Tracing ‘paper’, discovering people: three ethnographic case studies exploring the use of health information to improve health services in Gugulethu

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Abstract

Health information plays a vital role in the larger health system. Over the last twenty-five years, South Africa has developed several health information systems (HISs) that aim to collect high-quality health information to be used to inform clinical decision-making, shape new policies and programmes and strengthen other components of the health system. To date, most research in this area has focused on the production of health information and the technical challenges that appear when developing and implementing HISs. Much less is known about how health information is used in practice.

This research explores how both community actors and frontline health actors gain access to, use and exchange health information, both for their own decision-making and practice, and to address persistent health challenges. This research adopted an ethnographic approach, whereby I conducted extensive qualitative research for a period of 18 months in Gugulethu, an underprivileged peri-urban neighbourhood in Cape Town. Three case studies emerged from this research that provide a lens to analysing the role of health information in South Africa.

The use and exchange of health information in the larger health system is inherently complex. Key findings from this research project show that firstly, there is a wide interest among frontline health actors, including community representatives and NGOs, to use health information. Secondly, despite the interest for using health information, this data is not always available for a variety of reasons, which encourages stakeholders to develop creative strategies to collect new forms of evidence or to gain access to existing forms of health information. Thirdly, adopting new strategies, health actors use a combination of routinely collected, semi-formal, and informal information, often concurrently. Lastly, this research demonstrates that health information is never neutral or value-free, but is produced, used and exchanged within a larger social, cultural and religious context, and is thus shaped by these contexts.

This research challenges several assumptions about how health information is used in South Africa, and who can, or should, have access to this information. To answer these questions, it is important to open the health information system (HIS) to a more a diverse group of people actively in order to make available a variety of information that informs health stakeholders' daily work, influences health programmes and provides new perspectives on current health issues. Lastly, to further stimulate the use and exchange of health information for health system strengthening purposes, there is a need to provide a dedicated *third space*, where establishing new relationships and strengthening existing ones among actors at different levels of the health system is actively encouraged as a way to stimulate further use and sharing of health information.

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Contents

List of acronyms and abbreviations

AHP: Adolescent Health Profile

ANT: Actor Network Theory

ART: Antiretroviral therapy

ARV: Antiretrovirals

AYFSP: Adolescent and Youth Friendly Services Programme

CBHIS: Community-Based Health Information System

CBM: Community Based Monitoring

CBPR: Community Based Participatory Research

CD4: Cluster of Differentiation 4

CHMIS: Community Health Management Information System

CHC: Community Health Clinic

CHP: Community Health Profile

CoCT: City of Cape Town

DHIS: District-based Health Information System

DBE: Department of Basic Education

DSBS: Division of Social and Behavioural Sciences

DTHF: Desmond Tutu HIV Foundation

EKAPA: Evaluation of the Khayelitsha AIDS Programme

GBV: Gender-Based Violence

LGBTQ+: Lesbian, Gay, Bisexual, Transgender, Queer

HIS: Health Information System

HISP: Health Information System Programme

HREC: Human Research Ethics Council

iALARM: Using information to Align Services and Link and Retain Men in the HIV Cascade

iALARM RT: the iALARM Research Team

iALARM TT: the iALARM Retention in Care Task Team

ICRM: Ideal Clinic Realisation and Maintenance programme

ISHP: Integrated School Health Policy

LMIC: Low- and middle-income country

LTFU: Loss-to-follow-up

MCSJ: Movement for Change and Social Justice

MDG: Millennium Development Goals

MSF: Médecins Sans Frontières

MSAT: Multi-sectorial Action Team

MWC: Men’s Wellness Centre

NDP: National Development Plan

NGO: Non-governmental organisation

NHI: National Health Insurance

NORAD: Norwegian Agency for Development Cooperation

PHDC: Provincial Health Data Centre

PHICS: Primary Health Care Information System

PHM: People’s Health Movement South Africa

PREHMIS: Patient Registration and Health Management Information System

PrEP: Pre-exposure Prophylaxis

RHIS: Routine Health Information System

RMR: Routine Management Report

SASH: South African Social Science and HIV Programme

SDG: Sustainable Development Goals

SGB: School Governing Body

SJC: Social Justice Coalition

Sonke: Sonke Gender Justice

TAC: Treatment Action Campaign

TB: Tuberculosis

UCT: University of Cape Town

UNAIDS: The Joint United Nations Programme on HIV and AIDS

UWC: University of the Western Cape

VMMC: Voluntary Medical Male Circumcision

WCDoH: Western Cape Department of Health

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Chapter 1: Introduction

"You cannot make informed choices without information" – Andy Oxman

1.1 Setting the scene

In the midst of frantically trying to finish this doctoral thesis, I attended a conference in Cape Town, South Africa. The theme of the conference, which was organised by Cochrane South Africa, was 'Trusted evidence for better health decisions in Africa'. I was invited by the organising committee to present a poster on the use of health information as part of implementing a new youth health programme in South African clinics. This poster was informed by one of the case studies presented in this thesis (Chapter Six).

While attending the plenary sessions on the first day of the conference, I was struck by a quote from Dr. Andy Oxman, an accomplished health services researcher who works at the Norwegian Institute of Public Health. He started his presentation by stating that '*you cannot make informed decisions without information'*. Although most of his talk focused on which messages are effective for children when trying to change health behaviour, the first slide of his talk resonated with me and made me think about the topic for this doctoral thesis, as well as events in my own life—which has drastically changed over the past few months.

The quote, '*you cannot make informed decisions without information*' made me think: what is an informed decision, actually? And what is information? How much information does one need to make a decision, and when do you know that this decision is well-informed? Furthermore, what kind of information do you need during the decision-making process? Within public health research, we often assume that people who operate within the health system—including policy makers, programme designers and practitioners—inform their decisions with different forms of evidence. But what do we understand this evidence to be?

According to the Collins Advanced Dictionary, there are two interpretations for the word 'evidence'. The first one explains evidence as "*anything you see, experience, read or are told that causes you to believe something is true or has really happened*". The other explanation sees evidence as "*the information which is used in the court of law to try to prove something*". Evidence is obtained from documents, objects or witnesses (Sinclair et al., 2000). In the health information literature, evidence is often understood as scientific proof, or results that derive from good-quality scientific studies that have been designed to answer a specific research question (Straus and McAlister, 2000).

Evidence, as used for decision-making, can also be based on other forms of knowledge or information, which might or might not be scientifically based. Whatever type of information is used, most people make health-related decisions on a daily basis—and these decisions are influenced by information we access every day.

I soon became aware of the immense amount of information, mostly health promotion material, I absorb every day when I found out I was pregnant. Immediately after I saw the result of the test, my husband and I started planning and Googling. What do we need to do now? Do we need to go to the gynaecologist straight away, or do we make an appointment at the general practitioner? What unhealthy habits do I need to shed? And what foods are recommended or banned from my diet during the first trimester? To get some answers and make these first decisions during this new, exciting and slightly scary phase of our lives, we had multiple discussions, spoke to our parents, consulted with a health professional and also listened to our 'inner voices' which often happened to be the calming voices of reason that would echo, 'you are ready for this, take it one day at the time and everything will be fine.'

Thankfully, a pregnancy is normally forty weeks long, which gave us plenty of time to think about the enormous amount of choices we had to make before welcoming a new person into the world—including considering birthing rituals, upbringing, schooling, values, morals and future relationships with others. But in these first weeks after I found out we were expecting a baby, I gathered many valuable insights about how I use information and where this valued information comes from. Firstly, when it comes to pregnancy-related questions, I would rather read a trustworthy book then relying on the thousands of resources that you can find online. I also consult my mom about little ailments and discomforts. Or, I WhatsApp my best friend, sister or other friends who have walked the motherhood journey before me. I also realised that my decisions are shaped by my personal history and the cultural context I grew up in. I was born and raised in the Netherlands—the Valhalla of homebirths—and do strongly believe that the private health care system in South Africa is highly over-medicalised and that some of the medical interventions offered are not always necessary.

Returning to the statement *'you cannot make informed choices without information',* the excerpt above shows that decision-making is a complex and multi-layered process that is impacted by the type of health information that is available, the context in which the information is produced, and those people who interact with this information. All of these factors affect the messaging and meaning of health information. Even though my personal experience with health evidence was informed by 'health topic information' and 'health promotion material', information, this little snippet does highlight the complexity of using information to make decisions about health and emphasizes how context and relationships with others impact our relationship with different types information.

The role of health information is crucial for patients(like myself) , but also plays a significant role among those who operate at every level of both the public and private health system, including policymakers, clinicians, health workers, clerks, NGO representatives, community health workers (CHWs) and community members (Aqil et al., 2009, Lippeveld, 2017). In one capacity or another, everyone in the health systems uses health information to manage decision-making processes. Health information also shapes new policies or programmes in the health system, improves service delivery, informs daily practices in facilities and serves to educate patients and the larger public.

1.2 Context and current gaps in research

Over the last twenty years, there has been an increasing demand for health information, and the development of health information systems has become an integral part of broader efforts to strengthen health systems (Braa et al., 2004, Braa and Hedberg, 2002). The production, use and exchange of health information is part of ‘information and research’, one of the six building blocks in the World Health Organization (WHO) health system framework (Gilson, 2012, World Health Organisation, 2007). Most research on health information systems (HISs) is focused on the collection, storage and communication of a variety of routinely collected health information, including patient records, facility surveys, routine management reports and disease surveillance reports.

Ideally, all of this collected information is stored in and communicated via a Routine Health Information System (RHIS), which operates electronically and produces reliable, accurate and up-to-date health information (Garrib et al., 2008). Unfortunately, in many low- and middle-income countries (LMICs), including South Africa, the reality is often different, and both the production and use of information is relatively limited. This can be caused by a shortage of resources including staff, hardware and software, lack of leadership and governance, fragmentation and ill-defined information needs (Lippeveld, 2001, Garrib et al., 2008).

To address the shortcomings in strengthening HISs, there have been several initiatives in the past 15 years that have placed HISs and health information research firmly on the global health agenda, such as including HISs in Millennium Development Goals (MDGs), the Sustainable Development Goals (SDGs) and through setting up a Health Metrics Network (HMN) (Lippeveld, 2017). This network focuses on improving the performance of HISs in LMICs and aims to strengthen community-based health information systems (CBHISs) and empowering decision-makers across the health system.

South Africa has a complicated history of colonialism, racial segregation and apartheid, which impacted all aspects of everyday life, including the quality of and access to health care. These inequalities contributed to the quadruple burden of disease and a fragmented public health system which is permanently overstretched. Despite these challenges, South Africa has made tremendous progress over the past 25 years by developing compatible HISs that produce relevant and high-quality health information (Braa et al., 2007). Much of this success can be attributed to the implementation of District-Based Health Information Systems (DHISs) which were introduced in 1996 by the Health Information Systems Program (HISP), a collaborative research and development programme, spearheaded by the University of the Western Cape (UWC), the University of Oslo and the National Department of Health (NDoH) (Igira et al., 2007, Braa and Hedberg, 2002). In line with the reorganisation of the health sector in the country, HISP developed a new, decentralised HISs to assist managers with decision-making on district and sub-district level. Following from HISP and other health information strengthening interventions, the Western Cape Department of Health (WCDoH) is currently in the process of developing a Provincial Health Data Center (PHDC), whereby individual level health information from different databases is captured in one central provincial database (Schmidt, 2019).

The need for the swift development of electronic HISs in South Africa and neighbouring countries was also spurred by the rapid spread of HIV/AIDS in the late 1990s. The HIV/AIDS epidemic increased the need for large amounts of patient-level information that was collected systematically, as this information proved to be vital to informing the HIV response (Aqil et al., 2009). Health information was used to determine HIV hotspots, and provided much needed evidence about vulnerable populations; it also informed larger-scale HIV awareness and community campaigns, which used health information and other evidence to demand access to antiretroviral (ARV) treatment (Colvin and Lurie, 2014). Although ARV treatment is now widely available and affordable in South Africa, health information still plays a crucial role in the scale-up of HIV services, and facilitates better linkage and retention of patients in HIV care (Kilmarx and Mutasa-Apollo, 2013).

Unfortunately, there are still problems with how RHISs and HISs function in LMICs, including South Africa. Systems remain technocratic and fragmented, which hinders the access to and flow of health information (Aqil et al., 2009). Factors that hinder the development of HISs may include, firstly, technical difficulties, including the absence of computers, reliable electricity or internet or incompatible software (Aqil et al., 2009, Garrib et al., 2008). Secondly, challenges that pertain to the access to and use of health information can be attributed to malfunctioning organisational structures, lack of human resources and inadequate provision of training (Schonfeldt et al., 2011). Thirdly, political leadership, organisational mismanagement, or a lack of communication among different levels of the health system also drastically affect the use and exchange of health information (Garrib et al., 2008, AbouZahr and Boerma, 2005). Fourth, much is still unknown about the complex role that health information plays in the health system, how we can meet the demand for health information and monitor the impact of health information as part of improving the health system (Colvin et al., 2018).

1.3 Persistent gaps in research and rationale

Despite tremendous efforts made over recent decades to improve the collection and storage of high-quality health information in electronic databases—information which is ideally used to inform daily decision-making and shape new health policies and programmes—we know much less about the actual use of health information in practice. This gap raises some important questions about who uses health information in the health system, what kind of information is used and why health actors use, or would have an interest in using health information.

Who?

In health information literature, most of the available research focuses on the need for health information to inform decisions for managers who operate on district level, provincial level or national level of the health system (Lippeveld, 2017, Lippeveld, 2001). Unfortunately, much less is known about other actors who operate on other levels of the health system. What information do they use, and for what purposes? There is a small body of research that investigates the need among health facility managers to use health information, but very little is known about the need for and use of health information among other stakeholders in the health system, including frontline workers. What information is needed for nurses, family physicians and community health workers to make decisions in their daily work? Furthermore, there is almost no empirical research that focuses on the need for health information among people who might operate on the periphery of the health system, including researchers, patients, and community representatives (Lippeveld, 2017). Although these actors may not play a formal role in the health services, they might have an interest in using health information to address health system issues and keep the health system accountable by raising questions about the access to and quality of health services provided. Over the last few years, there has been a push to develop CBHISs to collect information from neighbourhoods and communities that can be used to shape new policies and programmes in LMICs (Jeremie et al., 2014). Although CBHISs might be able to advise on the health needs of the community, there is little information about if and how community stakeholders and NGOs are using the information generated through these information systems and to what extent community stakeholders have access to routine collected health information.

What kind?

Directly linked to the question of who is using health information is the question of what—what kind of health information is used, and is needed to strengthen health services and inform decision-making. Existing literature often only considers patient records, routine management reports, and other target-driven information that is ideally stored within well-functioning electronic databases (Garrib et al., 2008, Aqil et al., 2009). However, there is a range of other forms of health information that might also be of interest to health actors, including academic evidence and research findings, demographic data, health statistics and information on disease prevalence (AbouZahr and Boerma, 2005). This information can either be collected routinely, or can be gathered informally. A few scholars have conducted research about the use of informal forms of information within the health system in Sub-Saharan Africa, but there are other avenues to explore the role of informal information among health managers, but we know little about the use of informal information among community stakeholders (Scott, 2016, Williamson and Kaasbøll, 2009). Within this thesis, I use the term health information when referring to health (management) information that is used among front-line workers and community members. In the individual case studies, I will furthermore specify what type of health information is relevant, such as reports or testimonies.

Why?

Another important piece of the puzzle is the need explore why community and frontline health actors want to use health information. Often, gaining access to routinely collected health information is based on the need to monitor daily operation in a clinic or existing health programme, or to set or realign targets within facilities, districts or provinces. However, we have little insights into how individual health actors use health information within their daily work, or even when implementing new guidelines or policies (Schonfeldt et al., 2011). Despite the fact that health information is understood by the WHO as the foundation for the improvement of health services across all levels of health system, we struggle to understand the semantics of health information and how exactly this information is used to strengthen the health system (World Health Organisation, 2007). Consequently, several important questions remain unanswered, including; what information is useful for health actors on a daily basis, and why? How is health information used when implementing new health programmes or services? In which scenarios is health information unnecessary, and why?

1.4 Research questions, objectives & overarching approach

Summarising the pertinent gaps in research above, it becomes clear that the role of health information in the HIS is much more complex and multifaceted than often acknowledged in the literature. To better understand the role and potential of health information in the larger health system, this thesis uses three distinct case studies to explore how health system actors and community representatives navigate access to, use and exchange health information to improve health services and health service delivery. All three case studies follow a different group of frontline health workers, researchers and community actors who all work in Gugulethu, an underprivileged neighbourhood in Klipfontein sub-district, Cape Town. The study employs a qualitative research design with a strong focus on ethnography.

The following three questions guided this research process:

1) How do frontline health actors and community representatives access, produce and make use of health information in Gugulethu?
2) What are the factors that frontline health actors and community representatives experience which hinder or facilitate the access to, production and use of health information?
3) What strategies are used by frontline health workers and community representatives to improve their access to health information in Gugulethu, and what is the effect of those strategies?

The research process for this thesis was rooted in a grounded, bottom-up approach, and the design of the research was flexible. The research questions outlined above therefore differ from those which were initially outlined in my research proposal, which focused more on the social meaning of health information in the health system. Reason to shift the approach were the preliminary findings in the research process which revealed that both frontline health actors and community representatives did not only use and exchange health information to support their efforts to improve health services, but also would actively produce and create health information when existing information was either inaccessible or did not exist at all. These unexpected results allowed me to broaden the scope of my project and refine my research questions to further explore how these creative strategies impact the use of health information in the health system of Gugulethu. The three case studies all explore the role of health information, and highlight that not all health system actors have equal access to health information. Data for this research was collected in the community of Gugulethu, an underprivileged neighbourhood in Cape Town which is part of the Klipfontein sub-district.

Although different in content and context, all three case studies are embedded in the iALARM study (Using **i**nformation to **A**lign Services and **L**ink **a**nd **R**etain **M**en in the HIV Cascade) (see more in Chapters Three and Four). iALARM is a larger research project that aims to shift some of the ways that health information is produced, used and communicated, attempting to broaden the perspectives of health system actors of who should have access to health information and how people understand health information. Through the use of a health information intervention, iALARM offers a select group of health system stakeholders innovative ways of engaging with health information, focusing mainly on HIV and men.

This PhD research is comprised of three distinct but interlinked ethnographic case studies that all provide a lens through which to explore how health system actors and community actors create, make use of, and exchange different forms of health information in Gugulethu. In the case studies, I follow three different groups of health systems and community actors. The first case study explores the role of health information within the iALARM intervention, whereby UCT actively collaborated with a group of stakeholders from different levels of the health system to create a space where both qualitative and quantitative health information could be shared. This information aimed to improve the collaboration between health system actors who were all interested in better linking men to HIV care in Cape Town. The second case study follows members of Movement for Change and Social Justice (MCSJ), a community activism group in Gugulethu, on their quest to access different forms of health information to support different health campaigns in the neighbourhood. The last case study explores the role that health information plays during a policy implementation process. This case study follows a group of front-line health workers on their journey to access the needed information to populate an adolescent health profile as part of a larger programme that aims to improve health services for young people in South Africa.

Albeit different, all three case studies provide a unique opportunity to explore the intricacies of collecting and using health information, to better understand the challenges and experiences of those who interact with health information, and to analyse the different strategies that participants employed to access health information to improve health services in Gugulethu.

Within the three case studies, I argue that in the health system of Gugulethu, there is a wide interest among different actors to use health information to address a range of health system and service delivery issues. This health information might be routinely collected, or can be semi-formal or informal types of information. The participants in the case studies have different reasons to use health information, which motivates them to collect data from a variety of sources. This information is not always readily available, which stimulates the actors to adapt their own creative strategies to collect their own data. This creativity encourages further information-sharing within the health system and larger community.

1.5 Chapter outline

After this introductory chapter, **Chapter Two** provides a literature review which outlines the history of HISs in South Africa and how HISs are embedded in, and affected by, the larger health system. This literature review also explores the main challenges that complicate the demand for and use of health information and outlines the work of scholars who aim to bring alternatives perspectives of what constitutes health information. The second part of the literature focuses on the need to rethink HISs not only as technical innovations, but as socio-technical systems which are embedded in the context of the larger health system. Lastly, I provide an overview of the theoretical frameworks that are most often employed within HIS research and describe concepts I have used to analyse my own qualitative results.

The literature review is followed by the methods chapter in **Chapter Three**. Chapter Three gives more detail about the socio-economic and cultural background of Gugulethu and Klipfontein sub-district and introduces some of the key informants who played a crucial role in my fieldwork. I also outline the ethnographic study design which was employed for this research project and provide more detail on the methods of data collection, ethical considerations and my own positionality within this study.

My first case study will be introduced in **Chapter Four**. This case study derived directly from the iALARM intervention, and followed the designing process and implementation of the iALARM intervention. The specific focus of the case study was to explore what happens when academic researchers bring together a diverse group of health systems actors, NGOs and community actors, offering them access to a wide range of health information in an effort to change how they think about health information and how to use information in their own work.

The case study in **Chapter Five** highlights what occurs when actors who normally operate on the periphery or outside the health system make active use of health information for their own goals. For this case study, I worked closely with a group of community activists from the Movement of Change and Social Justice (MCSJ) who challenged the conventional use of health information, used their own, inventive ways of collecting health information, and actively reimagined traditional ideas about health information and their role within HISs. This case study varies slightly from the other chapters, as it also includes health topic information which is used to inform the public about health challenges in their communities and focuses less on routine information as used in clinical settings.

The last case study is introduced in **Chapter Six** and follows a group of frontline health workers from Gugulethu on their journey to collect the necessary health information required for the implementation of a new clinic policy. The aim of this policy was to improve health services for young people in the community. The chapter explores the complexities of implementing this new initiative, which was initially seen as a routine and largely technical exercise but proved to be extremely complicated. When unpacking these complications, this case study reveals the assumptions people have about health information, the challenges that are experienced when trying to effectively use health information, and the imaginative ways in which health system actors try to solve these problems.

The final chapter, **Chapter Seven**, provides a discussion of some of the intersecting themes that derive from the individual case studies and links these themes to a larger body of literature about health information and health systems. This chapter synthesises and reflects on the findings from Chapters Four, Five and Six, and shows how the complexity of health information impacts the lives and daily work of those operating inside and on the periphery of the health system. In line with overarching arguments of this thesis, the discussion chapter highlights that there is a persistent need for different forms of both routinely and informal information to improve health services in Gugulethu, but that not everyone has access to these resources. Therefore, there is a need to provide a more inclusive health information framework that acknowledges the importance of different actors and types of information which shape the health system.

Chapter 2: Literature review

2.1 Introduction

Health information plays a crucial role in the larger health system, impacting different aspects of health care and health service delivery. Unfortunately, many health actors in the health system do not use health information sufficiently and effectively, which compromises practice, decision-making, policy, and programme development and implementation. Despite the focus on developing comprehensive health information systems (HISs), which stimulates the collection of high-quality health information, there are several persistent gaps in the literature which remain largely unexplored, namely: 1) what are the effects of using informal health information within the larger health system? and 2) what role do different actors play in the larger HIS and how do they use health information to try and improve health services? Also, despite the consistent production of health information within the health system, there is little evidence on how this information is used in day-to-day health practices.

This literature review serves as a roadmap to navigate the case studies that follow in Chapters Four, Five and Six of this thesis, and will deal with some pertinent research questions along the way. In this chapter, I will provide a comprehensive overview of the use of health information in the larger health system and outline the historical events that impacted the current public health landscape in South Africa, before exploring the persistent gaps in HISs literature. One persistent gap in the literature that I will unpack in this chapter is the need to reconceptualise health information systems for community actors, and specifically, the interest that community actors may have in using health information to address health services issues and keeping the health system accountable. Another gap which will be addressed in this chapter is the need to rethink the understanding of what health information consists of, in order to make HISs more inclusive and to promote a culture of information. Although this literature focuses mostly on the development of HISs that focus on routine health information collection, literature review acknowledges and describes types of information that are not considered RHI, which will be described in detail below.

The second part of this literature review will explore a selection of theoretical frameworks that are used within HISs research and were essential when analysing information from the three different case studies. Understanding and unpacking these theoretical frameworks is essential for the rest of this thesis, as it provides an analytical lens though which to interpret the qualitative information provided in the chapters that follow.

2.2 Health information and the larger health system: history, context and current challenges

There is a growing recognition that health information and HISs play a fundamental role in the larger health system, and that improving the access to and use of health information can positively impact health care services and delivery (Aqil et al., 2009, Lippeveld, 2017, Lippeveld, 2001). On both global and local levels, effective, integrated information systems are invaluable components when implementing and monitoring health interventions that aim to reduce the burden of disease and improve health outcomes of patients (Williamson and Kaasbøll, 2009, Braa et al., 2004, Nutley, 2012, Nutley and Reynolds, 2013). In line with the Alma Ata Act of 1978, the development of high-quality HISs that understand the needs of both the patient and health provider is crucial in providing health for all (Nutley and Reynolds, 2013).

Recognising the need to strengthen the use of health information and development of HISs is important, but what exactly is health information, what is a HIS, and what role do both phenomena play in the health system? In short, health information is all the information that is essential for decision-making in health care. This encompasses information about patients, including visits, treatment routines and pharmaceutical data, but also surveillance data, specific reports about diseases and other conditions, facility surveys, treatment guidelines, routine management reports and health services statistics (Garrib et al., 2008, Schonfeldt et al., 2011). It can also include information on health determinants (including socio-economic status and environmental factors), performance targets in the health system, information on health outcomes (including mortality and morbidity), or academic evidence (AbouZahr and Boerma, 2005). Comprehensive health information is usable, useful data that user-friendly and not complex (Nutley et al., 2014). When employed well, health information for decision-making include the proactive and interactive interactions health actors have with information as part of programme monitoring, review, planning, and advocacy and policy development (Garrib et al., 2008, Nutley and Reynolds, 2013). Additionally, health information can contribute to the improvement of the functioning of health facilities as well as the health system at large (AbouZahr and Boerma, 2005).

Health information can be collected, stored and used on local levels of the health system, as well as on district, provincial, or national levels, in health information systems (HISs) or health management information systems (HMISs). According to the WHO, HISs and HMISs are the “foundation for the generation of good-quality data and integrates the collection, processing, reporting and use of information for improvement of efficiency of health services through the enhancement of management at all levels of the health system” (Schonfeldt et al., 2011, World Health Organisation, 2007).

A well-functioning HIS has four key functions; 1) data generation, 2) compilation, 3) analysis and syntheses, and 4) communication and use (World Health Organisation, 2007). This HIS produces relevant, timeous, high-quality and up-to-date health information, and uses this high-quality health information to support health system decision-making (Lippeveld, 2001). An adequate HIS addresses the needs of both the user and the producer of information and is, ideally, run electronically to ensure that health information can be captured and managed efficiently (Aqil et al., 2009). Preferably, the collection of information is conducted routinely as routine health information (RHI) and stored within a routine management information systems (RHIS). RHI is essential for informing new health programmes and policies and to guide decision-making at all levels of the health system. Decision-making can be understood as the process whereby a group of people, in this case health actors, aim to reach consensus on a particular health service challenge, using different forms of relevant information provided to them (Wickremasinghe et al., 2016).

Included in RHI are paper-based or electronic reports of the services delivered within facilities, patient records and management reports (Garrib et al., 2008). This information is collected on a regular basis and used to monitor the progress within facilities, to set targets, or for programme design at higher levels of the health system. Ideally, RHIS performance should lead to improved information quality and the continuous use of information (Aqil et al., 2009). A well-developed HIS or RHIS can further track documents, follow the progress of interventions, set health targets and inform disease-specific strategies (Braa et al., 2007, Braa and Hedberg, 2002). Ideally, RHIS performance should lead to improved quality and the continuous use of information (Aqil et al., 2009).

A well-functioning HIS or RHIS does not only collect and store high-quality information for policy and programming, but also improves health information use and exchange (HIE). HIE is the process of sharing patient-level electronic health information between different organisations and making previously unavailable patient-level information available to healthcare professionals (Vest and Gamm, 2010). The exchange of health information informs individual actors in the health system about new policies, programmes, and health services, or may communicate disease-specific information.

Once health information is collected and stored within HISs on both local and national levels, there are health actors who use health information for different purposes. Firstly, policy makers and programme developers use it to inform new policies and health programmes which aim to improve health outcomes for patients or strengthen health services on national, regional and local levels (Braa et al., 2007). Health information can also inform new or updated clinical guidelines, and is used to develop country reports—which are in turn employed by international organisations such as the WHO and UNAIDS to set global goals. These goals might include the Millennium Development Goals (MDGs), Sustainable Development Goals (SDGs) or 90-90-90 targets (World Health Organisation, 2006, World Health Organisation, 2013, Unaids, 2014, Gilks et al., 2006, Bain et al., 2017). On district and provincial levels, health information can be used to set regional targets or district-level targets, or to measure the performance of individual clinics. Health information can also be used for management level training and decision-making about new guidelines. District-level health information is also crucial to compare which areas are under-resourced or under-covered; this information may be important for immunisation campaigns, for example. At facility level, health information is collected by facility managers to report progress to districts, but is also used to track patient visits and monthly targets that are set for dedicated health campaigns, such as Pap smears or HIV testing. The information also informs the coordination of management teams and daily practice within the clinic. At individual and community level, health information informs clinical management, assesses the extent to which services are meeting the needs and demands of communities, and can help to structure community care (AbouZahr and Boerma, 2005).

Although there has been an increased interest in strengthening HISs and improving the use of information among health system stakeholders on national and international levels, information does not always form the basis for decision-making in the health system. Sometimes, the needed information is not available or the health information is accurately synthesized (Nutley and Reynolds, 2013). Other times, the information might be available, but only accessible for a few. Some HISs are developed too rapidly and without any long-term planning, which means that they are not able to generate the needed information (AbouZahr and Boerma, 2005). Other problems can be attributed to a lack of interaction between systems designers—the producers of the data, and those who use the information—which leads to ineffective linkage of different forms of information and a lack of trust between data users and data producers (Nutley and Reynolds, 2013).

Additionally, there is a perception health system actors only view the collection of health information as a part of their management duties. This leads to an overload of produced information that is reported from lower levels to higher levels of the health system, but to little information is redistributed within the health system (AbouZahr and Boerma, 2005, Aqil et al., 2009, Lippeveld, 2001). One reason for the lack of distribution of information the absence of a relationship health actors have with information or the absence of a clear incentive to share health information across different levels of the health system (Berg, 2001). Only when data users and data producers are effectively linked to each other's work is there an ability to strengthen the information cycle, improve information-informed decisions and effectively enhance health programmes (Nutley and Reynolds, 2013, Lippeveld, 2017).

As mentioned in the first paragraph, health information and HIS are an integral part of the larger health system, which is, according to the WHO framework, divided into six different building blocks, namely; 1) leadership and governance, 2) health care financing, 3) *information and research,* 4) medical products and technologies, 5) health workforce and 6) service delivery (Van Olmen et al., 2012). Although described as separate components, all of the building blocks are closely connected and influence each other (Van Olmen et al., 2012). The availability or lack of health information or well-designed HISs affects the ways in which facilities are led and provincial health departments are governed. The status of HISs may also impact which health services get funded and prioritised, and which clinics require more staff. Together, all of these separate factors influence the health system as a whole, and ultimately, the health outcomes of individual patients.

2.3 A brief historical overview of the South African health system

To better understand and address the current challenges and opportunities within HISs in South Africa, it is important to briefly zoom out and give an overview of the historical events that shape the South African health system. The South African health system has been impacted by a colonial past which impacted all facets of life, including the provision of health care. The fragmentation of the health system, which is still present today, has been driven largely by the apartheid regime, a political system of total segregation between 'Whites', 'Coloureds', 'Indian' and 'Black' people (Coovadia et al., 2009). By introducing dedicated apartheid policies, health services became instruments of the apartheid regime to maintain White supremacy through to maintain White supremacy through restructuring health service expenditure and financing, overseeing family planning, and unequally distributing health resources between urban and rural areas (Price, 1986, Parnell, 1993).

Even before the apartheid government came to power in 1948, Black, Coloured and Indian people had already been deprived of economic and social opportunities, as settlers colonised South Africa and the country came under Dutch and later, English colonial rule. Together, these historical roots affected both the development of the health system and led to the current quadruple burden of disease that is affecting South Africa's population, which includes high rates of maternal, new born and child morbidity and mortality; HIV/AIDS and TB; non-communicable disease; and violence and injury (Feng et al., 2019).

Apartheid policy and large-scale labour migration from small towns and rural areas to cities affected every part of life, including sexual and reproductive health, family life and economic opportunities (Sanders and Chopra, 2006). Migration often led to families being broken up for long periods of time, a lack of stable income for both those in the homelands and in the city and the possible exploration of new sexual relationships. Black, Coloured and Indian people had fewer work opportunities, earned less, were disadvantaged educationally and were forced to live in dedicated areas such as Bantustans or townships, away from social services and health services (Coovadia et al., 2009). After the discovery of gold and diamonds in both Johannesburg and Kimberly in the nineteenth century, more migrant labour was needed, and many people flocked to the urban areas to find work. This migration and mobilisation led to a growth of informal settlements and housing crises in the rapidly-growing cities, as well as a rise in interpersonal violence and gang violence. These factors all contributed to the skewed health outcomes between different groups of people (Coovadia et al., 2009, Sanders and Haines, 2006, Sanders and Chopra, 2006).

During apartheid, access to and quality of health services differed drastically among different groups of people, as well as between urban and rural areas. In the Bantustans (homelands), and townships, very limited health services were offered, preventative and curative health services were separated, and even health departments were racially segregated (Price, 1986, Parnell, 1993). Although centrally governed by the National Department of Health in Pretoria, vast differences in quality of care and allocation of resources and staff existed (Mayosi et al., 2012). In 1942, just before the National Party came to power, the Gluckmann Commission proposed an ambitious plan to introduce a number of community health centres, which were seen as the "forerunners of community-based primary health care" (Coovadia et al., 2009, p.821). Unfortunately, due to the change in political leadership, these community centres were never developed. Despite the introduction of the Alma Ata Declaration in 1978—which protects and promotes access to primary health care for everyone in the world—the legacy of apartheid still persists in the health care system in South Africa, as health services remain unevenly distributed (Mayosi et al., 2012).

2.4 South African Health Information Systems in context: persistent challenges and latest successes

In the previous paragraphs, I have outlined how South African's history has impacted the health system and I have discussed persistent challenges caused by many years of inequality and apartheid, which racially divided every aspect of life, including health service provision and access to health care. As with the larger health system, HISs in South Africa have also been impacted by the country's troubled history (Braa and Hedberg, 2002). Like other aspects of health care, during apartheid, the collection and distribution of health information had different standards for different groups of people (Braa and Hedberg, 2002). Until 1994, the country's health system administration was divided into 14 separate Departments of Health, with one 'general' Department of Health, three specific Departments for 'White, Coloured and Indian' people, and ten Departments for 'Black people' living in the homelands. For each district, there were different rules, regulations and guidelines for what information needed to be collected and what forms were used for patients and procedures (Braa and Hedberg, 2002).

One of the major challenges during the early years post-apartheid was to provide equity in the provision of health services for all people in the country, irrespective of race, colour or background (Braa and Hedberg, 2002, Vidgen and Braa, 1997). This process included the decentralisation of services, which was realised by dividing provincial services into different health districts. Each of these health districts are managed by the Provincial Departments of Health. These departments are now responsible for providing health services, including implementing HISs. This new way of structuring health services provided a ‘blank slate’ to develop new standards and ideas for creating HISs on both district and national levels. In 1995, the Western Cape Province proposed to change the health information management system by piloting the Health Information System Program (HISP) in collaboration with two South African universities, the University of the Western Cape (UWC) and the University of Cape Town (UCT), as well as with the Norwegian Agency for Development (NORAD) (Braa and Hedberg, 2002). HISP was first piloted in three different districts in the Western Cape and based on two interconnected aims: the development of standardised data to better store health information, and the accompanying information software to store and use these datasets (Braa and Hedberg, 2002, Lippeveld, 2001). The project was set up at grassroots level and developed to support health services at the local level. After the initial pilot phase, HISP proved to be very successful; after the results were presented at a conference in Cape Town in 1998, the developed datasets and standards were adapted by other provinces and the project received several large grants over the following years. This scale-up made it possible to roll out the HISP project in several other LMICs, including Mozambique, Malawi and India, where numerous district health information systems (DHIS) were developed (Braa and Hedberg, 2002, Braa et al., 2004, Braa et al., 2007).

The HISP project, and the implementation of a DHIS in South Africa and other countries, teaches us several important lessons about the complexity of health information use and exchange and the various challenges currently being experienced in the development and strengthening of HISs.

Firstly, the HISP project proved that even health information solutions which are locally designed and use a bottom-up approach are impacted by political forces, both on provincial and national levels (Braa et al., 2004). One of these political factors is the commitment from local and international donors who provide funding to develop interventions for specific diseases (Aqil et al., 2009). This mode of funding means that health information strengthening projects only produce pilot interventions, but provide no long-term outcomes (Lippeveld, 2017). Additionally, within the HISs and larger health system, professional and managerial environments are constantly fluctuating due to staff turnover, which makes planning for long-term development difficult (Herbst et al., 1999, AbouZahr and Boerma, 2005). Luckily, the HISP project proved to be different, as there was continuous buy-in from Norwegian sponsors and universities, South African universities, and international donors. Getting both the financial and political buy-in for the HISP project has been a continuous process of action and building alliances on the ground in the context of a post-apartheid South Africa.

Secondly, although health information interventions were appropriated for the Global South, the original formats for many HISs were developed in Northern Europe (Braa et al., 2004). Compared to countries in the North, South Africa is extremely diverse, and the income gap between privileged and underprivileged groups is one of the highest in the world (Ramudzuli, 2019, Woolard, 2002. This economic and social inequality affects access to technology—and in particular, internet and electricity, two essential components of electronic information databases that are the core of information systems {Braa, 2004 #1189, Herbst et al., 1999, Garrib et al., 2008). Even when all the necessary technical components are in place, constant technical support is needed to keep the HISs up-to-date, which is not always feasible (Schonfeldt et al., 2011).

Thirdly, there are several health systems issues that affect the development of HISs and the use and exchange of health information in LMICs such as South Africa; these issues are often related to organisational structure, and may include lack of human resources and overburdened facilities (Herbst et al., 1999, Garrib et al., 2008, Schonfeldt et al., 2011). Shortage of personnel means that there is less dedicated time to spend on the collection of health information, or to learn how new HISs work in practice. There is often too little training provided for managers and health workers to implement information systems accurately (Schonfeldt et al., 2011, Garrib et al., 2008). This absence of training can lead to a lack of understanding about the usefulness of information, limited buy-in from data managers or duplication of information (Garrib et al., 2008). Furthermore, there is often too little communication between managers and health personnel, which leads to a lack of feedback about the HIS that further compromises both the availability and quality of health information.

Fourth, once developed and implemented, HISs are not always compatible with each other, which limits the information exchange between different systems (Schonfeldt et al., 2011). Often HISs are developed with little legislative planning and many good ideas—for instance, to integrate public and private information systems. The operationalisation of these ideas, however, is often more complicated than anticipated, which can lead to duplication and issues around transferring paper-based files to an electronic system (Garrib et al., 2008). Additionally, when implemented, HISs are rarely evaluated in LMICs, even though evaluation is a fundamental component to ensure that systems are operating efficiently and that they produce high-quality information that is easy accessible by different health actors (Herbst et al., 1999, Bailey and Pang, 2004).

Other challenges reported are delays in information submission, a lack of understanding of which information is important to capture, and an absence of tradition on using information for decision-making in the health system (Garrib et al., 2008). Although the importance of strengthening HISs is acknowledged on the provincial and country level—as HISs inform management decision-making, policies and health programmes—there is little information-sharing from higher-level health management to staff in individual districts, facilities and communities (AbouZahr and Boerma, 2005). This lack of coordination reaffirms the notion that health information is only collected for upward reporting and target-driven management meetings, and fails to recognise the importance of using health information in everyday practice and decision-making.

Lastly, the larger health system in South Africa remains fragmented; while this is partly caused by the issues described above, including organisational mismanagement, lack of training and resource allocation, it is also affected by the political leadership in the country. In the Western Cape, for instance, where this study took place, health services are not all managed by the central government, but facilities are either under management of the Western Cape Department of Health (WDoH) or City of Cape Town (CoCT) (for more info on clinic structures, see Chapter Three). Although often in close proximity of each other, this difference in governance can result the lack of communication between individual clinics, but also affects the use of health information exchange and sharing, as provincial clinics and city clinics have separate HISs that are not always sufficiently linked (Schmidt, 2019).

Opportunities and latest developments

Despite the challenges experienced, HISs in South Africa have improved significantly since 1994, and several initiatives have been developed that highlight the importance of HIS strengthening to increase the use and exchange of information for decision-making in the health system (AbouZahr and Boerma, 2005, Braa and Hedberg, 2002). Part of this success is the allocation of more resources to HIS interventions, better data collection tools, trained personnel and the development of new strategies to improve information use and dissemination. All of these factors facilitate the collection of health information in community settings, clinics, and health districts (Schonfeldt et al., 2011). Furthermore, the completeness and quality of health information collected in the different HISs have improved (Garrib et al., 2008).

Compared to other provinces in South Africa, the Western Cape has several well-developed HISs and many promising initiatives. This is partly due to the HISP project that used the province as their site to pilot and implement the district health information systems; the health information technology in the province is well-developed, and almost all facilities have an electronic database that is easily accessible (Braa and Hedberg, 2002). HISP and other initiatives also led to increased recognition about the importance of health information strengthening as a core strategy to re-engineer the public health system in South Africa (Schonfeldt et al., 2011). Currently, HISP is running several projects in South Africa that all aim to further improve both the quantity and quality of HISs, including the National Health Information Repository and Data Warehouse project (NHIRD), which aims to harmonise different types of information in an integrated repository. Ideally, this health information includes annual HIV and Syphilis surveys, demography and health surveys, resources on child health, financial data about facilities, and information about health-related human resources (Health Information Systems Program South Africa, 2015).

In line with the National Development Plan (NDP), which aims to significantly improve health outcomes for South Africans by 2030, the WCDoH aims to: “ensure alignment in health information systems (including revenue and billing, patient, pharmaceutical application, network infrastructure, etc) between the province and other national ICT systems to for effective coordinator in the health sector” (Engelbrecht, 2012). According to Dr. Beth Engelbrecht, Head of the WCDoH, this means that on provincial level, improvements need to be made to link individual patient-level information to support clinical care, routine reporting and health intelligence (Engelbrecht, 2012). Increased linkage of individual patient information can improve the tracking of patients across different clinics, reduce duplicate folders and prevent loss-to-follow-up (LTFU) among mobile patients.

Currently, there are still various HISs in the Western Cape that capture various forms of information. Firstly, there is the Patient Registration and Health Management Information System (PREHMIS), which is used for patient administration and collecting health information for clinics under management of the City of Cape Town (Nicol et al., 2016). Secondly, the province has the Evaluation of the Khayelitsha AIDS Programme (EKAPA). This programme stores HIV- and TB-related clinical information, and is currently slowly being integrated into the Electronic Medical Record System (EMRS) (Schmidt, 2016, Schmidt, 2019).

Another initiative that is being materialised at present is to harmonise different sources of health information in in the Western Cape is the Primary Health Care Information System (PHCIS). This programme is developed by the WCDoH and collects patient information, clinical visits and admissions to provincial clinics. PHCIS, EKAPA and PREHMIS are not currently integrated into a collective database, but the Provincial Health Data Centre (PHDC), a collaboration between the WCDoH and researchers from UCT, is developing solutions to better integrate the different systems and give people the chance to find up-to-date patient information (Mehta et al., 2018). PHDC started in 2015 and aims to integrate individual-level patient data from different, often disconnected databases and capture information in a provincial data repository (Schmidt, 2019). This information can include but is not limited to demographic data, clinical data, pharmacy data or visitation and treatment data.

Harmonising different sources and individual-level patient data is a complex and socio-technical process and PHDC is experiencing many challenges in their attempt to establish and optimise the central provincial information repository. Factors that make data integration difficult include the fragmentation among different large-scale databases and accessing HIV-related information. Furthermore, the project also experiences a disjuncture between the aspirations of the PHDC to harmonise individual-level patient data at provincial scale and feasibility and practical reality (Schmidt, 2019).

Despite the experiences challenges, PHDC is making tremendous progress in trying to harmonise different HISs in the province (Schmidt, 2019, Mehta et al., 2018). Although there is little published research about the long term benefits of these data harmonisation processes on health outcomes in patients linked to the public health care system, a recent trial among pregnant women in the Western Cape showed that the information collected on the use of chronic medication by PHDC were more reliable than the information collected in the medical records of the medical hospitals (Mehta et al., 2018).

In addition to HISs in the public health care system in South Africa, private clinics use their own information systems which capture patient level data. These systems are not linked to any of the primary, secondary or tertiary public health care facilities (Matsoso and Fryatt, 2013). Lastly, NGOs and NPOs also often have their own data systems that collect health information, which are primarily used for monitoring and evaluation purposes and to track the success and challenges of implemented health programmes. The Desmond Tutu HIV Foundation (DTHF), one of the largest NGOs in South Africa, developed their own biometric system to capture patients medical history and progress through the HIV cascade (Nglazi et al., 2012). The DTHF currently runs the Zimele project, a large-scale HIV study that aims to provide HIV services to more than twenty thousand participants in Cape Town. Using the Broccoli biometric system allows the NGO to track their participants through the cascade of care and evaluate the programme at the same time (Nglazi et al., 2012). Other NGOs such as Grassroots soccer and Sonke Gender Justice also have their own ways of capturing health information which is used for research outputs, informs new programmes and are used to support funding proposals (Merrill et al., 2018).

In conclusion, this section shows that in post-apartheid South Africa, there have been several important initiatives which have reshaped and improved the use of health information and enhanced the development of HISs in the country. However, there are still persistent challenges that remain, which include the lack of linkage of health information systems between different levels of the health system and other organisational and political problems which effect the use and exchange of health information in the health system.

2.5 Expanding the view of what health information is – understanding the culture of information and informal information

In the sections above, I have explored the important role of that health information plays in the larger health system and situated this role into the historical context of South African health services. I have also outlined the development and strengthening of (routine) HISs in post-apartheid South Africa and highlighted some the challenges both the designers and users have encountered along the way. In the paragraphs that follow, I will address two current gaps in the literature on health information that currently exist. The first one is the lack of knowledge about the role of informal health information within the health system. The second gap focuses on the need to include community actors as active users of health information, who use creative strategies to get access to information, but are often seen as only passive recipients of information.

Until now, I have used the term health information to primarily describe the complexities of storing, using and distributing *routinely* collected health information. Routine information is often comprised of information that is collected in a systematic way and stored electronically. Ideally, routine information is updated regularly and accessed easily to facility decision-making in the health system (Braa and Hedberg, 2002, Lippeveld, 2001). Routine information can be produced through monthly or quarterly statistics, performance reports, or patient records that can be used to inform new health policies, programmes or practices.

Albeit important, health system actors use a variety of information in their daily work, which includes both routinely and non-routinely collected and 'soft' or 'informal' information (Scott, 2016). Informal information is often underused in efforts to strengthen health information use and exchange. It is therefore crucial to understand what informal health information is and what this type of health information plays in the health system.

Informal information or *soft information* can include experiences, conversations, narratives and tacit knowledge (Mutemwa, 2005, Scott et al., 2014, Williamson and Kaasbøll, 2009, Østmo, 2007, Hendriks et al., 2016, Scott, 2016). In this context, tacit knowledge constitutes the not-easily-transferable expertise, the type of information that is difficult to record and capture, but derives from people's individual experiences and wisdom (Grant, 2007). Other types of tacit knowledge also includes observation, experience through work or training, gut feeling, or practical understandings of how the world works (Holste and Fields, 2010, Hendriks et al., 2016). Tacit knowledge is often divided in *informal* tacit knowledge and *formal* tacit knowledge. Informal tacit knowledge is learned through interaction with others, which can include friends, acquaintances, colleagues or patients (Clarke and Rollo, 2001). Formal tacit knowledge, on the other hand, is learned in more institutional ways, such as through training, education or when attending conferences or workshops (Clarke and Rollo, 2001). Both *informal* and *formal* forms of tacit knowledge are important forms of informal health information, especially as they recognise that not all information is easily measured and transferred. Therefore, tacit knowledge, as Holste and Fields (2010) argue, is the unwritten memory of an organisation, which cannot be stored within an technological system, but can be accrued through training, team-building and skill-building (Holste and Fields, 2010).

In the health system, informal health information is mainly collected and distributed through communication with staff, colleagues, and mentors; it informs the daily practice of actors in the health system, and can be seen as part of health actors' internal decision-making (Klein, 2008). Informal health information is not always systematically collected and can be based on intrinsic experiences, this type of information is harder to measure and therefore remains largely unacknowledged as useful evidence in decision-making processes (Williamson and Kaasbøll, 2009). Examples of informal, or soft information include patient complaints, observations during rounds, feedback from other staff members and experiences in the hospital. According to Williamson and Kaasbøll (2009), it is unfortunate that soft information is excluded from formal HISs; their work showed that facility managers in Cape Town used both routine and informal information during their work in the clinic (Williamson and Kaasbøll, 2009). To optimise the use of informal information in the health system and to make this type of health information more visible, Williamson and Kaasbøll suggest the development of *informal information systems,* which actively includes information collected through the interaction with peers, colleagues, patients and other managers (Scott et al., 2014, Williamson and Kaasbøll, 2009). This informal information system aims to compliment the traditional RHISs and can be used for decision-making in the health system.

While research on the use and effects of informal health information in the health system is scarce, there are some notable exceptions, which include scholars such as Østmo (2007), Mutemwa (2005) and Scott (2016). Vera Scott focused her doctoral research on the role of routine and informal health information among managers in several clinics in Klipfontein sub-district, the same geographical area as the iALARM study (Scott, 2016). Within her work, she found that managers used a diverse range of health information in their work, and especially valued the role of informal information when dealing with day-to-day problems in the clinic. Furthermore, her study showed that managers did not only use information that was available to them, but also generated their own health information which informed their routines and practices. Using several case studies, Scott demonstrates the interdependent relationship between informal and formal health information and emphasises the potential to use both types of information concurrently to improve service delivery and practice among managers (Scott, 2016).

Østmo and Mutemwa also conducted research in Sub-Saharan Africa, and similarly to Scott, they also found that the use and impact of informal information in the health system is much more common than acknowledged (Mutemwa, 2005, Østmo, 2007). Mutemwa's work focused on the use of information among district managers in the health management information system (HMIS) in Zambia. He found that managers, especially within meetings, used a combination of verbal, training-derived and experimental information to contribute to the conversation and rarely used routine information within this setting (Mutemwa, 2005). Furthermore, he demonstrated that, when managers used routine information, this process was often messy and non-linear. Mutemwa also points out that decision-making in the district health system was often guided by verbal information-sharing, and with respect to these complexities, there is need to rethink HMISs to be more inclusive of informal health information (Mutemwa, 2005). Elise Østmo's thesis, which was a part of the HISP evaluation project, analysed the role of health information among facility managers in the Cape Town Metropole. Her research attempted to disprove the understanding that facility managers do not use health information due to lack of interest and lack of training. She found that facility managers did use several kinds of information in their daily work, including routine forms of health information, but similarly to Scott, relied heavily on informal forms of information when making decisions in the clinic (Østmo, 2007). In summary, Scott, Mutemwa, Williamson, Kaasbøll and Østmo all urge us to reconceptualise HISs and make them more adaptable to incorporate various forms of information, including both routine and infromal health information. Furthermore, findings from the research above show that there is a need to broaden our understanding of what health information is, how it is used and what role it plays in the health system.

