan an electronic HIS. However, qualitative case study research has the opportunity to highlight other questions. While the nurse herself thinks that all the recording is quite a lot, in particular at busy times, she is happy to keep the duplicate (or more) records as a backup since occasionally something may go wrong with the book-keeping. This may result in questioning, and in that case the nurse has something to show to prove that she has not done anything improper. Hence, it is important to acknowledge that:

- Laborious, redundant IS work may have 'positive' aspects for the person who is doing that work

- These aspects may not easily come up in traditional IS research or in implementing ISs. Yet, it is important to identify and address these aspects when assessing needs and creating systems. For instance, if the nurse feels that she should have back up records for whatever reason, she might be inclined to keep additional personal records, no matter how sophisticated an electronic system is made available.

- There may be something in the context that has an impact on how the system has been built (for instance systemic mistrust which only relies on constant checks and validation). In such a case, it might be worth considering whether there is anything at all to be done in that context and to occasionally challenge the preconceptions behind how the system has been built.

Vignette 7-3: Multiple reporting within one data flow: formula milk information in the PMTCT programme.

A CASE STUDY WITHIN A CASE STUDY

Multiple reporting across the different data flows:
CD4 count of a patient with several health conditions

Consider TB-HIV co-infected patient X. Beginning with the HIV testing, her CD4 count would likely end up in her patient file in hand written form in the clinic notes or something similar (1). Second, the CD4 count would be hand written in the HIV Counselling and Testing Client Record at the facility level (2). Third, it would also be rewritten by hand (not the actual result, but that the CD4 count, amongst others, had been done) into the Monthly HIV Counselling and Testing Facility Record in which the information of HIV Counselling and Testing Client Record is compiled in more aggregated form (3). At the sub-district level, the aggregated information on CD4 count is captured manually both in Sinjani (4) and an Excel sheet (5), since at the time of the data collection the case study sub-district was running a duplicate system, as described previously. After this point, there is further manual work with Excel and further aggregation, but it is not counted here as there is no cell-by-cell data entry beyond this level.

However, returning back to the facility level, the CD4 count would also be hand-written onto the Patient Routine Management Report Input Sheet (6) and captured in PREHMIS information system (7). Moreover, when the patient is diagnosed with TB, the CD4 count is required for the paper-based TB register at the facility level (8) and entered into the electronic TB register ETR.Net at the sub-district level (9). If the patient X was eligible for ART, the CD4 count would be hand written at least once in the ART stationery (10) and captured in Tier.Net. (11)

Then, it turns out that Patient X is pregnant. In Khayelitsha, a TB-HIV co-infected pregnant mother would not be an unusual case. The CD4 count would be hand-written in the PMTCT register (12). Since the monthly aggregation is done manually at the facility level, the information on the CD4 count (not the actual result, but that the CD4 count, amongst others, had been done) would be recorded first on paper at the clinic (13) and then entered into Excel by another person at the sub-district office (14).

Finally, there are other possible places where the CD4 count, or the information that it has been conducted, might be written in actual or in aggregated form, such as on the facility level RMR sheet, but these are left out from this analysis due to the lack of

exact knowledge. Furthermore, there could be other conditions (such as TB developing into MDR) that would increase the replication of CD4 counts in the records.

In summary, it can be estimated that patient X's CD4 count would be hand written at least 6 times, captured in electronic form another 6 times and otherwise managed in more aggregated form at least twice at the case study setting. This is likely to be an under-estimate. Hence, patient X's CD4 count is a good example of replication and aggregation of information across data flows due to nature of the South African reporting system, consisting of several vertical largely segregated systems within the TB and HIV information system.

Vignette 7-4: Multiple reporting across the different data flows: CD4 count of a patient with several health conditions.

The multiple nature of the reporting detailed here is widely **perceived as a key challenge** by the informants. It is acknowledged virtually at all levels of the health system. The informants, however, also know that it is not easy to improve the current situation.

> *"I think we often overwhelm staff with paper work that creates a lot of inefficiencies. And I think for me the ideal in the ideal world would be to have one database where all patient information is sourced, but you are then able to extract specific program information out of there, that obviates the need to kept- or duplicate repetitively the same fields and elements around a patient. But that's the ideal world."* (Informant in decision making / data use position)

The contributors to multiple reporting are largely the same as for the volume of reporting: each programme having their own reporting requirements. Moreover, the presence of two health authorities operating at the case study setting is likely to have a complicating effect on the data flows. The consequences are similar to those for excessive reporting, including increased costs and a distraction for healthcare professionals from providing care. McCellan (2009) has noted that existence of multiple records for a single patient, can have negative effects on registration and billing systems and may result in healthcare professionals missing critical information (because it is not located in the particular record that the professional is examining) leading to compromised patient safety. These aspects were not strongly present in the data but informants identified that

multiple reporting is generally a **waste of resources, makes information fragmented and error-prone** and may impact **data quality**.

> *"the bits and pieces of paperwork that goes to different people.... You cannot be sure if that is really the...the true reflection of what is going on."* (Informant, field level)

> *[There are] "mistakes that we are making, just by having these different systems in different domains creating different powerhouses."* (Informant, provincial level)

> *"...so we are desperately in need of getting all of these systems together. ...We're wasting a lot. We are wasting a lot of everything with our separate systems."* (Informant, provincial level)

While most informants are aware of the challenge, each person may feel that they only have limited power or means to tackle the problem. However, small innovations to reduce duplicate work have been developed. For instance, with the registers that are locally developed, a space big enough to put a sticker on have been included on the register. For instance, with the registers that are locally developed, a space big enough for a label has been included on the register. In other words, staff can affix a pre-printed label with the patient's name, address et cetera. This avoids the necessity to rewrite the basic demographic information by hand in that particular register.

7.3.4 Paper-based reporting

As it may have come across implicitly, some of the challenge regarding the volume and the repetitiveness of reporting has to do with the fact that much of the reporting is still **paper-based**, particularly at the clinic level. Besides being **time-consuming** and **laborious** to work with, experience from elsewhere in LMIC context has shown that hand-written documents are frequently **incomplete** and **illegible**, and contribute to misunderstandings (Chilundo and Aanestad, 2003; Burke et al., 2011). The alternative, electronic reporting is wished for by various informants at several levels of authority:

> *"loads of work that is being done in paperwork it could be done electronically in touch of button and that send the things away."* (Informant, field level)

> *"the electronic register to me it's more hassle free I would say rather than lots of paperwork. I think the more we do away with these papers, it can be much much better."* (Another informant, field level)

In particular, converting the TB register (ETR.Net) into electronic form at the facility level is on the wish list of various informants. Moreover, the informants who are involved with various paper registers suspect that a change from paper to electronic would **free up their time to conduct more analysis and validation**. This is somewhat contrary to the results of Cline and Luiz (2013) from the South African hospital context. Cline and Luiz (2013) propose that the perceptions of inefficiency concerning paper-driven processes are not a major factor for hospital staff who are used to operating in a non-automated environment. For instance, the majority of doctors disagreed with the statement that paper processes led to more of their time being dedicated to administrative activities. They explain this finding by the lower importance of detailed clinical notes than in countries where there is a higher threat of being sued for medical liability, as well as a possible unwillingness to adopt new workflows that required data to be accessed through and entered into an electronic HIS. While Cline and Luiz's findings on doctor's perceptions are not directly comparable to the findings of this study where a large range of health professionals (including those who work in health governance), there were no indications in the data at all that anyone would consider paper-based reporting as fast or efficient or faster / more efficient than computer-based processes. However, one informant perceived the **paper-based registers as more visual** than an electronic system:

> *"People mustn't think that by putting in the electronic systems in place sorts it all out. Because, um, my experience over the years with developing the [removed] database and the quality of the data in there, people see there's a big black box in front of them, stuff's got in there but I can't get it out and see it. But if I offer them the register in paper, and I can highlight there and I can highlight there, it's more visual."* (Informant)

The researcher interprets this as meaning that if a HIS is perceived tangible and

'real', it may contribute to people's perception of the importance of the data and how accountable they are for it, which in turn may contribute to data quality. In other words, in a paper-based register the data is 'all there in back and white' and having the weight of a written document, which is traditionally perceived as more important than, for instance, verbal communication, whereas with computers it 'all kind of disappears' – at least for those who have limited access to or limited ability to utilise the end product of the raw data: information.

It, however, seems that most informants were inclined to think that most registers' **data quality would benefit** from the registers being in electronic form at the facility level. Besides staff members having more time for validation, for instance, HCT lay counsellors have experienced challenges in understanding the data definitions and adding up the numbers correctly in certain HCT related registers. Hence, the sub-district level staff have developed their own mechanisms to train them with the help of simple 'data validation rules' that the lay counsellors are supposed to keep in mind: if you have 16 men and 14 women, the total column should have 30. That means that the self-referred HIV positive + TB client HIV-positive + STI Client HIV-positive + Other Medical HIV-positive should also add up to 30. However, this is **work that a computer could easily do**.

Finally, a register being electronic at the facility level could also improve **care delivery and reduce workload.** For instance, the PMTCT nurse has to, by looking at the date on which the CD4 count is done in the PMTCT register, calculate the next testing date (for example 6 months) and remember to send the mother for a new blood test if it is due. Furthermore, there can be exceptions that the nurse has to take into consideration when she is making vital clinical decisions on the basis of her hand written numbers, such as the CD4 count: *"And then we have to, like for an example, this one is 359 so the mother can come here in 3 months. Because we start now on from 350."* (Informant, field level) In other words she is deciding to call in the mother earlier than usual, as she is already close to the ART eligibility line. Clinical decision making of the nurse takes place within the framework of changing clinical guidelines: *"It used to be less than 200.... So now it's from 350"* (Informant, field level). Finally, there are other exceptions to the 'rules'. For instance, if a mother is already on lifelong

ARV drugs and breastfeeding, she needs at some point to stop using one medicine and continue with another until the baby's results are negative. One would assume that keeping up with each mother's testing and treatment schedule, as well as the clinical situations that may alter the 'basic' schedule, is very difficult, depending how busy the clinic is, as the hand-written register would include all the month's and finally the year's mothers. A computer based register without the challenge of messy handwriting and with automatic alerts would decrease the chance of unintentional delays due to human error and pressure of work. Nonetheless, many of the informants also recognise that computerisation by itself is not a sufficient answer if other structural deficiencies, such as limited analytical skills are not addressed. This is consistent with what is reported earlier from South Africa (Garrib et al., 2008). These structural issues are further discussed in section 7.5.

7.3.5 Unnecessary reporting of the entire database

Finally, there exists yet another kind of multiple reporting. This is somewhat different to the types of **unnecessary replication** of information mentioned earlier in that it does not require somebody doing additional manual work. However, other challenges arise. The researcher means that many think that it makes sense to report data as a pyramid (i.e. one collects the most at the lowest level and reports smaller amount of aggregated data towards the higher levels). Braa and colleagues (2007) describe this approach in connection with developing DHIS in South Africa. According to them, it was demanding to get a real breakthrough in the negotiations about minimal data sets, because of the diverse needs of the various programmes and governance structures. These challenges were addressed by deciding that, on the one hand, as "*it is not possible to agree on everything, we should agree on a basic minimum*," and on the other hand, that participants were free to collect the additional data they wanted (Braa et al., 2007). This approach was encapsulated as a "*hierarchy of standards*", (see Figure 7-1, left side) and according to the authors it was a precondition for consensus during the standardisation process in South Africa. The bottom of the triangle in Figure 7-1 illustrates the information that is required at the facility

level and the top of the triangle refers to information that is required at the national level.

However, with ETR.Net this is not the case: **all** the data is reported up. This is shown on the right side of Figure 7-1.

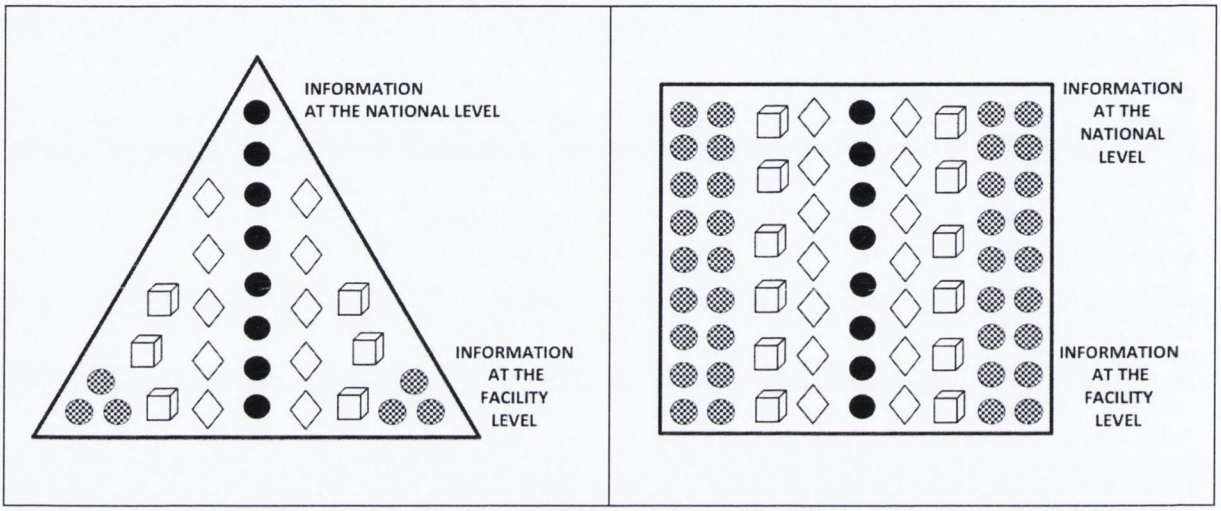


Figure 7-1, Left: Hierarchy of information needs. Figure modified from Shaw, 2005. For the original, see Shaw, 2005, revisited in Braa et al., 2007. Right: Information required in case of ETR.net. The illustration is by the researcher.

Not all think that this is sensible *"I can't understand what provincial or national wants with the names and addresses of all...for the whole database. ... I'm not interested in the names of the patients, but um the system that they've designed and the system they've worked is that you export the data from here...everything, not the summary"* (District level informant). The researcher assumes that this possibly relates to TB notifications: the notification of TB patients in public clinics is sent via ETR.Net. But even taking that into consideration, it still does not seem necessary and it also represents a risk to patient confidentiality and data security. After all, TB as a disease still has a stigma attached to it and also a TB patient's HIV status can be easily seen in the data. This is also against WHO guidelines: they state that personal identifiers should be removed as soon as possible in the data collection or reporting process once they are no longer required for matching purposes. For this reason, information reported to districts or for collecting indicators in general should not include patient-level information (WHO, 2009). Furthermore, when considering the fact that the whole database is sent in the form of memory sticks and CDs via a courier service, as mentioned in

Chapter 5, this practice seems redundant and risky. Finally, there are likely to be other information systems where, according to the researcher's personal observations, a patient's clinical data including his name and other personal details is accessible to people who work in M&E, administration and governance rather than just to those in clinical roles at the district and other levels. The researcher assumes that with such a disease burden, and in the absence of a patient confidentiality protocol (Cline and Luiz, 2013) data security and audit trails are not a priority, but they may become so in the future.

7.3.6 Conclusions, reflections, good practice

This section has provided insight on the TB and HIV related reporting at the case study setting. To summarise: there is a lot of it, it is laborious and time-consuming particularly at the facility level, much of it is paper-based at that level, and some of it duplicated and redundant. The main contribution of this section is the detailed approach to multiple reporting, i.e. items 1-3 in section 7.3.3. The detailed approach is essential because:

- The **distinction** (i.e. between the different examples) has to be made since they have different dynamics, root causes, consequences and solutions. For instance, number 1 relates to the vertical and parallel nature of systems within the TB and HIV system in South Africa, whereas 2a-c and 3 are more concerned with infrastructure and resources. Furthermore, points 1a, c, d have specifically to do with the 'silo approach' in reporting where as 1b concerns the 'silo approach' in care delivery. Similarly, the possible (negative) consequences in 1a and 1b may be experienced by the patient but all of them may cause (negative) consequences, such as unnecessary work, for the staff. Hence, for the sake of a balanced discussion aimed at HIS and overall health system development, as well as further research, it is important to identify and distinguish the different acts of collecting, entering and reporting of data in a manner that may be unnecessary or replicative.

- In addition to looking at them separately, it is crucial to look at them **together**. It would be beneficial to analyse, on a system-wide basis, who is collecting or entering what, why and at what cost? Moreover, that analysis

should include the 'digitisation' and aggregation of data albeit this may seem unnecessary at first glance. Each person is just 'doing their job' and for them, for instance 2 or 3 are not that much extra work, or indeed it is often somebody's job. However, only by considering 1, 2 and 3 in all their aspects as an *entity*, will the true burden of the M&E activities for the system be uncovered. Similarly, a manager in the HIV programme may have a good idea about the work load and information replication within her own information flow but one must consider all the data flows in order to appreciate the whole load and costs for the health system and to find the best synergies.

While good practice was not identified within this section, when discussing data quality, however, it was clear that there were continuous efforts to improve the quality of data. The same applies to the quality of functioning of the reporting system: there seems to be a strong motivation at various levels to identify gaps and *"straighten the system as we go along"* (Infromant). This seemingly simple thing can be seen as a strength that can be applicable elsewhere. In other words, organisations where it is accepted that there is room for continuous improvement in the functioning of health information systems and the key people are motivated and equipped to address deficiencies, are more likely to succeed compared to those where deficiencies are not recognised or they are accepted as the status quo.

A locally developed pre-printed labelling system, aimed at reducing multiple hand-writing, was mentioned in this section. Another informant described a (physical) box system, where certain documents were placed in order to make sure that at the end of the month it was possible to double-check that the data in the official system corresponded with the items of data in the box. The researcher would not necessarily recommend this particular system as good practice. However, what can be recommended may be the encouragement of small, inexpensive field-level innovations to address gaps, reduce workload or multiple reporting or otherwise improve the functioning of the HIS while simultaneously tackling wide structural deficiencies.

7.4 DUAL HEALTH GOVERNANCE STRUCTURES COMPLICATING THE FUNCTIONING OF THE TB AND HIV SYSTEM

7.4.1 Introduction

When examining why the TB and HIV information system in the case study setting has developed into what it is, it becomes clear that the vertical nature of the HIS and the health system is not the whole story. The Cape Town Metro[68] District is one of the health districts of the Western Cape, and it is the only district that has both a municipal health component and a provincial health component delivering primary healthcare (PHC) services. A key finding that emerged from the data was that the co-existence of two influential health authorities in the Western Cape has a complicating effect on how TB and HIV related data is collected and reported, as well as on delivery of the health services in general. It is publicly recognised in the official documents that the fragmentation of the delivery of PHC services in the Cape Town Metro District between provincial and local government (i.e. the Western Cape Government and the City of Cape Town[69]) remains a challenge, is inefficient and ultimately compromises the quality of care (APP, 2013/2014). The dual, overarching responsibility of two operators contributes to making the system highly complex and hierarchical (Elloker et al., 2013). The vast majority of informants acknowledge the issue:

> *"you have a large Metro within the Province. And that you have this parallel thing...I think it makes it very difficult."* (Informant, Province)

> *"It would be better to have one authority. It would simplify things a lot. But who the authority should be, there are different opinions."* (Informant, City)

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[68] "Metro" is used in the official South African documentation (instead of "metropolitan") – hence it is also used here.

[69] Specifically: The health service delivery in Khayelitsha sub-district is under the dual authority of the Metro District Health System (MDHS) of the Western Cape Department of Health and the City of Cape Town (CoCT) health department.

Besides following the programme-specific silos, the data flows are also dictated by the authorities that are involved in providing services. As described in Chapter 5, although data flows from the case study clinic seem to move in a vertical direction (from clinic to sub-district to district to provincial level and back down in the form of feedback) **in certain programmes there are actually provincial and city authorities operating at the same level in the health system**. The next sections review the challenges arising from the division of duties between the two health authorities with reference to planning and health governance (section 7.4.2); care delivery (7.4.3); information systems and M&E (7.4.4). Finally, other actors with their own possibly conflicting agendas are introduced (7.4.5). Section 7.4.6 provides a summary and conclusions.

7.4.2 Parallel health authority structures

As a rule of thumb, according to informants, the City of Cape Town is responsible for the majority of primary health care (PHC) services, whereas curative health services are the Provincial Government's responsibility. More specifically, the situation is as follows, although there were some gaps in the official documentation, some information is added from a more current source (from 2014) and the situation was and is in a state of flux.

Table 7-1. The provision of healthcare services in the Metropolitan (Metro) Municipality by the City of Cape Town and the Western Cape Province.

City = the City of Cape Town Municipality (via City Health)	**Province = the Western Cape Government (via DoH)**
PHC 112 clinics/facilities providing primary health care* (At the time of the data collection, clinics also existed that were shared by both authorities)	**PHC** 47 community day centres and community health centres + > 100 fixed and non-fixed facilities where a more limited service is provided by clinical nurse practitioners (APP, 2013/2014). (At the time of the data collection, clinics also existed that were shared by both authorities)

Curative Care City provides some *"Appropriate curative health services"***	**Curative care** 34 district hospitals (APP, 2013/2014), + tertiary/regional hospitals, emergency care.
TB At the time of the data collection, according to informants, the City provided the majority of TB services.	**TB** - The Province is rendering HAST services (a PHC service for HIV/AIDS, STIs and TB) (APP, 2013/2014). However, at the time of the data collection, only 6 facilities from the provincial side provided TB services. - TB hospitals and much of MDR care, (which, however, was moving towards the primary care).
HIV - HCT*** - Treatment of associated (opportunistic) infections and monitoring of clients suffering from HIV infection (non-hospital care)*** - Condom distribution***	**HIV** - ART - At the time of the study, according to informants the ART is managed predominantly by the Province. ART is available at 80 designated sites throughout the Province***** - Moreover, the Province is rendering HAST services (APP, 2013/2014) - HCT and treatment of associated (opportunistic) infections are available at most clinics****
PMTCT - PMTCT (coordinated by Provincial Administration of the Western Cape)*** - PMTCT babies' follow-up	**PMTCT** - PMTCT antenatal & intrapartum care (mothers) - Maternal Obstetric Units (MOUs)******
Other: - Preventative & promotive health** - Environmental health** - Specialised health support services**	**Other:** - Certain home/community based services (APP, 2013/2014)

*www.capetown.gov.za/en/CityHealth/ContactUs/Documents/Clinic_List_CityHealth.pdf
**www.capetown.gov.za/en/CityHealth/Pages/CityHealth.aspx
***www.capetown.gov.za/en/CityHealth/CommunityHealth/Pages/HivAids.aspx
****www.westerncape.gov.za/dept/health/services/689/17798 and www.westerncape.gov.za/dept/health/services/689/17801
*****www.westerncape.gov.za/service/anti-retroviral-therapy
******www.capetown.gov.za/en/CityHealth/Documents/Maternity_Facilities_8SubDistricts.pdf

All accessed 7 March 2014

The information in this table is not exhaustive and areas of service delivery that have no relevance to the topic of this chapter have been left out.

As the table indicates, the historical drivers, whether they have been related to capacities, funding or politics have lead to a situation where both authorities have drifted into assuming responsibility for partially overlapping areas of health authority. Elloker et al. (2013) point out that the organisational complexity at Cape Metro has historical and cultural dimensions, and differences in various actors' past service responsibilities continue to impact on their interactions with other health system stakeholders. In addition, the management structures of the two authorities have developed at different paces. The researcher of this study would argue also that, as the HIV epidemic has matured, the division of labour between 'you take TB and I take HIV' has become an unsustainable strategy. However, after years of monetary, HR and other investments in taking health policy responsibility, each side is more or less 'stuck' in their positions: *It would become expensive exercise and the whole human resources reshuffling for the Metro, the City of Cape Town, to change that system now* (Informant, Province). As detailed in section 2.8, there has been and there are constant efforts for more integrated service, but:

> *"...what we've trying to do now is to put all the services in one pool... And that's basically our challenge, but when you deal with different authorities there's always lots of politics and stuff."* (Informant, City)

Similarly as the programme-specific 'silo approach' both reflects and embodies health governance structures, the presence of two health authorities also has a significant effect on the health policy and planning that takes place in the Metro area of the Western Cape. When new plans are made and new policies or systems need to be implemented, the presence of two health authorities may make the process more difficult and time-consuming.

