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Understanding user profiles for oral PrEP uptake: A qualitative study with adolescent girls, young women and men in Vulindlela, South Africa

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DECLARATION

College of Humanities – Plagiarism

I, *Nqobile Thobile Ndzinisa*, hereby declare that the research reported in this dissertation, except where otherwise indicated, is my original research. This dissertation has not been submitted for any degree or examination at any other university; and it does not contain other person's data, pictures, graphs or other information unless specifically acknowledged according to the Harvard reference style. The dissertation does not contain other person's writing unless specifically acknowledged as being from other researchers. Where other sources have been quoted i) their words have been re-written, but retains the meaning and is referenced, ii) where their exact words have been used then their words have been placed in quotation marks and referenced appropriately. I also declare that this dissertation does contain text, graphics or tablets copied and pasted from the internet unless specifically acknowledged and the source being detailed in the dissertation and in the Reference section.

Signature: _____ Date: 12/03/2018

Supervisor: _____ Date: 12 March 2018

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For the completion of this dissertation all glory and honour goes to my Lord and Saviour, Jesus Christ… "*For you are great and do marvellous deeds; you alone are God*" **Psalm 86:10**. This work is the result of His unfailing grace.

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Map of South Africa and grey scale area location of Vulindlela, KwaZulu Natal

Figure 1: A map of South Africa (www.places.co.za/html/visualfind.html)

Figure 2: Greyscale area location of Vulindlela, KwaZulu –Natal (www.maphill.com/search/vulindlela/)

Abstract

HIV and Acquired Immuno Deficiency Syndrome (AIDS) have become a global public health problem. About 36.7 million people were living with HIV in 2016 and Sub-Saharan Africa accounts for 19.4 million of those living with HIV. Women account for 59% of those living with HIV in the Sub-Saharan region. While HIV affects both men and women in South Africa, 60% of new infections in the country occur among young women. New prevention methods including prevention of mother-to child-transmission (PMTCT) and voluntary medical male circumcision (VMMC) have shown tremendous promise. Yet, women, especially young women, have not maximally benefited from these interventions because they are not women-initiated. Thus, oral PrEP has the potential to reduce HIV transmission among adolescent girls and young women as it holds great promise as a female-initiated method in the prevention of HIV.

Drawing on the concepts of the Health Belief Model (HBM) and the Social Ecology Model for Communication and Health Behaviour (SEMCHB) to understand user profiles for oral Pre-Exposure Prophylaxis (PrEP) among high- risk adolescent girls and young women (AGYW) aged 15 -25 years and men who are likely to benefit from the use of oral PrEP as a new Human Immuno Virus (HIV) prevention method in Vulindlela, South Africa. In this qualitative study, three focus group discussions were held with adolescent girls and young women (AGYW) aged 15- 25 years and men aged 25-35 in Vulindlela, South Africa to understand perceptions of risk among this key population. Further, in-depth interviews were held with the HIV testing and counseling counselor and the clinic nurse to understand how perceptions of health providers may influence the acceptability of oral PrEP among AGYW. Data were analysed using the constructs of the HBM and the SEMCHB. Thematic analysis was used to develop sub-themes that emerged from the data collected.

Key findings in this study revealed that perception of risk was high among participants. However, perceived susceptibility and perceived severity was low. Further, there was a lack of knowledge about oral PrEP, which contributed to negative perceptions about this new HIV prevention method.

Key words: Oral PrEP, user profiles, adolescent girls and young women, women empowerment.

LIST OF KEY WORDS AND ACRONYMS

ACRONYM	WORD(S)
ABC	Abstain, Be Faithful, Condomise
AGYW	Adolescent girls and young women
AIDS	Acquired Immuno deficiency Syndrome
ARV	Antiretroviral
AVAC	Global Advocacy for HIV Prevention
CAPRISA	Centre for the AIDS Programme of Research in South Africa
CCMS	Centre for Culture, Communication and Media Studies
DOH	Department of Health
FGD	Focus Group Discussions
FTC	Emtricitabine
HBM	Health Belief Model
HIV	Human Immune-virus
KZN	KwaZulu-Natal
MMC	Medical Male Circumcision
MSM	Men who Have Sex with Men
PMTCT	Prevention of Mother-to-Child HIV Transmission
PrEP	Pre-Exposure Prophylaxis
SEMCHB	Social Ecology Model of Communication and Health Behaviour
STI	Sexually Transmitted Infection
TDF	Tenofovir Disoproxil Fumarate
UNAIDS	Joint United Nations Programme on HIV and AIDS
WHO	World Health Organization

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CHAPTER 1: INTRODUCTION

Introduction

This study sets out to understand and establish user profiles for oral Pre-Exposure Prophylaxis (PrEP) through specific segments or groupings of high-risk adolescent girls and young women (AGYW) (ages 15-25 years) and men who are likely to benefit from the use of oral PrEP as a new Human Immuno Virus (HIV) prevention method in Vulindlela, South Africa. Oral PrEP is an anti-retroviral drug in the form of a tablet taken by HIV-negative people on a daily basis to significantly reduce their risk of getting infected with HIV (AVAC, 2016a).

By way of introduction, this chapter highlights how HIV has become a global health problem in the last three decades since it was first discovered. It briefly accounts for women's vulnerability to HIV infection when compared to men within the South African context. This chapter further contextualises methods of HIV prevention in the past three decades, leading up to the initiation of oral PrEP as a new HIV prevention method. The chapter articulates the need to understand the factors that influence young women's possible acceptance or rejection of oral PrEP as a new HIV prevention method. This study uses the Health Belief Model (HBM) to explore the dynamics that influence perception of risk and how this impacts perceptions of oral PrEP, with the aim of establishing key user profiles for oral PrEP. It aknowledges that the acceptence or rejection of new HIV prevention methods is influenced by the context in which an individual resides, therefore, the study locates the HBM within the Social Ecology Model for Health and Behaviour Communication. An indepth discussion of this aspect of the study is presented in Chapter Three.

Background

Both HIV and Acquired Immuno Deficiency Syndrome (AIDS) have become a global public health problem (Dellar *et al*., 2015, Kharsany *et al.*, 2014). Approximately 36.7 million people were living with HIV in 2016. Sub-Saharan Africa accounts for 19.4 million of those living with HIV (UNAIDS, 2017a). Women account for 59% of those living with HIV in the Sub-Saharan region (UNAIDS, 2017a). This highlights the fact that adolescent girls and young women aged 15–25 years bear a disproportionate burden of HIV infection when compared to their male counterparts (Baxter and Abdool Karim, 2016). Globally, 1.8 million people died from AIDS related illnesses in 2016, with 420 000 AIDS-related deaths reported in Sub-Saharan Africa

(UNAIDS, 2017a). These statistics emphasise that HIV and AIDS continue to be a major cause of loss of life in the region. This is despite numerous awareness campaigns and various interventions put in place by governments and non-governmental organisations (NGOs), both locally and internationally.

Globally, South Africa has the largest number of people living with HIV (Whiteside and Strauss, 2014). Out of all the nine provinces of South Africa, KwaZulu-Natal has recorded the highest provincial prevalence and in keeping with regional trends, prevalence is higher among African women in the age group 15–25 years (Zuma *et al.*, 2016). HIV infection rates are eight times higher in female adolescents than in their male counterparts (Karim *et al*., 2017). This difference is attributed to sexual relationships of young women with older men where these women, in turn, infect young men that they engage in sexual relationships with (de Oliveira *et al.*, 2017, Gouws and Williams, 2017). Thus, one of the most crucial challenges in HIV prevention in Africa is reducing the high infection rates among young women (Baxter and Abdool Karim, 2016). Research has suggested that cultural, biological, socio-economic and contextual factors contribute to the vulnerability of women when it comes to HIV infection (Karim *et al.*, 2011, Naranbhai *et al.*, 2012). These factors are discussed in detail in Chapter Two.

Research further suggests that the most common way of contracting HIV in South Africa is through heterosexual sex (Zuma *et al.*, 2016). Current effective means of HIV prevention include HIV counselling and testing (HCT) as the first step to knowing one's status towards prevention and consistent condom use. However, while a woman can proactively test for HIV, condom use is male-driven and leaves women with little or no autonomy over their sexual health (Celum, 2009). Therefore, the need for more women-initiated HIV prevention technologies still remains a key priority, due to the existing practices that legitimise men's dominant position and justifies the subordination of women in South Africa (Govender *et al.*, 2017).

Successful health communication strategies have the potential to increase the acceptability and uptake of new HIV prevention technologies (Baxter and Abdool Karim, 2016, Dellar *et al.*, 2015). Nevertheless, this requires an in-depth understanding of potential users as well as the determinants that may influence acceptance and uptake of the product (Govender *et al.*, 2017). Currently, there are inadequate safe and effective women-centred HIV prevention options, therefore oral PrEP has the potential to reduce transmission of HIV among adolescent girls and young women.

Problem statement

There is a need to consider contextual factors when designing HIV interventions. While HIV affects both men and women in South Africa, 60% of new infections in the country occur among young women (Karim, 2016, Karim *et al*., 2017). Moreover, women are eight times more likely to become infected with HIV when compared to their male counterparts, and they also acquire HIV at least five to seven years earlier than men (Kharsany *et al.*, 2014). New prevention methods including prevention of mother-to- child- transmission (PMTCT) and voluntary medical male circumcision (VMMC) have shown tremendous promise. Yet, women, especially young women, have not maximally benefited from these interventions because they are not women-initiated (Celum, 2009). However, as part of HIV combination prevention, there is a need for strategies that integrate anti retroviral treatment (ART) and oral PrEP because neither approach can eliminate HIV on its own (Baeten *et al*., 2016). Thus, oral PrEP has the potential to reduce HIV transmission among AGYW as it holds great promise as a female-initiated method in the prevention of HIV (Thomson *et al.*, 2016). However, the success of oral PrEP will depend on understanding how best to come up with innovative solutions to HIV prevention that can be implemented seamlessly and incorporated into broad HIV prevention packages for diverse users.

Research questions

1. What are perceptions of HIV risk among adolescent girls, young women and men in Vulindlela, South Africa?
2. What is the acceptability of oral PrEP as a new HIV preventive method among adolescent girls, young women and men in Vulindlela, South Africa?
3. What are the barriers and enablers that influence acceptability of oral PrEP among adolescent girls, young women and men in Vulindlela, South Africa?

Research objectives

1. To understand the perception of HIV risk among adolescent girls, young women and men in Vulindlela, South Africa.

A woman's ability to use a new HIV prevention method or adopt any sexual reproductive health behaviour is influenced by a range of factors. These factors include beliefs and expectations about the product and perceived need and ability to use the product. However, before a woman can even consider a new HIV prevention method, she must perceive herself at risk of HIV infection. Therefore, this objective seeks to understand perceptions of risk among adolescent girls and women and men in Vulindlela, South Africa. Consequently, it is necessary to understand how perception of risk affects individual women's interest and willingness to try oral PrEP as a new HIV prevention method in different circumstances.

2. To establish the key influences under which adolescent girls, young women and men in Vulindlela, South Africa are willing to use oral PrEP.

This objective seeks to establish how the different groups of women aim to use oral PrEP. This will assist with understanding why women may or may not develop an interest to use oral PrEP. Understanding the acceptability of oral PrEP will allow for the establishment of user profiles which will inform communication about the benefits of oral PrEP within a context that is mindful of the perceptions, attitudes, safety and effectiveness of this population health intervention.

3. To understand barriers and enablers that influence the acceptability of oral PrEP among adolescent girls, young women and men in Vulindlela, South Africa.

While oral PrEP is seen as a women-centred HIV prevention technology, studies show that partner involvement ultimately plays a critical role in whether oral PrEP is adopted or rejected. Therefore, it is important to understand how men perceive the product to ensure that any negative perceptions are addressed in both individual and interpersonal communication about oral PrEP. Similarly, barriers and enablers affecting acceptability of oral PrEP among adolescent girls and young women need to be understood because research has shown that this key population contracts HIV from older men with whom they engage in sexual relations with, either for economic or other reasons. These women, in turn, infect the men in their age group. Therefore, addressing barriers and encouraging enablers could ensure acceptability and uptake of oral PrEP, leading to the reduction of HIV prevalence among AGYW.

Conceptual framework

The study employs concepts from the Health Belief Model (HBM) to explore the reasons why specific groups of users might accept or reject oral PrEP. The HBM has six primary concepts that predict why people will take action to prevent, screen for or control illness conditions (Champion and Skinner, 2008). These concepts are; perceived severity, perceived susceptibility, perceived benefits, perceived barriers, cues to action and self efficacy (Janz and Becker, 1984). Whereas immediate factors of the spread of HIV relate to behaviour, the basic influences that contribute to risky behaviour are located in the social environment and include poverty, under- development and gender inequality (Hittner *et al*., 2016). Therefore, for purposes of this study, the HBM will be embedded in the Social Ecology Model for Communication and Health Behaviour (SEMCHB). Using the interpersonal level of the SEMCHB allowed the researcher to understand influences of interpersonal relationships on the individual's perception of oral PrEP and how these affect acceptance or rejection of this new HIV prevention method. This is important because behaviour change is not only influenced by individual preceptions, but also by the environment in which the individual resides.

The SEMCHB is considered a meta-theory because it consists of four interacting levels that work together to form one comprehensive model (Sallis *et al*., 2008). The four interacting levels are influenced by, and in turn influence health behaviour (McLeroy *et al*., 1988). The four levels or spheres are: the individual (intrapersonal), interpersonal, community and the environment (Kincaid *et al*., 2007). At the individual level, the SEMCHB employs the HBM, which assists to understand why an audience's perceptions are not in favour of change *(*McKee *et al*., 2014). These theories are relevant because the current study seeks to understand perceptions of risk and how these inform acceptibility of oral PrEP as a new HIV prevention method.

The purpose of the current study, therefore, is to understand user profiles for oral PrEP uptake in Vulindlela, South Africa. It uses the HBM to explore the dynamics that influence perceptions of risk and how these perceptions influence the acceptability of oral PrEP. Doing soallows the researcher to understand the type of users that could have an interest in utilising oral PrEP. After these user profiles are established, tailored communication efforts can be developed to ensure that those women who need oral PrEP understand where and how to access and utilise it. With vaginal creams and injectables still under clinical trials, potentially demonstrating product efficacy on the

heels of oral PrEP, it is important to understand how best to introduce these new options to achieve reductions of HIV risk at individual and community levels (Hankins and de Zalduondo, 2010).

Setting the scene: AGYW as a key population in Vulindlela

The current study is located in Vulindlela, a rural community of approximately 90,000 people located on the edge of the Mooi River, about 150kms from Durban in the Umgungundlovu district of KwaZulu-Natal. This district is one of the five districts in South Africa with the highest HIV burden, where HIV prevalence rates exceed 40% among pregnant women. There are three wards in Vulindlela namely; Inadi, Mpumuza and Mafunze which are all administered through both tribal and democratically elected local government structures.

The current study was conducted at two sites in Vulindlela; Mafakathini clinic, which offers antenatal and family planning services to adolescent girls and young women as well as voluntary counselling and testing for adolescent girls and young women as well as young men. The second site is Ngcendomhlophe High School. It was beyond the scope of this study to extend to all three districts, hence the current study sampled from AGYW and men accessing the clinic and AGYW attending the local high school within the district. The existing partnership between Centre for the Aids Research Programme in South Africa (CAPRISA) and the Community Outreach Programme in Vulindlela (COMOSAT) with the primary health clinics allowed for access to the adolescent girls, young women and young men.

Vulindlela is ideal for the current study because HIV prevalence among adolescent girls and young women remains disturbingly high in South Africa, despite the scale-up of antiretroviral therapy (ART) and HIV prevention strategies (Karim, 2016). Furthermore, by exploring HIV prevalence among young pregnant women aged between 15 and 25 years visiting ante-natal clinics for the first time in Vulindlela over a period of 12 years from 2001, researchers established that instead of the HIV prevalence declining in response to increasing levels of prevention and treatment interventions, it rose from 35.3% in the years 2001 to 2003 before anti-retroviral therapy (ART) was available. The HIV prevalence rate rose to 39% from 2004 to 2008, which were the early years of ART provision before reaching 39.3% in the years 2009 to 2013 when ART roll-out was fully implemented (Karim, 2016). These statistics establish the high HIV prevalence rates among adolescent girls and young women in South Africa and highlight the burden of HIV in Vulindlela.

Purpose of the study

The purpose of the current study is to understand perceptions of risk and establish user profiles for oral PrEP uptake in Vulindlela, South Africa. This will ensure that oral PrEP is made available to vulnerable populations who need it most, resulting in reduced rates of new HIV infections.

Objectives of the study

The current study aims to contribute to the understanding of perceptions of risk among AGYW and men in Vulindlela, South Africa as well how these preceptions may influence the acceptability of oral PrEP as a new HIV prevention method.

Structure of the dissertation

Chapter One provides a brief background of the current study by highlighting how the burden of HIV and AIDS has become a global health problem in the last three decades since it was first discovered. Moreover, this section accounts for women's vulnerability to HIV and AIDS infection when compared to men within the South African context. This chapter further contextualises methods of HIV prevention in the past three decades, leading up to the availabaility of oral PrEP as a new prevention method. Finally, the chapter suggests the need to understand the factors that influence young women's possible acceptance or rejection of PrEP as a new HIV prevention method through the HBM. It explores the dynamics that influence the uptake of oral PrEP, with the ultimate aim of establishing key user profiles for PrEP.

Chapter Two This section provides an overview of HIV and AIDS globally, regionally and locally (South Africa), emphasizing the factors that pepertuate women's vulnerability to HIV infection. It examines key factors contributing to women being more vulnerable to HIV infection than their male counterparts. The chapter further discusses diverse methods of HIV prevention utilised in the past three decades, leading up to the introduction of PrEP as possible new HIV prevention method that can reduce HIV prevalence among young women in the age group 15-25 years. To conclude, the chapter discusses possible barriers and enablers to the acceptance of oral PrEP as an HIV prevention method.

Chapter Three presents the conceptual framework on which this study rests. The study is located in the Health Belief Model, which assists the researcher to understand perception of risk among

AGYW and men in Vulindlela. The HBM further assists in understanding user profiles of oral PrEP and unpack the influences of why these specific groups of users may accept or reject oral PrEP. In this study, the HBM is embedded in the Social Ecology Model for Communication and Health Behaviour (SEMCHB). This assists the researcher to take into consideration the reality of the contextual scenario that surrounds the individual and acknowledge the importance of their context in this study.

Chapter Four presents the research methodology and study methods. This chapter presents and describes the research design, research paradigm, selection of participants, data collection and data analysis procedures. Moreover, the chapter assesses issues of credibility, transferebility and ethical considerations involved in the current study.

Chapter Five presents the qualitative data collected through focus groups and indepth interviews. Data collected is analysed thematically and descriptively.

Chapter Six presents the analysis and discussion of findings. The analysis is informed by the various tenets of the conceptual framework. Reference is also made to relevant literature.

Chapter Seven presents the conclusions and recommendations based on the findings of the current study.

CHAPTER 2: LITERATURE REVIEW

Introduction

A substantial body of literature reveals that adolescent girls and young women (AGYW) aged 15 – 25 years are more vulnerable to Human Immune Virus (HIV) infection than their male counterparts (Cowan *et al*., 2016, Karim *et al.*, 2017). The aim of the current study is to understand perceptions of risk and establish user profiles for oral PrEP among AGYW and men in Vulindlela. This will lead to the understanding of who is most at risk of HIV infection and which individuals within this high-risk group are likely to initiate oral Pre-Exposure Prophylaxis (PrEP).

Oral PrEP is an anti-retroviral drug in the form of a tablet taken by HIV negative people daily to significantly reduce their chances of HIV infection (AVAC, 2016a). While women are the focus of the current study, it is important to note that men have not been excluded from the dialogue. Therefore, the current chapter explores literature on HIV and AIDS globally, regionally and locally (South Africa). This review of relevant literature seeks to provide a background to the AIDS epidemic. It also focuses on factors contributing to AGYW's vulnerability to high HIV incidence. A discussion on the complexities of previous HIV prevention methods and the urgency for new HIV prevention technologies is provided in this chapter. The advances in clinical trials in recent years are explored and the relevance of oral PrEP in HIV high burden settings are highlighted.

The HIV and AIDS epidemic: an overview

The story of HIV and AIDS began in 1979 and 1980 when doctors in the United States of America (USA) observed clusters of previously extremely rare diseases (Barnett and Whiteside, 2002). When HIV was first diagnosed, the world was caught unaware and early efforts to contain the virus were disjointed, piecemeal and enormously under-resourced (Hankins *et al*., 2006). The first cases of HIV were among gay men and as such, it was called Gay-Related Immune Deficiency Syndrome (GRID) (Barnett and Whiteside, 2002, Karim, 2005). However, HIV and AIDS was reported in every country, globally (Hunter, 2003). Through the 1980s, South Africa seemed to be unaware of the epidemic that was rapidly spreading in both developed and developing countries (Marks, 2002). By the mid-1980s, it was clear that the disease's incidence and progress from HIV infection to full-blown AIDS was faster in African countries, and affected a far broader band of society than in the developed world (Marks, 2002). Whereas HIV was common in homosexual

males in the USA and drug injecting homosexual men in the United Kingdom (Merson *et al*., 2008), young adults of both sexes, aged between 15 and 50 years, were particularly affected in Africa (Barnett and Whiteside, 2002). This group comprised men and women who were productive members of society. This resulted in children being left to care for their sick parents and the elderly becoming primary caregivers to orphaned children (Cohen *et al.,* 2008).