As pointed out above, many HISs researchers emphasise the need to think about health information more holistically and to improve the use and sharing of information in the health system. This can be achieved by creating a more inclusive HIS that embraces the collection, use and exchange of both routine and infromal health information, but also through the promotion of a *culture of information* (Østmo, 2007, Aqil et al., 2009, Lippeveld, 2017, Akhlaq et al., 2015). This term, which is borrowed from organisational studies and information technology (IT) research, and according to Curry and Moore (2003) describes: "a culture in which the value and utility of information in achieving operational success and strategic success is recognised, where information forms the basis of organisational decision-making and IT is readily exploited as an enabler for effective Information Systems" (Curry and Moore, 2003, p.94). Deriving from this explanation, Aqil et al. (2009) define a culture of information within HISs as the need to encourage health systems actors to actively use routine health information in their decision-making processes (Aqil et al., 2009). This can be done by collecting, analysing and using information as part of daily practices. Aqil et. al (2009) and Lippeveld (2017) acknowledge that the effect of promoting a culture of information is difficult to measure, as the values are related to organisational processes, the quality of information and feedback of other health systems actors can be subjective (Aqil et al., 2009, Lippeveld, 2017). Furthermore, the word 'culture' has many different meanings and is a complex phenomenon, depending on the context or discipline in which it is used (Geertz, 2008). Regardless of the vague explanation of the *culture of information* in HISs literature, the term does create new opportunities and opens up conversations for researchers and interventionists to start thinking about a more inclusive health information system whereby the importance of both formal and informal information is acknowledged.

2.6 The role of health information and community engagement

As demonstrated in the previous sections, health information, whether routinely or informally collected, plays a significant role in improving access to, distribution of and quality of health services in South Africa. The second big gap in literature that I want to address in this literature review is the absence of community stakeholders in understandings of active users of health information.

In most of the health information systems literature, community members, citizens and patients are considered to be passive actors in the health system; but in fact, they may also be active agents who have an interest in using health information to address public health service delivery issues or keep the health system accountable. Often, the health system produces information that is distributed to the community, for instance, through health education initiatives or mHealth campaigns. These distribution channels strive to inform community members and patients about new programmes, policies, guidelines or services, or remind patients about their next appointment or need to visit the clinic (Nachega et al., 2016). These forms of information-sharing are important, with the goal to inform and alert patients, but they are not intended to improve active use of information-sharing across different health systems actors. Within HIS strengthening efforts, there is often an acknowledgment of community stakeholders as actors in the larger health system, but there is very little empirical research on the role of community members as active users of health information (Akhlaq et al., 2015).

This points to a persistent gap in health information research that focuses on the active use of and demand for health information as a part of community engagement, not just to inform patients and community members about new health programmes and guidelines. Some information produced by the health system is distributed to the community through education initiatives or mHealth campaigns. These initiatives strive to inform community members and patients about new programmes, policies, guidelines or services, or remind patients about their next appointment or need to visit the clinic (Nachega et al., 2016). Albeit important, they do not necessarily provide the information needed for community organisations to strategize their own health strengthening campaigns.

In the past few decades, the demand for health information has increased, which has led to the development of new HISs and information harmonisation projects. These endeavours have included some incentives to both collect health information from communities to support health system decision-making, as well as to more actively distribute health information from health systems actors to the larger community (Colvin et al., 2018, Byrne and Sahay, 2007, Vest and Gamm, 2010). These initiatives are realised through community health management information systems (CHMISs) or community-based health information systems (CBHIS), central dashboards that collect individual health information, demographic information and other health information from the community to support decision-making and inform health programmes (Vest and Gamm, 2010, Jeremie et al., 2014). The ideas for establishing CBHISs in LMICs was first introduced in the 1970s by international development agencies, who argued that the active involvement of marginalised people in health and decision-making could lead to broader empowerment and positively improve social development programmes (Dreze and Sen, 1999). Providing access to information was one of the strategies to promote community engagement and improve community health.

In South Africa, Elaine Byrne and Sundeep Sahay (2007) conducted research on a CBHIS intervention to monitor child health within a community in rural South Africa (Byrne and Sahay, 2007). Their work focused on the participation of community members in the design of the information intervention that monitored child health. Their research found that for CBHISs to work, both the users and the producers of the information need to be involved in the process of the information system design, as field-level health workers spend a significant amount of time collecting, storing and reporting health information. To make effective use of a CBHIS, there is a need to understand the local reality of the people who are going to use that information, as well as the cultural context in which they operate (Byrne and Sahay, 2007). It is furthermore important that the information collected is distributed to local government structures, as well as presented to the community in accessible formats, which include presentations at village health days, or through poetry and dance performances (Byrne and Shafer, 2014).

Another example of the successful implementation of CBHISs is provided by Jeremie et al. (2014) who explored the use of community-level health information to action decision-making within the larger health system of Kenya (Jeremie et al., 2014). The CBHIS was developed as part of the Kenya Essential Care Package, which, promotes evidence-based community meetings to regularly share collected health information. The information was collected by CHWs and members from clinic committees and included demographic and disease-specific information, as well as evidence to monitor and evaluate existing health interventions (Jeremie et al., 2014). Findings from this study show that storing information within a CBHIS as well as sharing the health information with the community has contributed to bridging the interface between community and health by providing regular, evidence-informed dialogues (Jeremie et al., 2014). The positive effect of information-sharing between community representatives and other health system actors are similar to the findings from Igara et al. (2007), who conducted pilot study in Zanzibar organising health information sessions with information users from different levels of the health system. Igara et al. found that when the active use of health information was promoted among participants from different levels of the health system, it led to better decision-making processes and increased use of health information in day-to-day health practices (Igira et al., 2007).

Despite the development of several initiatives that promote the use of community health information in health system decision-making among health scholars, most interventions only focus on collecting information from the community to feed into higher levels of the health system, but are not necessarily designed to disseminate health information from the established HISs back to the community. Reported barriers are poor quality, poor access to information, lack of training and poor identification of information needs (Lippeveld, 2017). The availability of too much, irrelevant, outdated or incomplete information is also viewed as a challenge to effective health information-sharing between community members and other stakeholders in the health system (Akhlaq et al., 2015). As with other health information interventions, the production of health information does not necessarily translate to better information use and exchange. Other implementation issues with CHMISs in LMICs include the absence of affordable and effective technology, and the lack of long-term finances and dependence on donor funding, which results in the development of many pilot projects which are never implemented on a large scale (Vest and Gamm, 2010). This is unfortunate, as understanding the use of health information among community stakeholders can impact development and implementation of health programmes in communities, inform health workers about persistent health services issues, empower community members and encourage community mobilisation (George et al., 2015b).

While community actors are not always prioritised in health information research and are rarely considered as active users of health information, this does not mean that this group of actors does not have a need or desire to use information to address health challenges or to keep the health system accountable.

In South Africa, community organisations have effectively used health information and evidence to address major public health issues, as happened during the height of the AIDS epidemic in the 1990s and early 2000s. By studying and distributing academic information produced in the North about the disease and available treatment, the Treatment Action Campaign (TAC) paved the way to get ARV treatment rolled out in South Africa, to destigmatise the disease, improve health services and influence health policies in the country (Colvin, 2014, Heywood, 2009). Within their advocacy efforts, TAC campaigned for “greater access to treatment for all South Africans, by raising public awareness and understanding about issues surrounding the availability, affordability and use of HIV treatments” (Friedman, 2010). Through the use of clinical and scientific data on HIV/AIDS, which was mostly produced in the Global North, TAC was able to show the gap between evidence and treatment in Western countries and promote the distribution of treatment in the Global South. Furthermore, TAC addressed the pricing of pharmaceutical drugs and need for affordable ARV treatment; broke down stigma attached to HIV/AIDS; and advocated for marginalised groups, including immigrants, members of the LGBTQ+ community, sex workers and other vulnerable populations (Heywood, 2009). To achieve maximum reach, TAC distributed the necessary information to the community by using novel strategies—such training expert patients who would educate fellow community members about HIV and the patient's right to care (Colvin, 2014). Although antiretroviral therapy (ART) is now widely available, the need to distribute health information to the community remains; for instance, to inform patients about new, preventative HIV services such as voluntary male medical circumcision (VMMC) and Pre-Exposure Prophylaxis (PrEP), as well as the effects of long-term treatment on the risk of developing other non-communicable diseases, such as cervical and prostate cancer (Colvin, 2014). Part of TAC's long term strategy is to improve the availability and affordability for both HIV care and other health care services, and to inform, educate and empower patients through actively sharing academic evidence and other health information (Colvin, 2014, Heywood, 2009). Using this form of evidence-based activism shapes TAC's campaigns both strategically and politically, and has informed many other health advocacy initiatives, including the work of the Social Justice Coalition (SJC) and Ndifuna Ukwazi, an organisation that uses research and legal litigation to emphasise spatial apartheid and to convince the government to build more affordable housing structures in densely populated urban areas (Social Justice Coalition, 2008) (Ndifuna Ukwazi, 2017). Although often not actively promoted among community members, there are several sources of information which are open for public use, and which regularly collect information. Stats SA publishes census information every ten years, and the website of the South African Police Service publishes yearly crime statistics that are subdivided per police precinct (South African Police Service, 2018).

In South Africa, community members can also demand health information from health facilities, which happens often through clinic committees. These committees are allowed to demand reports and statistics from individual clinics to address health services concerns, or to inform community members outside of the health committee (Western Cape Department of Health, 2016). Health committees are formal structures through which community members are specifically appointed to monitor the performance of public health facilities, with the aim to improve health services and patient health outcomes (McCoy et al., 2011). According to the Western Cape Health Facilities Board and Committees Act (2016), the clinic committee has the power to "obtain information it requires from the management of the primary health care facility if the information does not violate the rights of a patient or staff member to privacy and confidentiality; and request from the management of the primary health care facility copies of routine progress reports that have been generated" (Western Cape Department of Health, 2016, p.7). They can use that information to educate and inform the community, to mobilise, to put pressure on the facility to improve the services, and to give feedback to facility managers.

While there is little empirical research conducted in South Africa on when and how clinic committees ask for and distribute health information, a conference paper written by Colvin, Schkolne and Swartz (2011) illustrates how a clinic committee interacts with health information in Town Two, Khayelitsha, Cape Town. The paper describes how an eager sub-district health manager actively feeds back weekly statistics on diarrhoea and other local health information to a clinic committee during a regular meeting. Although understanding the information presented, clinic committee members did not interact with the actual information, but used the opportunity to raise other health issues and needs in the community (Colvin et al., 2011). This research shows that there is a potential to share health information within health committees, but that the outcome might be different as expected, due to the relationship people have with the information, the context in which in the information is presented, and other health issues that might be prioritised by community members. Furthermore, these findings also show that community members have a right to demand information to address health service issues and to keep the health system accountable (Colvin et al., 2011). Although not particularly focused on the use of health information, research from other LMICs such as Kenya, Zimbabwe, Peru and Uganda shows that clinic committees have a positive impact on health services, including the improvement of referral systems and better communication between health staff and communities (McCoy et al., 2011).

Even though there is a lack of access to information for community members, this does not mean that community members do not have a need to use health information. Health information can be a useful tool to inform community health interventions or drive community participation campaigns (George et al., 2015b). In LMICs, community participation forms an integral part of the health system, but community groups rarely become involved in information use and exchange (George et al., 2015b). In South Africa, there are a few examples whereby the community actively participates in collecting health information for health service improvement, predominantly through conducting social audits (Andersson et al., 2004). In these cases, community members, NGOs and government officials actively work together and conduct interviews, surveys and focus groups with clinical staff and patients to develop targeted action plans to improve provincial health services in Limpopo, Gauteng and the Eastern Cape (Andersson et al., 2004). The Social Justice Coalition (SJC) have also collected their own statistics to advocate for better sanitary conditions and to monitor government services in Khayelitsha. Through the use of social audits, SJC showed that there is a lack of communal toilets in Khayelitsha, and those that are available are often in disrepair or unusable; through this social audit, they urged the City of Cape Town to increase the maintenance budget and to provide janitorial services (Colvin et al., 2011).

The techniques that SJC used to address the sanitation issues in Khayelitsha derive from India, where community participation often takes the form of community-based monitoring (CBM), a tool employed by community members and NGOs to keep health services accountable for the quality of care provided in public health care facilities (Shukla et al., 2011, Balestra et al., 2018, Garg and Laskar, 2010). This participatory process allows community representatives to collect their own evidence to show deficits and shortcomings in health services and to keep the health system accountable (Balestra et al., 2018). CBM was officially introduced in India in 2007 as part of a governmental programme to improve health service delivery; since then, it has also improved communities' relationships with the state, empowered the community through knowledge and education, promoted gender equality and uplifted marginalised groups (Balestra et al., 2018, Shukla et al., 2011). Another CBM project that proved successful was undertaken in rural Uganda, where NGOs encouraged communities to be more involved in improving local health services and keeping the health system accountable for their performance (Björkman and Svensson, 2009, Bjorkman Nyqvist et al., 2014). This monitoring was done through an experimental intervention which used patient report cards to collect health information on the performance of the clinic, and later discussed these cards during village meetings. This form of health information dissemination and open dialogues triggered health staff to improve their services, which led to reduced child mortality and increased child weight (Björkman and Svensson, 2009).

Another way in which the community actively engages with various forms of information is through the use of 'local knowledge'. According to Jason Corburn (2003), who analysed the use of local knowledge among community members to stress emerging environmental issues in vulnerable neighbourhoods in the United States, community activists actively draw from their personal experiences, stories of other community members, sights, smells and observations to convince environmental and public health planners to listen to them and conduct research and intervene where needed (Corburn, 2003). This rich local accounts of issues on the ground and active collaboration with communities can fill in important evidence gaps in health data bases and can be included to set research priorities in environmental health planning (Corburn, 2003).

Similar to Corburn, Kamanda et al. (2013) also stress the importance of engaging with the community during research and advocate for the use of community based participatory research (CBPR), but argue that community engagement is important at all stages of public health research, whether qualitatively or quantitively conducted. The authors employed CBPR during a longitudinal cohort study to examine the health and well-being of orphaned and other vulnerable children in Kenya. Through using CBPR, Kamanda et al. (2013) were able to get access to the community through Community Advisory Boards and by setting up relationships with chiefs and religious leaders. They were also able to more easily recruit participants and follow-up on them during the study (Kamanda et al., 2013). CBPR also played a role in the analysis, interpretation and dissemination of research findings back to the community, as community leaders play analysed and translated research data into an accessible format for dissemination to community members and participants (Kamanda et al., 2013).Summarising the above, it becomes apparent that health information whether routinely or informal plays a significant role in the larger health system, but the complexity of health information is not always adequately explored in health information systems literature. Furthermore, although most literature only focuses on the use of health information as a tool for decision-making among managers, others in the health system or community who use health services may also be interested in using health information. As exemplified in the previous sections, community members often actively seek access to information, collect their own forms of evidence or use other strategies that rely on health information to address health services issues and keep the health system accountable.

2.7 Exploring theoretical frameworks to understand the complex role of health information

In the first six sections of this chapter, I have sketched the landscape of health information research and situated this in the larger health system. I also pointed to the important role that health information plays in the different building blocks of the health system, with a focus on LMICs. After that I have outlined the context in which health information is produced and used, and have highlighted some of the pertinent gaps in HIS research, such as the lack of empirical research on how health information is used in practice, the role of informal forms of health information within the HIS, and how information is and can be used within community engagement.

In this section of the literature review, I lay out several different conceptual frameworks that effectively engage with the production, use and exchange of health information and how they were used to guide this research. I have deliberately used a combination of health systems and HISs frameworks and supplemented these with social theory, due to the complexity of the topic area and the diverse contexts in which my case studies are situated. As this work aims to understand health information from a social and cultural perspective, I have chosen different frameworks and theories that firstly, acknowledge that HISs are built as more than merely technical systems, and secondly, also account for the social context in which health information is produced, used and exchanged. By using these various frameworks and theories, I am able to contextualise the multitude of ways in which health information in Gugulethu is used and exchanged, and to explore the complex role that health actors play in this process.

The PRISM Framework

The Performance of Routine Information System Management, or PRISM, framework was introduced by Aqil et al. in 2009, and focuses on strengthening the use of routine health information within HISs that are developed to collect and produce health information on a country level (Aqil et al., 2009). The framework was developed to provide an alternative perspective to HMISs in LMICs, which were often modelled upon epidemiological surveillance systems, would focus on collecting information on one single disease (such as diarrhoea or HIV), and were heavily influenced by international donors such as USAID and UNICEF. Despite the importance of collecting this information, the actual information that was produced in HMISs was often incomplete and of low quality (Lind and Lind, 2005).

In order to improve both the information quality and the continuous use of information, Aqil et al. argue that it is important to develop health information interventions based on three different types of factors: 1) technical, 2) organisational and 3) behavioural (Aqil et al., 2009). These different factors together influence the process of collecting routine health information and impact the quality and usefulness of the information. The technical factors include the complexity of the design of the HIS, or unusable computer software. Organisational factors can include training capacity for health workers, governance, or the availability of resources. Behavioural factors can include the competency and confidence of actors to work with the information, as well as the demand for or quality of information. Together, all of these determinants impact the HIS strengthening processes, as well as the use of health information and ultimately the health status of the patient. According to Aqil et al., improving the performance HISs can only be achieved when analysing the role of each of the components and developing interventions that address the complex role of each of these components (Aqil et al., 2009). Lastly, the PRISM framework draws attention to neglected processes in the HIS, including information quality and feedback loops among health managers from different levels of the health system (Aqil et al., 2009).

MEASURE Evaluation Initiative

Another framework that was developed to strengthen health information use and exchange in LMICs and better understand the outcomes of health interventions in the health system is the MEASURE Evaluation Initiative, which has facilitated HISs strengthening initiatives since 1991 (Foreit et al., 2006). The initiative is funded by USAID and aims to improve information demand, collection and analysis in low-resource countries with a high burden of disease. MEASURE focuses mostly on HIV programmes, but also promotes the use of all kinds of health information to guide policymaking, programme design, management and series provision (Foreit et al., 2006). The MEASURE framework is intended to assist health actors to better understand the role of information in policy and practice. MEASURE strongly promotes the use of routine health information for evidence-based decision-making on a country level and uses different strategies to evaluate the use of and demand for health information (Nutley and Reynolds, 2013). Most of MEASURE’s evaluation projects are strongly informed by the PRISM framework and research conducted by the Health Metrics Network, but compared to PRISM focuses on the use of health information in decision-making and practice, and does not necessarily evaluate the ways in which this information is produced. Although the MEASURE Evaluation Initiative promotes the use of routinely collected health information, it does acknowledge that health systems actors use various other forms of information to inform their decision-making and do not only rely on routinely collected health information. Furthermore, the MEASURE Evaluation Initiative recognises the political power and context in which HISs in LMICs are developed, and also acknowledges that information can be used and demanded by people who are not health care staff (Foreit et al., 2006).

Interactive Sociotechnical Analysis (ISTA)

Closely aligned with the perspectives of Aqil et al., is the consideration that HISs, and health care systems in general, are sociotechnical systems (Harrison et al., 2007). A sociotechnical system, as understood by Harrison, Koppel and Bar-Lev (2007), assumes that when implementing new solutions to strengthen HISs, technical problems will arise, but many consequences and failures also derive from sociotechnical interactions (Harrison et al., 2007, Harrison and Nutley, 2010). These sociotechnical interactions are formed by organisational cultures, social interactions and physical environments of those operating in the health system (Harrison and Nutley, 2010). When observing HISs as sociotechnical systems, it is therefore key to acknowledge the relationship people have with the technology, as well as with each other, as this shapes the system, as well as the outcome of efforts to strengthen the system. To better evaluate the unintended consequences of new health information technology (HIT) from a social perspective, Harrison et al. developed the Interactive Sociotechnical Analysis (ISTA) framework, which emphasises the complexity of sociotechnical interactions and rejects the presumptions that problems in the HIS can be solved by only introducing technology. Furthermore, the framework encourages those who interact with HISs to see the challenges that may arise as opportunities for learning and improvement, not as barriers (Harrison et al., 2007, Harrison and Nutley, 2010). The ISTA framework is mostly used within implementation research of new technologies. In line with Harrison and Nutley, Karsh et al. (2010) argue that within HISs strengthening, there is no one-size-fits-all solution and it short-sighted to assume that people are unaffected by the technology they use (Karsh et al., 2010). According to Karsh et al. there is insufficient contextual research conducted to meaningfully support the social aspects of HISs strengthening. This is problematic, as new systems can only be effective if they facilitate collaborations between health workers, patients and families, and if HISs researchers acknowledge that the informational needs might differ across context and between actors (Karsh et al., 2010).

Framework	Key concepts	Strengths	Weaknesses
PRISM	Focuses on how 1) technical, 2) organisational, 3) behavioural factors impact the development of RHISs.	• Understands how different determinants and contexts in the larger health system affect the production and collection of routine health information. • Has been widely used to strengthen HISs in LMICs.	• Only focuses on the development and strengthening of RHIS on country level (or regional level) of the health system. • Emphasises primarily the production and collection of information, less about how this information is used in practice.
MEASURE	Evaluates and monitors how health information is generated and used on local, national and global levels.	• Acknowledges the social complexities of the health system. • Identifies the need to develop community-based health information system and community led interventions.	• Strong emphasis on HIV information. • Mostly focuses on the use of information, not the production of health information (or lack thereof).
ISTA	Describes how social interactions affect and impact new health information technologies.	• Focuses on how new information technologies are shaped by social interactions and what the social interplay is between old and new technologies.	• Focuses mainly on the technological design HISs, not on the quality of information it produces or who has access to it.

Table 2.1: Comparative overview of HISs frameworks

In **Table 2.1**, I give a comparative overview of the three different HISs frameworks. As the table indicates, all frameworks have strengths and weaknesses. Therefore, I used different elements of all three models to conceptualise my PhD thesis and to analyse the information which I collected during my research. I used the PRISM framework to explore and better understand how the needs and values of people tasked with producing the data (data people) and managers who need to use the data (action people) are not always aligned, and how this can cause friction that affects the use of and access to health information (Aqil et al., 2009, Lind and Lind, 2005). I also used the PRISM framework to understand how the lack of training, supervision, resources and absence of a culture of information potentially impact on the use of health information among managers and other health systems actors. Additionally, Karsh et al. (2010) and Harrison et al. (2010) informed my thinking and analysis in my case studies, as their ideas assisted me to identify and unpack the sociotechnical factors that are impacting the access to and use of health information in Gugulethu. Furthermore, similarly to the MEASURE Evaluation Initiative, I explore how health information is embedded in a larger socio-political context, which includes who has access to health information and how it can be used.

Actor Network Theory

To further make sense of my information, I also drew on several social theories that are embedded within health information research. One of the most-used theories in HISs research and IT research is Actor Network Theory (ANT). ANT was developed by the philosopher Bruno Latour in the late 1970s to address the complexity of technology studies from a social science perspective. ANT is inspired by Latour's earlier observations and descriptions of the 'Laboratory Life' (Latour, 2005, Latour and Woolgar, 2013). In his book, 'Laboratory Life: the construction of scientific facts' (1979), Latour describes the daily activities of scientists in a university laboratory, focusing primarily on the interaction between scientists and their equipment, and argues that this interaction is not completely scientific and objective, as the measurements of scientific facts are constructed through dialogue, diagrams and documents (Latour and Woolgar, 2013, Latour and Woolgar, 1979). Latour states that scientific facts can be understood as sociological, as they are created by the whole scientific community or network, and not one individual (Latour, 2005, Latour and Woolgar, 2013). In his early research on the 'Laboratory Life', Latour acknowledges the power of the scientific network and argues that the people and instruments in the laboratory collectively construct scientific knowledge—and therefore that knowledge, or information, is socially produced (Latour and Woolgar, 1979).

Latour's findings from 'Laboratory Life' have been adopted by Law and Mol, who developed the sociotechnical framework, which is used widely in Information System Research (IS) and HISs research (Law, 2009). Latour and Law developed this sociotechnical argument further and suggested that non-human entities such as computers, data, schedules and folders all have agency, similar to human entities (Latour, 2005, Cresswell et al., 2010, Ihde, 1995). The scholars dismiss the idea that technology impacts humans as an external force, and deconstruct the idea that technology is a 'black box' that contains information; rather, technology plays an active role that is determined by its position in the ever-changing network (Cresswell et al., 2010, Callon, 1984) It is the relationship between these human and non-human entities, the network of actors, that is under investigation in this theory, not the individual human or non-human entities. ANT is particularly developed to describe the processes that occur between technologies and people, as well as understand the process of development of the actual technology. For Latour, both human and non-human entities are equally balanced in agency and power, and are therefore named ‘actants’ (Gourlay et al., 2015, Latour, 2005, Law, 2009).

ANT has been adopted by several HIS scholars to investigate the unintended consequences of the implementation of new technological systems that aim to improve the use of and demand for health information. Braa and Hedberg (2002) used ANT in combination with action research when analysing case materials from the HISP project in South Africa (Braa and Hedberg, 2002). ANT was also applied by Braa, Monteiro and Sahay (2004) to develop their ‘Networks of Action’ to build sustainable health information interventions in developing countries and used by Cresswell, Worth and Sheikh (2010) to interpret the complexities of data harmonisation and data use within different health care settings (Braa et al., 2004, Cresswell et al., 2010).

ANT has received substantial criticism over the years, as some scholars argue that the theory might offer too little constructive criticism, as you can investigate processes within networks endlessly without any tangible outcomes (Latour, 2005, Ihde, 1995). Secondly, ANT claims that people and things have the same agency, which dismisses several powerful characteristics of society (which consists of human actors) that might be internally or externally constructed, such as inequality, racism, gender dynamics and power relations and hierarchy (Ihde, 1995). Latour focuses on the power dynamics that are created through the associations and relationships of two equal actors, which can in reality never be completely equal (Ihde, 1995). Thirdly, the theory offers little room for reflexivity and positionality when doing research (Law, 2009). Despite these critiques, ANT is still extremely popular as both a theory and a method when conducting health information research.

Understanding health information as ‘institutional glue’

The second theory I used to explore the demand for and use of health information is Jorn Braa’s theory that views health information as ‘institutional glue’. Jorn Braa was one first researchers who was tasked with redesigning and decentralising health information systems in post-apartheid South Africa, and developed and monitored several Health Information System Programs (HISP) in different provinces in the country between 1996 and 2001 (Braa et al., 2007, Braa and Hedberg, 2002, Braa et al., 2004). During this process, he was confronted with fragmented systems and realised that a large amount of health information was scattered unevenly within and between different provinces and districts. Attempting to streamline the various systems and databases across these different places, he developed a ‘flexible standardisation theory’, which enabled health managers to implement their own systems to produce health information, but within the parameters of minimum requirements which ensure that the health information was high-quality (Braa et al., 2007, Braa and Hedberg, 2002). These flexible standards ensured that high-quality information was produced regularly, but also allowed the data to be tweaked and changed according to the needs of the district or sub-district (Braa et al., 2007). Throughout the roll-out of the HISP on a district-level, Braa observed individuals' interaction with the new reporting system and concluded that the use of health information differed drastically between health actors, based on the social relationships between health workers and health managers (Braa et al., 2007). This realisation convinced Braa to rethink the complexity of health information, this is often 'institutional glue' of the HIS. Here, Braa points to active use and exchange of health information as the 'social fabric of the health system', as it "reproduces the social relationships and contracts" (Braa et al., 2007, p.119). These producers, which can either be the technology or the human who collects that information are always interconnected and indefinitely linked to other networks, of which may lie outside of the HIS.

In his work, Jorn Braa also compared the exchange of information with the interchange of 'gifts', a concept developed by Marcel Mauss which explains the power of giving and reciprocation as a way of building social solidarity (Braa et al., 2007). The act of giving, receiving and interchanging 'gifts' happens, according to Mauss, in every society, and creates both obligations that are embedded by morality, and relationships between those who give and who receive (Mauss and Halls, 2000). This connection is laden with power, as it forces the receiver to reciprocate, creating a relationship of dependency and obligation (Mauss, 1925). Braa's theory of 'institutional glue' and Mauss's concept of 'gifts' both emphasise the complex role that health information plays within the larger health system. In different ways, Mauss and Braa demonstrate that the practice of exchanging any form of information is often intangible, but the actual data changes meaning over time, as health information moves between different health actors who form and reinforce relationships that are laden with power (Mauss, 1925, Braa et al., 2007, Braa et al., 2004).

In the paragraphs above, I have summarized different frameworks and explained their position within the HISs literature. Albeit different, all frameworks and social theories have contributed to the analysis of my research findings and assist me to examine how, when and why health information is used, or not used in the larger health system. The PRISM framework has sensitized me to the fact that the use of RHI is inherently impacted by technical, organisational and behavioural factors. These factors are also acknowledged in the interactive socio-technical analysis model (ISTA), but Harrison, Koppel and Bar-Level also encourage researchers to investigate contextual factors that impact the use of health information, which can differ across context and between various actors (Harrison et al., 2007). Jorn Braa (2007) agrees with the ISTA and PRISM models and concretizes the contextual factors that come into play when producing health information by developing a 'flexible standardization theory' that allows health managers to implement flexible health information systems that still accommodate the requirements of the district (Braa et al., 2007). A more philosophical approach is taken by Bruno Latour, who uses Actor Network Theory to explain that both human entities, those who work with health information, as well as non-human entities – the information itself – have agency (Latour and Woolgar, 2013). According to Latour, it is the interaction between the two that should be studied to better understand interconnectedness between people and processes. This theory has been adopted by several scholars in the HIS, including Braa and Hedberg and Cresswell et al. Lastly, together with the ISTA, PRISM and MEASURE frameworks as described above, social theories as described above provide a new lens which allows me to showcase the complex role health information plays in the larger health system. Without committing to one theoretical framework, I have used elements of the concepts above to examine the findings which are described in the case studies in chapter four, five and six.

2.8 Conclusion

This literature review aimed to provide a roadmap for understanding the three case studies in Chapters Four, Five and Six. It describes the important role that health information fulfils in the larger health system and emphasises why the use of health information and the development of HISs cannot be understood as a purely technical exercise—as both the data and the actors who collect, use and exchange health information, operate within a larger socio-cultural context. Furthermore, this chapter stresses the importance of expanding our understanding of what health information is and explores the role of informal information as part of promoting a 'culture of information' within the health system. This chapter also explores different ways in which community representatives can be meaningfully included in the HIS and health information literature, as they are part of the health system, but not seen as active users of health information. Additionally, this chapter has outlined several theoretical frameworks that informed the collection and analysis of the information in the three case studies that will follow. It is important to note that besides the MEASURE Evaluation Initiative, none of the frameworks recognise community health actors as active agents in the HIS.

This doctoral research aims to make several contributions to the existing HIS literature as described in this chapter. The three case studies provide exclusive ethnographic insights into the complex use of health information within a peri-urban community setting in South Africa. Each case study longitudinally follows a diverse group of health systems actors who all have different interests and incentives to seek, collect, and use health information, and have various methods that they employ in this process. Furthermore, this study provides a deep contextual understanding on how health information is shaped and transformed within different health systems contexts and how the larger health system is changed by the availability and use of health information. The study also contributes to the work of Scott (2015), Mutemwa (2005) and others as it highlights the role of informal or alternative forms of information and emphasizes how these forms of information can provide vital additions to existing HIS. Furthermore, by employing ideas from theoretical and conceptual frameworks as a suggested by Aqil et al. (2009), Braa (2002) and Latour (2005), this thesis showcases the importance of understanding HISs as a rich sociotechnical system that should constantly acknowledge the invaluable role of information, different types of stakeholders and the context in which this information is produced, used and exchanged.

Chapter 3: Methodology

3.1 Introduction

Qualitative research, including ethnography, plays a crucial role in public health research, as it allows scholars to explore the intricacies of health programmes, interventions and decision-making of those operating in the health system (Ulin et al., 2005). This research was part of the iALARM (Using **I**nformation to **A**lign Services and **L**ink **a**nd **R**etain **M**en in the HIV Cascade) project, a longitudinal mixed methods study that aims to better link men to HIV care in Gugulethu through improving collaboration and communication among stakeholders across all levels of the health system. There were several questions that led this research, which required the employment of a qualitative research design, including: how do people in the health system in Gugulethu interact with health information? How do health system and community actors navigate access to and the use and exchange of information? What factors contribute to the use of health information and how does information change health services and the relationships of people that operate in the health system? These questions formed the basis of my research, an ethnographic journey to better understand the complexity of health information in the health system of Gugulethu.

This chapter provides an overview of the qualitative study design and methods which I used to collect information for the three case studies in Chapters Four, Five and Six. To contextualise the findings of the case studies, I also give a detailed overview of Gugulethu and the larger Klipfontein sub-district and introduce the key participants of this research. Lastly, I will describe my own role as a researcher within the larger iALARM project and the ethical dilemmas I navigated whilst in the field.

In this chapter, and the rest of this thesis, I will use several abbreviations to distinguish between the different groups of stakeholders in the iALARM project. The iALARM RT corresponds with Research Team and includes different researchers, support staff and students who participated in the project. The iALARM TT points to the Retention in Care Task Team, a group of health system and community actors who would come together regularly to discuss health information, as part of the iALARM Intervention. An extensive background to the iALARM study is provided in Chapter Four, and different participants and informants to this research project will be introduced throughout this chapter.

3.2 Overview Gugulethu – Our Pride

When doing fieldwork in Gugulethu and the larger Klipfontein sub-district, I would either drive along with one of my colleagues, or take an Uber or metered taxi into the neighbourhood. From the Health Sciences Campus at the University of Cape Town, where the Division of Social and Behavioural

Sciences (DSBS) is based, it takes about twenty minutes to drive to Gugulethu. A straightforward trip along the N2 highway, turning off just before Cape Town International Airport, takes you straight onto Duinefontein Road, which divides the sub-district into the former Black communities and Coloured neighbourhoods that were established during the apartheid regime (Mpofana, 2002). Gugulethu and many other townships in South Africa were developed after the enactment of the Native Urban Area Act in 1923 and the Group Areas Act, which was first enforced in 1950. The Group Areas Act prohibited Coloured and Black people to live in areas designated for White people only, such as the Cape Town Metropole, the lush Southern Suburbs and breezy coastal areas including Sea Point, Clifton and Camps Bay (Teppo, 2018). The neighbourhoods, also called the Cape Flats, were designed outside of the affluent areas: far enough away to not pose a threat to White people, close enough to provide a workforce when needed. Gugulethu and the larger Klipfontein sub-district were planned in a similar way to other large townships—with one access way into the area, and continuous racial segregation through separate housing, clinics, schools and shops. According to the apartheid regime, racial segregation would not allow people from African descent (Black), Coloured people (a multiracial ethnic group, in Afrikaans called *kleurlingen*), Indians (people from Indian/Malay descent) and Europeans (White people) to live together (Mpofana, 2002). Therefore, the Coloured townships of Klipfontein, with communities like Manenberg, Hanover Park and Heideveld were located on one side of the Duinefontein Road, and Gugulethu, Nyanga and Crossroads, all Black townships, on the other (**Figure 3.1**).

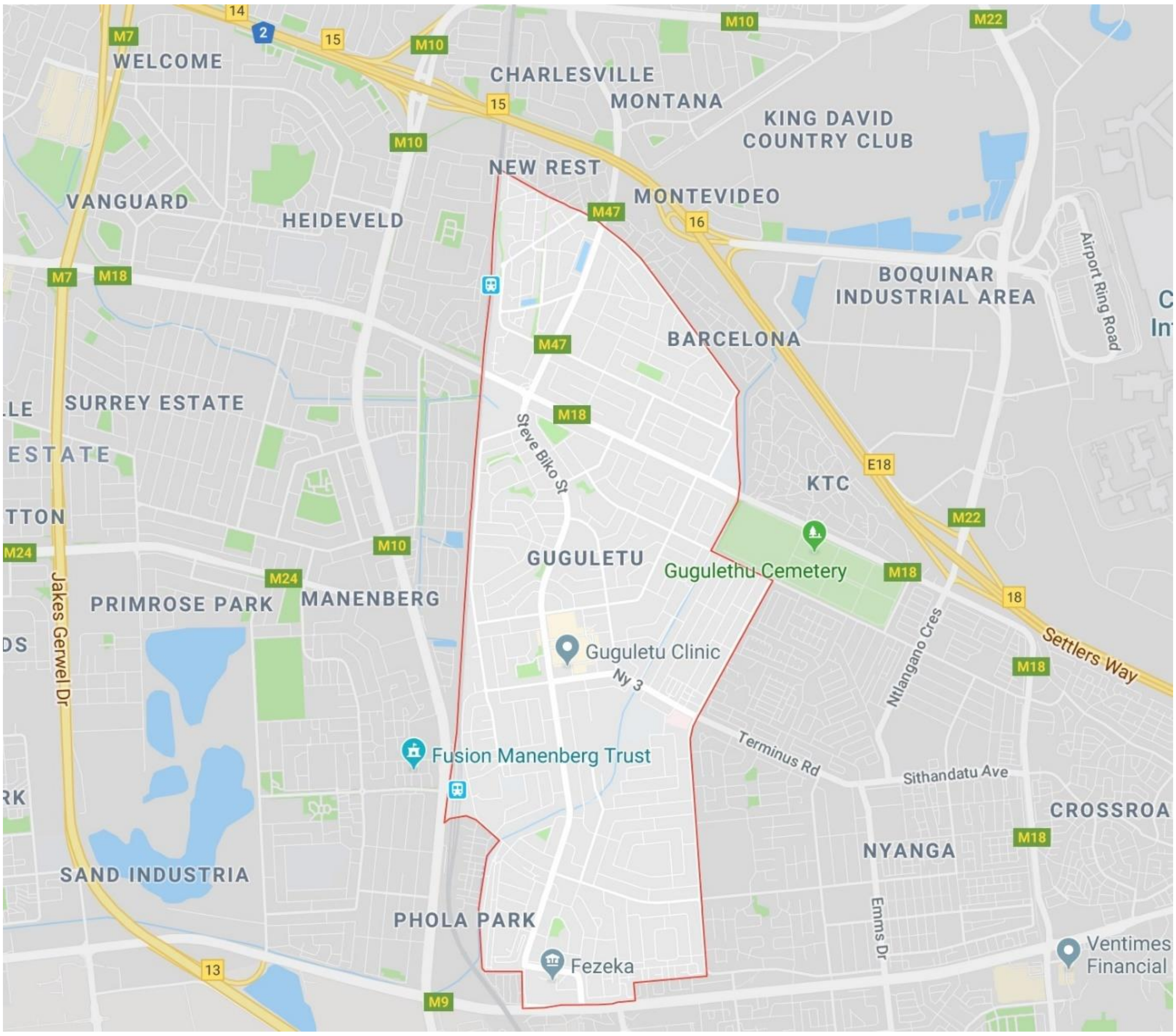

Figure 3.1: Overview of Gugulethu within the larger Klipfontein sub-district

Even 25 years post-apartheid, this segregation largely remains. When driving on Duinefontein Road, which is also known as the M10, you see that racial groups, Coloured and Black, rarely mix, except at the public transport hubs at Nyanga Junction, a train and bus station that transports commuters to the city and other suburbs (see more in Chapter Six). The lingering effect of this racial segregation is still a daily reality for most people living in Klipfontein. Both sets of neighbourhoods are culturally and linguistically distinct, but geographically extremely close. Despite their differences, the neighbourhoods share the same political leadership and governance.

Gugulethu, which means ‘Our Pride’ in isiXhosa, was officially established in 1958, and is still predominantly inhabited by Black people, of whom 85 percent speak isiXhosa (StatsSa, 2011). The township was formally known as Nyanga West and most of the families were forcibly removed from neighbourhoods such as Mowbray, Retreat and District Six in the late 1950s. In total, almost 100,000 people call Gugulethu home, and more than 90 percent of people live in permanent brick housing structures with running water and electricity (StatsSa, 2011). Most of these houses have a small garden where you can find little Wendy houses or shacks build in the yards of brick houses that are rented out to family members or 'backyard dwellers'.

Although Gugulethu is fairly well-developed and has modernised in recent years with brick houses, a shopping mall with supermarkets, municipal offices and other infrastructure, the neighbourhood is surrounded by informal settlements (also called shanty towns), including KTC, Barcelona and Kanana. Compared to the original residents from Gugulethu who were removed from Cape Town, the informal settlements are mostly populated by people from the former Transkei and Ciskei homelands (now in the Eastern Cape Province) who moved to Cape Town after apartheid seeking economic opportunities.

Despite the upgrading of Gugulethu over time, there are still limited economic opportunities inside the community and more than 55 percent of inhabitants live below the poverty line[1] (StatsSa, 2011). Unemployment in Gugulethu is high and many people rely on social grants, including pensions for people over 60 which are valued at R1700 per month (about 100 Euro) or Child Support Grants of R410 per month (about 24 Euro). Often, income through employment or grants is shared within the household, which consists often of two or three generations living under the same roof (Swartz, 2017). The high unemployment rates and limited economic opportunities in Gugulethu results in a lack of upward mobility among people within the area and often affect the position of youth in the area. About 20 percent of the youth between 14-25 years in Gugulethu are considered to be multi-dimensionally poor (StatsSa, 2011). This means that 20 percent of young people are affected by low levels of education, poor nutrition, limited access to health services, lack of employment, poor living conditions and exposure to violence—all of which drastically impact their future (Frame et al., 2016).

Similar to other underprivileged places in South Africa, Gugulethu has high crime rates, varying from murder to robbery and sexual assault. Although Gugulethu is slightly safer than neighbouring communities like Nyanga, KTC and Kanana, the community still had more than 180 reported murders in 2018, 166 reported rape cases and more than almost 2,000 drug-related crimes reported to the South African Police Services (South African Police Service, 2018). In 2013, interpersonal violence was recorded as the leading cause of mortality among people in Gugulethu and Klipfontein sub-district by the South African Medical Research Council (Benatar, 2013).

3.3 Health and health care in Gugulethu and Klipfontein sub-district

South Africa has a quadruple burden of disease, which means that the country has high rates of HIV/AIDS, a high burden of tuberculosis (TB), high maternal and child mortality as well as non-communicable diseases; violence and injuries (Sanders and Chopra, 2006, Mayosi et al., 2012). In

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[1] Stats SA's 2015 upper-bound poverty line of R779 per person per month in 2011 prices is used to define income poverty

Gugulethu and the larger Klipfontein sub-district, HIV/AIDS is the second leading cause of death, followed by TB and non-communicable diseases such as diabetes and ischaemic heart disease (South African Medical Research Council, 2016). Interpersonal violence, gender-based violence, STIs and unwanted pregnancies are other issues faced by residents in Klipfontein. Klipfontein is one of eight health sub-districts that fall under the Cape Town Metropolitan municipality and includes the neighbourhoods of Gugulethu, Nyanga, Manenberg, Hanover Park, Heideveld, KTC and Crossroads.

Most people in Klipfontein rely on free public health care, which is provided by the South African government. In Cape Town, primary health services are either provided by the Western Cape Province, or the City of Cape Town. In the Klipfontein sub-district, there are five community health clinics (CHC), which are under management of the Western Cape Department of Health (WCDoH), and nine clinics and three satellite clinics which are managed by the City of Cape Town (CoCT). Both provincial and city clinics are often located in close proximity to each other, sometimes even on the same grounds, but are under different leadership. In **Figure 3.2**, the different facilities in the Klipfontein sub-district are outlined, as well as the distances from the Gugulethu clinic, hereafter NY3. The NY3 clinic was the primary field site for the iALARM study and is also the location of Sonke's Men's Wellness Centre (MWC) (See more Chapter Four).

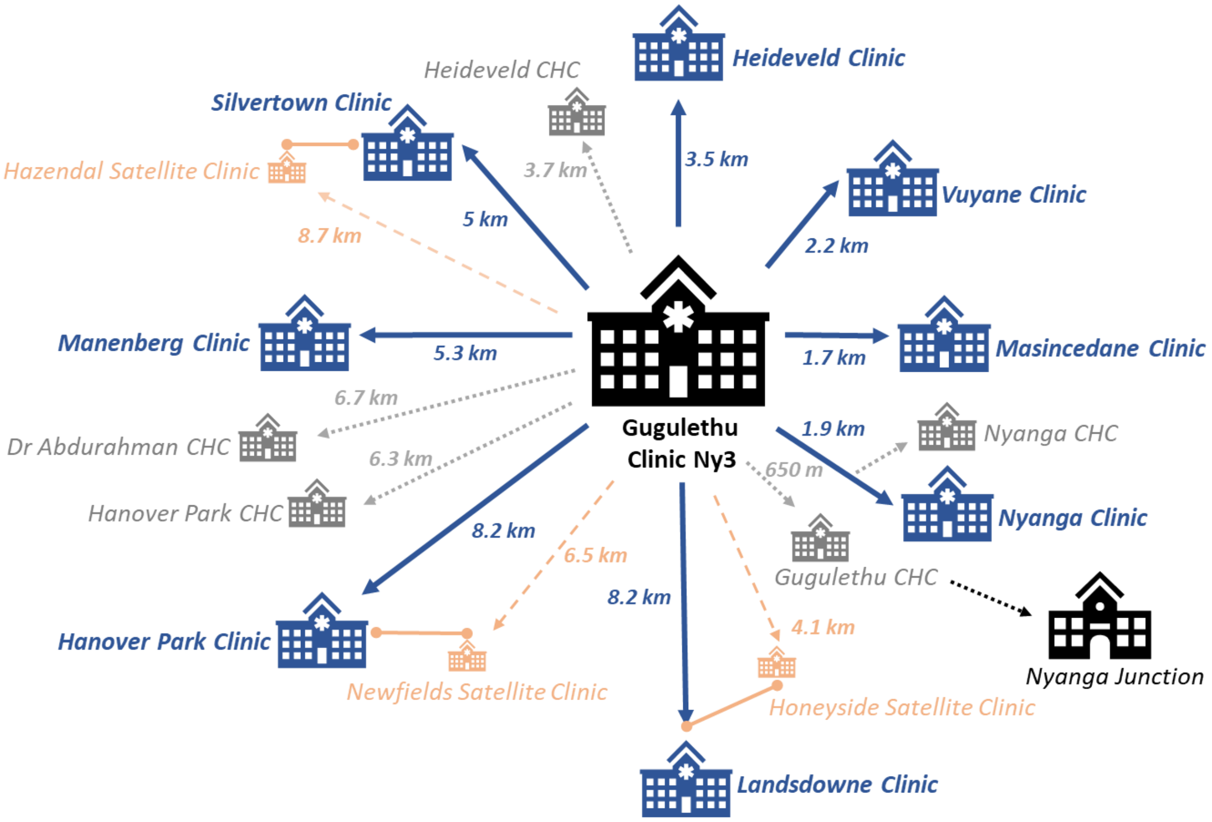

Figure 3.2 : Overview of health services in Klipfontein sub-district

In a community clinic (indicated in blue in Figure 3.2), a range of primary health services are offered and the clinic is open at least eight hours a day, four days a week. Primary health services include HIV and chronic illness screening, reproductive health services, and vaccinations for children. Satellite clinics (indicated in orange in Figure 3.2) offer fewer primary health services than do community clinics (both the ones under management of WCDoH and the CoCT), and are open fewer than four days a week. Satellite clinics do often offer basic services such as HIV screening and sexual and reproductive health services, but these clinics often have limited medication stock and are closely connected to other clinics. Nyanga Junction Reproductive Health Centre, which is described in more detail in Chapter Six, is an example of a satellite clinic, and falls under Gugulethu CHC, managed by the WCDoH. A CHC (indicated in grey in Figure 3.2) is a facility that is open 24 hours a day, seven days a week, and offers a broad range of primary health services, including emergency services and midwife obstetric units (MOU). CHCs often have operating rooms, but typically refer patients to larger secondary and tertiary care hospitals for surgery under general anaesthesia.

The field office for the iALARM project is located in a container on the grounds of the NY3 clinic, in the heart of Gugulethu. The container (see **Figure 3.3**) is located next to the Men's Wellness Centre (MWC), a centre offering health services tailored to men, an initiative from Sonke Gender Justice (Sonke), the strategic partner of iALARM (see more in Chapter Four). In the containers, there are offices for Sonke's staff, an examination room where clients can be seen by a male nurse, and a room for workshops and meetings.

Figure 3.3: The iALARM field offices in in Gugulethu

Using the iALARM field office as my base, I travelled through most of the Klipfontein sub-district to visit the different clinics, and spoke to numerous clinic staff about various topics, including HIV, larger health system issues and the role of health information for the facilities and larger community. During a regular day in the field, I would first visit the NY3 clinic before heading to Gugulethu CHC, the Gugulethu ARV centre, Nyanga CHC, Nyanga Clinic and Vuyani Clinic. Throughout my fieldwork, I established a close relationship with Sister (Sr.) Vece from Nyanga Junction Reproductive Health Centre, as we developed an adolescent health profile (AHP) (see more in Chapter Six). Both my role in the iALARM project and my involvement in the Movement for Change and Social Justice (MCSJ) also allowed me to visit clinics outside of Klipfontein, including those in Philippi, Mitchells Plain and Khayelitsha.

Besides regular visits to clinics, my PhD fieldwork also gave me the opportunity to interact with various non-governmental organisations (NGOs) in Gugulethu and the surrounding communities, including the Desmond Tutu HIV Foundation (DTHF), Grassroots Soccer, Etafeni, Sonke, TAC, the J.L. Zwane Presbyterian Church (J.L. Zwane) and the Parent Centre. NGOs play a significant role in community health care and the larger health system (George et al., 2015), although these relationships are often complex and fragile. During my fieldwork, I was able to explore these complexities, which are further explained in Chapter Five.

3.4 Key participants, informants and relationships

Since the start of my PhD fieldwork in early 2016, I visited Gugulethu and other communities at least two times a week. During these visits, I met new informants or reconnected with participants on different occasions, including church services, community meetings, protest marches, personal interviews and clinic visits. Over time, I created several meaningful long-term and short-term relationships, which were vital for information collection. **Figure 3.4** gives an overview of the different networks that were crucial for my information collection. Sometimes, I would meet more than fifty new people in a day, especially when participating in a community meeting or protest march. Other times, I would have informal conversations with some of my key informants, indicated in Figure 3.4 as ‘the inner circle’. This inner circle of key informants grew organically over time, due to requests for health information, the responsibility to assist MCSJ with their administrative tasks or through networking activities for the iALARM TT.