> *"So in the Metro at times it can be a bit slow, a big stumbling block is the two health facilities offering or providing health services, in that the local government have their set of rules,*

provincial government is saying we are going this way, they might be saying we are not ready and then you take a step back but eventually things do happen." (Informant, Province)

7.4.3 Parallel care delivery

As a consequence of intersecting health governance areas, both authorities have drifted into delivering partially overlapping health services. While the most of the informants tend to agree that one authority is better than two in delivering PHC, their willingness to reveal their stance on which one it should be varies from implicit hints and at least seemingly neutral statements to clear expression of views:

> *...Although in terms of the Constitution, the City of Cape Town should only do Environmental Health... ...In the rural areas that system has changed: the Provincial Government are doing all the health services. Whereas in the Metro region of City of Cape Town there's still the split between City of Cape Town and Provincial Health."* (Informant, Province)

> *"There is this view that primary health care and the district level hospitals it should be part of the same. ...I think the City would be best to take over all the primary health care, first level contact with the staff with the community. And I think Province would be better off just ensuring monitoring and evaluation of the services provided by the City of the primary health care, and seeing that the next level of district and tertiary care fits in."* (Informant, City)

With at least partially parallel health care system with overlapping health service delivery it is difficult to avoid **monetary and HR consequences, confusion in roles and responsibilities**, as well as **sub-optimal health system performance**. The example of the co-infected pregnant mother having to attend three different facilities (in 7.2.3) reveals the challenge which may be experienced by a patient, but the dynamics of two authorities also presents a system-wide challenge in the context of already stretched resources and a high disease burden. Finally, particular additional deficiencies were reported regarding the combined clinics: *"in some circumstances its quite complex at the delivery level, because they work from the same building, same premises but it's two authorities"* (Informant) where people delivering care side by side may end up earning different salaries. Further challenges have also occurred in provincially

run clinics which, however, ought to report on the care delivered to certain City employed authorities, who do not have a line management function over them.

7.4.4 Parallel information systems and M&E processes

The dual health responsibility at the case study setting and the consequent parallel and somewhat overlapping care delivery in certain areas have contributed to **HIS development and M&E processes becoming more complex** than they would have otherwise become. This is reflected in how the TB, HIV and other data flows at the case study setting compared to rural areas:

> *"The flow of data is quite good, but it's also quite poor. So if you look at the rural district it's really good whereas the Metro is a bit haphazard at times."* (Informant working with data flows)

The following example illustrates the complexity. At the time of the study, M&E SOP (standard operating procedure) had recently been created around the ART data flow in order to address the gaps, ambiguity with lines of accountability and other challenges created by the situation. Informants indicated that creating an SOP was not a quick or smooth process. A similar process had been happening around other data sets, too.

> *"It took us I can't tell you how many months to agree on in the Metro what the flow of data should be ...and the person in the Provincial Office, when we finally came up with this version said to me "now I'm sorry we can't have this because there are too many arrows, it's too confusing" And I said "well unfortunately it is too confusing to have two authorities but that is the reality, so we have to have all those arrows because otherwise it doesn't reflect the reality on the ground.""*(Anonymous quote)
>
> *"I think the painful part of this was ...the local government reporting, to jell with the provincial government reporting system"* (Informant, Province)

As may be inferred from the quotes, it is both the negotiation process between the stakeholders and the fragmented reporting environment caused by multiple stakeholders acting under two health authorities providing similar services that

makes the situation challenging. Moreover, creating a document is not the challenge but the 'doing of it'. This includes making all the stakeholders understand their roles and equip them to fill those roles. It may be argued that there is not enough understanding about change management considering the challenging situation resulting from the parallel health governance structures.

The abnormal HIV and TB related M&E structures in the Metro area (in comparison to rural districts) have contributed to the situation, which can be called *"a fight between the two authorities to amalgamate data"* (Informant working with data). The presence of two health authorities makes it **more difficult to streamline the M&E process** and multiple stakeholders open up risks of **gaps** and **errors.** Extra work may be required to make sure that the accurate and **appropriate versions of data sets are reported**.

> *"At the sub-district level there has to be communication between the City and the Provincial side and the same got to happen at the district level. Because there are authorities that are sitting on the City and on the Provincial side at the same level on the health in the system. The complexities are [about] making sure that only one dataset comes out at the each level otherwise you start getting different data being reported to high-level authorities. ... You better make sure that there is only one dataset travelling between the... but who's gonna sign it off before it travels up? And what's gonna happen before that? That's the complexity when there are two authorities."* (Informant, City)

In addition to the need to identify the correct information, it is essential for the authorities to have **complete information**, i.e. to be able to look at the 'big picture'. However, it is vital that each authority does not only look at its own services, since that would only give a partial truth. Hence, it can be argued that the presence of two health authorities makes it **more laborious to examine the coverage and roll-out of programmes,** as well as estimate the **whole disease burden** as the required data needs to be collected from various sources over the authority limits to achieve a complete data set.

> *"we have to work very closely together to make sure that the data, when it's finally used and presented and fed back to people, that it reflects the dataset of all the services in that specific geographical area. ...that is where some of the gaps happen, in the combining, and some of the tasks in terms of everybody, it's not only around the relationship between the different levels of*

> *healthcare and the different levels of service we provide but also a lot at the same level, backwards and forwards in terms of how that should happen."* (Informant, City)
>
> *"It's really the two authorities need to work together to make sure that we know, we actually know what the burden of disease is out there. Um, and I think it's working, but it could probably be improved upon."* (Informant, Province)

According to a City informant, in the past the Province did not have an infrastructure for middle management, and the City had to fill the void. It meant that a lot of the data was collected by the City no matter under whose authority it was, and then passed on to the Province. Now, as the Province is developing its own infrastructure, they seek to take over some of the M&E, resulting in some of the information is flowing to City and Province offices along separate channels.

Therefore, further consequences of the presence of two health authorities may be lowered **data quality**, particularly in terms of completeness:

> *" ...I would say it used to be fairly good, but since the split of who was taking responsibility for what, there have been now some datasets that have been incomplete."* (Informant, City)
>
> *"if the[re is] problem, that normally are the gaps, that you'll find it's Metro. In Metro –...we have City of Cape Town – and we have the district health services. ...In the rural districts there are no challenges as such because it is the same people. But here we have two."* (Informant, Province)

The researcher suspects that availability, timeliness, coherence and comparability of data are also inclined to suffer as a result of the shared health governance responsibility - or at least involve extra effort to maintain the desired data quality.

The presence of two health authorities contributes to conflicting agendas and ideas about the tools that are used to collect and report the data. The next two Vignettes, 7-5 and 7-6, describe how the use of the Sinjani information system and the number of indicators collected represent an area of conflict between the two health authorities.

A CASE STUDY WITHIN A CASE STUDY

DHIS or Sinjani?

As mentioned in section 5.7, South Africa, except for the Western Cape, uses the District Health Information System (DHIS) to collect aggregated routine data from all public health facilities in the country. DHIS was adopted in South Africa in 1999 (Department of Health, 2011a) and extended to the entire country by 2001 (Garrib, 2008). However, the Western Cape Department of Health (WCDoH) has developed its own health information system to collect routine health data, called Sinjani, since *"the DHIS software is limited and is reportedly inadequate to meet the needs in the Western Cape Province."* (WCDoH, 2009) According to an informant, increasing dissatisfaction with insufficient technical support for DHIS contributed to the decision to begin developing their own HIS instead of using the nationally prescribed one: *"...they could not support the so growing needs for information of the Western Cape. Because when they needed changes – and there were a lot of version changes, and when somebody needed them to assist, they were just not there. They were either in China, or Nigeria or somewhere. People had to wait about two months, three months before the person is able to come and assist with the changes. So there were really no support for version changes, or hardware or software problems when it concerns the DHIS. That's why the Western Cape developed their own system called Sinjani."* (Informant, Province)

Sinjani implements the prescribed national data elements i.e. produces the required DHIS reports to the National Department of Health but is more responsive to provincial M&E needs (WCDoH, 2009). Sinjani has been operational in all the districts of the Western Cape, including the Metropolitan District (the City of Cape Town) from around 2009 (WCDoH, 2009). Sinjani is web-based while DHIS is a stand-alone system. The health facilities in the Western Cape (including the City run facilities) are required to use Sinjani to report routine health data.

However, with DHIS it is possible to change the data set collected according to local needs, but in Sinjani the data elements are standardised, which may feel like a limitation for local decision-making: *"...Sinjani, it is sort of, you can only capture the data that they want at the provincial level. So it becomes provincial collection tool rather than facility collection tool."* (Informant, Province) Besides or because Sinjani is perceived as a provincial tool (and because it is argued to be slow), DHIS is viewed as being more user-friendly. Indeed, there are still sub-districts that enter the required routine health data into both Sinjani (because they have to) AND to the DHIS since they are more familiar

with and prefer the pivots and the tools provided by DHIS. Basically: *"...some people are still just more comfortable with DHIS because... Sinjani is not giving us everything that we got from DHIS"* (Informant, working with data flows). Obviously, capturing the same data twice is a waste of resources. Moreover, the researcher suspects that this may adversely affect data quality in Sinjani in terms of accuracy, completeness or timeliness:

...so some people are still doing dual capturing which is a big danger...Because they start in DHIS and then capture in Sinjani... They see that DHIS is more of an accurate system because that is what they used to go and report on and kind of – I am making a big statement here - and kind of: "Well, they want it in Sinjani, I've captured it in Sinjani" (Informant, working with data flows).

This may lead to inconsistencies in the 'same' data between Sinjani and DHIS, but that may happen also because the indicators may be formed slightly differently, as illustrated below. The informant does not see it as a major challenge though:

"it definitely makes a difference, or difficult with our province using Sinjani compared to the rest of the country using DHIS and national using DHIS. Coz often they will come into the province with, and show us our data, but they pull it from DHIS... ...and for instance with my follow-up babies, we've got a 6 months cohorts and you're not always sure which babies are they now pulling for transmission rates against which babies we are pulling because we work 6 months back because we wait till the cohorts turn in. So sometimes these are a bit of discrepancies our data set and their data set. But, um, overall we kind of make it work. It's not major train smashes, its...it's just here there that there's a bit of a glitch." (Anonymous quote)

Challenges also arise because of the transition process in roles and how the data is supposed to flow: *"The data that has not been entered for certain facilities because of this issue of now that the Provincial people are entering it in Sinjani therefore they won't submit it to the City's people to enter in the old Excel version. So suddenly there are gaps in the data..."* (Informant, City)

However, the dispute over a data collection tool seems to be more than just about the tool and it may have an impact on how the stakeholders perceive each other.

"I think at the moment Sinjani has left such a bad taste in our mouths because when we want, when we ask for anything to be added that was in DHIS, it's like the City of Cape Town is...anti new systems, we're resistant to change. And it's not that." (Another City informant)

It may be argued that in HIS development and implementation processes some disputes are about tools and functionalities; some tools are better than others and some work for certain clients but not so well for others in different environments for a variety of reasons. Some disputes could be avoided if all counterparts were fully and equally involved with the HIS design, development and decision-making. Finally, some disputes are really not that much about tools and functionalities; rather the tools and the disagreements over them may represent wider competing agendas or power relations.

Vignette 7-5: DHIS or Sinjani?

Braa et al. (2007) have described the development of the minimal data set in South Africa. Several revisions have been made on the data set since the work was started in 1994 in the Western Cape. Braa and colleagues describe how at each revision, *"the debate rages as to which data elements get included and which do not get included".* The data set was expanded to a national indicator data set (NIDS), the term 'indicator' denoting to information obtained from data elements, and which is used to measure the extent to which health targets are met (Braa et al., 2007). The next Vignette, 7-6, continues with the topics of Sinjani and DHIS and demonstrates how the tension over which indicators to collect continues to be a somewhat volatile issue.

A CASE STUDY WITHIN A CASE STUDY

DHIS, Sinjani and tension over indicators

At the time of the study, the provincial authority had decided to reduce the number of indicators to be aligned with the requirements of the national level. Some informants felt that the revision of a data set is a multifaceted phenomenon and there are ways to influence it, as well as accommodating the changes.

"At the moment there is a lot of transition on what data elements are to be collected or not. The various levels feed into those kinds of discussions. So that is an on-going thing. We do have ways of interacting around what is and what is not going to be collected." (Informant in decision making / data use position)

However, several informants expressed concern or discontent at the decision to cut down the amount of data to be collected, both on the City and provincial sides:

"I always feel that they are important, you cannot leave them out. I would have preferred that at the provincial level we have the same; because there are a lot of indicators at the provincial level that were left out." (Informant, Province)

"I don't know what they're going to use for intervention at the facility level...[what] the poor facility manager is going to say." (Informant, City)

The City has even considered leaving Sinjani and return to DHIS for a while: *"...we've got problems, not with the system but problems with management of all of this now, because the Western Cape, Provincial Western Cape has decided that they're going to reduce the number of items that they are going to collect... Which they have done, which means that...we felt that we wanted to continue, so now because we're using their system, we're stuck. We can't continue so we might have to revert back to DHIS..."* (Anonymous quote) However, replacing Sinjani with DHIS, which is a stand-alone system, does not sound like a very cost-effective or sustainable option after all the costs, work and training that has gone to Sinjani and which habitually comes with implementing any HIS. For the researcher, the quote reveals about the 'political' nature of the contexts that surround IS infrastructure development in the Western Cape and probably in other countries as well.

Finally, an informant in a Programme Management position felt that the Programme Management would have had better knowledge than Information Management on which indicators are needed at the provincial level. However, they felt they were not adequately consulted: *"...there was no engagement with the programme people when those decisions were made."*

Vignette 7-6: DHIS, Sinjani and tension over indicators.

In conclusion, the policy decisions around the data collection and indicators can be seen as a dynamic negotiation process, which expresses various power relations, such as City vs. Province. Yet, these decisions also influence the same power relations. Braa et al. (2007) suspect that the tension over which indicators are included in the NIDS is constantly present, and may in fact never be resolved. The findings of this study indicate that since the issues seem to be the same or similar now as approximately 20 years ago when the process was started, this may indeed be the case. Hence, it is clear that when studying or developing a HIS, it is crucial to be aware of the context in a very wide sense. Ignoring the context may result in sub-optimal use of the system with lower data quality or

expensive exercises in the different corners of the health system. Whilst there are more cooperation and joint forums for discussion now than previously, HIS development related situations still arise which would have benefitted from further coordination between the health authorities. For instance, at the time of the data collection there was an application that the City and the Province had begun to develop at the same time. It would surely have been cost-effective if only one had undertaken the development work but:

> *"we more or less started at the same time with our applications, and no one was going to let go of what they did. And the best we could do was to say ok we'll make sure that our systems talk to one another and continue to ...make sure that our systems are sort in-sync with one another."* (Anonymous quote)

As a result, both counterparts use the same modules but a different programming language. Moreover, much of the stakeholder's HIS development has been based on information needs that have been different compared to each other. However, the needs are not in fact that different in the current situation, considering the overlapping areas of responsibility for health care delivery. Hence, it is difficult to decide on the best policies and possibly face letting go of one's own projects: *"it's almost like there's a race. Who's got many, who's got the most extra modules on their systems?"* (Informant working with data flows)

7.4.5 Other power domains, other conflicting interests

It would be an oversimplification to assume that the occasionally competing interests and agendas of the City and the Province form the only power struggle in the Western Cape health policy scene and if that were to be solved, all health policy and consequently M&E challenges would disappear. On the contrary, there **are other powerful agents** and **other conflicts of interest**. One of them is the relationship of the national level to the lower levels, chiefly the provincial level.

In the Vignettes concerning indicators, DHIS and Sinjani (7-5 and 7-6), it was explained how a number of indicators and data items collected represent an area of disagreement and/or a manifestation of power relations and struggles. In

the same way that the data set revision at the provincial level did not get approved without at least some degree of objection by the lower levels, there also seem to be conflicting interests between the provincial and national levels.

> *"They are still busy negotiating with National, because National is asking for some things that the Province says "no we are not going to do it anymore.""* (Informant, Province)

> *"It's reported on National level because we need to be aligned, you know? If you are reporting at National level on an indicator that the Province don't prioritise, there is always that gap whereby you'll end up really not prioritising those ones."* (Informant in decision making / data use position)

From the latter quote, the researcher infers that when there is no buy-in at the lower levels regarding the national level's reporting requirements, this may have an impact on data quality, such as accuracy or timeliness. Another example of disagreement on a data set concerns an indicator that is required at the national level and seems to be collected at the facility level but for *"various reasons"* (Informant, Province) it is not reported from the provincial level to the national level. That results in 'no data' answer from the Western Cape while other provinces do report the information. The provincial level *"has not yet decided that they feel this is an indicator that needs to be reported"* which has led to a situation where *"you just imagine the tension between province and national if you say you can't report on something"* (Informant, Province). Hence, if one looks at a health statistic, produced by an M&E system, it is not only 'epidemiological facts' but also a result of the continuously changing health policy negotiation process. This aspect of HISs has received rather limited attention in the field of HIS or M&E studies.

Sometimes data is lost or the national level is said to use data that is different from the data sent by the provincial level. These kinds of situations require *"a lot of damage control that needs to take place all the time."* (Another informant, Province) and *"proving"* that those who sent the data were not wrong: *"...you basically say this is my proof that I sent you, so what you are reflecting is not what I sent you, and then it's the backwards and forwards of emails, and later on sometimes we have to write a formal letter to say this is what we have*

sent, we sent it on that day." These kinds of examples reinforce the researcher's impression of a rigid and hierarchical reporting and health governance system.

Among other challenges, the informants reported long response times by the national level to feed back and react to complaints and gaps: *"it took years. Not one or two but like three, four years. It was very deflating, because now we were getting feedback about stuff that happened years ago"* (Informant, City). It can be argued that this kind of process can be frustrating and induce mistrust, as well as have a negative influence on the operation of the M&E system.

Finally, it is perceived by the informants that the national level can be very strict in demanding that the lower levels use the nationally (and internationally) approved, probably funder recommended HISs, such as ETR.Net: *"No excuses, you will use this"* (Anonymous quote). Restrictions to local autonomy may evoke resentment and have an influence on stakeholders' perception of one another, as well as of the tools that they are asked to work with.

Putting aside the relationship to the National DoH, there is yet another lens through which to examine the relations amongst the actors that may have an impact on the HIS, namely, the lack of cohesion of between those whose duties are to run programmes and those whose responsibility is to collect, capture and manage data. This lack of cohesion can be found at many levels of the health system; in particular the researcher believes that some schism may exist between Programme Management and Information Management at the Provincial Government. So far in this study, the provincial health authority has been portrayed as a unanimous, almost monolithic entity. It does, however, consist of different units, groups and individuals just like any other organisation. Sometimes, the units within the organisation may have conflicting interests or competing agendas. While in the City it seems that there is more integration and communication between Information Management and the key officials in Programme Management, in the provincial DoH, there is a strong programme orientation and subsequently more separate Information Management with the responsibility for other public health information. A few informants gave their account on why they think this is.

> *"Historically it's just been that the Information Management never really took it on. ...I think the HAST came along because the*

> *expertise wasn't within the Information Management and they were reluctant to take the datasets as well. And then when it was formulated there was this kind of rivalry that was established. Because: "it's your dataset, it's HAST dataset, not Information Management". ... And I think just recently in the rural districts they've started to come closer together and they have started to work together, whereas in the Metro it's a bit difficult. And that does affect the way the data flows. Because now we have 2 parallel systems. We have HAST and we have general Information Management data, public health data that is flowing through Information Management... ...And it really comes down to the relationship that is been kind of fostered between Information Management and HAST. In the rural districts, it's really, there's really cohesion whereas in the Metro it's really broken up a bit."* (Informant working with data flows)

The previously described ongoing issue of what data should be collected and what not has been considerably influenced by the lack of cohesion between Information and Programme Management:

> *"...with many of our indicators, Information Management wants to try and make the indicator data set smaller, they wanna tighten it. Whereas we [Programme Management] are asking them to add... so apart from Programmes sometimes questioning whether we need the indicator, Information Management is very keen on dropping indicators they're not keen in adding."* (Informant in Programme Management)

In other words, Information Management's approach and needs regarding data collection stem from different premises to those of Programme Management.

Previously, in connection with data quality, the various data validation mechanisms were discussed. The next quote informs us about how the lack of cohesion between people who are responsible for data and people who are responsible for the programmes contributes to the issue. The informant perceives that the Information Management's oversight of data is insufficient.

> *"Because if you bypass the programme person, the data clerk or the info person doesn't know much about the programme. So it should have been actually before it gets to the provincial info management, that it goes via the programme person ...to look at the data and say, is this a true reflection of my district? So that's where the gap has been. We said to ...the programme managers:*

> *Even if the SOP doesn't stipulate that from this info management... ...it's your responsibility to work as a team with info management people, at the district or even the sub-district level so that nothing leaves your office or your district without you having verified and said this is a true reflection. So if there are gaps you can go back and say don't actually capture this, let me fix it, so when the data that leaves your district, you're 100% that it's a true reflection of what happened."* (Another informant in Programme Management)

This view that people whose main tasks are around data do not understand the programmes and *"what the data indicators are all about"* (Informant) and also vice versa, was shared by several informants. Moreover, some informants seemed to think that over time more of the M&E responsibility will be given to Information Management, which may possibly be asked to take over all the data flows. However, not everybody was completely pleased about such plans, as they were concerned that Information Management's inclusion may compromise data quality.

The researcher further considers the fact that she was not given any interviews at provincial Information Management, whilst she was granted several interviews at Programme Management, and the fact that there are M&E positions within Programme Management, as an implication that there is, if not a schism, at least a division of labour that may distance the counterparts from each other. Amongst the root causes for division is likely that many of the programmes were started off with external funds by stakeholders with additional information needs.

Furthermore, as explained regarding formulating an SOP, there is an ART M&E SOP that is almost finished. At the time of the data collection it had gone through many steps and had already been field-tested with a view to being accepted very shortly by the top management. However, the following quote reveals that provincial Information Management had not been part of that process: *"then of course I think just in time also were having a meeting with Mr [somebody at the Information Management] this morning, to look at data and data flow... And that's gonna be an ongoing thing, on a monthly basis we will spend some time with him...until we can amalgamate all of the data."* (Anonymous quote) The researcher infers from the quote that there is probably more cooperation to come, but it seems surprising there had not been more

extensive cooperation already regarding the ART M&E SOP and Information Management seemed to be included in the process only at the very last minute.

7.4.6 Conclusion, reflections, good practice

To conclude, when examining why the Western Cape TB & HIV information system has become what it has, it is not enough to consider vertical programme-specific nature of the health system. The tensions and sometimes conflicting interests between the City and the Province have contributed to some of the deficiencies identified. Amongst other issues, parallel health governance structures have complicated data flows and reporting processes and increased fragmentation, which in turn gives rise to gaps and may contribute to poorer data quality. In particular, the presence of two health authorities makes it more difficult to have full data on, for instance, intervention coverage regarding one geographic area, since the data have to be obtained from two or more sources. Besides City-Province dynamics, other external tensions (such as the issues described in the relationship between the national level and other levels of health authority) as well as the internal ones between different divisions of one organisation have also influenced many of the challenges in the TB and HIV information system. These relationships contribute to how the implementation of health information systems is perceived and ultimately how they are used. Myriad systems and parallel data flows are not likely to disappear in the near future:

> *"There are many different stakeholders and there are advantages and disadvantages to each of the systems that they have developed or not. And it's tied up also because data doesn't sit outside of the decisions around everything else, so it's also tied up with the complexity of anyway this problem of two health authorities delivering primary healthcare services at the district level. So I think that until those kind of more political decisions are made, it's very difficult to make sensible decisions around the M&E systems."* (Informant, City)

In particular, decisions on what data to collect and what not seem to be a difficult question, because different stakeholders have different needs. As noted

by Boerma and Abou-Zahr (2007) *"Statistics do not exist in a vacuum; every number has a political and a technical dimension. Controversies are often described in technical terms when the debate is about political implications and conflict of interest."* Similarly, the disagreements on what data should be collected, by whom and with which HIS, may reflect vested interests and political aspirations.