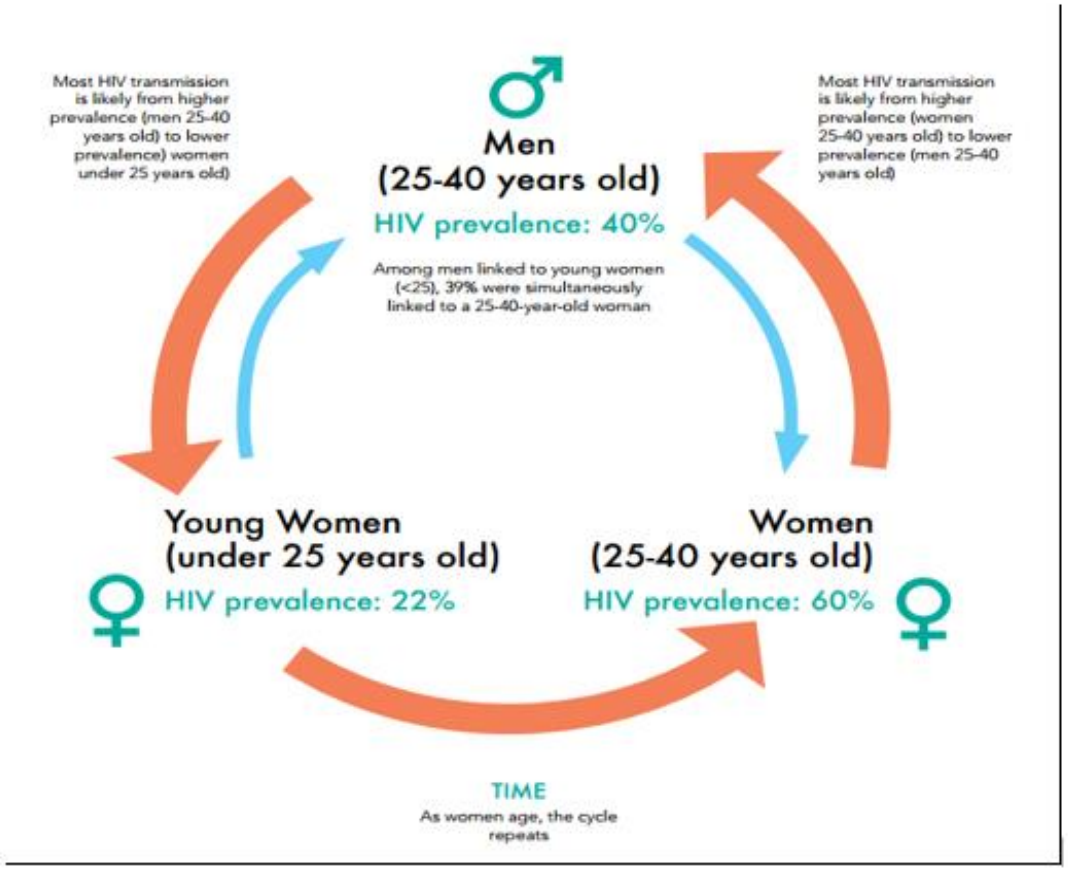
AIDS seemed to be concentrated in marginalised populations and a number of governments, including those in heavily affected sub-Saharan Africa, denied that HIV or its accompanying risk behaviours existed in their countries (Merson *et al*., 2008). Early prevention successes were the result of joint reactions generated by people living with HIV, community and civic groups such as the Treatment Action Campaign (TAC), and these confronted the stigma, discrimination, and denial associated with the disease in South Africa (Tomaselli, 2011). Despite the fact that HIV prevention education was being carried out through pamphlets and mass media campaigns, the provision of treatment was generally slow (Tomaselli, 2011). This was due to the then President, Thabo Mbeki and then Minister of Public Health, Manto Tshabalala-Msimang's denialist stance, resulting in their promotion of nutrition over anti-retroviral treatment (Mbali, 2004). The Minister publicly promoted a brew of beetroot, olive oil, garlic, spinach and extracts from the African potato for treating AIDS while the President told journalists he would not take an HIV test (Tomaselli, 2011). This served to undermine the epidemic's impact on social, political and human rights (Tomaselli, 2011).

Conversely, with better understanding and strong government policy on HIV and AIDS, there has been a significant reduction of HIV infections in sub-Saharan Africa (Isbell *et al*., 2016). In 2013, an estimated 24.7 million people were living with HIV in the region (UNAIDS, 2014b) nonetheless, statistics reveal that in 2016, the number of people living with HIV in the region had been reduced to 19.4 million (UNAIDS, 2017a). However, although global and regional trends show a decline in HIV infection rates among adults, adolescent girls and young women still account for more than half (59%) of the total number of people living with HIV in sub-Saharan Africa (Baxter and Abdool Karim, 2016).

South Africa has one of the highest numbers of HIV infection in the world with 7 million people living with HIV in the country in 2016 (Karim, 2016, UNAIDS, 2017a). In keeping with regional trends, women are the most affected with approximately 4 million women reported to be living

with HIV in the same year (UNAIDS, 2017a). Heterosexual sex is the most common method of HIV transmission and acquisition (Zuma *et al*., 2016). Out of all the nine provinces of South Africa, KwaZulu –Natal has recorded the highest provincial HIV prevalence (Zuma *et al*., 2016). These statistics are important because they expose the probable direction of transmission as moving from high to low prevalence (UNAIDS, 2016b), as illustrated below.

Figure 2.1: HIV transmission trends in South Africa



Source: UNAIDS (2016b).

The data above suggests that men living with HIV who are aged 25 – 40 years are infecting younger women (ages 15-25years), but these men are infected by women who are aged 25- 40 years. Over time, the younger women grow older and this cycle is expected to continue. Due to a youth bulge that is particularly pronounced in sub-Saharan Africa, there are far more young men and women today than there were at the beginning of the epidemic (AVAC, 2016b). Today, rates of HIV in young women continue to increase and research shows that there are 30% more young

women than there were when the HIV epidemic began (AVAC, 2016b). I argue that if prevention is not effectively targeted at this population, there is potential for early gains in the fight against the epidemic to be reversed. Consequently, understanding AGYW's HIV incidence and the reasons for the high risk of HIV infection is important because it allows health communication specialists to design and implement age-specific, targeted interventions that can make an impact on the epidemic where others thus far have failed (Karim, 2016).

The scope of HIV prevention and treatment options has never been wider than it is today (Sakarombe, 2014, UNAIDS, 2017b). HIV prevention interventions such as the reduction of mother to child transmission have ensured that children are born HIV free. Significant gains have been made to ensure a healthy young population with anti-retroviral medicines averting 1.6 million new HIV infections among children since 2000 (UNAIDS, 2016b). However, adolescence is a turbulent time, especially for young women living in sub-Saharan Africa who are at greater risk of contracting HIV. Therefore, empowering adolescent girls and young women gives them the means to protect themselves from becoming infected with HIV. It also promotes their access to HIV prevention services.

Factors contributing to young women's vulnerability to HIV infection

Although South Africa has a generalised HIV epidemic, some sub-populations are at a higher risk of contracting HIV (Karim *et al.*, 2017). Furthermore, the burden of disease is not the same across all areas. It is therefore, important to ensure that HIV prevention services in each district are tailored to the specific needs of these groups based on a comprehensive package of appropriate interventions (Department of Health – DOH, 2016b).

Data sourced from seven longitudinal studies in six locations in Eastern and Southern Africa from 2010 – 2014 reveals that young women aged 15-25 years accounted for 23% of new HIV infections while boys and young men in the same age group accounted for 11% of new HIV infections (UNAIDS, 2016a). The same studies show that young women constitute as much as 91% of new infections in the same age group in some cohort studies in sub–Saharan Africa (UNAIDS, 2016a). In South Africa, evidence shows that adolescent girls and young women (AGYW) are a key population, significantly affected by HIV and account for a disproportionate number of new HIV infections (Baxter and Abdool Karim, 2016). Thus, this illustrates that HIV preventions have neither reached nor benefitted this key population (Nota, 2015, DOH, 2016). However, adolescent

girls and young women's heightened susceptibility to HIV goes far beyond physiology: it is intricately linked to entrenched gender inequalities, harmful gender norms, and structures of patriarchy that limit women and girls from reaching their full potential and leave them vulnerable to HIV infection (Karim, 2016, Naicker *et al.,* 2015). Therefore, behavioural, biological and cultural factors make women more vulnerable to HIV infection. These are explored in detail below.

Behavioural factors

Several studies point towards behavioural factors through which women negotiate safe-sex practices or condom use with their male partners (Ma *et al.*, 2009, Simbayi *et al.*, 2014). Risky behaviour such as unprotected sex and multiple concurrent sexual partners are still common among young women (Jewkes *et al.*, 2010). In sub–Saharan Africa, adolescent girls and young women tend to acquire HIV at a much earlier age when compared to their male peers (Karim *et al*., 2017). This disproportion of age and sex in infection rates is a result of young girls becoming sexually involved with men who are about 5 – 10 years older than them. These men are either living with HIV but are not on treatment or have just been recently infected (Karim *et al*., 2017). In such cases, gender inequality and the threat of intimate partner violence limit a woman's ability to successfully negotiate condom use with male partners, to insist on mutual monogamy, or to convince partners to have an HIV test (Saag, 2015).

Young women often have various reasons for engaging in sexual relationships with older men. Although some relationships are based on love or sexual curiosity, in some instances, particularly for those from impoverished backgrounds, young women may engage in transactional sex and benefit financially from such relationships (Karim *et al*., 2017). Therefore, poverty, labour migration and urbanisation contribute to young women's increased susceptibility to HIV. Thus, understanding the drivers of this partnering pattern and learning more about these male partners is critical to addressing the prevention needs of adolescent girls and young women.

Biological factors

Biological factors further compound adolescent girls and young women's vulnerability to HIV in Southern Africa, which results in them being up to eight times more likely to be infected when compared to their male peers (Dellar *et al.*, 2015). Scholars agree that the biological factors that make women more vulnerable than men in acquiring HIV have not been fully established (Klatt

et al., 2017, Selhorst *et al*., 2017). However, it has been suggested that the inflammation of the genital tract increases the risk of HIV infection (Selhorst *et al*., 2017). This is because bacterial vaginosis is linked to reduced reproductive health outcomes in women (Klatt *et al.*, 2017). Moreover, factors which affect the integrity of the genital tract such as sexually transmitted infections (STIs) and intra–vaginal insertion practices, either for cleansing or enhancing sex, may increase susceptibility to HIV by facilitating viral entry (Naicker *et al*., 2015). This biological vulnerability of adolescent girls places them at higher risk than older women and men in general.

Cultural factors

Culture plays a prominent role in influencing levels of health in the individual, the family and the community (Airhihenbuwa and Webster, 2004a). Therefore, it is essential to explore cultural factors that contribute to women's increased vulnerability to HIV infection in comparison to their male counterparts.

The Zulu culture is characterised by gender inequality, and the socio-cultural *isoka* ideal of multiple sexual partnerships (Varga, 1997). It is also synonymous with lack of discussion on matters of sexuality in the home and between sexual partners, the conditioning of both men and women to accept sexual violence as 'normal' masculine behaviour along with the 'right' of men to control sexual encounters and the existence of increasingly acrimonious and debated gender scripts (Leclerc-Madlala, 1994). For example, while a young man may be admired and praised for having multiple sexual partners as per the *isoka* cultural practice, a woman with numerous boyfriends is likely to be called "isifebe", the Zulu word for whore (Leclerc-Madlala, 2001). *Isoka* refers to the cultural practice of a man having more than one known girlfriend. This construction of masculinity often means that even when a man is emotionally invested in a long term relationship with a female partner, he is able to make a distinction between this relationship and other relationships he has with other women (Gibbs *et al.*, 2014). These relationships are usually short term and focused on sexual gratification. This has a direct impact on the high HIV infection statistics among women because having multiple concurrent sexual partners increases the risk of contracting the virus.

Gender and power inequaltities often expose women in relationships to HIV infection (Mthembu *et al.*, 2016). Thus, a woman who is a victim of violence is often at a disadvantage when it comes to negotiating condom use in a relationship. Additionally, even without violence in a relationship,

women still need to negotiate condom use with their partners who may or may not agree to use a condom. This is because most HIV prevention methods do not give women power for autonomous decision making (Baxter and Abdool Karim, 2016). Relying on their partners for permission to use condoms is problematic because women have limited control over whether their male partners remain faithful or not.

Furthermore, socio-cultural beliefs about how young women should conduct themselves sexually have encouraged them to be sexually available to partners and allow male partners to have sexual decision making authority (Casale *et al*., 2011). Therefore, gendered expectations of behaviour in the Zulu culture play a role in the vulnerability of women. Although other scholars argue that females are not always submissive and passive participants in sexual relationships that may appear unequal (Bernstein and Osman, 2016, Shefer, 2016), a woman's circumstances can leave her more exposed to infection.

HIV prevention methods have evolved since the advent of HIV, but these have not been without their own challenges. While oral PrEP is seen as a women-centred HIV prevention technology, studies show that partner involvement ultimately plays a role in whether oral PrEP is adopted or rejected (Minnis *et al*., 2013, Montgomery *et al*., 2015). Therefore, it is important to understand how men perceive the product to ensure that any negative perceptions are addressed in targeted communication about oral PrEP. Similarly, barriers and enablers affecting acceptability of PrEP among AGYW need to be understood because research has shown that this key population contracts HIV from older men that they are involved with. These men, in turn, infect the women in their age group (UNAIDS, 2016b). Therefore, understanding barriers and enablers cto oral PrEP uptake, may lead to the reduction of HIV prevalence in this key population. It is for this reason that in the quest to understand user profiles of oral PrEP in Vulindlela, KwaZulu –Natal, this study also engages men who are also at risk of HIV infection.

Role of culture in HIV prevention

Culture is defined as a structure of interconnected values dynamic enough to inform and shape perception, decision-making, behaviour and communication, and behaviour in a given society (Airhihenbuwa and Webster, 2004b). Research has established that health and well-being are inherently linked to culture (Wilson *et al*., 2016). This is epecially significant in the African context, where culture plays a part in influencing the level of health of the individual, the family

and the community (Airhihenbuwa and Webster, 2004b). Consequently, culture is often presented as a factor in the numerous ways in which HIV and AIDS have had an impact in Africa (Airhihenbuwa *et al*., 2014). Such factors range from sexuality including the accepted number of sexual partners one is expected to have; gender equality, condom use and the construction of masculinity in African culture (Airhihenbuwa and Webster, 2004b). Thus, associating culture and HIV transmission problematises culture and results in a narrow view of HIV prevention.

As a matter of fact, a number of theories about health behavior in public health and health promotion tend to conceptualise health behaviours as challenges occuring as a result of an individual's failure to adopt recommended preventive behaviours or treatment (Airhihenbuwa *et al*., 2014). However, Mohan Dutta (2008) suggests that engaging a culture-centered approach to health means functioning from within the culture to identify health issues that community members consider important and relevant. In this way, people's failure to adopt preventive behaviours is not only credited to the individual, instead it is attributed to the insufficient attention given to the part and influence of culture. Therefore, to be effective HIV prevention interventions need to address those broader concerns.

Scholars have contended that a health intervention's success rests upon the extent to which it is customised to the local cultural context (Olson and Anderson, 2013). Thus, if negative health behaviours are to be changed, it is imperative to identify and encourage positive health behaviours from within the cultural logic of its environments (Asad and Kay, 2015). If acceptance and uptake of oral PrEP is to be ensured, it is imperative to begin with a focus on individual cultural contexts where individual values, attitudes, beliefs, and behaviours are explored (Trickett *et al.*, 2011). This will give an indication of the type of person that is interested in using oral PrEP as well as a classification of influences in which one is likely to use oral PrEP. Once an understanding of influences that determine acceptance and uptake at individual level has been achieved, an exploration of influences at contextual level can be undertaken.

Perception of risk in HIV prevention

Literature suggests that perception of risk is one of the important factors that promote risk behaviours or create barriers to safer sexual practices (Gallagher *et al.*, 2014). Risk is generally regarded as conssisting of two components: the likelihood and the severity of negative outcomes (Landovitz *et al.*, 2013). Perceived risk is one of several key constructs in many theories of health

behavior change, such as the health belief model and the protection motivation theory (Corneli *et al*., 2014). While individuals may be motivated to take action to reduce risk behaviors if they perceive some risk in such frameworks, they may may also be discouraged to change their risk behaviours if they perceive no risk (Caldwell and Mathews, 2016). Thus, low perceived risk is a risk factor because it reduces the motivation to take the necessary precautions.

The lack of women-initiated HIV prevention methods is well documented (Celum, 2009). With proven results regarding efficacy, oral PrEP could potentially reduce the high incidence of HIV infection among AGYW (Karim, 2016). However, for individuals to take advantage of oral PrEP as a new HIV prevention method, they must first perceive themselves at risk of HIV and consider oral PrEP as a viable method to prevent HIV. Therefore, the current study seeks to understand perceptions of risk among AGYW and men in Vulindlela, South Africa. Understanding perceptions of risk will lead to an exploration of how these perceptions influence the acceptability of oral PrEP among this key population group.

Complexities of current HIV prevention methods

The HIV epidemic in South Africa is firmly established within the generalised heterosexual community, but local key populations with high incidence include sex workers as well as adolescent girls and young women (Venter *et al.*, 2015). The current study focuses on adolescent girls, young women and men. Numerous HIV prevention methods and interventions have been implemented globally and in South Africa since HIV was first diagnosed, but these have not been without challenges (Bhana and Petersen, 2009). The following section addresses HIV prevention interventions and their shortcomings particularly regarding their use by AGYW.

The ABC approach

Most of the world's governments implemented the Abstain, Be faithful, and Condomise (ABC) approach not only to curb the social and economic impacts of HIV and AIDS (Murphy *et al.*, 2006), but also to mitigate the epidemic as a public health threat (Baxter and Abdool Karim, 2016). This approach was particularly lauded in Uganda and Thailand, where it was credited with reducing the number of HIV infections (Murphy *et al*., 2006, Wilson, 2004). The A and B components of this strategy focus on avoiding risk, while the C component is aimed at reducing risk (Thomas *et al.*, 2017). Although "Be faithful" literally implies monogamy, it also includes

reductions in casual sex and multiple sexual partnerships (and related issues of partner selection) that would reduce higher risk sex. Based on this approach, Thailand's "100% condom" approach in brothels was widely credited with reversing its more concentrated epidemic (Wilson, 2004). In Uganda, a large national decline in HIV infection across all age groups between 1989 and 1995 was reported (Shelton *et al*., 2004). While the ABC approach contributed to a decline in HIV infections in these countries, it is important to note that it was not very practical. This is because abstinence until marriage cannot be guaranteed, especially among the youth. Further, this approach does not consider cases where women are sexually abused or cannot negotiate condom use in relationships due to gender scripts common in African culture (Moodley, 2007).

The condom

The condom is a highly effective device in preventing HIV transmission if it is used correctly and consistently (Hearst and Chen, 2004). However, despite evidence of the efficacy of condoms in preventing HIV transmission, studies have found that consistent use of condoms is still significantly low, particularly with primary partners (Yam *et al*., 2016).

The male condom

Strategies to change risk behaviours have remained a main priority for HIV prevention. These strategies have tended to focus on condom use as a means of risk reduction. The South African government has implemented the male condom since 1992 (Beksinska *et al.*, 2012). However, subsequent to fears that public sector condoms were of inferior quality, the Department of Health (DOH) launched the rebranded male condom known as "*Choice*^{tm}" (Johnson *et al*., 2010). Public perceptions about the *Choice* condoms were mixed, with many members of the public complaining about their smell, packaging and poor quality of the latex (Beksinskai *et al.*, 2017). In 2016, the Choice condoms underwent another rebranding exercise. They were designed to appeal to the sexually active youth and encourage them to practice safe sex (Chiu *et al.*, 2017). They are now known as *the Max* and come in a variety of colours and scents.

Figure 2.2 Choice and Max condoms

Source: DOH (2016a)

However, three important elements hinder the practical effectiveness of this method. Firstly, inconsistent use of condoms provides no protection against transmission of HIV and STIs. Research shows that exposure to condom education and increased awareness of risk does not always result in safer sex choices when adolescents are sexually aroused and only a minority of people engaging in risky sexual behaviour use condoms regularly (Dokubo *et al*., 2014, Matthews *et al*., 2015). Secondly, condoms provide limited protection against sexually transmitted infections such as the human papillomavirus (HPV) and syphilis, among others (Jemmott III *et al*., 2014). Thus direct skin contact with pathogens throughout the external genital area compromises the protection offered by the condom. Finally, rates of mechanical failure and user error are significantly high, especially in young people (Hensel *et al*., 2016).

Condom use tends to be challenging for young women in the South African context (Harrison *et al*., 2015). Condoms are stigmatised in intimate relationships, and female partners who suggest the use of condoms may be accused of unfaithfulness in relationships (Shisana *et al*., 2016). Further, adolscent girls and young women are inconsistent in condom use in casual relationships often made worse by alcohol and other substance abuse (Evans *et al*., 2016, Harrison *et al.*, 2015). Therefore, it can be argued that the male condom perptuates male dominance and promotes the idea ascribed by patriarchal societies that men are entitled to sex, thus increasing the risk of HIV infection for women (Madiba and Ngwenya, 2017).

The female condom

The year 1998 saw the introduction of the female condom as part of a national family planning programme in South Africa (HSRC, 2014). The female condom differs from the male condom in that it has an elongated casing that has a fixed ring on the outer open side and a loose ring on the inner closed side to help with insertion into the vagina (HSRC, 2014). It was introduced as a response to concerns over the lack of women-controlled HIV prevention methods. Thus, the female condom would allow women to gain control over their sexuality and protect themselves from HIV infection (Peters, 2016).

Figure 2.3 Differences between the male and female condom

Source: Planned Parenthood (2017)

Nevertheless, the introduction of the female condom was beset by challenges. First, it proved to be more expensive when compared to the male condom and this became a prohibitive factor for women (Ackerson and Zielinski, 2017). Moreover, while the South African government took the initiative to distribute the female condoms as it did the male condoms, distribution was at a lower scale for female condoms (Tallis, 2012). This meant that even if women wanted to use the female condoms, lack of access proved to be a barrier. Furthermore, women would still need to rely on their sexual partners for permission to use the female condom. This is contrary to its purpose as a female-initiated intervention, which was to empower women to protect themselves against HIV infection.

Although the effectiveness of the male condom in blocking HIV transmission was never in question, widespread promotion of male condoms ignored the need for female-initiated prevention methods (Guerra *et al*., 2016). One of the studies conducted in South Africa reveal that men were interested in using the female condom for experience in terms of ease of use and sensation, to share responsibility of using condoms with their partners and because their partners wanted to try it (Masvawure *et al*., 2014).

HIV counselling and testing (HCT)

HIV counselling and testing (HCT) has been another cornerstone of HIV management in South Africa (Mambanga *et al*., 2016). HCT is an intervention that comprises a minimum of pre- and post- test counselling associated with testing (Shitaye *et al*., 2017). It is about knowing your status so that those positive can seek medical treatment and those negative can take steps to remain negative (Phillip *et al*., 2014). The main aim of HCT is to encourage people to change their sexual behaviour to avoid transmitting HIV to sexual partners if they are HIV positive, and to remain HIV negative if testing proves negative. Thus, HCT is the entry point in any aspect of HIV prevention (UNAIDS, 2016).