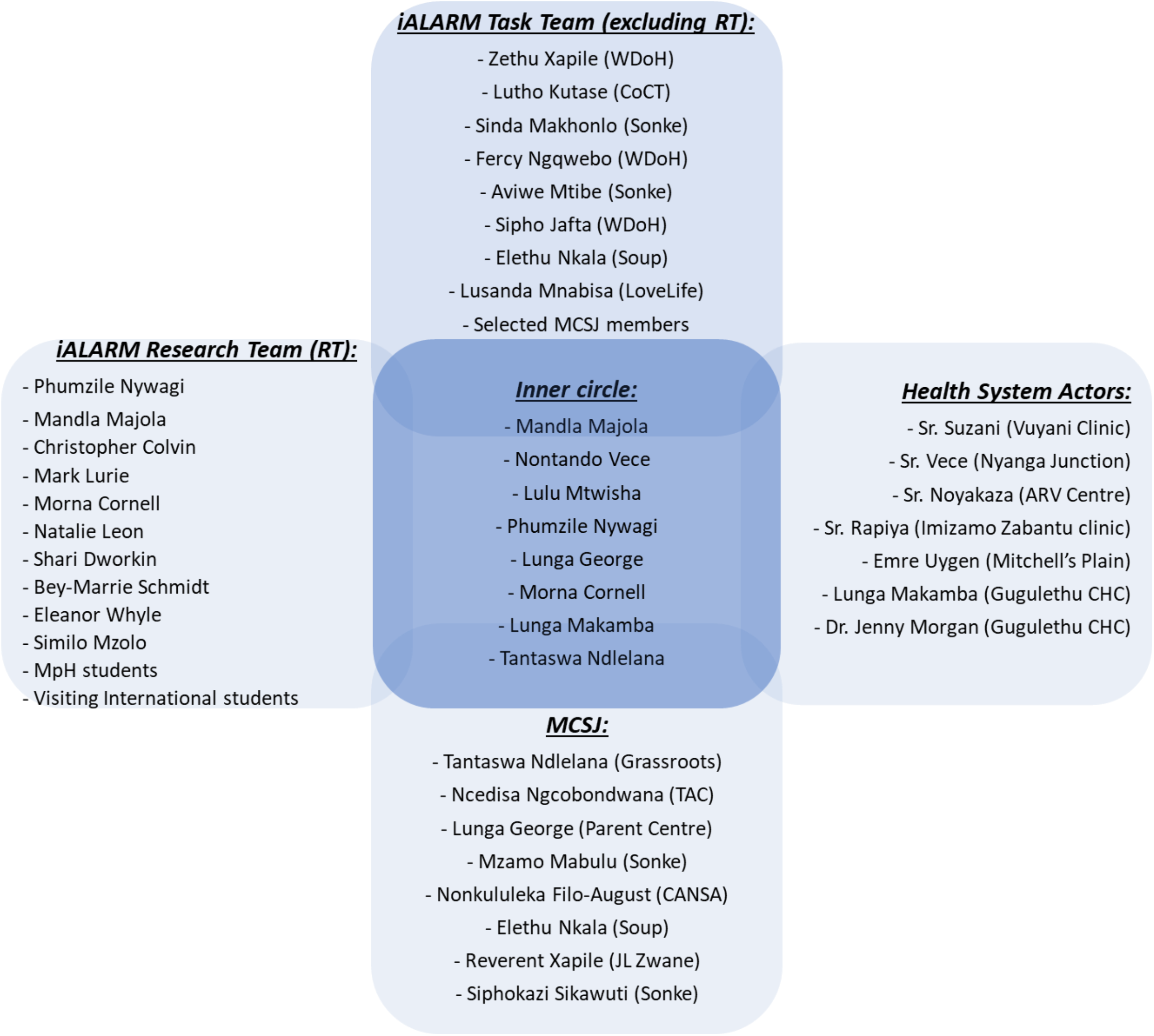

Figure 3.4 Participants and key informants

In the context of my ongoing relationships with people in the inner circle, I was able to learn more about the history of Gugulethu, the ongoing health issues in the community and the relationships between the health system and community actors. All this information became vital for this thesis. Most of my participants and inner circle key informants will be formally introduced in the case studies in Chapters Four, Five and Six, but a small summary is provided here. **Mandla Majola** and **Phumzile Nywagi** are two colleagues within the iALARM RT who taught me everything I needed to know about Gugulethu and Klipfontein sub-district. Both Mandla and Phumzile grew up in Gugulethu and have a tremendous amount of knowledge about the health system and other civil services in the area. Mandla is one of the founders of MCSJ and has worked as a community organiser for many years. Mandla fulfilled various roles in the Treatment Action Campaign (TAC) and collaborated with University of Cape Town (UCT) and Stellenbosch University (SU) in several research projects. Phumzile is a community activist who worked in several different organisations and ran his own support group for impoverished HIV-positive men in Gugulethu, called Khululeka (Colvin et al., 2010). Both Phumzile and Mandla believe that men in Gugulethu need better access to health services and health education and they would often facilitate talks in the community about masculinity and gender equality. In their role as iALARM field coordinators, Mandla and Phumzile were translators and gatekeepers for myself and other researchers in the iALARM RT. Through their contacts, experience and personality, they offered me the chance to extend my own networks in Gugulethu, get access to clinics and establish relationships with various stakeholders in the community.

Since the start of MCSJ in 2016, I have participated in the organisation in various roles (see more chapter five) and developed some long-standing relationships with MCSJ members, including **Lunga George** and **Tantaswa Ndlelana.** Both Lunga and Tantaswa were involved in MCSJ since its inception, and over time, I got to know them very well. We would often sit in meetings together, share notes or go out to clinics to lobby or talk about health issues with community members or health staff. Lunga George works at the Parent Centre in Gugulethu, a Cape Town-based NGO that supports parents raising their children through community empowerment and offering classes specifically designed to assist teenage parents navigate parenthood. When I met her Tantaswa worked at Grassroots Soccer, an organisation that uses soccer as a way to empower young people and to educate them about life and health, focusing particularly on sexual reproductive health and HIV. She now fulfils the role of secretary for MCSJ.

Lunga Makamba is the facility manager at Gugulethu CHC, where I spent plenty of time during my fieldwork. This community clinic, located in the heart of Gugulethu, was often overcrowded and understaffed, which sometimes resulted in protests whereby community organisations, including MCSJ, would demand improved service delivery. As a facility manager, Mr. Makamba was often the first port of call during these tumultuous situations and I met him on several of these occasions. Despite limited budgets, staff shortages and other issues in the clinic, Mr. Makamba had a vested interest in collaborating and communicating with the community and was a member of the iALARM TT.

Nontando Vece, or Sr. Vece, was the facility manager of Nyanga Junction Reproductive Health Centre. I met Sr. Vece through Phumzile, as Nyanga Junction was the only clinic in Gugulethu with a dedicated male nurse, Kathlego Ndovu. Over time, Sr. Vece and I became acquainted, as I assisted her request to create the AHP as part of the Adolescent Youth-Friendly Services Programme (AYFSP). She also introduced me to Sr. Lulu, Lusanda and other participants in this study. Chapter Six provides more details about the relationship I had with Sr. Vece, as well the challenges we experienced when trying to develop the AHP. Unfortunately, Nyanga Junction Reproductive Health Centre closed its doors in October 2018. Sr. Vece now works as a facility manager at Imizamo Zabantu clinic in Philippi.

The last of the inner circle is **Dr. Morna Cornell**. Morna is an epidemiologist and researcher at the University of Cape Town and one of the investigators on the iALARM RT. She has more than 25 years of experience in HIV research and has a particular interest in the meaningful inclusion of men into HIV care. Morna has published widely on these topics and loves to share her knowledge within and outside of the academic community (Hermans et al., 2019, Brazier et al., 2019, Chammartin et al., 2018, Cornell, 2013). Morna played a crucial role during my data collection, as we had numerous conversations about the project, would sometimes run iALARM TT meetings and workshops together, and over time realised that we had many common interests. In the last two years, Morna became an informant, participant and mentor for myself and others in the iALARM RT.

3.5 Study design

The fieldwork for this PhD research was conducted between March 2016 and September 2018, using qualitative data collection methods, rooted in the ethnography. The term ethnography is to ‘write about people and cultures. The word derives from the Greek word *Ethnos* – which means people and *Grahei,* which means documenting or writing’ (Marvasti, 2004). Ethnography derived from sociology and anthropology, and is built on the premise that through long-term, in-depth observation from within a society, a researcher is able to understand behaviour and decision-making processes which are embedded within a cultural context (Hahn and Inhorn, 2009, Green and Thorogood, 2018, Liamputtong and Serry, 2013, Liamputtong and Ezzy, 2005). Key concepts in ethnography are, according to Reeves et al (2008), “the strong focus on exploring the nature of a particular social phenomenon, a tendency for researchers to work primarily with unstructured data and the examination of a small group of people” (Reeves et al., 2008, p.512). As Wittgenstein (1967) summarized well in his work; “Anthropology is supplying remarks on the natural history of human beings; we are not contributing curiosities however, but observations which no one has doubted, but which have escaped remark only because they are always before our eyes” (Wittgenstein, 1967). This includes a thorough investigation on how taken for granted categories and terms, in this case information are used as well as understanding how people interact with information within as part of their daily practice. Although ethnography derived from the social sciences, the method is rapidly gaining popularity in public health and health sciences, and is often used in addition to or in conjunction with quantitative methods (Hahn and Inhorn, 2009, Liamputtong and Ezzy, 2005). One of the strengths of ethnography is the capacity to, using qualitative methods, understand, address, contextualise and respond to local perspectives, concerns and values. This is crucial when exploring health behaviour among patients, but can also be used to explore the localised impact of policy and practice of health care within a community (Hahn and Inhorn, 2009, Green and Thorogood, 2018). Additionally, ethnography is an important method for understanding the processes involved in developing and implementing public health interventions (Hahn and Inhorn, 2009). According to Hahn and Inhorn, anthropologists can play a leading role in the design, development, management and evaluation of health interventions, as anthropologists understand and facilitate local participation and have an in-depth knowledge of the field through conducting situational analysis (Hahn and Inhorn, 2009). Ethnography also serves to investigate and address relations of power and domination within the historical contexts of existing health programmes, as health intervention development is primarily a process embedded within a social and cultural context that is constantly changing (Hahn and Inhorn, 2009). During this ethnographic study, I was not necessarily interested in the health behaviour of patients in Gugulethu, but aimed to explore the relationship that community members and health system stakeholders have with each other and with health information. I also tried to understand how health information is accessed, used and exchanged, either within a policy implementation space, an information intervention space, or in community-driven health advocacy campaigns.

Based on my research questions, the ethnographic study design was appropriate, as it allows researchers to investigate and address relations between people within the historical contexts of existing health programmes, as health intervention development is primarily a process of social and cultural change (Evans and Lambert, 2008, Hahn and Inhorn, 2009). Conducting ethnographic research alongside the development of the iALARM intervention allowed me to obtain an insider's perspective on the complexities of health information, largely without interfering in the project design or manipulating proposed outcomes (Willis and Trondman, 2000, Hemment, 2007). Although my involvement as a researcher in iALARM granted me access to participate in meetings and easily build and maintain relationships with stakeholders, I also often had to 'wear two hats at the same time' and simultaneously be an student and an observer. On some occasions, this would complicate my data collection, as participants would ask me for assistance or work-related favours, which would interfere with my interviews or participant observation.

The iALARM project started in 2015, and runs until 2020. This means that both qualitative and quantitative data collection for the larger study was well underway before I started to collect my own data . **Figure 3.5** shows how the phases of my fieldwork were intertwined with the iALARM study. Some of the data is collected in conjunction with important milestones of the iALARM study, such as the first iALARM TT meeting, strategic planning meetings or other get-togethers. The primary method was participant observation, written up in detailed fieldnotes, as well as audio recordings. Participant observation was complemented with semi-structured interviews and document analysis.

Figure 3.5: Timelines for iALARM Intervention and PhD research

3.6 Data collection methods

3.6.1 Participant observation

Participant observation is the most important data collection method when conducting ethnographic research. According to Hine (2000), participant observation is collecting data from participants by being there, participating in people's daily activities and opening up as a researcher to learning (Hine, 2008). Boyle (1991) explains participant observation slightly different, by arguing that through this method, the researcher is participating directly in the informant's life, and aims to understand their reality by talking to and observing their lives (Boyle, 1991). By doing research in this way, the ethnographer learns about the code of social actors to better understand the meaning of their actions (Liamputtong and Ezzy, 2005).

Participant observation allows the researcher to play an active role in the community. Participant observation also gives one an opportunity to experience life as an insider, participating in activities, as well as critique these activities as an outsider, conducting distanced observation (Murchison, 2010). Historically, participant observation was as a method used by anthropologists who immersed themselves in the daily lives of a rural tribe by being alienated from any familiar circumstances (Liamputtong and Ezzy, 2005, Green and Thorogood, 2018). Over the years, the method has evolved and is now regarded an interdisciplinary method which can be applied in a multitude of setting. Participant observation is gaining more popularity in disciplines aside from anthropology, such as public health, communication studies and sociology (Bernard, 1998).

For me, a typical day in Gugulethu would be spent mainly conducting participant observation. Normally, I would meet Mandla or Phumzile at the iALARM field office at NY3 clinic in Gugulethu between 9 and 10 o'clock in the morning. We would have a cup of tea, catch up on the latest events and

I would pop my head in at the MWC to greet the Sonke staff. After this, we would either walk, drive or take an informal taxi—also called amaphela—to the clinics we needed to visit. Clinic staff would expect us to come between 10 in the morning and midday, and would try to make time for us between seeing patients. When networking for the iALARM TT especially, we would try to visit two or three clinics a day before heading back to the field office to debrief about the events of the day. We would often speak about our experience in the clinic, which also gave me the opportunity to ask clarifying questions. Other times, we would have conversations with community members or visit NGOs in the area. After a day in the field, I would head back to UCT to write my fieldnotes and start planning for my next visit to Gugulethu. When conducting participant observation, fieldnotes are used by ethnographers to record their findings in the field. They are detailed accounts written about the researcher's experience, based on conversations and observations (Sanjek, 1990). Fieldnotes are not a list of verbatim quotes or exact transcriptions of the actual event, but also include personal interpretations, emotional notes or self-reflection (Sanjek, 1990, Liamputtong and Ezzy, 2005, Ulin et al., 2005). Therefore, fieldnotes can be compared to diary entries and can also include drawings or photographs. I would try and finish my fieldnotes within one or two days, based on a combination of handwritten notes from the field and audio recordings which I would record in the car back to the University of Cape Town.

Over time, my own positionality in the field changed slightly, as well as the course of the iALARM project. Due to my work in the iALARM project and my relationship with Mandla and Phumzile, I became more involved in MCSJ in 2017 and members would often ask me to participate in meetings, give administrative assistance and write minutes. Regularly, MCSJ members would invite me to join their advocacy campaigns, protest marches or appointments with health system managers. This allowed me to become more engaged into the organisation's structure and gave me easy access to participants and informants. Besides writing the minutes of meeting, assisting with administrative tasks and giving input when required, I tried not to interfere too much with the objectives, values and morals of the young organisation. Therefore, it sometimes felt that I was a passive observer, which differs from active participant observation (Green and Thorogood, 2018). However, being asked to document the minutes during workshops and meetings allowed me to write extensive fieldnotes and rapidly collect crucial data. I used the minutes as part of my findings and added reflective writing to complete the fieldnotes.

Lastly, I also conducted participant observation as a iALARM researcher in the iALARM RT. Over the course of three years, I was funded by this research project and had several responsibilities within the team. I would be part of iALARM TT planning meetings, assisted with the formation of the TT and often assisted with planning and content for the monthly TT meetings. I wrote my own detailed fieldnotes about my experiences in the iALARM RT and used meeting notes, presentations, reports and other research materials as part of my data collection.

3.6.2 Interviews

In qualitative public health research, interviews are the most common method for data collection (Green and Thorogood, 2018). An interview is a conversation which is directed by the researcher to extract the information required to answer the research question (Green and Thorogood, 2018). There are several types of interviews ranging from informal conversations to in-depth interviews.

For my fieldwork, I used semi-structured interviews in combination with participant observation. In the beginning of my research in 2016, I interviewed several health workers from various facilities in the Klipfontein sub-district about their expectations of the iALARM project, their informational needs and interest in being part of the iALARM intervention. I had a set interview guide, which I used to direct the conversation, but often, the interview was unintentionally steered into a different direction, focusing on day-to-day struggles within the facility, rather than long-term informational support needed to better link men to HIV care. I have an undergraduate diploma in journalism, and through my experience conducting interviews for newspapers and magazines, I learned that deviating from questions can have unexpected outcomes, which are not revealed when strictly adhering to interview guides. Unintentionally, the data from these first interviews became a large part of the findings and provided unique knowledge and insights about the complexities and context of the health system in the Western Cape. Due to the ongoing responsibilities of the health workers, these interviews were often not longer than 30 minutes, but I continued the conversations on other occasions or during follow-up interviews.

I also conducted interviews with various iALARM RT members and iALARM TT members about their experience participating in the project, their expectations and prognosis about the future of the iALARM project. Based on my previous experience when writing detailed interview guides, I decided to structure these interviews differently, using keywords that might provoke reactions and feelings from the participants. Table 3.1 shows how I used the different time periods during the iALARM project to probe questions. I asked my participants to tell me what their initial hopes and intentions were before joining the iALARM study, the challenges they experienced over time, and how they envisioned the future of the iALARM intervention. I interviewed iALARM researchers, students and investigators in the project, as well as several members of the health system who were part of the TT. By using these key words, I was able to stimulate participants to speak about their involvement without posing a directed set of questions. The interviews with the TT were often between 60-90 minutes and were audio-recorded and later transcribed.

iALARM Project Phase	Key words
A) **iALARM project set-up/grant**	1. Hopes (history/background)
B) **iALARM Task Team**	2. Reality (current)
C) **iALARM Intervention**	3. Challenges (over time)
D) **iALARM Future**	4. Successes (over time)
	5. Dreams (Future)

Table 3.1: Interview guide iALARM interviews

3.6.3 Ndiyathetha isiXhosa kancinci (I speak a little isiXhosa): a note on language and translation

In qualitative research methods, especially in interviews, participant observations and focus groups, language plays a crucial role. Language is primarily understood as *data information*, the result that is extracted through different forms of collection, but language is more active and dynamic than that. This means that language can also be explored as a *method* in itself (Green and Thorogood, 2018). According to Green and Thorogood (2018), language is a crucial part of research, as it shapes and explains how we make sense of the world and interact with each other and is used by both participants and researchers. Language is furthermore used within a social context and is continuously in flux (Green and Thorogood, 2018). This study took place in Gugulethu and Klipfontein, predominantly isiXhosa and Afrikaans speaking communities, but most data was collected in English. I grew up in the Netherlands, and before embarking on my fieldwork journey, I had little understanding of isiXhosa, but could read and understand Afrikaans moderately. Trying to advance my isiXhosa skills, I took an introductory course offered by UCT, whereby I learned basic words, sentences and grammar. Although I could introduce myself and my research topic in isiXhosa, I was not able to master the language beyond that. As described earlier in this chapter, I sat in many meetings over the course of my fieldwork, where isiXhosa would be the preferred language; I presumed that writing notes, either for myself or for MCSJ, would be challenging. At first, this was definitely the case, but through careful listing and observing non-verbal language, I was able to understand most of the conversation. As with many other languages, isiXhosa is anglicised, and in urban settings such as Gugulethu, Xhosa words are mixed with English, especially when discussing medical terms or social issues. When confused, I would ask the person next to me to translate or type a few sentences for me, or I would later ask Mandla or Phumzile to look over my notes after the meeting to reassure myself that I had fully comprehended the conversation.

In clinical settings, most conversations between patient and provider or among health workers are conducted in English and almost all material for health education and health promotion is provided in English, Afrikaans and isiXhosa. Therefore, I chose to conduct all my interviews and informal conversations with my participants in English, which proved to be a pleasant experience, as I did not have to be reliant on a translator. I could make my own appointments with interviewees, transcribe all the interviews myself and easily keep in contact with my participants via email or phone. This was a huge advantage and major difference compared to other research projects on which I had previously worked, where I worked with Deaf people and always had to rely on the availability of sign language interpreters. Although I was not always able to interview participants in their own language, because I interacted several times with most of my informants, I was able to ask for clarity when needed or to follow up on unfinished conversations or discussions.

3.7 Data Analysis

For this research, I analysed most of my data either manually or in QSR NVivo, a well-known data analysis programme that is used mainly within qualitative studies (Bernauer et al., 2013). In ethnography, data analysis is a continuous iterative process which occurs during all stages of the research. As ethnography is both a sensory and embodied experience, which includes feelings, perceptions and empathic knowledge, it is important to analyse the collected data within this context (Polanyi, 2015). This also means that researchers often view qualitative data analysis as unsystematic and slightly chaotic, as one needs to try and make sense of different sources and material, which can be written, or audio-visual. QSR NVivo is a programme that accommodates different forms of data and provides tools to analyse this data in a rigorous and systematic way, as the programme offers tools to organise, code, restructure and query data, allowing information to be used in a non-linear manner. The tool also allows for the retracing of data at all times, providing a logbook of the researcher's reflection and sense-making (Bernauer et al., 2013). Additionally, QSR NVivo is used to explore relationships between themes and participants, which is a vital component of the research project. For me, QSR NVivo was a great program to organise the different sources of data n and group them together by participant. I used codes to distinguish between different themes and findings of interest and tried to explore commonality between the different observations. I coded most of my fieldnotes, diary entries and interview transcriptions manually, and used comment boxes in Word to document my thoughts and initial findings. Besides empirical data such as interviews and fieldnotes, I also used secondary sources including minutes from meetings, policy documents, pamphlets and information collected from social media channels. These sources, together with the empirically collected data all became part of this doctoral thesis.

3.8 Ethical considerations

As this doctoral research is part of the larger iALARM project, ethical approvals from the Human Research Ethics Committee (HREC) (Reference **802/2014**) were obtained for the larger project, as well as my individual study (Reference **380/2017**) (**Appendix 3.2**). This meant that I had the privilege to conduct research in both the WCDoH clinics as well as CoCT facilities. As described throughout this chapter, I met various people during the time I conducted fieldwork and due to the nature of some of the meetings, I was not able to get written consent from all my participants and informants, but ensured that I obtained verbal consent. I would always explain the reason for participating in meetings, or even just being in the space; I carried my UCT card at all times and would briefly explain my research. I always asked permission to be part of gatherings and told my participants to be honest when they felt uncomfortable or had any concerns about the process. I was not able to able to ensure anonymity for my participants, especially within a group setting, whereby participants would introduce themselves and speak about their experiences in the clinic or organisation. Most participants were proud of the role they fulfilled in the community and happily shared their stories with other like-minded people.

Sometimes when visiting clinics, I would interact with patients who would ask me questions about their illness or medication, assuming that I was a clinical doctor. I was always open and honest about my role as a researcher, and would refer them to the nearest health provider or pharmacy or give them phone numbers of relevant organisations which could be useful. As I worked primarily with informants who were almost all officially employed in the health system, by NGOs or through research institutions, I did not pay them for their participation in the research. However, I tried to 'give back' by providing administrative support, printing documents, helping out with information requests or providing snacks for meetings.

Personal note on being a reflexive researcher

Reflexivity is a difficult word with many definitions. The definitions change according to who uses it, who interprets it and who analyses or criticises it. For me personally, being reflexive is living like a chameleon, who changes her appearance according to circumstance and space. Being born in the Netherlands and living and conducting research in South Africa, being a chameleon is second nature for me. In the academic space and on the university grounds, I see myself as an analyst, academic writer and feminist. Out in the field, I work especially with isiXhosa men, who might see me as foreign or different (umlungu means white/foreigner in isiXhosa). In the field, I can be an activist, a listener, an observer, a comrade, colleague or friend. I know that I am an outsider, but I try and blend in as much as possible. My chameleon skin might be 'spotted' at times and can never completely camouflage, but I think of that as a strength. Keeping one's own thoughts, morals and values is crucial and even though researchers try to be as true and honest to the research, complete objectivity is a myth that, in qualitative research, can never be completely accomplished.

On reflexivity

Reflexivity is a complicated and ongoing process that is an integral part of qualitative research, but not always adequately explored in public health research (Finlay and Gough, 2008, Lynch, 2000). In ethnographic research, being reflexive means that you acknowledge and understand that both the researcher and the participants are impacted by the world they live in, as it shapes our political values, morals and views and social context (Nguyen and Moyer, 2018, Green and Thorogood, 2018). This impacts the data collected, but also its interpretation by the researcher. Being reflexive, according to Ulin et al., means that you need to be 'reflecting critically on the research itself, not just the outcomes' (Ulin et al., 2005). Researchers need to be self-aware and equally observant of their own positionality as well as the position of the participants. This includes the documentation of your own role in the research project, including assumptions, biases or reactions that might impact the research outcomes.

Attempting to explain my own personality and positionality within the iALARM project and Gugulethu, I wrote a short narrative in my PhD proposal, which is included on the previous page. During my fieldwork as well as my data analysis, I reread the excerpt a couple of times and even whilst writing up this thesis, I still believe that the term 'chameleon' captures the spirit of my own being, both within my research as well as my personal life. Although this is not a perfect metaphor, I feel like a chameleon, a person with a fluid identity that shifts according to situation, trying to adapt as best as possible to ever-changing circumstances. I have a very different life history than the people I worked with on a daily basis, as I grew up in the Netherlands in the 1990s, with access to good schools and free high-quality health care services. I have never experienced many of the struggles my participants have faced, but was able to listen to their stories and sometimes weigh in as an outsider. Although I did not share the same life history, I have been living, studying and working in South Africa for more than ten years. I am familiar with the complex history and inequality that is deeply rooted in every aspect of life in South Africa. On a personal level, I also felt a deep connection with nurses and health workers who participated in the study, as my mother is a trained nurse and worked as a facility manager and case manager in various health care institutions in the Netherlands during her career, including maternity units and geriatric departments. When I was little, she would take me to the old-age home she was managing, walk with me through the wards, interact with the elderly patients and introduce me to her colleagues.

Albeit different in context, many of the challenges shared by health workers were familiar to me, and I was able to empathise and share my own narrative during my time in the field. At times, it was challenging to be an emerging female public health researcher, working in a project that focuses on men's health and HIV care, but most of my participants were open-minded about gender, sexuality and talking about health care, whether personally or in a professional capacity. Other difficulties that arose from time to time were related to the power dynamic of being part of an academic team and working in a low-income context. When interacting with community members, it was sometimes assumed that researchers in the iALARM RT could provide services, advice or material goods that were not directly linked to the project objectives, which led to slightly uncomfortable situations. Even though I worked as both an ethnographer and a participant researcher within a larger study, this never led to any significant issues, as I was always highly aware of my role and positionality in the project. As I conducted 18 months of intensive fieldwork in Gugulethu, I was able to create meaningful relationships with my iALARM colleagues, community partners and health workers (see inner circle). This gave me the opportunity to not only collect data for my own dissertation, but to also co-create knowledge and seek advice from comrades and fellow researchers when needed.

3.9 Conclusion

This doctoral research was grounded in purely qualitative methods, using ethnographic methods. Besides being trained in ethnography through my masters' degree in Social Anthropology, this methodological approach also proved to be an appropriate way to collect data for the three case studies that follow in the next three chapters. Using ethnographic methods allowed me to engage with a diverse group of stakeholders and follow them on their quest to access, use and exchange different forms of health information without actively interfering in the process. As described in this chapter, engaging in ethnography over a long period of time enabled me to create long-term relationships with participants and colleagues, and share spaces with them without directly interfering with their work. To contextualise the three case studies in the chapters that follow, this chapter provided a detailed overview of Gugulethu, the field site which was the centre stage of my research; described the available public health services; outlined the data collection methods; and discussed the different ways in which the data was analysed. Furthermore, this chapter described my own positionality through a personal reflection section which is part of the constant ethical decision-making that is crucial in qualitative research.

Chapter 4: 'HIV reports and living testimonies' – The role of health information in the iALARM intervention

4.1 Introduction

Sub-Saharan Africa has the largest HIV burden in the world, accounting for 71% of new HIV infections. South Africa has also the greatest number of people living with HIV and the largest antiretroviral therapy (ART) program in the world, with 3.39 million patients on ART in 2015 (Johnson et al., 2015). The ART programme in South Africa is continuously scaled up and an integral part of the larger health system. HIV is biomedically, socially, politically and culturally a complex disease, and although ART treatment is available and free, there are still significant challenges with trying to get patients to test for HIV, as well as with linking them to care and supporting adherence (Kilmarx and Mutasa-Apollo, 2013, Kippax et al., 2013, Pascoe et al., 2018).

One of the key components to enrolling and retaining patients into HIV care is through the collection and use of high-quality health information which can guide clinical decision-making and inform new programmes (Gourlay et al., 2015). Unfortunately, the fragmentation in HISs in South Africa hinders the access to and use of HIV information for health systems actors, as information is still scattered across different databases (Oluoch et al., 2015, Braa and Hedberg, 2002). To streamline the upscaling of HIV care in South Africa and monitor progress, a well-functioning and integrated HIS is crucial, but often not available. This is caused partially by the fact that facilities, districts and provinces have different ways of collecting, storing and using HIV information. International donors—who sponsor many of the HIV programmes in South Africa—develop their own systems to monitor the provision of HIV care, which further complicates the access to and use of HIV.

This is challenging, as HIV care becomes more and more decentralised to relieve the pressure in facilities, and clinical tasks are shifted from clinicians to nurses and community health workers who often operate outside the clinical space. This shift means that the demand for and use of health information also changes, but is not accommodated by the information system available. For example, NGOs who offer testing services have systems in place to record testing information and communicate information to funders, but this data does not always get shared with hospitals who provide cluster of differentiation four (CD4) tests and link patients to care. This lack of sharing of information can lead to patients being lost to follow-up (LTFU), tested multiple times, or not adhering to ART (Kilmarx and Mutasa-Apollo, 2013, Govindasamy et al., 2014). Besides the effect on health outcomes for patients, the lack of information-sharing (in this case HIV information) can also lead to misunderstandings and miscommunication between stakeholders in facilities, NGOs and other stakeholders in the health system.

These health information issues formed the objectives of the iALARM project, a five-year NIH-funded study which aims to better link men to HIV care in the community of Gugulethu and the larger Klipfontein sub-district. The study focused specifically on men: compared to women, men in South Africa are more at risk of being LTFU at all stages of the HIV cascade, and have lower CD4 counts when they are initiated into care. These factors impact men’s health, and heightens the risk of them infecting others. During the five-year study, an intervention would be developed, providing reliable, understandable and accessible HIV reports that would be presented to a diverse group of stakeholders in the health system. The study aimed for the information presented to stimulate collaboration and communication among the group, trigger new ideas to improve men’s health and wellness, and also tackle other long-standing health issues in Gugulethu.

This first case study followed the designing process and implementation of the iALARM intervention. This chapter specifically highlights what happens when academic researchers bring together a diverse group of health systems actors, NGOs and community actors, offering them access to a wide range of health information in an effort to change how they think about information and how to use health information in their own work. The iALARM Research Team (iALARM RT) explored the impact of different types of routinely collected information, including as easy-to-read HIV reports or academic research reports, with the iALARM Task Team (iALARM TT). This iALARM TT consisted of a dedicated group of stakeholders who operated on different levels of the health system. Most of the iALARM TT members were familiar with the use of routinely collected health information for reporting purposes, but we explored how this information could be used to stimulate other kinds of action.

Following the process of collecting HIV information for the intervention, as well as observing the implementation of the intervention, revealed several interesting findings. Firstly, it became clear that there is a lack of HIV information that is available in Gugulethu, which leads to an increased appetite for information among stakeholders. Furthermore, both routine and informally collected health information sparked discussion and conversation among the stakeholders about HIV and men’s health generally. Informal health information was often shared anecdotally through informal conversations and almost directly led to follow-up campaigns. This was surprising, as the iALARM researchers expected that that only routine information would initiate action. Finally, and unexpectedly, the information presented and meetings in particular also became an opportunity for stakeholders to strengthen relationships and to share personal experiences about working with men in Gugulethu.

4.2 Background iALARM project

The iALARM (using **I**nformation to **A**lign services and **L**ink **a**nd **R**etain **M**en in the HIV-cascade) project is a collaboration between Brown University in the United States and UCT in South Africa. iALARM is a NIH-funded study that was developed in 2014/2015 after Associate Professor Christopher Colvin and Associate Professor Mark Lurie, the study's Principal Investigators (PIs), completed a successful NIH funding application to strengthen the research capacity for HIV and social sciences in Southern Africa through the South African Social Sciences and HIV programme (SASH). As the SASH programme was started, another NIH grant opportunity emerged, with a call for applications which aimed to improve partnerships between universities in the United States and South Africa, focusing on HIV and TB research. Chris and Mark brainstormed ideas which represented their combined areas of expertise, masculinity, HIV and epidemiology, and found several research gaps that could be addressed in the grant: 1) to better link men to HIV care, 2) to improve communication between the health system and the community, and 3) to provide routinely collected health information to improve service delivery in Gugulethu.

Aim 2 derived from a long-standing issue between the Sonke's Men's Wellness Centre (MWC) and the neighbouring NY3 clinic, which are both located on the same premises in the heart of Gugulethu. The MWC was opened in 2012 as Sonke's first centre that would focus on the wellbeing of men in the community through education, clinical services, support groups and outreach campaigns. The MWC was meant to collaborate closely with the NY3 clinic and share services, ideas and information. Although plans were made to have a dedicated male nurse appointed at the MWC, this was not realised until October 2017, which meant that until then, all health services for men were rendered through the NY3 clinic.

Although the NY3 clinic and MWC are located within a stone's throw of each other, there have been communication issues between the two facilities for years. Chris, who had worked with Sonke for more than ten years, became interested in better understanding and improving the lack of communication and collaboration between the two facilities, which could hinder the effective linkage of male patients in Gugulethu to HIV care.

> Chris: "*So there was this great opportunity of different groups [both NGO and service delivery] that should be working well together, and were in close proximity of each other, but somehow did not communicate well together. Sonke envisioned that the communication would flow better if there would be an exchange of information between the MWC and NY3 clinic, but Sonke did not know how this would look like*."

During an interview in early 2018, Chris spoke about his previous experiences at Sonke's MWC and was surprised that every month, staff members in the MWC would send their routinely collected statistics via Sonke's head office to the Western Cape Department of Health (WCDoH). In return, Sonke would receive a monthly routine management report (RMR) which would stipulate all the procedures done in the MWC, as well as the NY3 clinic. Unfortunately, the technical RMRs were difficult to decipher for Sonke staff, as many of them were not clinically trained.

The relationship between the MWC and the NY3 clinic as well as the ambiguity about the availability and use of HIV information encouraged iALARM researchers to design an intervention to improve the communication between NY3 and the MWC and strengthen information-sharing between both facilities, which would ideally result in more effectively linking men to HIV services in Gugulethu. The iALARM RT also aimed to track a group of men through the HIV-cascade by using a retrospective and prospective cohort study to better understand where men were getting lost in the HIV cascade. This information was designed to be collected from different health information repositories and combined HIV disease information, as well as laboratory and dispensing information which would be presented in a 'dashboard' format and contain aggregated information that could be accessed by health managers and MWC staff. To further improve health outcomes and the linkage of men to HIV care, the second part of the intervention aimed to share HIV specific information among a group of health system stakeholders to open up conversations about the men and HIV. These sessions would include the staff from the MWC and NY3 clinic as well as invited members of the clinic committee, health managers and members of the community. Together, these stakeholders formed the iALARM TT.

The iALARM project has welcomed many international students and researchers since 2015, all of whom contributed to different parts of the study and played essential roles in establishing relationships with health system stakeholders, which formed the iALARM TT (see more in Figure 3.4). The iALARM RT planned to use the Multisectoral Action Team (MSAT) to network within the Klipfontein sub-district and to use this structure to recruit members for the iALARM TT through this platform. MSATs were established in the mid-2000s in the Western Cape to streamline the HIV response (this is outlined in more detail in Chapter Five). Unfortunately, due to ongoing leadership issues, lack of steady resources and organisational problems, the MSAT was not functioning effectively and there was very little interest from individual MSAT members to participate in the iALARM TT.

Given the instability of the MSAT structure, the iALARM RT had to employ new strategies to network with relevant stakeholders in Gugulethu. Firstly, the team mapped all the services in the area with whom the researchers already established relationships, and which ones still needed to be targeted. The mapping exercise was part of a larger formative research study and proved to be a valuable way to better understand the community, as well as the movement of patients and information. Together with field coordinators Mandla and Phumzile, the iALARM RT visited NGOs and clinics in and around Gugulethu on a regular basis to establish relationships and invite interested health actors to the iALARM TT. Although nobody exactly knew yet how the iALARM intervention would shape up, the initial response of frontline health staff, CHWs, NGOs, and community members were positive; through our networking efforts, the iALARM RT gained information about HIV and other health issues in the community and learned about the movement of HIV health information between different stakeholders in Gugulethu.

In the initial conversations between the iALARM RT and possible stakeholders in the health system, it was revealed that the lack of available HIV information was not the only factor that prevented health systems actors to effectively link men to HIV care. Other issues in the facilities were the growing influx of patients, lack of treatment space and shortage of staff that impacted effective follow-up of patients after HIV diagnosis. Not being able to adequately link men to adherence clubs was also an integral part of the problem. Adherence clubs in South Africa were established to relieve the burden of primary care clinics by creating different groups of patients who are stable on ARV treatment for more than six months. These patients do not have to wait in line for their medication at the pharmacy, but can pick up their subscription once a month at a dedicated time, either within the clinic, or at a community centre or church (Bango et al., 2016, Tsondai et al., 2017, Venables et al., 2017). Adherence clubs were historically designed to further serve as support groups for HIV-positive people and are run either by clinical staff or CHWs (Tsondai et al., 2017). With the new Test and Treat policy implemented in 2015, the adherence clubs became even more important, due to the early initiation of patients onto HIV care and the increasing demand for ARVs at the clinics and the pharmacy (Grimsrud et al., 2016). Currently, men only represent 30 percent of people who are enrolled in adherence clubs in Cape Town (Tsondai et al., 2017). In Gugulethu, not all adherence clubs were well-managed; due to funding and leadership issues, CHWs were replaced or shifted around regularly without this being communicated to the patients, which dented the trust and impacted the relationships between patients and providers (Venables et al., 2017).

After months of mapping services, networking with stakeholders and trying to understand the movement of HIV information and patients in the community, the iALARM RT brought together a group of actors from different parts of the health system who were interested in better linking men to HIV care. Since the first meeting in May 2017, the iALARM TT grew from a group of 10-15 health systems stakeholders to 25-30 people. The rapid growth of the iALARM TT can be partly attributed to informal setting in which the meetings are held, and the fact that the agenda for the TT meetings is largely set by members of the iALARM TT and can differ from the initial research agenda. Currently, the iALARM TT consists of nurses, clinic managers, NGO representatives, iALARM RT researchers and sub-district health and information managers (see **Table 4.1**).

Health workers	NGO + Community	Sub-district management	iALARM RT
• NY3 Clinic* • Vuyani Clinic* • Gugulethu Community Health Centre* • Nyanga Junction Clinic*$ • Nyanga Community Health Clinic • Sonke Men's Wellness Clinic	• Men's Forum • Movement for Change and Social Justice (MCSJ) • Sonke Gender Justice • Desmond Tutu HIV Foundation (DTHF) • Lovelife • SOUP • Parent Centre • Cancer Association of South Africa (CANSA) • Grassroots Soccer • Etafeni	• Primary care manager+ • Health Information Manager+ • Health Promotion Manager+ • HAAST Coordinator# • Health Promotion Officer#	• Principal Investigators • Co-Investigators • iALARM Project Coordinator • iALARM Research Coordinator • PhD Candidates/Researchers • MPH Students • Visiting Students • Administrative Staff • iALARM Field Coordinators

* *Gugulethu;* $ *Heideveld*
\+ *WCDoH;* #*CoCT*

Table 4.1: Members iALARM TT

After the iALARM TT was assembled, the first official meeting was set for May 2017. In this meeting, the iALARM RT wanted to present information on HIV and men in the Gugulethu community. Ideally, the researchers wanted to build their own HIV cascade reports, which would show in which stages of the HIV cascade men would be likely to be LTFU and would also track individual patients. Retrieving complete, up-to-date and relevant HIV information to build up this cascade is a complex process and it turned out to be more challenging than the iALARM RT initially anticipated.

One of the primary challenges in trying to develop the HIV reports was the fact that clinics in Klipfontein sub-district, of which Gugulethu is a neighbourhood, are either under management of the Western Cape Department of Health (WCDoH) or the City of Cape Town (CoCT) (see more in Chapter Three). This complicates not only the use of service delivery, but also the movement of health information, as patient data is collected in separate information systems that are not adequately linked. This makes it difficult to track the movement of patients through the HIV cascade (Osler and Boulle, 2010). To better streamline the production of routine health information in the province, the Provincial Health Information Centre (PHDC) has developed a set of data harmonisation processes that aim to integrate the different databases into a single platform which can be used for surveillance, longitudinal follow-up of patients and informing decision-making processes in the health system (Schmidt, 2019). Parts of the datasets produced by PHDC were used to compile the first HIV reports for the TT meetings.

All iALARM TT meetings took place at the MWC in Gugulethu and required a bit of logistical planning for the iALARM RT, as we needed to move the team, equipment, refreshments and paperwork from UCT to the MWC. The meeting room is a large rectangular-shaped shipping container (see Figure 3.3) which is a multi-purpose room that Sonke uses for workshops, staff meetings, interviews and stocking condoms or promotion material. The container is located right next to the Steve Biko Rd. (NY1), a busy road that runs from one end of Gugulethu to the other. Right next to the container is the Gugulethu Mall, a bustling shopping centre where hawkers set up fruit stalls or light fires to braai sausage, pork chops or chicken livers on a stick. During the first four meetings in 2017, the iALARM RT set the agenda for the TT meeting and would provide HIV reports and other forms of information to discuss in the container. Over time, the iALARM RT received several direct requests from individual TT members; these included assisting with the development of the Adolescent Health Profile (AHP) (see Chapter Six), or organising community meetings (see Chapter Five), which slightly changed the focus and set-up of the TT meetings.

4.3 ‘Yes we can’: Mobilising routine health information within the iALARM TT

After months of planning, organising and lobbying, the first TT meeting commenced on 19 May 2017. Together with PHDC, the iALARM RT had put together a four-page HIV report (see Appendix 4.1) , which outlined parts of the HIV cascade, explained the different steps of the cascade in more detail and showed the movement of both men and women in Klipfontein through the HIV cascade. The iALARM RT did not include testing data, as this information was not yet available.

The iALARM RT was well-prepared for this first meeting, but knew that some of the data was outdated, as we were only able to collect information until 2013. Since then, HIV guidelines had changed, including the ART eligibility criteria, as patients would now be immediately initiated onto ART, regardless of CD4 counts. Nevertheless, the HIV report provided an overview of the movement of patients through HIV care in Klipfontein for both men and women. Chris Colvin kicked off the meeting by explaining the idea of the HIV cascade and how the cascade related to the UNAIDS 90-90-90 targets that were promoted in South African clinics. The 90-90-90 targets were set by the World Health Organisation to eliminate new HIV/AIDS infections by 2030. In order to accomplish this goal, they indicated that, by 2020, 90 percent of the world’s population should know their status; of those who are

HIV-positive, 90 percent should be on ARV treatment; and of those on treatment, 90 percent should be virally supressed (McMahon and Medland, 2014, Unaids, 2014, Bain et al., 2017). With more than 65 percent of men not being aware of their HIV status, South Africa still has a long way to go to reach these targets (Cornell, 2013, Cornell et al., 2017).

After this introduction, he spoke about the movement of men in the HIV cascade and showed that compared to women, men in Klipfontein are less likely to obtain a CD4 test, successfully link to care, and be virally supressed (**Figure 4.1**). As expected, many of the TT members did not seem to be surprised that men performed worse than women at every step of the cascade, but some participants immediately felt the need to explain why this happened. Sr. Mavume, the clinic manager from NY3, commented that; "*Sometimes, one man is coming in with four different women. Every day, the man brings another woman to test. That is why there are more women in the facility then men*."

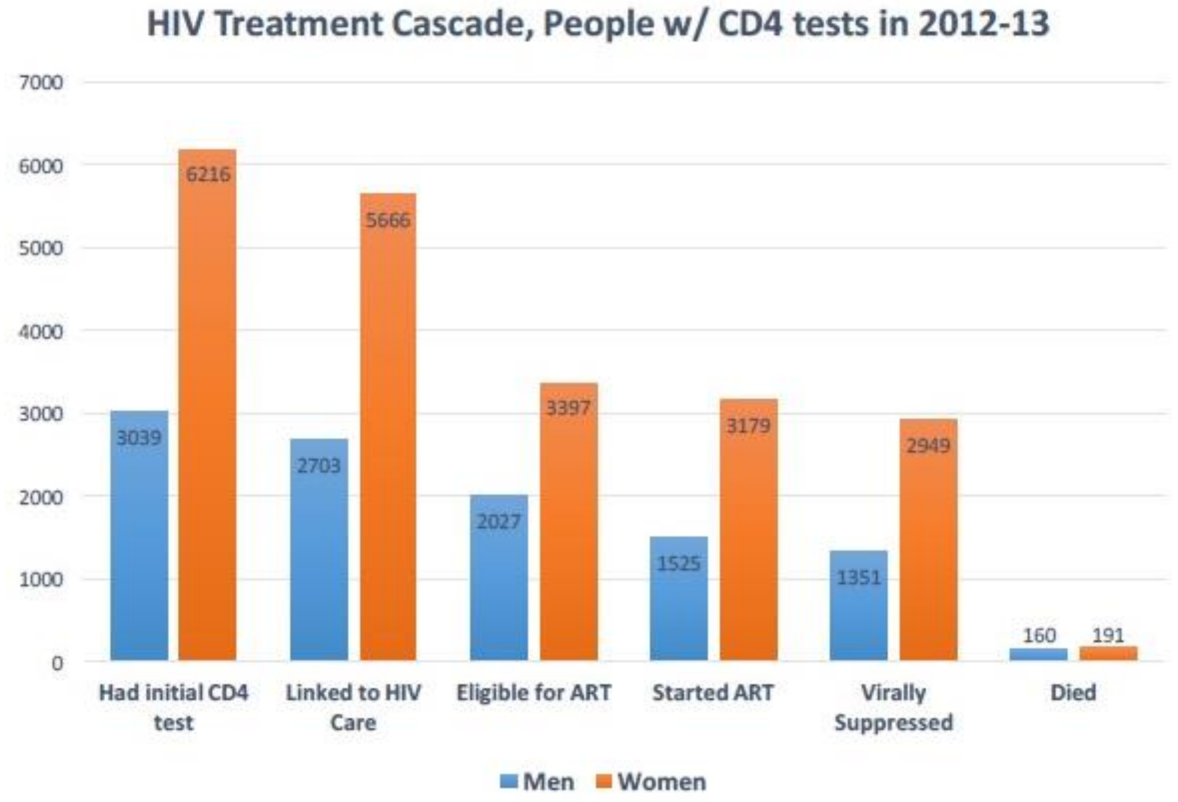

Figure 4.1: HIV cascade, part of the iALARM HIV Report #1 May 2017

Another participant mentioned that; "*Men just don't care about their wellness. They do not follow their appointments and run away from the stigma of HIV*." Lunga George from the Parent Centre added; "*Some men think that the clinical environment is not conducive for men. If you go to the clinic, all the charts represent women. The clinic is just not well catered for men*." According to the TT members, most men do not have time to go to the clinic, as they are working 12 hours a day, or "*They think when their wife is negative, they are negative*."

Relieved that the initial conversation about the HIV report was well-received, Chris was ready to discuss the rest of the document. He barely got the chance to do this, as participants were already proposing several ideas that could encourage men to test and better link them to care. Sr. Mavume spoke first. "*We need to urge people to disclose their status. Disclose and bring your partner to the clinic, so he/she can also get tested. They need the support from their friends and family.*" "*Yes*", another TT member agreed. "*We need to chase the men and their partners to come and test.*" Ms. Xapile, the primary care manager for the sub-district, also emphasised the need to act. "*We need to have conversations with men in the community, and see what their needs are.*" "*It's all about men*", another participant added, "*We need to engage with the men to understand their needs and welcome them more openly into the clinic*." Siphokazi, one of the trainers from Sonke, already developed a strategy to convince men to come to the clinic. "*We need to have one-on-one conversations with men. This report can help us with that. Because this is what is been gathered in our community. Maybe we should have a couples counselling session in isiXhosa and share with clients this information*."

The input from the TT members at the meeting only grew in the following TT meetings, as well as the call to take action. Although the HIV reports would cover different stages of the HIV-cascade, each month, all reports provoked the need for the iALARM TT to change the status quo and more meaningfully include men in the HIV response in Gugulethu. Several slogans were prominent:

> *"We need to go out into the community"*
>
> *"We need to get men to test"*
>
> *"We need to educate people about HIV"*
>
> *"We should demolish stigma"*
>
> *"We need to make men come into the clinic"*

The iALARM RT was excited about the response from the participants in the first meeting and appreciated the concrete action plans that seem to shape up quickly after presenting the first HIV report. Interestingly, the HIV information presented was relevant to the Gugulethu community, but not up to date. Since 2013, the HIV landscape has shifted, but this did not seem to bother the TT members, who used the data as an incentive to brainstorm about plans to improve engagement with men and more effectively link them to care.

The iALARM RT tried to pinpoint what exactly drove their enthusiasm to take action. Was it the fact that someone brought them HIV information that was specific to their community? Or that the reports were written for a large audience and tried to deal with a complex biomedical and social problem by dividing the HIV trajectory into different phases of the cascade? Although every step poses distinct challenges for both patients and health providers, some of them would overlap too.

One of the possible explanations for the initial enthusiasm among participants at the meeting was the format in which the HIV reports were developed, which are very different from the routine management reports (RMR) used to collect monthly statistics. Furthermore, the request from the iALARM RT was open-ended; the HIV reports were developed as part of the intervention, but the research project did not require any specific input from the health actors. The reports were designed to be interpreted in various ways and to start a dialogue about the movement of men in HIV-care. Despite the fact that the information was outdated, a sense of urgency arose among the TT who expressed that it was important to start focusing on the trajectory of men in care and come up with ideas to more actively invite them into the clinical space. There was a need to bring health information, in this case routinely collected, to the TT members on a regular basis. This HIV information was the beginning of a larger conversation about the status of men's health in Gugulethu.

4.4 The role of informal health information in the iALARM intervention

As described in the previous sections, the TT members took the HIV reports and information presented during the first TT meetings seriously, and the content of the reports incentivised the TT members to develop ideas to better link and retain men to HIV care. In the first few meetings, the TT members spoke about creating male-friendly posters that would make men feel welcome in the clinic (see **Appendix 4.2**) and designing outreach campaigns to try and further destigmatise HIV. TT members also wanted to educate communities about the new ARV guidelines such as the universal Test and Treat policy that was implemented in South Africa in 2015 (Iwuji et al., 2018).

In the HIV reports, the iALARM RT explained the movement of men through HIV care by highlighting a different part of the HIV cascade each month. In June 2017, the RT focused on HIV testing for men and used three different sources of information to do so. Firstly, the June HIV Report (see **Appendix 4.3**) would be discussed, which included testing rates for both and women in Gugulethu and would give estimates of people who still needed testing. According to the information, in 2012, 78 percent of men in Gugulethu were eligible for HIV testing. Of the 22 percent of Gugulethu men who were tested, two percent of the men tested positive in 2012 (**Figure 4.2**) Compared to 60 percent of women who were untested in 2012, men were performing worse in this first step of the HIV cascade. The initial discussion of the HIV report, highlighting those in need of HIV testing, sparked further conversation about the different groups of men who were hard to reach, including migrants, refugees and prisoners. Mzamo, a trainer at Sonke who runs a programme to reintegrate ex-convicts, commented that men who are released from prison face many different challenges and often struggle to access treatment, as they feel stigmatised and are afraid to tell health workers that they were incarcerated. According to Mzamo, some men try to change their name or go back to prison to access treatment there when they get sick, rather than opening a new folder in a public hospital. This practice puts prisoners at high risk, as they are vulnerable to contracting HIV when in jail or awaiting trial, and also are easily LTFU once sentenced. The report also initiated a larger debate about the mobility of male patients and the need to find new ways to better track men through the HIV cascade.