However, good practice can be found. A lot of **communication** between the different stakeholders is included to share information and foster cooperation. To put it another way: *"they are finding ways to work together"* (Informant) or *"they are working on... kind of making those two jell a bit better"* (Another informant)[70]. Third informant asserts that via regular meetings there is *"real interaction within the services"*. Resources and effort have been invested in increasing linking systems to each other.

> *"you often get a message ...they're using a system ...in this province and in the meantime you discover that one clinic or two hospitals out of the many hospitals are using it and the other hospitals are using something else and so on and so on. But what we've done in the Western Cape because we've got different authorities also and it makes it even more complicated, we have managed to agree on different applications; we've managed to agree to make sure that our applications talk to one another."* (Informant, City)

Hence, it is likely that the best option would be not to have parallel primary health care services, but if that is not possible, fostering communication and cooperation between stakeholders may decrease costs and workload. **SOP**s, as mentioned in this section, **data flow diagrams** and **joint data flow policies** are a great way to facilitate that communication, as they make gaps, roles, accountability structures and the timelines clearer to all stakeholders. They may also improve and enable more open and regular the engagement between the stakeholders.

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[70] In the first quote the researcher's interpretation is that two refers to City and Province and in the second quote the discussion is about Information and Programme Management.

7.5 CONTEXTUAL CHALLENGES IN THE FUNCTIONING OF THE TB AND HIV SYSTEM

7.5.1 Introduction

The final section on the findings and their analysis concentrates on the wider socio-economic context of the TB and HIV information system at the case study setting. The availability of qualified and skilled personnel is an essential factor governing the sustainability of information systems (Cibulskis and Hiawalyer, 2002), as well as a health system in general. Whilst the Western Cape is in many instances in a more favourable position than other provinces in South Africa, limited resources and capacity were repeatedly quoted by the informants as a continuous challenge and an underlining cause for deficiencies in the health system, including the TB and HIV information system. Although challenges concerning funding and financial resources did not come up strongly in the data, **human resource (HR)** related issues were frequently reported. **Availability** of HR is examined in section 7.5.2, followed by discussion on the **competence** of HR (in 7.5.3). Additionally, **challenges with the physical infrastructure** were noted by the informants, as well as observed by the researcher, as elaborated in section 7.5.4. Section 7.5.5 focuses on challenges regarding **commitment**. Finally, it is a well-documented fact that *"the conditions in which people are born, grow, live, work and age"* (Marmot, 2011) i.e. the social determinants of health, have a fundamental effect on people's health and lives. However, it is rarely considered how these things affect the functioning of a health system and to the researcher's knowledge the influence which they might have on a TB and HIV information system has never been examined or even considered. This study takes a tentative step in that direction by exploring the wider social context at the origin of the data flows (in 7.5.6), followed by conclusions (section 7.5.7).

7.5.2 Availability of Human Resources.

Only a few studies have examined the people aspect of HIS, and these have focused on the **availability** of human resources (Loveday et al., 2006 in Nicol et al., 2013) rather than on **competence** (Nicol et al., 2013). However, both

aspects came up in the data, availability less often than competence. In Chapter 2, an account of the HR crisis in health in South Africa was given. It showed that the critical shortage of key health workers is a significant barrier to the delivery, implementation and sustainability of health services in South Africa (Dookie and Singh, 2012). WHO recommends a minimum of 1 doctor per 1000 patients (Mwenda, 2012) and an ideal ratio of 1:600. However, in the Western Cape, there were 0.45 medical practitioners per 1000 patients in the public health care in 2010 (Department of Health, 2011b). Indeed, according to the national HR strategy, South Africa would need 60,000 more doctors to have the same doctor-patient ratio as Brazil (ibid). In line with these figures, several informants considered limited human resources as a significant challenge. Informants reported various aspects of limited HR availability: high staff turn-over in general, staff resigning and difficulties in retaining staff, (temporary) staff shortages and a continuously inadequate number of workers in certain cadres. All of these have slightly different dynamics in terms of why the phenomenon is happening and what can be done about it. According to the informants, limited HR availability concern clinical and nursing staff, data capturers and TB-HIV coordinators, but also M&E professionals and Information Management. Moreover, some of the key informants interviewed were also either leaving their position or were very new in their jobs. Finally, there are problems filling certain higher-level positions in management which has led to the involvement of staff from the University of Cape Town (UCT):

> *"There was certain functions that needed to be moved over but because there is some missing staff, some management staff is missing they haven't been able to transfer that to that person. The post is vacant. So UCT has always been doing certain things for us. So they have supported us to a great degree as well. I think lot of the work has been contracted to them..."* (Informant)

Limited human resources have obvious consequences for the health system, but also to the functioning of HISs. Regarding South Africa, Heunis et al. (2011) argue that a lack of accompanying infrastructural and human resource improvements may undermine the investments aimed at increasing data quality in the TB information system within their research setting. This finding is reinforced in international literature, as discussed in connection with challenges

in HIS structures, functions and capabilities in the literature review. In other words, inadequate numbers of skilled staff has been identified as a barrier to optimal HIS functioning (Ledikwe et al., 2014; Peersman et al., 2009; Makombe et al., 2008). Tacit knowledge disappears with the resigning staff and additional training is required. For instance, according to an informant, high staff turn-over in provincial Information Management has impaired the feedback system: *We had meetings on a monthly basis that died off now, because the turnover of staff* (Informant) and according to another informant it has caused gaps to the point that it may have affected the quality of data. Moreover, it was argued that at the field level, the agency staff hired to fill the vacancies on a short-term basis do not always have an adequate understanding of how the registers and HISs work. Furthermore, regarding data capturers, it was stated that if there were more of them, that would free up the nurses to do their nursing duties in the strained health system. NGOs sometimes support the functioning of the information systems by providing data capturers, but they are also poaching them from the public service by offering better salaries.

However, not everything is down to financial rewards. The literature has identified both monetary and non-monetary factors that influence health workers' decisions about where to work. These factors either push workers away or pull them towards the desired places such as the private sector, urban area or another country (Department of Health, 2011b; Buchan, 2006; George et al., 2013; Lehmann, 2008; Bateman, 2007; Clemens and Pettersson, 2008). George et al. (2013) have identified reasons that contribute to health workers dissatisfaction in the public sector in South Africa. Amongst these are poor working conditions, high levels of stress, high levels of workload, low levels of remuneration, poor standard of work premises, the lack of human resources and limited possibility for in-service training. These results are largely echoed in another recent survey (Wolvaardt et al., 2014[71]). Regarding the high turnover of

[71] Workplace and resources, work culture, advancement, communication and non-financial recognition and financial recognition were attributes that the health workers in public sector were least satisfied with in the survey by an NGO called Africa Health Placements in 2013 (Wolvaardt et al., 2014)

HIV-TB Coordinators, it was suggested that the demanding nature of their work may be a contributing factor: *"It's [their job] interesting ...but I think they just can't keep up at times ...because it's a lot"* (Informant). The researcher interprets this as relating to the high levels of stress, as identified by George et al. (2013). Generally, it was hoped that: *"I wish we had more ability to monitor. And it's not the monitoring and evaluation; it's actually the mentorship and supervision part."* (Informant in decision making / data use position) For the researcher, this indicates that adding volume in HR is not sufficient. Rather, the quotes echo what is argued by Goerge et al. (2012): viewing the HR situation merely in terms of inadequate numbers of personnel will not solve the country's health work force crisis.

7.5.3 Competence of Human Resources

There are ways to measure actual skills of the health workforce and to assess their confidence and competence levels for routine tasks. Such assessments have not been made within this study. Rather, this study reports issues that are perceived as challenges by informants, and the limited competence of human resources is a central finding that emerged from the data.

First of all, there are issues regarding the **language barrier**. Hussay (2013) has noted that for a large proportion of the population, the language barrier continues to compromise the quality of and access to healthcare services in South Africa. The data of the current study suggests that such challenges may occur at every level, but the issue is specifically pressing at the facility level: a lot of time is spent *"getting information out of people"* (Informant, field level). This is in line with Hussay's finding that the language barrier makes communication more time consuming. Most patients speak Xhosa as their first language at the case study clinic and sub-district. Since most whites/coloureds cannot speak Xhosa, facility and sub-district level recruitment needs to be done very locally. Therefore, there is less diversity in the staff in Khayelitsha than in other places. All the forms, registers and HISs that the researcher observed,

however, are in English. Hussay (2013) argues that the language barrier reduces work efficiency and the provision of holistic care. Since communication becomes more difficult and time consuming, frustration levels increase. The researcher would add to Hussay's findings that not only the health care delivery suffers, but also the functioning of the health information system.

Second, a big component of society still lacks an adequate basic education. Amongst that component are individuals who work in the health system or with a close connection to it (such as TB community workers). They may be providing lifesaving care, but still have **rather limited basic mathematical, reading and writing skills**. According to the informants, this may induce challenges in understanding basic concepts. This reinforces the message from research from elsewhere in South Africa (Nicol et al., 2013; Garrib et al., 2008). Nicol et al. (2013) analysed human factors influencing the quality of routinely collected data in connection with DHIS. They found that 64% of the respondents had poor numerical skills and limited statistical and data quality validation skills. Although the average confidence levels at performing routine health information related tasks was 69%, only 22% actually displayed competence above 50%.

The case study setting does not seem to differ much. For example, the HAST Coordinator, after going to a higher-level meeting, will usually print out the report for the TB staff at the clinic or attend the meeting of TB DOTS community workers and explain the trends in a way that they understand. The key points need likely to be explained in the language that the majority speaks. Moreover, the **basic concepts that help in interpreting data might be unfamiliar**. This is consistent with the study by Nicol et al., since they also identified considerable shortcomings in respondents' competency to interpret the data. For instance, at the case study setting *"sometimes they don't understand this percentage thing. So I have to explain to them"* (Informant, field level). Or *"graphs gotta be very basic, bar graphs, you can't go for pies or anything just bar graphs, just plain and simple"* (Another informant) and even the bars need to be fully explained: *"This bar means this. This bar means that. What we are looking for is to see this bar going up"* (Informant). Furthermore, it may not be just particular terms or concepts that are unclear to some people. Rather, it is the whole entity:

limited analysis skills and difficulties to assume control over the abstract and unfamiliar health information system's world.

> *"...they do not understand the computer stuff; databases and that and that. To them, is like you're talking another language. ...And sometimes they don't understand when you try explain to them that, these sheets that you are bringing to me they have to be captured on the computer. They have no idea."* (Informant, City)

> *"They [nurses] are not used to doing that kind of reporting"* (Informant, Province)

> *"They [People in facilities] don't know how to monitor and evaluate the service based on information"* (Informant, Province)

Regarding the last quote, Doherty et al. (2009) used a highly data driven and participatory research approach in their study on PMTCT in South Africa in order to *"develop the skills of the mid level managers to conduct assessments of their own programmes and to interpret and act on the findings".* The researcher of the current study takes that as a further indication of it being common in South Africa that staff at the different levels of the health system may have difficulties benefitting from the data that they have. The quotes, however, do not mean that all the staff at all levels experience these kinds of challenges.

Third, several informants indicated that **poor computer literacy** prevails at the hospitals and the clinics. Mushi and Maharaj (2013) have studied HIS in Tanzania and they remark that the new generation of health professionals entering the health workforce, who may already be equipped with ICT skills prefer not to work in an inefficient and unconnected working environment and hence aim to migrate into any workplace where their ICT and professional competencies are appreciated and rewarded (Mushi and Maharaj, 2013; Republic of Tanzania, 2010). It may be that also in South Africa, those who remain in under-privileged public health facilities tend to be those with poorer computer literacy skills.

While most of the facility managers have email already (except in the smaller clinics) they may not be confident using it or other modes of electronic communication. Informants cite fear of technology and the typical worries that 'if one touches computer, it will break'. Many agreed that further computerisation

should not be attempted until staff are a lot more information savvy, since the health workforce does not fully possess the necessary skills in Information Management and in the use of the data tools. It was argued that even the management level has difficulties understanding and utilising technology. Finally, it was also stated that the HAST programme officials have inadequate computer skills in terms of data entry and that has previously led to some gaps in the data. Furthermore, **data security skills** are often also lacking. For instance, facility staff members use their own memory sticks on the computers, introducing viruses. The researcher assumes that in places like Khayelitsha, most healthcare workers do not have computers at home nor easy access to the Internet, so when they need to, they might be inclined to use the computer at work for non-work related activities.

More training would be very helpful. However, most of the time staff would have to be sent away for training in computer skills, and that costs money as well as being difficult to arrange when staff capacity in many places is overextended already. Moreover, the training tends to be software specific, and not generally about understanding data and information management.

Fourth, **lacking epidemiological skills / deeper understanding of data elements and indicators** was mentioned. This finding is also mentioned in the literature (Garrib, 2008). At the case study setting staff working for the Programme Management were keen to make a difference to those who work mainly with information:

> *"they don't pick up the errors, so they are not Programme people; they're just punching numbers ...because for us from Programmes you can very easily spot something that looks funny... ...whereas someone who's just punching number; if they punch 1,2,3...1,2,3,48 they won't necessarily think about the 48, whereas you would immediately realise that, that 48 can't be."*
> (Informant in Programme Management)

A few informants argued that data capturers require support and training on *"what the data indicators are all about"*. Also it was suggested that other staff whose responsibilities are within Information Management do not understand the programmes.

In line with Nicol et al. (2013), the researcher argues that poor numerical and literacy skills, limited understanding of data elements, as well as any other of the abovementioned challenges may lead to sub-optimal HIS functioning and limited data quality. However, since the data is validated several times, it mitigates the shortcomings regarding data quality to some extent. Garrib (2008) connects the deficiencies in HR competence also to the lack of data utilisation.

In the previous section, the involvement of the University of Cape Town (UCT) was mentioned with regard to availability of staff. However, it is also because *"...in some cases some of the skills are not there as well."* (Informant working with data flows). Amongst other things, UCT compiles the Quarterly ART Report on behalf of the Provincial Government, assists with HIV related target setting, takes part in various meetings including Provincial HIV M&E Task Team meeting, assisted with the ART M&E SOP and advises the National Department of Health on their M&E data flow policies. Moreover, they are also consultants for the Tier.Net and eKapa systems. While UCT's support is regarded as an advantage (or even a necessity) by many, there are various sides to the issue that could be discussed. For instance, Cibulskis and Hiawalyer (2002) have pointed out that due to the lack of experienced personnel, many countries (particularly the developing countries) are faced with the stark choice of either neglecting ISs or relying on external assistance whose goals may be different to those of the government.

7.5.4 Physical Surroundings

Basically, the previous sections have argued that HR, whether they refer to the administrative, management or healthcare personnel, should *be there* and they should *possess the necessary skills*. However, the kind of environment in which they conduct their day-to-day work should not be ignored. While the higher-level health authorities at the case study setting work in an office environment that would not differ much from that in Finland or Ireland, the physical surroundings at the facility level are demanding. The clinics are small and rather basic, considering the patient load. For instance, power cuts have occurred and can be a problem in Khayelitsha. Moreover, there have been burglaries where

computers have been stolen, which obviously impedes the functioning of the HIS. The computers do not always work, and the staff at the case study clinic experience a variety of hardware and software problems. There are also sometimes problems with Internet connectivity. Besides the lack of computer skills and other related issues discussed previously, these challenges are also mentioned as a reason why further computerisation is not the right or the whole answer to the question 'how to improve the functioning of the HIS' at the case study setting.

Finally, since the facilities (including the case study clinic) tend to be small and therefore crowded, the environment can be quite distracting:

> *"...there's networking, they have computers: but whether it is the right environment for the person to sit in, I think it's a different cup of tea. Because sometimes the information person is sitting where everybody else is walking around and becomes a bit distraction if you have to capture the data if people are busy talking to you, interfering and walking around you. So it impacts on the productivity of the person."* (Anonymous quote)

7.5.5 Limited buy-in towards data responsibilities but a sense of pride about one's work

Even when a person is available for the job, has the desired skills and an adequate working environment that is not enough. The person has to have the right attitude to the job. The importance of *engaging* health workforce in improving data collection and its use has been noted in several African countries (Mutale et al., 2013). A key finding of the current study, one that was reported more often than, for instance, availability of HR or challenges in the physical environment, was something that the informants referred to as **'lack of buy-in'** of the personnel. The lack of buy-in is particularly evident with reference to **understanding the value of data**. This finding is consistent with what others have argued about South African health workers (Wolvaardt et al., 2014; Nicol et al., 2013; Garrib et al., 2008). Also Mphatswe et al.'s intervention aimed at achieving better PMTCT data quality included specific training for the healthcare workers *on the importance of data* (2012), suggesting challenges in this area.

Nicol et al. (2013) however, report relatively high *motivation* of the health workers of their study, but the discrepancy (or what looks like discrepancy) may be that lack of buy-in is not exactly the same as lack of motivation. Nevertheless, the motivation of health workers was unfortunately not reflected in their competence in routine health information tasks (ibid.).

According to the informants, many people do not recognise the importance of reporting, or appreciate the data, particularly at the source where it is produced. They would need a *"mind shift"* (Informant, working with data flows), to understand how significant the data is. Indeed:

> *"A lot of people think it's just a whole bunch of numbers, that aren't really important. When you speak about data, they get really bored, they switch of... They do know that what they do is important but they don't realise the value of the few numbers that they submit."* (Informant, working with data flows)

Basically, for many, data collection is seen as a burden that is added on the top of their responsibilities.

First of all, the lack of buy-in and not appreciating data concerns the data clerks and capturers. Often, they feel that they do not have the power to ensure that they are given with all the information and folders they need to do their jobs properly. Moreover, the clerks feel that their input is not appreciated by others:

> *"..as a clerk, you don't get appreciated for what you are doing. The people ...who get recognition are the Sisters. But we are the ones who are doing the work. Coz if we don't capture, they won't have any stats..."* (Informant, field level)

Yet, if there is something wrong with the data, they are blamed (anonymous quote). The perceived under-appreciation of clerks and data-capturers is probably directly related to their limited buy-in and motivation.

Second, nursing staff and clinicians, who see **providing the health service as their main responsibility** do not appreciate the importance of reporting duties; *"very often if you ask them, they'll say what is the data? I mean what do you care about the data? I provided this service, I made the diagnosis, I gave the treatment, what is this tick?"* (Informant). The researcher

can fully appreciate nursing / clinical staff's wish to focus on treatment in the context of such unfavourable patient-clinician ratios and high disease burden. The same has been reported to happen in other resource-limited contexts: for instance, in Mozambique laboratory workers felt that their obligation and loyalty was directed towards primary users of the laboratory services instead of reporting duties (Chilundo and Aanestad, 2003).

Third, it was argued that facility managers lack buy-in. This is consistent with *"inadequate data ownership by all levels of management"* as reported in South African Health Review (Wolvaardt et al., 2014). One of the reasons may be that *"they've got a big plate ...facility managers got to do everything. ...and still do clinical work. ...So things are challenging for them, just to do normal reporting because it's not just the ARV programme, its everything: it's TB and all RMR data..."* (Informant in decision making / data use position)

The researcher concludes from the quote, that the **bulky and multiple reporting induced by the vertical and 'silo approach' driven health system is likely to decrease one's motivation and buy-in in reporting** and that this is probably connected also to the lack of ownership of programme implementation at facility level, which Doherty et al. (2009) have identified. In other words, the researcher suspects that multiple reporting responsibilities make it difficult to have the energy to fully engage in A) those reporting tasks and B) other work, of which there is plenty and vice versa: the large amount of other work stemming from the vertical system decreases the buy-in to A) to that work B) reporting tasks, in particular when a person knows that some of it is duplicative or avoidable.

In addition to the **amount of data** that needs to be captured and reported every day, **under-appreciation by others**, the **business**, **stress**, one's **other responsibilities** and **low salaries** in public service at the facility level are likely to contribute to the limited commitment to data related duties. Indeed, at the time of the study there were negotiations under way to move the data capturers to a higher employment grade in order to raise their value and salary.

A further reason for lack of buy-in was argued to be that the staff **may not realise the negative implications of inadequate reporting**. In other

words, if only some patients are entered into the system, it looks as though the facility is serving only a small number of patients. Hence, it is not going receive, for instance, another nurse, when the higher-level management is allocating resources. However, there is

> *"a disconnect between I am entering all this data every day and maybe at the end of the year they gonna decide that I need another clerk or now I need another nurse. So they don't see how capturing that information actually is benefitting them. It's like too long the time between one thing and the another."* (Anonymous quote)

Yet, the researcher would argue that it is more than simply the **delay** between the action and the benefits. She is inclined to believe that the informant is explaining that there is a disconnection between *"the whole thing"*, as expressed by an informant. The staff may think that

> *"it's [name removed] that is making a fuss about this, they don't really see what the fuss is about, you know. So they do it because I expect them to and I keep an eye on things and I call them to line if they... anyway, so that's how they see it. ...They do it carelessly, they do it with lots of incompleteness, inconsistency et cetera. And they're short-sighted in the way that, in seeing how not capturing the data actually makes them look bad."* (Anonymous quote)

As can be seen from the quote, the limited understanding of the benefits of the M&E and the consequent sub-optimal commitment to reporting duties have direct consequences for **the quality of the required data**.

Finally, it was also maintained that lack of buy-in and interest do not only affect data collection and reporting but **any policy change or developments**. Limited buy-in was argued to take place at the facility level where exhausted staff may have a *"what is in it for me?"* attitude but also at the top management level (Informant, Province).

Having said all this, there is also evidence that seems contradictory to the lack of buy-in. Heidebrecht et al. (2011) note regarding the TB information system in South Africa that users were *"passionate"* about their contributions and

invested in working towards improving overall system operations. This **'passion'** was very much present also in the current study's data. The researcher would argue that the passion is more present at the case study setting than in many developed countries where people perform their work in much easier surroundings assisted by state-of-art technology.

> *"Health information is my passion"* (Informant working with data flows, district level)
>
> *"it is a great opportunity for me to work in the facility... I feel that I make a great difference to our people"* (Informant, field level)
>
> *"It's an interesting job that we're doing, and being involved into these programs it's really an eye-opener... There are new things every day, and TB is evolving and things that I was doing in year 2000 are completely different from what am doing presently. And ah, it's an interesting now TB then HIV came and also with HIV you learn a lot. Then ARVs came; as much as am not involved in actual doing, giving treatment to patients but it's an interesting...part...of this job, because you're really dealing with numbers and you...you get, you get the information from the people and you learn as you go along even if you're not directly involved in the patients..."* (Another informant, field level)
>
> *"The one thing that is very key is if ever any new service needs to be established, there is a real positivity around staff to take on. ...because we still take it to heart that our patients, our communities need the services."* (Third field level informant)

For Heidebrecht et al. (2011) the specific factors for such acceptability for TB HIS are unclear, and to a certain degree they remain a mystery for the researcher of the current study as well. Heidebrecht et al. suspect that the ability to observe meaningful application of their work, as well as responsive leadership, are major contributors. The researcher is inclined to agree. Earlier, a survey (from 2013) of health workers' and managers' work satisfaction and retention, was mentioned. In the survey, "meaningful work" received the highest rating indicating that the public sector health workers feel that their work makes a difference and adds value (Wolvaardt et al., 2014). This may be connected to the passion and pride found in the current study.