In an effort to control the aggressive HIV epidemic whose catastrophic effects were already evident, the South African government had established more than 450 voluntary counselling and testing centres with more than 800 counsellors around the country by 2003 (Kalichman and Simbayi, 2003). However, uptake was slow due to negative perceptions of testing services and AIDS related stigmas in the early implementation phases (Kalichman and Simbayi, 2003). Hence, AIDS related stigmas created barriers to seeking HCT, but not to learning one's test results. Furthermore, people often did not return for their test results when they had to wait days for test result notification (Herek *et al.*, 2002). To overcome this challenge, South Africa introduced the rapid testing offering same day results (Van Rooyen *et al.*, 2013). However, the focus on early detection and anti-retroviral treatment (ART) as well as Universal Test and Treat served to normalise HIV testing and counselling in South Africa. Because public health clinics offered free sexually transmitted infections (STIs) services and HIV testing free of charge, providers could initiate patients on HTC (Leon *et al*., 2014).

In this way, HIV positive patients are linked to HIV care services where they can access ART while HIV negative patients are guided on how to maintain their negative status. Furthermore, integrating HIV testing into standard clinical care has played a big role in noramilising HTC (Mambanga *et al.*, 2016). This takes away the voluntary aspect of HTC, focusing on getting a lot more people tested. Thus, HCT is the entry point to prevention, treatment, care, and support for the HIV infected individual and for voluntary medical male circumcision (VMMC) (Kurth *et al.*, 2015).

Voluntary medical male circumcision

VMMC is the removal of all or part of the foreskin of the penis facilitated by a trained health professional (AVAC, 2016). Whereas VMMC has been found to reduce men's risk of acquiring HIV from their female partners by roughly 60% (Bailey *et al*., 2007), male circumcision as a HIV prevention strategy has many challenges. Such challenges include the need for abstinence after circumcision, fear that the procedure may cause sexual dysfunction, and the pain associated with the procedure (Evens *et al*., 2014, Sgaier *et al*., 2016). Once a man undergoes circumcision, the procedure is irreversible and the partial protection continues throughout his lifetime. In South Africa, some of the reported barriers to VMMC include age, ethic group, culture, lack of time and fear of pain (Marshall *et al*., 2016). Thus, older men who belong to ethic groups and cultures where circumcision is not a cultural practice tend to resist VMMC.

There is a growing concern that men who undergo VMCC may cultivate a false sense of protection against HIV and lead to such behaviour as poor adherence to consistent and correct condom use, which supplements chances of failure (Njeuhmeli *et al*., 2011, Shisana *et al*., 2014). Thus, in spite of the encouraging trial results, valid concerns remain about the possibility that VMMC could lead to increases in high-risk sexual behaviour (George *et al.*, 2014). A rise in risky sexual behaviour after circumcision could potentially offset positive results of circumcision if not prevented by means of appropriate health education, including testing for HIV (Westercamp *et al*., 2010). These concerns are important to consider in South Africa as it is one of the 14 countries that were considered for a rapid scale-up of VMMC services due to its high HIV prevalence (Rech *et al.*, 2014).

Universal test and treat

Universal test and treat (UTT) is a prevention strategy that promotes high levels of HIV testing and beginning antiretroviral therapy upon diagnosis, regardless of CD4 cell count (Cambiano *et al*., 2011). The strategy was launched at the 20th International AIDS Conference in Melbourne in 2014, in the form of the 90–90–90 targets, which have become a central pillar of the global quest to end the AIDS epidemic (UNAIDS, 2014a). In December 2013, the UNAIDS Programme Coordinating Board called on UNAIDS to support country and region-led efforts to establish new targets for HIV treatment scale-up beyond 2015 (UNAIDS, 2014a).

This led to the development of the 90–90–90 strategy. This initiative is now building momentum towards a new narrative on HIV treatment and a new, final, ambitious, but achievable target. The target is to ensure that by 2020, 90% of all people living with HIV will know their HIV status, 90% of all people with diagnosed HIV infection will receive sustained antiretroviral therapy and 90% of all people receiving antiretroviral therapy will have viral suppression as illustrated in Figure 2.4 below (Baxter and Abdool Karim, 2016). Therefore, the UTT strategy has the potential to decrease HIV transmission by the early recognition and treatment of HIV infection (Colby *et al.*, 2015).

As hopes for ending the AIDS epidemic depend in a large measure on the world's ability to provide HIV treatment to all who need it, final targets for universal treatment access are critical. Nevertheless, treatment alone will not be enough to end HIV, consequently supporting prevetion efforts still remain critical (Isbell *et al*., 2016). Thus, meeting these ambitious targets requires a scale-up of effective HIV prevention methods and creative ways to reach key populations who may not yet know their HIV status (Baxter and Abdool Karim, 2016).

Figure 2.4 The 90–90–90 targets in regions, countries and communities

Source: (UNAIDS, 2014a)

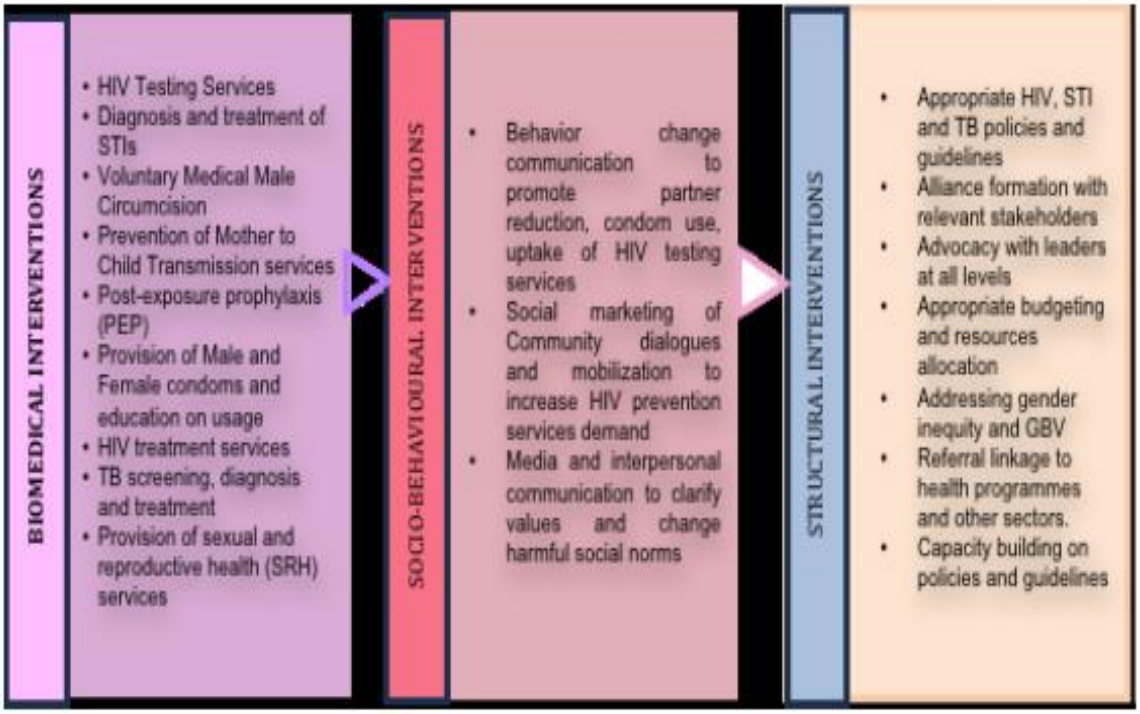
To align with the UNAIDS 90-90-90 strategy, South Africa developed the National Development Plan 2030, the Health Sector HIV Prevention Strategy, 2016 and the Strategic Plan of the National Department of Health 2015-2020 (DOH, 2016, DOH, 2015). These documents are regarded as an important step for South Africa in keeping pace with global guidance and recommendations and both have a strong focus on HIV combination treatment.

Combination prevention

Combination prevention refers to the notion of integrating biomedical and structural interventions with socio-behavioural approaches to achieve maximum impact on HIV, thus preventing new HIV infections (Baxter and Abdool Karim, 2016). Despite the fact that these HIV prevention methods have contributed to the reduction of HIV infection individually, they have not been successful in completely eradicating the epidemic (Celum *et al*., 2013, Karim *et al*., 2017). While prevention efforts might reduce HIV incidence, they are unlikely to eliminate the disease on their own, considering that there were approximately 36 million people living with HIV in 2016 (UNAIDS, 2017a). Therefore, prevention efforts must not focus on those that are already infected, but must consider at-risk groups as well (Karim, 2016). In South Africa, the DOH has identified at risk populations that can benefit from combination treatment, and these include AGYW. The

department's strategy is to provide biomedical, socio-behavioral and structural interventions to address factors contributing to the vulnerability to key populations.

Figure 2.5: Combination prevention packages



Source: DOH (2016)

A massive expansion of antiretroviral therapy (ART) has reduced the global number of people dying from HIV related causes to about 1.1 million in 2016, compared to 2005 when 2.5 people died of HIV related causes (UNAIDS, 2016a). This significant improvement has been attributed to the provision of combination antiretroviral therapy (Fox *et al.*, 2016, Tanser *et al.*, 2013). Along with HCT, VMMC is a core component of HIV combination prevention. Other elements of combination prevention include HIV testing, access to PrEP for HIV negative people as well as male and female condoms (AVAC, 2016).

Combination prevention recognises that no single intervention is fully effective in preventing HIV infection. Thus, oral PrEP as a public health intervention is important, especially if it is targeted at AGYW as a key population (Venter *et al.*, 2015). Oral PrEP is currently the first biomedical intervention that has demonstrated effectiveness in reducing HIV transmission (Baxter and Abdool

Karim, 2016, Karim, 2016). It is also the first biomedical intervention for which several African countries such as Kenya, Lesotho, Malawi, Namibia, Tanzania, Swaziland, Zambia and Zimbabwe have already approved guidelines for individuals at substantial risk of HIV as part of combination HIV prevention (Cowan *et al.*, 2016). Therefore, prevention interventions for girls and young women aged 15-24 years must become the highest priority among health authorities and services at every level.

HIV prevention methods have continued to evolve over time, but none of these HIV prevention methods allows women autonomy over their own bodies yet they are highly vulnerable to HIV infection. Therefore, this discussion underscores the fact that the need for more women-centred HIV prevention technologies still remains a key priority, especially in South Africa (Govender *et al*., 2017).

Microbicides

Current HIV prevention methods have had a very limited impact on reducing high HIV infection rates among AGYW in sub-Saharan Africa (Karim *et al*., 2010, Sánchez-Rodríguez *et al*., 2015). In response, research has moved in three new directions. Firstly, new agents now include antiretroviral compounds that specifically prevent HIV duplication, which might be effective for prevention of HIV transmission than their non-specific counterparts (Cottrell and Kashuba, 2014). Secondly, formulation research is moving towards long-acting dispersal methods and away from products that need to be frequently applied or those that require application just before sexual intercourse (Patel and Rohan, 2017). Thirdly, combination products composed of several different compounds with different mechanisms of action are undergoing preclinical assessment (Smith, 2017). Microbicides are products that can be applied vaginally or in the rectum to reduce the risk of acquiring HIV and otherSTIs (Karim *et al*., 2010). However, challenges on this method persist. One of the challenges included limited effectiveness due to poor adherance to the product (Karim *et al*., 2010, Nota, 2015).

The Centre for the AIDS Program of Research in South Africa's (CAPRISA) 004 trial evaluated he effectiveness and safety of a 1% vaginal gel formulation of tenofovir, to prevent HIV infection in women (Karim *et al*., 2010). Although the study's sample was small and therefore cannot be

generalised, results were quite promising. Data shows that tenofovir gel appears safe and effective in preventing HIV infection (Karim *et al.*, 2010). Thus, trials and demonstration projects on oral and topical microbicides are ongoing in South Africa and other sub-Saharan countries, as illustrated in Table 2.1.

Table 2.1. Ongoing and planned demonstration oral, topical, and open label extension projects involving women, men, MSM, sex worker and discordant couples

Study/ Project	Population	Description	Location	Status
Partners demonstration project	1000 HIV serodiscordant couples	Open label Daily Truvada (TVD) oral as bridge to treatment in infected partner. F/up 24 months	Kenya, Uganda	Enrolling Results 2014/ 15
CAPRISA 008	150 young men and women (15-19 yr)	Open label 1% TDF vaginal gel BAT 24	South Africa	Enrolling Results 2013
CHAMPS-SA PrEP	Not stated	Open label TVD oral	South Africa	Enrolling Results 2015/6
SAPPHIRE FSW RCT	2800 MSM	Open label Oral daily TVD	Zimbabwe	Enrolling
TAPs: Expanded use of ART for treatment and prevention for female sex workers in South Africa	400 FSW	Open label PrEP and immediate ART for FSWLWHIV	South Africa	Enrolling
Sibanye MSM Project	200 MSM	Open label (adult MSM)	South Africa	Enrolling Results 2015/16
PrEP FOR MSM	300 MSM	Open label (adult MSM)	South Africa	Under review
ASPIRE	2629 heterosexual women	Placebo RCT Dapivirine vaginal ring	Zimbabwe, Malawi, Uganda, South Africa	Enrolling 2015
RING study	1959 heterosexual women	Placebo RCT Dapivirine vaginal ring	South Africa	Enrolling 2015

Source: Venter *et al.* (2015)

As shown in Table 2.1, the efficacy of microbicides such as tenofovir (TDF) or TDF co-formulated with emtricibine and dapivirine is currently being studied under various projects in South Africa, Kenya, Uganda, Malawi and Zimbabwe. These studies include populations that are at high risk of HIV infection such as men who have sex with men (MSM), heterosexual women, female sex workers, sero-discordant couples as well as young men and women.

While microbicides have the potential to reduce the high HIV infection rates in South Africa, challenges abound. There are concerns about the relevance of microbicides in HIV prevention. This is because microbicides do not address underlying issues such as unequal gender-power relations and complex socio-cultural issues, which contribute to women being disproportionately affected by HIV infection (Nota, 2015). Additionally, perceptions, knowledge and acceptance influence uptake of HIV prevention methods such as microbicides, therefeore, these need to be investigated before interventions are made available to the public (Nota, 2015). Finally, there is a need to consider the structural and human resources in the public health system to ensure that the addition of new HIV prevention methods such as microbicides does not burden an already constrained public health system in South Africa (Eyles *et al*., 2015, Nota, 2015).

However, while research is ongoing on the efficacy of topical gels in HIV prevention, great strides have been made regarding oral PrEP. While the current study acknowledges the history of clinical trials and various dosing options, the focus is on oral PrEP because it is currently the only biomedical intervention that has not only been proven to be highly effective in preventing HIV acquisition, but also been approved for use (Baxter and Abdool Karim, 2016, Venter *et al.*, 2015).

Oral PrEP

The global need for effective HIV prevention programmes has never been more urgent. The number of people receiving antiretroviral drugs in low- and middle-income countries has increased immensely in the last seven years (Idele *et al.*, 2017), with 11.7 million people accessing antiretroviral therapy in eastern and southern Africa in 2016 (UNAIDS, 2016a) compared to 4.1 million people in the region in 2010 (UNAIDS, 2011).

The first widespread use of antiretroviral drugs for prevention started in the 1990s with antiretroviral prophylaxis to prevent mother-to-child transmission of HIV (Hatcher *et al*., 2016). Research shows that when used in mother-to-child transmission, antiretroviral prophylaxis has three effects: firstly, it reduces infectiousness by lowering the infected mother's viral load, secondly, it provides Pre-Exposure Prophylaxis (PrEP) to the infant, and thirdly, it provides post-exposure prophylaxis for the infant after birth (Gumede-Moyo *et al*., 2017, Nachega *et al*., 2016).

Since 2010, evidence for the protective benefits of oral pre-exposure prophylaxis (PrEP) has been consistent in numerous settings and populations (Baxter and Abdool Karim, 2016). The use of

antiviral medications by HIV negative people to prevent acquisition of HIV or pre-exposure prophylaxis (PrEP) has shown promising results in recent trials (Eisingerich *et al.*, 2012). Therefore, oral PrEP has the potential to reduce the high infection rates among key population groups such as AGYW.

The past few years have seen substantial new advances in knowledge regarding antiretroviral-based PrEP, including definitive demonstration that PrEP is highly effective in preventing HIV acquisition (Baeten and Grant, 2013). In fact, PrEP "with oral tenofovir (TDF) or TDF co-formulated with emtricibine (TDF/FTC), also called Truvada, demonstrated HIV prevention benefits of up to 75% reduction in HIV incidence" (Celum *et al*., 2015). This data was reported in four trials conducted among men who have sex with men (MSM) in a multi country study, injection drug users in Asia and in HIV serodiscordant couples and young men and women in Africa (Choopanya *et al*., 2013, Thigpen *et al.*, 2012). A sero-discordant couple refers to people who are in relationships where one partner is HIV positive and the other is HIV negative (El-Bassel *et al.*, 2014).

Clinical trials show that if taken daily as prescribed, oral PrEP has high efficacy as an HIV prevention strategy. However, data from the same clinical trials indicates that most participants did not take oral PrEP as prescribed (Auerbach *et al*., 2015). Adherence is an important factor because it determines the efficacy of the treatment, therefore, studies exploring determining factors that affect adherence are still needed (Auerbach *et al*., 2015), however, this issue is outside the scope of this study. A clear benefit of oral PrEP is its potential to address the issue of lack of agency and control among women when it comes to HIV prevention methods (Montgomery *et al.*, 2015, Wechsberg *et al.*, 2015). Whereas women have had to depend on their male partners' willingness to use condoms as their primary prevention strategy, oral PrEP offers women the possibility of autonomy over their own bodies by allowing them to take oral PrEP without their partner's knowledge if they so wish. Moreover, the fact that oral PrEP can be taken any time during the day and not have it interrupt sexual activity is advantageous (Auerbach *et al*., 2015). This makes oral PrEP convenient and unobtrusive, which is uncommon in many HIV prevention methods. Further, oral PrEP is already available globally and locally in both branded and lower cost generic formulations (Celum *et al*., 2015). This makes it a viable HIV prevention strategy when compared to other microbicides-based options like the gel and injection, which are still under

clinical trial (AVAC, 2016a, Celum *et al*., 2015). Therefore, with strong evidence for the efficacy and effectiveness of oral PrEP across multiple studies, it is essential to understand possible facilitators and barriers to the uptake of oral PrEP for HIV prevention among AGYW.

Possible barriers and facilitators to uptake of oral PrEP

In a pilot study with key populations to understand ability and content validity in India, Kenya and South Africa, it was discovered that participants were generally willing to accept oral PrEP and adopt it as soon as it becomes available despite multiple barriers and uncertainty (Eisingerich *et al*., 2012). While oral PrEP is seen as a women-centred HIV prevention technology, studies show that partner involvement ultimately plays a role in whether it is adopted or rejected as a viable HIV prevention method (Montgomery *et al*., 2015, Nota, 2015). In the same pilot study, (Eisingerich *et al*., 2012) participants indicated that they would want their partners to know that they were using oral PrEP therefore, it is important to understand men's perceptions of oral PrEP to ensure that any negative perceptions are addressed in targeted communication. Similarly, barriers and enablers affecting acceptability of oral PrEP among AGYW need to be understood. Literature suggests that this key population contracts HIV from older sexual partners and in turn, they infect the men in their age group (Karim, 2016, UNAIDS, 2017b). Therefore, addressing barriers and encouraging enablers could ensure uptake of oral PrEP, possibly leading to the reduction of the high HIV prevalence in this key population group.

Concerns about the health impacts of oral PrEP

In one study, participants expressed concern about oral PrEP's long-term consequences and short-term side effects (Golub *et al.*, 2013). Side effects such as nausea were present for a time frame of about four weeks during the iPrEX trial and could be managed through the use of over the counter medication (Amico *et al*., 2011, Grant *et al.*, 2010). In contrast, some literature suggests that tenofovir oral PrEP may be associated with significant, though modest, renal function problems and these findings seem supported by low rates of renal problems among participants across PrEP studies (Karim *et al.*, 2010, Solomon *et al.*, 2014). There are also concerns about future infection and potential drug resistance in the event people become infected with HIV (Thomson *et al.*, 2016). Other people have expressed fear that PrEP might not provide complete protection against HIV (Golub *et al.*, 2013). Therefore, information about PrEP should address such health concerns and

provide potential PrEP users with information about side effects and their management to address this possible barrier to the uptake of oral PrEP.

Interpreting the efficacy of oral PrEP

An understanding of the effectiveness of oral PrEP emerged as an important barrier to potential and effective use in another study (Young and McDaid, 2014b). Although participants were informed that oral PrEP was highly effective when taken regularly, many participants indicated that anything that provided less than 100% protection against HIV infection was insufficient to prevent transmission on its own (Young and McDaid, 2014b). Participants expressed concern at what they termed the ‘‘partial efficacy’’ of oral PrEP, suggesting that they may evaluating whether to use oral PrEP as an alternative to condom use (Greene *et al*., 2017). In a study that examined oral PrEP awareness amongst sub-groups of MSM communities, participants also expressed a general scepticism about oral PrEP, which emerged in two ways. Firstly, some participants thought that the advice to use condoms with oral PrEP indicated a continued scientific uncertainty (Frankis *et al*., 2016). Secondly, other participants expressed scepticism in relation to the inconsistency in reported efficacy rates pertaining adherence, and consequently, there was an unwillingness to trust these unless they came from someone they trusted personally (Frankis *et al.*, 2016). This suggests a need to ensure concise and consistent messages about the efficacy of oral PrEP while emphasizing adherence to address this possible barrier to uptake of prevention option.

PrEP candidacy and low perceptions of HIV risk

Perception of risk was identified as an important psychological barrier to candidacy for oral PrEP (Frankis et al., 2016, Young et al., 2014a). Many people have expressed doubt about taking oral PrEP daily, particularly if they were not always exposed to or at risk of HIV infection (Young *et al.*, 2014a). Therefore, the HIV status of potential users of oral PrEP may have an impact on influencing uptake. One exploratory study found that HIV-negative participants commonly expressed an unwillingness to consider oral PrEP as a way to prevent HIV infection in a sero-discordant relationship (Young and McDaid, 2014b). These participants' responses were generally framed by fear of any sexual contact with a known HIV-positive sexual partner, which implies that they would never knowingly engage in sexual relationships with people who are HIV positive. However, for the rest of the largely HIV-positive participants, oral PrEP was not embraced as a

primary prevention strategy because of a low perception of risk of HIV transmission and a perceived lack of need for additional protection (Young and McDaid, 2014b). HIV positive participants considered current HIV prevention methods, such as condom use, as sufficient to prevent re-infection. This is an important finding because it reveals two potential barriers to uptake of oral PrEP. Firstly, there seems to be stigma surrounding the notion of being in a serodiscordant relationship. This is a cause for concern because in a country like South Africa where the HIV epidemic is generalised, there is higher risk of unknowingly choosing a partner who is already infected with HIV (Karim *et al*., 2017). Secondly, this observation affects disclosure. In a society where people are stigmatized and discriminated against for being HIV positive, such people are unlikely to disclose their status. Furthermore, this serves as a deterrent towards testing for HIV even among people who may still not know their HIV status.