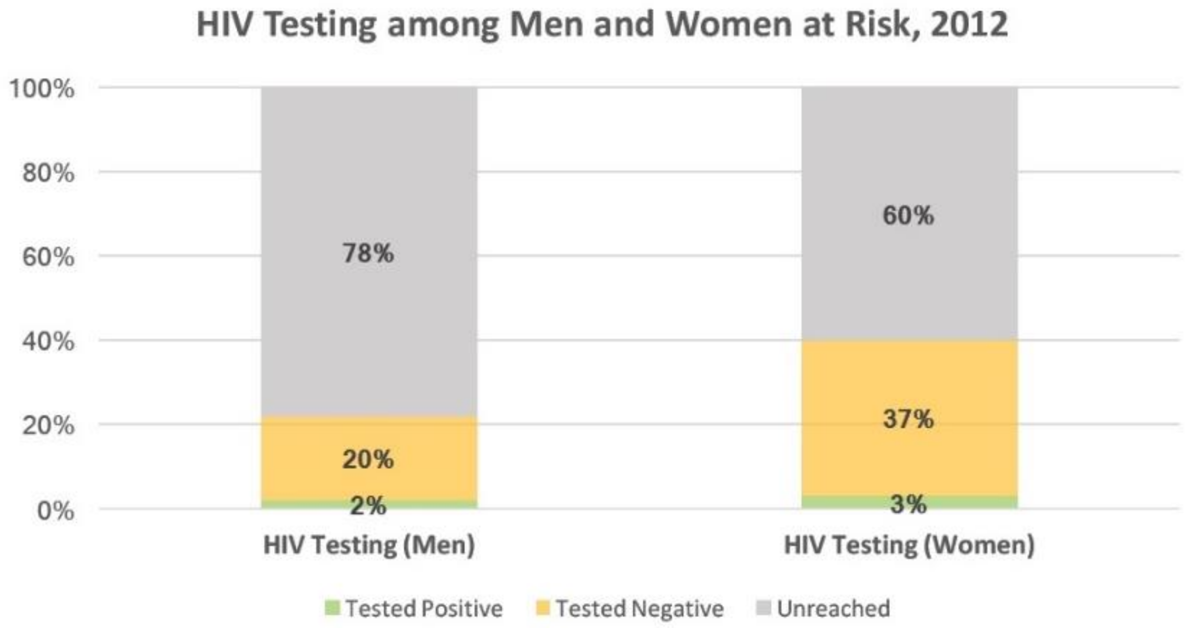

Figure 4.2: HIV testing among men and women, part of iALARM HIV Report #2 June 2017

The second part of the TT meeting in June 2017 was reserved for presentations from Phumzile and myself. I shared the qualitative research findings of two MPH students, Sithembiso and Genoviva. Both projects focused on the experiences and perceptions of HIV testing among men in Gugulethu. In the presentation, I shared ‘the voices of men’ and spoke about men’s knowledge of HIV testing, the barriers to testing and different forms of support which would enable men to go for testing. One of the most notable findings in the MPH research was that fact that most men were very well-informed about the process of HIV testing and did not necessarily prefer a male provider over a female one. This finding indicated that the lack of HIV information or shortage of male health providers were not seen as barriers to HIV testing among the participants in this research. However, denialism, lack of support from family and stigma did prove to be barriers for men to test for HIV.

After I presented the research findings, Phumzile shared his personal story of living with HIV in Gugulethu. He mostly spoke about how HIV services in South Africa have changed over the years.

Phumzile was diagnosed with HIV in 2001 and was one of the first beneficiaries of the ARV programme rolled out by Médecins Sans Frontières (MSF) in Khayelitsha in 2005.

> "*I am here as a man, a Gugulethu man. And I am shocked about the stories and the numbers that I hear in these iALARM meetings. We need to put in more effort to get men tested. There is a lot of activism is this community, we just do not see it. I have seen a big shift since 2012, the data that is used in the HIV reports and I think the health of men is actually deteriorating, rather than improving. What do we do, as were still struggling here in Gugulethu. We really need to start with our facilities and speak to the staff. That they need to put men on the agenda. Speak to men and about men. And we need to start organising men's dialogues and initiate male adherence clubs that are led by men like me, HIV+ men. I have been living with HIV for more than 16 years and have really benefited from the support that I got in my own support group for men, Khululeka. We, as men, should also be more present in the waiting rooms of the clinics and share our stories. Show that we are not afraid to disclose, that we live positively. When I come into Hanan Crusaid (the ARV centre in Gugulethu, part of the larger Gugulethu CHC), some male patients know me but are shy to speak to me, as I know they are HIV+. There is stigma in places like Hanan Crusaid, which we should tackle. We should speak to men and tell them that we support them. That we have the information and are happy to share. But we also need to tell them that it is their responsibility to take care of themselves and their families. That condom use is non-negotiable. That a healthy (or healthier) lifestyle is important. We need to reach out to men with living testimonies, just like me*."

With his story, Phumzile tried to tackle several long-standing issues men face in Gugulethu, including stigma, lack of support and secrecy about HIV in the community.

Although most of Phumzile's personal story covered topics similar to the research findings from the MPH students, his words visibly impacted the TT members. Phumzile's testimony provoked a debate among health providers who largely shared his sentiment and immediately endorsed his experience. One TT member commented that since the early 2000s, not much had changed in Gugulethu. Although ART was now available, the stigma and assumptions about HIV were largely the same as 15 years earlier. He spoke about a friend who was courageous enough to disclose his status during a party and how people literally left the room and ignored him after he told some people that he was HIV-positive. Another TT member argued that "*The ball is our court. We need to create more male-friendly health services in Gugulethu if we want to effectively include men*."

Several interventions were proposed in the discussion following Phumzile's testimony. The first strategy was to provide psychological support to men who want to disclose their status to their loved ones. The second one was to set up male-only support groups: *"In most CHCs, there are no support* *groups,"* a TT member stated. *"People grab their medication and go, there are no open dialogues about people's experiences living with HIV."*

Sr. Noyakaza, the ARV nurse from the ARV centre at Gugulethu CHC, invited Phumzile to share his story in the waiting room of the clinic, as he would be an inspiration for all. Many TT members called him '*the living testimony*' and an '*exemplary patient*'. On Mandela Day, 16 July 2017, Phumzile told his story at the clinic. Several months after this, a Men's Forum was established, a support group for men to speak about HIV and other health issues. The Men's Forum is led by MCSJ and Sonke and meets every couple of weeks at the MWC.

The reactions and discussions that originated after Phumzile shared his testimony with the iALARM TT members in June 2017 highlighted that participants in the TT, as well as other stakeholders in the health system, use a combination of different forms of health information within their work and are informed by various sources, rather than being solely reliable on the access to and availability of routine health information. Therefore, as researchers, we should not underestimate the power of personal narratives as described above (Stevens and Tighe Doerr, 1997, Ezzy, 1998). Nevertheless, there were still several questions that puzzled the iALARM RT, such as: why did Phumzile's story provoke a strong reaction from participants in the iALARM TT? Health workers in particular meet HIV-positive patients in their clinics on a daily basis, which means that Phumzile's story is not unique. Furthermore, Phumzile is quite well-known in the community and has worked with many different NGOs, including Sonke and Etafeni, where he would share his story with community members. This unexpected response of the TT participants was paired with a sense of urgency to re-evaluate how men are approached in health services, and opened a larger debate to rethink the ways in which current systems of care are designed.

4.5 'But what about listeriosis?' – Disseminating health information from the iALARM intervention to the community

Since the start of the iALARM TT in 2017, the representation of stakeholders had shifted slightly and over time, more community members joined the TT meetings. This shift was triggered by the rapid growth of MCSJ (see more in Chapter Five) and participants of the Men's Forum who were interested in learning more about HIV. By attending the TT meetings, the Men's Forum representatives were informed regularly about issues related to HIV and some of the men wanted to further disseminate the information to the larger community. During the TT meetings, as well as in personal conversations, male participants would pose many questions about new ARV treatment programmes, side effects of ART and the impacts of HIV on other chronic illnesses, especially for men above 40.

One hot morning in March 2018, I travelled to Gugulethu to interview Sinda, the newly-appointed male nurse at Sonke's MWC. The interview was delayed slightly, as Sinda was first seeing a client and needed some privacy. I waited in the iALARM field office next to the MWC containers. Here, I met four representatives from the Men's Forum who were busy planning activities for the month. Although I did not want to interfere with their work, Zolani, one of the members, called me aside and started to ask me questions about the link between listeriosis and HIV.

Listeriosis is a food-borne infectious disease that spread through South Africa in 2017 and 2018, infecting almost 1,000 people and killing 183 people (Chersich et al., 2018). Infection occurs mainly through the consumption of infected processed meat products, such as bacon, ham or 'polony' (a cheap sandwich meat that is often referred to as bologna). These products were recalled from many supermarkets and shops. People most at risk for infection include pregnant women, neonates, young children and people with a compromised immune system.

> **Zolani:** *"Myrna, can I ask you a question?"*
>
> **Myrna:** *"Yes, go ahead"*
>
> **Zolani:** *"Do you think that people with HIV can get listeriosis?"*
>
> **Myrna:** *"I am not sure, why do you ask that? Do you know people who are infected with listeriosis?"*
>
> **Zolani:** *"No, not really. But aren't people with HIV at risk? As they get sick more often? And then does it interfere with their meds (ARVs) when they have it? What do you think?"*
>
> **Myrna:** *"Jeez, Zolani, I am not sure. It makes sense, as it occurs earlier with people who have a bad immune system, but I guess when you are using ARVs and your viral load is undetectable, you should be fine. But to be honest, I cannot really answer your question, as I am not a medical doctor. It is better to ask an ARV nurse for this kind of information."*

On that day, I was not able to chat more with Zolani, but the question lingered in my head for a while—partly because the question was relevant to the iALARM project, as we would often discuss how HIV relates to other diseases during our meetings. Zolani and other members of the Men's Forum seemed to have absorbed the information from earlier meetings, used it within their own local context, and had taken this opportunity to explore other HIV-related health issues. While this was positive, I was still surprised that Zolani asked me this question in the first place, as the iALARM container is located on the premises of both the NY3 clinic and the MWC, which means that Zolani had access to several health workers and counsellors who would be able to provide more information. He could have just walked into the next-door container to ask Sinda, or speak to Sr. Mavume or any of the other nurses in the NY3 clinic about the dangers of listeriosis for HIV-positive people. Besides that, the listeriosis outbreak was a hot topic in the South African media, with daily reporting in newspapers, radio, television and through social media channels. Curious to find out more, I shared my encounter with Mandla.

> "*I have not picked up on the issue of listeriosis yet, but you know, I understand it. People are generally worried and this also sticks to this issue of… well… education and information. You know Myrna, if we can have people in different sections of Gugulethu trained. People who are easily accessible to people on the street. Then yes, people can be educated and up to date quickly. The problem now is that information is difficult for people to get. Sometimes, they can only get it [the information] from nurses. Or through the hospital and clinic officials. What we need to try to do is to develop cadres that are fully informed, that can mingle with people and get the information".*

Mandla's answer give some insights into the meaning of and need for health information in the community. Firstly, both Zolani and Mandla acknowledged the lack of trustworthy and timely health information to inform the community. This void was partly filled with the information shared at the iALARM TT meetings as well as the spin-off projects, such as the poster campaign. The conversation above also exemplifies how different forms of information presented in the TT meetings were trickling down to a community level and empowering community members to inform themselves and others. Mandla's strategy to develop cadres of empowered health representatives who channel information from academic sources such as the TT meeting to inform others around them to improve health literacy also emphasises the need to empower the community about HIV and HIV-related issues by sharing different forms of health information, including research information as provided in the iALARM TT. This strategy has been used by the Treatment Action Campaign (TAC), who would aim to inform individuals about their right to HIV services, ARV treatment and social support. Through their campaigns, TAC was able to largely destigmatise HIV, empower patients and place the epidemic into a larger social and political landscape (Colvin, 2014, Heywood, 2009).

Furthermore, the listeriosis example also illustrates a pattern that was shown repeatedly during my fieldwork: the appetite or hunger for information among community members in the TT. In the TT meetings, the iALARM RT regularly presented findings to update participants about the newest research outcomes, including student projects and academic publications. After presenting the results, MCSJ members and other community representatives would request a pamphlet or summary of the findings, so they could use it for future training, or distribute it in their neighbourhood. This appetite for information might be generated by the ways in which the information in the TT was presented and discussed in the meetings, or may be attributed to the fact that many of the community members would not regularly interact with health information. Repeated interaction with MCSJ and other community members in the TT showed that, despite the fact that health information might be available (either in clinics or elsewhere), community members experience barriers accessing these sources of information, which results in unmet information needs within the iALARM TT.

4.6 On neutral ground? The iALARM TT as a safe space for information-sharing

During the time of my fieldwork, not only did the formation of the iALARM TT change, but the content of the meetings also evolved, as the iALARM RT stimulated the TT members to set the agenda for the meetings and request information. Another observation which I experienced was the changing level of motivation among the TT members and shifting relationships between individual participants. It seemed to me that, over time, the container—the big white box where it was always too cold, too warm or too noisy—became a safe space for the TT members to speak openly about some of their challenges, ask for advice, make new contacts or strengthen existing relationships. The information presented in the meetings often initiated an open conversation among health system stakeholders, but the actual space and the dedicated time also provided opportunities for new collaborations and encouraged the TT members to share personal experiences.

During the TT meeting in November 2017, the last meeting of that year, the iALARM RT gave an overview of the progress made during the previous meetings, including the development of the AHP (see more in Chapter Six), the plans for the Men's Forum and the male-friendly posters (**Appendix 4.2**). We also briefly revisited some strategies which were developed to encourage male patients to come to the clinic and inform them about the need to test for HIV, STIs and other health conditions. For Sr. Thandi, a nurse at Nyanga CHC who just joined the TT, hearing the strategies encouraged her to share some of her own stories from the clinic. She asked other TT members to explain to her why men were not coming to her clinic to test for HIV and screen for TB, but would seek alternative medication for their ailments instead.

> *"How can we get men to the clinic if there is a container next door where someone is selling these green herbal teas. They claim it is for general wellness and HIV. So they can come all the way to that container for the green tea, for which they pay R15 a cup, but cannot come to the clinic for a real and free HIV test."*

After her comment, she looked around the room, appealing directly to the men in the group and openly seeking support from other health workers. I could sense that she was failing to understand the health behaviour of some of her male patients who would not be afraid to take herbal medication, but would not visit the next-door medical clinic. Although she did not receive a concrete answer from the TT members as to why men would choose herbal medicine over biomedical care, there was a discussion about the need to target elderly men to test for HIV and to find strategies to break popular beliefs that link HIV to witchcraft, and to convince male patients that traditional medication such as green tea is not a cure for HIV.

The excerpt above is just one of many times that TT members openly shared their experiences with male patients, trying to learn from male participants. Presenting these stories also served as a way to learn from colleagues, to seek advice from their managers and connect with potential patients. For many health workers, their daily work and schedule did not provide the opportunity to participate in collaborations such as the iALARM TT. When working with health data, most health workers would report on routine health information collected in RMR reports, and send these reports to the sub-district on a monthly basis. Often, the only time health workers would actively interact with this sources of information would be during managerial meetings where the focus often was on clinic targets; there was little time to discuss the underlying social meaning of the information. The TT meetings held in the container became a space and platform where the iALARM RT did not just provide the information about HIV in the Klipfontein sub-district, but also created an opportunity for a group of stakeholders to engage with the information.

Furthermore, the container space also served many other purposes and needs, including strengthening existing relationships between TT members and solving long-standing communication issues. As described previously in this chapter, there were long-standing collaboration and communication issues between the NY3 clinic and the MWC. These problems also surfaced during the meetings. Sometimes, the iALARM RT would pose questions to the TT members about referrals of patients, as part of trying to determine why men would not link to care after testing for HIV. In a preliminary meeting in early 2016, Thulani, a senior trainer from Sonke, acknowledged that the lack of communication between the MWC and NY3 could be a contributing factor for men becoming LTFU.

> *"We do not have a male nurse, so now we work with referral letters, whereby we send patients from the MWC to NY3 to get tested, but the men disappear and we do not know why. We really need to improve the communication between us and the clinic, because we need to get the men tested and linked to care. That is more important than our differences."*

Thulani directly spoke about the communication issues between the NY3 clinic and the MWC, but did not clarify what exactly needed to be resolved. One of the challenges that surfaced over time was folders disappearing at the NY3 clinic. Male patients would complain to MWC staff that their folders, which contain personal and medical information, would go missing, or would just be '*lying around*'. This carelessness increased the risk of involuntary HIV disclosure, and, according to the manager of the MWC: "*kept men away from the facility as they are scared to lose their anonymity*". This was problematic, as the MWC staff had to refer their male patients to the NY3 clinic, because Sonke did not have their own male nurse at that time.

According to one of the managers at Sonke, a way of solving the problem of disappearing folders would be to keep folders at the MWC, and not at NY3. His idea was that male patients would pick their folders up at the MWC and take them to the NY3 clinic for their appointments.

The allegations from the MWC staff about disappearing folders and other small disputes showed a lack of trust in the clinic staff and hesitation to collaborate with the NY3 clinic on men's health issues. Even after Sinda, the male nurse, was appointed by Sonke in October 2017, and even as both facilities shared services, resources and clients, there was still limited communication between the facility manager, Sr. Mavume, and Sinda. In an interview I conducted with Sinda, he said:

> "*We only meet when we really have to discuss things together, but not often. I am just doing my clients here and she [Sr. Mavume] just gave me permission to order anything at the pharmacist. And the clients come directly to me, so there is no need for me to interact with her….. All the capturing of the folders is done in the clinic, and I then just submit my report to Sonke, which states amount of clients tested. And then I send them [the monthly reports] to Sonke and the Department of Health."*

Sr. Mavume acknowledged the strenuous relationship between NY3 and the MWC, but during an interview in late 2017, she also indicated that the TT meetings were an opportunity to speak about the ongoing issues and strategize together to improving men's services.

> *"It is important to recognise that the issues are political. Working with NGOs is an opportunity for NY3 but also a threat. But we are really trying and are doing better with the adherence clubs. We listened in this forum and we are now trying to take male patients in early and to have them out by nine a.m., so they do not have to wait too long."*

Despite the fact that Sinda did not often communicate directly with Sr. Mavume and preferred to speak to the pharmacist or clerk, he was not shy to ask her advice in the TT meeting. During a TT meeting in early 2018, Sinda and Sr. Mavuma shared ideas to promote male health services rendered through the MWC. To better inform patients, Sr. Mavume offered to inform the security guards at NY3 clinic about the opening times of the MWC, and distribute Sonke flyers to patients through the guards and clerks. *"The men will first encounter the security before they even enter the clinic. So, if they are up to date, we will lose less men*." In turn, Sinda was willing to start consultations earlier to synchronise opening times with the clinic. "*When we start at the same time, we are able to catch more men who otherwise would be waiting till 9.00 AM to visit the MWC*."

The improved relationship between Sinda and Sr. Mavume also inspired others to approach the NY3 clinic staff directly and reconcile earlier disputes. During a meeting in April 2018, Sr. Mavume invited Sonke trainers to come and conduct regular health talks in the clinic. "*I really want to invite them to come into the clinic and do health education talks. And people from MCSJ are also welcome."* Responding to the invite, Lunga George, one of the MCSJ members, admitted that MCSJ had not communicated constructively with NY3 clinic staff in the past.

> *"I also want to apologise on behalf of MCSJ that we should have connected with NY3 earlier and make ourselves visible in the space. MCSJ and the Men's Forum should introduce themselves to your staff and share the activities we undertook in the past, so we can see how the clinic and MCSJ can help each other in the future."*

The excerpts from different meetings described above highlight how the iALARM TT meetings accommodated new and revived relationships between individual stakeholders and strengthened the iALARM TT. Providing a regular space where meetings could occur outside daily work obligations facilitated the development of ideas and follow-up projects and provided a platform for health actors to share personal experiences and seek advice from others with similar interests.

4.7 Discussion: Reflecting on the iALARM intervention

Through the use of different examples, this case study has explored the role of different forms of health information in the iALARM intervention. The chapter highlights how formal and informal health information are being used within the iALARM project and how this impacts a group of health system stakeholders who all have an interest in working with HIV information. The first section of the chapter showed how routinely collected health information was received by the TT. Although hard to retrieve and slightly outdated, the HIV reports triggered a sense of urgency and call to action among participants that eventually influenced follow-up projects. The second example pointed out the unintended consequences of informal health information within the iALARM intervention. Example three follows the movement of health information from the iALARM TT into the community, which shows how health information is used as a starting point for a larger conversations about health in Gugulethu. The last observation explores how a shared space can lead to improved communication and collaboration between health actors, and stimulates problem solving and information-sharing.

Although the examples in the case study differ from one another, they all demonstrate new insights into the complex role of health information within the intervention space and the larger health information system (HIS). iALARM was designed as a project that would primarily use routinely collected HIV information to change practices in the health system of Gugulethu, but accessing this information proved not always easy and straightforward. Although the HIV information available did not allow the iALARM RT to track individual patients through the HIV cascade, the reports did raise awareness about the mobility of both male and female patients in HIV care in the Klipfontein sub-district. Additionally, other forms of data, such as testimonies and informal discussions, would provide alternative health information which complimented the HIV reports and proved to be useful resources that were well-received in the iALARM TT meeting.

Historically, health information management interventions focus on the movement of patients through care, but only focus on the technical aspects of information use (Braa and Hedberg, 2002). Most research emphasises linking databases together, implementing e-health solutions or exploring the options of using unique patients identifiers to streamline care (Gagnon et al., 2009). Although important, these interventions often only focus on the production of routine health information, but not on the usability of and engagement with this data in daily practices in the health system (Nutley and Reynolds, 2013, Nutley et al., 2014). This case study shows that the development of a health information intervention is complex, and success cannot only be attributed to technical enhancements only, but other factors are crucial too, such as the type of information that is produced, used and exchanged. This requires continuous engagement between health system actors and the health information provided.

Findings in this case study are in line with Nutley and Reynolds (2013) who, within their work, also aim to rethink the technocratic approach that is normally used in health information interventions (Nutley and Reynolds, 2013). Within their work, Nutley and Reynolds argue that; “Too often, data sits in reports, on shelves and in databases and are not utilised in policy programme development, improvement, strategic planning and advocacy” (Nutley and Reynolds, 2013, p.1). Nutley and Reynolds also claim that a good health information system should focus on “assessing and improving the data use context; engaging data users and data producers; improving data quality; improving and data availability; identifying information needs; building capacity in information use core competencies; strengthening the organisation's information demand and use infrastructure; and monitoring, evaluating and communicating results of data use interventions”(Nutley and Reynolds, 2013, p.3). Similar to what was observed in the iALARM intervention, these authors advocate for a stronger collaboration between data users and producers. “When they work together, they better understand the data information collection methods and processes, available information sources, and the quality of the information, which can address barriers to information use” (Nutley and Reynolds, 2013, p.6).

The iALARM intervention also provided a platform to facilitate a conversation between the producers of health information and its users within a safe environment. Having primary care managers in the container next to clinic managers, nurses and community members—sometimes patients themselves—provided an atypical situation, as all stakeholders would interact with each other in the same space about men and HIV in Gugulethu. The common interests of the participants also instigated new and meaningful relationships between TT members. As shown in this chapter, the intervention opened up conversations patients and health providers and to address long-standing disputes between stakeholders. This was unique, as due to existing hierarchy structures in the health system, the connection that individual health actors have with each other is often not recognised.

Designing, piloting and implementing a health information intervention is a long and complex process (Harrison et al., 2006, Braa et al., 2004, Aqil et al., 2009). The iALARM intervention and the iALARM RT faced several challenges along the way, such as: limited HIV information that was reliable and up to date; lack of commitment from TT members; and long-standing differences between individuals that hindered meaningful collaboration between health system stakeholders. As with many other health systems endeavours, these challenges emphasised the importance of adapting the intervention to the local context of Gugulethu, rather than designing a ‘one-size-fits-all’ solution. The lack of communication and information-sharing between CoCT and WCDoH facilities proved to be problematic, as did the lack of HIV testing information available to populate the HIV reports. Both issues hindered the development of the HIV reports. Furthermore, the iALARM RT had not anticipated that the iALARM TT would attract a growing number of community members who were interested in sharing the presented health information to educate a larger audience. This altered the iALARM intervention, which thankfully had a malleable design. However, the flexibility of the intervention also provided a chance to respond to specific information requests, such as the development of a male-friendly poster, providing information for the Adolescent Health Profile (AHP) or disseminating research findings to the larger community of Gugulethu.

Chapter 5: ‘In community activism, we need to be serious; we cannot cry wolf’ – The role of health information in MCSJ

5.1 Introduction

Health information plays a significant role in the health system, but not everyone has equal access to health information, which impacts practice and decision-making (Garrib et al., 2008). When trying to strengthen HISs and promoting the use and exchange of health information within the health system, the emphasis often lies on creating solutions that improve the collection of health information from the community or facility level to inform guidelines or programmes on the district or provincial level. In this process, we often fail to acknowledge the role of community members, who often rely on public health services and might have a particular interest in using health information for community engagement activities (McCoy et al., 2011).

There have been several attempts to include communities, and those working on the periphery, into the HIS, but there is very limited empirical research that explores the use of and need for health information in the community. We also know very little about information seeking behaviour of community stakeholders. Furthermore, a lot is unknown about how communities collect their own formal and informal information to address issues in the health system, and to inform themselves and others about new health policies or programmes. This leads to the following questions: what information is used in communities? Where is this information collected, how is this information distributed, and what impact does this health information have on service delivery, practice and decision-making within the community?

Many scholars working in HIS research acknowledge the lack of access to information for community members; they critique that the use of and access to information should be equal, and that information should move multi-directionally to and from communities. Unfortunately, in reality, the community is asked to provide information for the HISs in facilities or districts, but this information is rarely distributed back to the community. Even when setting up community-based health information systems (CHBISs), which are specifically designed to improve information-sharing between facilities and the community and are linked to community clinics, information is often fed from the community into the CHBIS but not used by community members. This leads to a gap between having information for planning and the use of this information, which can inform community dialogues and be used for health education purposes. In the few instances where the demand for and use of health information in CHBISs is an equal and straightforward process, information creates awareness and increased trust and responsibility among those using the information.

The demand for and use of health information by community members within Gugulethu is the basis for this case study. This case study explores how community actors, who normally operate on the periphery or outside of the health system, make active use of health information for their own goals and campaigns. For this case study, I followed a group of community members who challenged the conventional use of health information; used their own, inventive ways of collecting health information; and actively reimagined traditional ideas about health information within the HIS. I spent extensive time with community members in Gugulethu who are part of the Movement for Change and Social Justice (MCSJ), an advocacy group that aims to improve the provision of health care within Gugulethu and the surrounding areas, and educate the community about their health system and right to health. MCSJ as an initiative derived from the work of iALARM, and MCSJ members were often involved in the research project. However, findings described in this chapter were part of MCSJ's engagement with health information that far exceeded the objectives of the iALARM study.

During my time in Gugulethu, I observed how MCSJ members collected their own formal, informal and health topic information for advocacy campaigns and used this data to raise the alarm about systemic service delivery issues in the community. This chapter provides several insights that highlight the lack of health information within the community of Gugulethu and the creative ways in which MCSJ tried to collect, use and transform health information for their own campaigns. This chapter also describes the complex use of health information within a community setting and shows why, in some circumstances, informally collected forms of information supersede routine information within decision-making processes. This chapter furthermore shows that strong relationships between academic researchers, community members and other health system stakeholders facilitate better information-sharing. Lastly, this chapter explores the role of MCSJ as a mediating force whose members were able to bridge the perceived distance between health professionals and community members through facilitating active health information-sharing.

5.2 Background Movement for Change and Social Justice

On the first Wednesday of every month, I would make my way to Fazeka, the Cape Town municipal offices in Gugulethu. Here, I would connect with my colleagues Phumzile and Mandla for a meeting with the Multisectoral Action Team (MSAT). The MSAT was set up in mid-2007 to organise the community response to the HIV epidemic. At that time, ARVs were not yet widely available, and the epidemic was spreading rapidly within disadvantaged urban areas such as Gugulethu and Khayelitsha (Govindasamy et al., 2013, Walensky et al., 2008). During these years, it was crucial for NGOs, government and health services to closely collaborate on prevention and care strategies within communities (Colvin and Wills, 2008). Educating and informing people about the risk of contracting HIV, destigmatising the disease and organising large-scale HIV testing campaigns were core activities which needed to be streamlined across different community stakeholders (Govindasamy et al., 2014). MSATs were started all over the Western Cape, financially supported by the Global Fund and run by the Western Cape Department of Health (WCDoH). Preferably, every sub-district in the province would have their own MSAT structure.

The monthly MSAT meetings in Gugulethu would traditionally be held in the municipal office's boardroom—a conference room with an oval table that was slightly too large for the space, oversized fake leather chairs, and a jug of water in the middle of the table with glasses that nobody could really reach. In summer, the air-conditioning would be blasting cold air to cool the room to a temperature at least ten degrees lower than outside. Traditionally, MSAT meetings would start at 10.00 AM, but Mandla, Phumzile and I were often the first ones to arrive. At 10.15 AM, if the room was still empty, Mandla would start knocking on the doors of the surrounding offices, asking who would attend the monthly MSAT meeting and asking for some support from the MSAT coordinator, a position that rotated frequently.

Sitting next to Mandla and Phumzile during the meetings, I could feel their growing sense of discomfort about organisational capacity of the MSAT. Both Mandla and Phumzile, who have years of experience mobilising communities and running HIV campaigns, regularly shared their ideas of trying to better link patients to HIV care in the meetings, based on their knowledge of the community and understanding of the current issues in Gugulethu. Although most of the MSAT members were sympathetic about the health challenges in the community, the meetings rarely led to concrete plans or community outreach campaigns.

I asked the MSAT coordinator about the history and current challenges of the MSAT during an interview. According to her, the MSAT had lost momentum, due to the changing HIV landscape and availability of treatment, which shifted the focus of the HIV response in the community. Furthermore, most of the funding sources had been discontinued, which made it difficult to keep momentum and to actively involve new organisations.

> *"Where MSAT stood for when we started in 2007, was to empower and support local organisations who were passionate about HIV prevention. NACOSA [National Aids Convention of South Africa] was very involved during that time and there was money for workshops and education programs. When the allocated funding came to an end, most of the organisations dropped out, and that is how it remained. We were so supportive of each other in the beginning….but we have lost focus, vision and spirit."*

When I shared this quote with Mandla during a conversation a few weeks later, he was not surprised, and despite his frustration with the MSAT coordinator, he sympathised with her. "*The spirit of activism* *is very low in Gugulethu, especially on issues of HIV. Khayelitsha is miles ahead, as Medicines Sans Frontiers (MSF) is based there and different NGOs work together on the issues of HIV and TB. But in Gugulethu, people are working in silos and the community is very complacent*."

Mandla's frustrations extended beyond his experiences at the MSAT meetings, as he felt strongly that long-standing public health issues were either ignored or not addressed effectively in Gugulethu. "*I was invited to go to a conference organised by the People's Health Movement South Africa (PHM), an initiative that aims to bring together community activist groups, civil society and academic scholars to organise health campaigns (People's Health Movement, 2018). Although their ideas are great and the speakers are passionate about addressing long-standing health issues, the activism is largely driven by academia, not by the people who are affected daily by the long queues at the clinics, stock-out of medication or stigmatisation."* After attending several events and speaking at length with Chris Colvin, Phumzile, Lunga George and other comrades, Mandla realised that there was a real need for different NGOs, CBOs and other interested parties to come together and tackle service delivery issues in Gugulethu and the surrounding areas. "*We also received many complaints from the men we interviewed for the iALARM research, who spoke openly about their experiences at the facility and how this affects their overall health"*.

For both Mandla and Phumzile, one story caught their attention and became the focus of the inaugural campaign, which officially marked the start of the MCSJ. One weekend, Mandla was approached by Sipho[2], a childhood acquaintance whom Mandla had known for years. Sipho is epileptic and was very angry with the way in which he was treated at a facility in Gugulethu. He suffered an episode at work the previous week, on Tuesday, and was sent home by his employer, as he indicated he had run out of medication and had scheduled an appointment at the clinic of the next day. Although he went to the clinic on Wednesday to pick up the medication as planned, he waited the whole day and left the clinic empty-handed at 4 PM. He missed another day of work on Thursday to go back to the facility, where he again left disappointed, as the medication was still not available. After two days of waiting, Sipho became anxious about suffering another epileptic episode, but was also frustrated, as the pharmacist did not provide him with any information on why his medication was not available, or why there was a backlog. Eventually, Sipho was able to pick up his pills on Friday afternoon, but missed almost a week of work, and pay.

Shocked to hear this story, Mandla wrote down Sipho's story and contact details, which he first shared with fellow activists from Treatment Action Campaign (TAC), the Parent Centre, and other organisations, before setting up a meeting with the facility managers to discuss the issue. *"Sipho was so angry about the money and time lost, but especially the way he was treated at the pharmacy, that he*

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[2] Pseudonym

was very willing to come forward and to speak about his experience. He was not afraid to be victimised, as he realised that something needed to be done." Together with other organisations, Mandla and Phumzile spoke to the facility manager, who was also shocked about the way in which this patient was treated, also because the facility manager knew the patient personally as they used to be neighbours. For a few weeks after Sipho escalated the story of his experience at the pharmacy, Mandla, Phumzile and Mr. Makamba lobbied with the primary care manager to get a pharmacist hired to streamline the service in the pharmacy and address the backlog of medication stock-outs at Gugulethu CHC. The lobbying was successful, as the sub-district hired an extra pharmacist who was able to tackle some of the issues raised and improve the delivery of services at Gugulethu CHC.

This first campaign marked the start of MCSJ, a non-political and non-religious organisation that promotes active citizenship in the community and organises short- and long-term campaigns to address health issues in Gugulethu and the surrounding neighbourhoods (**Appendix 5.1**). MCSJ has between 25 and 40 active members who organise different activities, including community dialogues, protest marches, discussions with health system actors, and workshops. Current campaigns focus on educating people about gender-based violence (GBV) in Gugulethu, organising leadership training, advocating for free supply of sanitary pads and condoms in schools, and raising awareness for the demand of rapid implementation of the National Health Insurance (NHI) in South Africa.

Similar to the MSAT, the structure of MCSJ is inter-sectoral, which means that the organisation actively tries to establish partnerships with government structures, the WCDoH, health workers, and research institutions such as the University of Cape Town. In the last six months, MCSJ has grown beyond the borders of Gugulethu and has set up sub-divisions in the neighbouring communities of Kanana, Crossroads, Nyanga East and Philippi.

5.3 Trouble at the dentistry: negotiating service improvement using testimonials as evidence

Shortly after MCSJ successfully lobbied for an extra pharmacist to be employed at Gugulethu CHC, the movement became involved in a new initiative, whereby it aimed to address long queues and waiting times at the dentistry at the NY3 clinic—another long-standing health service delivery issue in Gugulethu. To provide necessary evidence for this campaign, MCSJ used a variety of health information, which was collected in several different ways.

The reason MCSJ tackled the issues at the dentistry, which is located in the heart of the community, was the fact that the clinic could only serve 30 patients daily. If you wanted to be seen by the dentist, you would either have to queue in the early hours of the morning, or buy a ticket from someone who would wait in line for you. This ticket would cost R30.00, approximately, 1,8 Euro. Furthermore, the dentist would only operate four days a week instead of five, as the clinic was closed every Wednesday.

MCSJ was notified of the issues by Mandla's sister, who recently bought a ticket for R30.00 when she went to the dentist. Initially, Mandla was upset with his sister that she had paid money to get a service that should be free for all South Africans (Dhai, 2011). According to Mandla, his sister was complacent, buying into a corrupt health system that did not care about the well-being of their patients. In her defence, Mandla's sister answered: *"my tooth hurt and I had to get it fixed. If you pay the money, someone else stands in the queue for you. I do not have time to stand in line from 6.00 AM to be helped by the dentist."*

The experiences of Mandla's sister appeared not be an isolated incident, as many MCSJ members heard similar stories in the community and were equally concerned by way in which the dentistry was run. Patients should not have to pay money to get access to health services that are offered for free. But the alternative—having to queue in the dark to secure one of the 30 available spots—also posed several safety risks, as waiting outside in the dark made people vulnerable for robbery or harassment. MCSJ raised the issue with the facility manager of the clinic and the primary health manager of the sub-district. Although both managers sympathised with the issue at hand, the primary care manager claimed she could not take any action without 'supporting evidence'.

To comply with the request of 'supporting evidence', MCSJ members collected testimonials of patients who were waiting outside the dentistry. The MCSJ activists woke up one early morning to go to the dentistry and count how many people would line up for dental services at the NY3 clinic. They would then register the details of the patients who were rejected during the course of the day, including names, cell phone numbers, ID numbers and residential addresses. This method of collecting evidence is also called self-census, and has been used as a strategy among South African community activists to show problems in the health systems and address services delivery issues (Robins, 2003, Colvin, 2014). The evidence collected by MCSJ through self-census showed that 74 patients were rejected for dental services in one day. The first patient arrived at the clinic as early as 3.30 AM and the majority of the patients lined up between 6.30 – 8 AM, well before the opening time of the clinic. On Wednesdays, the dentistry was indeed closed, often without notice, leaving many patients dissatisfied, having to spend double the amount of transport money and time to come the next day.

I asked Mandla and other MCSJ members about the reason why they would collect such detailed information about the patients in line, as this seemed confidential and I wondered whether people felt comfortable sharing these details with community activists. *"Of course, you need to get permission of the patient, and if he or she is afraid of victimisation we need to be keep them anonymous. But when they agree to give their ID number, exact names and addresses, it matters. To show, as an activist, that* *you are not falsifying and coming up with ghost people. If we want to keep the health system accountable, we need to be truthful and honest at all times."*

Although I was not familiar with using self-census to collect evidence, health activism groups such as TAC and the Social Justice Coalition (SJC) used the method in the past. *"We used the same method at the Khayelitsha District Hospital in 2014", Mandla told me. "We collected testimonials from patients to show issues with service delivery and overcrowding in the facility. Eventually, it helped, but the health promotor called everyone on the self-census list to check if the complaints were real."*

As requested, MCSJ took the 74 testimonials to a meeting at the facility where the dentist, the dentistry nurse, primary care manager and facility manager were present. I was invited by MCSJ to come along to take notes of the meeting and immediately sensed that there was a tense atmosphere in the room. After a round of introductions, the facility manager described the issue at hand and allowed MCSJ members to present the testimonials to the dentist. *"Here, in this book"*, Mandla pointed out, *"we have collected the more than 70 stories of people who were waiting in line and would not receive dental care that day. People are waiting in the dark, which is unsafe. We need to do something."* To emphasise his point, he told the story of an elderly lady who was sent away several days in a row without receiving treatment.

The dentist nodded understandably, but also seemed frustrated that his daily operations were questioned. Apparently, it was not the first time that the dentistry clinic was criticised: in 2013, an article was published on the IOL news website, outlining largely the same issues (Fokazi, 2013) . The dentist tried to explain the circumstances under which he and his team were operating in dentistry. *"I empathise with the patients who are turned away, but there is not much we can do. I am the only dentist who is working in the clinic, which means we can only serve 30 patients a day. That is 10-15 minutes per patient. I can assist more people when I get interns from the University of the Western Cape, but their commitment is interrupted due to the ongoing students protests and frequent holidays, so I am by myself most of the time."* The dentist also explained why the dentistry was closed on Wednesdays. *"One day a week, I go to Pollsmoor Prison to provide voluntary dentistry services to the inmates. I have done this for years and I am one of the only dentists who caters for this group of people."*

Knowing he would be questioned about the rejection of patients and long queues outside, the dentist brought his own evidence in the form of monthly and yearly target reports. He passed these reports on to the rest of the attendees before continuing his argument. Pointing at the reports, he claimed; *"if you compare our performance to the other clinics, we are doing better than all the other ones. Even if we only operate four days a week."*

A closer look at other clinics in the same district indeed demonstrated that the dentistry was performing much better than other facilities, and in fact, absorbing many patients from other practices. *"If you look here"*, the facility manager said, pointing at the target sheet, *"you can see that that this dental clinic has treated 12,000 patients in the past 18 months, compared to second dentistry on the list, Mitchells Plain, that only treated 7,700 people in the same time period. The other clinics perform worse." "And"*, the dental nurse added, *"when you register the patients, you find out that many of them are not only from Gugulethu, but also from other communities. So we are also treating patients from surrounding neighbourhoods. And we are really trying to do our best, but have to send people away if we do not have interns."*

Analysing the two sources of health information presented at this meeting to address the perceived shortcoming in the dental services in Gugulethu raises a set of questions about the complex role of health information within the health system and how evidence is perceived by different actors. Initially, both sources of information did appear to be official or routine. Interestingly, in this example, both MCSJ and the health service providers (which includes the managers, nurse and dentist) use different evidence and strategies to substantiate their arguments, but within their own frames of reference. The community activists collected health information in the form of testimonials by focusing on the number of patients in need of care, and the people in line not being helped by the dentist in reasonable time. By collecting this data, MCSJ was able to show the shortcomings of the dental services, not only through the number of testimonials, but also the way in which MCSJ presented these testimonials during the meeting. MCSJ members humanised the numbers of patients by providing accompanying narratives from patients and showing that many of them have to travel before the crack of dawn to make their way to the dentistry, join the queue in the dark and cold, and risking getting harassed or robbed whilst seeking care. Furthermore, providing the personal details of patients, including ID numbers and addresses, also proves that these are real patients, not '*ghost peopl*e', as MCSJ members used to call anonymous patients. Presenting these detailed testimonials in the meeting and emphasising that patients resorted to buying tickets worth R30,00 to be guaranteed dental care also portrayed the message that '*we have a right to health care, and by sending patients away, this right is violated. It is now up to the health system to provide a solution to this human rights issue.*'

Contrasting with the evidence shared by MCSJ was the clinical information supplied by the facility manager, dentist, and dental nurse. They all brought their own forms of evidence in the form of routinely collected target information, which highlighted the capacity for patients who were being cared for at the facility. Although the group of health actors knew that they were not able to help all of the people in the queue during their opening hours, they provided substantiated evidence that they were assisting the maximum number of potential patients per day, giving each patient between 8-15 minutes per procedure. Their frame of reference was the patient targets set by the sub-district. These targets are often based on historical performance of facilities, the ratio of health care providers and patients within a catchment area, or the supply of services within a set budget (Braa and Hedberg, 2002). According to the statistics they presented, the dentistry officially overperformed and even absorbed patients from surrounding clinics, which resulted in further strain on the service providers and the swelling queues outside the facility in Gugulethu.

Listening to the arguments of both parties, the primary care manager, who had been observing the situation whilst scribbling in her notebook, took in both pieces of presented evidence and asked for time to analyse the health information and consult with her colleague about the best cause of action. She promised to speak about this issue in the next sub-district management meeting, and would try to lobby for assistance in the dentistry to relieve the pressure on the dentist, reduce the queues outside, and ensure that the dental clinic was operational five days a week. A few weeks later, MCSJ was briefed about the outcome of the meeting. After careful consideration, the primary care manager decided to hire an extra locum dentist four days a week to help with the patient load at the dentistry in Gugulethu. For a while, this resolved the queues at the dentistry, as the clinic became operational five days a week and, on most days, all of the patients in line received dental treatment. Unfortunately, this solution did not prove to be durable in the long term, but was rather used as a stop-gap measure: Gugulethu residents have recently echoed similar concerns about the long waiting times at the NY3 dentistry.

5.4 Safe sex or God’s work? Promoting condom use in high schools in Gugulethu

Another initiative MCSJ started in which health information played a crucial role was a campaign to promote condom use in high schools in Gugulethu. This campaign, which commenced in 2017, aimed to tackle high rates of teenage pregnancy, and reduce HIV and STI rates in adolescents in the community through distributing condoms and upscaling sexual and reproductive health education at the three secondary schools in Gugulethu.

In South Africa, teenage pregnancy is a widespread problem, with more than 100,000 teenage pregnancies reported in 2013 (Reddy et al., 2016) . According to the latest statistics, in 2016, 29% of young women between the ages of 18-24 gave birth in South Africa (Poverty and Equality Initiative, 2017). Among those who fall pregnant, 6,4% of women are below 18 years of age. In Gugulethu, the rate of young women giving birth is slightly lower, at 23.6% (Poverty and Equality Initiative, 2017). According to a study by Marteleto et al. (2008), most young people in South Africa become sexually active whilst attending high school (Marteleto et al., 2008).

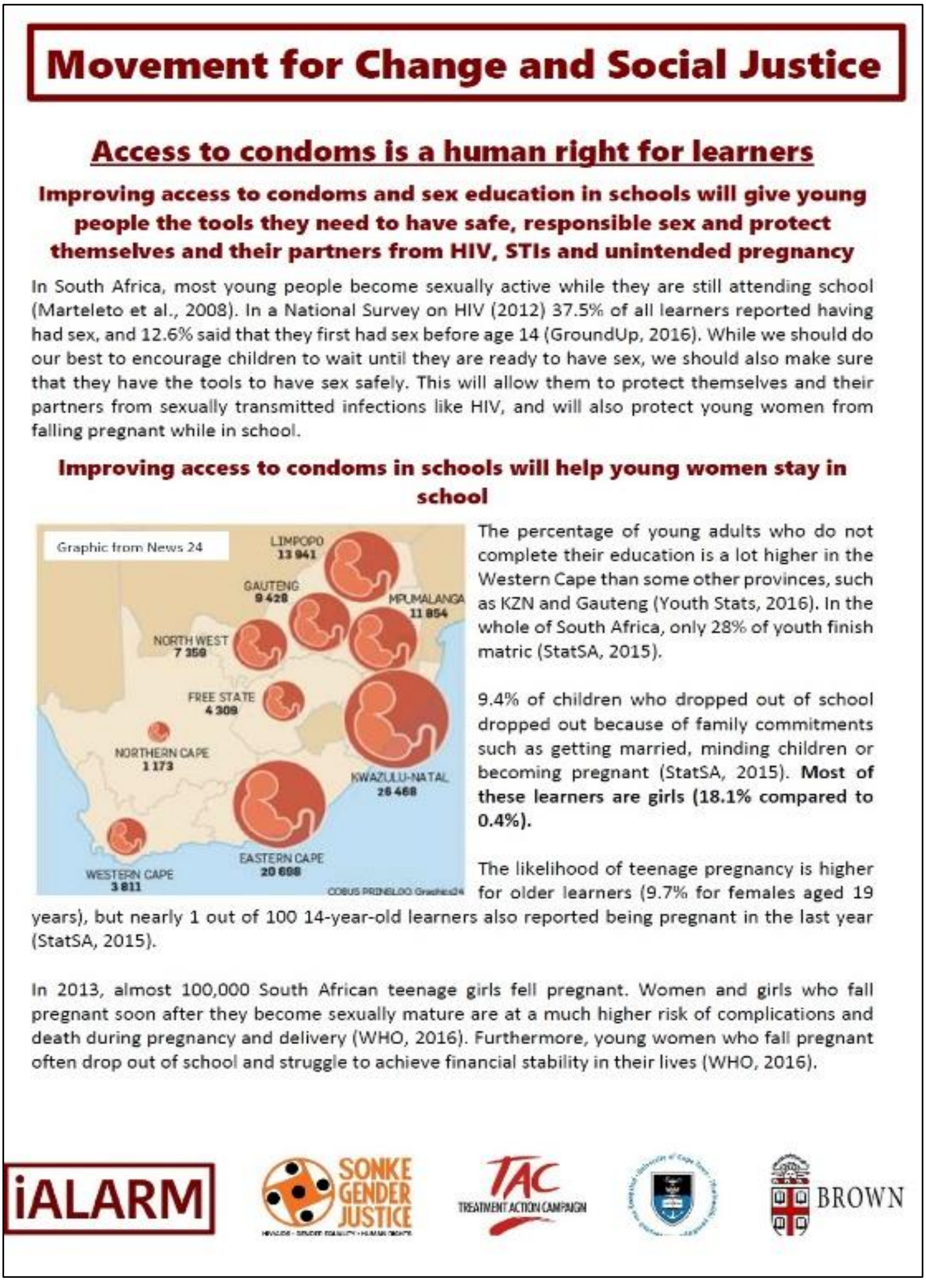
When teenage girls fall pregnant while still attending school, they very often drop out of school to take care of their children and rarely re-enrol. This decreases their chances to pursue tertiary education, get a well-paid job and become financially independent. In addition to the risk of pregnancy, low rates of condom use also increase the risk of HIV and STI infections, which is a major concern, as the HIV and STI incidence among young people has risen significantly in the past five years (Frigati et al., 2019).

Despite the high rates of teenage pregnancy in South Africa as well as the risk of HIV and STI infections, most high schools in South Africa do not allow condom distribution on their premises or condom demonstration during sexual education classes (Han and Bennish, 2009, Khoza et al., 2019). This is partly attributed to the fact that in the past ten years, several policies and interventions have been developed, including the Integrated School Health Policy (ISHP) in 2012, but these policies are not supported by the Department of Basic Education (DBE), who argue that school governing body (SGB) is responsible for the implementation of these policies (Nkosi and Pretorius, 2019, Khoza et al., 2019). Although school nurses and life orientation teachers often actively promote the distribution of condoms in schools to limit the risk of pregnancy, STIs, and HIV infections, the final decision about condom availability is ultimately made by the SGB. The SGB is composed of teachers, principals, learners and community members who collaboratively oversee the activities and curriculum of the school, as well as its financial and social structure (Van Wyk, 2007).

The debate over whether or not condoms should be distributed in high schools, and the quality of sexual education, flared up after MCSJ members heard the story about a girl who allegedly gave birth in the bathroom stalls of one of the high schools in Gugulethu. According to the parent who shared the story, the girl was not aware that she was pregnant. This story alarmed parents and NGOs in the area who reached out to MCSJ and urged the organisation to take action and start a campaign to convince the SGBs of the high schools to make condoms available for learners.

For Mandla and Phumzile, the unavailability of condoms in schools was a long-standing issue which they, in their role as community activists, had tried to address for more than 15 years. "*Even when I was still with TAC and ARVs were not widely available, we tried to get condoms to high schools"*, Mandla told me. "*But the school governing bodies are old-school and would not allow them, even though the learners would get pregnant or be infected with HIV. Even when pupils walk around with big bellies, they still refuse to believe that learners are sexually active.*" Besides Phumzile and Mandla, MCSJ member Lunga George was also passionate about tackling this issue, as he counselled many young parents at the Parent Centre. This NGO, based in Cape Town, provides support programmes for teenage parents and caregivers. Within his daily work, Lunga met many school learners who fell pregnant at a very young age.

As part of their strategy, MCSJ planned to develop a pamphlet (**see Figures 5.1 and 5.2**) to educate the community and parents of high school learners about the importance of making condoms available and improving the sexual health programmes in high schools. By convincing a large group of people about the issue at hand, they hoped that the SGBs would reconsider their ideas and allow for an open conversation about sex and contraceptives in schools and, in the long term, reduce the prevalence of teenage pregnancies and HIV and STI infections in Gugulethu. As a strategic partner, MCSJ choose to collaborate with Reverend Dr. Xapile, the spiritual leader of J.L. Zwane, a Presbyterian church in the heart of Gugulethu.



Movement for Change and Social Justice

Access to condoms is a human right for learners

Improving access to condoms and sex education in schools will give young people the tools they need to have safe, responsible sex and protect themselves and their partners from HIV, STIs and unintended pregnancy

In South Africa, most young people become sexually active while they are still attending school (Marteleto et al., 2008). In a National Survey on HIV (2012) 37.5% of all learners reported having had sex, and 12.6% said that they first had sex before age 14 (GroundUp, 2016). While we should do our best to encourage children to wait until they are ready to have sex, we should also make sure that they have the tools to have sex safely. This will allow them to protect themselves and their partners from sexually transmitted infections like HIV, and will also protect young women from falling pregnant while in school.