A possibly related example can be found from the current study. Contrary to drug susceptible TB (i.e. the 'ordinary' TB), the role of the TB M&E official is very limited with reference to the *MDR-TB* data. Regarding the main TB data, a sense of ownership, expertise and analysis could clearly be observed. However, with MDR data, all the official can do is some simple arithmetic to see if the numbers in the report add up before sending the report to the national level. Even the Excel template used for the reporting is designed by the National DoH. Since the official feels that there is no means to verify or validate the information, the role is "*kind of a post office*" (anonymous quote). In other words, with main TB data, there is more responsibility and skills needed and hence it allows for the person to feel that his or her input is meaningful and important, whereas with MDR data forwarding something without having any control over it or choice how to go about the task, may cause lack of buy-in. The example shows how different tasks within the same job may either enhance or decrease 'buy-in'. Moreover, the example makes one wonder, if a HIS, which is very hierarchical and has rigid structures that have been created to ensure efficiency and data quality, may at the same time influence negatively on how people feel about their input. Therefore, through that mechanism, rigid and hierarchical structures actually adversely affect the efficiency of the HIS and the quality of data. The co-existence of lack of buy-in and sense of pride about one's work, however, requires further research.

7.5.6 Beyond the immediate surroundings

The previous section has discussed the reported 'lack of buy-in' of various occupational groups who work with TB, HIV and their M&E at the case study setting. However, it is not the purpose of this study to blame the health care workers (or anyone else for that matter) for having the wrong kind of attitude. On the contrary, it is the setting, **the environment that the people live and work in every day, which does not support the full use of their capacities**.

Informants are unanimous in that Khayelitsha is an extremely difficult area in which to work. This issue can be illustrated by revisiting Vignette 4-1. The Vignette demonstrated some safety issues, which the researcher had to take into consideration in Khayelitsha. What has this to do with the collection and

reporting of TB and HIV information? To begin, it is not just the inexperienced researchers, the members of the community do not feel safe either. According to the O'Regan-Pikoli Commission of Inquiry into policing in Khayelitsha, more than 80% of the residents of the township do not feel safe in their homes. People are assaulted, robbed, raped and so on while conducting their daily tasks, such as using the toilets or accessing transport to work (ibid., 2014). Among the countries for which statistics are available, South Africa has among the highest rates of reported sexual violence against women in a country that is not at war. The worst estimates predict that one woman in three can expect to be raped in her lifetime (Moffett, 2006; Human Rights Watch, 2011). As mentioned earlier, a major part of recruitment in Khayelitsha is done locally. Hence, the health care providers and data capturers are in many instances part of that community and are affected by the same issues that affect the community.

Crime and safety are not the only problems: particularly at the facility / sub-district level the challenges range from financial to family worries to the staff themselves being sick or having sick family members. Moreover, culturally, they are expected to support a very large extended family, financially and in other ways (there are a variety of 'family responsibilities'). Often, this is in return for the support they have received earlier. Furthermore, many health workers are not from Khayelitsha so they do not have their safety nets of family around them to look after children. Consequently, when a family disaster happens, staff may abuse sick leave to take time off.

Khayelitsha and Mitchell's Plain are argued to be the busiest sub-districts in Cape Town; with a higher population and a larger proportion of sick and disadvantaged people. However, the limited number of staff and the busy and crowded facility environment mean that only the sickest will come and wait all day to be treated. Prevention and health promotion tends to be diminished, which in turn increases the number of seriously ill patients in the long term. The staff members are exhausted and experience the pressure and the challenges while simultaneously struggling in their own personal lives. The way the informants describe how many staff members feel makes the researcher believe that they suffer from compassion fatigue:

> *"It's you know the problems are just too big... But it's also staff themselves, and the pressure, personally, in their own personal lives. And still coming to work and having to have this enthusiastic attitude towards the work, when actually they are having problems... It's a lot for people to cope. Life is difficult. Especially life in places like Khayelitsha. And it's just... you just can't...* ***you don't have it to give it anymore****."* (Informant, *emphasis by the researcher)*

It is obvious for the researcher that living and working in that kind of environment makes it very difficult to engage people in quality improvement projects and the like.

7.5.7 Conclusions, reflections, good practice

In conclusion, there are several contextual factors that contribute to the challenges in the South African TB and HIV information system. They can also be viewed, and they have been viewed by the informants, as challenges *in* the system. The availability of HR, as well as their competence, was cited as a barrier to optimal functioning of HIS at the case study setting. In particular, challenges with language, numerical and literacy skills, data analysis and interpretation skills, computer literacy and understanding of data elements hamper the functioning the TB and HIV information system. In addition to deficiencies in the physical environment where the HR conducts their daily work, and lack of buy-in was reported. It seems that the lack of buy-in concerns particularly the facility level but it also occurs at other levels of the health system. In this study, lack of buy-in towards information related responsibilities is predominant, but the data suggests that there is also a lack of buy-in to policy and system developments.

A relatively strong **leadership** was suggested as a positive aspect of the Western Cape health system by a few informants: *"We've got a very good senior management direction and commitment. It's really working for us. You feel that you're part of the team"* (Informant, Province). This can be seen as good practice and it is related to all of the challenges mentioned in this section. With strong leadership there are more possibilities to build capacity and attract funding and

skills, as well as to inspire people to be more committed in all aspects of their work. In connection with the perceived lack of buy-in, this section also introduced a seemingly opposite phenomenon, pride in one's work. The right kind of leadership is required to facilitate pride, too. The findings about co-existence of feelings that the work is meaningful and being proud of it, and simultaneously not really buying into all parts of it, however, remain mixed. The next chapter introduces further related findings that offer more insight.

Finally, this section discussed the fact that it is very difficult and stressful to live and work in a place like Khayelitsha, which again is likely to decrease buy-in. One may ask is it even realistic to expect that people in such an environment would show high motivation (and precision) towards ticking the various sheets and registers or demonstrate great commitment to data quality.

For the researcher, there are two routes that one can take. First, it can be argued that the analysis of the social context, that goes this far from the actual place of work, is largely irrelevant and does not have enough to do with information systems and even if it does, there is not much that can be done about it. Alternatively, it can be argued that the analysis of the larger social environment, even when it goes as far as pointing out that a data capturer may not feel safe at home, is relevant and important. This is for various reasons:

- An under-privileged and unfavourable contextual setting is likely to influence all parts of a data capturer's work, through the limited buy-in, motivation, commitment and ability to concentrate on the tasks at hand. This, in turn, can lead to a sub-optimally functioning HIS and varying data quality.

- These are not challenges that affect just the HIS. The whole health system, the nursing staff and the sub-district office staff are also affected by the harsh social environment of the township. As reported earlier, there occurs lack of enthusiasm towards policy changes (not just towards the data tasks), and the lack of involvement may also occur at the higher levels of the health system.

- This kind of comprehensive analysis will help contextualise the expectations. It assists in deciding whether and how one wishes to improve the functioning

of a HIS or whether one decides that 'alright, this is a level of data quality (for instance) that we are currently happy with. If we want to improve something we can try this or that (for instance training) but we accept that there will probably still be a certain number of discrepancies at the lowest level for the reasons that are beyond our control'.

- When designing and implementing new HISs or applications, ignoring the social context would probably lead to a limited understanding why the new system may fail to produce all the predicted benefits.

- This kind of deeply contextual analysis helps to actually appreciate the people part of the HIS, which may often be side-lined by the traditional or highly technical approaches within the IS science. At the end of the day, are not the people the most important part?

- Even though there are a plethora of challenges that can make the facility or sub-district level staff struggle in their personal lives in a way that is eventually reflected in the functioning of the health system and HIS, maybe something can actually be done. Whether the answer is yes or no, analysis that looks at the social context has at least *brought up* the question, and hence enabled the discussion. This is a novel approach and it calls for a holistic, cross-sectoral and co-operative way to look at how systems are connected to people's personal lives.

Chapter 8 Analysis of Findings: Utilisation of data in the South African TB and HIV information system

8.1 OVERVIEW

The overall quality of the South African TB and HIV HIS has been examined from two angles so far. In Chapter 6, the quality of the data produced by this system was analysed in terms of its accuracy, timeliness and other vital aspects. Chapter 7 provided insight on issues that were perceived as the key deficiencies in the functioning of the TB and HIV information system by those who operate within that system. In this chapter, the focus is turned to the issue of **utilisation of the data** produced by South African TB and HIV HIS. By utilisation, the researcher means the use of data for meaningful purposes, including feedback. Ndabarora et al. (2014), when investigating utilisation of data in LMIC, included the use of data in research. This topic, however, is beyond the limited scope of this research.

The utilisation of data is examined as follows: section 8.2 examines the use of data in the case study setting and compares it to what has been reported about the topic earlier. Section 8.3 demonstrates how the data is used in an institutionalised way in formal meetings where different public health entities are measured against various public health targets. Section 8.4 focuses on the issue of feedback at the different levels of the health system. Finally, section 8.5 concludes with a summary and further reflection on the issues discussed here.

8.2 THE USE OF DATA FOR MEANINGFUL PURPOSES

As seen in Chapter 3, in many low and middle-income countries, data from routine health information systems is not used effectively for decision-making (Braa et al., 2012; Sæbø et al., 2011; Wilkins et al., 2008; Kimaro et al., 2008; Plaza et al., 2012; Simba, 2004; Hanna and Kangolle, 2010; Mliga, 2003). With exception of Heunis et al. (2011), previous evaluations of health information systems have identified limited data use also in South Africa (Garrib et al., 2008; Shaw, 2005) with a universal *"culture of reporting"* instead of a *"culture of using"*

the data (Byskov and Ohlson, 2005). Also Auld et al. (2013) noted that many of their study respondents were frustrated and felt that they see no local benefit from their participation in collection of data. Finally, Wolvaardt and colleagues argue in the most recent South African Health Review that managers *"do not consistently and effectively use data for evidence-based decision-making"*, especially with reference to planning and performance management (Wolvaardt et al., 2014).

Against this backdrop, the findings at the case study setting regarding the use of data are somewhat the opposite. **A central finding is that much of the data is actually used for meaningful purposes**, the case study setting referring to all levels from the case study clinic to the case study province. Indeed, most informants working in some sort of a coordinator, managerial or health governance position specifically emphasise analysing the data and using it for various purposes **including planning, interventions, allocating resources, improving services, justifying HR requests,** as well as **addressing gaps and training needs.** The next group of quotes illustrates how the informants at a lower and higher level of the system **use data** on a **daily** and **monthly** basis to pinpoint challenges in care delivery, since the data makes the challenges more explicit.

> *"So from that type of information we are able to make plans around that. Because once you find that some, one facility is lacking on perhaps taking of sputum at two months then we ask the people to focus on that. Then if they are lacking ...in doing HIV testing all the patients that are coming in for the first time then they will highlight that and say let's work around that let's correct this one."* (Informant, sub-district level)

> *"...the data when it comes to me has already been checked by all the, ...M&E people... ...and Sub-Directorates as well. And by the time it comes to me then I'm very assured that they've looked at it and interrogated it and often they've already made comments and tell me, 'Look at that, here's a problem, there's a problem', and then I can look at it further, and I can say 'Ok we need to engage' and then I give direction on how we can engage the District Managers further. ...it's a daily sort of use of the information"* (Informant, provincial level)

The data is also collected and used **quarterly**, and **yearly**, although the yearly data in particular seems to be less timely for using it addressing *immediate*

problems. Rather, this data is needed for higher-level reporting purposes, including reporting on the allocated funds and ensuring future funding.

> *"...Then um on a quarterly basis we ...collate a quarterly report and that report, so that's when we use the information on as well as the comments and what's been done and who's doing what about it to solve the problems. That gets sort of put into a formal report.*
>
> *...Then we report to the um the National Treasury. They give us the money ...the Conditional Grant budget. Then we will report to them to tell them what we're doing with their money."* (Antoher informant in decision making / data use position)

At the case study setting there was one particular informant who emphasised the use of data in decision-making.

> *"I take a particular interest in looking at data and trying to make sense of it and I use data for management practices every day. I tend not to make decisions without first checking the facts and the figures. ...and I make an effort to look at the data and to report it back to people that produced it."* (Anonymous quote)

The researcher believes that at the case study setting there is acknowledgment that in the past there have been substantial challenges with data use and hence a lot of emphasis is being put into it currently. More specifically, the researcher believes that there may be three factors at play.

First, it is possible that the various actors in the health system at the Western Cape are actually utilising data to a greater degree than their colleagues elsewhere in South Africa. The situation has probably also improved since the study of Garrib et al. (2008). Nonetheless, since the 2013/2014 South African Health Review includes statements as harsh as *"Decisions are not based on any evidence."* (Wolvaardt et al., 2014), the findings of this study for which the data is collected in 2012 cannot be attributed to just general improvement in the use of data over time.

Second, it is possible that the recognition of the past deficiencies in this area has contributed to informants' eagerness to bring the improved issue up or

respond slightly 'over positively' to the inquiries on data use. In this case, the findings could be considered somewhat biased if the purpose was to measure the actual degree of utilisation of data in the Western Cape. However, since the purpose of this study is to identify and understand challenges and strengths in the South African TB and HIV information system as perceived by actors within that system, this is not a problem.

Third, the health research authorities responsible for study permits suggested this sub-district as the case study sub-district. This sub-district seemed to be particularly keen to use data as evidence. Hence, it is possible that the authorities preferred it to some other sub-district where things are not running as smoothly. Again, while in that sense there may be bias in the process, it does not make the study biased, as the case study sub-district does not have to be representative of all sub-districts.[72] Indeed, a key informant admitted that the practice of quite extensive use of data as evidence does not necessarily happen elsewhere in the Western Cape or South Africa.

The researcher concludes from the evidence that the phenomenon of actually **using relevant data for decision-making** at the case study setting, and **using it more than elsewhere in South Africa**, is true. This is because this notion not only came through in many interviews, but also because it could be verified by observation. For instance, in the sub-district office there were several current graphs on the wall about various relevant health issues (such as number of distributed condoms as bar charts per month in that sub-district or number of performed tests against certain targets). Moreover, Wolvaardt et al. (2014) cited poor data availability, data quality issues including timeliness, integrity and validity, as well as the sheer quantity of data as reasons for sub-optimal use. Since the informants feel that the Western Cape has more of the best practices compared to other provinces in data collection and reporting (*"...we're still better off from the other provinces. The system, it's not a problem."* (Informant) and better data quality (*"HAST data sets are known for being a fairly good reflection of what is happening"* (Another informant) it may be that the data is more usable than elsewhere. In other words, some of the negative issues

[72] For more information, see 4.4.3

identified by Wolvaardt et al. decreasing data use may be less negative in the Western Cape. However, having said that the phenomenon is true, the researcher also thinks that it was emphasised in the data because of a combination of the second and third reasons mentioned above.

In section 7.5.5, limited appreciation for data was discussed. In contrast to that finding, an informant sees that though the data flow is just unidirectional for some people:

> *"in the Western Cape and especially around the HAST data and in general, it has quite an awareness of the value of the data and* ***how to use it****. ... There is quite a lot of engagement and* ***use****, as I say it generates all sorts of offsprings for the data itself."* (Informant in decision making / data use position, emphasis by the researcher).

This is in line with the findings regarding high use of data in the Western Cape and the link made in the academic literature between understanding the value of data and its usage. It also proposes that using the data probably advances further utilisation of it.

In addition, the City of Cape Town collects and captures death data at the district level in a form that suits the district, and feeds it back to the lower levels for intervention and other purposes. According to a district level informant, this is done instead of waiting two years for the statistics to come from the national level. For the researcher, this example further indicates an active approach towards the utilisation of data.

Finally, Kawonga et al. (2013) have noted in their case study in South Africa that the use of HIV information is largely under the control of vertical (i.e. HIV programme related) managers who may use HIV data in even smaller sub-programme-specific silos (such as PMTCT). In the current study, there were no specific questions on the use of data outside the programme silos. Based on anecdotal evidence and observation, the researcher is inclined to think that except the few occupational groups that are made responsible for a whole clinic's or sub-district's management and data, everybody else is primarily interested in the data that *directly* concerns their own specific programme. Therefore, it may

be that the vertical and often separate structures that can be found in data collection can also be found in some of the data use.

8.3 TARGETS, ACCOUNTABILITY AND PLATFORMS FOR DATA USE

When asked how or to what extent data is used, many of the informants referred to certain **regular and formal meetings**, which are used to make collective decisions in public health in South Africa (Elloker et al., 2013). Joint meetings at different levels facilitate coordination between health authorities. The meetings within each line of authority at different system levels, in turn, provide opportunities for higher-level managers to communicate with managers lower down the system, hold them accountable for their performance as well as offer them support (Elloker et al., 2013). **Clear target setting,** which was identified as a well functioning aspect of the Western Cape health system by some informants, is directly connected to the use of data in these meetings.

> *"what is really working well is the fact that we have set targets, we have per facilities or per sub-districts and that we are reporting on that target achievement on quarterly basis"* (Informant)

An important thing to note is that the **targets are defined with the help of data**. A quote below shows how data is used for target setting for HCT for new financial year:

> *...because we had a HCT, HIV counselling and testing campaign, last year... ...we looked at the campaign data that we got, we looked at all the historical data that we had, we also looked at the need that could be out there, and we looked at the antenatal survey which is a survey that is being done every year.... ...That team then from UCT assisted us in scientifically setting the targets for the new year. So now, once the targets have been set we communicate with the districts and we say looking at what you have, looking at the facilities that we need to expand the services to, because we have to make sure that those people in need, as identified, that have health facilities available so that they can have access to the treatment.* (Another informant)

What follows, and was also considered a successful aspect of the health system at the case study setting, is **performance and line management accountability.**

> *"I think one of the systems in Cape Town that has really worked well is empowering our sub-district managers, and them holding lower-down food chain accountable. So, performance is poor in a sub-district, that's when a sub-district manager wants to know why. They will scuttle off the coordinators to say 'please go and investigate what's happening here, come back and tell me'. They will hold that line manager of that particular facility accountable. And that facility manager will have to find that poor old TB nurse and find out why she isn't doing her job properly.*
>
> *So it's kind of – we sound quite rigid and strict, kind of police, but …it's not that, it's just, …so entrenched into the system and accountability is so entrenched."* (Informant in decision making / data use position)

However, what makes the situation somewhat peculiar is that the line management accountability structures are largely within the City Health (i.e. district, sub-district and facility level) but these levels are not accountable for the health authorities of the provincial government, which has to do with the co-existence of two health authorities in the Western Cape.

Elloker et al. also note the considerable emphasis on performance accountability. According to them, it is indicated by the naming of several meetings as "plan, do, review (PDR) meetings". As suggested by the name, these meetings are used to review service performance indicators against target levels with the objective of detecting problems that impair service delivery and of finding solutions (2013). The majority of informants of this study identify regular monthly, quarterly and yearly meetings with different groups of participants making decisions. In line with Elloker et al.'s view on the Plan Do and Review practice, they seem to consider the activities, namely the "quarterly meetings" and related quarterly reporting, as most important. So, it is not just the targets that are defined with the data, but routinely **collected data is used to monitor progress** in the form of approximately 70 indicators, and people are held accountable for the results:

> *"So another role is then that once the targets have been set, we then monitor on a monthly basis how are we going, how are we moving, how positive things are against reaching our targets."* (Informant, provincial level)

> *..."we'd go through all of these and each of the managers would sit in a meeting and they'll explain why they've got those percentages, especially the ones in red and they'll explain why they did not reach the target and that explanation is recorded."* (Informant, district level)

Since the targets as well as the performance indicators are based on the collected data, the meetings can be considered as meaningful utilisation of that data – indeed an informant calls it an *"institutionalised"* way to use the collected data. According to another informant, the use of data as evidence helps with **identifying** not only **challenges** but **lessons learnt** and the **scaling up** of good practice.

> *"...we analyse "so ok what was our target, how well did we do and what went wrong? Why are these ones doing so well and these ones not?" You know? We are looking at the outliers and we are trying to explore what is it that makes you do so well. And then can we replicate those lessons? So sharing those practices is working very well. We have a number of forums where people at that same level are interacting with the data and sharing that practice. And those practices then get scaled up and replicated elsewhere."* (Informant in decision making / data use position)

In conclusion, the system at the case study site allows extensive data use – and it is indeed built on data use. **Data quality issues are also discussed** in some of these meetings, which supports further use. However, with such strict target and accountability structures, the system does sound somewhat rigid, top-down and hierarchical. Moreover, some lower level informants at the source of data told that they are not invited to certain meetings where they would like to participate. For the researcher, this is a lost opportunity for increasing buy-in and appreciation for data.

8.4 FEEDBACK

8.4.1 Introduction

Feedback can be seen as a form of utilising data. Prior to the data collection phase, the researcher had a preconception that feedback might be seen as a challenge at the case study setting. This was mainly due to reports in international and South African academic literature. As reviewed earlier, many studies have identified deficiencies in feedback mechanisms in public health in the LMIC context (Otwombe et al., 2007; Mavimbe, 2005; Mutale et al., 2013; Ledikwe et al., 2014; Wilkins, 2008; Ndabarora et al., 2014). The South African situation has not appeared to be any better. According to Garrib et al. (2008), feedback to clinics occurs very seldom and a lack of human resources, particularly with sufficient data interpreting skills, is a contributing factor. In Auld et al.'s study, the respondents felt that they rarely receive reports back from central levels, which they contrasted with the amount of data collection that they are responsible for (2013). More frequent feedback was also on the wish list by TB nurses in Heunis et al., 2011. Against this backdrop, the researcher expected to find evidence of dysfunctional feedback loop and hear from the informants that they do not receive enough feedback.

However, the evidence was mixed, with the **majority of informants feeling that they receive and are able to give a meaningful amount and kind of feedback**. They also mentioned names of the people providing them feedback and forums and documents where feedback was given. Indeed it was argued that:

> *"There is processes for feeding back the data quite extensively at the sub-district and the district level"* (Informant, district level)
>
> *"A lot of emphasis that we put on this feedback to... clinics. And I mean I've got examples of presentations that are put together, the feedback that we get every quarter"* (Informant, district level)
>
> *"...once they have sent up their data to our office, its validated, interrogated, then there is a feedback mechanism to the district as well, to say for instance: if any issue has been picked up here, and corrections had to be made, it will be fed back to the districts and say "now this is your final dataset, and this what you can work on". Obviously there would be "why did you do that?", "How*

> *did you interrogate the data?" ...So, there is always interaction between the districts and the provincial office. We make sure that we do not miss numbers, or whether we're using the same validation rules and all those things are there... ...and can then be sorted. So yes, there's constant interaction."* (Informant, provincial level)

As can be seen from the last quote feedback concerns not only substance (i.e. performance and care delivery) but also any **issues in data quality**.

With the topic of data use the researcher speculated whether the positive findings should be attributed to situation's 'general' improvement over time. The same concerns feedback. The previous three positive quotes (above) on feedback can be contrasted with a negative one by an informant who used to work within the South African TB and HIV information system and whose interview was used primarily for providing historical data:

> *"Oh my experience has been that people always collects the data because it's needed on another level. They don't collect the data for them to use it themselves, and I think the feedback loop hasn't improved either. I don't think it has improved now and it will take a long time for it to improve. Because people collect data, send it to next level but it doesn't come back to say "this is your current situation, why are you why is this happening? Why don't you improve it?" So that feedback loop doesn't happen."* (Anonymous quote)

The provincial level informant clearly does not believe that there has been progress in the feedback system. However, since there have been several years since he/she had been working within the system and since the majority of other evidence is against this claim, the researcher is inclined to believe that the feedback has improved significantly since the informant's, as well as Garrib and colleagues' days. A few informants also argue that there has been substantial improvement over time. However, the researcher also feels that the Western Cape may have been more successful in developing the feedback system than other provinces (which partially explains the difference with studies that have been done elsewhere in South Africa). In addition, the researcher suspects that similarly to the topic of data use, the awareness of past problems in the feedback

system may have contributed to how the informants brought the theme up and possibly even to the selection of the case study sub-district.