Stigma and partner knowledge in oral PrEP uptake

The use of antiviral medications by HIV negative people to prevent acquisition of HIV or PrEP has shown promising results in recent trials (Baxter and Abdool Karim, 2016, Karim et al., 2017). Data suggests that women consider oral PrEP as an essential HIV prevention option for themselves and their communities, and that they would contemplate using it if it was offered free of charge, is highly effective, provided by trusted providers in trusted venues and if the side effects are minimal (Auerbach et al., 2015, Fisher et al., 2017). However, some participants in another study mentioned that the thought of taking PrEP made them feel anxious, although they also indicated that taking PrEP would not be embarrassing and they would want their partner or partners to know (Eisingerich *et al*., 2012). Researchers located participants' anxiety in the hypothetical nature of most of the presented oral PrEP characteristics, the stigma associated with HIV and in some settings, the criminalisation of sex work, injected drug use and homosexuality (Eisingerich *et al*., 2012)

These are potential facilitators to the uptake of oral PrEP among users, therefore communicating the benefits and disadvantages of oral PrEP in a transparent, unbiased and concise manner will help to dispel users' anxieties and promote uptake.

Knowledge and acceptability of oral PrEP

It is important to highlight that awareness of oral PrEP is not always related to its acceptability. In a study examining oral PrEP awareness among a sub-group of key populations in the United Kingdom, data suggests that oral PrEP awareness was affected by proximity to HIV (Frankis *et al.*, 2016). Thus, participants who reported knowledge of oral PrEP were more likely to be HIV-positive, have friends who were, or who worked in the field of sexual health (Frankis *et al.*, 2016). In another study, women were concerned that they had not been hearing about oral PrEP even though it was approved for use in 2012 (Auerbach *et al*., 2015). Since the participants viewed their doctors as trusted sources of information, they expressed concern that their providers may be equally unaware of PrEP and its application for women (Auerbach *et al.*, 2015). Therefore, this observation makes it necessary to explore the knowledge and perceptions of health care providers as they could have an impact on uptake of oral PrEP among the intended user group.

Furthermore, participants' lack of knowledge about oral PrEP reinforces the idea that information alone is insufficient to support uptake of oral PrEP and underlines the need for both awareness-raising and support for the use of oral PrEP to enable cost effective targeting (Frankis *et al*., 2016). While it is important to promote oral PrEP and laud its benefits among potential users, such knowledge becomes a barrier if it does not translate to uptake and usage.

Thus, oral pre-exposure prophylaxis (PrEP) can reduce HIV incidence among at-risk persons, however, health care providers need to know about the product to prescribe it to patients (Krakower *et al*., 2014). However, it is important to understand the role of health care providers in encouraging the use of oral PrEP as a woman initiated HIV prevention method. HIV testing is a critical entry point for primary and secondary prevention as well as care and treatment for young people, including key populations of vulnerable youth (Kurth *et al*., 2015). The primary goal of HIV care is viral suppression which minimizes risk for transmission (Merson et al., 2008, UNAIDS, 2014a) therefore, health care providers have an opportunity to suggest oral PrEP as a possible HIV prevention method. Consequently, it is important to understand their perceptions and knowledge of oral PrEP and its efficacy in reducing HIV infection because this has a bearing on whether they will recommend it to possible users.

Health care providers and their role in the uptake of oral PrEP

Health care providers are experienced in using antiretroviral medications, and could readily provide oral PrEP, but may not care for HIV-uninfected patients. Therefore, a priority for oral PrEP implementation is to identify groups of clinicians that provide care to at-risk persons and assess their prescribing intentions. Depending on the setting, there are three different groups of clinicians that are likely to encounter individuals who may benefit from oral PrEP (Krakower and Mayer, 2016). These are primary care providers (PCPs), providers who work in clinics that specialise in managing STIs (STI clinicians), and HIV specialists (Krakower *et al.*, 2014). Most at-risk people are likely to receive care in primary care clinics, and most STI clinicians are likely to provide care to key populations at highest risk of acquiring HIV. However, PCPs and STI clinicians may have limited experience in prescribing antiretroviral medications when compared with HIV clinicians.

Oral PrEP offers hope to the reduction of high HIV transmission rates among key populations, however, it is also thought to be ethically complex (Venter *et al.*, 2014). This is because health providers' beliefs, perceptions and own cultural beliefs could influence willingness to promote oral PrEP as an HIV prevention strategy. A number of studies have focused on oral PrEP implementation by healthcare providers, however, these tend to be biased towards the provision of oral PrEP to men who have sex with men (MSM) (Adams and Balderson, 2016, Krakower et al., 2014). This could possibly be due to the location of MSM in countries where these (MSM) are a key population (Tang *et al.*, 2014). These studies suggest that some health providers are knowledgeable about oral PrEP, but many are not, or express misgivings (Krakower and Mayer, 2012). Health providers have raised concerns that oral PrEP will increase risk of resistance to antiretroviral treatment medications, reduce condom use and compete with resources to expand access to HIV treatment (Mugo *et al.*, 2016). However, there is need to explore perceptions of primary health providers in a local context.

Studies have established that health communication can play a role in influencing behaviour change (Friedman *et al*., 2016). Effective communication regarding risk and probability will be essential to oral PrEP adoption because this intervention is unlikely to provide complete protection from HIV infection on its own (García-Lerma *et al.*, 2011). Thus, public information and provider-

based education about oral PrEP must effectively communicate information about efficacy in a manner that allows high-risk populations to make informed decisions about its use (Golub *et al*., 2010). Therefore, health comunication has an important role to play in communicating oral PrEP and it's potential to halt new infections among key populations such as adolescent girls and young women.

Health communication and oral PrEP

In the context of HIV prevention, health communication can be used to address issues such as a lack of information about HIV prevention interventions, misperceptions about diseases and treatment and stigma, among others (Tomori *et al.*, 2014). Such communication typically occurs through prevention campaigns. However, many prevention campaigns were modelled on individual-level theories and as such, tended to focus on individual-level human behaviour, which resulted in short term behavioural change (Dutta-Bergman, 2005). Therefore, to influence individual or social change, health communication strategies must be driven by research and strategically planned and centred on the audience's values, needs, concerns, and motivations (Friedman *et al*., 2016). The current study recognises that behaviour change at individual level is unsustainable due to contextual factors surrounding the individual, however, individual-level motivations for acceptance and adoption of HIV prevention methods still remain relevant in HIV prevention.

This is relevant for oral PrEP implementation as health communication is the vehicle through which messages about the product will be sent. South Africa has made great strides in the field of health communication, with HIV campaigns such as *Brothers for Life* and *Zazi*, among numerous others adopting multi-level strategies to address various issues and audiences in HIV prevention. Consequently, it will be an imperative for health communicators to adopt some of the lessons learned to facilitate oral PrEP acceptance and uptake among AGYW.

Conclusion

This chapter presented literature related to understanding the perception of HIV risk among AGYW and men of Vulindlela, South Africa as well understanding awareness, perceptions and acceptability of oral risk PrEP among these key populations. It provided an overview of HIV and AIDS globally, regionally and locally (South Africa), emphasizing factors that perpetuate

women's vulnerability to HIV infection. Secondly, the chapter focused on economic, biological, and cultural factors contributing to women being more vulnerable to HIV infection when compared to their male counterparts. This chapter further discussed methods of HIV prevention in the past three decades, leading up to the advent of oral PrEP as a possible new HIV prevention method that has potential to reduce HIV prevalence among young women in the 15-24 years age group. To conclude, the chapter discussed possible barriers and facilitators to the uptake of oral PrEP as an HIV prevention method. It is important to understand and address barriers that could affect the adoption of PrEP as a woman controlled HIV prevention method.

The next chapter presents the theoretical framework on which this study rests. This study is informed by the Health Belief Model (HBM). Using the HBM helps the researcher to understand the user profiles of oral PrEP and unpack the influences of why these specific groups of users may accept or reject PrEP. For purposes of this study, the HBM is imbedded in the Social Ecology Model for Health Behaviour (SEMCHB). This allows the researcher to take into consideration the reality of the contextual scenario that surrounds the individual and acknowledge the importance of the influence of interpersonal relationships in informing perceptions of oral PrEP among AGYW.

CHAPTER 3: CONCEPTUAL FRAMEWORK

Introduction

This study draws on the concepts of the Health Belief Model (HBM) and the Social Ecology Model for Communication and Health Behaviour (SEMCHB) to understand user profiles for oral Pre-Exposure Prophylaxis (PrEP) among high-risk adolescent girls and young women (AGYW) aged 15 -25 years and men who are likely to benefit from the use of oral PrEP as a new Human Immuno Virus (HIV) prevention method in Vulindlela, South Africa.

To begin, this chapter defines public health as the setting for the roll-out of oral PrEP and further justifies the need for public health communication to inform people about new HIV prevention interventions such as oral PrEP. The chapter further traces the developments in health communication from the era of behaviour change to the application of social and behaviour change communication approaches in HIV prevention. A discussion on the role of theory in HIV prevention follows. In conclusion, the chapter delves into a comprehensive discussion on the history and origins of the conceptual frameworks upon which this study rests as well as how they apply to this study.

Defining public health

Public health is an abstract notion that is often hard to pin down. One argument holds that the term public health refers to two different concepts that are related. While public health may refer to the general state of people's health, it can also denote the measures that people collectively take as a society to bring about and maintain that improvement to their general state of health (Schneider and Schneider, 2016). Thus, public health is mostly understood as a concept that broadly involves population-based activities that prevent disease, promote health, and protect people from harm (Maycock, 2015). Understanding the concept of public health is relevant in this study because once oral PrEP is readily available, it will be delivered through the public health system in South Africa.

Public health is interested in the optimum health of all the people in the population (Chasi, 2014b). Consequently, seen in this way, public health is defined as a practice that seeks to suspend or eliminate illness among the people of any given society (Brownson *et al*., 2017). However, even the notion of health is also a difficult concept to define. Whereas one person may describe health as the absence of disease, another may live with a chronic illness and define health in terms of his

ability to enjoy life despite the presence of disease (Chasi, 2014b). However, despite how individuals in a society perceive health, it is necessary for every person to benefit from public health.

Since the purpose of public health is to undertake and support practices that produce and reproduce conditions and actual experiences of well-being, it is imperative to locate HIV prevention in the public health approach (Brownson *et al*., 2017, WHO, 2016). Thus, adopting a public health approach in HIV prevention ensures access to high-quality services at the population level, while striking a balance between the best proven standard of care and what is feasible on a large scale especially in resource-constrained settings, such as South Africa (Jones *et al.*, 2014). The health and security of any society depends heavily on a robust public health system, but this is impossible to achieve if the critical role of strategic, timely, and effective communication in public health is ignored (Kaufman *et al.*, 2014a). South Africa has a two-tier public health system; private and public health care. Private health care provides excellent care and attention to those who can afford to pay for it while public health care tends to be plagued by challenges such as a shortage of medical staff and lack of essential equipment, resulting in the provision of a lesser standard of care (Crush and Tawodzera, 2014). Consequently, it is important to understand ways to leverage public health communication to ensure that the populace is aware of new HIV prevention methods such as oral PrEP and their benefits. Furthermore, effective public health communication informs people of where and how to access such interventions as well as how to use them.

The case for public health communication

Defining public health is relevant to understanding public health communication and its importance in advancing oral PrEP. Before one can define public health communication, it is important to think about the concept of communication.

There are two ways of thinking about communication. Perhaps the most common way is understanding communication as the process of sending information to a receiver (Tomaselli and Chasi, 2011). On the other hand, one can also think of communication as an effort to exchange meaning (Chasi, 2014a). This approach focuses on the idea of culture and at its core is the understanding that an individual attempts to share meaning verbally within systems of meaning that are informed by their environment (Tomaselli and Chasi, 2011). Promoting health and

protecting the public, therefore, requires both sound science and effective public health communication (Eldredge *et al.*, 2016). Consequently, public health communication is defined as the process of constructing, adapting and disseminating messages about preventing disease and promoting the health of broader society (Harvey and Koteyko, 2012). This study seeks to understand how the AGYW and men of Vulindlela, South Africa perceive oral PrEP. The study considers the ways in which the environment and lived experiences of AGYW and men contribute to the formation of their perceptions about oral PrEP as well as how these perceptions inform their likely acceptance or rejection of this new HIV prevention method. This will allow the researcher to establish user profiles for this new HIV prevention method. These user profiles will inform future public health communication on oral PrEP to encourage uptake among specific user groups.

The development of biomedical interventions such as oral PrEP provides an opportunity to reduce the escalating HIV infection rates among key populations, which include AGYW in South Africa (Calabrese *et al.*, 2016). These key populations comprise people who depend on the public health system for care. Therefore, there is a need to ensure that efficacy and availability of such interventions is communicated to key populations that require to access them (Jones *et al*., 2014). Thus, public health communication becomes the vehicle through which such information is conveyed. In this way, positive outcomes in the delivery and uptake of HIV prevention interventions such as anti-retroviral therapy for women and oral PrEP can be achieved (Ahmed *et al.*, 2013, Colvin *et al.*, 2014). However, before one can leverage on the power of public health communication, there is a need to understand the evolution of health communication.

Paradigm shifts in health communication

There has been a tendency to position HIV as either a health problem or a development problem (Govender, 2010, Wilkins *et al*., 2014) . As a result, approaches to the prevention and control of the HIV/AIDS epidemic in sub-Saharan Africa have followed early experiences and policies from developed countries, where the disease affects different key risk groups (Wilkins *et al*., 2014). This resulted in poor acceptance and uptake of HIV prevention interventions leading to minimal impact in reducing high HIV infection rates in the region (Auerbach *et al*., 2011).

Behaviour change communication

Two main schools of thought arose in health communication during the transition with development (McQuail and Windahl, 2015) . The first was Behaviour Change Communication (BCC) and the second was Social Change Communication (SCC).

BCC is founded on the idea that the urgency of the HIV pandemic requires a high focus on individual behaviour and uses targeted messages to reduce risk taking and promote health (Koenker *et al.*, 2014). This strategic response to promote positive health outcomes is based on proven theories and models of behaviour change such as the social cognitive theory and the health belief model. BCC has been primarily employed in the promotion of biomedical interventions in HIV prevention (Bekalu *et al*., 2017). Researchers have typically released reports about the effectiveness of an HIV prevention method, such as condoms and anti-retroviral drugs. Thereafter, such technologies are made available to the public, usually through the public health system, often accompanied by media campaigns about their advantages and reasons why people should adopt them (Lalla-Edward *et al*., 2016).

However, while BCC approaches acknowledge that people have a capacity to choose to adopt or abandon a certain behaviour, they tend to be limited by a series of abstract and contextual issues (Govender, 2011). If the case of oral PrEP were taken as an example, applying strictly BCC approaches would not result in effective uptake of this biomedical technology. This is because while AGYW may understand their vulnerability to HIV infection, they may not use oral PrEP due to contextual factors such as negative perceptions of the intervention, power dynamics in relationships or even lack of knowledge about oral PrEP. Therefore, this makes it imperative to consider the environment in which the target of any health communication resides. This observation translated to the need to develop communication strategies that do not only focus on BCC, but to consider social context as well.

Social change communication

The changes in paradigms of development resulted in changes in the way HIV prevention interventions were communicated in the era of BCC. Critics of BCC oriented programmes noted the disadvantages of this approach and called for move towards a social change communication (SCC) approach (Chandwani and Gopal, 2010, Figueroa *et al*., 2002). This call was based on the

argument that communication responses must account for the environment in which the epidemic is entrenched (Obregon and Waisbord, 2012). Thus, understanding the underlying aspects of HIV transmission cannot be divorced from a wider context of poverty, inequality, and social exclusion. Thus SCC views people and communities as agents of their own change and underscores community empowerment which creates an environment of change that is not only process oriented, but also provides a voice for communities and opportunities for dialogue (Govender, 2010). It further takes into account the environment in which the pandemic is located. The Centre for Communication, Media and Society (CCMS) at the University of KwaZulu-Natal compiled an anthology of work by students in which aspects of SCC are applied in research. Investigating Communication, Health and Development (Durden and Govender, 2012) is a compilation of research carried out over 10 years, which consistently proves that any intervention applied in HIV prevention is unlikely to have a great impact on the society if it does not take in to account factors such as behaviour and the social environment in which key populations reside.

In this light, I argue that it is important to understand that simply presenting oral PrEP as a viable method to prevent HIV acquisition is not the end goal. This is because it has been proven that simply making an HIV prevention intervention available does not translate to uptake (Logie *et al*., 2017, Robinson *et al.*, 2017). Thus, it is necessary to explore the underlying factors that could prove to be barriers or enablers for acceptance and uptake of oral PrEP among AGYW. This leads to the need for a more comprehensive approach that will account for all the factors that influence uptake of HIV prevention methods.

Social and behaviour change communication

Evidence strongly suggests that the most effective approach to reducing the new HIV infections is a combination of biomedical, behavioral, and structural intervention that both reduces vulnerability to HIV infection and accelerates uptake of key prevention methods (Isbell et al., 2016, Karim et al., 2017). Therefore, there is a need for communication that takes into account the individual, the context and structural factors that contribute to the rising rates of HIV among AGYW. Social and Behaviour Change Communication (SBCC) is based on the notion that people's behaviours need to be understood and addressed within a system comprised of social relations to cultural norms, policies and values that form the world in which individuals live (Christofides *et al.*, 2013). Thus, in order for interventions to make an impact at the population level, SBCC-informed strategies

need to draw from the various disciplines such as sociology, political science, communication, and marketing, to name a few (Kaufman *et al*., 2014a). These disciplines in tandem with epidemiology, health policy analysis and health economics come together to form the basis of SBCC (Christofides *et al*., 2013).

Therefore, the current study adopts the perspective of SBCC. This viewpoint allows for innovative HIV prevention measures such as oral PrEP to be viewed as part of a comprehensive combination prevention approach to achieve universal access to HIV prevention, treatment, care, and support for both the general and the key populations. In this way, oral PrEP is not only offered as a solution to high rates of HIV infection among AGYW, bute emphasis is made on sustained HIV testing for HIV and the continued consistent use of condoms. Thus, this approach offers the best prospects for addressing documented weaknesses in HIV prevention programming and for generating significant and sustained reductions in HIV incidence in diverse settings. For example, HCT is the entry point into HIV prevention, treatment, care and support (Young *et al*., 2014a). However, for a country where HIV incidence is so high, HCT rates remain less than optimal (Kelvin *et al.*, 2016). Barriers to HIV testing include lack of privacy and confidentiality as well as long distances and long waiting hours at the clinic (Kalibala *et al*., 2014). While self-testing could address some of these challenges, self-testing is often met with its own psycho-social challenges. Concerns have been raised about possible psychological distress associated with testing without a counsellor present (Kelvin *et al*., 2016). Such concerns are valid because they have a direct impact on the implementation of oral PrEP, particularly because this HIV prevention method is targeted towards HIV negative people. However, people can only find out their HIV status by undergoing HCT.

The evolution of HIV prevention has resulted in the understanding of how to translate the efficiency of HIV prevention methods and behaviours to results at population level (Hargreaves *et al*., 2016). In this way innovative HIV prevention tools such as oral PrEP can be integrated into combination prevention packages that include biomedical, structural and behavioural interventions (Krishnaratne et al., 2016, Williams et al., 2017).

The role of theory in HIV prevention

Growing evidence suggests that public health and health communication interventions that are based on social and behavioural science theories are more effective than those that lack a theoretical base (Fishbein, 2000, Glanz and Bishop, 2010). Thus, theories and models explain

behaviour and suggest ways to achieve behaviour and social change. Theories can be used to understand why people are not following public health advice, pinpoint what one needs to know when developing an intervention or identify what should be measured and compared when evaluating a health programme (Fishbein, 2000). For an intervention to be effective, it must be behaviour specific and target only one behaviour at a time (Fishbein, 2000). In terms of oral PrEP, the focus is on convincing key populations to take the tablet. However, there are other factors that influence any individual's acceptance of oral PrEP. These include perceptions about the product, belief in its efficacy, confidence that one can successfully stick to the prescribed regimen and so forth. In this case, constructs of the Health Belief Model are invaluable in understanding these factors.

There are numerous theories used in HIV prevention in South Africa. An example is the Soul City, a flagship television programme that was launched in 1994 (SoulCity, 2001). Through drama, the series sought to challenge social norms, attitudes and practices, and empowered individuals and communities to make informed healthy choices (Peltzer and Promtussananon, 2003). Using the social learning theory (Bandura, 1986), the Soul City drama series encouraged viewers to observe, model and adopt positive behaviour portrayed by the characters through observational learning. The social learning theory presents core elements that influence an individual's adoption of a new behaviour (Bandura, 2004). These factors include awareness of health risks, perceived self-efficacy, perceived benefits, perceived facilitators, and social and structural obstacles to the change they want to make (Bandura, 2004). The Brothers for Life movement, on the other hand, employed the Social Ecology Model of Communication and Health Behaviour (SEMCHB) as the theory driving the campaign. The core idea of the campaign was to forward a new set of masculine norms and as such it was necessary to tap into influences of the community, interpersonal relationships among men as well as individual perceptions (Collinge *et al.*, 2013).

The loveLife campaign that was launched in 1999 mainly used social marketing to promote condom use among young people (Lubinga *et al*., 2014). Social marketing refers to the use of marketing philosophies, using communications as a promotion strategy, while also taking advantage of product, place, and pricing strategies for behavioural or social change (Friedman *et al*., 2016).

This is by no means an exhaustive discussion of the theories applied in HIV prevention strategies in South Africa. However, the above presentation serves to illustrate that theory can be applied in different ways to achieve varying results.

Principal theories in the current study

The principal theories that inform this study are the Health Belief Model (HBM) and the Social Ecology Model of Communication and Health Behaviour (SEMCHB) (Kincaid *et al*., 2007, Sallis *et al*., 2008). On the one hand, the HBM seeks to unpack the influences of why specific groups of users accept preventative health services and why they do or do not adhere to other kinds of health care regimens (Rimer, 2008). In the context of the current study, the HBM assisted the researcher to understand why specific groups of AGYW aged 15 – 25 years in Vulindlela, South Africa would accept or reject oral PrEP as a new HIV prevention method. On the other hand, the SEMCHB model seeks to present the different levels at which individual behaviour change occurs. While the HBM focuses on behavioural change at the individual level, in keeping with this study, the SEMCHB acknowledges that structural and contextual factors influence behaviour change. Therefore, the SEMCHB recognises that interpersonal relationships, by the community, and the society in which an individual resides play a role in influencing behaviour change.