Improving access to condoms in schools will help young women stay in school

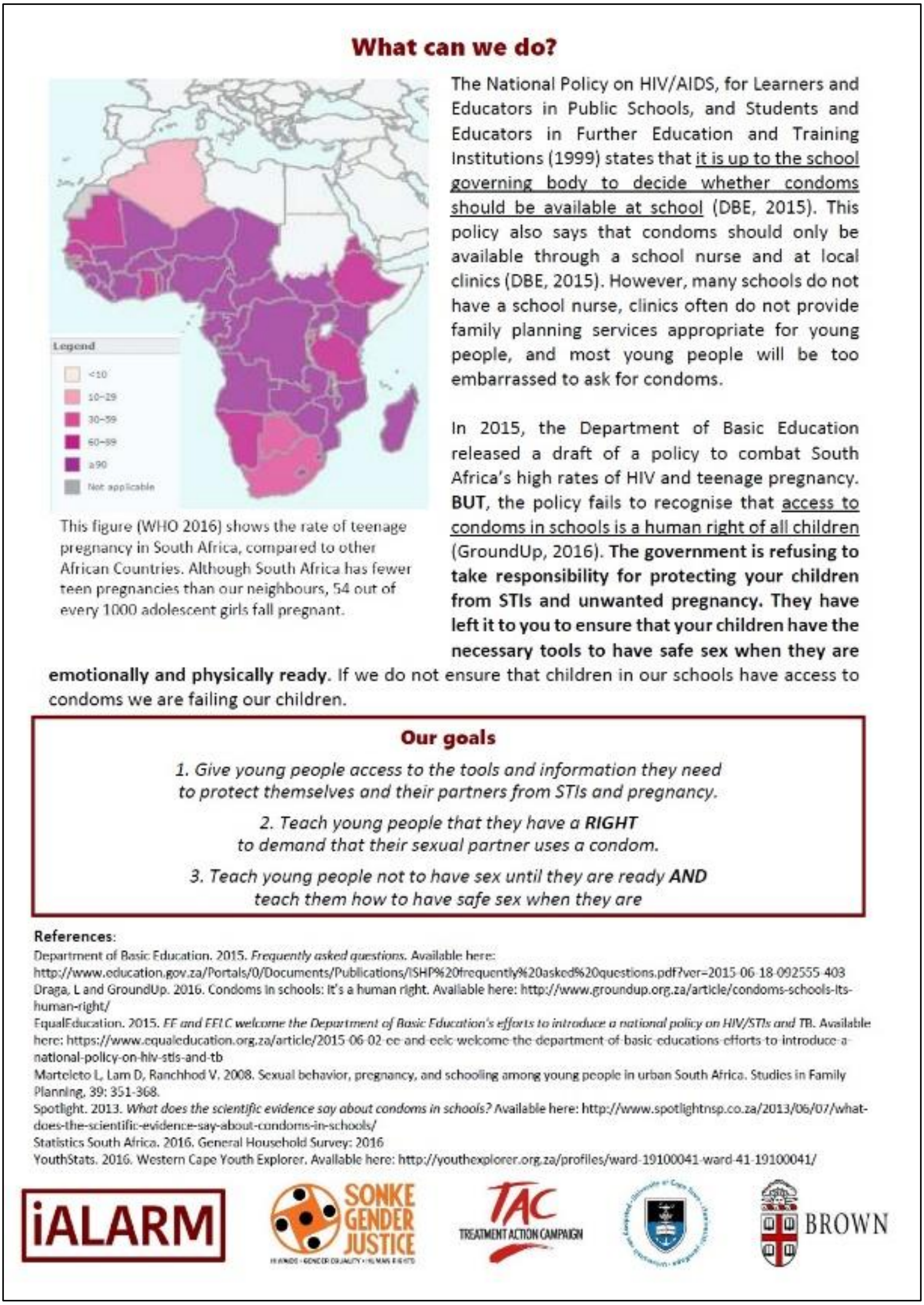
The percentage of young adults who do not complete their education is a lot higher in the Western Cape than some other provinces, such as KZN and Gauteng (Youth Stats, 2016). In the whole of South Africa, only 28% of youth finish matric (StatSA, 2015).

9.4% of children who dropped out of school dropped out because of family commitments such as getting married, minding children or becoming pregnant (StatSA, 2015). **Most of these learners are girls (18.1% compared to 0.4%).**

The likelihood of teenage pregnancy is higher for older learners (9.7% for females aged 19 years), but nearly 1 out of 100 14-year-old learners also reported being pregnant in the last year (StatSA, 2015).

In 2013, almost 100,000 South African teenage girls fell pregnant. Women and girls who fall pregnant soon after they become sexually mature are at a much higher risk of complications and death during pregnancy and delivery (WHO, 2016). Furthermore, young women who fall pregnant often drop out of school and struggle to achieve financial stability in their lives (WHO, 2016).

Figure 5.1: Front of original "Condoms in school" pamphlet.



What can we do?

This figure (WHO 2016) shows the rate of teenage pregnancy in South Africa, compared to other African Countries. Although South Africa has fewer teen pregnancies than our neighbours, 54 out of every 1000 adolescent girls fall pregnant.

The National Policy on HIV/AIDS, for Learners and Educators in Public Schools, and Students and Educators in Further Education and Training Institutions (1999) states that it is up to the school governing body to decide whether condoms should be available at school (DBE, 2015). This policy also says that condoms should only be available through a school nurse and at local clinics (DBE, 2015). However, many schools do not have a school nurse, clinics often do not provide family planning services appropriate for young people, and most young people will be too embarrassed to ask for condoms.

In 2015, the Department of Basic Education released a draft of a policy to combat South Africa's high rates of HIV and teenage pregnancy. **BUT**, the policy fails to recognise that access to condoms in schools is a human right of all children (GroundUp, 2016). **The government is refusing to take responsibility for protecting your children from STIs and unwanted pregnancy. They have left it to you to ensure that your children have the necessary tools to have safe sex when they are emotionally and physically ready.** If we do not ensure that children in our schools have access to condoms we are failing our children.

Our goals

1. Give young people access to the tools and information they need to protect themselves and their partners from STIs and pregnancy.

*2. Teach young people that they have a **RIGHT** to demand that their sexual partner uses a condom.*

*3. Teach young people not to have sex until they are ready **AND** teach them how to have safe sex when they are*

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Figure 5.2: Back of original "Condoms in school" pamphlet

J.L. Zwane is a church which was established in 1952 by Reverend J.L. Zwane and was originally located in the neighbouring township of Langa. In 1989, the congregation moved to Langa under leadership of Reverend Xapile, and was upgraded in 1994 in collaboration with Stellenbosch University. Besides being a place of worship, the J.L. Zwane Church was also an essential meeting place during the anti-apartheid struggle, as the church hosted many community campaigns and welcomed many political leaders and freedom fighters during this time (JL Zwane, 2019).

During the late 1990s, J.L. Zwane also fulfilled an essential role in the HIV/AIDS response, as they ran one of the earliest progressive Christian AIDS campaigns, which were later rolled out in other faith-based organisations in Cape Town and beyond (Burchardt, 2014). In the early years of the AIDS campaigns, the church functioned largely as a meeting place where activists would give educational talks and lobby for protest marches, which were held to demand access to ARV treatment. Later, the church set up their own support groups for HIV-positive patients and built a hospice and treatment dispensary, which are still running today (Burchardt, 2014). Growing up close to the church, Mandla also had a special connection with J.L. Zwane. "*This place has been really important for me. Not only as a place of worship, but also as a place for activism. When I was still working for TAC, I used this church to give to educate people about HIV and encourage them to test and use condoms. At that time, there was so much stigma that nobody talked about the disease, but there were funerals for AIDS victims every week.*"

Mandla invited me to come to a meeting with Reverend Xapile and MCSJ members to speak about the issues of condom and teenage pregnancy. Running programmes at the church, Xapile was well-informed about the issue at hand, and acknowledged that most young people become sexually active during their high school years. During the meeting, he spoke freely about the lack of sexual education and knowledge about contraceptives among high school learners and agreed with MCSJ members that both the ignorance of parents and the SGBs was inherent to the problem. The reverend also indicated that he knew many people within the SGBs and would be happy to lobby with them on the behalf of MCSJ. There was also a get-together planned for elderly church members the following week, and if we could provide a pamphlet in both English and IsiXhosa, the reverend would distribute them among the group and discuss the matter at hand. He also wanted to take some of these pamphlets to the congregation during his upcoming trip to the Eastern Cape Province.

For the pamphlet, MCSJ asked the iALARM RT for assistance, as they wanted the message to be based on scientific evidence that would represent the problem at hand. Reverend Xapile also stressed that it was important to have updated health information in the pamphlet, as this would show the gravity of the problem and would hopefully convince SGBs to rethink their outdated policies and replace them with more progressive alternatives. The iALARM Team was happy to provide the information and develop the pamphlet, as this request fit in neatly with aims of the study: to strengthen collaborations between different organisations by providing relevant health information. Ideally, the pamphlet would open up a larger dialogue about HIV and prevention in the community and inspire new campaigns in Gugulethu.

Being researchers in the iALARM RT and having a relationship with MCSJ, my colleague Eleanor and I composed a pamphlet we thought would capture the aim of MCSJ's campaign to convince parents, SGBs and community members to make condoms available in high schools. We wrote the pamphlet in accessible language and provided some appealing graphs that visualised the problem (**Figures 5.1** and **5.2**; see also **Appendix 5.2**). To populate the pamphlet, we used a combination of international and national policy documents, census information and media articles. As the deadline was approaching swiftly, Eleanor and I presented the pamphlet one day later to the iALARM RT, resolved some small grammatical mistakes and other semantics before sending off the pamphlet to J.L. Zwane for translation from English into isiXhosa.

A few hours after sending off the pamphlet, I received the following reaction from Dr. Xapile:

> *"Theo and I have worked on what we think would be an appropriate introductory document for a conversation that really matters. We feel it should not be too prescriptive at this stage in order for us to have a buy in of parents, teachers and learners. We are convinced that soon, we will be having a conclusive document that talks a lot about condom distribution. Please look at the attachment make whatever changes you feel must go into it and please have it printed in both English and IsiXhosa. We are expecting not less than 300 senior citizens tomorrow and it would be great if the conversation with parents would be introduced tomorrow.*
>
> *We have the names and contact details of chairpersons of Fezeka High School, ID Mkhize High School and Gugulethu Comprehensive High School. We have spoken to them except that of Fezeka and we will be following on conversations."*

Even before opening the attachment with the updated pamphlet, I could sense from the tone of the email and the words used that the pamphlet had changed significantly from its original formal. I downloaded the attachment and swiftly screened the new document (**Figure 5.3**).

"The pamphlet has changed quite significantly", I told Eleanor. Look at this sentence: '*while we should do our best to encourage children to wait until the they are ready to have sex, it is important that they raise the question of protection if they cannot control themselves.'* Instead of promoting the use of condoms among teenagers, the church promoted abstinence. To better see the differences in the pamphlet, Eleanor compared both versions of the pamphlet in a word document. We discovered that they shifted the tone of voice of the pamphlet, and although they kept the statistics about teenage pregnancy in South Africa, they took out the word ‘condom’. In our version, we had used the word condom 12 times; in the J.L. Zwane pamphlet, the word was not mentioned at all. Secondly, they also removed links to sex and sexual education from the document.

Comparing the text in the two pamphlets (and the isiXhosa translation) with each other (**see Figure 5.3**) the iALARM RT and MCSJ were surprised that the J.L. Zwane staff changed not only the wording of the pamphlet, but also the tone and the actual take-home message was reconstructed. The original message, urging young people to practice sex safely—protecting themselves against teenage pregnancy, HIV and STIs—was changed to convincing the youth to abstain from sex altogether. Mandla especially was disappointed in the way J.L. Zwane had doctored the wording of the pamphlet, as the religious views which permeated the text opposed the ideas which were discussed in the meeting between MCSJ and the reverend the previous week. *“I still cannot believe the way in which this played out”,* Mandla commented, *“as Reverend Xapile has always been so liberal and open-minded. In the past, he allowed me to speak to his congregation about the consequences of unsafe sex and he played an invaluable role in the height of the HIV epidemic. He was never shy to speak about sex, but now he comes across as conservative.”*

For the iALARM RT, reflecting on the experience with the text on the pamphlet revealed several key insights about the complex and unexpected role that health information can play, both within the community and between organisations, which can lead to unintended consequences in the use and exchange of health information. Firstly, the iALARM RT saw the request for information largely as a technical exercise and did not expect that the health information would be read and understood, in a larger social, cultural and religious context. When MCSJ members asked the iALARM RT for assistance, the way in which the problem was described was as a need to provide relevant health information to be a reference through which to frame a larger public health problem (the prevention of teenage pregnancy, HIV and STIs among young people). As UCT collected academic evidence to develop the pamphlet, many of the involved stakeholders did not think about the fact that even this type of information would not be completely value-free and objective. However, J.L. Zwane, iALARM and MCSJ all operated within their own frames of reference, each formed by individual beliefs, values and world views. We therefore also selected what type of health information would be most important to include and what information felt irrelevant for the frameworks in which we were operating. These frameworks can be fed by cultural, social, scientific or religious beliefs, which all impacted the type of health information we used. Even academic institutions, including UCT, are not neutral in this case, and neither is the knowledge or evidence that these institutions produce.

(a) Original pamphlet

Access to condoms is a human right for learners

Improving access to condoms and sex education in schools will give young people the tools they need to have safe, responsible sex and protect themselves and their partners from HIV, STIs and unintended pregnancy

In South Africa, most young people become sexually active while they are still attending school (Marteleto et al., 2008). In a National Survey on HIV (2012) 37.5% of all learners reported having had sex, and 12.6% said that they first had sex before age 14 (GroundUp, 2016). ***While we should do our best to encourage children to wait until they are ready to have sex, we should also make sure that they have the tools to have sex safely.*** This will allow them to protect themselves and their partners from sexually transmitted infections like HIV, and will also protect young women from falling pregnant while in school.

(b) Interpretation J.L. Zwane

The issue of protection for learners and youth in general –A human rights issue.

In South Africa, most young people become sexually active while they are still attending school (Marteleto et al., 2008). In a National Survey on HIV (2012) 37.5% of all learners reported having had sex, and 12.6% said that they first had sex before age 14 (GroundUp, 2016***).*** ***While we should do our best to encourage children to wait until they are ready to have sex, it is important that they themselves raise the question of protection if they cannot control themselves.*** How do young people protect themselves and their partners from STIs' including HIV and prevent falling pregnant while in school.

(c) isiXhosa translation

The issue of youth protecting themselves in schools and other place so that they do not perish – your right

In South Africa, young people start having sex at an early age. They start doing so while still in school. They start doing so when they are still in school. According to research conducted, there is a high number of people before the age of 14. ***Even though we do not want children to engage in sexual intercourse at young age, they need to teach other about the dangers as well as ways to protect themselves when they cannot control themselves.*** They question is what could they do to protect themselves and peers from sexual transmitted infections such as HIV so that they do not get pregnant while studying.

Figure 5.3 : (a) Original pamphlet (b) Interpretation JL Zwane (c) isiXhosa translation

Similar to the experience of MCSJ members, the ALARM RT also had to straddle competing interests when conducting research or working with other academic or community partners. When the pamphlet was sent back without the word ‘condom’, it became a valuable lessons for both the iALARM RT as well as MCSJ that health information is never neutral. The information is always embedded in values and assumptions, even when we do not expect it to be, as researchers can trick themselves into the idea that health information, including academic evidence, is ‘just science’ and therefore, always value-free.

Secondly, seeing the different messages in the pamphlets next to each other also reveals that we might have different perceptions of the actors that are collecting, using, and exchanging health information. Both MCSJ members and the iALARM RT did not expect that Reverend Xapile would take such a conservative stance, as his demeanour appeared to be more progressive and open-minded during earlier conversations. Additionally, Reverend Xapile might have personally agreed with the message in the pamphlet, but when reading the actual words on paper, might have realised that he would not be able to sell this message to his congregation.

Thirdly, the example as described above also reveals the complexity of the use academic evidence in community advocacy campaigns, and shows how individual beliefs of actors who are producing, using and distributing this data impact this evidence. Health information, here in the format of a pamphlet, is neither context- or value-free and is created within a moral, cultural and social context. The actors involved in this campaign, the iALARM RT, MCSJ and J.L. Zwane, all had their own intentions and expectations of what information should be incorporated into the pamphlet and how the message should be conveyed to a larger audience.

Due to the different views and messages in the pamphlet, the condom campaign initially came to an impasse as MCSJ did not feel comfortable relying on J.L. Zwane as a partner to convince SGBs to allow the provision of condoms in high school. Without the support of J.L. Zwane, MCSJ continued with the campaign and created a documentary about the success of providing condoms in schools in Khayelitsha (Umbono Art Media, 2017). In this documentary, they interviewed participants about their own experiences being teenage parents, and highlighted the risks of unsafe sex and its potential impacts on the health and future of the youth in underprivileged areas of Cape Town. The documentary, which was directed largely under MCSJ’s supervision, was used by community activists who went to the three high schools in Gugulethu to show it to learners and to lobby with teachers and parents. MCSJ still makes use of the initial pamphlet as provided by the iALARM RT in this campaign.

5.5 Triage and impatient patients: Mobilising information in the clinic space

Another example that explores the intricate relationships between health system and community actors and the way in which health information can be used, was during the development of a strategy to inform patients and community members of the triage procedures at the Gugulethu Community Health Centre (CHC). Gugulethu CHC is located in the heart of Gugulethu, and includes a trauma unit, a day hospital, an ARV centre and a Maternity and Obstetrics Unit (MOU) on its premises (see more Chapter Three).

The clinic is permanently overcrowded, and the trauma unit is especially busy during the weekend, when the level of interpersonal violence and road accidents increases. To structure the influx of patients and incidents, similarly to other hospitals, Gugulethu uses a triage system to prioritise admission, using the three-colour system to regulate patient flow (Bruijns et al., 2008). In this system, the colour red is used for patients who need acute care; orange used for seriously sick patients who need observation; and green used for patients who do not require immediate care.

Although the triage system is a widely used approach to manage acute care in busy hospitals, the concept is not always well-understood by some of the patients who come to Gugulethu CHC. This leads to the overcrowding of the trauma unit, especially on Saturdays and Sundays, and frustration among patients—which, in turn, leads to discontent about the health services provided and sometimes results in violence against clerks and other health staff. The overcrowding of the clinic is partly due to the increase in gang violence in the community and interpersonal violence that flares up during the weekend due to substance abuse, as well as the fact that other neighbouring facilities have stopped running 24/7 care. Another reason for the increased influx of patients, according to Mr. Makamba, the facility manager of Gugulethu CHC, is the fact that some patients would use the clinic in the weekend to pick up their chronic medication, which should have been collected at the pharmacy during weekly opening hours. This practice increases the strain on the trauma unit during busy weekend days.

Mr. Makamba explained how a standard weekend day at the trauma unit at Gugulethu CHC looks.

> *"Now you have people that we are not supposed to see on Saturday but they are here and they start complaining that they do not get the care. They are the ones that make a huge noise and make trouble in the waiting area. And now we need to explain the triage system and the 'green patients' are the ones that are complaining. Someone that is an orange or red takes priority. Because every time an emergency comes in, everyone runs there. The orange or red patients are about to die. But the green patients are not dying, they can go home and come to the clinic on Monday when we have a full staff available. And people need to understand that. So those are the challenges that we are having, as we do not know how to communicate this to the patients."*

Mr. Makamba and Dr. Jenny Morgan, the family physician in Gugulethu CHC, were of the opinion that the trauma unit would run more smoothly and peacefully if the community members and patients were well-informed and educated about the triage procedure in the clinic, as it would avoid miscommunication and hopefully eliminate friction between patients and staff members.

As part of their communication strategy, Mr. Makamba wanted MCSJ to assist to inform community members and disseminate information about the triage system to the public. Since the establishment of MCSJ, the organisation had rapidly developed a visible presence in Gugulethu and the surrounding townships. *"I hope MCSJ can help getting people together so we can speak to them. They can then ask questions and we can respond to them, so we can teach them how the triage system works."*

Mr. Makamba proposed a time and date for Dr. Jenny Morgan to speak to MCSJ members about the triage system and explain the procedures, with the idea that MCSJ could thereafter disseminate this information to the larger community. Hopefully, this would create perspective among patients and help their decision-making about whether or not to come to the clinic during the weekend for minor incidents. During an intensive meeting with Dr. Morgan, MCSJ members learned about the daily operations of the clinic. Repeatedly, Dr. Morgan stressed concerns about patients with minor health issues flocking to the trauma unit in the weekends. *"Patients might have a cough, backpain or flu, but still need to wait for more than six or seven hours to get it solved, or sometimes they are sent away completely. This increases the tension in the clinic and if there is annoyance among those patients , they might not come back at all, or resort in violence, which is really dangerous for me and my staff."* Additionally, Dr. Morgan also showed the number of patients coming to the hospital every weekend on the weekly statistic sheets, which depicted an influx of people on Saturday and Sunday compared to weekdays. Furthermore, the sheet showed steady increase of patients being admitted to the trauma unit, while the number of staff on duty remained the same. This trend resulted in longer waiting times, overcrowding and dissatisfaction among patients and staff.

During the meeting, Dr. Morgan also addressed the need for patients to collect their medication on time and urged MCSJ to inform the community about the new paediatrics unit that the hospital was running from 4pm to 8pm every weekday.

> *"We also really try to prioritise kids and run this after-hours clinics to encourage parents to come and immunise their kids and bring them in for regular check-ups, but the numbers of the paediatrics unit keep dropping. We are meeting to brainstorm about solutions that we can use to better inform patients about the hospital and its procedures, so the hospital is running more smoothly and the waiting times are getting less. We need to deal with the fact that influx of patients somehow, with the resources that we have. So, I hope that by better educating and informing the community, we are able to run our facility more smoothly".*

To inform the community about the triage system in the trauma unit, the clinic management team had developed a pamphlet in collaboration with the WCDoH. The pamphlet was available in English and isiXhosa, and showed the three triage colours and explained the system in more detail. Dr. Morgan wanted to distribute this among patients and was hoping that MCSJ would do the same. MCSJ and Dr. Morgan also agreed that she would come and give a talk about the new services in the clinic and the triage system during one of the larger MCSJ community meetings.

In collaboration with UCT and MCSJ, Dr. Morgan spoke about the triage system and current issues in the trauma unit during a large meeting at J.L. Zwane Church in Gugulethu in July 2018, with approximately 1,000 community members present. She also distributed the pamphlets with triage colours that had been developed. Her presentation was well-received and there was time left for participants to ask her questions directly, which were translated from isiXhosa to English. Although Dr. Morgan was not able to answer all the questions about service delivery, the effects of budget cuts and other larger health system issues, she was able to provide inside information about the operations of Gugulethu CHC, and urged community members to be calm when coming to the clinic during weekends and to be vigilant with picking up medication during weekdays if possible.

As I discussed the communication strategy with Mandla after the community meeting, he commented that her empathy and open attitude was crucial for the success of her communication strategy. "*She knows the community and has worked there for a long time. She is also incredibly patient and allowed participants to raise their concerns in isiXhosa, which made a difference. And you can see that there is a trustful relationship between her, Mr. Makamba and MCSJ, which helps too.*" Some community members commented that this was one of the first times that they were allowed to ask direct questions about the clinic and its services to the family physician, and that the explanation about the triage system enlightened them, as it gave unique insights about the daily operations in the facilities.

Reflecting on the communication strategy that staff from Gugulethu CHC employed to inform patients and the larger community of Gugulethu reveal some unique insights into the role of health information within the health system that are not usually explored.

Firstly, the type of health information that was shared by Dr. Morgan, both within the meeting with MCSJ as well during the community event, was unique. Most health providers do not voluntary share details about the service delivery of a facility or share the issues they encounter on a daily basis without being specifically asked for it. Topics such as the overcrowding of the clinic spaces or procedures in the trauma unit might be discussed in staff or management meetings, but are not often shared in the public domain. Health information that is shared with patients or the community is often communicated through health promotion campaigns, either to inform patients about new programmes, treatment or guidelines, or to influence patient behaviour. Therefore, the decision to openly share both routine health information about patient flows with MCSJ and procedural information about the triage system is unusual. In this case, the type of information and the way in which it was communicated was exceptional.

Secondly, this example shows that the flow of health information is much more dynamic than can be assumed. Traditionally, health service providers educate and inform patients through health education and health promotion programmes, which are fed to the community through top-down communication. In this process, there are limited opportunities to speak or actively interact with people through open dialogue. This makes communication channels stilted and one-sided, leaving little space for interaction with both the health information or the health actors who communicate this information. The way in which the triage system was explained at the community meeting opened a new channel of communication whereby Dr. Morgan actively sought feedback from both MCSJ members and the people of Gugulethu and provided a space for open dialogue between the health system and the community.

The third insight that surfaces through this example is strong relationship between MCSJ and the staff at Gugulethu CHC, which facilitates the dialogue about the triage system and creates a new platform to share new forms of health information, which are not normally communicated from the facility to the community. This relationship was formed over time and required people who shared a personal relationship based on respect and a mutual understanding of a common problem, such as Mr. Makamba and Mandla. Mandla was, together with MCSJ, able to provide a space where information was shared and open dialogue was facilitated between health system actors and community. Lastly, this example showed the importance of facility-level problem solving and highlighted the need to engage more health actors such as Mr. Makamba and Dr. Jenny Morgan who are willing to actively work with health information and communicate this data to a large audience, rather than waiting for sub-district managers to communicate and be proactive. This reveals that it is possible to open up spaces for people to work together through the hierarchy of the health system, rather than acting in silos.

5.6 Discussion: Unpacking the role of health information in community activism campaigns

In this case study, I explored the complex role of health information in community activism campaigns in Gugulethu by actively collaborating with MCSJ and participating in a number of their activities. The first example describes the collection and use of testimonials by MCSJ members to convince health service providers to improve the services of a dentistry in Gugulethu. The second example explores the social meaning of different forms of evidence in a campaign that aimed to stress the need to provide condoms in high schools in Gugulethu. By describing the dynamics between different community organisations, this example illustrates that evidence, here in the form of health information, is never value-free, and needs to be interpreted in a larger social and cultural context—as those who interact with information have their own frames of reference, which appear to be similar, but can differ in practice. The third example describing the triage system at Gugulethu CHC shows some of the unique strategies that are used by health system actors to inform patients and the larger community about service delivery issues in a local clinic, and highlights how open dialogue between health actors and community stakeholders leads to better communication about health information which is used to emphasise a health issue.

Findings in this chapter firstly highlight the unique role that health information plays within the community and illustrates how health information can facilitate health activism campaigns and can mobilise community organisations to keep the health system accountable. Secondly, the chapter shows that community activism groups such as MCSJ have a need to use health information for their campaigns. When they have no access to this information, they go and collect the evidence needed through self-census or request the information from partners who might have a way of accessing the required health information. Thirdly, the creative strategies that are used by MCSJ show that community members are not only passive recipients of information, and that the role of information in Gugulethu is dynamic and multi-faceted. This means that health information can be used for more purposes than just health education or health promotion to inform communities, as they proved to be active agents in the process.

The findings in this chapter feed into a larger acknowledgement among researchers, including Akhlaq et al. (2015) that recognise the role of community representatives within the health system and see the potential for community members to play a participatory role in the collection, use and exchange of health information (Akhlaq et al., 2015). Currently, several countries have introduced community-based health information systems (CBHISs) which aim to better understand the health needs of community members by collecting evidence from these communities which are then fed into more formally constructed HISs (Byrne and Sahay, 2007, Jeremie et al., 2014). Initially, these CBHISs were developed to inform and empower communities and to actively involve marginalised groups in health decision-making. Although important, in reality, information collected in CBHISs often does not get distributed back to the community, but is fed to higher levels of the health system to inform policies and programmes (Vest and Gamm, 2010). This chapter showcases that in Gugulethu, there is pertinent need for sharing health information among people operating on all levels of the health system, and this sharing can be facilitated by organisations such as MCSJ, who choose to play an active role in the health system.

A prerequisite to improving the sharing of information, which was made apparent in this chapter and in the iALARM study overall, is for community representatives to create strong relationships with health actors. The main goal of community organisations, which can include NGOs, such as MCSJ or more formally structured health committees (HCs), is to keep the health services accountable and to demand the improvement of services when needed. This, at times, can cause friction and misunderstanding, but community engagement improves drastically if there is strong link between the facility and the community (Tsondai et al., 2017, George et al., 2015b). In MCSJ, the relationship between Mandla and Mr. Makamba was unique, and due to their shared history and friendship, MCSJ had the opportunity to communicate with sub-district and primary care managers—health actors who normally do not interact directly with community organisations. This finding is in line with the results of Goodman et al. (2011), who observed that functionality of HCs in Kenya improved significantly after installing a nurse who was hired specifically to support the links between facilities, communities and the district by strengthening the management of committees (Goodman et al., 2011). In South African clinics, health promotors often fulfil the mediating role between facility staff and the community (Boulle et al., 2008).

Furthermore, the findings in this chapter emphasise that among community groups such as MCSJ, there is a need to make active use of different forms of health information, especially when access to routinely collected evidence is not sufficient. Sometimes, this information is collected through testimonials or self-census data, but MCSJ also used academic evidence and visual media (a documentary film) to campaign to make condoms available in high schools. Within health systems literature, the role of popular media in community engagement efforts is often under-explored, but media outputs such as documentary film and social media campaigns have a great potential to engage the broader community and raise health systems issues (George et al., 2015a, George et al., 2015b).

Chapter 6: 'From pillar to post' - the role of health information in policy implementation processes

6.1 Introduction

Policy development and policy implementation is an integral part of strengthening health systems and a core component when improving service delivery and developing new health programmes. Policymakers—on local and national levels—use a combination of formal and informal evidence when developing new policies or programmes.

Once a new policy or programme is approved, the process of policy implementation commences, which is often a complex, non-linear and multi-layered process that involves stakeholders at various levels of the health system and is impacted by different factors, including socio-political context, funding and leadership (Erasmus et al., 2014). Although researchers acknowledge the important role of health information that informs health policy, much less is known about the role of health information during the implementation process.

This case study explores how frontline health workers collect and make use of different forms of health information when attempting to implement new health information initiatives proposed directly by policymakers in the health system. As part of a new Adolescent and Youth Friendly Service programme (AYFSP), each clinic in South Africa has to develop an Adolescent Health Profile (AHP), a document that gives an overview of the different health-related challenges for youth in the catchment area of the facility. This profile was initially seen as a routine and largely technical exercise, but proved to be more complicated and less straightforward than anticipated.

The chapter follows a group of health workers on their journey to develop the AHP for their facilities and reports on the challenges they faced along the way, which included the lack of access to relevant routinely collected health information, little guidance and support from implementing partners and the absence of clear guidelines and templates. Despite these challenges, this case study also shows the imaginative ways in which health system actors try to solve these problems, which include using informal information and creating new relationships and collaborations with stakeholders inside the facility and the community.

6.2 Background of Adolescent Health Profiles in South Africa and beyond

The first time I met Nonthando Vece (hereafter Sr. Vece), the clinic manager from Nyanga Junction Clinic in Gugulethu, was in April 2017. My colleague Phumzile and I were busy mapping out the male-friendly health services in the area in anticipation for the first iALARM Task Team Meeting (TT meeting) and a staff member from Sonke Gender Justice told us that due to the absence of a male nurse in the Men's Wellness Centre (MWC), they would often refer male patients to a small clinic on the edge of Gugulethu, the closest clinic with a male nurse.

Phumzile and I planned to go to the clinic to personally invite the male nurse to the upcoming iALARM TT meeting. Although the MWC and the Nyanga Junction Clinic were only 500 meters apart, I was still slightly nervous, as the clinic is situated Nyanga Junction Station, a local train and bus station that connects a large part of the Cape Flats with Cape Town. The station and its surrounding areas are notorious for pickpocketing and armed robberies, and just before we planned our visit, people inside the station were held hostage in an attack for a number of hours.

The train station is also a local business place, where vendors sell everything from live chickens and herbal medicine to clothing and electronic supplies. The shopping mall is built over the train tracks and harbours a Shoprite supermarket, a fish and chips shop, a church, tailors and a few ATMs. Phumzile told me that the clinic used to be located in the front of the station, in a little corner, with just one examination room and no official waiting area. *"People used to queue outside this clinic for hours"*, he explained. *"Even in the blasting sun or pouring rain, people would stand in line for hours to be assisted, being at risk of being harassed or robbed."* The new location of the clinic has been a major improvement, with an air-conditioned waiting room, private security, and four examination rooms. Nyanga Junction Clinic only offers basic reproductive health services, such as STI/HIV testing and referrals, family planning, and health screening. Despite the limited health services offered, the clinic is extremely busy.

When we arrived at 9.30 AM, the waiting room was full and the male nurse we wanted to see only had time to quickly shake our hands before going back to his patients. Sr. Vece, the facility manager, took some time out of her busy schedule to speak to us. She ushered us into her office, which also functioned as an examination room. To make room for us to sit, Sr. Vece shovelled massive piles of papers aside, which she jokingly called '*her treasure'*. "*Your treasure"*, I asked puzzled. *"What do you mean by that?" "This clinic has computers, but we are not connected to the central data system from the WCDoH, as we are officially a satellite facility. But I do report all the stats to the sub-district every month."*

She dug into the pile on her desk and took out a piece of paper. *"These are the amount of condoms that were distributed this month, most of them were taken from the clinic, others were given away during outreach projects and events that we do in the community. All patients have handwritten folders which are captured at reception. That is how we do our data capturing."*

Conscious of the time Phumzile and I were taking from Sr. Vece and the full waiting room, we handed her the invitation for the TT meeting, briefly introduced the iALARM project and asked her if she wanted to add anything to the agenda for the upcoming meeting. *"Yes"*, she immediately answered. *"I am setting up a youth clinic and there are several standards that need to be accredited before I can render the service. I am already stuck at the fist request. Question 1.1 is: Has a health profile been conducted within the last 2 years?"* She handed me the booklet that she received from the WCDoH and also pulled up a Word document on her computer which showed some NGOs that work with youth in Gugulethu, contact details of the nearest library and an overview of the schools in the neighbourhood.

> *"I need to make a whole community profile, can you imagine, it is something like eight or nine pages with things I need to fill in. When do I even have the time to do that, to collect all the information? I need to go into the community to get the information that I need and that takes time. I could really use assistance from someone and I know it needs to be done, otherwise I cannot officially ask for funding for the clinic."*

Sr. Vece's explanation of the youth clinic pointed to the Adolescent and Youth Friendly Services programme (AYFSP), recently initiated by the National Department of Health (NDoH). The AYFSP, which is embedded in the larger National Adolescent & Youth Policy (AYFP), aims to improve health services for the youth, with a particular focus on sexual and reproductive health (Western Cape Department of Health, 2017. Several interventions are integrated in the AYFSP to enhance youth health services, including a designated waiting room for the youth, flexible opening times that suit learners' schedules and mobile apps that provide health education and health promotion materials {Western Cape Department of Health, 2017 #489)

To measure the youth-friendliness of individual clinics, a special assessment tool was developed, which included 40 different performance criteria and was divided into ten different standards (**Figure 6.1**). To achieve the status of a youth-friendly clinic, Standards 1, 3, 4, 6 and 10 must be approved by the NDoH as a minimum requirement. Criterion 1.1 from Standard 1 is to produce an adolescent health profile (AHP), which needs to be updated every two years. This AHP is an overview of the lives of youth in the catchment area of the clinic. According to the limited information in the AYFSP handbook, the AHP should map the youths' sexual and reproductive health behaviour, as well as map the current socio-economic challenges and opportunities that impact the health of young people who come to the clinic (**Appendix 6.1**).

Currently, the AYFSP is linked to the larger Ideal Clinic Realisation and Maintenance (ICRM) programme that is currently being realised in South Africa (Republic Of South Africa, 2017, Hunter et al., 2017). The goal of these programmes is to re-engineer primary health care (PHC) and prepare public health facilities for the implementation of the National Health Insurance (NHI). The NHI is developed to assist South Africa to strive for Universal Health Coverage (UHC), which aims to provide high-quality health care for all South Africans, regardless of income or financial hardship (Mayosi et al., 2012, Ataguba and McIntyre, 2012, Fryatt and Hunter, 2014) The Ideal Clinic Initiative aims to prepare primary care clinics for the NHI scheme, improve the quality of care and increase safety in care through improving governance and leadership. According to the NDoH, 'an Ideal Clinic is a clinic which has good infrastructure, adequate staff, adequate medicine and supplies plus good administrative processes, protocols and guidelines to ensure the provision of accurate community-based curative, preventative, promotive, rehabilitative and palliative services' (Fryatt and Hunter, 2014, Hunter et al., 2017).

The AYFSP Standards
1. Management System Support for the effective provision of adolescent and youth friendly health services
2. Policies and processes that support the rights of adolescents
3. Appropriate adolescent health services are available and accessible
4. The clinic has a physical environment conducive to the provision of adolescent friendly health services
5. The clinic has adequate drugs, supplies and equipment necessary to provide the essential service package for youth-friendly healthcare
6. Provision of relevant information, education and communication (IEC) promoting behaviour change and consistent with the YFS essential service package
7. Systems in place to train and develop staff to provide effective adolescent-friendly health services
8. Adolescents receive adequate psycho-social and physical assessments
9. Adolescents receive individualised care based on standard case management guidelines/protocols
10. The clinic provides continuity of care for adolescents: proper referral systems are in place

Figure 6.1: Standards of AYFSP

In South Africa, the PHC system comprises 3,500 clinics and health centres across the nine provinces, who together provide care to 81.7% of the households in the country (Government of South Africa, 2019). This clinical care is complemented by other community-based health services such as community health workers programmes, environmental health and school health programmes (Fryatt and Hunter, 2014, Hunter et al., 2017).

The AYFSP, which is connected to the Ideal Clinic Initiative, plays a crucial role in improving health services for the youth in the country. The AYFSP aims to create a welcoming clinic space for young people where they feel safe and receive a high standard of services with a particular focus on sexual and reproductive health (Western Cape Department of Health, 2017). Several interventions are integrated in the AYFSP aims to improve youth health services, such as a designated waiting room for the youth, flexible opening times that suit learners' school schedules and mobile apps that provide health education and health promotion materials (Western Cape Department of Health, 2017). During the implementation of the AYFSP, a dedicated nurse or manager who is experienced in working with youth is appointed to track the progress. He or she is called a champion and is the one communicating with the WCDoH.

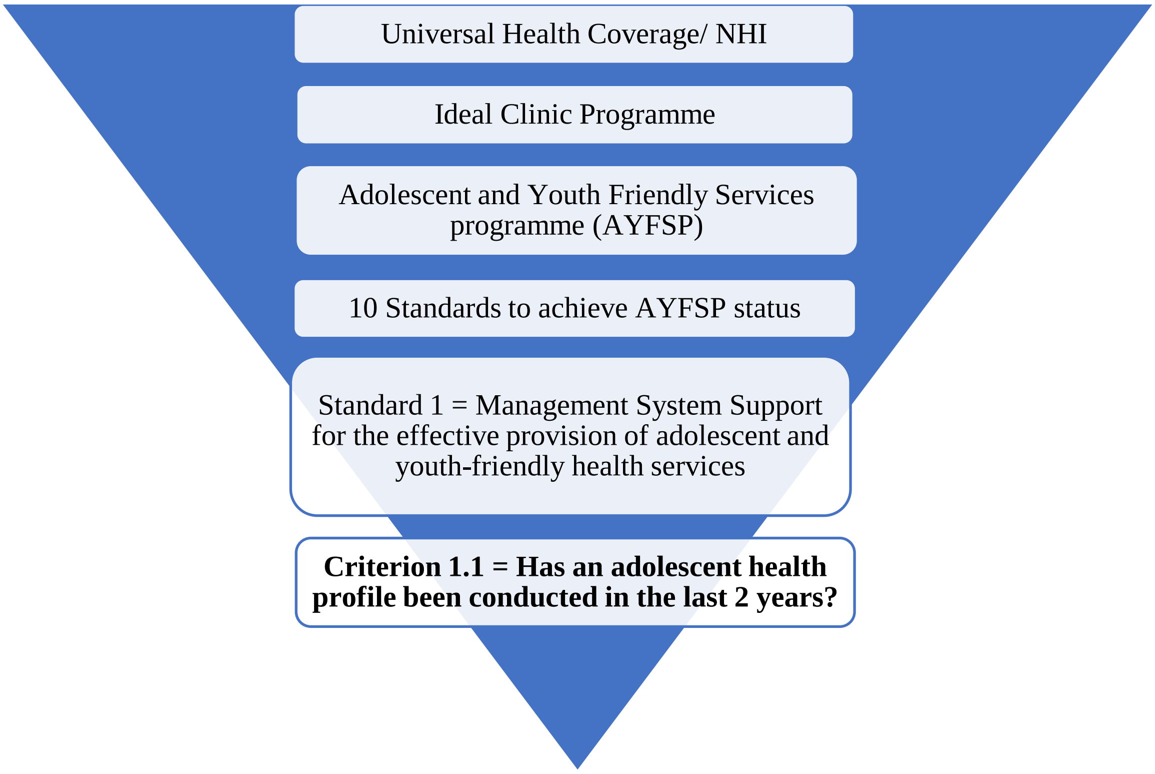


Figure 6.2: Adolescent Health Profiles in the AYFSP

According to the AYFSP guidelines, AHPs give an overview of the life, health, challenges and opportunities of the youth in the catchment area of a particular clinic. AHPs can therefore also be seen as a profile of the youth in the community, or a community health profile (CHP).

In South Africa, there is very little research conducted on CHPs and AHPs. In high-income countries such as the United Kingdom and the United States, CHPs are more widely used and impact local health policy (Link and Phelan, 2002). Most of the research on CHPs aims to describes how health information is used to develop the CHPs, but do not focus on the practicality or usability of profiles in practice or show how CHPs are used in daily decision-making (Sauliūnė et al., 2014).

Most CHPs are developed to underline and explore how the social determinants of health impact well-being and health-seeking behaviour in communities. Social determinants of health include racial segregation, poverty, poor access to health services and high rates of violence (Marmot et al., 2008). These determinants of health differ between high-, middle- and low-income countries, but also affect individual neighbourhoods (Bailey et al., 2017). In countries such as the UK and the US, CHPs are used to report on factors that influence the health of populations, to track trends in diseases provide a snapshot overview of health determinants for each local authority (National Center for Environmental Health, 2015). They are “conversation starters, highlighting issues that can affect health in each locality” (Public Health England, 2019). Information is mostly collected through population data, self-reported health data, patient records or interviews with health workers and community members. The most important aspect of CHPs is the link between the social determinants of health and individual health outcomes.

During my first visit with Sr. Vece, we did not get the chance to further discuss the requirements of the AHP, but I stayed in touch with Sr. Vece and would meet her regularly to discuss the possibility to discuss how iALARM could assist her developing an AHP as part of the AYFSP.

Our meetings often took place in the iALARM field office in Gugulethu on Mondays, as it was close to Gugulethu CHC, the clinic where she had weekly management meetings. Our get-togethers habitually started with some discussion about the daily practices in the clinic, the shortage of staff, constant budget cuts and pressure from her line managers. Sometimes, Sr. Vece was seeking advice, but other times she just wanted to let off some steam. After this, we would spend some time debating the requirements for the AHP and brainstorming about resources we could use for the AHP. For Sr. Vece, the AHP appeared to be a matter of urgency, as it was the last outstanding requirement for her to be certified as a youth-friendly clinic.

> *“So, they [the WCDoH] want me to create this profile, but I have no idea where to get the statistics from. They are not willing to give me anything, and the stats that I have from my own clinic are not complete enough. The complication is that my clients come from all over Cape Town and even further than that. They have different backgrounds and languages, which makes things very complicated. So, I would like to get stats from the whole of Klipfontein and Manenberg. I went to Stats SA, but they could not help me either. That is why I am coming to you, as you have such a great reports that you present every month. Maybe you could help me as well?”*

This excerpt above clearly reveals some of the hardships and realities in trying to access information for the AHP, whilst trying to manage a busy community clinic with little infrastructure. With only two clinical nurses on staff, Sr. Vece is a health practitioner first, and then fulfils the role of manager. Patients start queuing for services early as 7.00 AM and although most patients wait patiently, nursing staff have to work non-stop from 8.00 AM to 4.00 PM to manage the influx of patients. Improving the clinics’ infrastructure or implementing new programmes, such as the AYFSP, has to be done ‘in between seeing patients’ or after hours. Weekly meetings with line managers and other managerial responsibilities further cut into effective working time.

This situation is not unique to Sr. Vece’s experience, as many South African health professionals work in the complex environment of an overburdened and fragmented health system with ever-changing policies and guidelines that need to be implemented with very little support (Gilson, 2016). The AYFSP forms part of the health workers' responsibilities, and has to be implemented as part of their daily tasks. With patients waiting to be seen, reports to be submitted and other daily activities, there is little dedicated time left for health workers to focus on the AYFSP. Nevertheless, there is constant pressure from managers, implementing partners and the WCDoH to make progress on the implementation. Some of the daily challenges health workers face include overcrowded clinics, stock outs of medication, lack of electricity and water, and little access to reliable health information, which was key for the development of the AHP. Due the packed schedules of clinic staff and their many responsibilities, there is often no spare time to dedicate to reading, discussing and planning the implementation of new programmes and policies.

During my first interactions with Sr. Vece, she commented regularly about the lack of statistics available and sometimes mentioned that she did not feel supported in her quest to get the required information for the AHP. Often, the implementation of new programmes is the responsibility of one health worker in the clinic, the 'champion'. These champions do not always receive the required support from colleagues and line managers, and rarely get extra time off to implement new programmes or services. The lack of support also became apparent when Sr. Vece presented her idea of compiling an AHP in the iALARM Task Team meeting in August 2017. In this meeting, where several of her direct line managers were present, Sr. Vece gave an overview of her attempts to collect the required health information to populate the AHP. After describing the different steps and meetings she had with me, she kindly asked all of the participants for input and assistance. The initial reaction was limited. One of the attendants shared the details of the allocated AYSFP implementing partner, LoveLife; one data manager from the sub-district offered her assistance, but provided very little concrete advice about next steps. One the managers acknowledged Sr. Vece's concerns, but noted that his team at Gugulethu CHC was also struggling to develop the AHP and appeared to be poorly informed about the AYFSP implementation process.

> *"We are on the same boat as Sr. Vece. We also need to make a AHP. We have the assistance of a peer navigator who is closely connected to the youth that comes to the clinic, but we are still training him and would love to have some assistance."*

6.3 Trial and error – drafting the first Adolescent Health Profile

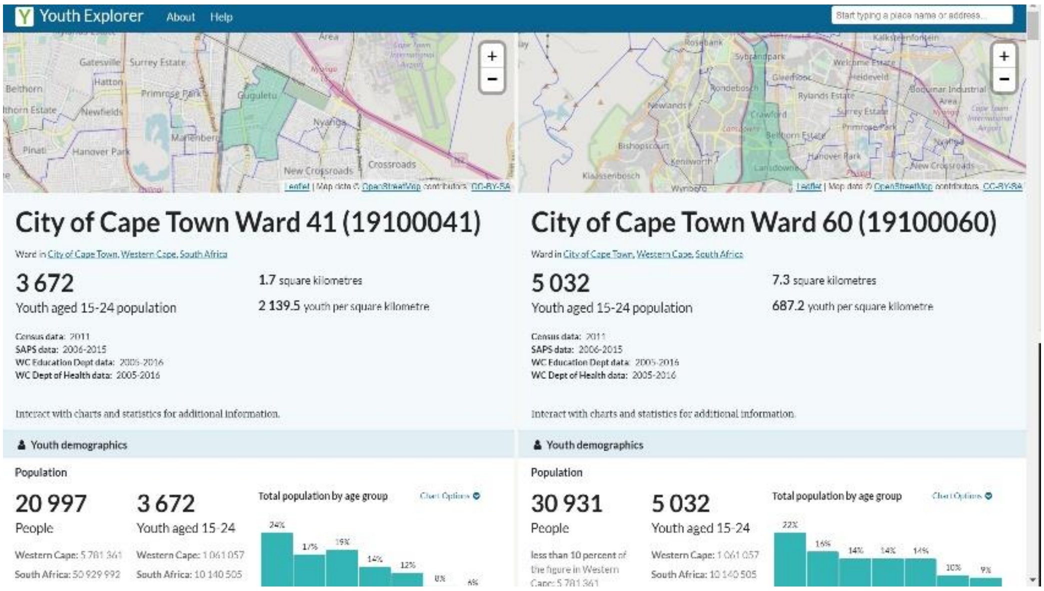
After the AHP was officially introduced by Sr. Vece in one of the iALARM TT meetings, it became clear that there was substantial ambiguity about the process of setting up an AHP. As the request for information fit in well with the aims of the iALARM intervention, the iALARM RT was eager to assist

Sr. Vece with the development the first version of the profile. The timeline was tight, as Sr. Vece wanted to present her AHP at a meeting with the WCDoH a few weeks later.

As Sr. Vece had not received any guidelines about how to populate an AHP, I had several meetings with her and other colleagues in the RT to determine what information we should add to the profile. Firstly, we chose which neighbourhoods to include in the AHP, a process which was not straightforward due to the diversity and mobility of patients. In a discussion with my colleagues Mandla and Phumzile and Sr. Vece, we agreed that we would use the neighbourhoods of Nyanga, Gugulethu and Manenberg, as they were the closest to the clinic. We also decided that the AHP would be more useful if we would not only collect statistics about the youth in the area, but also sketched a narrative that would explain the social determinants that impacted the health of the youth in the area.

Similar to our experience when trying to find up-to-date HIV information to compile HIV reports for the iALARM Task Team meetings (see more in Chapter Four), the iALARM RT struggled to find relevant, reliable and up-to-date information about the youth in Gugulethu, Nyanga and Manenberg. To structure the AHP, the iALARM RT divided the AHP into different sections including household setting, schooling, youth unemployment rate and health outcomes (**Appendix 6.1**). After this, we attempted to show how the youth is impacted by poverty, lack of formal housing, household setting and exposure to crime, sexual abuse and drugs.

The first source that the iALARM RT used was the Youth Explorer website (**Figure 6.3**). This platform provides statistical information about young people in South Africa. Youth Explorer is a platform created by UCT's Poverty and Inequality Initiative and OpenUP, an organisation that provides free government statistics to communities (Poverty and Equality Initiative, 2017). The web-based application provides information on young peoples' living conditions, schooling and health status. This information is provided per ward; it is easy to read, visually appealing and allows users to compare different wards with each other.



City of Cape Town Ward 41 (19100041)

Ward in City of Cape Town, Western Cape, South Africa

3 672
Youth aged 15-24 population

1.7 square kilometres

2 139.5 youth per square kilometre

Census data: 2011
SAPS data: 2006-2015
WC Education Dept data: 2005-2016
WC Dept of Health data: 2005-2016

Interact with charts and statistics for additional information.

Youth demographics

Population

20 997
People
Western Cape: 5 781 361
South Africa: 50 929 992

3 672
Youth aged 15-24
Western Cape: 1 061 057
South Africa: 10 140 505

Total population by age group

City of Cape Town Ward 60 (19100060)

Ward in City of Cape Town, Western Cape, South Africa

5 032
Youth aged 15-24 population

7.3 square kilometres

687.2 youth per square kilometre

Census data: 2011
SAPS data: 2006-2015
WC Education Dept data: 2005-2016
WC Dept of Health data: 2005-2016

Interact with charts and statistics for additional information.

Youth demographics

Population

30 931
People
less than 10 percent of the figure in Western Cape: 5 781 361

5 032
Youth aged 15-24
Western Cape: 1 061 057
South Africa: 10 140 505

Total population by age group

Figure 6.3: Impression Youth Explorer

A community is often comprised of more than one ward, which meant that the iALARM RT had to combine the information to get an accurate representation of the different neighbourhoods. Most of the information is provided by Stats SA, and although some information is outdated, Youth Explorer gives a comprehensive overview of the greatest challenges faced by youth in South African communities (Poverty and Equality Initiative, 2017). The website also has a tool to compare wards with one another, which is helpful when trying to comprehend the differences and similarities between youth in connected neighbourhoods.

Besides Youth Explorer, the iALARM RT pulled together information from several other sources, including crime statistics from the South African Police Service (SAPS), information about the burden of disease in South Africa. The team also added some of the statistics on teenage pregnancy from a pamphlet that was used for a MCSJ campaign (see Chapter five and Appendix 5.2).

Dr. Morna Cornell, an investigator in the iALARM RT and epidemiologist at UCT, was one of the researchers who assisted with populating the AHP. She provided some information about violence and mortality in the Western Cape and tried to find up-to-date HIV and STI information. According to Dr. Cornell, collecting this information proved to be a challenge, even for someone who is working as an epidemiologist at UCT. I interviewed Dr. Cornell about her experience assisting with the population of the AHP. She thought that it was problematic that the already-overworked health staff and lower-level management was also asked to create a AHP on top of their daily workload.