Besides the amount or frequency of feedback, according to informants, more emphasis has been put into **how** feedback is given:

> *"...I think it's always very important to have knowledge when people are doing well....You've gotta say 'well done' before you say 'you've done a bad job'. The human psyche and how we react. Um, and then we highlight the issues where the gaps are that people... need to go back and where to focus. Um, and I can really say... that over the years the quality of the data has improved significantly."* (Informant, district level)
>
> *"We really see it as a support role and not as in finger pointing. So it's really supporting them out there and saying "how can we assist"."* (Informant, provincial level)
>
> *"We always try to make it educational"* (Informant, sub-district level)

Paying a little attention to how the feedback is given is probably the cheapest and easiest way to try to affect motivation and buy-in, which again has an effect on the overall functioning of a HIS. Feedback and how it is given can also be associated with, and as the first quote indicates, is perceived to contribute to data quality.

As a rule of thumb, the national DoH provides feedback to the province, the province to the district level, the district level to sub-district offices which in turn feed back the key messages to the facilities, as illustrated in a simplified manner in Figure 8-1.

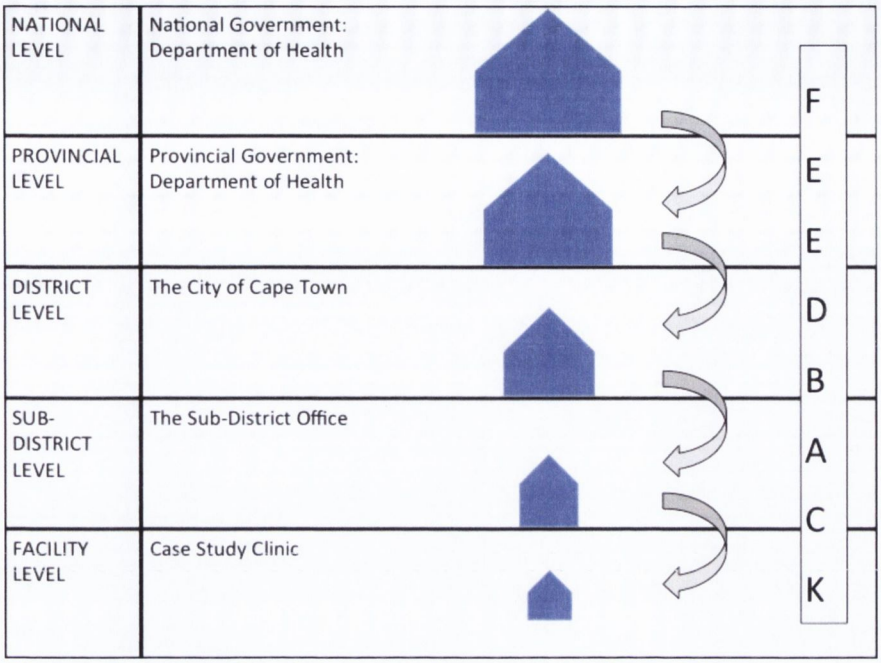


Figure 8-1. Feedback loop at the case study setting.

The next three sections provide more detail on how feedback is experienced at the different levels of the health system in the case study setting.

8.4.2 Feedback – From national to provincial level

Beginning with how the provincial level at the case study setting is experiencing the feedback they receive, there are feedback mechanisms, however, some informants felt that these mechanisms are somewhat narrow-focused and limited: *"It's basically acknowledging that the data has been received"*. According to another informant, the national level does not question (and hence does not give feedback) on data quality of the Western Cape data: *"They would really take what we send them as gospel. They would report on this"*. The performance of the province is examined, but it seems that if is perceived efficient, there is not that much feedback on that either: *"If they don't mention the report then they're happy with the report, you know."* (Informant in decision making / data use position) The feedback is given in a verbal form in routine quarterly meetings, certain steering groups and workshops:

> *"there's a DORA workshop where they bring all the provinces together, the provinces present their data and then we get feedback from the National at that workshop and they'd tell us if we're doing well or if we're not doing well and where we need to pick up slack and that type of thing."* (Informant)

However, it seems that the feedback could be more consistent, frequent, better targeted and personal:

> *"But there is some times when there is a breakdown in reporting back to the province; there's no other formal structure of which I am aware of, of monthly feedback to say "this is how you have performed, why are you not reaching your targets?" It always happens on a quarterly meeting... ...but there is* ***no personal interaction*** *at the provincial level.*
>
> *Researcher: Would you find it helpful...*
>
> *"Yes. Most definitely. You know there are various platforms of interaction of data from the National Department. For instance, we have the conditional grant. ...we have to report on certain indicators, and they would also come maybe once a quarter, because they need to do a review on finances and programme performance. If they do not come to the province on a quarterly basis it could be twice a year, but* ***then it's still a matter of us reporting on a quarterly basis on specific indicators that they are requesting from us****."* (Informant, provincial level)

The researcher interprets from the quote that the current feedback mechanism from the national level to provinces may be seen as a lost opportunity and it could be strengthened. Scrutinising how the Rands have been spent and whether a certain health indicator is 82 or 87 per cent from the target is probably necessary but may not be enough. A question whether these meetings provide a genuine chance for real interaction, a true opportunity to ask for support and hear how similar challenges have been tackled at the other provinces, remains unsolved.

An informant considered that instead of verbal feedback in meetings it could be beneficial to have formalised written feedback.

> *"I'm comfortable with the way it's going. But it will be nice if it can be formalised. But then again there's a lot of people who will disagree with me. ...Because a lot of people feel that once you formalise it, you create a platform to be um scrutinised even more."* (Informant in decision making / data use position)

As can be interpreted from the quote, the informant sees that while in a way he/she feels that the national level could be investing more effort in the manner

they deliver the feedback, the current less formal situation allows the provincial level to address the feedback in possibly a more relaxed manner.

In the past, data quality issues at the national level have led to feedback being provided too late or the data has been just too unreliable:

> *"eventually I realised that they take ages to get the information from the various provinces and essentially they [the national level] can't produce any feedback. And when they do have data it so rubbish that it means nothing, it's just rubbish in, rubbish out"* (Anonymous quote)

Data quality has been improved, however there are still challenges. Earlier it was reported that, according to an informant, the ART data set is a *"complete mess"* (anonymous quote) and the Western Cape is probably the only province that has data beyond the number of people that have started on the treatment. The data quality issues at the data set at the national level mean that they cannot provide feedback about it to the provincial DoHs.

> *"I think as things evolve, that would be useful to have better feedback. And I think the potential for feedback is there. Our provincial colleagues do have contact with national, I think potentially they would be bringing it back to us if it existed."* (Informant)

This serves as an example of a situation where there is certain information that could be useful, but the national data is so incomplete or unreliable, that it is not meaningful to feed it back for comparisons to provincial level or to any of the lower levels that have been part of collecting and reporting it.

Although the routine feedback loop at the national level has improved over the years, responding to specific requests to address deficiencies have often taken, and may still take a long time. There are examples in PMTCT and STIs amongst others, with more than 3 years response time by the national authority.

> *"...you forever engage with them... - we actually gave them the data ...and tell them this is what needs to go on your system, and we sat for 2 days with them, but nothing to this day has been affected. And you go back and you do follow ups, you go and do follow ups, and there are promises as if it's going to happen. You know, you tend to actually think HELLO what's happening, you're fighting a losing battle. I know that there were no challenges that*

> *we took it up to the senior members of staff but if there is a gap that needs to be resolved, it needs to be resolved, it shouldn't be taking 3 years."* (Informant, provincial level)

Earlier, power struggles and tensions between different health authorities were discussed. Shortcomings in timely feedback and responding to questions will certainly have a negative influence on relationships between national and provincial levels at the case study setting, as well as amid any actors within any health system.

8.4.3 Feedback – From provincial to district and district to sub-district level

The Province provides feedback to all of its districts, including the metropolitan municipality i.e. the City of Cape Town. As mentioned earlier, the role of the provincial government is to set and communicate national policies and guidelines but the health authorities in the province have no line management function over the health authorities in Cape Town. This results in a slightly asymmetrical situation. The facilities and the subsequent levels are responsible for reporting the TB and HIV data all the way to provincial level and beyond, but much of the feedback on that data happens within the districts.

> *"As far as the feedback is concerned... ...the districts mainly function almost independently. But they get the direction from the provincial office"* (Informant)

> *"We [in the province] are in a position to give feedback but not... ...the purpose for us to give feedback is so that basically people in the districts know how the programme is performing. So we would touch on data issues and data quality, but it's not really... ...I wouldn't say it's not....it's not our core function. Because that feedback loop happens ...within the districts."* (Informant, provincial level)

As can be read from the second quote, feedback concerns the quality of performance but also the quality of the data used to report on the performance.

Although the Province does not usually give the kind of feedback to the City of Cape Town in which it would compare Cape Town to other regions, an independent NGO called Health Systems Trust generates an annual District Health Barometer, where they measure the 52 health districts in the country with each other. This gives the City of Cape Town an opportunity to compare themselves to other places in South Africa.

The City Health feeds back the key messages for all of the eight sub-districts in Cape Town, including Khayelitsha. Similarly to the higher levels discussed previously, feedback looks at the gaps in performance *"why haven't sputum results been done, why haven't all the patients had an HIV test? Those that are eligible for ARVs, why haven't they been actually started on ...ARVs?"* (Informant) but may also concern data quality. Some of the routine feedback from district to sub-district is provided via Plan Do and Review process i.e. comparing their performance against the agreed targets. In addition, there is other routine feedback related to priority diseases, such as TB and HIV. According to an informant, routine TB related feedback is given within six weeks of receiving TB data as a written report and a PowerPoint presentation. The reports not only compare sub-districts or clinics against each other, but examine trends over time. This sounds highly useful. However, since this is something separate to the PDR process, it appears as a 'silo approach' in care delivery and reporting may also contribute to somewhat disconnected programme-specific 'feedback silos'.

An interesting feature regarding feedback at the district and sub-district levels is the (physical) **awarding for good performance.** At the district level there is an annual award ceremony, in which the staff members are given awards for excelling in a particular area. The awarding of good performance against targets in a public way also takes place at the sub-district level (i.e. between facilities). At the annual ceremony, there are award categories as in the Oscars or Academy Awards. The District Health Barometer, amongst other data, is used to identify the success stories. An informant finds the ceremony very helpful:

> *"...staff, particularly working in the clinics in these volumes of patients coming in, often forget the impact that they're making in terms of the data we're wanting them to collect. So I always find*

> *that very useful, at least once a year, to contextualize the work they do in the clinic, and how they've been measured, and how they then compared to the compatriots in the country."* (Informant in decision making / data use position)

Contextualising and indeed thanking for the job well done is an extremely simple way to increase the buy-in and commitment of the health work force. According to another informant, the public awarding involves a lot of people and creates

> *"...healthy competition, where people say "oh I am gonna try and do my best, I want to be the one that's gonna have everybody clapping." ...Because it takes this thing that the people don't understand why are we doing this. You know, it's [name removed] driving us crazy. Ehm, that is kind of, it's no longer that woman, but that woman is just one in a kind of number of others that value the work that has been done and keep track of it and you know if we do well, we're gonna shine. We're gonna be on the spot and we're gonna shine... So that is going very well. There is a strong sense of pride; the various sub-districts want to be the best. That works."* (Anonymous quote)

In other words, the public awarding motivates people by making it more explicit and concrete that their performance is followed and a job well done is appreciated. The ceremony also appeals to basic human instincts including wanting to perform better than the neighbour and being pleased and proud when that is publicly recognised, particularly as the tokens of appreciation are visible and concrete, such as silver cups and certificates. This seems to reflect in a way how the sub-district office staff feel about the quarterly meetings and how they are interested in their own and their fellows' performance.

> *"Even before that, that meeting that we attend, we usually go there knowing how we've performed in the sub-district. Because we look at our own data even before we go there we know that this is where we stand... ...as Khayalitsha, we don't go there and get surprises of something that we don't know.*
>
> *...We don't know the other Sub-Districts, but we as the coordinators we phone each other, how did you do and all that...* (Informant, field level)

8.4.4 Feedback - From sub-district to facility level:

Many of the informants argue that there is a particularly well-established feedback mechanism to the facility level. The researcher could see graphs and presentations on the wall of the staff tea-room. However, according to one informant, some of the information that could be useful at the lower levels of health system never reaches those levels:

> *"...But lot of the things on these circulars gets to the offices but it doesn't filter down to the clinic level you know. ...The feedback from directors down to... [clinics]. The district management system is the you've got the director, you've got the deputy-director for comprehensive health and you've got a deputy-director for primary health care, you know. And under the primary health care ones you have the facility managers... So it might still get to the comprehensive one or maybe the primary health care one but it hasn't fallen down to the clinics or to the facility manager... ...and then to the clinic or to the itself, to out-patient department or whatever."* (Informant)

The researcher interprets from the quote that the hierarchical and bureaucratic type of the South African health system may slow down or weaken the feedback loop. Moreover, in the quote, the information, if it reaches the clinic, is targeted to the facility manager or maybe someone who is managing an entity within the facility. Another informant feels the same: he argues that in the past, and maybe also currently, the **feedback never reaches the person who collected the information**. In other words, feedback is presented back to people who are in a position to make decisions, but it may not meet the person who is the source of information (Informant, different to previous quote). This view is reinforced in the data: some of the facility level informants who do not have decision-making power were not as happy as others with feedback they were given and they also would have wanted to participate in some meetings to which they were not routinely invited. It could be beneficial to try to address this gap as the enhanced feedback would increase the buy-in, which has been argued to be a challenge in particular at the lowest levels. Indeed, an informant argues that if one can sufficiently feed the data back to the staff, and the people would see the difference and that would be *"empowering"*, increasing the motivation and buy-in (Informant).

Finally, deficiencies in infrastructure may impair the feedback system. For instance, managers in smaller clinics may not be on email yet, which can be seen as a barrier to efficient feedback and communication. Moreover, the sub-district level informants who give feedback to the facility level identify the limited skills and competences of their audience (as elaborated in 7.5.3) as an impediment for successful feedback.

8.5 CONCLUSIONS, REFLECTIONS, GOOD PRACTICE

To conclude, contrary to some of the academic literature and the researcher's preconceptions, the case study setting demonstrated a high degree of data utilisation. TB and HIV related data, amongst other available data, is used for various meaningful purposes at the different levels of the health system. Several simple and inexpensive ways to improve data use can be identified from the case study experience, including using the data in a visible manner, such as placing relevant graphs on the wall.

The data quality chapter introduced the case study setting's various data validation and checking mechanisms as a possible best practice. It was also mentioned in passing that the key posts have been made accountable for the quality of data. In this chapter this aspect is revisited, since these people are not only accountable for data but for performance as well. The performance targets are determined with data, the performance against these targets is monitored with the routine data and people responsible for each area have to answer for the results. Accountability is a central aspect of the system and much connected to 'buy-in'. The system, emphasising and indeed building on regular data use, may be recommended as a best practice, but whether it is enough, or whether it is the best system to support meaningful data use, optimal HIS and health system functioning and high data quality, remains unanswered.

In addition to data use, an active approach to feedback was a key finding at the case study setting. While using data for feedback and other meaningful purposes was present in much of the research data, there were a couple of key people who were particularly engaged:

> *"...started realising that if I want feedback I must look, I must do it myself. I can't wait for somebody to produce the feedback, those things do take some time. Those very high-level reports, those very bigger pictures, it takes time and I shouldn't organise my life waiting to hear from them. I should organise my life with the information that I produce. And the same as I pass it out, I must analyse it at my level and I must share it horizontally"* (Anonymous quote)

The deficiencies at the national level to produce timely high-quality feedback have contributed why some informants have adopted a pro-active approach. Leading by example can be seen as best practice. Indeed, Cibulskis & Hiawalyer (2002) have noted that when the management level seeks information and uses it openly, the value of information is reinforced through the whole health system. The key persons' example on a high level helps to legitimise data requests also from other health workers and mid-level management. Another 'lesson learnt' that can be recommended, is paying attention to *how* the feedback is given.

Having said all this, this chapter also identified aspects in the feedback system in which there is room for improvement. The provincial level felt that the feedback from the national level could be more formal, consistent, frequent and simultaneously more personal and better targeted. Moreover, it looks like there were 'feedback silos' (as well as possible 'data use silos') around priority diseases at the case study setting. This is a difficult question, because not everybody needs to know everything, and sometimes it is better to focus on a targeted audience and a target message. Finally, it was argued that at the facility level feedback never reaches the person who collected the information. Not all who were part of the collection of data were invited to the meetings where decisions were made based on this data. The researcher suggests addressing the gaps in particular at the facility level since: *"Feedback is a form of training and directly addresses the causes of poor quality data and enhances awareness of the importance of data"* (Garrib et al., 2008).

In 7.5.6 it was contemplated how limited buy-in and a sense of pride can co-exist at the case study setting. The public awarding may be the missing link. There are huge struggles in people's personal lives and the work in Khayelitsha is very difficult with seemingly endless number of patients of whom many will have sad destinies. All that makes it very difficult to keep the staff involved and

committed. However, when there happens little successes, contextualising staff's efforts, awarding and publicly thanking them for the job well done mitigates that lack of buy-in and reminds them that their work is something to be proud of. That, in turn, probably increases the data quality and improves HIS and health system functioning. The researcher quite likes the idea of silver cups, certificates and applause, but it may be that the idea needs to be culturally adapted so it would work optimally in different environments.

Chapter 9 Discussion and Conclusions

9.1 OVERVIEW

In this thesis it has been argued that all stakeholders including patients, health care professionals, policy makers and the general public need access to accurate, complete and up-to-date information so as to make choices and decisions (HIQA, 2013). Moreover, it has been demonstrated in the literature review and in the analysis of the findings that this is often very far from the reality in LMICs and particularly in highly underprivileged settings, such as Khayelitsha in South Africa. However, reflecting the challenges involved, it is often far from reality even in many developed countries. This makes this study relevant for a broader audience than just the local health professionals and decision-makers in the Western Cape. The current, and final, chapter of the thesis returns to and reviews some of the key aspects of this study in the following manner: the research question and objectives behind this study are revisited in section 9.2. Section 9.3 highlights the core findings, shows how they are connected to each other, discusses some of the key messages derived from the analysis of the findings and presents conclusions. Section 9.4 considers the potential for generalisation of the findings. In section 9.5, limitations of the study are identified. Moreover, based on the findings and limitations of the current study, as well as identified gaps in related studies, proposals for future research are included. Section 9.6 proposes study contributions. Finally, section 9.7 presents final conclusions and remarks.

9.2 RESEARCH QUESTION, OBJECTIVES AND THESIS STRUCTURE REVISITED

The purpose of the study, and consequently the purpose of the research question, was to establish understanding of the central challenges in a HIS in an underprivileged setting. In the context of the township of Khayelitsha in South Africa, the research question was:

> **What are the key challenges in the current TB and HIV information system in an underprivileged community?**

The study aimed to identify and analyse the key challenges in the current TB and HIV information system in South Africa through the lens of a case study by following a number of data flows. The data flows were defined as

1. being TB or HIV related

2. originating from one public health clinic in Khayelitsha, which is a part of the City of Cape Town, in Cape Town Metropolitan District of the Western Cape Province in South Africa.

A number of research objectives were derived to achieve the study aim:

A. To research relevant academic and grey literature that supports identifying and analysing key challenges and good practice in health information systems in under-privileged settings.

B. To examine how TB and HIV related information is collected, reported and used currently in Khayelitsha in the Western Cape Province in South Africa.

C. To identify the key challenges in systems and practices as perceived by the local health professionals.

D. To analyse and categorise these challenges in order to identify where systemic improvements are needed.

The study used qualitative case study methodology to address the research question and to meet the objectives, drawing on a wide range of relevant literature and data collection comprising interviews, observation and document analysis. The research process resulted in a research output, i.e. the thesis, consisting of nine chapters, as summarised in Table 9-1.

Table 9-1. Summary of the thesis structure.

Chapter	Summary
CHAPTER 1 Introduction	Chapter 1 provided an overview of the study indicating the reasons why it was done, as well as its research question, scope and objectives. A brief account of the research methodology and expected outcomes and contributions was given. Table 1-1 provided an overview of the chapters and how they relate to the research objectives.
CHAPTER 2 Background	In Chapter 2, the South African healthcare landscape was explored in terms of its historical roots and their impact on the current situation. The case study setting, Khayelitsha, was introduced. Relevant factors impacting on the South African TB and HIV information system were reviewed, including the burden of TB, HIV and co-infection; HR crisis in health; relevant paradigm shifts and developments in global health and with reference to South Africa; and vertical vs. comprehensive health care model.
CHAPTER 3 Literature Review	Given the multiple strands of the literature which had to be drawn on for this research, the literature review in Chapter 3 had to be wide-ranging. It covered fields, such as: different ways to classify a HIS; significance of information in health care; challenges in data quality, HIS functioning and utilisation of data in LMICs; and the global dynamics of the reporting of priority diseases. It also reviewed South African HIS studies that the researcher considered the most relevant to her subject area.
CHAPTER 4 Methodology	Chapter 4 detailed the research approach considering the epistemological assumptions that are appropriate for this type of research. While Chapter 1 provided only a snapshot on the methodology used, Chapter 4 elaborated on the topic by giving a detailed account of the research methodology and steps and describing the methods by which the data was collected and analysed.
CHAPTER 5 Empirical Findings: Description of TB and HIV related data flows	Chapter 5 presented the empirical findings of the research. The data flows originating from the case study clinic were depicted in detail, and followed up to the provincial health authority. This formed a foundation for a holistic analysis of the key challenges in connection with the data flows, covered in the subsequent chapters.
CHAPTERS 6-8 Analysis of Findings	Chapters 6 to 8 presented an analysis and presentation of the case study findings. Specifically, Chapter 6 focused on the data quality of South African TB and HIV information system, Chapter 7 on the functioning of the South African TB and HIV information system and

	Chapter 8 on the utilisation of the data produced by the system.
CHAPTER 9 Discussion and Conclusions	In Chapter 9, the research question is revisited and discussion and conclusions are presented. Other topics include generalisability of the findings; limitations; contributions of the study; and suggestions for future work.

Besides the aforementioned research objectives, another objective of the study was to identify and highlight good practice. This has been done alongside discussing challenges around the TB and HIV system in Chapters 6 to 8. In addition, the study aimed to discuss what kind of an approach might be appropriate in attempting to address the challenges by building on the literature and the identified examples of good practice. Another aim was to set the findings in the context of their generalisability. These objectives are discussed in this Chapter, in sections 9.3 and 9.4.

9.3 KEY FINDINGS, DISCUSSION AND CONCLUSIONS

9.3.1 Introduction

This research has identified several challenges in the current TB and HIV information system in the case study setting. The challenges were categorised in three categories: data quality, HIS functioning and utilisation of data. Whilst this study identified a number of shortcomings in each area, a central message of the study is that **each area is connected to other** and that any negative or positive developments in each category will impact the other. An inefficiently functioning HIS or health system has a difficult time producing high-quality data. If the data is not of sufficient quality, it will not be used. Poor use of data in decision-making and feedback weakens the HIS and therefore the whole health system functioning, and so on. Likewise, improvements in each category will reinforce the performance in other categories. Next, the key findings in each of the three categories are presented and discussed in sections 9.3.2 to 9.3.4 as illustrated in Figure 9-1, which aims to act as a roadmap.