The Health Belief Model (HBM)

Origins of the Model

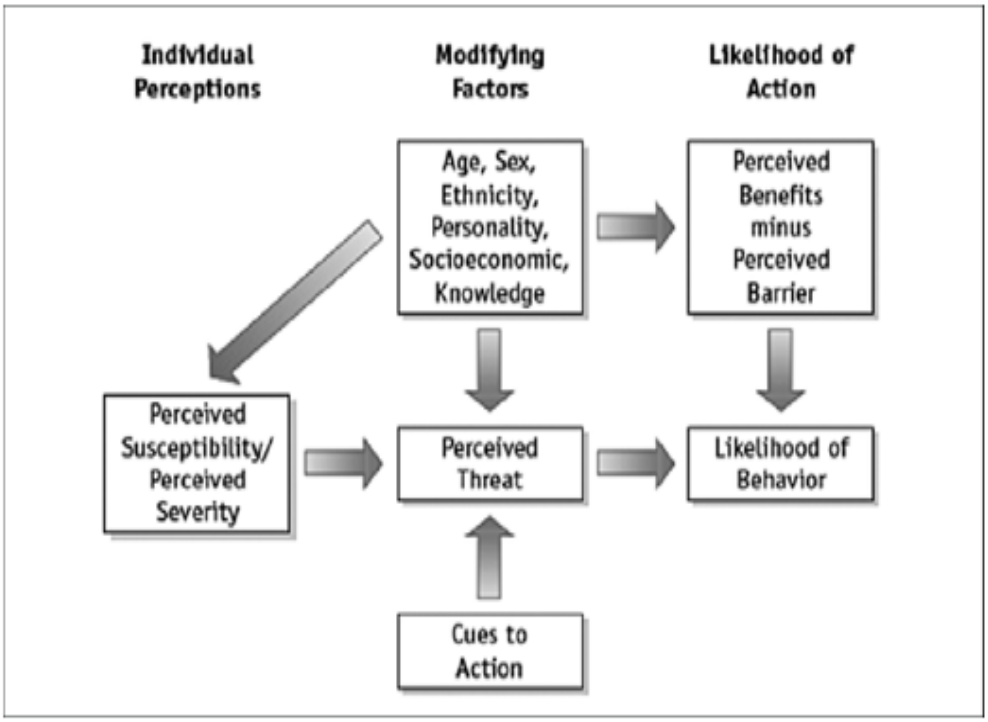
The HBM was developed by social psychologists in the United States Public Health Service in the 1950s to explain the prevalent failure of people to participate in programmes to prevent and detect disease (Rosenstock *et al.*, 1988). Gradually, the model was extended to understand people's reactions to symptoms and how they behave in response to a diagnosed illness, specifically adherence to health treatments (Champion and Skinner, 2008).

Key constructs

The Health Belief Model is located with the individual's rational choices of preventive behaviours. It has been extensively utilised to predict the adoption of preventive health behaviours (Dutta, 2008). The HBM's premise is that a person's likelihood to adopt preventive behaviour is based on their perception of risk. The model has six primary concepts or building blocks that predict why

people will take action to prevent, screen for or control illness conditions (Champion and Skinner, 2008). The six concepts are: perceived susceptibility, perceived severity, perceived benefits, perceived barriers, cues to action and self-efficacy. *Figure 3.1* shows the components of the HBM and their linkages.

Figure 3.1 The Health Belief Model, Components, and Linkages



Source: Glantz *et al.* (2008)

Perceived susceptibility and perceived severity in the HBM are the expected negative outcomes (Bandura, 2004). Perceived susceptibility refers to an individual's belief about their chances of experiencing risk or contracting a disease (Glantz *et al.*, 2008). In keeping with the current study, individuals denote the AGYW and men of Vulindlela, South Africa. Therefore, perceived susceptibility refers to the adolescent girls and young women and men's perceptions of own vulnerability to HIV infection. The Vulindlela community is at the epicentre of the HIV epidemic in KwaZulu-Natal, with HIV prevalence rates reported to exceed 40% among pregnant women (Abdool Karim, 2005, Karim et al., 2014b), however, it is necessary to evaluate the key population's recognition of risk in Vulindlela. Thus, it was imperative to engage AGYW and men

from this community and find out first, if they are aware of their vulnerability to HIV and secondly, their perception of their risk and its consequences, which according to the HBM is called, perceived severity. Literature suggests that oral PrEP awareness was affected by proximity to HIV (Frankis *et al.*, 2016). This suggests that people who reported knowledge of oral PrEP were more likely to be HIV-positive, have friends who were, or who worked in the field of sexual health (Frankis *et al.*, 2016). This is important because it establishes a link between understanding perceptions of risk and knowledge of existing or new HIV prevention methods. A person who has high perceptions of HIV risk is likely to be more accepting of new HIV prevention methods.

Perceived severity denotes an individual's belief about how serious a condition and its consequences are (Champion and Skinner, 2008). This has a direct influence on whether they find oral PrEP useful as a new woman-controlled HIV prevention method. Both susceptibility and severity need to be high for the individual to consider altering his or her behaviour (Dutta-Bergman, 2005).

Perceived benefits refer to an individual's belief that the intervention is effective and thus can reduce risk or serious impact (Champion and Skinner, 2008). In keeping with the current study, perceived benefits denote the individual's belief that oral PrEP is highly effective in reducing chances of HIV transmission. In the context of the current study, perceived benefits refers to the individual's belief that taking oral PrEP will help them to increase their chances of preventing HIV infection. Perceived benefits are weighted against perceived susceptibility and perceived severity. Therefore, the HBM suggests that if an individual perceives his/ her chances of acquiring HIV to be high and if that individual views the consequences of acquiring HIV as negative, then he/she or that person likely to consider the benefits of taking action to prevent HIV transmission.

Another construct of the HBM is perceived barriers which represents the individual's belief about the physical and psychological costs of the advised action (Champion and Skinner, 2008)., Literature suggests that perceived barriers include individuals' negative perceptions of oral PrEP arising from its standard use as anti-retroviral therapy, fear of side effects, costs, access etc. Consequently, perceived barriers lessen the individual's ability to implement preventative behaviour (Dutta, 2008). Therefore, understanding perceived barriers allows the researcher to understand reasons that influence the acceptability or rejection of oral PrEP as a new HIV prevention method among AGYW and men in Vulindlela, South Africa.

Cues to action are strategies to activate "readiness" (Glantz *et al*., 2008). These cues to action are defined as explicit incentives that are needed to prompt the correct health behaviour (Dutta, 2008). They could be messages that remind the individual to undertake preventative behaviour, which in the context of this study may include messages about oral PrEP's efficacy, or where and how an individual can access oral PrEP as well as dosing options.

Self-efficacy is a construct that was added later to the HBM. It is defined as the belief that one can positively implement the behaviour necessary to produce good results (Bandura, 1997). In other words, self-efficacy indicates an individual's confidence in his/ her ability to take action. In keeping with this study, therefore, self-efficacy would be the result of educating AGYW about how to use oral PrEP (for example, taking a pill daily). Self-efficacy, in this case, would be the direct result of AGYW feeling empowered to ensure their continued health and safety by using an effective HIV prevention method without having to negotiate with their sexual partners, if there is a need because it is in their own control. Literature suggests, however, that potential users would want their partner or partners to know that they are using oral PrEP (Eisingerich *et al*., 2012). This observation is important because self efficacy does not only depend on women having the ability to use oral PrEP. Thus, socio-psychological and structural aspects may influence perceptions and thus indirectly influence health related behaviour and a major critique of the HBM is that it does not consider this factor.

Ecology Models of Communication

Whereas immediate factors of the spread of HIV relate to behaviour which is covered by the HBM, literature suggests that the basic influences that contribute to risky behaviour are located in the social environment and include poverty, underdevelopment and gender inequality (Baxter and Abdool Karim, 2016) . Therefore, this section gives a background of Social Ecology Models and further discusses the Social Ecology Model for Communication and Health Behaviour (SEMCHB) and its application to this study in an effort to recognise the context in which an individual resides. It is for this reason that the HBM cannot be used on its own in the current study.

Background of Ecological Models

There has been a rapid increase in interest and application of ecological models in both research and practice in the last 20 years (Sallis *et al*., 2008). One of the reasons for this interest is that

ecological models show tremendous promise in guiding broad population-wide methods to changing behaviours that will reduce serious and common health problems (Sallis *et al.*, 2008). HIV is one such severe and prevalent health problem particularly because current HIV prevention methods are unrealistic for most women (Sidibe *et al*., 2014). The term 'ecology' is used by biological scientists to refer to "interrelations between organisms and their environments" (Sallis *et al*., 2008). However, as ecological models have evolved in behavioural sciences and public health they have come to represent people's interactions with their physical and socio-cultural environments (Sallis *et al*., 2008). The notion of ecological models is that behaviour can be influenced at multiple levels such as the intrapersonal (biological, psychological), interpersonal (social, cultural), organisational, community, society and policy levels (Sallis *et al*., 2008). Therefore, ecological models can integrate constructs from models that focus on psychological, social and organisational levels of influence to provide a comprehensive framework that incorporates multiple theories and further consider environments and policy in the broader community (Grzywacz and Fuqua, 2000).

The Social Ecology Model for Communication and Health Behaviour (SEMCHB)

The Social Ecology Model of Communication and Health Behaviour (SEMCHB), like other ecological models, is a meta-theory. It was developed after scholars observed that early use of theory in health communication emphasized individual –level theories of learning, influence and decision making as they relate to health behaviour and especially behaviour change (Stokols, 1996). The SEMCHB is viewed as a meta-theory because it consists of four interacting levels that work together to form one comprehensive model. The four interacting levels are influenced by, and in turn, influence health behaviour (McLeroy *et al*., 1988). This study is interested in the interpersonal level of the SEMCHB. In the context of this study, this level informs the understanding of how interpersonal relationships, either with family, friends or intimidate partners influence perceptions of oral PrEP among AGYW in Vulindlela, South Africa. This level assisted in the interrogation of how perceptions of partners and peers influence the acceptability and uptake of oral PrEP among AGYW. The four levels are: the individual (intrapersonal), interpersonal, community and society as illustrated in *Figure 3.2*.

At the individual level, interventions to promote health interventions focus on modifying a person's health-related attitudes, beliefs, and behaviour. This requires voluntary and sustained effort by the individual (Stokols, 1996). The HBM is applied at this level because it helps researchers to find out why an individual's perceptions are either in favour or not in favour of change (McKee *et al*., 2014). It is for this reason that the researcher selected the HBM as the theory underpinning this study. Embedding the HBM in the SEMCHB, therefore, allows the researcher to acknowledge that while there are multiple influences (including social networks, community, and society) of specific health behaviour it is still necessary to understand individual-level factors. This is particularly relevant in the current study, as the researcher seeks to understand the specific groupings of AGYW who may be interested in using oral PrEP as a new HIV prevention method.

Limitations of theory

Some limitations have been observed in the application of the HBM. The first major limitation is the model's focus on the individual and its tendency to perceive behaviour as rational (Champion and Skinner, 2008). Thus, the HBM fails to accommodate cultural situations where behaviour is located and influenced by the broader culture and its practices, which is common in the African and South African context (Dutta, 2007). Furthermore, while the complete model of the SEMCHB has four interacting levels, the current study only adopts the levels pertaining to the Intrapersonal and the Interpersonal aspects, which serves to limit the model (McKee *et al.*, 2014).

Conclusion

Public health is necessary for every person living in any society, thus it is necessary to ensure access to the public health system. This chapter has defined public health as the setting for the roll-out of oral PrEP and further justified the need for public health communication to inform people about new HIV prevention interventions such as oral PrEP. Without public health communication, it would be difficult to inform people about new HIV prevention options such as oral PrEP. However, both public health and health communication need to be theory based to ensure that maximum impact is achieved. The chapter has discussed the concept of communication and followed the developments in the field of health communication. To understand user profiles of oral PrEP among AGYW in Vulindlela, South Africa, the current study uses constructs of the

Health Belief Model and the Social Ecology Model for Communication and Health Behaviour. The next chapter discusses the methods and techniques used to collect data in the current study.

CHAPTER 4: METHODOLOGY

Introduction

Having identified a research problem, the researcher must select a research strategy and appropriate methodology for collecting information that will illuminate the problem (Creswell and Poth, 2017). This chapter describes the research methodology, specifically the research design and methods that were employed in this study to understand user profiles for oral Pre-Exposure Prophylaxis (PrEP) through specific segments or groupings of high – risk populations.

Understanding who is at risk of HIV infection, and who is willing to use oral PrEP will facilitate an understanding of user profiles among adolescent girls and young women (AGYW) that are likely to benefit the most from the use of oral PrEP as a new HIV prevention method. Research method refers to the processes used to execute the research project while research methodology denotes the discipline that makes use of these processes (Struwig and Stead, 2013). Therefore, this chapter describes the research paradigm, research design, data collection, selection of participants and the process of data analysis as laid out in Table 4.1 below. This chapter concludes by addressing issues of trustworthiness and ethical considerations that are specific to this study.

Table 4.1 Summary of methodology

Summary of methodology	
Research paradigm	Interpretivism
Research design	Qualitative research approach
Methods of data collection	Focus Groups, risk games and in-depth interviews
Selection of participants	Non random sampling; purposive sampling
Data analysis	Thematic analysis

Research paradigm: Interpretivism

A paradigm is a belief system or world view that directs the researcher, "not only in choices of method, but in ontological and epistemological ways" (Guba and Lincoln, 1994). Paradigms signify a worldview that defines the nature of the world, a person's place in the world and the possible relationships to that world for the individuals who subscribe to those paradigms (Punch, 2013). Epistemologically, interpretivism as a framework located in qualitative approaches, looks for interpretations of the social life-world which are derived from culture and historically situated (Ormston *et al*., 2014). Interpretivism stresses that natural reality and social reality are different

and as such, they require different kinds of methods (Gray, 2013). Therefore, interpretivists assume that individuals develop varied and multiple meanings of their experiences which are subjective, resulting in the researcher searching for complex views rather than constricting meaning into a few categories or ideas (Creswell, 2013). These subjective meanings are not simply reproduced on individuals but often they are formed through interaction with others and through the historical and cultural settings of participants. While this study applies concepts from the Health Belief Model to understand behavioural change at the individual level, concepts from the Social Ecology Model for Communication of Health Behaviour (SEMCHB) acknowledge that structural and contextual factors influence behaviour change. Therefore, the interpersonal level of the SEMCHB recognises that interpersonal relationships are influenced by the community as well as the culture and society in which the AGYW and men reside. This is significant because it illustrates that behaviour change can be influenced by numerous other factors that reside outside the individual's control (Flick, 2014). In this case, it was important for the researcher to understand how the AGYW and men of Vulindlela perceived their risk of HIV infection and how this could influence the uptake of oral PREP. Based on these risk profiles, user profiles of who is likely to use PrEP and the conditions under which they are likely to do so can be established. Historically, anti-retroviral dugs were used by people already infected with HIV to suppress their viral load. Therefore, the researcher was aware that such an association may lead to participants having negative perceptions of the product. Because the concept of oral PrEP is relatively new, data collection methods such as risk games and focus groups were used to elicit participants' views on this new biomedical approach to assess whether they had any knowledge of the product. Further, in-depth interviews were used to investigate how health providers' own perceptions could either encourage or discourage at-risk groups to accept and adopt oral PrEP as an HIV prevention method.

The current study adopts an interpretive paradigm with a nominalist stance. The nominalist assumes that an individual's experience of the world occurs through a system of interpretations and inner bias (Neuman, 2014). A woman's ability to use a new HIV prevention method or adopt any sexual reproductive health behaviour is influenced by a range of factors, including beliefs and expectations about the product as well as perceived need and ability to use the product (Kaufman *et al*., 2014b). However, women's demand and need for product can vary greatly by life context. Consequently, it was necessary to understand how these characteristics could possibly affect

individual women's interest and willingness to try oral PrEP as a new HIV prevention method in different circumstances with the ultimate purpose of establishing key user profiles for oral PrEP uptake.

In qualitative studies located in an interpretive paradigm, the researcher focuses on learning meanings that participants construct, interpret and hold about the problem or issue (Creswell, 2013). Any problem under investigation in research is understood as part of a social world and explained primarily from the point of view of the people directly involved in the social process (O'Connor, 2015). Although this study focuses on oral PrEP as a women-centred HIV prevention technology, studies show that partner involvement ultimately plays a role in whether the product is likely to be accepted or rejected (Minnis *et al*., 2013, Montgomery *et al.*, 2015). Therefore, it is imperative that researchers utilising the qualitative approach consider the context of their participants because they learn what is meaningful or relevant to the people they are studying and how they experience everyday life within their context.

Ontologically, the interpretive paradigm suggests that reality is the product of individual consciousness therefore the existence of an external world is rejected in favour of reality that is unique and particular to each individual (O'Connor, 2015). Furthermore, the researcher and participant influence each other, since they are both free and involved in the proactive role of creating meaning. This means participants are interactive beings and have the ability to create and interpret meaning in the study. Thus, meanings are not fixed or stable but are revised on the basis of experience. This experience was vital for the researcher to understand because it informs adolescent girls and young women's preferences when it comes to HIV prevention methods. These preferences have, therefore, assisted in categorising the type of young adolescent girl or young woman that would want to use oral PrEP. In this way, the researcher is able to meet one objective of this study, which is to generate user profiles for oral PrEP among at risk groups of AGYW in Vulindlela, South Africa.

Study setting and context

The current study is located in Vulindlela, 150 km west of Durban, KwaZulu- Natal. There are three wards in Vulindlela namely; Inadi, Mpumuza and Mafunze which are administered through both tribal and democratically elected local government structures. Data was collected at a high

school and the clinic both of which are located in the Inadi ward. The clinic offers antenatal and family planning services to adolescent girls and young women, and HIV counselling and testing (HCT) for adolescent girls and young women as well as men.

A survey in Vulindlela, KwaZulu-Natal, conducted by the Centre for the AIDS Programme of Research in South Africa (CAPRISA), found a high rate of teenage pregnancy associated with shockingly high HIV infection rates in this community (Karim *et al*., 2014a). Vulindlela is located in the Umgungundlovu district of KwaZulu-Natal and is one of the five districts in South Africa with the highest HIV burden, with HIV prevalence rates exceeding 40% among pregnant women (Karim *et al*., 2014b). The Vulindlela community is at the epicentre of the HIV epidemic in KwaZulu-Natal and the escalating epidemic underlined the importance of a community partnership between the traditional leaders in Vulindlela, the CAPRISA Vulindlela Research Site (VRS) and the Department of Health (CAPRISA, 2017). This partnership resulted in the establishment of the VRS, which located adjacent the primary health clinic and is run by CAPRISA. On site CAPRISA conducts trials of new generation microbicides, undertakes studies to understand the evolving HIV epidemic in South Africa and provides a comprehensive HIV/AIDS care package to people living with HIV/AIDS in the community (CAPRISA, 2017).

Thus, the effect of the HIV epidemic on young women makes it important to develop interventions that will protect them from HIV infection. Such interventions need to address risk factors for HIV infection, while simultaneously addressing the social, political, and economic factors that generate vulnerability and perpetuate risk (CAPRISA, 2017). Therefore, Vulindlela was purposively selected as the ideal location for this study because the community members have witnessed the devastating effects of HIV and have collaborated with CAPRISA and the government to reverse the adverse effects of the epidemic. Because this is a district with a high burden of HIV, any research carried out in Vulindlela has a local and global impact.

Entering the field

In order to collect data, the researcher often needs to negotiate access to participants. Usually, a researcher may be able to negotiate access through an 'insider' within a community (Harding, 2013). This 'insider' often serves as a gatekeeper. A gatekeeper is an individual or organisation that provides access to the people being studied (Creswell and Poth, 2017). The location of the

study in Vulindlela allowed the researcher to utilise the existing relationship between CAPRISA and the Community Outreach Programme in Vulindlela (COMOSAT). CAPRISA is a designated UNAIDS Collaborating Centre for HIV Prevention Research and is affiliated to the University of KwaZulu -Natal. The organisation runs a prevention and epidemiology programme in Vulindlela with partners such as COMOSAT. COMOSAT is a community outreach organisation that has on-going activities at Vulindlela and as such, served as the 'insider' through which access to participants could be negotiated. CAPRISA's link with COMOSAT was particularly useful because being an international student with no knowledge of local communities such as Vulindlela, exposure to the community or existing partnerships to assist with participant recruitment.

As the gatekeeper, COMOSAT facilitated access to the clinic and the high school. It was important for the researcher to be introduced to the community and to participants by an organisation such as COMOSAT because they have established and maintained a good rapport with residents through community engagement. An introduction by a respected member of the community or organisation strengthens the researcher's capacity to work in a community and thus it is likely to improve the quality of the data (Harding, 2013). This was particularly important for the current study because as stated, the researcher does not reside in Vulindlela and is not fluent in IsiZulu, however, participation was easy because COMOSAT arranged for community developers to introduce the researcher to make participants comfortable. While the researcher's home language, SiSwati and IsiZulu are similar, comprehension was not always guaranteed hence it was important for the community developers to be present to help with translation and ensure participants were not forced to speak English even when they were uncomfortable doing so.

Research design

Qualitative research is an approach that is used to explore and understand the importance that individuals or groups assign to a social or human problem (Creswell, 2013). Qualitative research produces descriptive data – people's own written or spoken words and observable behaviour (Taylor *et al.*, 2015). Thus, the qualitative approach proved ideal for the current study because it permitted an understanding of perceptions informed by the experiences of at- risk AGYW in Vulindlela, South Africa. The ultimate aim was to establish user profiles of who was likely to initiate on of oral PrEP, a new HIV prevention method. Qualitative research has the ability to generate elaborately nuanced, personal data. This occurs through the selection of knowledgeable

informants, open-ended questioning about their attitudes and experiences and inductive investigation of their replies (Namey and Trotter II, 2015). AGYW and men shared their experiences of current HIV protection methods as well how these experiences have shaped their perceptions of oral PrEP. Therefore, the researcher was able to investigate potential users' views of oral PrEP as well as understand key influences that could likely affect the acceptance or rejection of this new HIV prevention method.