> *"When I heard her [Sr. Vece] talking about the AHP, I felt extremely sorry for her. It is clear that this is important for the completion of the AYFSP, but has now created whole new burden on these people [clinic managers and champions]. They have to go through this complex process of trying to extract information from all these different sources. To me, that is really something that the Department of Health should take responsibility for. And they [the DoH] did not, which is problematic."*

When trying to retrieve the information for the AHP, Dr. Cornell realised how difficult it was access HIV information on community level.

> *"The up-to-date HIV and STI data is almost impossible to find. So first, I have my own resources to draw on, and secondly, I was speaking to people here, at UCT, to get more information. I also wrote to several people from the WCDoH as well. I was looking for granular data, not on provincial level, not even the district, but the sub-district and community level. One WCDoH official said to me what you do find 'is not worth the paper it is written on', which basically means that the available health information is useless. I looked in the district health system, I looked in the South African Health Review, I looked in all different sources and I could really not find a lot of useful information."*

When developing the first version of the AHP, the iALARM RT had not received any guidelines and therefore did not know what information would be essential to include. I asked Dr. Cornell what she thought was important.

> *"In my opinion, when creating a profile that shows the health of the community, there is no need to give an exhaustive report of the HIV data per age group and gender, but rather an overview of trends, so you can focus on the target groups that are underrepresented or underperform in the HIV cascade. In general, the AHP is extremely useful, not only for the facility, but for the whole community."*

Compiled using different forms of both routine and informal information, the first version of the AHP for Nyanga Junction was sent to Sr. Vece in time for her presentation to the WCDoH. I asked her to not share the information in the AHP to other clinics, as the iALARM RT felt that some of the information was outdated and we were trying to access more recent health information. Also, the information was relevant to Nyanga, Gugulethu and Manenberg, but would not be suitable for facilities in other neighbourhoods. To the iALARM RT, the first version of the AHP felt incomplete, but the document was well-received at the WCDoH meeting. Sr. Vece was as extremely excited about the outcome. She told me that her colleagues and managers praised her about the amount of work we put into the AHP.

> *"You are going to be very busy with these AHPs, young lady. But I am shielding you from the work and other people. We need to make some improvements together and only if mine is approved, I will give your phone numbers to other and you can assist other clinics. But they [the nurses] are dying to meet you. But please promise me that you help Gugulethu CHC first, as Mr Makamba is my boss and he really needs all the help he can get."*

When assisting Sr. Vece with this first draft of the AHP, the iALARM RT experienced several of the same challenges that were also highlighted by Sr. Vece during first conversations. The lack of guidelines hindered the collection of relevant information to populate the profile. It was also challenging to determine which communities and neighbourhoods should be included in the AHP, or what topics were essential to understand the health challenges for youth in South Africa. The iALARM RT did not know how the AHP would be used in the daily practice of the clinic. For this first draft of the AHP, my colleagues and I populated the document from different sources available, but also relied on experts from outside our team to provide relevant information. Similar to Sr. Vece's experience, the lack of an example really hindered the process, as it made her feel overwhelmed and insecure.

Furthermore, the iALARM RT realised the lack of health information available to draft the AHP. At first glance, the most reliable source for the AHP was the Youth Explorer platform. Although this website is easy to use and informative, the census data was far from complete and collected eight years ago. Within a fast-changing society such as South Africa, where townships are swelling and immigration rates are high, this information might not be as accurate now as it was seven years ago, as the demographics are shifting rapidly. Other routinely collected information, as in detailed described by Dr. Cornell, is either not easy to retrieve or highly unreliable. Even the WCDoH official Dr. Cornell consulted was doubtful that she would be able to get high-quality HIV and STI information, as he indicated that the information provided by the province is 'not worth the paper it is written on'.

Besides the challenges experienced by Sr. Vece and the iALARM RT, the request for developing the AHP also created new opportunities and shaped new relationships. Sr. Vece's attitude and drive to create a profile despite the lack of guidelines or available examples showed dedication and persistence which was contagious. She was determined to keep in close contact with the iALARM RT until the AHP for Nyanga Junction was completed and regularly asked us for updates and new information. Sr. Vece's resilient attitude also sparked new and creative ideas for how to compile an AHP for the clinic despite the lack of guidelines, and allowed her and the iALARM RT to collect health information outside of the traditional routine databases by exploring new information sources such as Youth Explorer. We were able to do this partly because there was not a set framework through which the AHP needed to be developed.

6.4 Understanding the labyrinth of guidelines and expanding the AHP footprint

The iALARM RT was pleased to hear from Sr. Vece that the first version of the AHP was so well-received by her colleagues, but also slightly surprised, as we thought that some health information in the profile was too incomplete or outdated. I also had many questions, as I could not believe that there was no template available for the AHP. I thought, there should be a blueprint somewhere, an example to work from. And why, I wondered, were there no guidelines available? I knew that the AHP was part of the larger AYFSP, but what did the actual policy say about it? And wasn't there any guidance or support that nurses and champions could rely on? Both the process of policy making and the implementation thereof are complex and multi-faceted (Gilson, 2016). In South Africa, policy implementation is hindered by fragmentation of the health system, overburdened clinics and overworked health staff who face many daily challenges. To assist with the implementation process, NGOs and research institutes play a direct role, as they provide guidance and support to clinic staff (Schneider et al., 2008, Schneider et al., 2015).

I asked Sr. Vece who the implementing partner for the AYFP was. She gave me details of loveLife, an organisation that focuses on improving the lives of young people in South Africa, reducing HIV infection and teenage pregnancy, and keeping young people in school (New loveLife Trust, 2019). LoveLife supports the health system in Cape Town with the Groundbreakers Programme, whereby young people trained by the organisation deliver health education programmes in the community and provide peer-to-peer education. LoveLife also appoints dedicated staff to support clinics implementing the AYFS programme. One of the implementers in the Western Cape is Thandi[3], who works with Sr. Vece and health workers in and around Gugulethu.

I was hoping Thandi could provide some clarity on the AHP guidelines and share some resources to improve the AHP for Nyanga Junction. I made an appointment to interview her about her role in loveLife and the current state of the AYFSP in Cape Town. Upon meeting her, Thandi gave me some background to the AYFSP, a health programme initially developed in 2001 that was never actively implemented. Now, the AYSFP has become part of the larger Ideal Clinic Initiative.

> *"The programme is going well, but it needs a lot of work and dedication. You need to change their [nurses'] attitudes. By educating them how to work with young people. They must learn every day. Young people have a lot of challenges which other people are not aware of. I do my mentoring once a month, and share with them new information. And I got WhatsApp groups where the nurses can ask questions."*

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[3] Pseudonym

I asked Thandi about the biggest challenges of the AYFSP implementation. She immediately acknowledged that some of the requirements of the programme were almost impossible to meet, such as creating dedicated youth waiting rooms when clinics are often overcrowded.

> *"Some challenges health workers face is with infrastructure and shortage of staff. Often, the champion is working in other parts of the clinic as well, and is also in charge of the AYFSP. And sometimes, there is no space to create a chill room, or no money to provide wi-fi. But they [the champion] must also step up and escalate the shortage of materials with their facility manager, and ask them for funding. And we have the posters to make waiting rooms more appealing for the youth."*

When I probed her about the challenges of setting up the AHP and shared the experience I had with Sr. Vece, she immediately sent me an email with the guidelines (**Appendix 6.2**) and looked at me puzzled when I told her that I had never seen these before. She explained:

> *"I have not worked a lot on the AHP yet, as we are still trying to sensitise the clinics around it. Clinic staff are supposed to create the AHP by themselves, but they do not have the time. They feel that it is a lot of work for them. And they still need to do their clinical duties. So, they end up looking for people who do it for them, such as you. Because you can get the accurate information. Because one of the clinics I worked with they had old information. Not current data we want in the AHP. This needs a lot of research*."

Thandi acknowledged that creating the AHP posed difficulties for the champions, but did not seem to know where to get the correct information either.

> *"They get info from Stats SA and their closest municipal offices. For the most updated HIV information, they have to go to the Desmond Tutu HIV Foundation and other HIV stakeholders. So NY3 has to ask Sonke for the stats. The AHP is an exercise for them to know the issues in the community... but also to think outside of the box."*

According to Thandi, the guidelines were developed by Lovelife and the NDoH and based on the latest UNAIDS and PEPFAR policy documents.

After the interview, I immediately sent the guidelines to Sr. Vece. I thought we could use this document to improve her AHP. However, Sr. Vece was annoyed with me for sending through the guidelines. "I have never seen them before and I asked Thandi and others for guidelines numerous times. I am not going to rewrite the AHP profile, this has already taken too much of my time."

I was relieved to get answers about the AHP guidelines, but also felt that support from LoveLife was not sufficient for the health workers. LoveLife had appointed only two implementers for the entire province, who could only visit each clinic once every month. Although the small initiatives Thandi launched to assist the champion and nurses were well-intended, LoveLife did not seem to have the expertise to assist with the collection of the necessary health information for the AHP.

Another implementation partner of the AYFSP in the Gugulethu area was the Desmond Tutu HIV Foundation (DTHF). This organisation, which is based at the University of Cape Town (UCT), is involved in epidemiological HIV research as well as clinical trials and health service research. Currently, the DTHF is running a large project, Zimele, that aims to render more tailored health and life skills services for young people between 10 and 24 years (Desmond Tutu HIV Foundation, 2019). Connected to the Zimele project is the Women of Worth (WoW) programme, a research component that aims to improve the lives of young women (19-24 years) by offering empowerment sessions. The aims of the WoW study are closely linked to the objectives of the AYFSP, and therefore, DTHF is collaborating with the WCDoH and LoveLife to assist clinics with the implementation of the programme (Desmond Tutu HIV Foundation, 2019). Lulu Mtwisha, or Sr. Lulu as everyone called her, would visit clinics regularly on behalf of DTHF and assist champion to streamline the implementation process. I knew that Sr. Vece had a good relationship with Sr. Lulu and that Sr. Lulu strongly believed in the AYFSP.

> *"I believe it is important to meet the youth around you and find out from them what they need before implementing the services. And the AHP is a sort of baseline study, to understand what the difficulties are that the youth faces in the community. They want to come in the afternoon, can we accommodate that. And they want a space because they hate to wait in the queues… There are so many myths that are situated in the community. That feeds into their ignorance. We need to know what these myths are to be able to demystify them."*

The myths that Sr. Lulu described pointed to the ignorance of the youth to learn more about their own sexual and reproductive health, which leads to and increase risk of contracting HIV, STIs or unwanted pregnancy. This ignorance is caused by a lack of sexual and reproductive health education in schools and fear among the youth to visit the clinic (Hindin and Fatusi, 2009). Sr. Lulu was very happy that the iALARM RT was able to assist Sr. Vece with developing the AHP, as Sr. Vece had approached her several times for assistance, but she also struggled to get the right information.

> *"If there was a template, everyone would be able to do this. That is where the problem lies. I have been saying this for a while and have been to municipal offices where they have some demographic information for the Gugulethu and Nyanga, but that is not enough for the health profile."*

Similar to my experience, the lack of a template seemed to also hinder Sr. Lulu's efforts, and even though she worked for the DTHF, HIV information for the Gugulethu area seemed hard to obtain.

> *"We tried to speak to the sub-structure if they could help us, and they do not have it, and they threw the ball back to us. And I even tried to ask people in my own organisation, but even they did not give me an overview of the HIV information in the area. If we can get help on it, we are on a highway to accreditation."*

Sr. Lulu invited us to share the first draft of the AHP for Nyanga Junction during a meeting from the WCDoH in Cape Town. When preparing my presentation, I asked Sr. Lulu what the focus of the talk should be. She replied to my email saying; "*I cannot interfere with your presentation, I do not have such expertise"*. I decided to give an overview of the different steps the iALARM RT the AHP and showed the participants the Youth Explorer tool. I also incorporated some questions about the guidelines Thandi gave to me to see if other clinics were using them and to learn more about the underlying ideology and policy, as I had still many questions about the AHP which remained unanswered.

After my presentation, I stayed for a while and observed the champion speaking about their progress and challenges in trying to implement the AYFSP. I was surprised by the extreme circumstances under which health workers were operating, as many champions were reporting on the shortage of staff and time to implement the AYFS programmes. Despite these challenges, many health workers adapted creative strategies to show the progress they had made while trying to comply with the AYFSP requirements. However, despite their creativity and hard work, none of health workers present seemed to have completed an AHP yet.

My interactions with Sr. Vece, Sr. Lulu and Thandi highlighted several insights about the challenges that Sr. Vece and other champions faced when trying to compile the AHP. Firstly, there were guidelines available for the AHP which were generated by the NDoH in collaboration with loveLife, but they did not seem to be distributed to the individual clinics. Seeing the guidelines cleared up some ambiguity about the purpose of the AHP, as well as the different resources that could be used, though this did not necessarily mean that the information was complete or up to date.

Not distributing the guidelines to the different clinics also showed that there was an apparent lack of support from LoveLife. This can be partly attributed to the shortage of implementers in the Western Cape, as two people cannot provide adequate assistance for a whole province, but it does not explain why the guidelines for the AHP were not distributed to all clinics in the Western Cape. The additional involvement of Sr. Lulu and the DTHF appeared more successful, as Sr. Lulu was an experienced nurse who identified and sympathised with the health workers; she provided some emotional support and acknowledged the challenging circumstances under which the champions were trying to implement the AYFSP.

The lack of distributed guidelines and absence of a clear template described in the interactions above point to some apparent policy implementation barriers that are caused by both organisational issues and larger socio-economic context (Walker and Gilson, 2004). Policy and programme implementation is a long and complex process that can be affected by the absence of training for those implementing the policy, as well as lack of resources, miscommunication and lack of consistent leadership (Walker and Gilson, 2004, Schneider et al., 2006, Gilson et al., 2014). Often, health policy development is a top-down process, which leads to resistance at the implementation level, as health workers and champions are faced with unintended consequences such as a lack of access to information, limited support from NGOs and implementing partners, and the absence of clear guidelines (Schneider et al., 2006).

6.5 Working together is key – Workshopping Adolescent Health Profiles

During the WCDoH meeting, it became clear that many of the individual clinics had not yet started developing their AHPs and experienced different challenges during the implementation process. I knew many of the clinic managers and champions at the meeting, I gave out my details and promised to give some assistance as needed. In early January 2018, I received several WhatsApp message and emails. Sr. Rapiya from Nyanga Clinic wrote:

> *"Morning/complements of the season its SR Rapiya. is it possible Myrna that u can the community profile the u e-mailed for just disappeared. I don't know how, or can please come and sit with management to when doing it or explaining it."*

Another request came from Mr. Makamba, the clinic manager from Gugulethu CHC. He called me on behalf of the social worker, the dedicated champion for the AYFSP, and invited me to visit the clinic and speak with his staff about setting up an AHP. The deadlines were tight, Mr. Makamba said, as the National Department of Health (NDoH) had announced that they were sending accreditation officials to the Western Cape to monitor the AYFSP. Mr. Makamba was determined to have an AHP for this clinic before the arrival of the NDoH representatives.

When I arrived at the clinic, Mr. Makamba had rounded up eight of his staff members, including the health promotor and youth nurse. I brought copies of the guidelines and, together with the team, I discussed the different sections of the profile step-by-step. I also tried to tap into the knowledge and experience of the staff members by asking them direct questions about what they could contribute to the AHP, as the social worker seemed overwhelmed by the different types of health information that were required to develop the profile. Observing the different staff members during their conversation about the AHP and facilitating a discussion about the health information required, I realised that by combining everyone's knowledge and experience, the clinic team was able to provide a large part of the required information for the AHP. The youth worker gave a list of schools in the area, the health promoter shared the names and NGOs he worked with, and the youth nurse promised to supply some recent statistics about the termination of pregnancy referrals and contraceptives. When discussing the guidelines step-by-step and listening to input from all of her colleagues, the social worker's face also visibly relaxed, as the idea of creating an AHP became a manageable task rather than an insurmountable obstacle.

During this roundtable discussion, the participants also expanded their views on what types of information could be used for the profile. Initially, most of the Gugulethu CHC staff only considered the data produced monthly in the Routine Management Reports (RMR) as being appropriate for the profile. They did not necessarily consider other types of collected information such as appointment cards, referral letters or informal conversations with patients as reliable sources of information. This became apparent when we discussed the circumcision rates among young men in Gugulethu. In the guidelines, there is no distinction made between male and female circumcision, or between voluntary medical male circumcision (VMMC) or traditional circumcision. The social worker quickly dismissed circumcision as a service that was not performed in the clinic and therefore is not measured. "*We refer for VMMC to the nearest hospital, as we do not perform VMCC in the clinic. But most of the boys go to bush for traditional circumcision in June and December, they go back to the Eastern Cape. That is our culture*". I completely understood the comment of the social worker and the cultural context that encouraged traditional circumcision among Xhosa boys, but encouraged the participants to think a bit outside the box. *"What about the referral letters for VMMC? Do you give them out and record this in your statistics? And when the boys go for the traditional circumcision school, don't they need a certificate signed by the nurse that they are fit for the five weeks in the bush?" "Yes",* one of the other participants commented; *"we do sign off medical certificates and check if the boys are fit to go to the bush."* I then suggested that they could maybe count the certificates and referral letters to collect the statistics for circumcision. Initially, the response was a little hesitant, but I tried to sensitise the team to the fact that, while monthly statistics are part of routine health information, follow-up appointments and referral letters could also function as health information, even if it is not necessarily routinely collected information.

In the next few weeks, I received many other requests from health workers, which stimulated the iALARM RT to organise an AHP workshop for clinics in and around Cape Town, as we could not honour every individual request. In preparation for the workshop, Dr. Cornell and I developed a template whereby we divided the guidelines into nine different sections (**Appendix 6.3**). From one of the clinics, we received an RMR, which we analysed to determine what information was suitable for the workshop and the profile. The RMR included much relevant health information, including different birth control options and referrals for termination of pregnancy. Unfortunately, some other requirements for the AHP were less clearly defined and difficult to answer, such as ‘measure the ART adherence in the catchment area by age and gender’. How did the NDoH, who developed the guidelines, define ART adherence? Was it done by CD4 count, return visits to the clinic or pharmacy when picking up ARVs, or enrolment in adherence clubs? And how can the ‘knowledge of sexual rights’ be determined and measured? Dr. Cornell and I had several informal conversations about the ambiguity of the guidelines, but decided to leave some of the questions as discussion points for the workshop.

The workshop was attended by 25 health workers from different facilities in the Klipfontein sub-district. The iALARM RT provided the templates for the AHPs as well as several computers and tablets with internet connections, so the participants could use some of the suggested internet sites and basic search engines to collect some of the necessary data for the profile. We also grouped the participants by neighbourhood, encouraging them to share information and discuss challenges they face in their respective clinics. During the workshop, participants spoke about their personal experiences and challenges working with youth. Being grouped together also encouraged the health workers to examine the RMR together and analyse the information used for the AHP. Some of the health workers admitted that using the RMR to populate the profile gave them new insights about their young patients and stimulated them to think about both the access to and provision of sexual and reproductive health in services at their facility. Although the health workers were familiar with using RMRs and other routinely collected information, most participants never thought about the broader use of these statistics, as they were typically solely used to report targets. Furthermore, when probed, the health workers were also very knowledgeable about the different health information systems they used in the facilities and pointed out their benefits and shortcomings and when trying to access health information.

At the workshop, I also explained the functionality of the Youth Explorer platform to the participants; similar to previous times, this resource was well-received, especially as we allocated some time for the health workers to look up information about their own wards and communities discuss this information among each other. We also had a lively discussion about ‘Section I’ of the AHP (Appendix 6.3) which requests the opinions and experiences of young people in the area. During an interactive brainstorming session, participants debated the consequences of social and economic challenges on the lives and opportunities of young people in Cape Town, including gangsterism, substance abuse, domestic violence, poverty, crime, HIV, STIs and unwanted pregnancies. Participants also revealed how easy it is to become desensitised to these challenges when hearing the same stories in the clinic every day. Naming, unpacking and discussing the impact of these challenges during the workshop became an invaluable resource for the AHPs.

After the workshop, the iALARM RT and participants reflected on the workshop. The health workers were grateful for the guidance, templates and additional resources the iALARM RT provided to populate the AHP, but more importantly, we created an opportunity for all the participants to come together and spend allocated time away from daily responsibilities to brainstorm and discuss setting up their own AHP. Additionally, the participants were able to explore their tacit knowledge and experiences which often remain unrecognised and unappreciated, but are valuable resources, especially when other forms of information are scarce or difficult to access.

The workshop also provided an opportunity for health workers to ask critical questions about the guidelines and to flexibly use the template to compile a product that would be useful in daily practice. In this case, the lack of available guidelines actually encouraged the participants to think creatively and use the ambiguity to their own advantage, as it granted them the opportunity to populate the profile with information that would beneficial for them, rather than using generic health information.

6.6 Answers from the highest level? Adolescent Health Profiles nationwide

During one of the presentations I gave at the WCDoH I met Lutho Kutase, the programme manager for School Health, Youth and Adolescent Health in the province. He invited me to present my findings about AHPs at a two-day symposium held in Johannesburg. This symposium is organised by the National Department of Health (NDoH) twice a year and in this case, brought together youth health representatives from all nine provinces to learn more about the AYFSP and larger Ideal Clinic Initiative.

My presentation was scheduled for Day Two of the symposium. This day kicked off with a feedback session where participants could voice their concerns about the AYFSP and the collaboration between NGOs and government structures. According to the participants, one of the challenges was the lack of accountability from the government and the ambiguity over who is ultimately responsible for the implementation of the programme. One representative from an NGO in Limpopo commented:

> *"For us it is also very difficult to coordinate between the involved schools, the Department of Education and the provincial Department of Health. We always feel that the Groundbreakers who are employed in the clinics are owned by the clinic managers and we do not have a say in the activities they actually do."*

Trying to resolve these issues and keep track of the implementation and success of the AYFSP, one of the delegates from NDoH proposed a template to report progress over time, which would then be shared between the different stakeholders. Adding to the comment, the representative NGO in Limpopo stated: *"You are right, if it is not written, it is not done…. We need to collaborate, work together, and share our experience in best practice workshops like these ones."*

The example above showed that even at the national and provincial level, there was still ambiguity about the guidance and support structures that should be provided to individual clinics, and that there was uncertainty about which government body was responsible for the successful implementation of the AYFSP.

The presentation I gave to the delegates in Johannesburg was largely similar to the earlier presentations, but I did take the opportunity to raise questions about the vague guidelines for the AHP and showed how the lack of support impacted the implementation process in individual clinics in the Western Cape. Although I was nervous about being overly critical, Mr. Kutase ensured me beforehand; *"it is good to question and challenge the NDoH every once in a while, so do not feel afraid to voice your opinion."* Unfortunately, none of the participants were able to provide more clarity about the guidelines, but one NDoH representative commented that the clinics who had received assistance from the iALARM RT should feel grateful, as it is the responsibility of the champion, together with their line manager, to create the AHP as part of the AYFS implementation.

During lunch I spoke to one of the women responsible for the AYFSP accreditation process of individual clinics in the NDoH. Together with another colleague, she travels around the country to inspect the state of the clinics and the programme. I asked her if she had come across clinics that were AYFS-accredited and if she had seen completed AHPs that I could use for future reference.

> *"There are no examples, as all the clinics will interpret the AHP in their own way. We tick off the AHP when we are in the clinic for accreditation, and then the AHP stays in the clinic. I think it is good what you do to share some knowledge and provide support for individual clinics to work together, but we do not have any examples that we can help you with."*

I asked again if she could give me a complete AHP number, or put me in touch with one of the clinics that had completed an AHP, but she only commented: *"Most of the clinics are in KwaZulu-Natal, and I do not know which ones exactly, so I cannot help you."* I also asked her about the deadlines for the AYFSP. *"There is no deadline"*, she told me. *"It depends on the provinces and the individual clinics. Every province is different, so there is no deadline. The Western Cape and KwaZulu-Natal are doing relatively well, but the Eastern Cape and other provinces are struggling."*

On the plane back from Johannesburg to Cape Town, I reflected on my experience at the AYFS symposium. For me, this trip marked the final stretch of my fieldwork, as I was going to start analysing my data soon after and was invited to present part of the findings from the AHP during several upcoming conferences. Personally, I thought that attending the symposium would give me an opportunity to finally get some answers from representatives from the NDoH about questions that had puzzled me since the first time I spoke to Sr. Vece. Instead, the list of questions about the AHP and the AYFSP had only grown. Among other things, I wondered who had decided to include the AHP into the AYFSP; what literature the policy developers had used to inform their decision; how a complete AHP might look; and how this profile would be used in the daily practice of the individual clinics. The concept of creating a profile that identifies the most significant health and social issues among youth in a particular community seems relevant and important when trying to better tailor health services for young people and improve their linkage to care. However, in reality, conceptualising this idea took precedence over the practical implications of actually developing a specific AHP for every clinic. Additionally, my visit to Johannesburg also revealed that even within NDoH, there was a lack of knowledge about the AHP use in daily decision-making in clinics. This made me wonder: if people from the highest level of the health system were not able to provide the right guidance, how can implementing partners at provincial and local levels be expected to give adequate support and assist health workers on their journey to implementing the AYFSP?

6.7 Discussion

In this chapter, I followed a group of health workers on their journey to develop AHPs as part of the AYFSP and reported the different challenges that they encountered along the way. This quest began with a request for information from Sr. Vece, who needed assistance with the AHP for the Nyanga Junction clinic. This request evolved over time, and showcases how health information is access, used and transformed within the daily practice of policy implementation. Findings in this case study also highlight some of the daily challenges that health workers face in South Africa, as they work in a fragmented health system, and attempt to implement new services and programmes without any extra allocated time, and with limited training and support. The challenges faced by health workers in accessing the necessary health information for the AHPs, was further complicated by the absence of user-friendly guidelines or templates.

Findings in this case study reveal several key insights about the complex role of health information in policy implementation. Within health policy development and implementation, there is often a disconnect between the intention of the policy or programme and the feasibility of implementing this policy within a real-life setting (McIntyre and Klugman, 2003, Gilson and McIntyre, 2008). The intentions of developing an evidence informed AHP were laudable: this profile was proposed as a way to analyse the greatest challenges impacting health among youth, and guide action to improve their health. However, the practical dilemmas of how to populate this profile were more complex in practice.

Despite these challenges, this case study also shows that health workers can be creative and resourceful in their efforts to implement new policies like the AYFSP, despite the challenges they faced. Health workers actively made use of strategic relationships with partners inside and outside the health system, and spent dedicated time working on collecting the necessary information for the AHP outside of the clinic space.

These strategies can be understood as a form of resilience. Despite the regular challenges health workers face, resilient health workers are able to maintain positive attitudes under challenging conditions and are resourceful in finding solutions to the problems they face during their work (Barasa et al., 2017). The concept of resilience offers a unique perspective to understand and measure the complex and dynamic process of policy implementation in individual clinics (Gilson, 2016, Barasa et al., 2017, Lodenstein et al., 2016). One of the resourceful strategies that health workers used to overcome the lack of access to health information was the use of informal health information to populate the profile. This is an interesting finding, as the importance of routine evidence is often stressed during the policy development process, but much less is known about the use of informal health information within the policy development and implementation process (McIntyre and Klugman, 2003, Gilson and McIntyre, 2008, Barasa et al., 2017). Another strategy was to forge strategic relationships with individuals inside and outside the health system. Through such collaborations, health workers were able to collect a large part of the necessary health information for the AHPs, despite the lack of support and guidance during the process (Mutemwa, 2005, Scott, 2016, Williamson and Kaasbøll, 2009). The health workers would gather this informal health information from referral letters, casual conversations with colleagues or patients, or information gathered from workshops and trainings. Although not officially seen as routine evidence, these types of informal information proved to be critical resources when compiling the AHP.

Chapter 7: Discussion - Rethinking health information and HISs in Gugulethu and beyond

7.1 Summary of findings

Through three individual but interlinked case studies, this thesis has explored how different stakeholders in the health system and community embody new practices when seeking to collect, transform and use both routine and informal health information. Some of the participants in the case studies had official roles in the health system, being employed as nurses, facility managers, community health workers, or NGO staff helping to run health care programmes. Others would either use the health system or conduct health systems research, but would not be officially employed by facilities or organisations. This cadre includes community activists and researchers. All case studies were conducted in the same geographical area of Gugulethu, a peri-urban, economically marginalised area with overcrowded health facilities and a high burden of communicable and non-communicable diseases and other health threats, including HIV/AIDS, TB, hypertension, diabetes and unwanted pregnancy.

In Chapter Four, I followed the design and implementation process of the iALARM intervention, a project that aimed to better link men to HIV care in Gugulethu by providing new forms of health information to a wide range of health systems stakeholders. The provision of different forms of information revealed new insights about both the use of and the demand for HIV information when shared among a diverse group of actors who were passionate about working within the men's health space. The chapter also demonstrates that both informal and formal information were well-received and that this information led to further conversations about men and HIV, new collaborations between stakeholders in the iALARM TT, and follow-up campaigns. The chapter also highlights that providing a dedicated space plus dedicated period of time stimulates discussions about health information, encourages new interactions and new relationship-building among health actors on all levels of the health system, and motivates health information exchange.

For the case study in Chapter Five, I spent extensive time with MCSJ, a health advocacy group in Gugulethu who develop campaigns that address the need to improve health service delivery within the community and raise awareness about long-standing health issues. Within their campaigns, MCSJ uses different forms of health information, but findings show that this information is not always available to them and sometimes MCSJ members had to collect their own evidence. Although this evidence was considered informal, soft or alternative, on some occasions, this information proved to be an effective instrument when addressing service delivery issues within the formal health system. The case study also shows that health information is often reported from the community to higher levels of the health system, but there is very little information that effectively gets communicated back to the community, showing the unequal distribution of health information across different levels of the health system.

The case study in Chapter Six follows a group of health workers in their quest to collect the required health information to set up an adolescent health profile (AHP) during the implementation process of the Adolescent and Youth Friendly Services Programme (AYFSP). Findings from this case study indicate that many health workers had very little access to health information, received little guidance when trying to obtain access to or collect the necessary health information, and were hindered by organisational processes such as ambiguous guidelines. Despite these challenges, the health workers in the AHP case studies adopted creative strategies to collect the necessary data for the required AHP.

7.2 Analysing the current health information landscape – where does this thesis fit in?

Taken together, findings from the three case studies presented in Chapters Four, Five and Six highlight that there is need to rethink what health information is and how it is used and can be used in practice, as health information is comprised of more than just management reports, patient records and other routinely collected data used in management decision-making and policy design (Braa and Hedberg, 2002, Colvin et al., 2018). Health information consists of both routine and informally collected information, which can be used by a broad group of stakeholders who operate inside and on the periphery of the health system (Scott et al., 2014, AbouZahr and Boerma, 2005, Scott, 2016). Using the examples collected in these three case studies, this thesis has provided a nuanced perspective on how we think about the production, use and exchange of health information, and what a health information system should look like; and in so doing, broadens the scope of who can access and use health information.

In the current health system literature, it has been acknowledged that health information plays a vital role in daily decision-making practices and strengthening health services delivery (Lippeveld, 2001, Vest and Gamm, 2010, AbouZahr and Boerma, 2005, Bailey and Pang, 2004). To facilitate this use of health information, there is a need for countries, communities and facilities to create a well-functioning HIS, which aims to improve information quality and continuous use of information within the health system (Aqil et al., 2009, Braa and Hedberg, 2002). Besides informing the daily decision-making within the clinic, a well-designed HIS can also shape new health programmes, inform health policies and can be used for health advocacy (Akhlaq et al., 2015). When functioning well, HISs have the potential to produce high-quality, complete, up-to-date and relevant health information that is easily accessible by stakeholders operating in different parts of the health system (Aqil et al., 2009).

Unfortunately, the reality of designing and sustaining well-functioning HISs is more complex than described above, and many LMICs, including South Africa, struggle to implement reliable and integrated HISs, which impacts the production, use and quality of health information (Lippeveld, 2017). Besides technical difficulties, fragmentation of the larger public health system also contributes to the struggle of designing maintainable HISs. These issues are often caused by larger socio-economic and cultural factors, including organisational culture and lack of financial and human resources (Aqil et al., 2009, Braa et al., 2004). Other challenges that hinder the development of HISs and the effective use of health information include the need to prioritise vertical health programmes and disease-specific reports which require a new way of collecting health information that focus on a single health condition, rather than a broad range of health determinants (AbouZahr and Boerma, 2005). This often leads to duplication of health information or can result in the development of parallel information systems, which produce similar data for the management of different diseases.

Despite the persistent challenges that largely prevent LMICs from developing efficient HISs, South Africa has made incredible process in strengthening both the health system and HISs since the end of apartheid (Mayosi et al., 2012, Coovadia et al., 2009, Braa and Hedberg, 2002). Early successes were the decentralisation of previously centrally controlled HISs into a district-based health system (HISP) and the standardisation of information collection into routine formats that could be used in different districts and be made available for different stakeholders in the health system. Due to the rapid spread of HIV/AIDS and TB in the 1990s and the ensuing lack of available medication, there was also an immediate need to respond and monitor individual patients, as well as collect information to inform new HIV programmes (Coovadia and Coovadia, 2008).

Unfortunately, some larger health system issues remain in South Africa and other LMICs, including a lack of resources, staff shortages, and weak leadership, all of which affect the development and sustainability of HISs. These issues contribute to the unequal access to health information and impacts the quality of health information. This can result in a unidirectional exchange of health information. When this occurs, interventions only focus on the strengthening of the use and exchange of health information for higher management-level decision-making, while the role of health information at other levels of the health system is barely acknowledged (Akhlaq et al., 2015, Lippeveld, 2017).

The findings described in the case studies show that, firstly, there is a real interest among stakeholders from all levels of the health system as well as among community actors to work with health information. These stakeholders, which can be health workers, researchers, managers or community members, all have their own reasons to use health information to address issues in health services, or to improve the existing health structures. Sometimes, when information is unavailable, actors also go to great lengths to obtain access to health information.

In the iALARM chapter, it was not the lack of HIV information that was striking, but the ways in which this information was presented. The use of HIV reports, for instance, provoked new ways of interpreting routine health information reports which are normally populated and used to report to line managers or to inform colleagues. In the MCSJ case study, community activists used a range of different forms of information to raise awareness for health issues within Gugulethu, including the overcrowded dentistry at the NY3 clinic and the lack of condoms and sexual education programmes in high schools. In the chapter exploring the AHP process, health workers and facility members actively reached out to one another and to iALARM researchers in a quest to find the information necessary to compile a AHP, as part of implementing a programme to strengthen health services for young people in primary health clinics.

The examples in the case studies collectively identify one of several existing limitations in HIS literature, which tends to focus on the need to provide health information for health managers, and rarely considers other health actors as active agents in the health information use and exchange process (Aqil et al., 2009). Although there are many researchers who acknowledge the shortcomings of focusing on the use of information on higher management level only, there is a very little empirical research conducted on the information-seeking practices of those operating in lower levels of the health system (Vest and Gamm, 2010, Colvin et al., 2018). Even when community-based health information systems (CBHISs) are in place, they are often developed to collect on community level to report to higher levels of the health system, but this evidence is rarely shared with the community (Jeremie et al., 2014, Byrne and Sahay, 2007).

Secondly, examples in this thesis show that, despite the interest among health and community actors to use health information to raise larger health systems issues in Gugulethu, the stakeholders in the different case studies often lacked access to the necessary information. These findings are in line with observations from AbouZhar and Boerma (2005), who argue that despite attempts to strengthen HISs, much less information is available than is typically needed to effectively address issues in the health system (AbouZahr and Boerma, 2005). For the health workers in the AHP chapter, there was barely any information available to populate the profiles required for the AYFSP; this meant that the participants had to explore new sources to collect the necessary information, which included census data from online platforms such as Youth Explorer, and pamphlets. Alongside these creative strategies come new forms of health information which might not have been considered important before. Examples from the MCSJ chapter also highlight the lack of information available to the health advocates who wanted to address the issues in the local dentistry, as well as campaign for sexual education and free condom distribution in schools. The iALARM chapter showcases the lack of up-to-date HIV information accessible to researchers which complicated the development of the HIV reports that were used during the iALARM TT meetings.

Thirdly, and intrinsically linked to points above, is the fact that the lack of access to information led to the need of participants in all three case studies to adapt creative strategies, to either gain access to existing forms of information or collect their own evidence. In the MCSJ chapter, I describe how activists went into the community to collect testimonies from those waiting in line to see the dentist. By collecting their own data, MCSJ members wanted to show the inherent need to improve dental services and employ more staff in the clinic. Albeit in a different context, iALARM researchers also needed to think creatively when compiling the HIV reports for the iALARM TT meetings, as the HIV testing information from individual clinics was either not available or was outdated.

By adapting creative strategies, participants in all three case studies negotiated several obstacles that hindered the collection of necessary evidence. This is especially well-described in the AHP chapter, where health workers would create new relationships with colleagues, managers or other health system actors to get access to health information and to negotiate control over access to information. Sr. Vece, for instance, was extremely tenacious once she created a relationship with the iALARM researchers, and was not willing to share any of the received data until her own AHP was complete and approved by NDoH officials. Another strategy that was adopted by health workers was to interview young patients and members of youth groups to get the necessary health information for the AHP. During the AHP workshop, which was organised by the iALARM RT, the social worker from one of the clinics, Sr. Rapiya, shared with iALARM researchers that she did not have access to the routine databases with the required information to populate the AHP. To collect the necessary evidence for the profile, she regularly met with a group of youngsters who would visit the clinics. She did not have space to create a safe space for the young people, so she would sit with them under a tree in the yard of the clinic and have discussions with the youth about their health challenges, experiences in the clinic and the improvements they would like to be implemented to make the clinic more youth-friendly. Over time, she created a relationship with the young people and would even send them out into the community to collect contact details of schools, NGOs and youth programmes. All this information proved to be valuable sources for her clinic's AHP.

Fourth, findings in this thesis show that the creative use of health information and the quest to collect different forms of information does not only show the interest of stakeholders to interact with health information, but also feeds into the larger debate of what health information actually is or should be, as many researchers have a very narrow view of what can be defined as health information and how it can be used in the health system (Garrib et al., 2008). Although a range of different forms of health information is essential for decision-making, most HISs researchers view health information as the routinely collected reports that are stored in electronic information databases (Schonfeldt et al., 2011). There are a few researchers that investigate the role of informally collected health information within decision-making processes and promote the use of different information sources to improve health systems and HISs in LMICs. Authors such as Østmo (2007), Scott (2015) and Mutemwa (2005) have conducted research among health managers in South Africa and Zambia and found that informal information, plays an important role in the health system (Scott, 2016, Østmo, 2007, Mutemwa, 2005). Informal information includes information that is collected through conversation, experience, training and different forms of tacit knowledge (Clarke and Rollo, 2001). Even though informal information is considered to be anecdotal, communicated through interactions with others and therefore not easy to measure, it is used by health systems actors to inform their decision-making and daily practice (Scott et al., 2014, Mutemwa, 2005).

Similar to conclusions from Scott, Mutemwa and others, this thesis highlights the need to acknowledge the important role that different forms of health information play in the health system. However, informal forms of health information are not only used by managers, but by many different health and community actors. The most apparent example of informal information can be found in the iALARM chapter, which describes Phumzile's testimony as an HIV-positive man who has been living with HIV for more than 20 years. His story, in which he encouraged other TT members to better support men in health services, provoked strong reactions among others in the group who not only endorsed his story, but answered to his lived experience with an immediate call to set up campaigns to encourage men to come to the clinic. The iALARM chapter also describes several other examples which attest to the impact of informal information, which includes discussions during the iALARM TT meetings and personal experiences from nurses and facility managers when interacting with male patients.

As noted in previous paragraphs, MCSJ activists used several different kinds of informal information to strengthen their health advocacy campaigns, including the collection of personal testimonies to show the service delivery issues at the dentistry at NY3; they also developed pamphlets and produced a documentary to address the need to provide condoms at schools. Although this information and the ways in which the data was collected can officially not be considered as routine, the information was also not collected accidentally, as there was a set premise and a distinctive method in which evidence was gathered. Therefore, one can understand the process of collecting information as *semi-formal*, as MCSJ was using formal methods in an open-ended way.

Both the type of information and the process of collecting this data in the MCSJ case study is different from the way in which information was used by the health workers in the AHP chapter. In addition to the availability of the routine information, the participants in this study used several forms of informal information when developing their AHPs, including work experience and knowledge gained at workshops and trainings provided by iALARM researchers.

Fifth, examples from the different case studies illustrate that health information, whether produced and used routinely or informally, can never be seen as completely neutral or value-free, as health information is created within a larger social, cultural and religious contexts, and therefore shaped by these contexts. The most apparent finding which accentuates the impact of context is the pamphlets which were developed by MCSJ, UCT and J.L. Zwane. The process of collecting the information, as well as the ways in which the content of the pamphlet changed, demonstrates that health actors have different personal values and beliefs, which impacts the ways in which information is produced and what type of information gets in included or excluded.

Lastly, the findings in this thesis show how the process of collecting, using and exchanging health information is impacted by wider health system changes and challenges. These persistent challenges can result in a lack of access to health information. Gathering the information needed to improve health services therefore requires a high level of flexibility and creativity among those operating in the health system. In many countries, including South Africa, the health care services are designed and implemented within the framework of new-managerialism, which emphasises the need to measure success and achievements based on measurable objectives and targets, constantly evaluating performance according to those targets, and promoting efficiency by constantly rationing resources and promoting task-shifting (Beardwood et al., 1999). These structures often work under the 'what does not get measured does not count' motto, which means that information and resources that are not easily quantified becomes undervalued or obsolete (Lynch, 2014). Furthermore, the target-driven structures which are encouraged within the new managerialism framework undermines the ingenuity of those working in the health system (Beardwood et al., 1999). The impact of target-driven health services especially became apparent in the AHP chapter. In this case study, examples show that although health workers are very passionate about the work they are doing and want to improve health services by implementing new programmes such as the AYFSP, they often have a packed day-to-day routine, giving them little freedom to think about implementation strategies or brainstorm with others about the difficulties they experience. The example of the roundtable discussion with team members from Gugulethu CHC as described in the AHP chapter clearly illustrates this. This excerpt demonstrates that although the employees from Gugulethu CHC were enthusiastic about developing a AHP, they assumed that the data required for the exercise would only be found in RMR reports and other forms of routinely collected information, and did not consider that alternative forms of evidence such as referrals letters could be relevant sources of information. Furthermore, the roundtable discussion showed that the group of health workers did not tap into the tacit knowledge and experiences of colleagues who, when asked, provided crucial information for the AHP.

Summarising the above, this thesis aims to emphasize that there is a need to expand the narrow understanding of what health information is, who can have access to it, and how it is used in daily decision-making in the health system. Across the chapters, case studies highlight that, although health information is not always accessible to those who need it, interested health actors use creative ways and innovative strategies to collect the necessary information. Along the way, health actors also create new collaborations and unexpected relationships, which can lead to improved information sharing and better use of heath information in practice.

7.3 When can information be a catalyst for change in the health system?

Findings in all case studies show that when used under the right conditions, health information can be a *catalyst* for change in the larger health system. In this chapter, I use the term *catalyst* flexibly to highlight the impact that health information can have on the daily work and lives of people who either actively operate in the health system, or those who try and keep the health system accountable and use the services, including community actors and patients (Lippeveld, 2017). The information itself, presented purely as evidence, is largely static, but gets activated and becomes meaningful and usable when it is used by a group of like-minded health actors. Another catalyst that improves the use information among health and community actors is the providing of a 'dedicated space' where information can be shared, explained and unpacked. In the following paragraphs, I will give different examples under which conditions health information can catalyse change, but before this, it is key to understand how the term *catalyst* is used within health systems literature.

According to the dictionary, a *catalyst* is 1) a substance that changes, or increases the rate of, a chemical reaction, but remains chemically unchanged, or 2) someone or something whose actions inspires further and usually more important events (Allen, 2003). The term derives from chemistry, but is often loosely used as a definition that describes how people, or things, can accelerate development processes and innovation when acting as a 'catalyst of change'. Within the health system, a group of health activists might act as a catalyst during the implementation process of new health policies in clinics. The policies would constitute the change that aims to improve the health services, and the involved activists would speed up the process through assisting health workers during the process or by keeping health workers accountable (George et al., 2015b). Another example is the implementation of electronically-based HISs in South Africa. In the South African health system, there had already been plans to improve HISs and move from a paper-based system to an electronic system (Braa and Hedberg, 2002). The HIV epidemic and lack of available treatment drastically sped up this process, as there was an immediate need to have a well-functioning electronic, and disease-specific, database to inform HIV policies, as well as to track individual patients and develop HIV prevention and management programmes (Myburgh et al., 2015). In this thesis, I use the term *catalyst* to describe the different factors that facilitated the access to and use of health information for health and community actors in Gugulethu.

Accessible, diverse and easy to use health information

As outlined in the paragraphs above as well as throughout the case studies, the access to and availability of different forms of health information proved to be the first essential catalyst to improve information-sharing and information use, both among individual health actors and between actors across all levels of the health system and within the larger community of Gugulethu.

Within the iALARM chapter especially, useful health information included a wide variety of sources which ranged from RMR and other management reports to pamphlets, personal testimonies and informal conversations. All of this information provided new insights about the state of health services and HIV care in Gugulethu, facilitated discussions and even inspired follow-up projects. One of the possible reasons that this variety of information served as a catalyst to take further action is the fact that both the HIV reports and other forms of data showed the localised burden of the epidemics and specified in detail which the patients were performing relatively well in the HIV cascade, as well as groups who were left behind. Providing this overview of HIV information on a micro-scale, rather than through broad overviews and summaries, proved to be an effective way to stimulate discussion and possible new campaigns. The impact of providing geographical HIV information to better manage the HIV response has also been established by the WHO, as they use the slogan 'know your epidemic' in their 2013 updated guidelines for HIV surveillance (World Health Organization, 2013). Within this policy, the WHO acknowledges that there are multiple HIV epidemics in the world, and that understanding local contexts and complexities is crucial when designing interventions to better link and retain patients in the HIV cascade (Wilson and Halperin, 2008, Sgaier et al., 2012). Providing high-quality health information plays a key role in the design of these interventions, as well as the shaping and implementation of new HIV policies (Sgaier et al., 2012).

Similar to the iALARM case study, findings in the AHP and MCSJ chapters also show the need to for easy-to-use and digestible health information which outlines current health issues in Gugulethu and the surrounding areas to shape health campaigns, both for community activists and health actors who work in local communities. This includes, but is not limited to, HIV-related information.

Stakeholders and their relationships

Different actors who seek, collect, transform and communicate health information can also function as important catalysts, encouraging the better use of health information. As such, it is important to not only focus on individual actors in the health system, but also to understand the relationships between and among health actors, as these relationships proved to be essential to facilitating better information-sharing within Gugulethu.

There are several examples from the three case studies that illustrate the important role that people play in the health information system. In the MCSJ chapter, both the roles of individual community activists and their relationships with stakeholders in the health system were crucial for the development of the health campaigns they were running. Individual activists, including Mandla, Tantaswa and Lunga, all had several years of experience working in NGOs and health activism movements, including the Treatment Action Campaign (TAC), Sonke Gender Justice (Sonke) and the People's Health Movement (PHM). These experiences equipped them with skills to collect their own evidence to raise health issues in the community, but they also have extensive experience encouraging community members and convincing them to support their campaigns. Besides their lobbying skills, most of the MCSJ activists also grew up in Gugulethu and the surrounding communities, which meant that they were passionate about long-standing health issues, had first-hand experience with these health issues in Gugulethu, and understood the cultural context of the community.

One of the core values for MCSJ activists was to create and maintain constructive relationships with stakeholders in the health system. Creating a strong relationship between MCSJ and several health facilities, health practitioners and clinic managers in Gugulethu proved to be fruitful, as it made it easier to facilitate open conversations, especially when addressing the issues with the pharmacy and dentistry. In both cases, Mr. Makamba, the facility manager of Gugulethu CHC, was able to quickly arrange a meeting with primary health managers and other mangers in the sub-district, something MCSJ might not have been able to achieve on such short notice.

In the AHP chapter, the group of participants were all health workers, facility managers or social workers. These health actors worked in clinics in and around Gugulethu, and while they often knew each other and operated in the same district, they mostly worked independently and in silos. This means that even when tasked with the implementation of the same AYFSP programme, there was very little incentive for the health workers to collect information together. When Sr. Vece approached the iALARM RT with her request for assistance to develop the AHP and shared that she had little access to the necessary evidence, we as researchers had no idea that so many other health workers were struggling with the same issues. When we offered the health actors a workshop to support the collection of information, they gladly came together to share their experiences and collectively were able to access large part of the required health information for the AHP. Even though some training and support was provided during the implementation process of the AYFSP, the issues of creating a AHP remained largely unnoticed, even among the health managers and NGOs who assisted the health workers during the implementation process. Within the chapter, several examples highlight how relationships affected access to health information and emphasised how individuals such as Sr. Vece would strategically negotiate her relationships with the iALARM RT, the DTHF and others to get access to more updated and different forms of health information to populate the AHP.

In the iALARM chapter, the diverse group of stakeholders that attended the iALARM TT meetings became a catalyst to better access and use more health information, as participants encouraged each other to better collaborate and to share more information within and outside the iALARM TT. The stakeholders represented in the iALARM TT all had different relationships with health information, as not all participants had equal access to information and had varied experience working with health information. For health information managers who were part of the TT, the data presented during the TT meetings was familiar, as they regularly engaged with routine health information as presented in the HIV reports. However, for other members of the TT, including NGO representatives, community health workers and activists, some of the information in the HIV reports was novel, which led to unexpected discussions and conversations about HIV and other chronic diseases in Gugulethu, the health-seeking behaviour of men in the community, and other long-standing health issues. These creative conversations were often kickstarted when one of the TT members would share their own experience about working with men, or would ‘raise the alarm’ about statistics included in the reports. Sometimes, the questions were surprising or even a little controversial, but the diverse group of stakeholders in the room allowed for open dialogue to occur, which led to new insights for participants and several follow-up projects.

Although existing literature is not always focusing on the impact that relationships and individual actors have on the use health information in practice, some scholars do acknowledge the importance of health actors when strengthening HIS and health information exchange. In the PRISM framework, for instance, Aqil et al. (2009) argue that human performance, training and collaboration are key organisational and behavioural factors that impact the routine health information system (RHISs) processes and the development and implementation of interventions that aim to strengthen HISs (Aqil et al., 2009). Furthermore, the PRISM Framework also acknowledges the impact of human relationships in the HIS, and recommends constant communication and feedback among managers from different levels of the health system to strengthen both the quality and the demand for routine health information (Aqil et al., 2009, McLaughlin and Kaluzny, 2004).

Similar to the PRISM framework, other scholars who consider HISs as socio-technical systems also acknowledge the importance of human relationships within systems development and systems building. Authors such as Harrison and Nutley (2010), who developed the Interactive Social Analysis (ISTA) framework, also value the impact of relationships, among health actors and relationships the people have with technology (Harrison and Nutley, 2010). Lastly, in line with the findings of the three case studies, Nutley and Reynolds (2013), Jeremie et. al (2014) and Braa et al. (2004), all recognise that health information can be demanded by stakeholders who are not health staff and understand the positive effect of sharing health information between community representatives and other health system actors (Nutley and Reynolds, 2013, Jeremie et al., 2014, Braa et al., 2004).

Within the case studies, there is one partnership which deserves special mention, which is the collaboration between UCT and the iALARM project. Not only did the iALARM project provide the financial resources to run workshops and iALARM TT meetings, but individual researchers from the university provided a new and fresh perspective which, disrupted existing patterns and expectations of who should interact with health information and why. By disrupting this pattern and actively providing health information to health system, and community actors, the iALARM RT was able to facilitate new relationships and open up new possibilities for collaborations between health actors who would otherwise work in silos. Findings in the iALARM chapter and other case studies highlight that this shift became possible through the use of several tactics, including the introduction of new sources of information, bringing different stakeholders together and providing new ways of supporting participants through sharing research findings and other academic evidence. This does not mean that UCT was the only organisation who could fill the demonstrated gap—as the support might have been provided by an NGO, the WCDoH, or another academic research institution—but it does highlight the need for a shift in thinking about how health information can be used in the health system, as it provides an opportunity to raise critical questions on who has the power to collect evidence and how this evidence should be used to strengthen the health system.