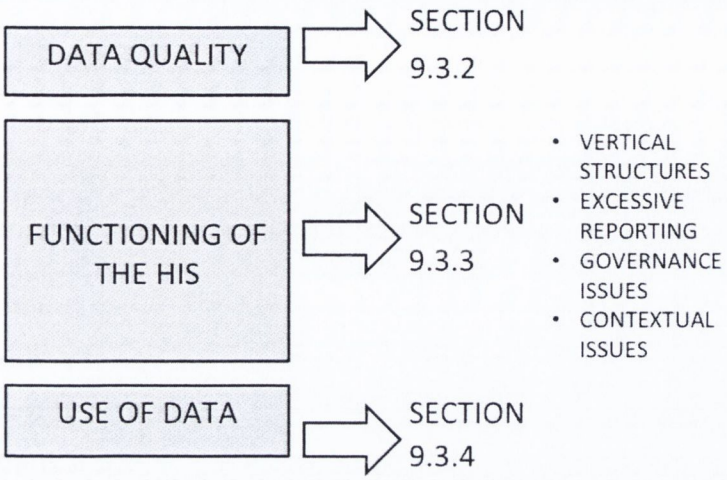


Figure 9-1. Organisation of sections 9.3.2-9.3.4.

As Figure 9-1 shows, functioning of the HIS is the broadest area, consisting of four further topics. Finally, building on the discussion in sections 9.3.2-9.3.4, section 9.3.5 describes two approaches that can be applied in understanding and examining a HIS.

9.3.2 Data quality in the South African TB and HIV information system

To begin with data quality, the study focused on *perceived* quality of data, which was discussed with the help of data quality dimensions including accuracy, completeness, timeliness, coherence, comparability and availability. The study identified a number of data quality related challenges at the case study setting. The data in the South African TB and HIV information system (as an entity) is not always accurate, complete, timely, coherent, comparable or even there. Nevertheless, while the researcher did not conduct any direct comparison, her interpretation from the evidence is that the end result is still better than in many other South African provinces or in a majority of the African countries. At the case study setting, the data quality depended largely on which data flow was inspected. Main TB data (excluding the MDR-TB) and HIV related data flows seemed to be of good quality, whereas the STI and RMR data were considered to be poorer quality. The quality of data also depended on the level of health

authority concerned. The data quality was considered to be a challenge particularly at the facility level. As discussed, a person who first receives a messy handwritten register at the last minute full of gaps would not see its accuracy, completeness, timeliness and other aspects in the same way as the person at the end of the reporting chain after 3 to 5 other people's improvements to the data. Informants also reported data quality issues at the national level. The researcher's interpretation is that this is due to the challenges in receiving, combining and reporting timely and high-quality data covering all the provinces.

The achieved level of data quality is largely the result of various data validation mechanisms, including audits, continuous efforts to improve data quality and data accountability structures in the Western Cape. These can be recommended elsewhere. However, it should be noted that a lot of time and effort is invested in maintaining a sufficient level of quality, as demonstrated with HCT data in Vignette 6-2. Therefore, questions remain. Can the quality be achieved in any other way? How best to allocate the limited resources for preventing, detecting or repairing poor data?

There are also further interesting points that should be discussed in terms of the findings relating to data quality and the analysis that has been conducted around them. First, the researcher's intuitive approach towards 'comprehensive health care versus focus on priority diseases' debate favours the first option. Interestingly, at the case study setting the well-established single programme monitoring systems around TB and HIV seemed to produce higher-quality data than for instance the RMR system, which can be seen as an attempt to report 'comprehensive' health data. This finding applies to both A) how data quality was perceived by informants and B) how the researcher interprets the data quality to be based on all the evidence. The observation raises a question: if a vertical single programme HIS ensures a better data quality, do integration efforts jeopardise it? The South African DoH has stated that HIV and TB services will be completely integrated with PHC services (see section 5.1). As the government is moving towards enhanced integration (as described in 2.8), it will be important to consider the type and level of integration from a data quality perspective. The individual data flows need to be checked and sometimes also first strengthened

to ensure data quality before attempting to integrate information systems or reporting functionalities, which is likely in turn to strengthen the whole system.

So, as argued before, the internationally prescribed HISs, which have been created with ample global funding and which come with internationally agreed case definitions, strict guidance and very limited flexibility, seem to produce relatively high-quality data in terms of accuracy, completeness, timeliness and so on. This brings us to the second issue that should be discussed: what is really meant by data quality, and in particular accuracy? Definitions used in this study were given in Table 6-1 and they were accepted and used by the informants. However, the source of the data is the clinical encounter between the patient and the nurse/doctor at the clinic. Although this issue did not directly come up in the actual research data, during the pre-research investigation the researcher was told that at busy clinics, data is sometimes recorded from memory long after the actual clinical encounter, and this may result in varying data quality. Therefore, what is considered 'accurate' may only be 'accurate' from a certain level of the reporting flow onwards. As explained in section 6.2.1, the researcher did not observe clinical encounters (or the original patient documentation) to see whether the data had been appropriately transcribed into the reporting system. Hence, this study cannot make judgements on the extent to which what happened in a real life situation is accurately reflected in the documentation or the consequent reporting flow. Instead, the perceptions by the health professionals at the case study setting about the data flows' data quality dimensions were recorded (they are summarised in Table 6-3). This is not the 'truth' either, but it may be an equally valuable topic for investigation. After all, is it not the *perceived* data quality which has an influence on whether the users decide to utilise or not to utilise the data? To clarify, 'accuracy' can be taken as an example, with options A, B and C. Beginning with option A: if one wishes to find out whether a particular clinical encounter is reflected accurately in a particular data, one should witness the actual situation, establish what exactly is meant by 'accuracy' and assess if a real life situation is captured sufficiently truthfully in the data in a way that is described in the accuracy definition. However, these kinds of assessments are rarely done, most likely because the observation can be disruptive for the patients' care and it may influence how the caregiver records the data (i.e. the results of this kind of a study might become

biased). Option B follows: if one aims to measure the data quality of a HIS in terms of accuracy or another agreed more technical dimension of data quality, it is acceptable to assess the concordance and consistency between data elements. Yet, if the actual clinical encounter is not observed, it measures consistency rather than quality per se. If one's choice is to perceive a HIS as a programme specific vertical M&E system, this may be a decent way to evaluate the system concerned and it certainly produces results that are helpful in finding gaps and deficiencies. Finally, option C: if one prefers to see a HIS in a more holistic way (for example in a socio-technical manner is used in this study, i.e. according to the definition by Tiihonen et al. (2010)) it may be interesting to examine the perceived accuracy of data because it influences how people appreciate it, use it and are motivated to collect it or complement the previously mentioned approaches, as illustrated in Table 9-2.

Table 9-2. Approaches to examine data quality in a less holistic and a holistic approach.[73]

Object of interest	**Less holistic approach**	**Holistic approach**
Data quality in a HIS	Option B = Investigation on the consistency of agreed technical dimension of data quality between data items. (or option A, if it is feasible)	Option C = Investigation of perceived data quality or a mixed methodology i.e. A+C or B+C, if feasible.

In conclusion, accuracy (as well as other data quality dimensions) can refer to various things. As argued previously, some systems in the Western Cape, such as the TB data collection system, were considered to produce relatively accurate data by the informants. But the third and final question to be raised is whether it is the *right* data for those who benefit from it most? The smear-positive pulmonary TB cases are reported through the system (ETR.Net). An informant

[73] Terms 'less holistic' and 'holistic' are elaborated in 9.3.5

points out that while the number of new smear positive cases has been decreasing it does not necessarily reflect the local TB burden on the ground:

> *"...We report on our new smear positive cases. ...And the number of new smear positives are getting smaller and smaller. So actually ...our achievement is... now gaged to only a small proportion of our patients. ...So now the next question is: what's happening to the, the proportion of our patients....that's growing? ...That's our ...smear negative patients and our HIV positive patients and our extra-pulmonary [cases]..."* (Informant in decision making / data use position)

According to the informant, the health authority concerned has therefore begun to collect treatment outcome data from all the other cases that are *"not on the global barometer"* such as smear negative TB cases, paediatric TB and patients with extra-pulmonary TB. This can be seen as an example of work and cost that could be avoided if an internationally prescribed system would lend itself to local needs. Moreover, anybody – a local policy-maker, global funder or general audience – consulting the figures produced by the official TB reporting system would not get a comprehensive picture reflecting the maturing epidemic on the ground, according to the informant:

> *"...even your targets and even your areas to look at change over time... ...as you look at your data ...it's not a clear picture if you, um, if you are quoted on 25 per cent of your patients only."* (Informant in decision making / data use position)

It is not within the scope of this study to make epidemiologic assessments about what really should be known about the TB and HIV epidemics in the Western Cape. However, it can be concluded that considering the monetary resources, HR, infrastructure and training that are invested in single programme HISs, they should be agile, responsive to local needs and produce maximum benefits in terms of the most fit-for-purpose, usable and appropriate data for different groups of users, particularly those groups who are producing it and directly benefiting from its use. Hence, 'accurate' or 'timely', albeit that they are vital aspects of data, do not always cut it. Consequently, Table 6-3 is not an end point but a starting point for further discussion.

9.3.3 The functioning of the South African TB and HIV information system

This takes us to the second and interrelated area of the findings: the functioning of the South African TB and HIV information system, as detailed in Chapter 7. Several interdependent issues hamper HIS functioning in the case study setting. Following the order of Chapter 7, this section discusses the key challenges relating to

- **vertical and parallel structures in the South African TB and HIV HIS**
- **excessive reporting** (produced by those structures)
- **health governance issues**, and
- **contextual issues** (that further challenge HIS functioning)

Vertical and parallel structures in the South African TB and HIV HIS: The root cause for many of the challenges in the current TB and HIV HIS at the case study setting is that the South African health governance and delivery structures are still considerably vertical, segregated and parallel, despite the government's endeavours towards a more comprehensive approach. In that sense, this research echoes what other South African studies have also found (see, for instance, Kawonga et al., 2012). What study may be adding to the existing literature is the local stakeholders' experience about these vertical structures in the health system. The term 'silo' was picked up from interviews and it seems that this 'silo approach' applies to a variety of fields in the South African health system: occupational titles and roles, planning, care delivery, data flows and reporting systems from stationery and reporting forms to electronic HISs. By examining TB and HIV related data flows, it became clear that collection, reporting and use of this data is not limited to TB and HIV silos, but TB, HCT, ART, PMTCT, STI and RMR programme silos, of which HCT, ART and PMTCT relate directly to HIV.

Section 7.2 argued that vertical governance structures producing largely vertically delivered health care may have negative consequences for the patient, health work force or the health system. Amongst other issues, inefficiencies and

duplication of work (likely resulting in avoidable costs), missed opportunities and 'plan fatigue' referring to multiple programme specific plans, were identified. In addition, the section proposed that there is a phenomenon that can be called 'internalisation' of the 'silo approach'. It seems that sometimes a 'silo approach' can become a part of the hegemonic discourse in a way that health professionals may stop questioning why they are doing what they are doing, and that may be reflected in the way they are conducting their tasks and how they communicate them to patients. An example of unnecessary Pap smears was given in this context. The patients were not educated enough to question the causes of duplicative interventions and the researcher felt that the health professionals were more focused on completing the tasks specified within the particular programme 'to get through the day' than investing resources in finding out if something similar was done to the patient in the neighbouring room. Something becoming part of hegemonic discourse is not a new idea as such, but the effects of the 'internalisation' of the 'silo approach' on health systems and HIS in terms of care delivery, professional development, motivation or data quality could be an interesting topic for further research. Finally, a unique patient identifier in public health was mentioned as a best practice in the Western Cape, which in the future will help integration efforts and the interlinking of HISs.

A central finding of this research was that the South African health system has, through the vertical health governance and care delivery silos around health priorities, resulted in largely vertical HIS including vertical reporting silos. For instance, there is TB data, which is largely collected by the TB nurse. The nurse writes it in the TB register from where it is captured by a clerk whom the TB data responsibility is assigned to, to a TB HIS to be reported to the TB manager at the higher level. There is data use and coordination that surpasses the reporting silo limits, but basically, much of the reporting is very programme specific, and this is considered as a major challenge itself, as well as a root cause for other deficiencies:

> Researcher: *"if you had a magic wand... how would you change the current TB and HIV data collection ...and use and reporting in the Western Cape?"*
>
> Informant: *"**Have all health data on as, one system. ....Have the patient reflected on the system and not the disease.** So wherever I will go... my HIV, my TB my everything will be there.*

> *Um, and I think that is where we are wasting a lot of effort, we are wasting a lot of time and we are wasting a lot of money because we, the systems are opening up the risk of duplication of activities."* (Anonymous quote, emphasis by the researcher)

Excessive reporting: vertical and parallel silos in reporting contribute to two serious challenges that undermine the functioning of the South African TB and HIV HIS: 1. excessive reporting requirements and 2. difficulties in obtaining holistic information that is not limited to a particular health condition. Beginning with the first, at the case study setting there occurs A) a lot of reporting in general and B) more importantly, multiple reporting, referring to unnecessary replication of information in the context of TB and HIV related information flows. In general, the informants perceived the recording and reporting time-consuming and laborious. A core of the challenge is that some of the data is collected and reported many times as part of different data flows (TB, HIV, PMTCT data flow and so on) which is particularly challenging considering the high TB-HIV co-infection rate (73%)[74] in South Africa. This systemic deficiency was illustrated with an example of reporting 14 times the CD4 count of one patient (Vignette 7-4).

This study identified three kinds of potentially unnecessary reporting: replication of information across the different data flows, replication of information within the same data flow, where data is copied from one place to another as it is within a certain programme-specific silo, as well as aggregation of data within the same data flow. This was discussed in 7.3.3 and 7.3.6. While in all health systems some data is collected or reported more than once and some of the described repetition is not actually repetition per se but, for instance, digitisation of data from paper to an electronic form, the distinction between different acts of collecting and reporting of data is useful. This is because the different acts have different dynamics, root causes, consequences and ways to be improved. Moreover, it is hugely important to examine them together as an

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[74] Percentage of TB patients who are HIV positive (Department of Health, 2012a). The estimates are different depending whether one is looking the proportion of PLWHA in TB patients or the proportion of PLWHA who have TB.

entity, as this will support system-wide analysis on who is collecting or entering what, why and with what cost? Because only by considering all the different acts of collecting and reporting of data will the true burden of the M&E for the health system be uncovered, allowing for the necessary improvements to be made and the best synergies to be found.

This study identified several consequences of bulky, multiple reporting, including that it is a waste of resources, makes information fragmented and error-prone and may influence data quality. Further challenges were identified, such as much of the reporting being paper-based at the lowest levels of the health system, as well as unnecessary reporting of entire databases.

It is the facility level health professionals who are expected to do the majority of the data collection alongside the care work. Considering the estimated shortage of 80,000 health professionals in the South African public health care system (see 2.5 and 7.5.2), as well as the large number of patients requiring care for TB, HIV and other health conditions, there would definitely be room for improvement in this area. Improving efficiency of reporting in a manner that gives more time and attention for doctors, medical officers and nurses to be directed towards the actual care delivery would shorten queues, likely increase work and patient satisfaction, improve the HIS and health system functioning and ultimately, the health outcomes.

The second serious challenge produced by vertical programme-specific reporting is the difficulty in obtaining joint or holistic information beyond a particular illness. The close connection between TB and HIV makes the information needs aggravated, since each illness may advance the other and deteriorate other's health outcome, and optimal timing of interventions may require knowledge of both diseases and their medication. This can be viewed as a challenge hampering care or even jeopardising the patient safety of an individual patient. The anecdotal evidence of this study suggested that at the clinic level staff may sometimes need to leave their room to fetch the appropriate patient folder or make a phone call to obtain the information that they need. In other words, the required data is not always readily available (as discussed also in 6.2.9). Moreover, this challenge occurs at health policy and planning level. As can be seen in Vignette 7-1, additional effort is required to estimate the TB-HIV

co-infection rate at the higher level of health authority, since the data needs to be compiled from several sources. Obviously, this arrangement opens up room for errors and gaps that may be detrimental in decision-making and resource allocation.

This case study found that in addition to joint TB-HIV information, obtaining holistic information on the basis of routinely collected data could be improved on. As described in Vignette 7-2, in maternal health 'getting the big picture' is vital, similarly to many other fields of medicine. The Vignette cites a staggering figure: almost half of the maternal deaths in the Western Cape are considered preventable (APP, 2013/2014). There is an increase in maternal deaths that are not due to the direct obstetric causes but other pre-existing conditions that are aggravated by physiological effects of pregnancy. Since different management interventions might make a difference to the outcome i.e. save lives, it is crucial that those who make the clinical decisions have accurate, fit-for-purpose, timely and holistic information beyond the programme-specific silos.

The intuitive approach for addressing the challenge of fragmented silo type of health system or HIS is to bring up the subject of integration. It is not within the scope of this research to discuss functional, organisational or clinical integration beyond the information context. What can be discussed, is summarised below by an informant:

> *"...if I really had the magic wand, my answer would be that I would want to change everything. Because changing TB and HIV data within the rest of the system... is going to make the rest of the system fail more... ...I would wanna change how we do data collection in totality, from facility level. ...But for me it would not be for TB and HIV, it would be for all. ...We've really got a challenge with verticalisation, um and to have verticalisation integrated is dependent on the rest of the system being in place and coping with it. ...So that's that really.* (Informant in decision making / data use position)

The quote highlights the need for the whole system to be strengthened and changed rather than just trying to integrate TB and HIV with each other or into PHC services. Moreover, it emphasises the need for the health system to actually

be capable of adapting to the changes and improvements. Again, the discussion returns to the high disease burden, under-staffing and other factors making the current South African health system very vulnerable and complicating the development of the system. However, there are even more pressing reasons why a 'silo approach' is dominating health reporting and why it may continue to do so. These reasons are rooted in politics and funding beyond the national level:

> *"Because, what's always so amazing to me is that we are developing, and you don't quote me on this one, we are developing an ETR.Net with USAID funding and PEPFAR-funding. Developing a Tier.Net with the USAID, we're developing eKapa with the same. We're developing all of these vertical systems with funding from the same or similar sources, and it stays vertical. ...And the reason why it's staying vertical is because it's somebody's territory. ...You see, whereas, [if it was], ...one funding source, pool that source together, [we would] try to start developing an integrated system. We've got this very nice Tier.Net and the very nice ETR and the very nice eKapa and the very nice everything else. But get it to, to one system or nearer..."*
> (Anonymous quote)

While full political and economic analysis was not within the scope of this research, the statements made by an informant about the funding sources are correct. Also EDR.Web (Electronic Drug-Resistant Tuberculosis Register) is supported by U.S. PEPFAR and U.S. Centers for Disease Control and Prevention. Diaz Andrade and Urquhart (2012) have analysed politics of ICT4D (information and communication technology for development). Synthesising earlier evidence (Wade, 2004; Thompson, 2005; Escobar, 1995, 2001; Schuurman, 2003) they argue that the ICT4D projects and discourse may embody hidden political and economic agendas of Western domination, market forces capitalism or neo-liberal agenda and contribute to a dependency between economic interests in high-income countries and the developing world. Citing examples including Intel's ClassMate laptop, AMD's computer targeting the Indian market and Quanta's XO-1 subnotebook for the One-Laptop-per-Child project, the authors remind that inspecting and understanding the underlying mechanisms of the multimillion dollar ICT projects targeted at helping millions of poor people is a legitimate exercise. There are different kinds of ICT projects and each project has a different degree to which it is country led or owned. With reference to the South African health information systems, besides the previous quote, the data

of this study has only anecdotal and vague evidence on the role of funding and politics.[75] However, this study has established an understanding about vertical and segregated programme-specific reporting systems (within the TB-HIV system) and shown that this kind of system has negative implications for a variety of areas. Hence, the researcher concludes that assessing the roles of funding and politics that seem to be among the driving forces behind why the South African TB-HIV HIS is what it is should be further examined, as these areas are closely connected with sustainability of a HIS.

What in particular should be done to address the deficiencies in the current TB and HIV information system and how, remains a difficult question. As stated in the literature review, 'integration' is a multifaceted concept and it means a different thing for different theorists (Uyei et al., 2014). Moreover, it seemed that the informants of the current study hold very different views on what integration means or how it should be achieved. An informant in a position to make operational decisions discussed staff-rotation and how in an integrated system, a patient should be seen by one nurse only. A clerk's concern about integration focuses on where to find and place the co-infected patients' folders. Finally, there seemed to be varying views on which HIS is going to be used for collecting which data, and which HIS should be the one in which some of the others will be integrated. The informants suggested several options. For instance, instead of locating in its own HIS, it was suggested that MDR-TB data should be integrated in ETR.Net (or vice versa) or that this should definitely not be done (another informant's view). Further suggestions included that some TB data should or is being integrated into eKapa, which is currently used for the ART data. Adding more TB elements or TB and HIV elements or connecting HCT or ART information to PREHMIS were suggested as solutions to inefficiencies; or that ART data should or will be captured in Sinjani, and that may eventually be the most important HIS. Obviously, some of views were conflicting. It was not

[75] Since it was not the particular subject of the current research, specific questions on it were not often asked. The researcher's interpretation is that the informants did not consider the topic as directly relevant, as many of them discussed their daily hands-on tasks and focused on the report or data flow of which they were responsible for. The researcher also consulted publicly available documents, but there was not enough data for a comprehensive policy analysis.

always quite clear from the data which of these developments are being currently implemented, which were formally planned changes, and which were things that an informant thought might or should happen. However, for this research it is not hugely important to make that distinction, since it is not the purpose of this study to assess which HIS has the technical and other qualities that best support the information needs of the diverse groups of users in the Western Cape and elsewhere. The researcher also knows that the situation has already matured from the time of the research. What did become clear is that there is a lot of complexity and ambiguity, great expectations and differing needs by different stakeholders. Hence, unless managed very carefully, any integration attempt may become a long and difficult process leaving important groups of users unsatisfied with the end-result.

Health governance issues: The previous statements on integration, complexity and varying needs are very much connected with health governance issues. As discussed in section 7.4, the Cape Town Metro District is one of the health districts of the Western Cape, and it is the only district that has both a municipal health component and a provincial health component delivering PHC services. A key finding that emerged from the data was that the co-existence of two influential health authorities in the Western Cape has a complicating effect on how TB and HIV related data is collected and reported. More specifically, there are partially parallel health authority structures; subsequently some overlap in health service delivery, and this may result in negative monetary and HR consequences and confusion in roles and responsibilities. With respect to HIS functioning, it opens up risks for gaps and errors and it makes it more difficult to have a full data set on disease burden, coverage and roll-out of programmes, as well as other issues covering a specific geographical area, since the data needs to be obtained from several sources. Moreover, the existence of parallel health authorities impedes any efforts to streamline the reporting processes, which are already complicated even without multiple stakeholders operating at the same level of the system. In addition, extra efforts may be needed to ensure that accurate and appropriate versions of data sets are reported. Finally, this study argued that the presence of two health authorities may decrease data quality, particularly in terms of completeness.

The study also found challenges in other complex power-relations that can potentially affect the flow of information and the optimal functioning of the HIS. These are namely the division of duties between Information and Programme Management, particularly at the provincial level, and the relationship between the national and provincial health authority. On the positive side, the study highlighted some well functioning features of the case study setting. These include continuous communication and improvement efforts, as well as SOPs, data flow diagrams and joint data flow policies, which are a good way to facilitate that communication, as they make gaps, roles, accountability structures and the timelines more clear to all stakeholders.