Selection of participants

The objective of selecting participants in qualitative research is to expand our understanding about a larger relationship or social scene (Neuman, 2014). Therefore, participants were purposively selected to suit this study. Purposive sampling is a type of non-probability sampling, which is most useful when one needs to explore a certain aspect of life with knowledgeable experts within a particular field (Etikan *et al*., 2016). Participants that are purposively sampled are considered key informants. They are observant, reflective members of the community of interest who know much about the culture and are both willing and able to share their knowledge (Robinson, 2014). In qualitative research, we select a few participants to provide awareness and understanding about issues or relationships in the social world (Neuman, 2014). Therefore, the researcher purposefully selected adolescent AGYW and men for this study. Adolescent girls had to be between the ages 15 – 18 years and attend the local high school. Furthermore, the researcher purposively sampled young women aged 18– 25 years accessing ante-natal and family planning services at the clinic. Finally, the researcher purposively sampled men aged 25– 35 years, who accessed HCT services at the local clinic. COMOSAT, using its links to the community, selected participants who met the requirements and recruited them to participate in the study after they showed interest and signed consent forms. This sample is important because research shows that men living with HIV who are aged 25 – 40 years are infecting younger women (ages 15-25), but these men are infected by women who are aged 25- 40 (Naicker *et al.*, 2015). COMOSAT further assisted with contact with the family planning nurse and HCT counsellor for in-depth interviews. Given the location of the current study which is Vulindlela, KwaZulu-Natal, participants were African, Zulu speakers. The young women and men who were accessing health services at the clinic had all completed high school, however, due to financial constraints had not been able to study further.

Inclusion criteria and justification

Adolescents are typically aged between 10 to 18 years (Zuma *et al*., 2016) and this study focused on adolescent girls in high school. To be included in this study, the girls had to be between 15 and 18 years old and attend the local high school located in Vulindlela. Participants were also supposed to reside in the area. The perspectives of this sample population is important because statistics show that this is the most vulnerable group when it comes to HIV infection (Naicker *et al.*, 2015). Furthermore, at this age they are likely to still be in school where they encounter issues such as peer pressure leading to early sexual debut and getting into relationships with older partners, which is a contributing factor to their vulnerability to HIV infection (Baxter and Abdool Karim, 2016, Zuma *et al*., 2016). Therefore, it was important to assess their knowledge and perceptions of oral PrEP because this has an impact on whether they are likely to accept or reject it as an HIV prevention method.

Sexually active young women aged 18-25 years were also an important sample group in the current study. Young women in this age group were purposefully selected because data suggests that when younger women date older men the power dynamics in such relationships often makes it difficult for them to negotiate condom use, making them susceptible to HIV infection (UNAIDS, 2016b). Thus, young women in this study had to be accessing family planning and ante-natal counselling services at the local clinic in Vulindlela. This is important because oral PrEP is targeted towards HIV negative women. While this study did not explicitly ask participants about their HIV status, sexual activity was used as an indicator of who was sexually active by virtue of them accessing sexual and reproductive health services at the clinic. Knowledge of HIV status was not a primary question because the study sought to explore these women's perceptions of their HIV risk and oral PrEP.

Another important sample population in this study consisted of men aged 25-35 years. As part of the recruitment criteria, men participating in the study had to reside in Vulindlela because of the impact that HIV has in this community. This population sample was important because young women go on to start families with their peers who are men aged 25– 35 years, and if they become infected the cycle of HIV infection continues (Naicker *et al.*, 2015, UNAIDS, 2016b). Thus, while oral PrEP is a women-centred HIV prevention method, it is important that men are included in the discourse, hence their inclusion in the current study.

The HCT counsellor and the clinic nurse's perspective were particularly relevant because literature suggests that awareness and perceptions of health care providers are important factors that affect the possible acceptance or rejection of a product (Krakower and Mayer, 2016). Such perceptions and beliefs are important to understand because they have a bearing on whether they recommend oral PrEP as a viable new HIV prevention method to at risk groups such as AGYW.

Methods of data collection

Data collection was conducted through three focus groups, each lasting an hour; risk mapping and two in-depth interviews. Risk mapping has been used extensively in HIV research; however, these particular games were developed by researchers at the Centre for Culture Communication, Media and Society (CCMS) at the University of KwaZulu-Natal. Having two or more focus groups adds trustworthiness to the findings, which is very important in any qualitative study (Harding, 2013). The two in-depth interviews were conducted with the family planning nurse and HCT counsellor.

Focus groups

A focus group is a type of open-ended interview through which data is collected through group interaction on a topic determined by the researcher (Morgan, 1996). In essence, focus groups can be defined as a type of group interview that exploits communication between research participants in order to generate data (Kitzinger, 1995). They rely on the methodical questioning of several people simultaneously in formal or informal settings (Fontana and Frey, 2000). Focus groups are considered a qualitative method of data collection because they explore participants' opinions, attitudes and attributes (Fern, 1982). This is important because it helps the researcher generate 'rich' data by supporting recollection in participants. Aiding recollection occurs because participants both question each other and explain themselves to each other (Morgan, 1996).

In focus groups, the researcher or moderator guides the discussion and interaction among participants in either a structured or unstructured fashion, depending on the purpose of the interview (Fontana and Frey, 2000). In the focus groups conducted for the current study, the researcher was the moderator although a Zulu speaking assistant from COMOSAT was present to help with note-taking and interpretation. The moderator's skills, personality and methodology used are critical in promoting group interaction (Fern, 1982). The moderator should be flexible, objective, empathic, persuasive and a good listener. Other important traits of the moderator are

compassion, character and a real interest in people (Stewart and Shamdasani, 2014). The presence of the moderator was important because, if participants are not monitored, they can turn a focus group into a debate or use it as group therapy (Morgan, 1996). Thus, as the moderator, the researcher was able to keep discussions focused on relevant topics that would assist in the generation of 'rich' data and encourage nervous and introverted members of the groups to participate.

Focus group size and composition

Although the number of participants in a focus group appears to be an important factor, researchers have not agreed on the ideal size of a focus group (Hopkins, 2007). Some scholars suggest that a focus group can be composed of as little as five participants to as many as 20 members, however, for purposes of proper management of the group, a focus group should consist of 10 members or less (Krueger and Casey, 2014, Morgan, 1996). In the current study, the focus group with young women comprised seven participants; six participants for the focus group with adolescent girls and the focus group with men had nine participants. These were participants who met the research criteria and consented to being part of the study. Group dynamics are important in a focus group and this can be influenced by the composition of the focus group. Scholars propose that members of a focus group should be identical in terms of the relevant selection criteria, but who do not know each other (Tonkiss and Seale, 2004). Although Peter Hopkins (2007) had participants who knew each other in his focus groups with Muslim young men, he acknowledged that this had not been an important part of his selection criteria. Further, having participants who know each other may be a disadvantage in a focus group that discusses sensitive topics such as HIV related issues because some may be reluctant to share information (Hopkins, 2007).

As part of the selection criteria for this study, participants did not have to know each other, however, they did have to share similar traits such as being in a certain age group, being female for two focus groups and male for another focus as well as being from Vulindlela and accessing HCT or antenatal services at the clinic. Knowing each other was not a disadvantage in the context of this study because the researcher was interested in participants' understanding of HIV prevention methods as well as their perceptions of oral PrEP and this did not require any participant to disclose their HIV status or any other sensitive information that they could have been reluctant to disclose. The focus groups were conducted at the CAPRISA research site in Vulindlela where

private rooms are available for privacy to allow participants to be comfortable. Further, restricting the focus group to participants of a similar age group and same sex served to ensure that there was no element of hierarchy between individuals. An element of hierarchy could inhibit the other participants and compromise the quality of data (Harding, 2013). I was also careful to avoid 'group think' in the focus groups. This occurs when participants end up agreeing with views and opinions expressed by a vocal member of the group, which they would not necessarily agree with in other circumstances. In the current study, group think was avoided by having participants write answers to verbal questions on pieces of paper. Furthermore, participants were asked to not write their names on these answer sheets. This ensured that they could be as honest as possible in their answers and that fellow participants did not influence their ideas and opinions.

Research tools

As part of the focus group, the researcher employed the traditional focus group guide that comprised open-ended questions. However, to introduce and map risk as well as get individual responses and collective perspectives three risk games were incorporated into the focus group guide. The questions in the focus group guide were generated from relevant literature, which presented gaps in current research on oral PrEP. The questions were framed according to the constructs of the Health Belief Model (HBM) to assess perceived susceptibility, perceived severity, perceived acceptability and perceived benefits. This research too is attached as Appendix 1.

Risk games

The first game was to assess participants' level of risk. This was done using one brand of sweets separated by colour. We pretended that the red sweets were poisonous and the green sweets were safe to eat. Participants were asked if they were willing to eat the bowl of good sweets with one poisonous candy in the bowl. The number of poisonous candies was gradually increased until participants stated that they would definitely not eat the combined safe and poisonous sweets in the bowl. The exercise was meant to illustrate that people have different levels of risk which they accept; however, it is important to know your risk, and the risk you are willing to accept.

The second game involved a process of risk mapping. This was done by designating three corners of the room into three zones: no risk, low risk and high risk. Participants were asked to stand in the various zones that they related to for each of the following five scenarios:

Scenario 1: having sex without a condom

Scenario 2: drinking lots of alcohol at the shebeen and having sex

Scenario 3: having more than one sexual partner

Scenario 4: having a Blesser relationship

Scenario 5: Taking a pill every day to prevent HIV infection

The risk mapping activity assisted the researcher to understand how participants perceived their susceptibility, their awareness of risk and perceived severity to HIV infection.

The third game assessed perceived susceptibility. In this game, the researcher handed out A4 sheets of paper where participants wrote down situations that put them at risk of contracting HIV. After this, participants were asked to write down whether these situations were high risk or low risk. Whilst the scenarios were about participants' perception of risk scenarios, the risk mapping was about personal risk. This game proved useful because participants could record situations that apply to them without feeling embarrassed and judged by other participants in the group. This also ensured privacy because they did not have to write their names on the sheets of paper.

This game led to a discussion in the traditional form of a focus group where the participants deliberated about their awareness and knowledge of current HIV prevention methods and an introduction to oral PrEP. The discussion progressed to deeper discussions about participants' views on oral PrEP and their feelings about this new HIV prevention method. Using these games was helpful because it served as both an ice-breaker and served to encourage all participants to share their views.

Data were collected in October 2017 and participants were each reimbursed an amount of R50.00 for travelling costs to attend the focus group discussions**.** Additionally, face to face in-depth interviews were conducted with one family planning /antenatal clinic nurse and one HIV counselling and testing counsellor (HCT). This was to explore their awareness and perceptions of oral PrEP and further understand whether these perceptions would be enablers or barriers in the

acceptance of oral PrEP by AGYW and men. The clinic nurse and HCT counsellor are the first point of contact for patients and as such, their perceptions may affect whether they recommend oral PrEP for use. These interviews were also conducted at the CAPRISA research site in Vulindlela. This venue proved ideal because it is centrally located and has private rooms where interviews can be conducted confidentially and without interruptions.

For the in-depth interviews with health providers, in this case the clinic nurse and the HCT counsellor, the researchers relied on an interview guide. Questions were generated from reading relevant literature that addressed challenges that may prevent health providers from recommending oral PrEP as a new HIV prevention method to potential users.

In-depth interviews

Interviewing is the most common mode of data collection in qualitative research (Ritchie *et al*., 2013). The 'form' of an interview, where one person poses questions and another answers, can be used for a variety of purposes (Silverman, 2016). However, in qualitative research interviews are used to improve knowledge (Creswell, 2013). In-depth interviews are often semi-structured in nature. Semi-structured interviews were suitable in this study because they offer structure and direction to the interviewer without taking the regular approach of the qualitative interview (Harding, 2013). This means that while the qualitative researcher presents pre-prepared questions through an interview guide, he or she can still probe the participant to get richer data. This form of interview allowing for the exploration of perceptions of the HCT counsellor and the ante-natal nurse on currently available HIV prevention methods as well as explore their knowledge and perceptions of oral PrEP.

Studies conducted in other settings have shown that often health providers were not aware of oral PrEP and its ability to reduce high incidence of HIV (Adams and Balderson, 2016, Tang *et al*., 2014). Health providers cannot be in a position to prescribe oral PrEP if they lack knowledge about the product or if they have misgivings about its effects, therefore it was important to explore health providers' perceptions of oral PrEP in Vulindlela. The interpersonal level of the Social Ecology Model for Communication and Health Behaviour suggests that social relationships influence a person's willingness to accept or reject HIV prevention methods. Thus, because health care providers are in a position of authority, it is important to understand their perceptions. Using open-

ended interviews was useful because the researcher was able to explore the reasons for the ideas and beliefs that these health providers hold.

Managing data

Data that has been collected needs to be managed for optimal analysis (Miles *et al.*, 2013). In the current study, all interviews were recorded with an audio recorder and a cellular phone for back up. As already described, the focus group discussion incorporated games that assisted with risk mapping. To cater for cases where participants had to indicate responses by other means such as going to a corner or raising up their hands, additional field notes were taken to document this. Furthermore, written responses were collected from participants and these were used in the analysis of data. Audio recorded data was transcribed word for word because verbatim transcriptions are more reliable (Saldaña, 2015).

Data analysis

Data analysis in qualitative research is an on-going process that involves continuous reflection about the data, asking analytic questions and writing notes throughout the study (Creswell, 2013). Therefore, data collection occurs concurrently with gathering and interpreting the data. In this study, data analysis commenced while all the focus groups and interviews were taking place. This involved not only listening to the participants, but also watching their body language and other non-verbal cues. This was useful in helping me understand how participants felt about particular points that were made in the discussions even if they did not express these feelings verbally.

Data were analysed thematically, guided by the constructs of the HBM and SEMCHB. However, thematic analysis was used to develop themes that emerged under the constructs of these conceptual frameworks. Thematic analysis is defined as a method for classifying, analysing and reporting patterns (themes) within data (Braun and Clarke, 2013). Thematic analysis not only organises and describes data in rich detail, but it also interprets various aspects of the research topic (Braun and Clarke, 2013). Researchers who conduct qualitative studies analyse data by organising it into categories based on themes, concepts or similar features (Neuman, 2014). Thus, themes followed the constructs of the two conceptual frameworks on which this study rests; the HBM and SEMCHB. Therefore, audio recorded data and written responses from focus group participants were also used to develop themes. This study is not grounded theory, however, in

order to let the themes emerge, the researcher had to use a way of coding, and for the purpose of this study the merits of open coding were drawn upon**.**

Open coding

Open coding refers to the first coding of qualitative data that scrutinises the data to summarise it into primary analytic categories or codes (Neuman, 2014). At this point, the researcher located themes and assigned initial codes in a first attempt to condense the mass of data into categories. Codes are labels for allocating units of meaning to the descriptive information compiled during a study (Miles *et al*., 2013). In this study, codes take the form of critical terms or themes generated from the initial research questions, concepts from literature, terms used by members in the focus groups or new thoughts stimulated by an immersion in the data. Thus, when using open coding, themes are brought to the surface from deep inside the data (Neuman, 2014). In cases where participants shared similar perspectives, such perspectives were coded into one theme. These themes were typed into Microsoft Word and highlighted as a preliminary record. This was done to allow the creation of new themes and merging of similar themes in subsequent analyses. This list of themes allows the researcher to see emerging themes at a glance, stimulates an awareness of more themes in future open coding and helps to build a universe of all themes in the study that can be reorganised and either be combined, discarded extended in further analysis (Neuman, 2014).

Axial coding

Axial coding is the second step in the process of thematic analysis described above. At the point, the researcher has an organised set of initial codes generated during open coding. Therefore, the focus moves from the data to the initial themes. Additional codes or new ideas that emerge at this point were noted, however, the primary task was to review and examine the initial codes. At this stage of the coding process, the researcher was actively asking questions about causes and consequences; conditions and interactions, strategies and processes. This assisted with organising related concepts into categories and to divide unrelated ones into subcategories. At this point, the researcher began with the colour- coded codes generated at open coding stage. These were used as

preliminary concepts and analysis focused on these initial codes. The researcher's task was to organise themes and identify the main concepts in analysis (Neuman, 2014). At this stage the researcher had generated 13 categories of data. It was evident that some themes were closely related and as such, could be combined. This served to reduce the data further and focus the findings concisely. For example, one theme reads: low knowledge of PrEP for HIV prevention. This led to the third stage of data reduction, called selective coding.

Selective coding

The last stage of the coding process is called selective coding. This stage inspects previous codes to classify and select data that will support the conceptual coding categories that previously established (Neuman, 2014). At this stage, all the data and previous codes were scanned, looking selectively for cases that revealed themes and comparing them once data collection was completed. Neuman (2014) suggests that selective coding should only begin after concepts have been well developed and several core ideas have been identified. Re-scanning the data and rechecking the themes allowed the researcher to find themes that were missed in the initial coding process as well as refine themes by combining similar themes and making sub-categories for emerging themes. The whole process of coding qualitative data as adopted in this study is illustrated in Figure 4.1.

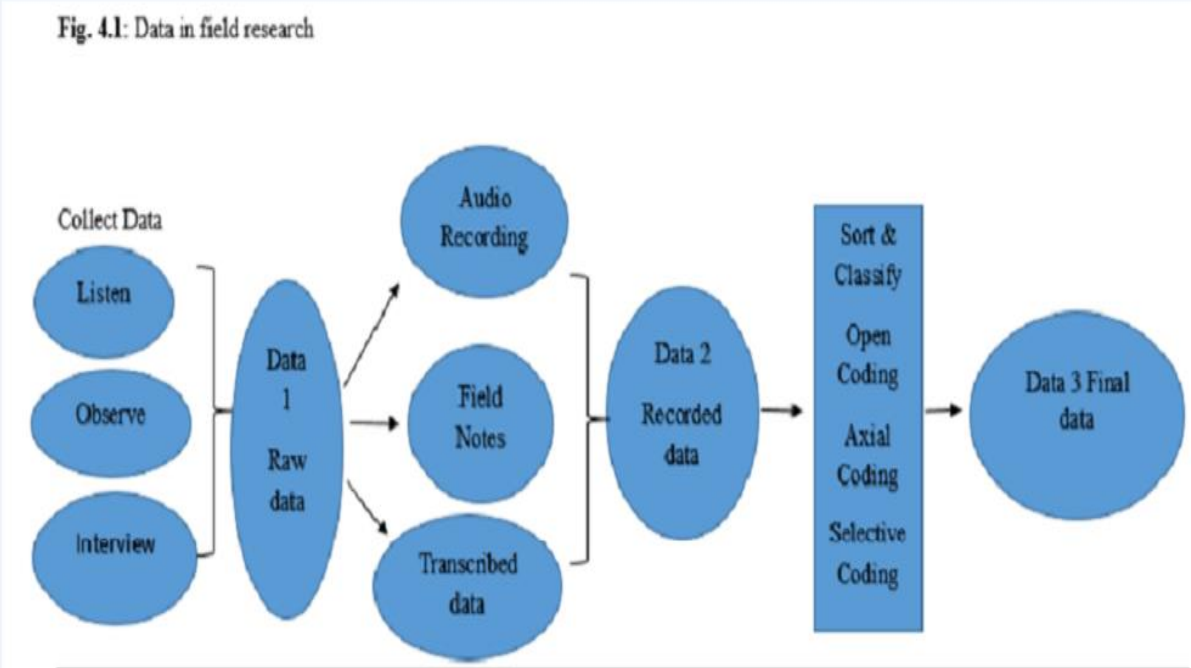


Fig. 4.1: Data in field research

(Data 1=raw data, experiences of researcher; Data 2= recorded data; Data 3= selected, processed data in a final report) **Source**: Adapted from Neuman (2014).

Trustworthiness of the study

Scholars have often observed the difficulty in establishing validity in qualitative research due to its subjective nature (Anney, 2014, Noble and Smith, 2015). Thus, qualitative research presents trustworthiness using terms such as credibility, transferability, dependability and conformability (Elo *et al*., 2014).

Credibility

Credibility refers to the confidence that the researcher has accurately documented the phenomena that forms the basis of the inquiry (Shenton, 2004). Because this study is qualitative in nature and seeks to understand perceptions of AGYW and men in Vulindlela, it was essential for the

researcher to conduct focus group discussions as a data collection method. Further, perspectives of health providers were necessary to help the researcher understand how their views and beliefs may influence their ability or desire to recommend oral PrEP as a new HIV prevention method. Thus in-depth interviews were ideal to explore these perceptions. Thus, triangulation by data sets was used. Data collected from focus groups and interviews was analysed analysed to assess what they had in common and where they differed. In this study, triangulation is viewed as a strategy that leads to a richer understanding of the subject of inquiry (Flick, 2004). Seen in this way, triangulation thereby becomes a step on the road to greater knowledge, and less towards validity and objectivity of interpretation (Flick, 2004).

This allowed the researcher to elicit a wide range of views and experiences. Additionally, these perspectives could be verified against others, resulting in richer data obtained from contributions of a wide range of people. Acess to the field was also provided by COMOSAT, a well known organisation in the area, which assisted with familiarity between the researchers and the participants. Employing games as part of the focus group discussion and having participants write down answers in answer sheets where they did not include their names allowed the reseacher to avoid social desirability bias, which tends to become a major issue in studies that explore socially sensitive issues such as drug use, religion or personal matters. Social desirability bias is a phenomenon where participants give socially desirable responses instead of choosing responses that are reflective of their true feelings (Rao *et al.*, 2017). This is because they were able to write about situations that apply in their own lives pertaining sexual risk, but could do this in complete anonymity because they did not have to write their names on the answer sheets.

Transferability

Transferability depends on the idea that findings can be generalised or transferred to other settings or groups (Cope, 2014). However, qualitative research is often carried out on a small scale and further takes into account contextual factors that may not apply in other settings (Shenton, 2004). To this end, this study has explained in great detail the contextual factors that apply. While the findings in this study do not presume to make general claims, its location in Vulindlela and the effects of HIV in the area, the study acknowledges that research carried out may have a local and global impact. The sample in this study was small, thus findings cannot be generalised, however, this study is transferable – bigger scale studies can be conducted on and are much needed.

Dependability

Dependability denotes "the stability of data over time and under different conditions" (Elo *et al.*, 2014). In this study, the researcher ensured dependability by describing the research design and how it was implemented as well as how data was collected in the field and managed afterwards. Self-reflexivity was also applied to assess the effectiveness of all the processes that were undertaken in the study.