Albeit in a different context, Jorn Braa and Calle Hedberg (2002) also repeatedly mention the positive outcome of collaborations between universities and health services, and within their work repeatedly show how the HISP project is an example of a fruitful long-standing relationships between provincial health services, South African universities and international research institutions (Braa and Hedberg, 2002, Braa et al., 2004). Although the HISP initiative focused largely on the technical aspects of the HISs, they also used a bottom-up approach and were flexible in the design of their proposed interventions, which led to positive outcomes and solutions which were tailor-made for stakeholders on the ground. Furthermore, Braa and Hedberg also acknowledge through their understanding of health information as 'institutional glue' that health information is not collected in a vacuum, but is socially constructed through the interaction between researchers and participants, which impacts research outcomes and the design of health information interventions (Braa and Hedberg, 2002, Braa et al., 2004).

A dedicated third space

Besides the provision of health information and the role that actors and their relationships play in increasing access to and use of health information in Gugulethu, there is a third catalysing factor that proved to be vital for the improved use of health information: namely, the access to a 'dedicated space' where health actors can share health information. Although this catalysing factor is most evident in the iALARM case study, findings from the other case studies also show that there was a need for health workers and community actors to come together at a dedicated time to think about the different types of health information that are required for their campaigns or policy implementation programmes.

At the iALARM TT meetings, the iALARM RT was able to bring people together on a regular basis in 2017 and 2018. During these meetings, iALARM RT welcomed a group of 20-25 interested stakeholders at the container in Gugulethu, and, rather than decreasing in size, the group increased over time. As described within the iALARM chapter, the interest in joining the iALARM TT emphasises stakeholders' curiosity for using health information and the lack of access to this information, but also stresses the need to create a conducive environment where people can share their experience with others who are interested in a common problem. Although the TT meetings comprised only a few hours per month, some of the stakeholders had to plan carefully to attend, or convince their line managers to be part of this group that discussed issues in the health system that were interesting, but sometimes not directly related to their daily work. Nevertheless, the time spent away from daily stresses and investing energy in sharing information and establishing new relationships in the health system proved to be valuable for those involved, as it created new networks, relationships and follow-up campaigns. Creating the space to share health information led to unexpected encounters and surprising interactions between stakeholders who would otherwise not collaborate. Albeit less regularly, the health actors in the AHP also showed that it was beneficial to have a dedicated time and space to work on the AHP, to share information and learn from each other.

The positive result of spending time away from daily work pressures with like-minded people in a dedicated space as highlighted in the three case studies can be linked to the concept of the 'third space'. The idea of a 'third space' is a theoretical framework which is often employed in social and political science, and it outlines the three different kinds of spaces in which people participate. The first two spaces are the official or structured spaces that people are operating in within their daily lives. These spaces are created and reinforced by governance structures (Pennington, 2018). The third space is a participatory space, invited space, or open space, whereby people are free to express their culture, identity or beliefs (Haricharan, 2019, Pennington, 2018, Xiaowei Zhou and Pilcher, 2019).

One of the most influential philosophers who conceptualised the third space is Homi Bhabha. In his famous text, 'The Location of Culture', he suggests that there is need to rethink the meaning of culture by understanding the world in three different spaces (Bhabha, 2012). By identifying the three spaces through which people move, we are able to rethink colonial history and make changes in the post-colonial world. Within the theory of 'third spaces' as understood by the neo-colonial theorist, the first space is understood as the 'home space', where people practice their indigenous behaviours and enact the things that they have learned through familial ties. The second space, as seen within colonialism, is the place where colonial structures were imposed on people. These structures need to be learned and might be foreign, such as the British laws and schooling system that was compulsory in African countries under British rule. The second space is more formal and forces people to change their social interactions, both through interactions with the state and with each other. Compared the first and the second space, the third space is much more hybrid: it is a space where people choose to come together and bring the different elements of the first and second spaces, where multiculturalism is formed on a voluntary basis. It is the place where new ideas are created and real cultural change is achieved (Bhabha, 2012, Routledge, 1996).

The framework of the third space, which has been explored by Bhabha and others, is also frequently used in linguistics, pedagogy, psychology and sociology (Routledge, 1996, Morgan, 2010, Gutiérrez et al., 1999). In the educational environment, for instance, the third space can be the schoolyard, where kids come together to play, but also share knowledge and learn from each other. Here, the first space is the home environment where children learn from their parents and caregivers, the second space is the classroom, where children are educated in a controlled and organised environment. In summary, the first space can also be seen as the 'unofficial space'; the second as the 'official space'; and between these two spaces lies the 'third space' (Gutiérrez et al., 1999).

In the health systems literature, examples of third spaces can be 'invited spaces', or 'participatory invited spaces', which include health committees, social audits and public hearings, whereby citizens can interact with health actors, actively voice their concerns about health services and keep the health system accountable (Renedo and Marston, 2015, Gutiérrez et al., 1999). In these spaces, community members, who normally move on the margins or outside of the health system, are invited to discuss issues with nurses, doctors or health managers. Although these spaces are often promising, the agency and power that community members have within the third space is often still limited, as health systems actors can decide what information to share within the health committees or other third spaces, and who to include and exclude into the invited space (Haricharan, 2019). Therefore, community members can participate, but often only within the legal margins that are set by governance structures.

Within the MCSJ chapter, findings show that creating a third space, where community activists and health actors come together to talk about health care, is an effective way to instigate dialogues about service delivery issues or to convey health information to a larger audience. Within the dentistry example, the third space was created by setting a meeting with Gugulethu CHC, whereby both health care actors and MCSJ members were able to present their evidence, in a confined space, away from daily work stresses and pressures. Within the parameters of the health system, MCSJ members were able to craft a personal sense of space through different forms community participation, which, in the long term, led to the improvement of dentistry services. In this way, MCSJ was able to use the third space to keep the health system accountable (Madon and Krishna, 2017).

In the other example in the MCSJ chapter, the condom pamphlet and the interactions between community activists and the reverent at JL Zwane church, there was no opportunity to explore the impact that the third space could have on the dialogues about condom use and sexual and reproductive in Gugulethu. In hindsight, if there would have been a dedicated third space for church leaders and community members to sit together and unpack the different perspectives on the sensitive subject matter, both parties might have attempted to think of suitable solutions that would be favourable for MCSJ members and JL Zwane leaders. Through open conversations in the third space, religious beliefs and personal values could be unpacked and discussed, which might have sensitized participants to continue to collaborate and rewrite the pamphlet in a way that was acceptable for everyone involved. In reality, MCSJ members decided to not actively use the pamphlet but to create a documentary instead.

The observations exemplified above are similar to the findings of Renedo and Marston (2015), who ethnographically mapped the involvement of citizens in a programme to improve patient care within the NHS in the United Kingdom. Within their work, Renedo and Marston found that when participants were involved in an invited space with clinic managers and other health staff, they used three different tactics to make these spaces more effective: through ‘plotting’, ‘transient combination’, and through ‘interconnecting’ (Madon and Krishna, 2017). The concept of ‘interconnecting’ is especially relevant, as participants used several different invited spaces to strengthen their personal relationships, push their own agendas, and use connection with others to apply pressure for their own goals (Renedo and Marston, 2015). Using the concept of interconnectedness, Renodo and Watson found that citizens were able to learn from health actors, collect information that was important to their causes, and distribute this information in several different invited spaces. MCSJ members and iALARM TT members both used similar approaches, to either gain more access to health information, or to convince others for the need to improve health services. People within the TT, including participants from MCSJ, came to meetings to learn more about men and HIV, but also to network and lobby for their own campaigns and interests, which were not necessarily aligned with the objectives of the iALARM study. Through this interconnectedness and cross-pollination between different health actors, the iALARM TT meeting and other community-led spaces became broader in scope and therefore proved to be ‘spaces for change’. Therefore, in line with Renodo, Watson and others, third spaces, including invited spaces, can bring new ways of problem solving and health care improvement, including the more effective use of health information (Madon and Krishna, 2017, Renedo and Marston, 2015).

Using a third space or dedicated space -whether provided through the iALARM TT, a workshop or a Research Indaba - allows frontline health workers and community actors to connect with each other and other health systems actors in a new and alternative way. By understanding the importance of the third space, we are able to demonstrate that stakeholders are connected within the health system and need an opportunity to work together to improve both the access to and use of health information. Often, HIS literature acknowledges that there are different stakeholders in the health system who are interested in working with health information, but there are few active attempts to link them together to enhance information use and sharing. As stipulated above, the third space provides the opportunity to interconnect and strengthen both new and existing relationships between different stakeholders and can stimulate conversations about the use of different types of health information, including both routine and informal information.

7.4 Towards a more inclusive health information system

Summarising the findings throughout this thesis and linking the observations to the different bodies of health system and HIS literature, it is evident that both health information and HISs are vital components within the larger health system, and can support health workers with their decision-making, inform new programmes and assist with the development and implementation of policies (Lippeveld, 2017, Garrib et al., 2008). Therefore, based on the observations in the three case studies, I propose an alternative framework, the ‘Inclusive Health Information Framework’ (**Figure 7.1**) which aims to expand the narrow understanding of how we imagine health information and HISs in South Africa and other LMICs.

The Inclusive Health Information Framework expands on several other theories and ideas which have been developed in the past 15 years that revaluate the function of HISs and RHISs. This includes the Interactive Sociotechnical Analysis (ISTA) framework, the Performance of Routine Information System Management (PRISM) framework, MEASURE Evaluation Initiative as well as Braa’s theory that values health information as ‘institutional glue’. All these frameworks analyse HISs through a socio-technical lens (Harrison and Nutley, 2010, Foreit et al., 2006, Nutley and Reynolds, 2013, Aqil et al., 2009, Harrison et al., 2007, Braa et al., 2007).

The evidence from Braa and Hedberg (2002, 2004) on the HISP project in South Africa, the PRISM framework and the MEASURE Evaluation Initiative have been widely used in health information and health system research and were adopted in monitoring and evaluation projects which aim to improve the demand for and use of routinely collected health information in LMICs (Braa et al., 2007, Braa and Hedberg, 2002, Braa et al., 2004, Foreit et al., 2006). Although these ideas and frameworks have been useful in rethinking the design of HISs and the role of health information within South Africa and beyond, most of the theories only focus on the use of routine health information on country level or provincial level and do not acknowledge the role of health information on lower levels of the health system, or even the need for community stakeholders to get access to health information.

Secondly, even when the need for multiple systems on different levels of the health system is encouraged and the importance of communication between facilities and clinics is acknowledged, there is little empirical research which analyses how health information is used in practice and how much of this information is useful to address health systems issues. Furthermore, the above frameworks and concepts fail to acknowledge the importance of incorporating informal and semi-formal forms of health information within HISs. The Inclusive Health Information Framework builds on the concepts from the scholars above, but also allows us to critically rethink and restructure models that allow for an integrated HIS: one that actively includes different forms of health information that can be accessed, collected and used among stakeholders across all levels of the health system. This information includes routinely collected health information, but also considers semi-formal and informal collected health information as part of the HIS (see Box 1), as all information inform decision-making and daily practices in the health systems (Østmo, 2007, Mutemwa, 2005, Scott, 2016). As mentioned above, whether the health information is routinely or informally collected, the information should be easily accessible and digestible to be useful for stakeholders in the health system.

The Inclusive Health Information Framework (Figure 7.1) also actively includes the different health systems stakeholders in Box 2. Initially, the design of HISs and interventions focused on providing more routinely collected information to inform national-level policies and assist in the daily practices and decision-making for higher-level managers in the health system (Lippeveld, 2017, AbouZahr and Boerma, 2005). In recent years, there has been a growing critique that health information is collected on community or facility level of the health system and reported to higher levels of the health system, but there little information-sharing back to the community (Vest and Gamm, 2010, Jeremie et al., 2014). This is problematic, as findings in my case studies show that health actors on all levels of the health system have an interest in working with health information, but often have no set entry point into the HIS. Therefore, it is important to develop a HIS that actively provides access to information for all people who have an interest in working with health information. This includes access to routine health information, which should be accompanied by relevant training allowing health actors to understand the information and encouraging them to meaningfully use this information when needed. Besides the role of individual health actors, Box 2 also describes the relationships health actors have with each other, as a strong relationship between individual health actors improves the access to and use of health information.

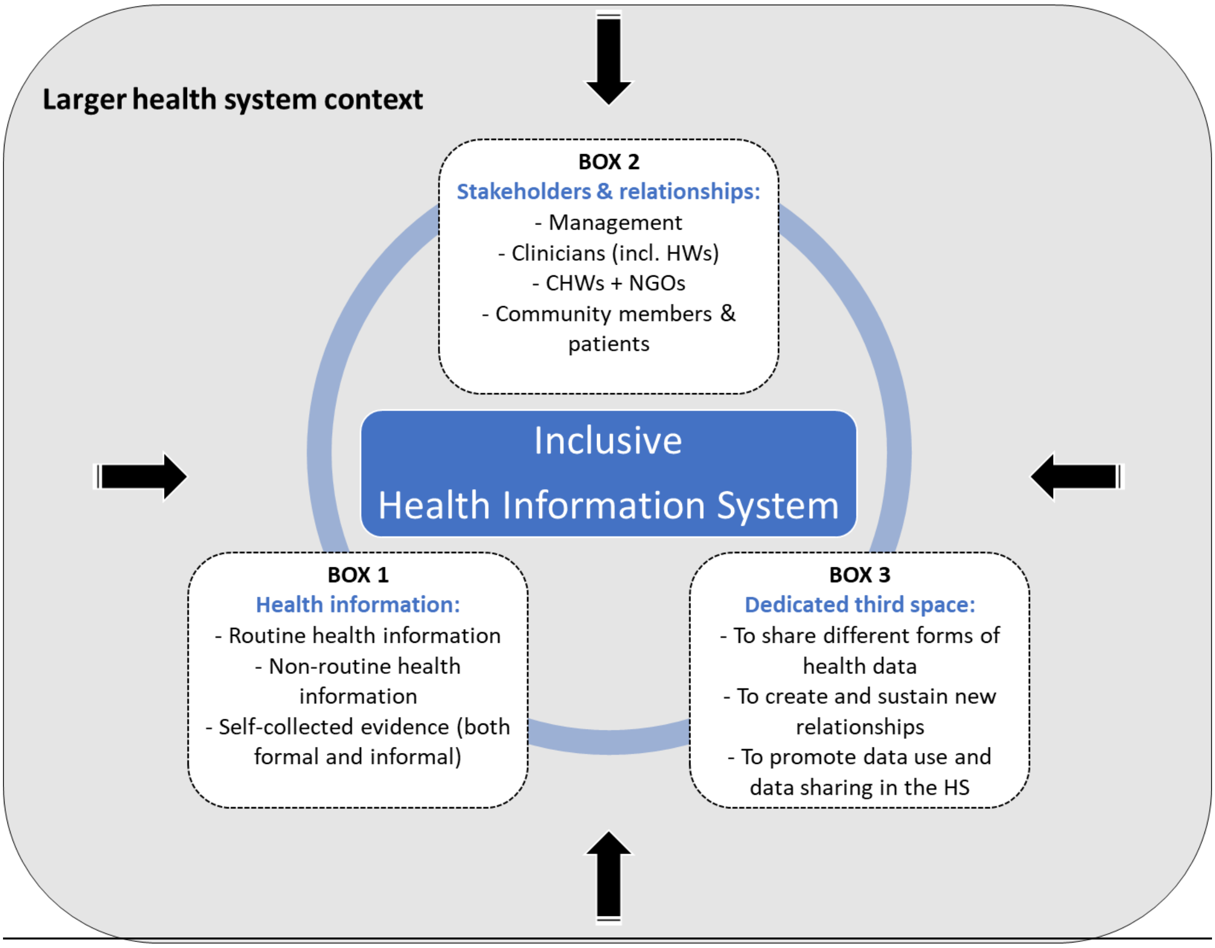

Figure 7.1: Framework of Inclusive Health Information System

Box 3 highlights the importance of a dedicated third space, as introduced earlier in this chapter, whereby health actors can share information with each other, and are given the opportunity to create new relationships and collaborations with people they would otherwise not necessarily work with. In line with Bhahba, Renedo and Martson and others, this space should ideally be created outside health actors' homes and professional environments, and be participatory in nature, so that active data use and data sharing can be encouraged to identify and resolve issues in the health system (Bhabha, 2012, Renedo and Marston, 2015).

In line with the WHO Health Systems Framework, the Inclusive Health Information Framework as proposed in Figure 7.1 should be linked to the larger health system and socio-economic context, as the access, use and exchange of health information is drastically impacted by contextual factors and the localised realities in which HISs are developed(World Health Organisation, 2012). As stressed by Akhlaq et al. (2015), the fragmented HIS and the lack of health information exchange in LMICs is often caused by political, environmental and cultural barriers, as well as financial constraints (Akhlaq et al., 2015). These barriers can also result in a lack of training, organisational mismanagement and a lack of supervision for those collecting and using health information (Akhlaq et al., 2015, Aqil et al., 2009).

These issues strongly affect Boxes 1 and 2, and can hinder the production and use of health information while also impacting the development of technical systems, which are a vital component of a HISs.

Understanding the three boxes that form the Inclusive Health Information Framework and acknowledging impact of the larger health system context encourages us to a) evaluate our previous understanding of HISs and health information exchange, and b) design more inclusive systems that can help to tackle a diverse range of issues in the health system and inform the daily practices of a diverse group of actors. During the design phase of new HISs, the Inclusive Health Information Framework can be used to ask critical questions such as; for who is this information system designed? Who else can benefit from this information system and does the system allow a variety of information to be stored? The framework also encourages researchers and interventionist to constantly keep the context in mind and investigate the circumstances under which the HIS are being developed, which is especially important when developing information systems within LMICs. Using the Inclusive Health Information Framework for monitoring and evaluating purposes allows researchers to assess why an existing HIS is successful or not successful and where it possibly can be improved. Questions which can be asked during this process include; for whom was this HIS designed and who has access to the information in real-life? Who else might have been interested in using the HIS and are there ways to make the system more inclusive, for instance, through providing a wider array of information? How is the information available in the HIS used for decision-making in the health system? How does the context and external circumstances impact how the HIS is (under)used? Lastly, the Inclusive Health Information Framework can be used for students and researchers to develop innovative research ideas, as the framework and the case studies in this study show that there are many questions about the access to, use and exchange of health information that remain unanswered.

7.5 Implications for HISs research and health systems research

Illustrated by the case studies in this thesis, there is a need to conduct more qualitative research studies that focus on the use of health information among actors on all levels of the health system, thereby foregrounding community members and community stakeholders. In the last 20 years, there has been a growing recognition that the development of well-functioning health information systems is an important part of strengthening health systems (Gilson, 2012). Within disease-specific programmes especially, there has been an international push and allocated donor funding to strengthen the production and distribution of health information. Despite these great initiatives, which have sparked numerous new research projects and interventions, there is still much we do not know about HISs and the use of health information for decision-making. One of the reasons why our understanding about the complexities of health information is limited is the fact that most research focuses on strengthening systems by developing large-scale interventions which are later measured in monitoring and evaluation research projects. Although these developments definitely strengthen HISs, there much less research conducted on the use of health information and the needs for improvement in the HIS on lower levels of the health system. There are a few researchers who focus on the use of health information among facility managers and district managers in Sub-Saharan Africa, such as Scott, Williamson and Kaasboll, Ostmo and Mutemwa (Scott, 2016, Williamson and Kaasbøll, 2009, Østmo, 2007, Mutemwa, 2005). Most of this research is conducted on a case study basis, which provides new insights and recommendations, but needs to be conducted frequently to effectively impact new HIS interventions and other health programmes.

Employing ethnographic methods is useful to better understand the intricacies of health information use, to comprehend the challenges that emerge when trying to access information, and to get an accurate overview of what information is missing. Ethnographic methods such as participant observation and focus groups allow the researcher to recognise the challenges in the health information system which might not be revealed when only interviewing participants (Ulin et al., 2005). Ethnography also enables one to explore how the lack of information affects the decision-making process and to design context-specific interventions rather than opt for a one-size-fits-all solution. Visual qualitative methods would also be well-suited for this area research, including journey-mapping or photovoice. Furthermore, conducting more empirical qualitative research allows researchers to better analyse changes in the health system and emphasise the larger contextual factors that shape both the role of health information and the relationship that actors have with information and with others in the health system.

Secondly, new interventions that aim to use health information to improve health services from a system perspective start to move away from vertical disease-specific programmes. This shift means that there is need to restructure HISs, but also rethink some key questions, such as: who should collect information, who is going to use it, and for what purposes? Within current public health research, there is an increased need to focus on the multiple burden of disease and co-morbidities, which require new ways of collecting and using health information (Mayosi et al., 2012). For example, with ART being widely available, patients with HIV live longer and stay healthier, but still may develop opportunistic infections and are at greater risk for prostate or cervical cancer (Narayan et al., 2014). It is therefore important to inform patients of these risks, to invite them for screening tests and to effectively link and track them through the cascade of care. Hereby, it is crucial for both provider and patient to have access to HIV information as well as cancer-related information. The same principle applies to non-communicable chronic diseases, which are increasing significantly in South Africa, such as diabetes, hypertension and high blood pressure (Kemp et al., 2018). To accommodate these changes, we need to develop HISs that can successfully integrate and disseminate this information among health actors on all levels of health system, but can also accurately inform community members and patients about preventative health programmes for chronic illnesses.

Thirdly, when developing new health information interventions to accommodate the rapidly changing health system, it is crucial to also emphasise the role of health actors and their relationships and how this impacts the access to and use of health information. Although relationships are often mentioned in HIS literature, there is very little in-depth research that illuminates the important role that individuals play in this process, or how relationships and collaborations can impact information use and sharing of information (Colvin et al., 2018). Findings in all three case studies highlight how positive relationships between health actors improve access to and use of health information. The impact of these relationships and possible collaborations are often underestimated, but are an integral component of the health information system and larger health system.

7.6 Strengths and limitations of the research

This thesis explores the complex role of health information within Gugulethu and shows how different health actors in the health system seek to access and interact with different forms of health information. As with any research project, this doctoral thesis and its study design had several strengths and limitations.

One of the main strengths of this research is the long-term engagement of the researcher with the research topic and the stakeholders who participated in the PhD project and larger iALARM study. I have been a student and researcher in the iALARM project since 2016 and was immediately able to visit Gugulethu, participate in research activities and interact with iALARM researchers and members of the iALARM TT. I was actively involved in the recruitment process of many of the TT members and would regularly visit clinics and NGOs to speak about the project and our research initiatives. This gave me the opportunity to establish long-lasting relationships with many of my informants with whom I am still regularly in contact with. I travelled to Gugulethu regularly during the three years of my PhD, which provided me a deep understanding of the community, its challenges and the daily lives of the people with whom I created relationships.

Furthermore, due to my own flexibility as well as employing a flexible research design, I was able to connect with informants who operated at all levels of the health system. One day I would visit NGOs and community meetings, while the next day I would be part of a workshop for facility managers or present iALARM research findings to the WDoH. These recurring interactions with informants gave me insights in their daily work and life challenges, and I gained a deep sense of respect for everyone who I met and who tried to improve health services in Gugulethu. This includes community activists, researchers, health workers, patients, CHWs and NGO representatives with whom I interacted along the way.

There are also several limitations to this research. I am aware of the fact that as a researcher within the iALARM project, I might have been perceived differently during my fieldwork, as informants may have had preconceived notions about my role within the iALARM team. Being a representative from a university who works in an international research project may have created several expectations which could not always be met. Although I tried to always be open about my role within the project and reason for visiting clinics or attending meetings, my position in the iALARM team might have resulted in an hierarchical difference between some of my participants and myself.

Additionally, this research project is rooted in purely qualitative methods and uses ethnographic data collection tools, which means that the outcomes and recommendation from this thesis are context specific. Nevertheless, the lessons learned from this research might be transferable to other similar socio-economic contexts in Sub-Saharan Africa and beyond, as some of the examples might be comparable despite taking place in a different setting. Therefore, the outcomes of this research might spark interest to conduct more qualitative studies in other countries that struggle with the effects of fragile and fragmented health systems.

7.7 Concluding remarks

Since concluding my fieldwork for this PhD research, the iALARM project has grown substantially and I am grateful to still be involved in the study as a research coordinator, whereby I regularly reconnect with many of my key informants, participants and colleagues. The iALARM TT meetings are still running on a bimonthly basis, and once a year, the iALARM RT and MCSJ jointly organise a Research Indaba whereby HIV researchers who conduct studies in Gugulethu share research findings with community members and health systems actors. This year's Indaba was held on Mandela Day, an unofficial South African holiday on Mandela's birthday (18 July) where people remember and celebrate his legacy. Using Mandela's quote: *'Health cannot be a question of income; it is a fundamental human right',* the iALARM RT invited 40 different NGOs, clinic staff and other health system stakeholders to discuss current health issues in the area, share the latest research findings and converse about possible solutions to address long-standing health issues in the area. We also gave the opportunity to NGOs to distribute their own pamphlets, and local clinics to offer their services, which include HIV testing, blood pressure, diabetes tests and pap smears.

In total, we approached 12 national and international researchers to give short presentations about their work, which included studies on HIV interventions and implementation research, empirical research and visual research. Among the topics presented were: young HIV-positive men and their experience of circumcision schools; HIV and gang violence; and people's experiences of participating in HIV research in Gugulethu. The day was divided into different plenary and parallel sessions, alternating with musical entertainment. We expected an audience of about 300 community members, but despite pouring rain and a temperature of only 12 degrees, we stopped counting attendees when we reached 500. I was assigned one of the parallel sessions and was about to start my presentation which summarised the findings of the MCJS case study (Chapter Five) and overall arguments of my thesis when I realised that I did not need a neatly-developed PowerPoint presentation to show the audience that this Research Indaba showcased the findings that I explored throughout my thesis. The sessions emphasized what I attempted to document for the last three years: that especially within a fragmented and fragile health system, there is a need for better information-sharing among people from both within and outside the health system, and that there is a need to collect and use a variety of different types of information which can be produced as academic evidence, routinely collected information, or informal forms of information, as especially community members have very little access to reliable health information. The informal third space that the iALARM RT created on that soggy day in July in the J.L. Zwane Church sparked a lively discussion about HIV and other health challenges that people in Gugulethu face, including a lack of basic health services and limited information about the impact of non-communicable diseases. During the interactive discussion session at the end of the day, participants asked questions about a possible cure for HIV, spoke about strategies to get women involved when trying to link young men to HIV care, and proposed possible projects which could be of interest for academic researchers. For me, the Research Indaba confirmed that although there are many different initiatives which aim to strengthen the health information system and the larger health system, South Africa faces significant challenges. To overcome these challenges, innovative and integrated approaches are needed, which can only succeed if we ‘Masisebezani sane’, if we work together.

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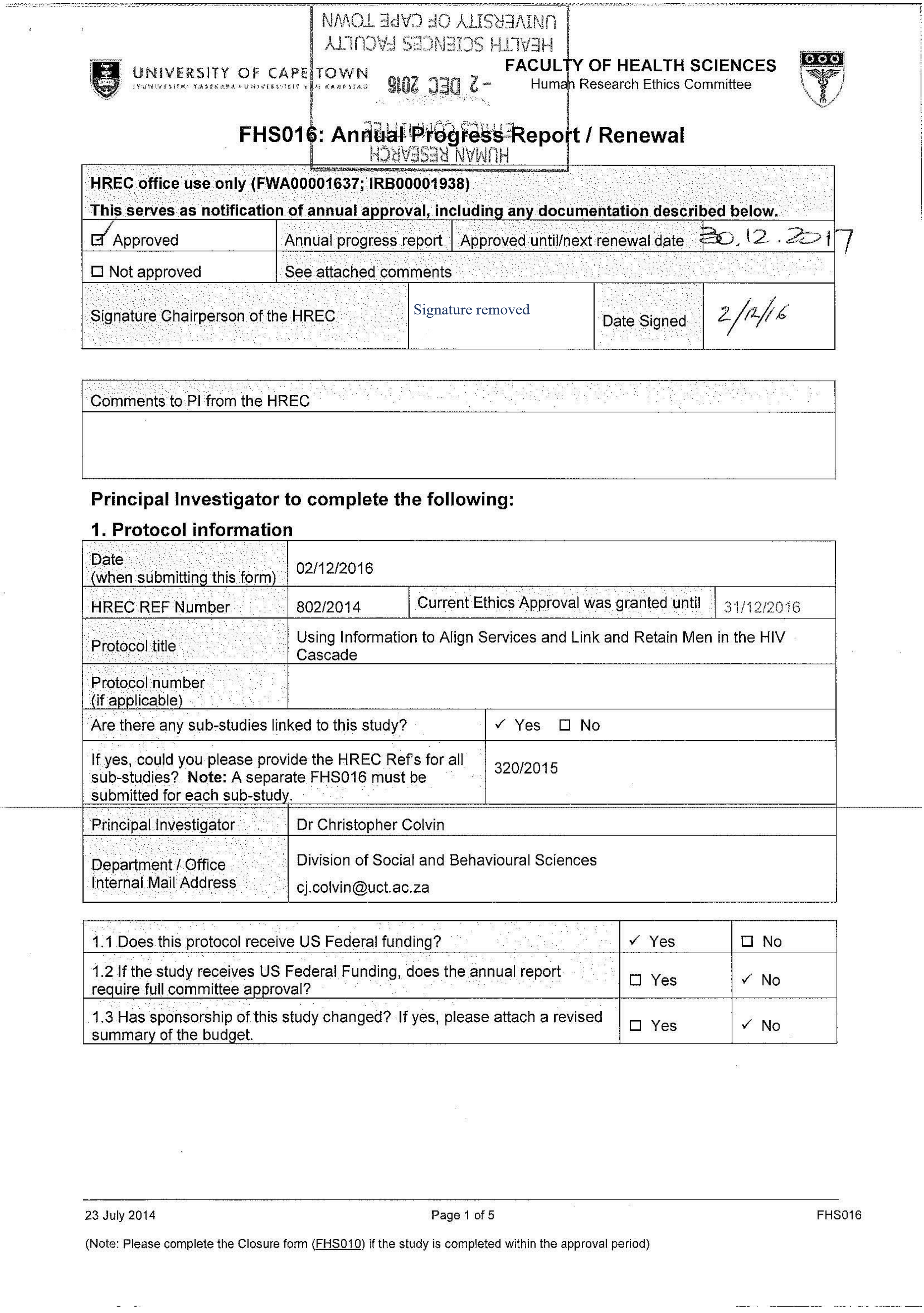
Appendices

Appendix 3.1: iALARM HREC Approval Letter (802/2014)



UNIVERSITY OF CAPE TOWN
HEALTH SCIENCES FACULTY
- 2 DEC 2016
HUMAN RESEARCH ETHICS COMMITTEE

UNIVERSITY OF CAPE TOWN
IYUNIVESITHI YASEKAPA • UNIVERSITEIT VAN KAAPSTAD

FACULTY OF HEALTH SCIENCES
Human Research Ethics Committee

FHS016: Annual Progress Report / Renewal

HREC office use only (FWA00001637; IRB00001938)

This serves as notification of annual approval, including any documentation described below.

☑ Approved	Annual progress report	Approved until/next renewal date	30.12.2017
☐ Not approved	See attached comments		

Signature Chairperson of the HREC	Signature removed	Date Signed	2/12/16

Comments to PI from the HREC

Principal Investigator to complete the following:

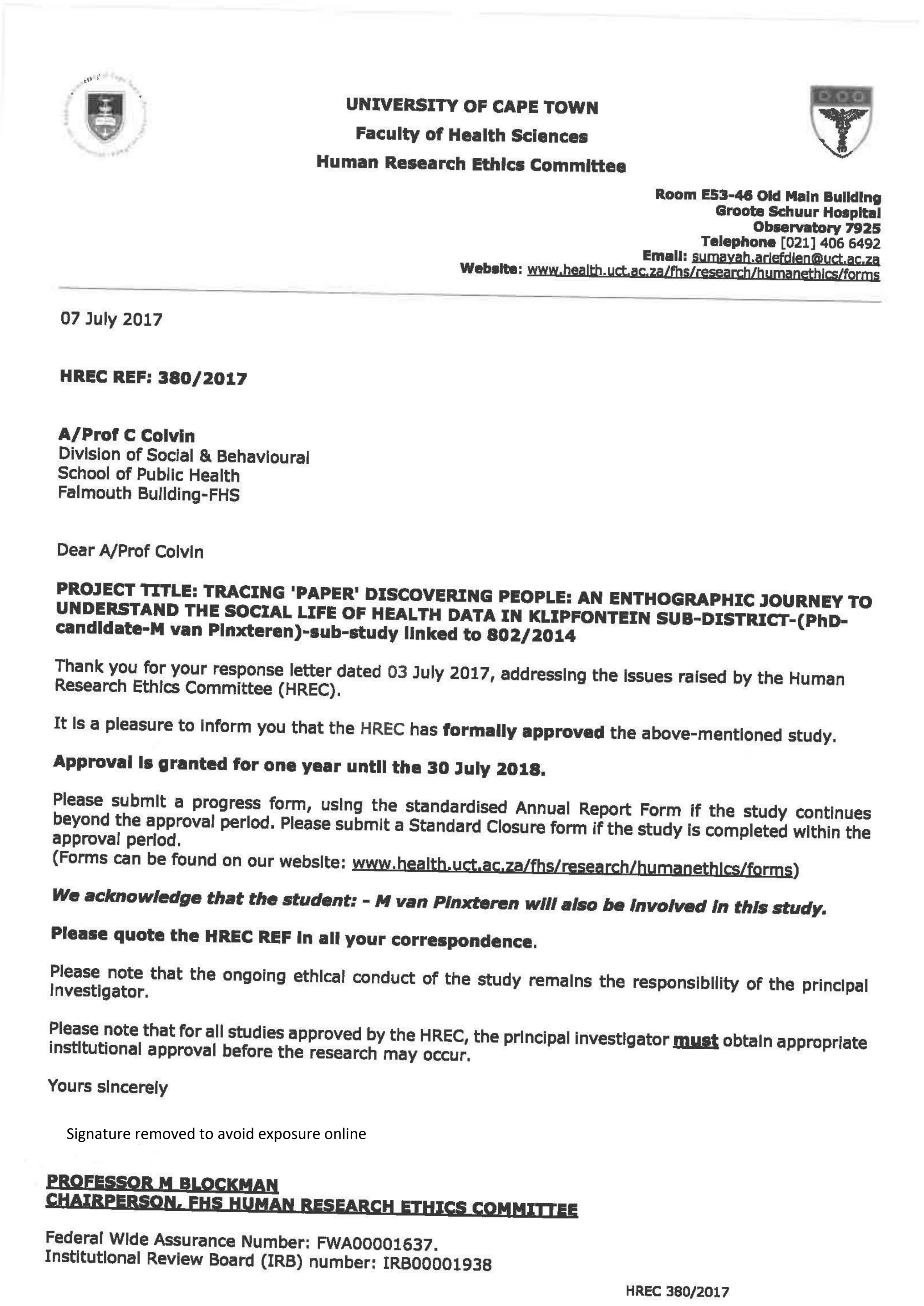
1. Protocol information

Date (when submitting this form)	02/12/2016		
HREC REF Number	802/2014	Current Ethics Approval was granted until	31/12/2016
Protocol title	Using Information to Align Services and Link and Retain Men in the HIV Cascade		
Protocol number (if applicable)			
Are there any sub-studies linked to this study?	✓ Yes ☐ No		
If yes, could you please provide the HREC Ref's for all sub-studies? **Note:** A separate FHS016 must be submitted for each sub-study.	320/2015		
Principal Investigator	Dr Christopher Colvin		
Department / Office Internal Mail Address	Division of Social and Behavioural Sciences cj.colvin@uct.ac.za		

1.1 Does this protocol receive US Federal funding?	✓ Yes	☐ No
1.2 If the study receives US Federal Funding, does the annual report require full committee approval?	☐ Yes	✓ No
1.3 Has sponsorship of this study changed? If yes, please attach a revised summary of the budget.	☐ Yes	✓ No

(Note: Please complete the Closure form (FHS010) if the study is completed within the approval period)

Appendix 3.2: Thesis HREC Approval Letter (380/2017)



UNIVERSITY OF CAPE TOWN
Faculty of Health Sciences
Human Research Ethics Committee

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Email: sumayah.ariefdien@uct.ac.za
Website: www.health.uct.ac.za/fhs/research/humanethics/forms

07 July 2017

HREC REF: 380/2017

A/Prof C Colvin
Division of Social & Behavioural
School of Public Health
Falmouth Building-FHS

Dear A/Prof Colvin

PROJECT TITLE: TRACING 'PAPER' DISCOVERING PEOPLE: AN ENTHOGRAPHIC JOURNEY TO UNDERSTAND THE SOCIAL LIFE OF HEALTH DATA IN KLIPFONTEIN SUB-DISTRICT-(PhD-candidate-M van Pinxteren)-sub-study linked to 802/2014

Thank you for your response letter dated 03 July 2017, addressing the issues raised by the Human Research Ethics Committee (HREC).

It is a pleasure to inform you that the HREC has **formally approved** the above-mentioned study.

Approval is granted for one year until the 30 July 2018.

Please submit a progress form, using the standardised Annual Report Form if the study continues beyond the approval period. Please submit a Standard Closure form if the study is completed within the approval period.
(Forms can be found on our website: www.health.uct.ac.za/fhs/research/humanethics/forms)

We acknowledge that the student: - M van Pinxteren will also be involved in this study.

Please quote the HREC REF in all your correspondence.

Please note that the ongoing ethical conduct of the study remains the responsibility of the principal investigator.

Please note that for all studies approved by the HREC, the principal investigator **must** obtain appropriate institutional approval before the research may occur.

Yours sincerely

Signature removed to avoid exposure online

PROFESSOR M BLOCKMAN
CHAIRPERSON, FHS HUMAN RESEARCH ETHICS COMMITTEE

Federal Wide Assurance Number: FWA00001637.
Institutional Review Board (IRB) number: IRB00001938

HREC 380/2017

Appendix 4.1: iALARM HIV Report #1 – May 2017

The iALARM HIV Report

Issue No. 1 (May 2017)

What is iALARM?

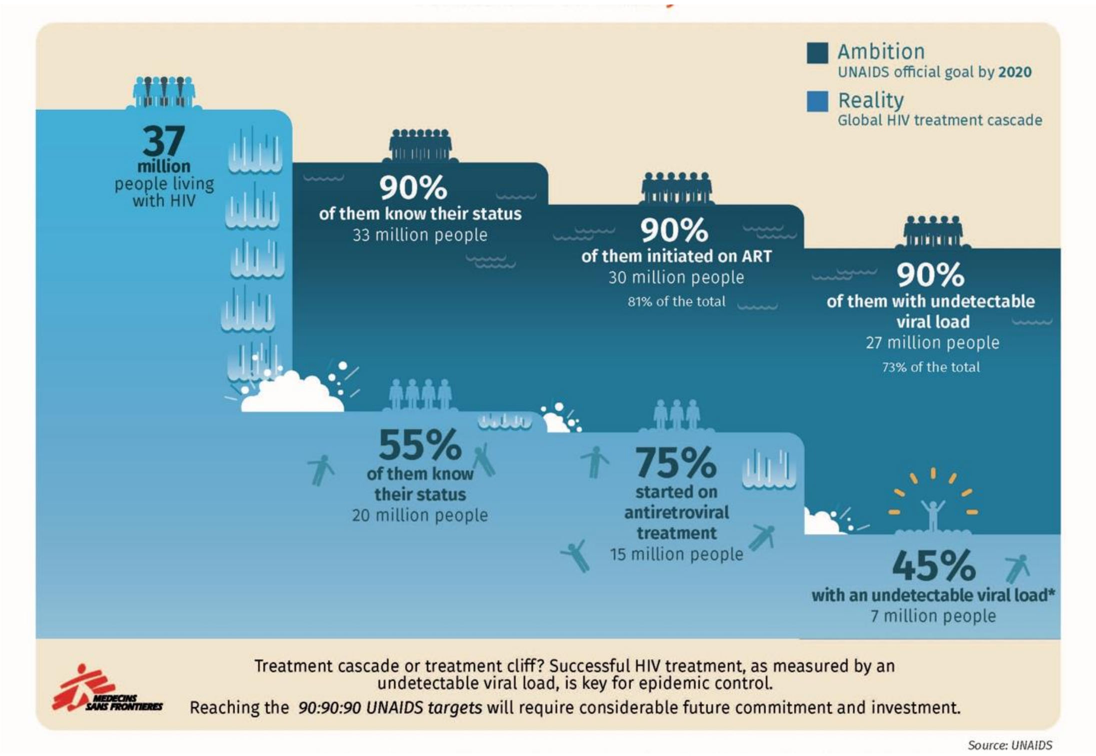
iALARM stands for '*Using Information to Align Services and Link and Retain Men in the HIV Cascade*'. It is a research project based in Gugulethu and surrounding communities that collects and analyses routine health information about HIV prevention, treatment and care. iALARM then brings this information in an easy to understand format to the community and health system members of the 'iALARM Task Team' to discuss what this information means and how community and healthcare providers can respond.

Welcome to the First 'iALARM HIV Report'

This is the first issue of the *iALARM HIV Report*. Each month we will distribute a new issue that provides a window into how well health system and community HIV services are supporting men in Gugulethu and surrounding communities. Each issue will have a broad theme under which we will combine routine health information, academic research and other forms of information about the HIV cascade.

This Issue's Theme: An Overview of the HIV Cascade in Klipfontein

One of iALARM's main goals is to better understand and improve the HIV 'cascade' of prevention, treatment and care for men in Gugulethu. A 'cascade' is simply a diagram that starts with all the people we are interested in helping and then follows them along the various steps of testing, starting treatment and achieving viral suppression.



Source: UNAIDS

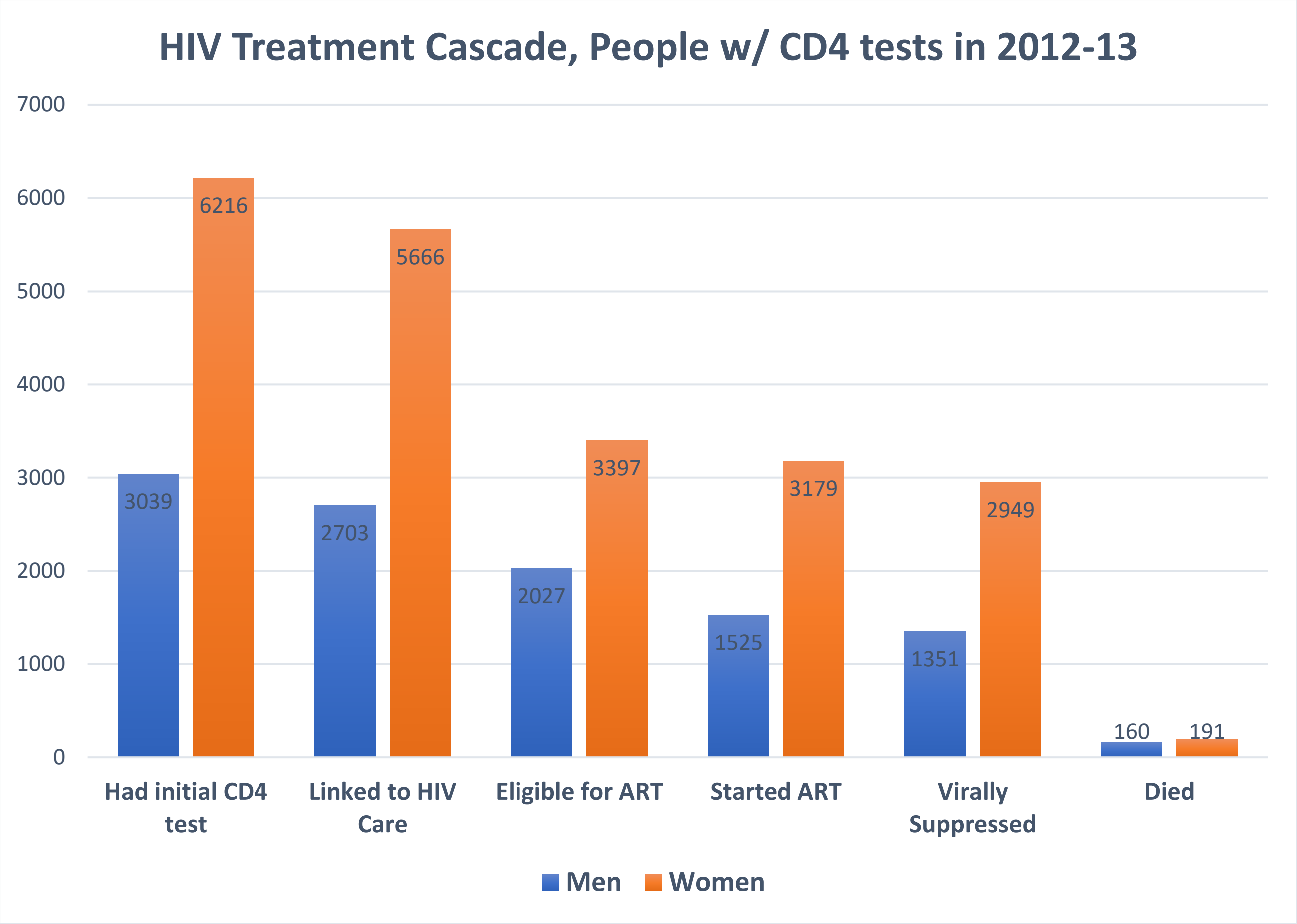
In a cascade, we want to see how many people—and which people—drop out at each step, and ultimately, how many people—and which people—manage to be successfully supported on long-term HIV treatment.

How well are men and women remaining engaged in HIV care in Klipfontein?

To start off our discussions of the HIV cascade, we first identified all of the people who had a first (post-diagnosis) CD4 test done between January 2012 and December 2013. We then collected all the available health information on these people through the middle of 2016 to see how many:

- linked to HIV care,
- were initially eligible for ART,
- started ART after they became eligible,
- were able to suppress the virus, and
- died at some point after this first CD4 test.

The overall picture of the cascade is below, broken down by men and women:



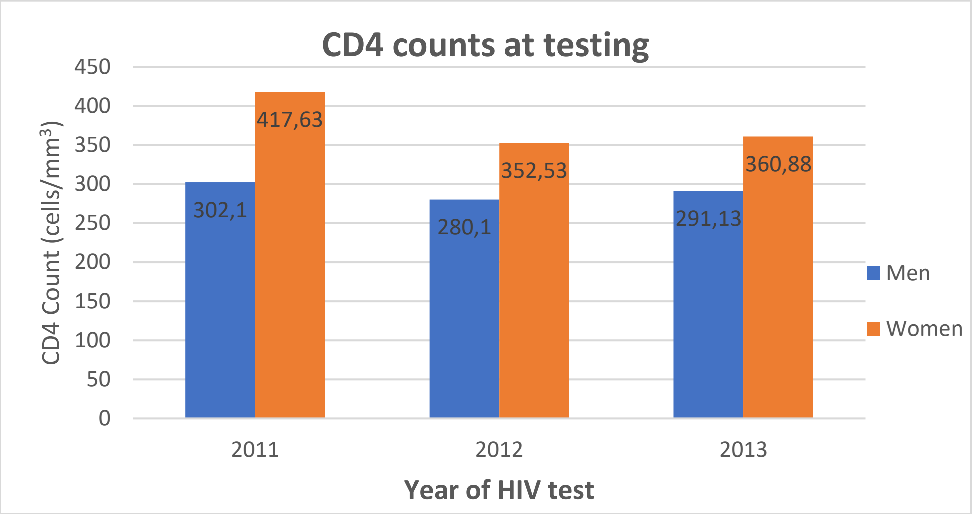
<u>Questions to consider</u>:

- Why are so many more men initially eligible for ART (why are they sicker when they enter care)?
- Why do fewer of the men who are eligible for ART make it onto treatment? (94% of eligible women start ART while only 75% of men do).
- What are the reasons that men are dying more frequently than women? (5.3% vs 3.1%)
- How do we understand the greater number of women who get a CD4 test? What is the difference in prevalence for men and women in Klipfontein?
- How many people in a two-year period should be testing positive?
- Do any of these figures surprise you? Do any seem inaccurate or different from your own experience?
- How do you think these figures compare to other areas in Cape Town? In South Africa?
- Do you think the numbers are different for people who have more recently entered the cascade?

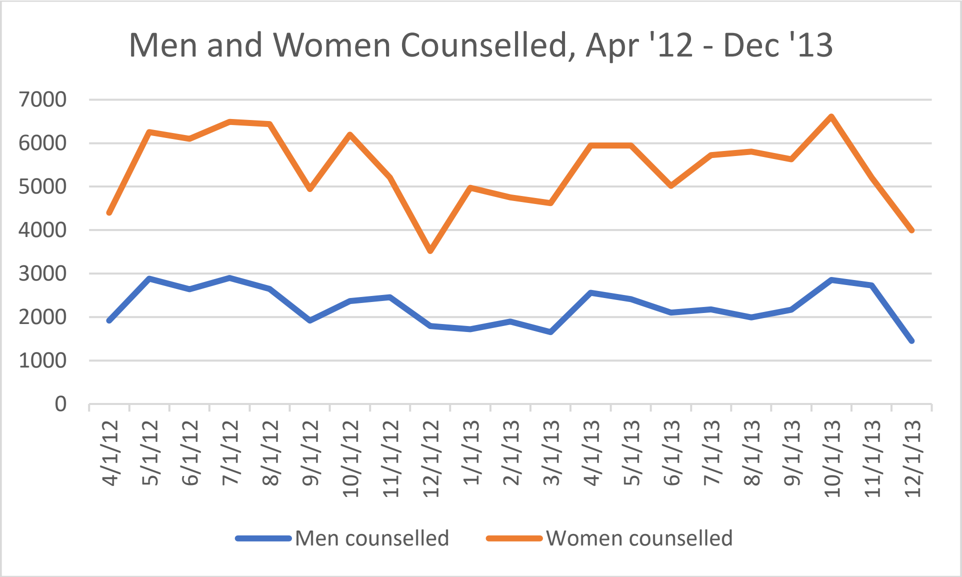
What about HIV Testing?

When we started collecting the information for the cascade above, we realized that it was going to be very difficult to collect good information on HIV testing patterns in Klipfontein. This partly because the City and Provincial facilities had not all switched to electronic registers during our time period, and partly because HIV testing is available in many different places such as NGOs, private GPs, community events, etc. Information on testing outside of clinics that have electronic registers is very hard to find.

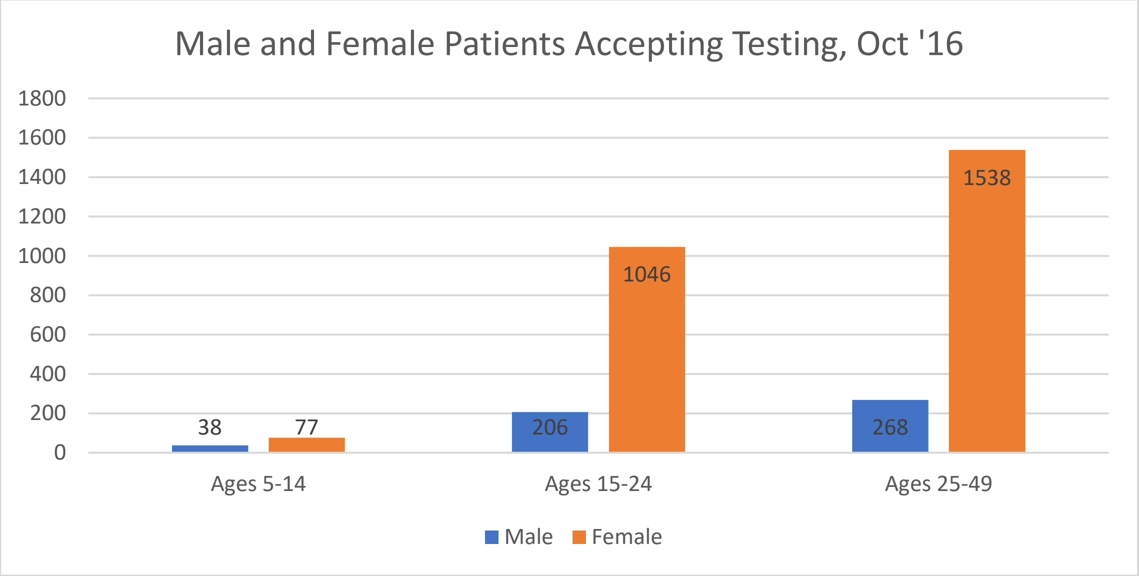
We did do a small study of the paper HIV testing registers. Many of these registers had CD4 test results as well and we found a similar pattern as above in terms of the baseline CD4 counts for men and women at diagnosis.