Vignettes 7-5 and 7-6 provided insight on the Sinjani information system that is used in the Western Cape to report the nationally required essential data set. Other provinces use DHIS. As demonstrated in the Vignettes, the provincial health authority has found DHIS inadequate to meet provincial information needs (hence the change into Sinjani) and conversely, some other stakeholders perceive Sinjani as a provincial tool (i.e. not sufficiently responsive to local needs) and argue that DHIS was easier to use. At worst, this means that at some clinics the health staff enter the same data twice: into DHIS because that is what they are familiar with and into Sinjani because they are obliged to do so. That is a waste of scarce resources and a liability to data quality. Mingers and Willcocks (2004) cited in Kabanda (2009) argue that ICT discourse can demonstrate how power relations in the context of decision-making affect discussions on the acceptability of solutions. The researcher of the current study sees the resemblance to the case study setting. In other words, the way Sinjani and other HISs are perceived and talked about, accepted or not accepted, reveals some underlying patterns of power and authority. Particularly, the power relations between the City and Province, and the Province and the national government can be examined from this point of view. Power and authority (or resistance towards it) is exercised through the decisions to use, not to use or make others use a particular HIS. Moreover, Mingers and Willcocks (2004) maintain that ICT can be used to reinforce or transform the status quo. This can be connected to the tension over which indicators every public health facility should be collecting and reporting as part of the national data set and with which HIS, as described in

Vignette 7-6. Several informants expressed concern over the indicators that were left out by provincial decision. Some felt that they were not heard when the decisions were made. This study made an analogy to Braa et al. (2007) who describe similar issues in South Africa approximately 20 years ago with their HISP project and the National Indicator Data Set. While some challenges may no longer be present after this study is published, this issue will likely continue to be a challenge, no matter how sophisticated the tool used to report the required data. Therefore, as argued by Kabanda (2009), understanding the issue of power and authority is critical in health information systems.

Contextual challenges: in section 4.2, the socio-technical approach and the LACASA model for context analysis were discussed with regard to how they inform the researcher's approach to research methodology. LACASA model identifies (amongst other things) a *"level of analysis",* which refers to Walsham's (2000) wish for the IS researchers to *"truly cover all levels of analysis from the individual to societal"* as recited by Korpela et al. (2001). Section 7.1 on the contextual challenges in the functioning of the TB and HIV information system tried to address that wish. The study identified challenges in the availability and competence of human resources. In particular, challenges with language, numerical, literacy, data analysis and interpretation skills, computer literacy and deeper understanding of data elements hamper the functioning the TB and HIV information system. Additionally, deficiencies in physical surroundings were found. A core finding of this study, one that was reported more often than, for instance, availability of HR or challenges in the physical environment, was something that the informants referred to as 'lack of buy-in' by the personnel. Similar findings have been recorded by other studies (Wolvaardt et al., 2014; Nicol et al., 2013; Garrib et al., 2008). The current study suggests that the lack of buy-in concerns particularly the facility level, but it also occurs at the other levels of the health system. A limited buy-in towards information related responsibilities is predominant, but there also occurs lack of buy-in to policy and system developments. Bulky and multiple reporting induced by the vertical and 'silo approach' driven health system is likely to decrease one's motivation and buy-in for reporting. Many of the informants at the facility level considered delivering care as their main responsibility and viewed reporting as secondary. Busyness, stress, lack of appreciation by others and inability to see the link

between reporting and resource allocation were proposed as reasons contributing to lack of buy-in. The limited understanding of the benefits of the M&E and the consequent sub-optimal commitment to reporting duties have direct consequences for various aspects of data quality. Interestingly, there were also expressions of pride and passion about one's work, in particular at the facility level. A relatively strong leadership was suggested as a positive aspect of the Western Cape health system, and that may contribute to this finding. Finally, it was argued that the environment that the people live and work in every day does not support the full use of one's capacities, and therefore hampers all aspects of health system functioning, including the functioning of the HIS. This key finding would not have been found if this study had applied a very narrow or technical approach instead of a holistic approach. The LACASA and Daisy models that informed the researcher's thinking about a holistic approach were introduced in Chapter 4. Below, Table 9-3 compares two options (A and B) to investigate HIS functioning.

Table 9-3. Approaches to examine HIS functioning in a less holistic and a holistic approach.

Object of interest	Less holistic approach	Holistic approach
HIS functioning	Option A = Investigation according to, for instance, the framework by Ledikwe et al., 2014 about: M&E structures, functions and capabilities; indicator definitions and reporting guidelines; data collection and reporting forms and tools; data management processes; and links with the national reporting system.	Option B = A bottom up approach covering the key aspects of Option A but also exploring further contextual issues in order to achieve even deeper understanding of the research topic and to identify also the unexpected issues. LACASA and DAISY models may be helpful.

To clarify, Ledikwe et al. (2014) assessed the data management and reporting systems of a HIS in Botswana with particular focus areas, as detailed in option A. This is by no means a poor way to examine HIS functioning and it is much more holistic than some other evaluation frameworks. However, as stated in 6.1, the researcher of the current study realised that this was not the most appropriate way to conduct her research, although there was some overlap. Hence, she has aimed to conduct the study in a manner described in option B.

This can be elaborated further. The LACASA model for context analysis and particularly the DAISY approach for a holistic IS development aim at *"understanding the contexts of healthcare providers"* and *"understanding the needs arising from the everyday life activities of healthcare "consumers" in communities".* At the case study setting the health HR recruitment is done locally to a large extent in order to overcome the language barrier. Therefore, the context and the needs arising from the everyday life activities of the healthcare consumers (patients) are essentially the same as those of the providers. Section 7.5.6 described the circumstances where people live and work every day at the case study setting, illustrating how people often struggle in their personal lives. Moreover, it made a link between the personal circumstances (challenges of living and working in under-privileged and even dangerous settings) and how it may reflect into work through compassion fatigue and decreased buy-in, and how that can result in sub-optimal data quality and HIS functioning. Reflecting on the various challenges, it raised the question if it is even realistic to expect that people would show high motivation (and precision) towards ticking the various sheets and registers or demonstrate great commitment to data quality. Mushi and Maharaj (2013) have recommended that any successful HIS development and implementation requires a detailed account of various contextual factors and challenges that have been identified and accentuated by researchers and practitioners. Therefore, the kind of analysis conducted here with attempts to uncover key challenges that may seemingly be far away from HIS functioning, is needed; ignoring it would result in a failure to reap the expected benefits of HIS development and understand why it happened.

9.3.4 Utilisation of data in the South African TB and HIV information system

The third part of the findings concern the utilisation of data in the South African TB and HIV information system, as reported in Chapter 8. By utilisation, this study means the use of data for meaningful purposes, including feedback as defined in section 8.1. As reviewed for this study, the research on routine health information systems in low and middle-income countries has suggested that data is not always used effectively for decision-making. Previous HIS assessments have identified limited data use also in South Africa (Garrib et al., 2008; Shaw; 2005) with a universal *"culture of reporting"* instead of a *"culture of using"* the data (Byskov and Ohlson, 2005). Against this backdrop, the current study found opposing evidence in that much of the data is actually used in an appropriate way for various meaningful purposes including planning, interventions, allocating resources, improving services, justifying HR requests, as well as addressing gaps and training needs. The current study also argued that the various actors in the health system at the Western Cape are possibly utilising data to a greater degree than their colleagues elsewhere in South Africa and that there were individuals at the case study setting who were particularly keen to use data in operational decision-making. This case study also highlighted the role of data use in target setting, monitoring and accountability. The performance targets of various public health units were determined with data and the performance against these targets was monitored with the routine data. Accountability for results was a central aspect of the system, and underscored the value of accurate data. This system may be recommended as good practice, but there may be other better ways to achieve adequate HIS performance and sufficient data quality without the entrenched accountability and rigid hierarchy structures.

With regard to feedback, which was viewed as a way to use data, the evidence was mixed. The majority of informants felt that they receive and are able to give a meaningful amount and kind of feedback. Feedback concerned both performance and data quality. The researchers interpretation is that feedback has significantly improved from earlier times, which have been portrayed, for instance, by Garrib et al. (2008). It seems that more attention is paid to how the key messages are fed back. The challenges identified in the

feedback process included that the national level could be more formal, consistent and simultaneously more personal and better targeted in their feedback to the provincial level. Moreover, there were indications in the data of 'feedback silos' around priority diseases at the case study setting. This is likely another result of a vertical and segregated TB and HIV HIS of South Africa and can be seen as a barrier to a well functioning feedback system. A further challenge in the feedback system is that while feedback is given to the facility level, it may not reach the actual people responsible for collecting the data that the feedback is based on. A positive lesson, which can be easily replicated elsewhere, is contextualising the achievements and indeed publicly thanking the health work force for the job well done. In the case study setting, it was done in a public way with silver cups and certificates. The rewarding could be different in different contexts, but the act of publicly acknowledging and appreciating achievements is an extremely simple and cost-effective way to increase the buy-in and commitment of the health work force.

However, a further issue relating to data use deserves attention. It also illustrates how different areas of challenges examined in this study are thoroughly interrelated. Previously, the lack of buy-in was discussed. As stated, the limited buy-in also concerns the commitment to the development efforts (not only data related tasks). The next quote reveals how data that is collected, and that is rather successfully used in planning and decision-making (as argued before), does not necessarily lead to positive changes at the facility level:

> *"The buy-in from the ground and the mentorship and the supervision to bring the plans that are made using information, the data collected, into implementation. That's the frustration. So we will go quarter after quarter, year after year with little or no progress. ...In the number of areas, just because we never did those things that we said we would."* (Informant in decision making / data use position)

In other words, there is a source of data, the facility level, where health care professionals collect much of it alongside the care delivery. The data is reported in various ways (as elaborated throughout this study) to people in decision-making positions who utilise this data by making choices and plans to address the deficiencies. However, there is a gap - or a barrier - that prevents the plans becoming tangible actions on the ground, and therefore the benefits of the

collected, reported and used data will not be fully reaped. Unfortunately, it is the facility and the community level that will miss out the most. In other words, the people who collected the data and patients who were the source of the data may not benefit from it due to the gap or barrier impeding the implementation and follow-through of the improvement proposals. Based on the research data, the gap or the barrier consists of a number of issues discussed in this study: the shortage and turnover of staff and their varied competence levels amongst the other contextual issues hampering the functioning of HIS; the hazardous work environment (as exemplified with the shooting of a doctor in Vignette 2-1) and the struggles in the personal lives of health workforce that contribute to the compassion-fatigue and lack of interest and buy-in; the vertical health system structures that produce, not only a multitude of reporting duties but also a number of programme-specific plans and development proposals; further complications by parallel health authorities that make some of the work more complex than it would otherwise be; variation in data quality that at worst might make a person second-guess whether it is truly useful and worth collecting (such as in Vignette 6-1).

In conclusion, while a less holistic approach (as in option A in Table 9-4) is a good way to examine data utilisation of a HIS, option B may be more fruitful.

Table 9-4. Approaches to examine data utilisation in a less holistic and a holistic approach

Object of interest	Less holistic approach	Holistic approach
Data utilisation of a HIS including feedback	Option A = Identification of deficiencies in data use and feedback loop. Investigating, if possible, to what extent the collected data features in the policy decisions.	Option B = Conducting option A, but also attempting to uncover what is the connection between the collected data and the *actual outcomes.*

To be specific, this study did not fully follow either option. This is because a thorough investigation on data utilisation in decision-making is rather difficult

and it would ideally require observing several policy meetings. What was done in the study is the first part of option A i.e. it identified at a general level how data was used in target setting and performance monitoring and pinpointed some deficiencies in data use and feedback loop. However, it also touched on option B by identifying the gap between the collected/seemingly 'used' data and the implementation/outcomes. Hence, this valuable finding stemming from the analysis is a decent starting point for further research. In section 8.1 the utilisation of data was defined as *"use of data for meaningful purposes".* It should be noted that if the definition was something different, such as 'use of data in a manner that results in positive changes' the findings of the study, (as well as the whole study) might be somewhat different.

9.3.5 Holistic and less holistic approaches to a HIS

Previous sections have introduced tables where a less holistic and holistic approach to examining a HIS are compared. The comparison is based on the analysis of the findings of this study. The final table (9-5) combines these tables together, but the focus is at a more general level than research methodology. The terms 'holistic' and particularly 'less holistic' are not quite as specific as the researcher would like. The academic literature on 'holistic' information systems or approaches is varied and rather vague about what is the term for a system or approach that is not holistic. 'Technologically oriented' or 'fragmented' IS development methods have been proposed as currently existing less holistic approaches (Korpela et al., 2013). Neumann (2006) compares holistic and 'nonholistic' approaches in energy, agriculture and health care. Since none of these terms is completely apt, the term used here is 'less holistic'.

Table 9-5. Approaches to examining a HIS in a less holistic and a holistic approach.

Object of interest	Less holistic approach	Holistic approach
How a HIS is viewed	An M&E system, single-programme reporting system or something similar, where the focus is on what the system needs.	A socio-technical HIS, where the focus is on what the people need
How data quality in a HIS is viewed	Consistency of agreed technical dimension of data quality between data items or something similar.	Data quality is understood widely, including perceived data quality.
How HIS functioning is viewed	HIS functioning is considered to include various features, such as M&E structures, functions and capabilities; indicator definitions and reporting guidelines; data collection and reporting forms and tools; data management processes; and links with the national reporting system, amongst other. These can be identified, examined and improved.	Besides the features on the left, a socio-technical HIS functioning is considered to include a wide range of contextual issues, which can also be unexpected. They can be identified, examined and improved. This is likely to require a bottom up approach that wants to understand, not just 'fix' issues.
How data utilisation of a HIS is viewed	Data use for meaningful purposes, including feedback.	Data use for meaningful purposes, including feedback and the connection between the collected data and the *actual outcomes.*

Three arguments can be made. First, this is a crude division, and a single study or a single health policy action is not probably fully holistic or fully less holistic.

Second, it may be that some South African health policy makers, who are in the end responsible for the South African TB and HIV information system, perceive it in the less holistic way. The less holistic way is also present in some of the academic literature about the topic. With regard to research, it does not make it any less acceptable: the less holistic research approach just produces a different kind of research outcomes. Third, the current research is an attempt to look at the South African TB and HIV information system more holistically. It can be argued that this approach has resulted in a human-centred study with rich, multifaceted data and a research output that provides new insight on the topic.

9.4 GENERALISABILITY OF THE FINDINGS

If the findings do not produce new knowledge that can be meaningfully used, the research cannot be said to have added value. In considering the potential for the generalisability of the findings beyond the case study setting, it should be noted that a case study does not need to be based on a positivist premise and the findings do not have to be statistically generalisable over time or to different populations, nor aim at theory-building, as discussed in Chapter 4. Following the idea by Keutel and Mellis (2011), the researcher is more interested in generalisation within a single setting instead of generalising a theory across different settings. By generalisation within a single setting, the researcher means that the researcher has attempted to *"derive meaningful explanations"* (Keutel and Mellis, 2011) *within* the case study context. This is what this research has aimed to do: increase understanding of a variety of issues around the TB and HIV information system in an underprivileged setting. This is also close to what Thomas calls exemplary knowledge (2011), as discussed in Chapter 4. According to him, the articulation and interpretation of the exemplary knowledge rests in the phronesis of the researcher and its understanding in the phronesis of the reader. Therefore, while the context of the case study is specific, it does not mean that there is nothing that can be learnt from it. Contrariwise, exemplary knowledge can be widely applied but it is the reader's responsibility to decide what to pick from those 'meaningful explanations' and how to apply them in different settings beyond Khayelitsha.

Nevertheless, suggestions can be offered. First, returning to the point made in the introduction of this chapter, not many developed countries can say that in their health system reliable, timely and fit-for-purpose information is always available for all the key stakeholders at every level of the health system and that information is translated into evidence-based decision-making producing improved health outcomes. In many health systems, resources may also be wasted in the process. In that respect, the *ethos* of this thesis is applicable almost everywhere, albeit that the lessons need to be interpreted according to context. At a more specific level, Kawonga et al. (2013) examined administrative integration of vertical HIV M&E into the South African health system. They conclude that their case study findings, such as using data in silos, are unlikely to be unique to the HIV programme. Similarly to Kawonga et al. the researcher anticipates broader relevance of her findings for other disease-specific programmes in South Africa and possibly in other countries where health care delivery is organised around priority health conditions. In line with what Kawonga et al. suspect about their findings the researcher believes that programmes which are managed by parallel bureaucracies, and in particular those with dedicated M&E systems may find the messages of this study relevant.

Finally, many of the challenges relating to this area are magnified in under-developed settings but they can be found in developed countries as well. The Literature Review (section 3.3) provided examples of various HIS related challenges in highly developed health systems, showing that fragmentation and HIS issues are by no means limited to low- and middle-income countries. One of the countries mentioned was Finland. The final Vignette (in Appendix E) returns to this topic by reflecting the findings of the current study to the researcher's personal work experience in the Finnish health system thereby showing that many phenomena found in extremely under-privileged and particular setting can be used in understanding and describing experiences in more general contexts across a wide range of different settings.

9.5 LIMITATIONS AND SUGGESTIONS FOR FURTHER STUDY

Despite the interesting findings recorded by this research, there are limitations in the significance of the work. These issues are addressed in this section, in the context of proposals for further work, which could arise from this study.

- Health systems and HISs are highly complex. It is not possible that a single study addresses all the aspects of the context. The researcher made a choice to cover a multitude of relevant versatile issues, even at the expense of some of them receiving only a little attention. In other words, due to the limited scope of a PhD study, the researcher could only briefly discuss several topics that influence the TB and HIV information system. This can be seen as a limitation. Consequently, some of them could be worthwhile topics on their own for further research.

- The researcher made a choice not to rely on any particular theoretical framework and apply that to her data. It can be argued that this is a limitation, but the researcher views it as a methodological choice. This allows a data-driven approach that supports finding issues that may not have been expected when entering the research setting. However, identifying relevant theories and applying them to the object of the research might be a fruitful way to obtain further knowledge on the topic.

- It may be argued that a relatively small number (28) of people were interviewed. This introduces the possibility that a specific idea by a particularly vocal and opinionated person or group of persons may be emphasised in the data or in the research output in a way that somebody else would argue to be unreflective of the 'reality'. This was discussed particularly in Chapter 8. However, rather than a limitation as such, this is the nature of non-positivist single-case studies. The same applies to the possible effects of the research permit authorities' contribution to the selection of the case study setting, as stated in 8.2 and 4.4.6. However, in qualitative case research, it is possible to conduct a case study even about one person (i.e. the person is the 'case'). Moreover, the researcher had an abundance of data (almost 160,000 words of interview data amongst the other data) which allows all kinds of voices to be heard, she did

acknowledge the above-mentioned facts as something to take into consideration, she assessed the findings through this lens and triangulated data to make her arguments. While the researcher is happy with the nuanced and detailed data that a case study approach can produce, it might be a worthwhile idea for the further research to validate some of the key findings by using another methodology, such as a survey.

- Linking to the previous, the researcher followed only one clinic, and that was a City managed public health facility. This may be seen as a limitation and certainly it can be argued that the findings would have been different if the facility were a provincially run clinic in Cape Town, a rural clinic in the Western Cape or a clinic in one of the least affluent provinces. The researcher willingly admits that the data flows and some of the findings would differ from those of the case study setting but as discussed with reference to generalisability, this is not a challenge as such. Having said that, further studies comparing different types of facilities could provide valuable insights.

- A further limitation to take into account is that some of the informants spoke Xhosa or Afrikaans as their first language, and English is not the first language of the researcher either. A possibility for misunderstanding cannot be ruled out. Considering all the acronyms and technical and medical phrases as well as sometimes very busy interview settings, it is actually remarkable how few gaps there are in the written transcripts. The researcher also sent the transcripts to those informants who wished to receive them, which was the majority of them. This means that the informants could have pointed out any areas where they felt that they had been misunderstood.

- A power relation between the researcher and the informants that may be perceived as unequal, particularly at the facility level, may be seen as a potential limitation. However, the attempts (described in 4.4.7) by the researcher to show respect and find common ground seemed to be appreciated. The researcher also takes the fact of actually gaining the

access and obtaining the almost 160,000 words of interview data as an indication that the majority of the informants could overcome any perceived barriers and feel comfortable enough to fully participate into the interview situation.

- Chapter 5 described the various data flows originating from the case study clinic and including TB or HIV data. There are possibly minor errors and gaps in them, which can be seen as a limitation. With regard to certain data flows, there are actually provincial and City authorities operating at the same level in the health system. However, due to the limited scope of this research, the researcher could not invest too much time in trying to identify them and a decision was made to focus on the main stakeholders. Moreover, the researcher was not granted interviews at the provincial Information Management, which also contributes to a degree of uncertainty in data flow depictions. However, the descriptions can be considered illustrative of how the data flows in a Cape Town administered public health clinic in the Western Cape and, since after a certain point there occurred no new themes in the interviews; the researcher believes that the saturation point was reached. In other words, while the data flow descriptions could have become slightly more specific, an inclusion of one or two more informants would not necessarily add much to the overall analysis of the data. Naturally, all the data flow descriptions provided here concern the time of the data collection (2012). A further study that would describe in detail the data flows beginning from the actual clinical encounter and possibly cover also the national level would be a valuable addition.

- The data collection period was relatively short due to visa and research permit related reasons. Nevertheless, the researcher was able to use the time efficiently, as well as incorporate what was learnt from the pre-research period that she spent in the area. Ideally, the researcher would have wanted to return to the case study setting to A) validate the findings and B) address the findings on the key challenges by seeking suggestions for solutions from the local stakeholders. For financial and personal reasons, this was not possible. A suggestion for further research could be

conducting a collaborative action research based study focusing on addressing HIS challenges with local stakeholders and possibly evaluating the impact of the improvements.

9.6 CONTRIBUTION OF THE STUDY

This research has made a theoretical contribution to HIS research in an LMIC setting. It also has relevance to practice. Specifically, the study improves understanding in the following areas:

TB or HIV related information systems: In the literature review, it was mentioned that a comprehensive evaluation of the experience with an electronic tuberculosis surveillance system in a low-income country has been published very rarely (Hoa et al., 2012). This study contributes by offering insight on the South African TB information system and showing how TB related data is also collected and reported outside of what is considered the TB system. Due to its holistic approach this study complements nicely what has been found out about the South African TB system already by other researchers, namely Heidebrecht et al. (2011) and Heunis et al. (2011). ETR.Net and similar TB monitoring systems have been implemented elsewhere in LMICs. Therefore, the successes and pitfalls identified in this case study may be interesting to those who want to evaluate TB information systems elsewhere. HIV information systems have been described slightly more often in the literature, for instance by Ledikwe et al., (2014) in Botswana. However, besides the work of Kawonga et al. (2012) qualitative assessment like this has not been conducted in South Africa and hence this study contributes towards the body of literature about HIV data flows and HIS in South Africa and LMICs.

THE ENTITY: A characteristic that sets this research apart from previous published studies on South African or LMIC's health information systems and M&E landscape, and one of the key contributions of this study is that it attempts to look at the all the data flows in one thematic area (TB and HIV related). Studies from different viewpoints of particular TB or HIV related information systems have been published in the developing country context before (Ledikwe et al., 2014; Amoroso et al., 2010; Hedt-Gauthier et al., 2012; Saeed et al.,

2013 to name but a few). A number of studies have examined one programme specific HIS in South Africa (including Heidebrecht et al., 2011; Osler et al., 2014, Kawonga et al., 2013; 2012) or the District Health Information System (DHIS) (Braa et al., 2007; Jacucci et al., 2006; Shaw, 2005) or data related to a specific health programme (for instance Mphatswe et al., 2012). In addition, Auld et al. (2013) and Heunis et al. (2011) look at certain aspects of TB and HIV information systems together. However, to the researcher's knowledge, precisely the kind of approach that has been applied in the current thesis has not been taken before. While this approach comes with certain challenges, it is a novel way to disclose in detail the health system barriers regarding the multiple data collection and reporting activities that have been built around priority diseases. In other words, a central contribution of this study has been about making more explicit how each area is connected to others and how health system strengthening, including HIS strengthening, requires examining the HIS as an entity.

VERTICAL PROGRAMME-SPECIFIC HIS AND INTEGRATION: Vertical structures in health governance and care delivery have been examined by certain authors in South Africa and elsewhere. However, how these structures contribute to the health *information* system has received less attention. This study contributes by offering a rather detailed analysis on the issue. Kawonga et al. (2013), citing Unger (2008) note that in the absence of conclusive evidence on the most effective integration models (Atun et al., 2010b), countries are advised to adopt context-specific arrangements that help optimise health system benefits. The findings of this study may be helpful, not that this study seeks to dictate how to conduct the integration of TB and HIV in to primary care or how to change the whole system, but making more explicit the various HIS related issues that may have to be taken into consideration when integrating services.