Confirmability

Confirmability refers to the likelihood that data will be comparable in meaning or relevance between two or more independent people (Anney, 2014). Stated in another way, conformability helps to ensure that the work presents findings sourced from the experiences of the participants, not the views and preferences of the researcher (Shenton, 2004). Thus, it is important for the researcher to acknowledge bias and take steps to ensure it does not sway the focus of the study. In the current study, the researcher has justified the use of all the research methods applied as well as the choice of the participants. Further, field notes and transcriptions of audio recordings were consistently consulted at analysis stage to ensure that findings reflected the experiences and views of participants.

Ethical considerations

A researcher has a moral responsibility to ensure that their study is conducted ethically (Harding, 2013). Researchers have an obligation to protect participants in their research, develop a trust with them, promote the integrity of the research and guard against impropriety that may affect their institutions (Creswell, 2013).

Before the study commenced, the researcher was required to present the proposal to the academic leader, academic staff and colleagues at the Centre for Culture, Media and Society. This was to obtain commentary on the proposed study and comply with the University of KwaZulu –Natal's Code of Conduct for research. The next step was to apply for ethical clearance through the University of KwaZulu- Natal Humanities and Social Science Research Ethics Committee. The study could not commence until ethical approval was granted. Once all ethical requirements were satisfied in the application, ethical clearance was granted under protocol reference number HSS/0909/017M.

It is important to remember that participants are being placed in an unfamiliar position when taking part in research therefore the consequences must be explained to them as clearly as possible (Harding, 2013). To meet this requirement, participants in this study were required to sign informed consent forms that clearly explained that participation was voluntary and participants may withdraw participation at any point (Corbin et al., 2014, Creswell and Poth, 2017). In the event of refusal or withdrawal, participants were informed that they would not incur any penalty or loss of treatment or other benefit to which they would be normally entitled. The informed consent form is attached as Appendix 2.

This was to ensure that adolescent girls were absolutely clear about the terms of their participation. To prevent harm to potential participants resulting from exclusion from the study, the researcher encouraged potential participants to take part in educational HIV prevention programmes at the school. The researcher explained that exclusion was only limited to this study, not to participation in current and future HIV prevention programmes in the school and in the community.

The researcher ensured all participants were informed of their right to disclose what they were comfortable with as a first step to preventing secondary psychological harm. A community developer was present in the event participants needed further help. The community developers have access to the school, meaning the participants know the community developers, ensuring further protection from secondary victimisation. In case the need for further counselling arose during the focus group discussions, considering the sensitive nature of the topic, the community developer was ready to contact one of the chosen referral mechanisms. *ChildLine* is understood to be the most appropriate as they have the skills and abilities to deal with a multitude of issues, they are free, they have a 24 hour counseling service, are able to give counseling in the participants' language and they provide counseling for physical, emotional and sexual abuse.

Focus group discussions and all interviews were audio recorded after permission was granted by the participants. The concepts of confidentiality and anonymity are often confused in qualitative research. Anonymity can only be promised only where nobody can identify which respondent provided which piece of information while confidentiality refers to the agreement between researcher and participants on how the data will be accessed and used (Harding, 2013). Therefore, while I could not promise anonymity because data was collected through focus group discussions, a certain level of confidentiality was provided because the researcher transcribed the recorded data

herself and did not use participants' names in presenting the data. Further, at no stage of the data collection process were participants asked to give their names. Focus group members were requested to keep the views of other group members confidential. Further, data will be stored in a secured office in the Centre for Culture, Communication and Media Studies at the University of KwaZulu Natal.

Conclusion

This chapter has explained the research methodology and method that was applied in this study. The chapter further described the research design and research paradigm, selection of participants, data collection and the process of data analysis that was carried out in this study. Additionally, issues pertaining to how trustworthiness was maintained in this qualitative study were addressed. To conclude, the chapter addressed ethical considerations and the steps taken to prevent potential harm among participants. The following chapter will present the data collected through focus groups and interviews.

CHAPTER 5: RESEARCH FINDINGS

Introduction

The goal of qualitative inquiry is to present findings (Merriam and Tisdell, 2015). Qualitative research focuses on the way people perceive and understand the world around them (Holloway and Galvin, 2016). This study sought to understand how AGYW and men in Vulindlela, South Africa perceive risk and how these perceptions inform acceptance of oral PrEP as well as barriers and enablers that affect acceptability of this new HIV prevention method. Thus, this chapter presents data on perceptions of HIV risk as well as acceptability and possible barriers and enablers that affect acceptability of oral Pre-Exposure Prophylaxis (PrEP) among adolescent girls and young women (AGYW) and men in Vulindlela, South Africa.

Qualitative research generates voluminous data (Miles *et al*., 2013). Therefore, the researcher needs to find a way to analyse and present the data. Qualitative data analysis involves the identification, exploration and explanation of themes and patterns in the data and determines how the emerging themes answer the research questions (Ritchie *et al*., 2013). In the current study, data was generated from three focus groups and two in-depth interviews. Focus groups comprised adolescent girls attending the local clinic aged 15 -18 years, young women aged 18-24 years accessing antenatal services at a localclinic and men aged 25-35 years accessing HIV counselling and testing (HCT) services at the local clinic. There was a total of 22 participants across all focus groups; six adolescent girls, seven young women and nine men. This selected sample population is relevant to this study because the HIV transmission cycle in South Africa highlights that AGYW are high risk groups, making them a key target population for tailored PrEP promotion. In-depth interviews were conducted with the HCT counsellor and clinic nurse. This was important because literature suggests that lack of knowledge about oral PrEP among health providers and their perceptions could prove to be a potential barrier to acceptance of oral PrEP. Each focus group discussion lasted for approximately one hour.

Although this is a qualitative study, findings are presented quantitatively because some responses were written down and some questions were value driven and could be quantified. Further,

findings are presented thematically; however, the researcher was guided by the Health Belief Model (HBM) and Social Ecology Model of Communicating Health Behaviour (SEMCHB) framework because the constructs of these models directly address the research questions. Thus, themes focused on specifically looking for issues of perceived risk, perceived susceptibility, perceived severity, perceived benefits and cues to action. The SEMCHB was also used to understand the theme relating to partner knowledge in the acceptance of oral PrEP. The interpersonal level of the SEMCHB argues that social relationships can influence the acceptability of new HIV prevention interventions such as oral PrEP. Therefore, it was important to understand partner perceptions of this product as well as how these perceptions influence AGYW's acceptability of oral PrEP. The themes are presented in Table 5.1 below.

Table 5.1: *Themes emerging from the data*

Theme	Aspect
1. Perceptions of risk of HIV	• Exploring beliefs about participants' vulnerability to HIV infection
2. Perceived susceptibility and perceived severity to HIV infection	• Understanding beliefs about participants' susceptibility and severity to HIV infection
3. Mapping risk among participants	• Exploring participants' ability to self-protect • Assessing risk against ability to adopt protective behaviour
5. Perceptions of oral PrEP	• Understanding awareness and knowledge of oral PrEP
6. Partner knowledge in oral PrEP acceptance	• Understanding intended use of oral PrEP among key user population
7. Acceptability of oral PrEP	• Exploring levels of acceptability of oral PrEP among AGYW and men in Vulindlela
8. Potential barriers and enablers affecting acceptance of oral PrEP	• Exploring potential enablers and barriers influencing acceptance of oral PrEP among participants

Presentation of findings

The study findings are presented and discussed using the Health Belief Model (HBM) and the Social Ecology Model of Communication for Health Behaviour (SEMCHB) which are the conceptual frameworks framing this study. This approach was used because data collection was done using a risk mapping tool to assess individual perception of risk, susceptibility, severity, benefits and self-efficacy. This was important because it allowed the researcher to develop user profiles for oral PrEP based on data sourced from participants on their perceptions of oral PrEP. However, the application of thematic analysis allowed the researcher to apply analytical perspectives to the data that emerged through categorising the data into specific themes. It is important to note that while the focus is on individuals, the context in which these individuals reside is not ignored, which is why the HBM is embedded in the SEMCHB. The focus on individuals was important at this stage because oral PrEP has not been implemented at a national scale, thus we needed to understand factors that would influence and encourage acceptability and uptake.

The five constructs of the HBM were used to explore participants' awareness, knowledge and perceptions of oral PrEP. The constructs are perceived susceptibility to HIV infection, perceived severity of HIV, perceived barriers to uptake of oral PrEP, perceived benefits of oral PrEP and cues to action to encourage uptake. The study further drew upon the interpersonal level of the SEMCHB to understand the social factors that influence perceptions of oral PrEP among adolescent girls, young women (AGYW) and men of Vulindlela, South Africa. As the conceptual framework chapter illustrates, constructs from both models were used in combination due to their complementary nature.

While constructs of the HBM account for individual behaviour and specific knowledge about HIV prevention and beliefs that individuals hold about oral PrEP, the interpersonal level of the SEMCHB accounts for social factors that influence an individual's perceptions. Thus, we acknowledge that while behaviour change may be an individual decision, social relations has a significant influence on an individual's ability to execute a decision.

Presentation and analysis of findings

Perceptions of risk of HIV

Before a woman can even consider a new HIV prevention method, she must perceive herself at risk of HIV infection. Participants' perceptions of risk have an influence on acceptability of oral PrEP. It was important to explore perceptions of risk among participants to understand how their perception of risk affects individual AGYW's interest and willingness to try oral PrEP as a new HIV prevention method in different circumstances. Understanding that perception of risk of others versus self-risk can be very different, the study adopted hypothetical scenarios of risk and opportunities for participants to identify personal risk to get a nuanced perspective of perceived risk.

Before participants could be asked about their acceptability of oral PrEP, it was important to firstly establish, if they consider themselves at risk of HIV and secondly, to determine the level of risk that they are willing to take. It was imperative to start at this point because it establishes the relevance of oral PrEP as a new HIV prevention method. Results from the three focus groups are presented in Table 5.2.

Table 5.2 Understanding perceived risk among participants

Level of risk	Adolescent girls (AG)	Young Women (YW)	Men
10%	1	0	4
20%	0	0	2
30%	0	0	2
40%	0	0	2

Table 5.2 presents the findings on perceived level of risk by AGYW and men participating in the study. To quantify the level of risk, a total of ten sweets were used to represent risk, with each sweet representing a 10% level of risk. Risk is cumulative, which means if one sweet represents a level of 10% then two represent a level of 20% and so on.

When risk was at 10%, one of six adolescent girls said she was likely to engage in risky behaviour compared to four out of nine men, and commented: "It won't affect me negatively because there is only one bad one" (P1 AGYW high school FGD: 24 October 2017). However, other young women said they would not risk their lives and thus, would abstain from participating in risky behaviour, whilst other women felt: "That is a poison so I will not eat. Little poison is still poison" (P5 AGYW clinic FGD: 12 October 2017).

When men were asked why they would be willing to overlook the risk, male participants stated that risk was insignificant, and as such it would not affect them. One male participant said: "I can take the risk, majority is green; green can beat red. Little poison" (P4 Men Clinic FGD: 12 October 2017), whilst another commented that "green is still dominating" (P2 Men Clinic FGD: 12 October 2017).

Perceived susceptibility and perceived severity

Two focus groups were used to collect data from AGYW in the local clinic and high school. However, because their views on perceived susceptibility and perceived severity were relatively consistent the data collected was presented together and compared with data from men in Table 5.3. In this study, perceived susceptibility refers to the participants' assessment of whether they believe they are at risk of HIV infection while perceived severity denotes their assessment of how likely they are to be exposed to HIV infection.

The first scenario assesses participants' perceptions about whether they believe having unprotected sex puts them at high risk of HIV. The data presented in Table 5.3 shows that while 50% of men who participated in this study believe that having sex without a condom presents a high risk of HIV, 10% of the men believe that this scenario presents low risk while 40% of male participants consider this a no risk scenario. This was significantly different when compared to AGYW who

all consider this a high risk scenario (i.e.: 100% of women). However, all participants concurred that drinking lots of alcohol at the shebeen and having sex presents a high risk of HIV infection.

The third scenario tries to assess participants' perceptions of whether having more than one sexual partner can increase their risk of infection. When asked to rate having more than one sexual partner only 20% of male participants consider multiple sexual partners a high risk scenarios compared to all AGYW who perceive this scenario as high risk (i.e. 100%). 20% men participating in the study said this scenario was low risk while 50% more male participants believed it presented no risk of HIV infection. 10% of AGYW participating believe that having a *blesser* relationship presents a low risk of HIV infection compared to 30% of male participants. 90% of AGYW believe that having a *blesser* is a high risk scenario compared to just 30% of male participants. 40% male participants reported that there was no risk of HIV in *blesser* relationships.

The final scenario tries to assess the participants' perception of whether taking a HIV prevention pill such as oral PrEP can in fact reduce their risk of infection. Data shows that 60% of AGYW participating in this study believe taking a pill every day to prevent HIV infection is low risk, compared to 30% of the male participants in this study. However, 70% of male participants believed that taking a pill to prevent HIV presents no risk of HIV infection compared to 40% of AGYW.

Overall, this suggests low perceived susceptibility and low severity to HIV risk among male participants. However, there is a high perceived susceptibility and high severity among AGYW participating in this study.

Mapping risk among participants

After exploring the level of risk among AGYW and men in this study, risk mapping was used to understand perceived self-efficacy. Self- efficacy is concerned with people's beliefs that they can exert control over their motivation and behaviour and over their social environment (Bandura, 1997). Thus, participants were asked to assess their own behaviour and discuss whether this behaviour put them at high or low risk of HIV. Two themes emerged from this data: perceived self- efficacy as well as perceived risk and perceived self-efficacy.

Self percepton of risk

Five adolescent girls participating in this study reported that they were not engaging in any sexual behaviour that could put them at risk of HIV infection. One participant stated: “I don’t do anything that can put me in a risky situation. I am not in risk” (P1 AGYW high school FDG: 24 October 2017). However, one participant stated that she was engaged in high risk behaviour by having sex with her boyfriend: “Having sex with my boyfriend without using a condom is a high risk” (P5 AGYW high school FGD: 24 October 2017). Another participant highlighted that she could be putting herself at risk of HIV by helping an injured person without protecting herself, however, she noted that this risk was low: “If I am helping someone who is bleeding without using gloves it is low risk”. (P6 AGYW high school FGD: 24 October 2017).

Young women participating in the study, on the other hand, reported engaging in behaviours such as unprotected sex, having sex with strangers, alcohol abuse and having multiple concurrent sexual partners. They further stated that their risk of HIV was high as a result of such behaviour. For example, one participant acknowledged that having unprotected sex was likely putting her at high risk of HIV: “Sex without a condom. This puts me at high risk" (P2 AGYW clinic FGD: 12 October 2017). Another participant also commented that having many sexual partners and having unprotected sex put her at high risk of HIV: “Sex without a condom and having sex with a lot of men. I am at high risk” (P4 AGYW clinic FGD: 12 October 2017). Another female participant said alcohol abuse and unprotected sex meant she was at high risk of HIV: “Drinking a lot of alcohol and having unprotected sex with my sexual partner means risk is high” (P5 AGYW clinic FGD: 12 October 2017).

Behaviour among men was equally risky. One male participant stated that being circumcised meant he was at low risk for HIV, however, he further acknowledged that having unprotected sex and having multiple sexual partners put him at high risk of HIV: “Having sex without a condom and having many sexual partners is a high risk. But having circumcision is low risk” (P2 Men clinic FGD: 12 October 2017). Another participant reported that alcohol abuse and having unplanned sex with strangers contributed to putting him at risk of HIV infection: “Drinking too much alcohol and having sex without a condom and also having unplanned sex with a stranger. All of this is high risk” (P4 Men clinic FGD: 12 October 2017). Behaviour such as having multiple concurrent sexual partners and having unprotected sex put another participant at high risk of HIV:

"Sex without a condom and having more than one sexual partner, also washing my child's wounds without wearing gloves make me high risk" (P7 Men clinic FGD: 12 October 2017).

Overall, this data suggests that adolescent girls are at low risk of HIV because they do not engage in risky behaviour. However, young women and men are at high risk of HIV due to the risky behaviour that they engage in.

Perceived risk and perceived self-efficacy

The Health Belief Model suggests that for an individual to change behaviour, knowledge of risk is important (Champion and Skinner, 2008). Further, the individual must understand the likelihood that he can be affected by the risky behaviour (susceptibility). The individual must then assess the harmful effects of the behaviour (severity) and possess confidence in their ability to undertake preventive action to prevent the behaviour (self-efficacy). This section discusses participants' perceived risk of HIV, susceptibility, severity and self-efficacy.

Despite all AGYW stating that all the scenarios in the exercise to understand perceived susceptibility and perceived severity were high risk as illustrated in Table 5.3, they reported that they did engage in behaviour such as having more than one sexual partner, drinking alcohol and then having sex, having unprotected sex and being involved in *blesser* relationships presents a high risk of HIV. One female participant stated that she engaged in unprotected and had many sexual partners: "I have sex without a condom and having sex with a lot of men." (P4 AGYW clinic FGD: 12 October 2017). Another female also stated that she engaged in unprotected sex: "I have sex without a condom" (P2 AGYW clinic FGD: 12 October 2017). "I have sex with my boyfriend without using a condom," reported another participant (P5 AGYW clinic FGD: 24 October 2017).

Men participating in this study reported similar behaviour, although this was in keeping with their low perception of susceptibility and severity to HIV as ascertained in previous exercises. One male participant said: "Having unprotected sex sometimes" (P1 Men clinic FGD: 12 October 2017). Another reported drinking excessively, having unprotected sex and having unplanned sex presents a high risk of HIV: "Drinking too much alcohol and sex without a condom as well as having unplanned sex with a stranger is high risk" (P4 Men clinic FGD: 12 October 2017). Having unprotected seemed to be a common theme among male participants in this study. Another participant also said having unprotected sex and having sex with many girls put him at high risk

of HIV: “Sex without a condom and sex with many girls makes me at risk” (P9 Men clinic FGD: 12 October 2017).

In summary, AGYW in both focus groups showed high perceptions of risk. They also had a high perception of susceptibility and severity. However, self-efficacy was low among AGYW participating in the focus group at the local clinic. Male participants in this study showed low perceptions of risk. However, they had high perceived susceptibility and high severity.

Perceptions of oral PrEP

Participants were asked to mention methods of preventing HIV infection that they were familiar with. Participants in all three focus groups mentioned condoms, circumcision, using gloves when helping injured people and not sharing needles. Participants in all three focus groups also stated that condoms were the most common method of preventing HIV. This knowledge is important because it helps to establish the baseline of what participants consider as HIV prevention methods. Two themes emerged from this data; ideas about oral PrEP and male involvement in oral PrEP.

Ideas about oral PrEP

Thereafter, participants were asked if they had heard about oral PrEP. Responses from all participants are presented in Table 5.4

Table 5.4 Knowledge about oral PrEP

	AGYW high school	YW clinic	Men
Heard about oral PrEP	2	6	2
Have not heard about oral PrEP	4	1	7
Total no. of participants per focus group	6	7	9

Data was collected in three focus groups in this study. The first focus group comprised six adolescent girls, the second focus group comprised seven young women and the third comprised nine men. Out of a total of 22 participants in three focus groups, only 10 participants said they had heard of oral PrEP. Two of the participants were in the focus group with adolescent girls in

high school; the other two participants were in the focus group with men while six of the participants were in the focus group with young women at the clinic. Four adolescent girls and one young woman said they had not heard about oral PrEP while seven men reported that they had not heard about oral PrEP. Everyone who said they heard about PrEP said they had heard about it at CAPRISA. CAPRISA is an organisation that carries out globally relevant and locally responsive research that contributes to understanding HIV pathogenesis, prevention and epidemiology as well as the links between tuberculosis and AIDS care (CAPRISA, 2017).

Out of a total of 22 participants in three focus groups, only 10 participants said they had heard of oral PrEP. Everyone who said they heard about PrEP said they had heard about it at CAPRISA. Two of these participants were in the focus group with adolescent girls. One participants in this focus group said she heard something about a pill, but she did not have much information about it: "I know nothing much. I don't have much information but I know that there is this pill. (P2 AGYW high school FGD: 24 October 2017)". Another participant in the focus group with adolescent girls stated that she heard oral PrEP was to be taken daily to reduce risk of HIV. However, she had no further information: "I heard that you take it every day to reduce risk of being infected with HIV" (P4 AGYW high school FGD: 24 October 2017). A third participants in the same focus group said she had about a pill that was taken after sex, however, she was unsure whether this was oral PrEP or not. However, she stated that the pill could be accessed at the pharmacy: "There is a pill that you take after sex. You get it at the chemist" (P1 AGYW high school FGD: 24 October 2017).

Two participants in the men's focus group said they had heard about oral PrEP, but only one participant could articulate what he had heard about oral PrEP: "What I heard is that when you use it every day you might not get infected" (P1 FGD: 12 Men clinic October 2017).

Six participants in the young women's focus group said they heard about oral PrEP. One participant in this focus group said she heard that the body could reject it: "I heard that the body can reject it" (P4 AGYW clinic FGD: 12 October 2017). Another participant in the same focus group seemed to be well informed about oral PrEP: "It's a pill that you take daily to prevent HIV even when you have sex with someone who has HIV (P7 AGYW clinic FDG: 12 October 2017). Only one participant seemed aware that oral PrEP could be taken only in seasons of high risk. She said: "You can take it and stop and then take it again when you need it" (P6 AGYW clinic FGD:

12 October 2017). The idea that oral PrEP should be taken daily seemed to be the most common thing that participants knew about oral PrEP: "One participant, who was pregnant, mentioned that she had heard that oral PrEP could be taken even when was pregnant: "What I know is that you can take it even when you are pregnant" (P3 AGYW clinic FGD: 12 October 2017).

Male involvement in oral PrEP implementation?

A brief presentation was made about oral PrEP in each focus group. Given the lack of oral PrEP introduction in the community, several questions were raised, particularly in the focus group with male participants.

One participant wanted to know if oral PrEP could be useful for sero-discordant couples: "So you mean I can have a partner who is HIV positive and protect myself with this pill?" (P1 Men clinic FDG: 12 October 2017). "Does oral PrEP could prevent HIV infection if I wanted to have a child," asked another participant. This was another question making reference to sero-discordant couples: "What about if you want to have a child, is it safe to use this pill?" (P6 Men clinic FGD: 12 October 2017). Another participant raised the issue of the level of protection that can be achieved with oral PrEP. He wanted to know if oral PrEP provided added protection after circumcision. "Does it mean that if I take the pill and have been circumcised, I have 100 percent protection?" (P7 Men clinic FGD: 12 October 2017). "Do I have to eat before I take the pill?" asked another participant (P2 Men FGD: 12 October 2017). Another male participant was concerned about the interaction of PrEP with other medication that he might have been taking: "What about if you are taking other medication?" (P9 Men FGD: 12 October 2017). One participant wanted to know what the consequences would be if he forgot to take oral PrEP and then have unprotected sex: "What happens if I forget to take PrEP and then have unprotected sex?" (P1 Men clinic FGD: 12 October 2017).