We do also have some HIV counselling and testing information from the City's sub-district's monthly reports. For example, we have the numbers of men and women counselled over a 20-month period in Klipfontein:



We also have some more recent testing information from October 2016. This shows the numbers of male and female patients accepting an HIV test:



Questions to consider:

- How big or meaningful is the difference between men and women's baseline CD4s on page 3? How much earlier would men need to test to match women's CD4s?
- What other information is available on HIV testing and what are we missing? What would be useful?
- Are men's and women's testing patterns different over the December holidays (page 3)?
- The gap between men's and women's testing rates seems to be much wider in 2016 compared to 2013. Does that fit your experience? What might be reasons for this?
- What are the key gaps or key questions in terms of HIV testing patterns?

Notes:

AN OVERVIEW OF iALARM: LINKING AND RETAINING MEN IN THE HIV CASCADE

What is iALARM?

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Why focus on men and HIV?

In South Africa, women continue to suffer higher rates of HIV infection than men and take on a greater burden of care for those living with the virus. These differences are driven largely by gender inequities that shape their sexual relationships, their risk of violence and sexual assault, and their exposure to stigma and other barriers to disclosure. Public health researchers are beginning to recognize, however, that when it comes to access to and success on antiretroviral therapy (ART), women are initiating and remaining retained and adherent in care at significantly higher rates than men. In fact, men do worse on nearly every indicator along the ART cascade of testing, treatment and care. Helping health system and community-based services better respond to the needs of men living with HIV is therefore an important public health goal, not only for the health of men themselves but also for the health of their partners, families and communities.

What research have we been doing?

We have conducted a number of qualitative studies exploring: experiences of men testing for HIV in the Klipfontein sub-district, men's ideas on how to improve HIV testing services, healthcare workers' understandings of the HIV care cascade and how to improve it to better retain men in HIV care, and the challenges and possibilities for information harmonization and cooperative information sharing in the sub-district.

The iALARM Task Team and the iALARM HIV Report

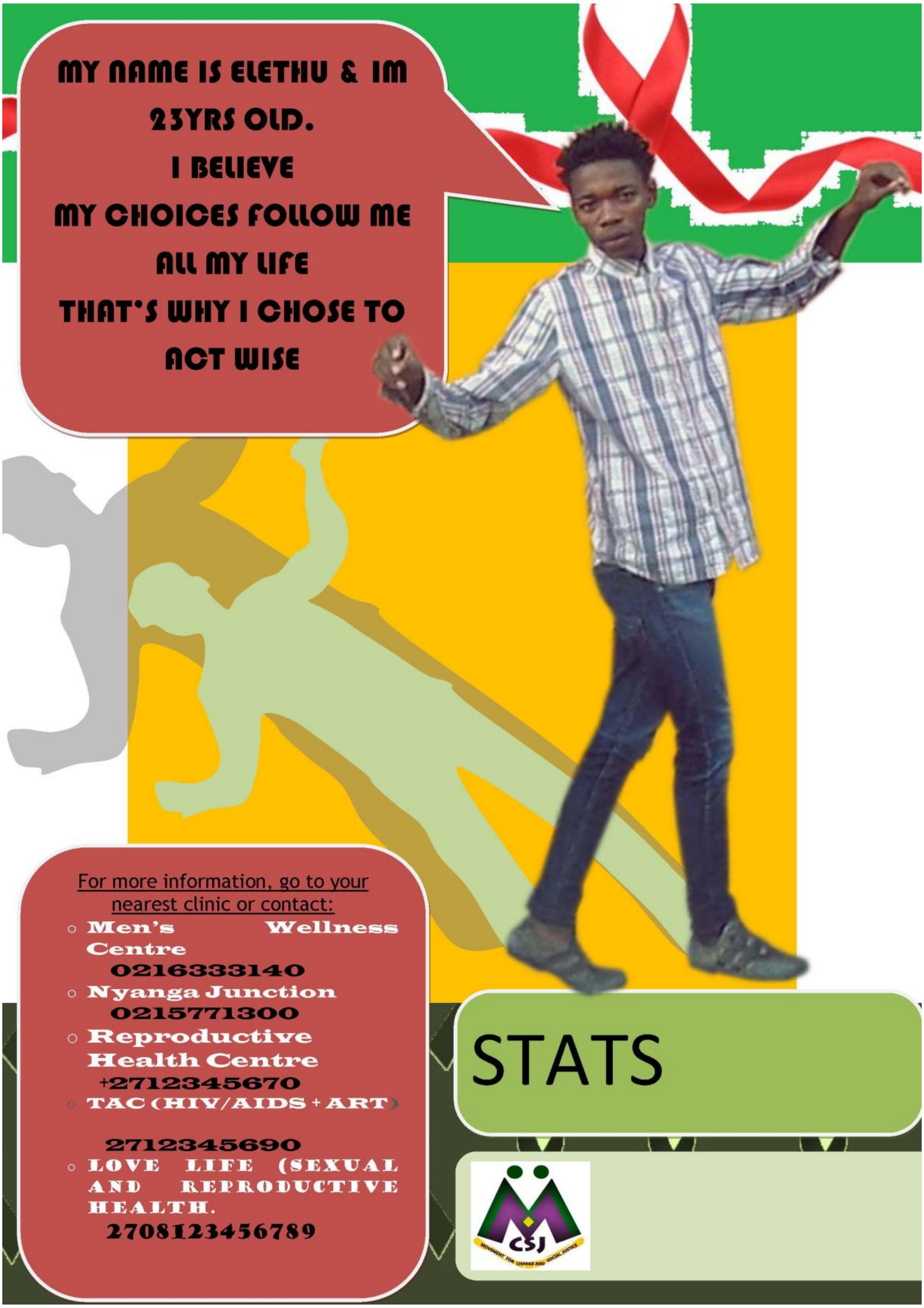
In addition to this qualitative research, iALARM also hosts a monthly 'iALARM Task Team (TT)', a forum that enables health system and community members to come together and share ideas and solve problems collectively. The Task Team will be comprised of representatives from all levels and sectors of the health system including, information managers, facility managers, healthcare workers, community health workers, community advocates and iALARM staff. At each meeting, iALARM will provide a new issue of the iALARM HVi Report. This report will be developed from various sources of information, including routine health information reports from the sub-structure and the sub-district, a cohort report of HIV-positive patients across city and province facilities, and information from the various iALARM research projects. The Report is intended to spark collective engagement on how to improve the alignment of services and strengthen the community health system for men with HIV.

We hope that by sharing available information among a wide range of actors, in a form that is relevant to the day-to-day work of health system stakeholders, we can create a community of practice working together to improve the lives of men with HIV in Klipfontein.

Who Can I Contact for More Information?

The intervention design is still in progress and we would love to hear your thoughts and ideas. If you have any comments on the design of the intervention, or would like to know more, please do not hesitate to contact Myrna van Pinxteren at myrna.vanpinxteren@gmail.com or 076 287 7919; or Similo Mzolo at: similo.mzolo@uct.ac.za.

Appendix 4.2: iALARM Male Poster – November 2017



MY NAME IS ELETHU & IM
23YRS OLD.
I BELIEVE
MY CHOICES FOLLOW ME
ALL MY LIFE
THAT'S WHY I CHOSE TO
ACT WISE

For more information, go to your nearest clinic or contact:

- Men's Wellness Centre
  0216333140
- Nyanga Junction
  0215771300
- Reproductive Health Centre
  +2712345670
- TAC (HIV/AIDS + ART)
  2712345690
- LOVE LIFE (SEXUAL AND REPRODUCTIVE HEALTH.
  2708123456789

STATS

Appendix 4.3: iALARM HIV Report #2 – June 2017

The iALARM HIV Report

Issue No. 2 (June 2017)

iALARM
SUPPORTING MEN
IN HIV PREVENTION,
TREATMENT AND CARE

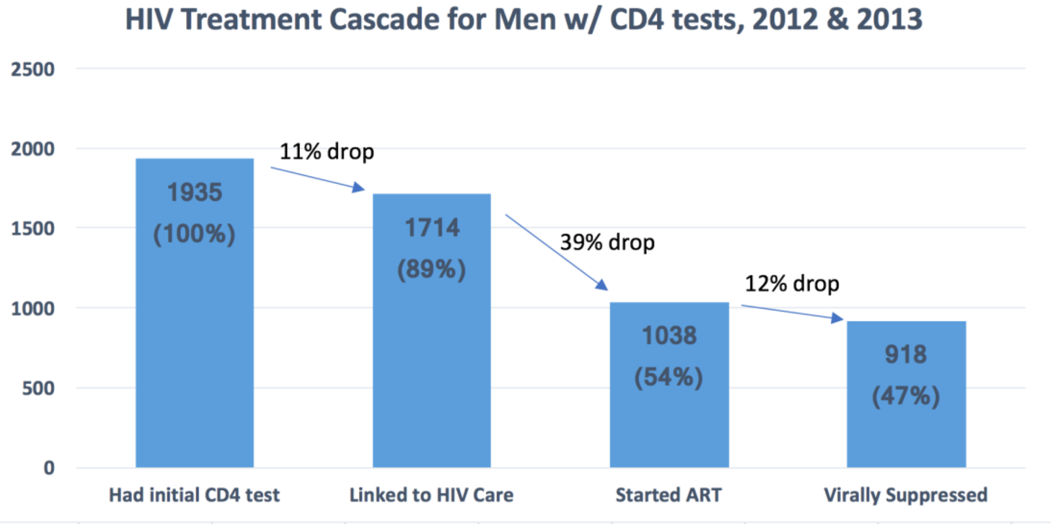
What is iALARM?

iALARM is a project that raises the alarm about men's difficulties in accessing HIV prevention, treatment and care. Men are less likely to get HIV testing, are sicker when they do seek care, and are more likely to drop out of ART. iALARM stands for '*Using Information to Align Services and Link and Retain Men in the HIV Cascade*'. It is a research project based in Gugulethu and surrounding communities that analyses routine health information about HIV prevention, treatment and care and brings this information to community and health system members of the 'iALARM Task Team' to discuss what it means and how to respond.

This Issue's Theme: HIV Testing in the Gugulethu Area

One of iALARM's goals is to better understand and improve the HIV 'cascade' of prevention, treatment and care for men in Gugulethu. In the HIV cascade, we typically use three kinds of numbers to describe how many people are 'moving through' the cascade, and how many are 'falling out'. In the cascade diagram below, which shows men entering into HIV care in Gugulethu and Nyanga in 2012 and 2013, we can either use:

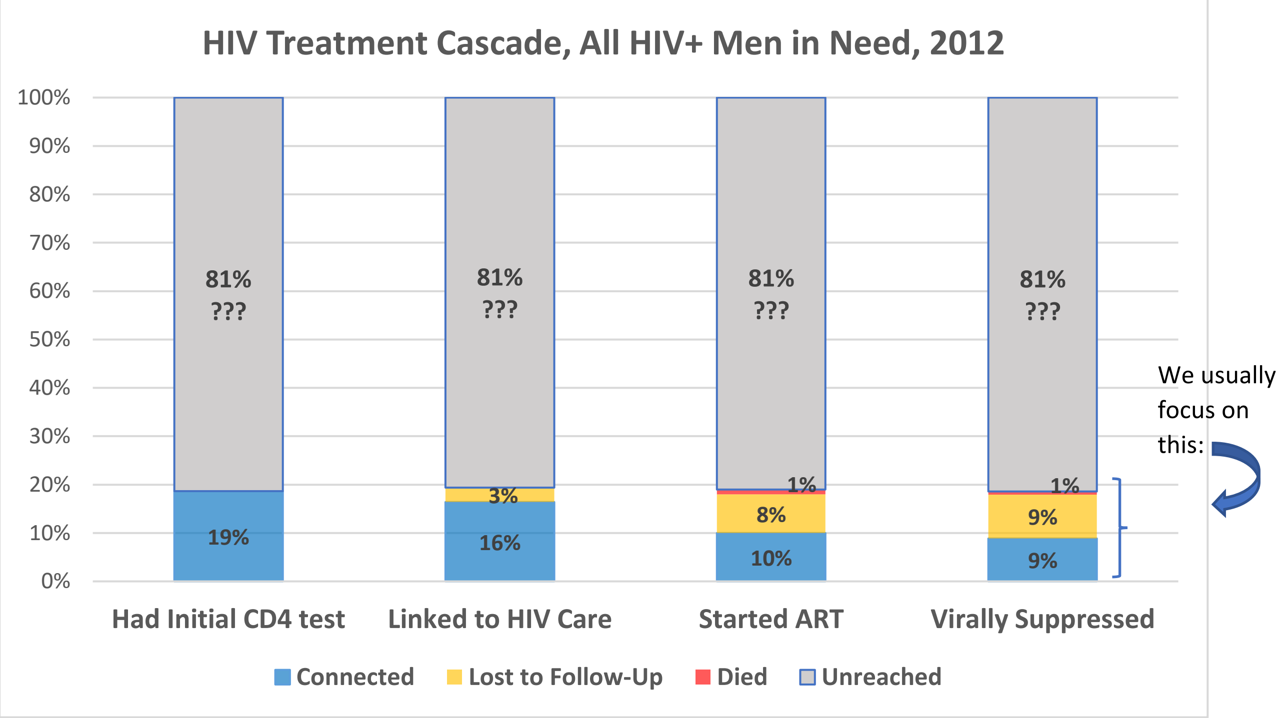
- The actual numbers of people remaining in each step:
  - 1935 → 1714 → 1038 → 918
- The number of people remaining at each step as a *percentage of the people who entered the cascade*:
  - 100% tested → 89% linked → 54% started ART → 47% were virally suppressed
- The number of people remaining at each step *as a percentage of the people in the previous step*:
  - 11% drop out between testing and linkage, 39% drop out between linkage and ART initiation



One of the problems with this approach to thinking about and displaying the cascade is that it only focuses on the ***practice population***, that is, the people who manage to get access to the clinical services for HIV. We tend to think of the people who make it to testing as the *beginning of the cascade*—as the 100% against which we will compare the later steps in treatment and care.

If we look at the ***population in need***, however, we see a very different picture. The cascade diagram below shows the same information the diagram on the first page, but it begins with an estimate of all of those people in the Gugulethu and Nyanga area who were HIV-positive and are not yet diagnosed or on ART in 2012—that is, everyone in 2012 who was in need of HIV testing and care because they were already infected and did not know it.

- The blue bars are the same figures as above but they are now shown as a percentage of all of the undiagnosed HIV-positive people.
- The grey bars are those in the area who needed testing but were not reached by health services.
- The yellow bars are people who tested, but then ‘fell out’ of the cascade or weren’t ART eligible.
- The red bars are those who tested but then later died for whatever reason. We don’t know how many of the unreached people (in grey) died during this year.



This chart highlights the fact that there are many people who we never see in the health services but who remain in need of testing and care. This is a very important public health fact to keep in mind.

One of the difficulties with making charts like this, though, is that we are not exactly sure how many people are in fact *in need*. To come up with the estimate we used, we had to combine:

- population size and gender/age profiles from census information,
- HIV testing and HIV prevalence rates from national surveys,
- ART coverage rates from provincial reports,

We also had to ignore the fact that:

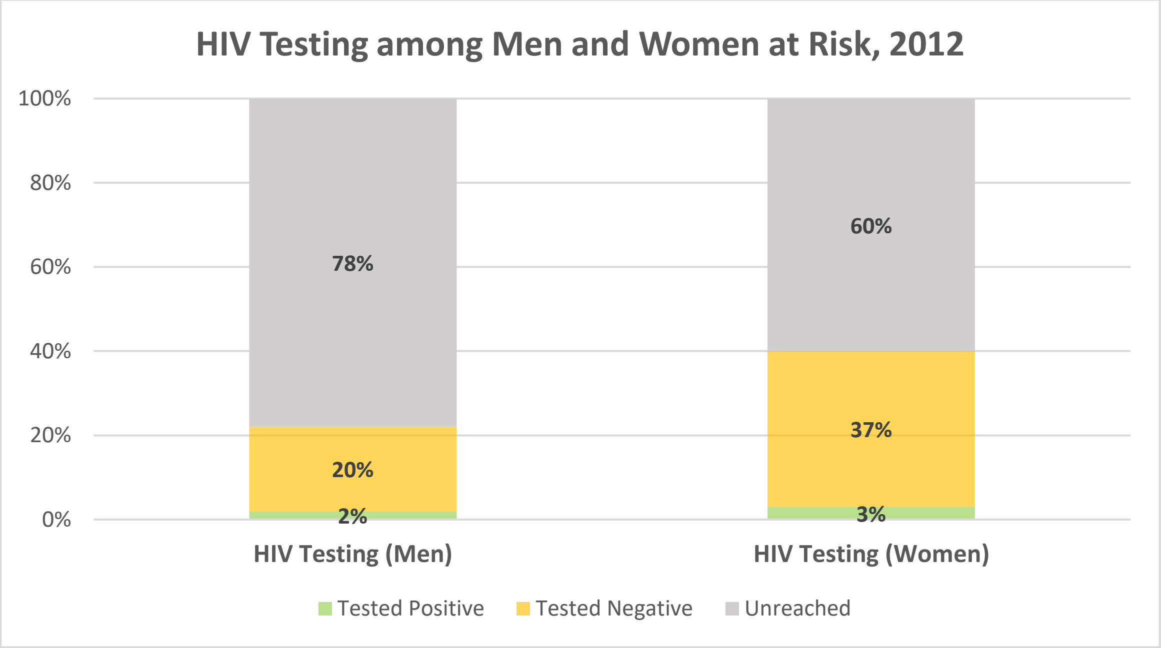
- people come from outside the area to get tested, and local residents may be tested outside the area
- people move in and out of the area
- we don't really know how many new HIV cases there are or how many deaths there are each year.

Even though the exact number of people in need is hard to figure out, it is crucial when we are thinking about how effective our health and community services are, and who might be missing from our programmes.

There is one more kind of population that matters for HIV testing: the **population at risk**. These are people that may or may not be positive, but are at risk for contracting HIV and we want them to test regularly. The make the chart below, we looked at:

- The total number of people (men on the left, women on the right) between the ages of 15 and 64 who don't have an HIV diagnosis (an estimate of the population at risk)
- The total number HIV tests in Gugulethu and Nyanga in 2012
- The total number of people in the area who were diagnosed with HIV in 2012

The total population at risk is 100%. If we assume that each HIV test represents a different person, we see that 78% of men at risk did not get tested, 20% of those at risked tested negative, and 2% of those tested positive. We also see that more of the women at risk are getting tested.



Questions to Consider

- How often should people at risk be testing for HIV?
- Do you have an idea about—or a specific number for—the number of people in your area who need HIV testing because they are:
    a) *in need*—that is, HIV positive but undiagnosed, or
    b) *at risk*—that is, engaged in activities that expose them to HIV?
- Do you know the HIV prevalence in your area?
- Do you know the percentage of HIV-positive people in your area who are on ART?
- Who are the 'unreached' people in the charts above?
- Are they different in some ways(s) from the people who are getting tested?

- How can health service and community-based services reach these ‘unreached’?
- Is there information about patterns of HIV testing in your area that would you would find useful in your work? What kind of information, and how would you use it?

Notes

Findings from Research with Men on HIV Testing

To understand why men are not testing for HIV or adherent to care, iALARM has conducted several qualitative research studies that try to understand what helps, or prevents, men from accessing HIV testing and treatment services in Gugulethu.

One of these studies focused on men’s knowledge of HIV testing services, their motivations for getting tested, and the barriers they faced in testing. This study was conducted by **Sithembiso Ndlovu**, a Masters of Public Health (MPH) student at UCT. It was based on 12 interviews with adult men in the area, the following themes and findings were identified:

Men’s knowledge of testing services

Sithembiso first asked his participants about their knowledge of the HIV testing services in the Gugulethu area. He found that:

- Men generally know where to test for HIV in Gugulethu. They know the location of clinics and mobile testing sites and how to access these services.
- Men learn about HIV services via different online and offline media
- Men do share knowledge about testing options with others informally, often during social gatherings and among friends
- Many male informants stressed the importance of knowing your HIV status

> *“Yes, HIV testing is important. It is one important thing, just to know whether you are HIV positive or not because if you know your HIV status, you will protect yourself and get medication as opposed to not being aware of your status so that you can stay healthy”.*
>
> *“As the youth, we are the leaders. So we have to convince people that they must test for HIV so that the person knows his HIV status and where they stand. There are times where we sit around as guys where we talk about testing and stuff but there is that one guy who has guilty conscience that he never went for HIV testing and then he would much more refrain from the conversation”.*

Men’s barriers to HIV testing

There were also several barriers to HIV testing, however. Sithembiso found that:

- Men often expressed a fear of being tested, especially after risky sexual encounters (that is, feeling like they were at greater risk of a positive diagnosis made them less likely to test)
- Men were concerned about being stereotyped when diagnosed HIV-positive, or being alienated and excluded from friends and family. Stigma is still a powerful barrier.

- Some of the men felt that clinics are not male-friendly places. They pointed to both the fact that there were very few male staff as well as the fact that most of the clients were women.

> *"I told myself I accepted myself but in the back of my mind there was all that knowledge that I did not accept myself."*
>
> *"First time you hear of the results, you go through the process of shock and denial".*

Men's motivations for HIV testing

Despite these barriers, many men do still get tested. When asked about the things that motivated them to get tested, men pointed to the importance of:

- Family and, in particular, peer-to-peer support
- Good counselling, having a plan, and friendly clinic staff
- A general interest in living a healthy lifestyle

> *"…in case I do get tested now and I'm HIV positive, I basically know I have people who are gonna support me in the background."*
>
> *"My brother, I can speak from experience. To me when I got my results, the first person I told was my sister and she accepted me you know, irrespective. Yes, and it helped me therefore I can say it helped me in a manner that I can talk with the next person about my status."*

Suggestions for increasing HIV testing among men

Finally, Sithembiso developed some suggestions for how the health services and its community partners might increase HIV testing among men:

- More male-focused interventions
- More male friendly clinics and male nurses, and better anonymity at the clinic
- Support groups for men (in addition to adherence clubs)
- Men's dialogues in the clinic waiting rooms or in community settings

Questions to Consider

- Were any of these findings surprising or confusing?
- Do you think things have gotten better or worse over the last few years for men and HIV testing?
- Do you think men know enough about HIV testing options outside of the regular clinics?
- What are some strategies you or your organization have used to encourage men to get into testing? Are there specific strategies for different groups of men (i.e. different ages, types of jobs, etc).
- How can we make more use of the finding that men get much of their advice and encouragement from other male peers?
- If men are less likely to test after a risky sexual experience, how and when should we try to reach them?

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Appendix 5.1: MCSJ Pamphlet – December 2016

Movement for Change and Social Justice

The Movement for Change and Social Justice (MCSJ) is an alliance of organizations aiming to improve the health and lives of people living in Gugulethu and surrounding areas**. MCSJ originated out of a need to address several health and social issues that have emerged in the various neighbourhoods of Klipfontein, including the lack of ARV's in clinics, long waiting times at community health facilities, and limited access to sanitary pads and condoms in schools. MCSJ is working to strengthen the relationship between various NGOs and community organizations in the area to address these issues and improve access to health and social services in Klipfontein.** To achieve these goals, MCSJ will host open dialogues about sensitive issues in the community, organize short-term campaigns to address specific challenges, and promote gender equality and the improvement of men's and women's health through health education and health promotion. MCSJ is a joint initiative between the University of Cape Town (UCT), Brown University in USA, Sonke Gender Justice (SGJ), Treatment Action Campaign (TAC) and several other partners who share the same values and would like to collaborate to bring about change in our community. MCSJ is a not-for-profit, non-political, and non-religious initiative and is based Men's Wellness Centre (MWC) on the premises of the NY3 clinic in Gugulethu. Our working area is the Klipfontein Sub-district which includes the neighbourhoods of Gugulethu, New Crossroads, Nyanga, Manenberg, KTC, Phillipi and Heideveld.

For more information or to join MSCJ, please contact:

Mandla Majola (field-coordinator UCT DSBS/MCSJ)
  tel: 076-6098818
  e-mail: majolam24@gmail.com
Phumzile Nywagi (field-coordinator UCT iALARM/MCSJ)
  tel: 076-6216077
  e-mail: phumzile.nywagi@gmail.com
Ncedisa Ngcobondwana (Treatment Action Campaign)
  tel: 078-8194303
  e-mail: ncedisancobondwanassp@gmail.com
Tantasa Ndlelani (Grassroot Soccer)
  tel: 083-4961479

Appendix 5.2: MCSJ Pamphlet 'Condoms in School' – May 2017

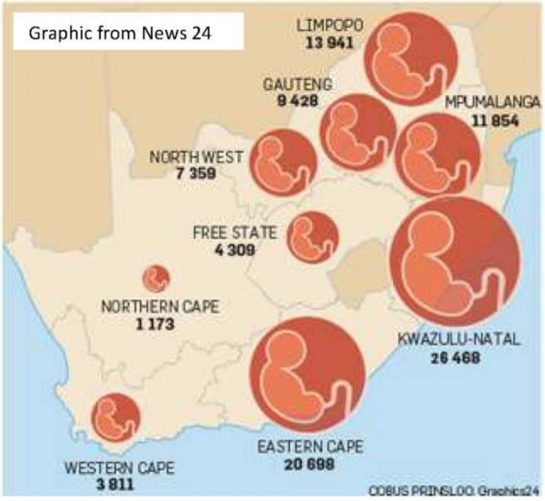
Movement for Change and Social Justice

Access to condoms is a human right for learners

Improving access to condoms and sex education in schools will give young people the tools they need to have safe, responsible sex and protect themselves and their partners from HIV, STIs and unintended pregnancy

In South Africa, most young people become sexually active while they are still attending school (Marteleto et al., 2008). In a National Survey on HIV (2012) 37.5% of all learners reported having had sex, and 12.6% said that they first had sex before age 14 (GroundUp, 2016). While we should do our best to encourage children to wait until they are ready to have sex, we should also make sure that they have the tools to have sex safely. This will allow them to protect themselves and their partners from sexually transmitted infections like HIV, and will also protect young women from falling pregnant while in school.

Improving access to condoms in schools will help young women stay in school


Graphic from News 24

COBUS PRINSLOO Graphics24

The percentage of young adults who do not complete their education is a lot higher in the Western Cape than some other provinces, such as KZN and Gauteng (Youth Stats, 2016). In the whole of South Africa, only 28% of youth finish matric (StatSA, 2015).

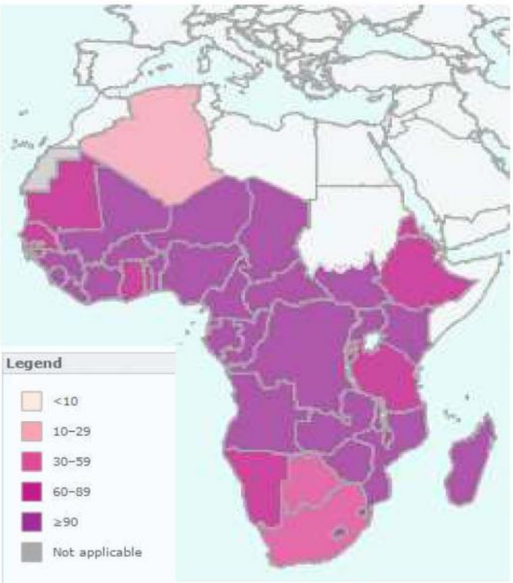
9.4% of children who dropped out of school dropped out because of family commitments such as getting married, minding children or becoming pregnant (StatSA, 2015). **Most of these learners are girls (18.1% compared to 0.4%).**

The likelihood of teenage pregnancy is higher for older learners (9.7% for females aged 19 years), but nearly 1 out of 100 14-year-old learners also reported being pregnant in the last year (StatSA, 2015).

In 2013, almost 100,000 South African teenage girls fell pregnant. Women and girls who fall pregnant soon after they become sexually mature are at a much higher risk of complications and death during pregnancy and delivery (WHO, 2016). Furthermore, young women who fall pregnant often drop out of school and struggle to achieve financial stability in their lives (WHO, 2016).

iALARM   SONKE GENDER JUSTICE HIV/AIDS • GENDER EQUALITY • HUMAN RIGHTS   TAC TREATMENT ACTION CAMPAIGN   University of Cape Town   BROWN

What can we do?



This figure (WHO 2016) shows the rate of teenage pregnancy in South Africa, compared to other African Countries. Although South Africa has fewer teen pregnancies than our neighbours, 54 out of every 1000 adolescent girls fall pregnant.

The National Policy on HIV/AIDS, for Learners and Educators in Public Schools, and Students and Educators in Further Education and Training Institutions (1999) states that it is up to the school governing body to decide whether condoms should be available at school (DBE, 2015). This policy also says that condoms should only be available through a school nurse and at local clinics (DBE, 2015). However, many schools do not have a school nurse, clinics often do not provide family planning services appropriate for young people, and most young people will be too embarrassed to ask for condoms.

In 2015, the Department of Basic Education released a draft of a policy to combat South Africa's high rates of HIV and teenage pregnancy. **BUT**, the policy fails to recognise that access to condoms in schools is a human right of all children (GroundUp, 2016). **The government is refusing to take responsibility for protecting your children from STIs and unwanted pregnancy. They have left it to you to ensure that your children have the necessary tools to have safe sex when they are emotionally and physically ready**. If we do not ensure that children in our schools have access to condoms we are failing our children.

Our goals

1. Give young people access to the tools and information they need to protect themselves and their partners from STIs and pregnancy.

*2. Teach young people that they have a **RIGHT** to demand that their sexual partner uses a condom.*

*3. Teach young people not to have sex until they are ready **AND** teach them how to have safe sex when they are*

References:

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Appendix 6.1: Draft 1.0 Adolescent Health Profile – September 2017

Community Health Profile (CHP):

Nyanga Junction Reproductive health centre

Draft #1; August 2017

Areas: Manenberg, Gugulethu, Nyanga

Introduction:

Nyanga Junction Reproductive Health Centre is a day clinic that specialises in STI's, HIV (TB) and reproductive health care, mostly at a preventative level. The clinic is closely connected to Gugulethu CHC and refers patients to either Heideveld/Manenberg, Hanover Park or Gugulethu CHC. Due to the convenient location of the health centre at the train station, Nyanga Junction has been extremely busy and serves patients from Klipfontein and far beyond. The increasing number of young people coming to the clinic has led to the need for establishing Youth Friendly Services at the facility. The groundwork for these services is ongoing. One of the requirements from the Department of Health (DoH) is to create a Community Health Profile (CHP) of the youth (age 12-24) to gain a better understanding of young peoples' sexual and reproductive health challenges in the community. Due to the mobility of the patients and the diverse group of youth that comes to the clinic, three different neighbourhoods are included in this CHP: Nyanga, Manenberg and Gugulethu.

Statistical information was collected form the following informationbases:

- *Census 2011 information from Stats SA*
- *Educational information from WC Educational department*

Health information from WC department (Western Cape Antenatal Survey Report 2014) (CHRIS AND ANGELA TO PROVIDE MORE DETAIL), MRC Burden of Disease unit Information used (online):

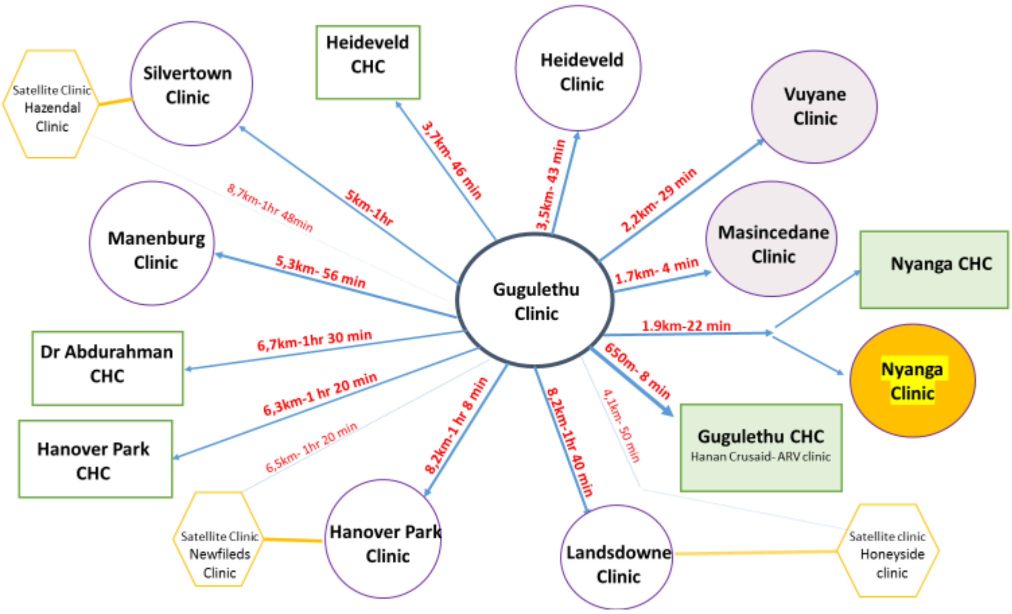
- *Link Manenberg (Ward 45): https://youthexplorer.org.za/profiles/ward-19100045-city-of-cape-town-ward-45-19100045/*
- *Link Gugulethu (Ward 41): https://youthexplorer.org.za/profiles/ward-19100041-city-of-cape-town-ward-41-19100041/*
- *Link Nyanga (ward 37): https://youthexplorer.org.za/profiles/ward-19100037-city-of-cape-town-ward-37-19100037*
- *Crime information from http://www.crimestatssa.com/precinct.php?id=1072. This is an extremely useful on-line source of crime statistics,*
- *Health information 1997-2012 (http://www.mrc.ac.za/bod/WesternCape2012.pdf)*

Overview community statistics

Table 1: Household setting

	Gugulethu	**Manenberg**	**Nyanga**
Population	20997	34281	22352
Youth 15-24	3672	6685	4648
Male/Female (15-24)	M: 49%; F:51	M: 50%; F: 50%	M: 48% F: 52%
Language	85% isiXhosa	61% Afrikaans	90% isiXhosa
Youth unemployment [4]	67.3%	62.4%	67.6%
Informal dwelling [5]	8.4%	7.1%	16.4%
Poor households[6]	55%	62.4%	72.7%

Overview of health services available in Klipfontein Sub-district



Household setting (narrative)

Health, also for the youth, is often determined by the household setting and housing structure, as well as the income per household; access to electricity; running water and the amount of people living in one household. All these factors can have an impact on health seeking behaviour for both young women and young men. For instance; in Nyanga, 36.3% of the youth lives in overcrowded households

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[4] According to the official definition, a person is unemployed if he or she is (a) without work, (b) available to work, and (c) actively seeking work. The expanded definition excludes criterion (c)

[5] An informal dwelling is a house in an unplanned settlement or areas where housing is not in compliance with current planning and building regulations (unauthorized housing)

[6] Stats SA's 2015 upper-bound poverty line of R779 per person per month in 2011 prices is used to define income poverty

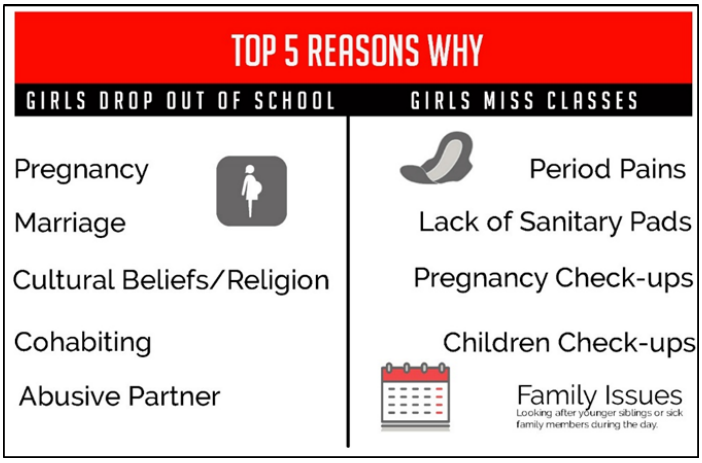


Figure 1: Why girls drop out of schools

compared to 19% in Manenberg. This difference can have far-reaching consequences, such as the lack of privacy, exposure to abuse and impact on personal and overall hygiene and hygienic standards [REFERENCE]. In Nyanga, Manenberg and Gugulethu, as well as many townships and informal settlements, children do not live (one of both of) their parents. In Nyanga, less than 60% (58.4) of the youth lives with one of the parents. As shown in research, the lack of a nuclear family and the absence of parents may have far reaching consequences, as the kids do often not have a role model to go to on a regular basis; which may impact their decision-making and judgement; especially among boys and young men. For both young men and women, this sometimes could result in criminal behaviour, as well as dropping out of school and youth unemployment (See more on education and youth unemployment in paragraph 5). The lack of income of within overcrowded and normal households can also lead to the lack of resources for basis hygienic necessities, such as sanitary pads for girls. Lack of access to sanitary products contributes to absenteeism and school drop-out, exposes girls and young women to health risks, and undermines their dignity. South Africa has shockingly high school drop-out rates. Most learners drop out after grade 9, and the highest under-enrolment is in grade 12, where only 54.5% of the appropriate school-age population is in school. This is problematic from an educational perspective, but also has significant public health consequences (See Figure 1).

➔ Morna Cornell to provide more information on young males (maybe with Chris Colvin)

Burden of disease → To filled in by Chris Colvin, Angela Rudick

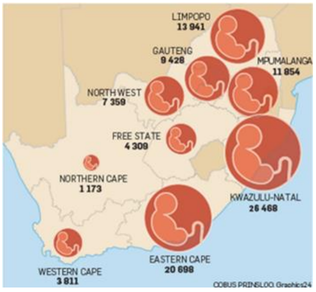
- HIV/AIDS specific information:
    - Antenatal prevalence in Klipfontein sub-district is high and appears to be increasing, from 22.3% in 2012 to 27.1% in 2014.
    - Because primary health care services are focused on women, men are less likely to be tested for HIV, to have a CD4 count, to start ART and to be retained in care than women. In 2012-2013, among those eligible to start ART in Klipfontein sub-district, 75% of males compared with 94% of females started treatment. In addition to the impact on men, this has major impact on transmission of HIV. Research has shown that the risk of transmitting HIV can be reduced by 96% if an HIV+ person is on ART and adherent to treatment.
- TB

- STI's
- Other chronic illnesses
    - Diabetes

Cancer Mortality risks are different by gender in the Western Cape. In 2011, the largest proportion of premature death in men was interpersonal violence (12.8%), while for women it was HIV/AIDS (15%).

Reproductive health & fertility

Child birth



Even though the statistics are little shaky here and many young women did not response to the question if they had a child in the past, we have some estimates below on the pregnancy rates in Nyanga, Gugulethu and Manenberg (see table 2). Especially when young girls are falling pregnant; this has dramatic effect on their health, as well as their education and future prospects in live. In 2013, almost 100,000 South African teenage girls fell pregnant. Women and girls who fall pregnant soon after they become sexually mature are at a much higher risk of complications and death during pregnancy and delivery (WHO, 2016). Furthermore, young women who fall pregnant often drop out of school and struggle to achieve financial stability in their lives (WHO, 2016). Interestingly, the rate of young girls getting pregnant is almost 10% lower in Gugulethu compared to Nyanga and Manenberg. As can be seen in paragraph 5; Gugelethu learners also perform better at school and have higher graduation rates.

Table 2; Childbearing age 15-24

	Gugulethu	**Nyanga**	**Manenberg**
Childbearing total	23%	31%	31.8%
Childbearing (15-19)	9%	14%	12%
Childbearing (20-24)	37%	44%	51%
Compared to SA Stats (31.1%)[7]	Lower than SA Stats	Same	Same

Crime

The table below reflects the excessively high crime statistics for the community in 2016. Nyanga is the murder capital of South Africa, followed by Gugulethu. Nyanga also has the highest number of sexual offences nationwide.

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[7] The average of girls and young women who get pregnant in South Africa age 14-25 is 31.1%.

	Murders	Sexual offences	Attempted murder	Serious assaults	Common assault
Nyanga	279	351	198	1053	1011
Gugulethu	184	243	114	686	528
Manenberg	60	109	130	275	649

Education and youth employment

Education is crucial for youth (both men and women) to succeed in life and have chances for employment and further education. The percentage of young adults who do not complete their education is a lot higher in the Western Cape than some other provinces, such as KZN and Gauteng (Youth Stats, 2016). In the whole of South Africa, only 28% of youth finish matric (StatSA, 2015). 9.4% of children who dropped out of school dropped out because of family commitments such as getting married, minding children or becoming pregnant (StatSA, 2015). In Nyanga; an average of only 38.8% matriculates, in Manenberg this is even lower, at 32.7%. Gugueltu is doing much better than the SA average; 55.4% of the youth finishes matric. Children and young adults who drop-out of school are more vulnerable to economic and social difficulties, face a greater risk of behavioural, mental and family disorders, and are more likely to be victims of sexual and physical abuse.[8]*For girls, dropping out of school puts them at a higher risk of HIV infection, other sexually transmitted diseases, rape, and unsafe abortion. For boys and young men; dropping out of school means that they have a bigger chance to get recruited by gangs, engage in violent behaviour or start using drugs or alcohol.*

The following programs are specifically designed to keep youth in school or assist them with after school activities:

1) Etafeni (Nyanga) – Fit for Life – Fit for work
   http://www.etafeni.org/portfolio/fit-for-life-fit-for-work/
2) Desmond Tutu Foundation (Philippi) – Women of Worth; The Zimele Project
   http://desmondtutuhivfoundation.org.za/research/adolescents-behaviour/
3) Grassroots Soccer (Guguelthu) – Youth Development Projects
   https://www.grassrootsoccer.org/youth-development/
4) Sonke Gender Justice (Gugelthu) - Youth community talks
   http://www.genderjustice.org.za/community-education-mobilisation/gugulethu-wellness-centre/

http://www.alhdc.org.za/static_content/?p=134

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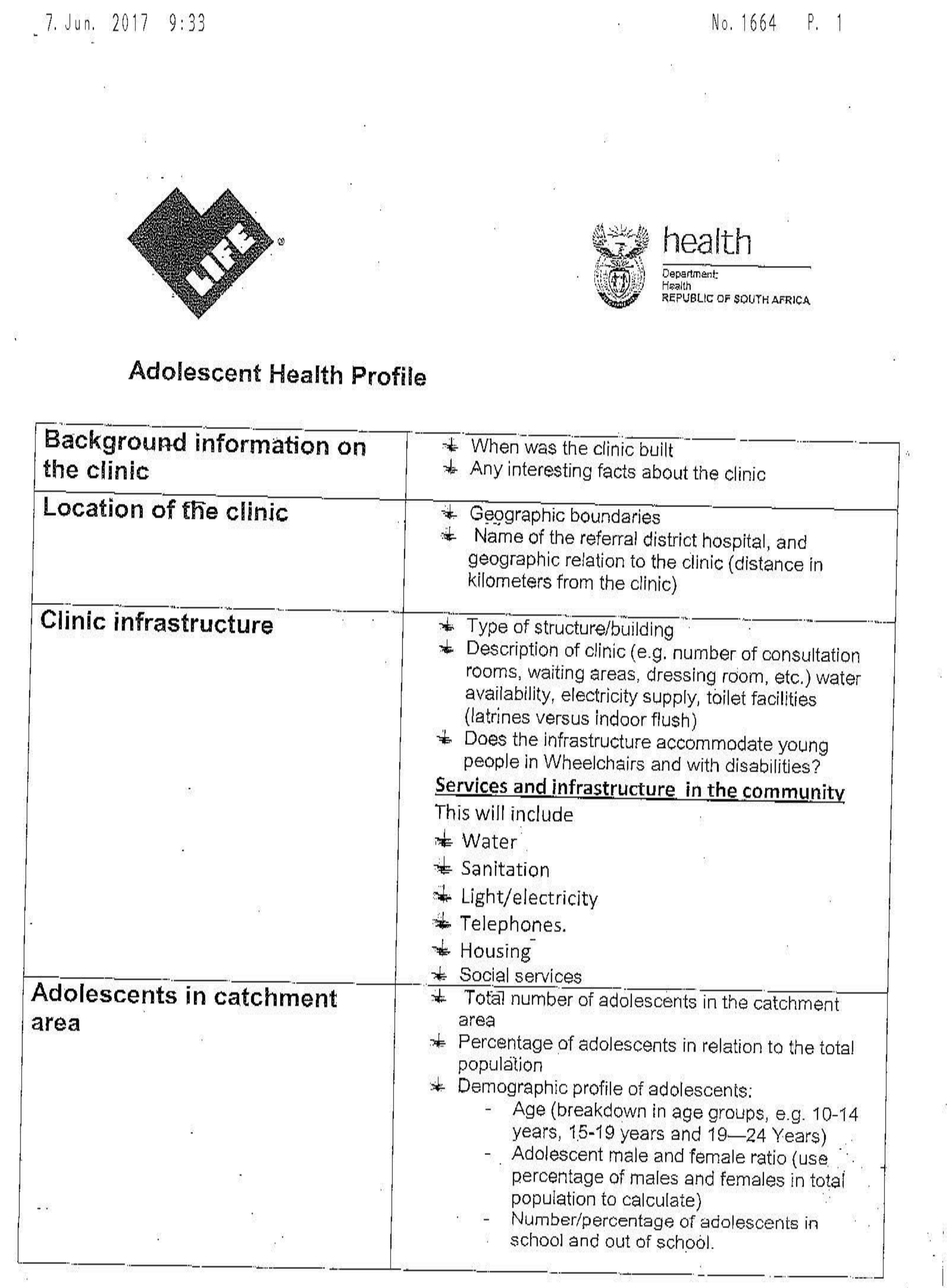
[8] Wegner, L., A. J. Flisher, P. Chikobvu, C. Lombard and G. King. 2008. "Leisure boredom and high school dropout in Cape Town, South Africa." Journal of Adolescence 31(3): 421-431.

Appendix 6.2: Guidelines Adolescent Health Profile – July 2017



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LIFE

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Health
REPUBLIC OF SOUTH AFRICA

Adolescent Health Profile

Background information on the clinic	- When was the clinic built - Any interesting facts about the clinic
Location of the clinic	- Geographic boundaries - Name of the referral district hospital, and geographic relation to the clinic (distance in kilometers from the clinic)
Clinic infrastructure	- Type of structure/building - Description of clinic (e.g. number of consultation rooms, waiting areas, dressing room, etc.) water availability, electricity supply, toilet facilities (latrines versus indoor flush) - Does the infrastructure accommodate young people in Wheelchairs and with disabilities? **Services and infrastructure in the community** This will include - Water - Sanitation - Light/electricity - Telephones. - Housing - Social services

Adolescents in catchment area	- Total number of adolescents in the catchment area
	- Percentage of adolescents in relation to the total population
	- Demographic profile of adolescents:
	  - Age (breakdown in age groups, e.g. 10-14 years, 15-19 years and 19—24 Years)
	  - Adolescent male and female ratio (use percentage of males and females in total population to calculate)
	  - Number/percentage of adolescents in school and out of school.

Youth serving organizations (Supporting Stakeholders)	✤ List of youth services (e.g. social services) and youth serving organizations in the catchment area ✤ Describe the purpose and the main activities of each service (Stakeholder e.g Lovelife Reduces the rate of HIV NEW INFECTIONS.) ✤ List appropriate contact details-
Schools	✤ List of primary and secondary schools in the catchment area ✤ Describe the main activities that the school conducts to educate adolescents about their sexual and reproductive health (including HIV/AIDS) ✤ List appropriate contact details
Adolescent SRHS/R	✤ The main sexual and reproductive health problems, including prevalence of: - Teenage pregnancy/births - Abortions (among adolescents) - Sexually transmitted infections (STIs) (among adolescents / by age and gender) - HIV/AIDS (among adolescents / by age and gender) including adherence - Circumcision - Uptake of condoms and contraceptives. - Partner notification - Knowledge about sexual rights
Opinions of young people in the catchment area	✤ The main problems that adolescents in the catchment area feel they face (e.g. drug/alcohol abuse, gangsterism, unemployment, depression, HIV/AIDS, orphanhood etc.) ✤ The key opportunities that adolescents in the catchment area feel they have (e.g. school, employment, involvement in sports, involvement in clubs etc.) ✤ Key Population
Focus Group Discussion, Clinic Information Health System and clinic Suggestion box, Client Exit Interview can assist in obtaining the relevant answers	

Line Manager ……………………Sign……………………………..Date…………………………………………

Facility Manager ………………………Sign…………………………..Date…………………………………………

Adolescent Health Profile

[Name of Clinic]

Prepared by: [insert name]

[Date]

A) Background Information on the Clinic		
When was the clinic built?		
Any interesting facts about the clinic?		
B) Location of the Clinic		
Geographic Boundaries		
Name of the Referral District Hospital		
Geographical Relation to Clinic (kms from clinic)		
C) Clinic Infrastructure		
Type of Structure/Building		
Description of Clinic:		
# consultation rooms, waiting rooms, dressing rooms, etc		
Water availability		
Electricity supply		
Toilet facilities		
Does the infrastructure accommodate young people in wheelchairs or with disabilities?		
D) Services and Infrastructure in the Community		
Water		
Sanitation		
Light/Electricity		
Telephones		
Housing		
Social Services		
E) Adolescents in Catchment Areas		
Total number of adolescents in catchment area		www.youthexplorer.org.za

Percentage of adolescents in relation to the total population		
# (or %) of adolescents 10-14 years		
# (or %) of adolescents 15-19 years		
# (or %) of adolescents 20-24 years		
Male to female ratio	[use ratio of male to females in overall population to estimate]	
# (or %) of adolescents in school		
F) Youth Serving Organisations		
List of youth serving organisations in the catchment area, main objectives, services provided, key activities, and contact details		
[Organisation 1]	[Name of organisation Main purpose Key services and activities Contact details]	
[Organisation 2]	[Name of organisation Main purpose Key services and activities Contact details]	
[Organisation 3]	[Name of organisation Main purpose Key services and activities Contact details]	
[Organisation 4]	[Name of organisation Main purpose Key services and activities Contact details]	
G) Schools		
List of primary and secondary school in the area		
[School 1]	[List of main sexual and reproductive health activities Contact details]	
[School 2]	[List of main sexual and reproductive health activities Contact details]	
[School 3]	[List of main sexual and reproductive health activities Contact details]	
[School 4]	[List of main sexual and reproductive health activities Contact details]	
H) Adolescent Sexual and Reproductive Health		
Main reproductive and sexual health problems, including prevalence		
Teenage pregnancy/births		

Abortions among adolescents		
STIs (by age and gender)		
HIV prevalence (by age and gender)		
ART adherence (by age and gender)		
Male Circumcision (# or %)		
Uptake of condoms		
Uptake of contraceptives		
Partner notification (STIs)		
Knowledge about sexual rights		
I) Opinions of Young People in the Area		
Main problems that adolescents feel they face		
Key opportunities that adolescents feel they have access to		
Key populations (among adolescents) in the area		