DATA QUALITY: Data quality related studies have been conducted every now and then in LMIC contexts, as reviewed by Ndabarora et al. (2014). Often, they measure the actual data quality by comparing two or more sources of data to calculate completeness rates, to see concordance and so on. This study contributes by investigating *perceived* data quality by the health workers and decision-makers within the health system. While this approach comes with certain limitations, it is also an interesting addition to the field of data quality

research. As argued in 9.3.2, is it not the *perceived* data quality which has an influence on whether the users decide to utilise or not to utilise the data?

DATA UTILISATION: Health data, including TB and HIV data, can be useful for various purposes including health service delivery, decision-making, evaluating existing programmes and in planning new ones. However, it may be under-utilised, particularly in the LMIC context. This study adds to the growing literature in HIS data utilisation in underprivileged settings. Moreover, it offers an important reminder by emphasising the connection between data utilisation and actual impacts.

HOLISTIC, CONTEXT EMBRACING APPROACH: The findings of this study reinforce the importance of socio-technical approaches to the development of HISs, although the 'socio' piece in the context of the current study is broader than which may be normally considered. It has been argued that many ICT4D projects fail because they are too technology-centred (Porter et al., 2012). An analogy may be made to allopathic medicine often treating only the symptoms, whereas holistic healthcare seeks to treat the mind and body as a whole in the context of the settings in which the individuals live (Neumann, 2006). This study takes a step towards the more holistic approach in HIS analysis, as detailed in Table 9-5. This approach can be proposed as a practical contribution, since it may be relevant to those who wish to examine, develop, improve or implement HISs, particularly in LMIC context.

9.7 CONCLUSIONS AND FINAL THOUGHTS

To conclude this study, some final thoughts are presented. Prior to the data collection the researcher was concerned that an attempt to examine vertical health governance structures and the consequent vertical reporting flows would be a bit of 'yesterday's news', particularly, since the debate about the benefits of vertical vs. horizontal approach towards health improvement had persisted at least since the 1960s. In addition, academic literature has already identified some of the negative consequences of the vertical approach in terms of M&E and reporting. Furthermore, the South African government had already conducted

some policy actions towards more integrated healthcare and it had announced that there was more to come. Maybe there would not be much new to find or to improve?

However, this concern turned out to be unwarranted. Approximately two decades ago, in the advent of post-apartheid South Africa, Braa and colleagues began the HISP project in the Western Cape and elsewhere (as discussed in sections 5.7, 7.3.5 and 7.4.4). As a legacy of the health system that had been organised to provide health services separately to the different racial groups, the health information reporting systems *"were equally fragmented and incompatible"* (Braa et al., 2007). To put it another way, much of reporting took place in race-related disconnected silos, and Braa and colleagues wanted to address that challenge. Now, approximately 20 years later, this study shows that the vertical and parallel health governance structures and consequent programme-specific health information silos are very much today's challenge at the case study setting, in South Africa and most likely, in many other countries, too. While the silos are not connected to the different racial groups, in South Africa, this kind of vertical single-programme reporting has contributed to various challenges in data quality in HIS, the overall functioning of the HIS and the utilisation of the data produced by the HIS. Yet, with a vast number of patients requiring care, it is crucial that resources would not be wasted because of a dysfunctional HIS.

How to address this group of interconnected HIS challenges? South Africa, amongst many other countries and health systems, has been trying a certain kind of top-down approach for a very long time. A need for change has been recognised. The right column of the previous table (9-5) may provide suggestions on how to approach this change. A holistic, bottom-up approach that begins with needs of the patients may be a valid starting point for a better health policy-making and HIS development. Otherwise, the challenges identified here and partly already 20 years ago may be tomorrow's news as well.

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Appendix A: An analysis on a global health paradigm shift

An analysis on a global health paradigm shift towards inter-linking, harmonisation and greater collaboration in global guidelines on TB and HIV related M&E.

	Name, author and year of publication	Excerpt of the publication content
1	**Electronic Recording and Reporting for Tuberculosis Care and Control** World Health Organization (2012a).	"Integrate systems whenever feasible making sure that the benefits of doing so are clearly defined"
2	**The Global Plan To Stop TB 2011–2015** World Health Organization (2011a).	"Scale up implementation of interlinked patient monitoring systems for TB/HIV"
3	**WHO policy on collaborative TB/HIV activities: Guidelines for national programmes and other stakeholders** World Health Organization (2012b)	"1. HIV programme and TB-control programmes should establish harmonized indicators and standard reporting and recording templates to collect data for monitoring and evaluation of collaborative TB/ HIV activities. 2. Organizations implementing collaborative TB/HIV activities should embrace harmonized indicators and establish a reporting mechanism to ensure that their data are captured by the national monitoring and evaluation system of the country. 3. The WHO guide to monitoring and evaluation of collaborative TB/HIV activities and the three interlinked patient monitoring systems for HIV care/ART, MCH/PMTCT and TB/HIV should be used as a basis to standardize country-specific monitoring and evaluation activities."
4	**A Guide to Monitoring and Evaluation for Collaborative TB/HIV activities**	"These indicators have been developed in collaboration with the 2008 PEPFAR revision process of TB/HIV indicators and are also incorporated into the latest

	Stop TB Department and Department of HIV/AIDS, World Health Organization (WHO), United States President's Emergency Plan for Aids Relief (PEPFAR) The Joint United Nations Programme on HIV/AIDS (UNAIDS) (WHO, 2009)	monitoring and evaluation tool kit (2009 version) produced by the Global Fund to Fight AIDS, Tuberculosis and Malaria (GFATM)."
5	**HIV Programme: Achieving Our Goals. Operational Plan 2014–2015** World Health Organization (2014f)	"In recent years, WHO and its partners have published a wide range of guidelines, tools and indicators for the generation of strategic information for the health sector response to HIV. A major priority for this biennium will be to update, consolidate and simplify all existing M&E guidance on strategic information for the health sector response to HIV, including understanding needs, tracking inputs, measuring treatment and prevention services, and documenting impact."
6	**Indicator Standards: Operational Guidelines for Selecting Indicators for the HIV Response** The Joint United Nations Programme on HIV/AIDS (UNAIDS, 2010)	"...the UNAIDS MERG launched an initiative to harmonise, improve the quality and reduce the quantity of indicators recommended for assessing responses to HIV and AIDS. The main aim of this initiative is to ensure that indicators provide decision-makers and key stakeholders at national and sub-national levels with useful, feasible and relevant information to help them manage and implement their country's response to the epidemic effectively. Indicator selection is not an end in itself. Rather, indicators need to be selected which will clearly demonstrate if desired results have been achieved."
7	**Three interlinked patient monitoring systems for HIV care/ART, MCH/PMTCT and TB/HIV: standardized minimum data set and illustrative tools** World Health Organization with the Joint United Nations Programme on HIV/AIDS (UNAIDS), UNICEF, and The Global Fund, (WHO, 2012c).	Supports "integrated service provision, follow up of mother-infant pair and monitoring of key TB-related and paediatric variables. The MCH minimum data set includes all routine core maternal and infant variables plus key HIV-related variables. The generic ART cohort report has been simplified and the cross-sectional quarterly report is now integrated to collect not only HIV indicators, but also key PMTCT, MCH and TB/HIV indicators."

Appendix B: Informed Consent Form

LEAD RESEARCHER: Annariina Koivu

BACKGROUND OF RESEARCH: Health is an information-intensive area, generating huge volumes of data every day. Doctors, nurses, and other health professionals spend a lot of time handling, collecting, storing or looking for information in order to make the best care decisions. Additionally, data is collected on a regular basis on district and national level for monitoring of diseases, planning of services and policy making. **This research looks at the TB & HIV information collection and reporting system in Western Cape.**

PROCEDURES OF THIS STUDY: It is entirely **voluntary** for you to take part in the study. During the study, the researcher will interview you individually or in a group to better understand the TB & HIV information collection and reporting system at the chosen clinic(s) and on the local / district / national level. Some of the information she receives from you may be modeled as a picture or map of information flows. Some of you may be asked to participate in a second interview to comment on the map. Being interviewed once does not obligate you to take part in any later interviews or in commenting on the map. Additionally to the interviews, the researcher learns about the situation by observing the collection, use and reporting of information, as well as analysing documents that you or other participants may have given her. The interviews will be recorded and transcribed (written on the paper afterwards). You will be able to get a paper copy of your transcribed interview by ticking a box in this form if you want to.

The study is not interested in patient data itself but its collection, use and reporting. The researcher is not interested in and will not ask about your HIV or TB status.

Participating in the research does not pose any physical or psychological stress to the participants to researcher's knowledge.

PUBLICATION: The research forms part of the Lead Researcher's PhD at Trinity College. The researcher aims to share the knowledge that the research will produce. This means that she will, in addition to the Dissertation, try to publish one or more article(s), report(s) or other documents about the results in international and/or local scientific publications or give presentations in appropriate events and/or seminars. Every effort will be made to protect your confidentiality. **Your name or the name of the clinic will NOT be revealed in any case**, however, the name of the area (Khayelitsha) may be revealed. Sometimes the researcher may want to highlight an issue with a quote. The quotes will be reported anonymously or under pseudonym concerning your profession (for example Nurse X, Doctor X). Similarly, we wish you not to mention anybody (co-workers, patients, etc) by name. Such replies will be also anonymised. Finally, if your profession is such that it may reveal your identity (for example Senior Official from Western Cape Department of Health) you may request an option where I send you the quote I wish to use by email and you will approve or disapprove it.

DECLARATION:

- I am 18 years or older and am competent to provide consent.
- I have read, or had read to me, a document providing information about this research and this consent form. I have had the opportunity to ask questions and all my questions have been answered to my satisfaction and understand the description of the research that is being provided to me.
- I agree that my data is used for scientific purposes and I have no objection that my data is published in scientific publications in the way described above.
- I understand that if I make illicit (illegal) activities known, these will be reported to appropriate authorities.
- I understand that I may opt out of being recorded or stop or pause electronic recordings at any time,

and that I may at any time, even after my participation have such recordings destroyed (except in situations such as above).

- I understand that, subject to the constraints above, no recordings will be replayed in any public forum or made available to any audience other than the current researchers / research team.
- I freely and voluntarily agree to be part of this research study, though without prejudice to my legal and ethical rights. I understand that I may refuse to answer any question and that I may withdraw at any time without penalty.
- I understand that my participation is anonymous in the way described before and that no personal details such as my name me will be reported.
- If the research involves viewing materials via a computer monitor I understand that if I or anyone in my family has a history of epilepsy then I am proceeding at my own risk.
- I give my consent to be observed.
- I have received a copy of this agreement.

PLEASE FILL:	**YES**	**NO**
• I wish to have a copy of my interview	□	□

Where will the copy be sent: _____

_____

PARTICIPANT'S NAME:

PARTICIPANT'S SIGNATURE:

DATE:

Statement of investigator's responsibility: I have explained the nature and purpose of this research study, the procedures to be undertaken and any risks that may be involved. I have offered to answer any questions and fully answered such questions. I believe that the participant understands my explanation and has freely given informed consent.

RESEARCHERS CONTACT DETAILS:

Ms. Annariina Koivu

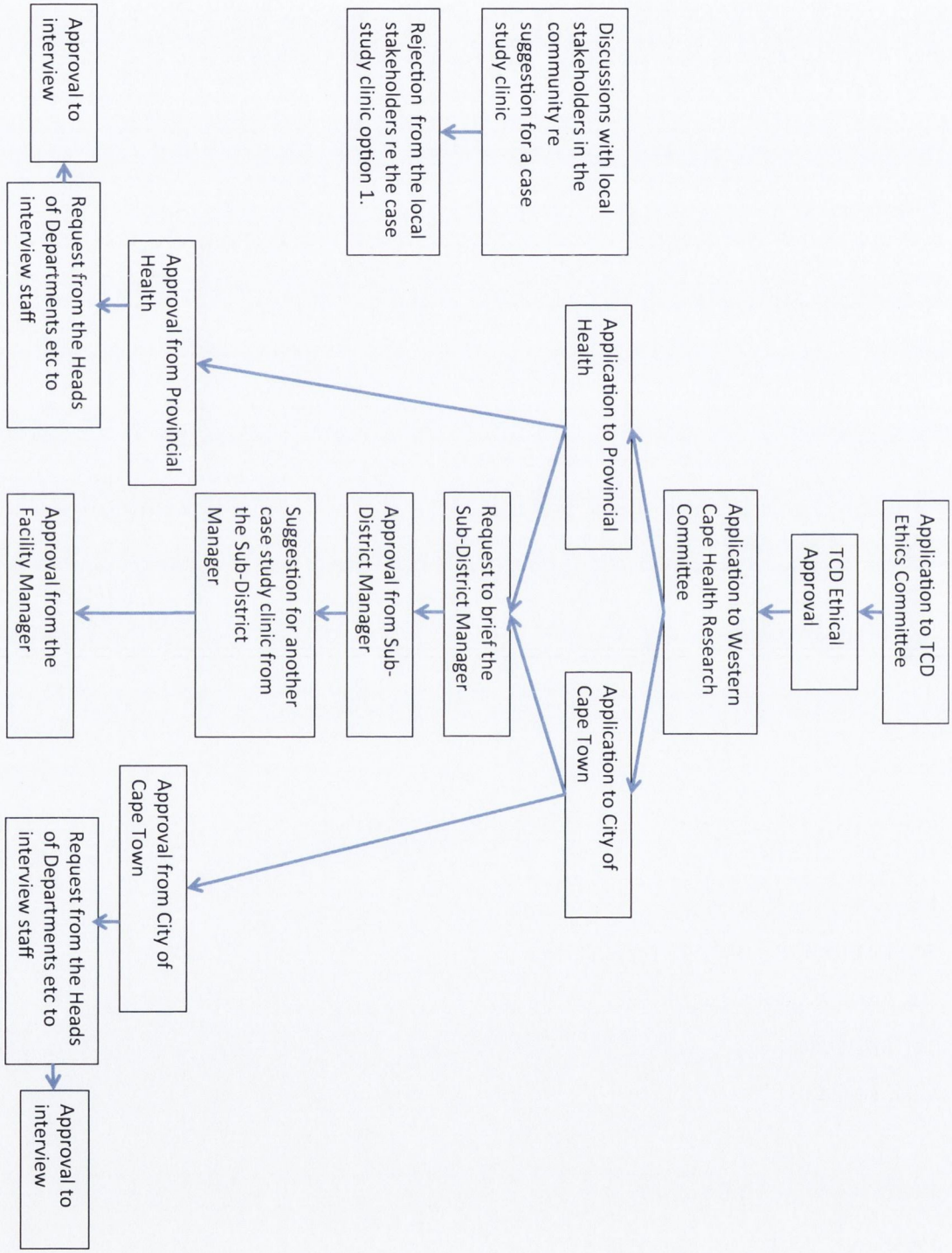
Tel: 0761563433

koivua@tcd.ie

INVESTIGATOR'S SIGNATURE:

DATE:

Appendix C: Approval Process



Appendix D: Collected Documents

During the study, the following documents were identified and obtained for the further analysis. They are listed here under A) Tuberculosis TB, B) HIV-AIDS, C) PMTCT D) Routine Monthly Reporting, E) Policy Documents, F) Data Flow descriptions, and G) Other.

A. Tuberculosis (TB)

- ETR.Net, (n.d.): *Tab: 'General'.* Registration details, Personal data, TB Diagnosis. (Screen capture, paper)
- ETR.Net, (n.d.): *Tab: 'Sputum'.* Sputum microscopy, Sputum culture and Susceptibility. (Screen capture, paper)
- ETR.Net, (n.d.): *Tab: 'Outcome'.* Outcome of Treatment Data. (Screen capture, paper)
- ETR.Net (n.d.): *Tab: 'Other'.* HIV Test. (Screen capture, paper)
- ETR.Net (n.d.): *Tab: 'Summary'*. (Screen capture, paper)
- Department of Health (National DoH), (n.d.). *Tuberculosis Register* "The pink A3 sheet" (Paper)
- Department of Health (National DoH), (n.d.). *Tuberculosis Register* "The yellow A3 sheet". (Paper)
- Department of Health (National DoH), (n.d.). *Tuberculosis Register* "The green A3 sheet". (Paper)
- Department of Health (National DoH), (n.d.). *Tuberculosis Register* "The white A3 sheet". (Paper)
- Department of Health (Western Cape DoH) (2011). *Western Cape Tuberculosis Programme, Case Finding Report. Report on New and Re-treatment Cases of Tuberculosis*. (Webarchive)
- Department of Health (Western Cape DoH) (2011). *Western Cape Tuberculosis Programme, Sputum Conversion Report. Report on Response to Initial Phase Tuberculosis Treatment*. (Webarchive)
- Department of Health (Western Cape DoH) (2011). *Western Cape Tuberculosis Programme, TB/HIV Collaborative Activities Report*. (Webarchive)

- Department of Health (Western Cape DoH) (2011). *Western Cape Tuberculosis Programme, Treatment Outcome Report. Report on the Outcome of Tuberculosis Treatment.* (Webarchive)

B. HIV-AIDS

- *Quarterly ART reporting form* (n.d.). (Pdf, from internet)
- *Quarterly ART reporting form* (n.d.). (Paper)
- Department of Health (Western Cape DoH) (n.d.). *Western Cape Monthly Validation Tool*. (Paper)
- *Monthly HIV Counselling and Testing Facility Report* (n.d.). "Yellow A3" (Paper)
- *HIV Counselling and Testing Client Records* (n.d.). "White A3" (Paper)
- *Antenatal HIV Counselling and Testing Client Records* (n.d.). "White A3" (Paper)
- Hennessey, C. and Hurter, T. (n.d.). *Tier.Net. HIV Electronic Register.* (Powerpoint)

C. PMTCT

- PMTCT Programme 0-18 Months baby register. (n.d.). (Paper)
- PMTCT register "Stats". (n.d.). (Paper)

D. Routine Monthly Reporting

- Department of Health (Western Cape DoH) (n.d.). *Routine Monthly Recording Sheet.* (Paper scanned as pdf)
- Department of Health (National DoH) (2012). *Facility Headcount Tick Register.* (Available on-line)
- Department of Health (National DoH) (2012). *Headcount Tick Register Summary Form.* (Available on-line)
- Department of Health (National DoH) (2012). *Primary Healthcare Facility Data Collation Form. Data Summary Form.* (Available on-line)

- Department of Health (National DoH) (2012). *Monthly Data Input Form.* (Available on-line)
- Department of Health (National DoH) (2012). *Facility Data Sign-off Form.* (Available on-line)

E. Data Flow Descriptions

- *Current HAST Data Flow.* Including TB, ART, STI VCT, PMTCT data flows. (2012) (Powerpoint)
- *Metro ART Data Flow* (2012) (Papercopy of Powerpoint)

F. Policy Documents

- Department of Health (National DoH), Republic of South Africa (2012). *District Health Management Information System (DHMIS). Standard Operating Procedures: Facility Level.* Pretoria: Department of Health. (Pdf, available on-line)
- Department of Health (National DoH), Republic of South Africa (2011). *District Health Management Information System (DHMIS) Policy.* Pretoria: Department of Health. (Pdf, available on-line)
- Department of Health (National DoH), Republic of South Africa (2011). *Health Data Advisory and Co-Ordination Committee (HDACC) Report.* Pretoria: Department of Health. (Pdf, available on-line)
- Department of Health (Western Cape DoH), Directorate Information Management (2010). *Standard Operating Procedures (SOP). HCT Campaign.* (Paper)
- Department of Health (Western Cape DoH) (2008 – apparently the most recent). *Information Management: Data Flow Policy Circular H85 20080001_1* (paper)
- Department of Health (Western Cape DoH), Directorate Information Management (n.d.). *HAST Central Repository Data Integration Proposal.* Draft. (Paper)
- Department of Health (Western Cape DoH), (2009). *Western Cape Department of Health Report of the Integrated Support Team*. Western Cape Department of Health. (Paper)

- *Policy and Procedures for the Monthly PHC Essential Data Set*. (n.d.).4th draft.

G. Other

- *HIV AND AIDS/STI/TB Programme Management on Provincial level. Organogram* (2012). (Paper)
- City of Cape Town (2011). *City Health Directorate* (Paper)
- City of Cape Town (2012). *City Health Department. List of facilities.* (Paper)
- Summary of TB & HIV clinical stationery (n.d.). (Paper)
- *PIDS Indicator set 2010_11. Indicator definitions 2010/11*. (Excel)

The researcher has received these documents from the study participants or they have been publicly available. There are number of other documents, such as national and international plans, reviews, guidelines and reports that have informed the researcher during the research process. Their topics include but are not limited to health and health outcomes in general, health policy, service delivery, integration, public policy, funding, M&E and information systems. Examples include District Health Barometers, Annual Performance Plans and so on. They are not listed here as collected documents but they are referenced in References if they are cited.

Appendix E: Reflecting the study's findings to researcher's personal experiences in highly developed health system

The last Vignette takes some of the study's findings and reflects them to the researcher's personal experiences in Finland. Finland is selected as an example, because it is a high-income country and the researcher is familiar with the Finnish health care system having worked in it for years.

A CASE STUDY WITHIN A CASE STUDY

HIS and health system related challenges in a high-income country: is it really that different?

Many of the HIS and related health system challenges idenfied in this study are magnified in under-developed settings. However, they can be found in developed countries as well. Considering, for instance, Finland, the following examples can be given. First, in South Africa many HIS challenges are aggravated because of the high number of TB and HIV patients. In Finland, TB and HIV are not major public health challenges with fewer than 300 new TB cases in 2013 and a consistent trend of fewer than 200 new HIV infections per year (Terveyden ja hyvinvoinnin laitos, 2014a, b). Instead, approximately 20% of the population is 65 years and older, and the proportion of people over 65 (and 80) years is estimated to increase at a faster pace than elsewhere in Europe. There is a vast discrepancy, particularly in some rural areas, between people who are in need of health services and people who can provide them (Tilastokeskus, 2013, 2003; Vaarama and Noro, 2005). Hence, both health systems may be considered burdened, albeit that the actual numbers are different and the reasons are different.

Finnish healthcare and social service system has been argued to be fragmented and suffer from difficulties in collaboration between various stakeholders (Halme et al., 2009). On the basis of public documents available, the researcher examined the care delivery and reporting of TB and HIV in Finland[76]. It seems that they are not any less

[76] A full analysis was not within the scope of this study.

vertical and disconnected than in South Africa. However, because of the extremely high disease burden and co-infection rate, and since the epidemics are generalised in South Africa, verticalisation presents a greater problem in South Africa than Finland. That being said, an individual patient might still benefit from a more comprehensive approach even in Finland. Furthermore, in the researcher's hometown there is an influential city and a hospital district, which is a joint municipal authority. They both provide health services in the area with their care delivery structures and information systems. Based on her personal experience stemming from working for and with these health authorities, the researcher argues that the tensions and challenges described here in connection with the City of Cape Town and the Western Cape Province are not unique to low and middle-income countries. Further examples can be given. In the case of diabetes in Finland, an often-heard complaint is that a diabetes nurse 'is only interested in diabetes'. Or, how often do we enter data in an employee time tracking system for any other reason except that 'it is required by admin'? Moreover, if the admin calls back on Friday afternoon saying that there is a task description missing for four hours six months ago, would we give a highly accurate response if it feels like that it does not really matter, as long as the work has been done? To conclude, many of the challenges identified around a particular HIS in a particular setting of an under-privileged area in South Africa, can be found elsewhere. Consequently, the lessons from this study are also applicable in other settings, as long as they are translated to the local context.

Vignette Appendix E-1: HIS and health system related challenges in a high-income country: is it really that different?