Acceptability of oral PrEP

Othering oral PrEP use

Acceptability of oral PrEP is highly likely to be influenced by potential users' perceptions about the product. To understand participants' perceptions of oral PrEP, participants were asked who

they thought would need oral PrEP the most. One participant in the focus group with adolescent girls said girls who like to go to parties were more likely to have to use oral PrEP: "Girls who like to go to parties" (P3 AGYW high school FGD: 24 October 2017). Another participant stated that those who were involved in *blesser* relationships would most likely need oral PrEP the most: "I think it is the blessees who need PrEP the most" (P2 AGYW high school FGD: 24 October 2017). This was confirmed by another participant who said: "If you are in a relationship with a *blesser*, he may not want to use a condom but PrEP can protect you" (P2 AGYW high school FGD: 12 October 2017). Peer pressure in the school setting was mentioned as a big influence among adolescents and participants stated that anyone who was affected by peer pressure would find oral PrEP useful: "Those affected by peer pressure" (P6 AGYW high school FGD: 24 October 2017).

In the focus group with young women, one participant stated that people with more than one sexual partner would benefit from oral PrEP: "Girls who have more than one sexual partner should use it" (P5 AGYW clinic FGD: 12 October 2017). Another participant observed that men often did not want to use condoms, therefore, young girls would benefit from oral PrEP: "Young girls because boys and men don't want to use condoms" (P6 AGYW clinic FGD: 24 October 2017). Another participant raised the issue of people who drink excessive alcohol and then have unprotected sex: "Most young girls take alcohol and then have sex. In that moment you don't remember to use a condom because everything is rushed. But at least if they take PrEP, they are protected because it will be in the blood [system] (P3 AGYW clinic FGD: 12 October 2017).

The male participants suggested that the youth as well as taxi and truck drivers would benefit most from oral PrEP. "Taxi and truck drivers would benefit from PrEP. They meet different women every day and this increases their chance of sleeping with someone unprepared" (P5 Men clinic FGD: 12 October 2017). One participant said both girls and boys would benefit from using oral PrEP because boys hosted parties where they had sex with many girls: "Youth, both boys and girls. Because boys have parties and have sex with many girls. Girls also need it because they have *blesser*" (P4 Men clinic FGD: 12 October 2017).

Overall, participants identified users who could benefit most from the use of oral PrEP based on situations that ye consider high risk. Participants suggested that truck drivers, taxi drivers, young people, people involved in unequal relationships and those who abuse alcohol and engage in unprotected sex would benefit most from the use of oral PrEP.

Oral PrEP as protection versus oral PrEP for promiscuity

Because oral PrEP is imagined as a women-initiated HIV prevention method in South Africa, female participants were asked what they thought their sexual partners would think if they found out that the participants were taking oral PrEP.

One participant in the focus group with young women stated that male sexual partners could misconstrue women's use of oral PrEP and think that she was cheating: "Your partner would think you are sleeping around when he sees them, especially because PrEP is ARV based" (P6 AGYW clinic FGD: 12 October 2017). Another participant concurred and said her partner had already informed her that he thought oral PrEP would make her "sleep around": "I told my partner about PrEP and he said that pill is going to make you go and sleep around with many boys and so he doesn't want these tablets" (P2 AGYW clinic FGD: 12 October 2017). "They may think you have HIV," said another participant (P4 AGYW clinic FGD: 24 October 2017).

A participant in the focus group with adolescent girls mentioned that if a woman is seen with oral PrEP, other people may think she is going to have sex: "They may think you are going to have sex" (P1 FGD: 24 October 2017). Another participant in this focus group concurred and stated that a girl using oral PrEP might be perceived as having more than one sexual partner: "They may also think that you have more than one sexual partner" (P2 AGYW high school FGD: 24 October 2017).

The male participants were asked what they would think of their sexual partners' use of oral PrEP. One participant stated that without knowledge of oral PrEP he would think the girl was HIV positive: "Without understanding I would say she is HIV positive, but with understanding I will say she is clever" (P2 Men clinic FGD: 12 October 2017. Another participant stated he would see his partner's use of oral PrEP as indication that she was cheating: "I would think she is cheating on me. Why do you use oral PrEP if you are faithful to me?" (P9 Men FGD: 12 October 2017).

Participants were asked how they would perceive other women who were using oral PrEP. One participant stated that if her sister or friend was using oral PrEP she would think her friend was protecting herself: "I would think that she is protecting herself" (P3 AGYW high school FGD: 12 October 2017). Another participant agreed and said now that she had been educated about oral PrEP she also thought of it as a way of protection: "I can say the same because now I am educated about PrEP and I know what it is for" (P6 AGYW clinic FGD: 12 October 2017).

A participant in the focus group with men observed that it was important to educate people about oral PrEP because this would ensure acceptance: "Anyone can accept PrEP with an explanation. We just need to make them understand about it, even in the family" (P9 Men clinic FGD: 12 October 2017). Another participant explained that if he came across a female who was taking oral PrEP he would think of her as being smart: "Without understanding I would say she is HIV positive, but with understanding I will say she is clever" (P6 Men clinic FGD: 12 October 2017).

In summary, before they were informed and educated, participants had negative perceptions of oral PrEP. Female participants associated oral PrEP with irresponsible behaviour, stating that people who used the product would likely be perceived as going to have sex or having many sexual partners. Male participants, on the other hand, associated oral PrEP use with infidelity, suggesting that women using oral PrEP would be highly likely to be involved in affairs. However, perceptions of oral PrEP became favourable once participants understood what PrEP was for. Participants started to think of oral PrEP as protection and of women who would use it as "smart".

Social relationships and their influence on perceptions of oral PrEP

Participants were asked if they believed that oral PrEP could lower their risk of contracting HIV and if they would be willing to take it. Table 5.4 presents that number of participants who said they would be willing to take oral PrEP.

Table 5.5: Willingness to take oral PrEP

	AG	YW	MEN
Would take oral PrEP	5	5	9
Unsure about taking oral PrEP	1	2	0
Total number of participants per focus group	6	7	9

While a majority of the participants in all the focus groups in the current study generally agreed that the idea of PrEP was hypothetically a good one, two participants expressed doubt about the efficacy of the product. One of the participants was in the focus group with young women. She

said she did not believe in the efficacy of oral PrEP. When probed further about why she did not believe oral PrEP was effective, she stated that she had never heard of anyone who had used oral PrEP and as such could not confirm its efficacy: "Maybe I can say I don't believe it can work because I've never heard someone say they use it and it has worked for them" (P1 AGYW clinic FGD: 12 October 2017).

Another participant who expressed doubts about using oral PrEP was in the focus group with adolescent girls. She said she would be unable to take oral PrEP because girls in her social circle might have negative perceptions about oral PrEP: "I wouldn't be able to take it because of the criticism from friends. They would have different views about this pill and as girls we are sensitive. We influence each other" (P5 FGD: 24 October 2017).

Overall, all the male participants said they would take oral PrEP. However, some of the female participants were unsure about taking oral PrEP. One participant mentioned that she had never heard anyone she knew confirming oral PrEP efficacy. The other participant who was unsure about using oral PrEP stated that negative perceptions from her social circle would prevent her from using oral PrEP.

Participant views on daily oral PrEP

Participants were asked how they would feel about taking oral PrEP daily. One participant explained that adhering to a daily regimen of oral PrEP would be difficult: "It is not easy. I don't know, maybe it can be better if you take it once a week. *Eish* that you have to take it every day, *ayi* no. It's hard to take a pill" (P1 AGYW clinic FGD: 12 October 2017). Another participant concurred and suggested that a dosing option of one tablet or in injection form would be better. She said: "*Ya*, it is better to take it once a week or even to take an injection" (P3 AGYW clinic FGD: 12 October 2017). A young woman stated that she had a problem taking tablets in general, even if they were meant for minor ailments and as such, taking oral PrEP daily would not work for her: "I have a problem taking pills, even if it's just for flu. I usually vomit, so taking oral PrEP for me would not work. It would just come back immediately after swallowing it" (P5 AGYW clinic FGD: 12 October 2017). Another participant said taking oral PrEP daily would be difficult because she would forget to take it: "It's easy to forget a pill" (P2 AGYW clinic FGD: 12 October 2017).

In response to a similar question, one male participant said taking oral PrEP was fine as long as he was protected: "It will be good because it will protect us" (P3 Men clinic FGD: 12 October 2017). Others agreed and observed that the idea of oral PrEP is a good one because they would be protected: "*Ya*, it's alright because we will be safe" (P1 Men clinic FGD: 12 October 2017). An observation was made that taking oral PrEP would require an adjustment because participants were unused to taking medication: "The first few days will be difficult because I am not used to taking pills every day in my daily routine. I might remember late in the night. I can take it but it will disturb my routine" (P9 Men clinic FGD: 12 October 2017). Participants found the idea of taking oral PrEP daily overwhelming: "I agree it will be difficult. Every day is too much" (P8 Men clinic FGD: 12 October 2017). However, other participants said taking PrEP daily would not be difficult: "I can take it in the morning when I wake up" (P3 Men clinic FGD: 12 October 2017).

Provider perspective

The HCT counsellor stated that people who came to the clinic and were informed about oral PrEP often expressed concern at the thought of taking a tablet daily, just as it was already a challenge in contraception. She said: "The most common thing is that AGYW have to take the pill daily. That is why even when the women come for family planning, they prefer to use the injection instead of taking the pill because they always say they will forget to take the pill" (I: 12 October 2017).

In summary, participants stated that taking oral PrEP daily would be a challenge. Reasons for such a challenged included that they would forget to take the pill or that it was simply overwhelming to be expected to take a pill daily.

Partner knowledge in oral PrEP

Does overt use of Oral PrEP mean women empowerment?

AGYW participating in this study were asked whether they would inform their sexual partners about their use of oral PrEP, or seek their permission to use oral PrEP or use it in secret. The men participating in this study were asked whether they would accept their sexual partners' covert use of oral PrEP or whether they would expect to be informed or asked for permission to use this new HIV prevention method.

An adolescent girl participating in the study said she would not seek her boyfriend's permission to use oral PrEP. She stated, however, that they could discuss the issue as a couple: "I don't need anyone's permission to protect myself, but we can discuss it. If he is against it then it is my own choice I have to protect myself" (P2 AGYW high school FGD: 24 October 2017). Another participant said the only person who could be expected to give permission would be her mother, not a boyfriend. She stated that she would inform her boyfriend and they could discuss it: "Maybe I can get permission from my mother because she has all the powers over me, but not a boyfriend. I do agree that we can discuss it just to let him know that I am using PrEP" (P1 AGYW high school FGD: 24 October 2017). Participants argued that using oral PrEP was a personal choice: "It's my own choice, we can break up if he says no" (P2 AGYW high school FGD: 24 October 2017).

In the focus group with young women, one participant she would inform her partner that she was using oral PrEP to avoid conflict."It is better if he knows about PrEP and what it does to avoid conflict" (P2 AGYW clinic FGD: 12 October 2017). One participant said she would tell her partner to assure him that she was not HIV positive: "I would tell him so that he knows I am not HIV positive, but rather I am simply protecting myself" (P4 AGYW clinic FGD: 12 October 2017).

The men participating in this study stated that they would not expect their partners to seek permission form them to use oral PrEP. However, they said they expected to be told about it. One participant said for the fact that they were in a relationship, he would expect his partner to inform him about her use of oral PrEP: "We are in a relationship, she must let me know" (P8 Men clinic FGD: 12 October 2017). Another participant concurred and stated that if she was a 'real' girlfriend she would let him know: "If she is a real girlfriend she must talk to you, not the stray ones that you get somewhere" (P9 Men clinic FGD: 12 October 2017).

Overall, both male and female participants agree that covert use of oral PrEP would not be accepted. Female participants stated that use of oral PrEP was a personal choice and as such, they would not seek permission from their male partners to use it. However, female participants said they would disclose their use of oral PrEP to their partners. Male participants acknowledged that they did not expect permission for oral PrEP to be sought by their sexual partners; however, they explained that they expected to be informed about use of oral PrEP.

Potential barriers and enablers affecting acceptance of oral PrEP

Oral PrEP is a relatively new HIV prevention method. Therefore, in order to ensure uptake, it is important to explore possible barriers and enablers influencing acceptance among key population groups. This section first addresses enablers affecting acceptance before the discussion on possible barriers.

Enablers affecting acceptance of oral PrEP

i. Perceptions of oral PrEP among health care providers

Health care providers in public clinics are often the first point of contact for members of the public. The HCT counsellor and clinic nurse were asked about their views on oral PrEP. The HTC counsellor stated that anything that promised to halt new infections was a good idea and she fully supported oral PrEP. She said: "It is a good thing. A lot of people are infected with HIV so if there is something that will prevent people from getting it then it is good, we are much happy (I: 12 October 2017). The clinic nurse concurred that oral PrEP was a good idea. She said: It's a good idea. Prevention is better than cure and anything that will prevent HIV is a great idea. I would encourage people to take it" (I: 12 October 2017).

ii. Perceptions of oral PrEP effectiveness

Participants observed that oral PrEP would be useful in protecting them from risk of HIV infection. A male participant said oral PrEP had potential as an HIV prevention method because it would save him: I think it will save me" (P6 Men clinic FGD: 12 October 2017). Oral PrEP was also perceived as useful because it reduces chances of acquiring HIV: "It will be good because it will reduce risks of getting HIV" (P3 Men clinic FGD: 12 October 2017). Another participant said oral PrEP would protect him from HIV. "Oral PrEP will protect me from HIV" (P1 Men FGD: 12 October 2017). One of the adolescent girls participating in the study said that oral PrEP would lower her risk of infection."Oral PrEP lowers my risk of infection under any circumstances" (P3 AGYW high school FGD: 24 October 2017). In the focus group with young women, one participant said that oral PrEP would be useful in preventing HIV infection: "Oral PrEP will protect me from my cheating boyfriend if he gets infected" (P6 AGYW clinic FGD: 12 October 2017).

Barriers affecting acceptance of oral PrEP

i. Structural issues in public health centres

In an effort to identify possible barriers that can affect acceptance of oral PrEP at the clinic setting, the HCT counsellor was asked to explain the referral system and how it differed between patients who come to the clinic for sexual transmissted infections and those who come to the clinic for family planning. The counsellor explained that she was the first point of contact before patients were referred to nurses. In this session, she finds out the patient's purpose for visiting the clinic and provides HIV testing and couselling services before she refers the patient to the relevant nurse. The counsellor identified gaps in this system: "They also see me first, but then I direct them to a nurse who is responsible for family planning. They don't go to the same nurse they would go to for PrEP[…] It would be much better if everything was in one place because this way we will miss them. That is a gap" (I: 12 October 2017).

A participant in the focus group with young women stated that she might not be able to use oral PrEP because she would not have time to fetch it at the clinic: "I won't have time to fetch it at the clinic" (P7 AGYW clinic FGD: 12 October 2017). This challenge was echoed by a participant in the focus group for adolescent girls who said she might not have time to fetch the tablets at the clinic due to being in school: "I might miss the day of going to the clinic because of being held back at school" (P5 AGYW high school FGD: 24 October 2017.

ii. Knowledge, attitudes and perceptions of parents

Participants in the focus group with adolescent girls observed that parental consent might be an issue that must be dealt with if they wanted to access oral PrEP. They stated that while they would not seek permission from their boyfriends to use oral PrEP, they might have to seek permission from their parents who are their guardians. One participant said she did not think parents would encourage their daughters to take oral PrEP as this could be construed as parents allowing their children to have sex: "I think most parents won't encourage us to take oral PrEP, especially mothers because they would think they are encouraging their children to have sex at a young age" (P5 AGYW high school FGD: 24 October 2017). Another participant observed, however, that HIV was a serious threat and as such, parents may want to encourage their children to protect themselves by using oral PrEP: "Some parents may agree [to let their children use oral PrEP]

because they want their children to be protected from HIV because HIV is a disease that you have until you die" (P3AGYW high school FGD: 24 October 2017).

iii. Other issues that can potentially affect the acceptance of oral PrEP

Participants in the study about possible hindrances that would prevent them from using oral PrEP. One participant in the focus group with young women said the side effects associated with oral PrEP would be a barrier for her: "The side effects will make me not to use oral PrEP" (P1 AGYW clinic FGD: 12 October 2017). This was also echoed by participants in both the focus with men and the one with adolescent girls. A participant in the focus group with men said a barrier for him would involve waking up early to go to work or drinking alcohol excessively and forgetting to take oral PrEP: "Waking early in the morning for work and drinking alcohol and forgetting to take the pill will be a problem for me" (P4 Men clinic FGD: 12 October 2017).

One participant in the focus group with adolescent girls said parental consent listed parental consent and availability of oral PrEP in clinics as barriers for her: "Parental permission, side effects of pills and availability of pills at the clinic will be a problem" (P4 AGYW high school FGD: 24 October 2017). A participant in the focus group with young women said her boyfriend might be a barrier because he does not trust tablets: "My boyfriend because he don't trust any pill" (P2 AGYW clinic FGD: 12 October 2017). Another participant in this focus group stated that her inability to take tablets would be a barrier for her: "Vomiting when I take any pill will make me not take oral PrEP" (P3 AGYW clinic FGD: 12 October 2017).

In the focus group with men, one participant stated that taking oral PrEP daily could prove to be a barrier for him: "Taking the pill everyday" (P1 Men clinic FGD: 12 October 2017). One participant said she would not take oral PrEP because people might think she had a *blesser* or was infected with HIV: "People may think I have HIV or *blesser*" (P3 AGYW high school FGD: 24 October 2017).

Conclusion

This chapter has presented the data collected through focus group discussions and interviews. The following chapter provides an analysis of the data in relation to the literature reviewed and the conceptual framework on which this study rests.

CHAPTER 6: ANALYSIS AND DISCUSSION OF FINDINGS

Introduction

The purpose of the current study was to understand user profiles for oral Pre-Exposure Prophylaxis (PrEP) through specific groupings of high-risk adolescent girls and young women (AGYW) (ages 15-25 years) and men who are likely to benefit from the use of oral PrEP in Vulindlela, South Africa.

This chapter analyses and discusses key findings from the data presented and collected in Chapter Five. Findings are analysed through constructs of the Health Belief Model (HBM) and the Social Ecology Model of Communication and Health Behaviour (SEMCHB), which are the conceptual frameworks underpinning this study. The chapter assess data collected in relation to the literature reviewed on existing research on HIV prevention in South Africa. Furthermore, the chapter presents user profiles for oral PrEP which have been generated from the data collected. Therefore, this chapter aims to address findings as they relate to the research objectives of the study.

Objective 1: To understand the perception of HIV risk among adolescent girls and young women and men in Vulindlela, South Africa

A substantial body of literature reviewed in this study suggests that women are disproportionately affected by HIV when compared to their male counterparts in Sub-Saharan Africa (Baxter and Abdool Karim, 2016). Literature further suggests that AGYW are eight times more likely to become infected with HIV and are infected earlier than men (Dellar *et al.*, 2015). A woman's ability to use a new HIV prevention method or adopt any sexual reproductive health behaviour is influenced by a range of factors including perceptions about risk and perceived need and ability to use the product. Perceived risk is one of the factors that influences decisions that relate to HIV prevention behaviour (Caldwell and Mathews, 2016). Firstly, an individual must understand that a specific risk exists. Secondly, the person must realise that the risk is significant enough to affect people negatively. Thirdly, the person must believe that they are vulnerable to the risk (Kidd *et al*., 2017). According to the HBM, these realisations should trigger behaviour change (Champion and Skinner, 2008).

Findings suggest that men from Vulindlela, South Africa who participated in this study had a higher willingness to engage in risky behaviour than AGYW. Participants in the men's focus group showed a willingness to engage in risky behaviour where the level of exposure to risk was up to 40%. In contrast, AGYW participating in the study were only willing to engage in risk activities with minimal exposure (i.e.: 10%). Therefore, the study found that willingness to take risk was lower among AGYW participating in the current study was higher when compared to male participants.

This study assessed HIV risk for condom-less sex among paticipants. Literature suggests that the condom is a highly effective device in preventing HIV transmission if it is used correctly and consistently (Hearst and Chen, 2004). Furthermore, studies have found that consistent use of condoms is still significantly low, particularly with primary partners (Yam *et al*., 2016). Data presented in Chapter Five shows that while 50% of men who participated in the current study believed that having sex without a condom presents a high risk of HIV, 10% of the men believed that this scenario presented low risk while 40% of male participants consider this a no risk scenario.

This was significantly different in comparison to AGYW who all consider this a high risk scenario (i.e.: 100% of women).

This finding suggested that male participants in this study had a low perception of risk when having sex without a condom, while women deemed condom-less sex as high risk. This raised questions for the introduction of PrEP. If risk perception is low and if an existing prevention method is available but not used, questions arise on the merit of a new innovation such as oral PrEP. Furthermore, other research suggests that condom use is often problematic age-disparate sexual relationships with older men or where women are victims of violence and sexual abuse (Brooks *et al*., 2012). In such cases women are often not in a position to negotiate condom use with their partners (Matthews *et al*., 2015).

Risk for multiple sexual partnerships was assessed among participants taking part in the current study. It is well documented in literature that having multiple sexual partners, either serially or concurrently, greatly increases risk of HIV infection (Naicker *et al*., 2015). However, sex with multiple concurrent partners still remains a factor contributing to the high prevalence of HIV in Sub - Saharan Africa, including South Africa (Shisana *et al*., 2014). Data in the current study shows only 20% of male participants consider multiple sexual partnerships a high risk scenario compared to all AGYW participating in the present study who perceived this scenario as high risk. 20% men participating in the study said this scenario was low risk while 50% more male participants believed that it presented no risk of HIV infection.

Whilst male participants had a low perception of multiple sexual partnerships, AGYW deemed multiple sexual partnerships as high risk. Whereas women have had to depend on their male partners' willingness to use condoms as their primary prevention strategy, oral PrEP offers women the possibility of autonomy over their own bodies by allowing them to take oral PrEP without their partner's knowledge if they so wish (Celum *et al*., 2013). Thus this finding established the relevance of oral PrEP as a woman-initiated HIV prevention method. However, studies show that oral PrEP is highly effective when used as part of combination prevention (Baxter and Abdool Karim, 2016). Furthermore, policy in South Africa has been adapted to ensure that combination prevention options are available for all high risk population groups, including AGYW. While oral PrEP has the potential to significantly reduce high infection rates among AGYW, questions still

remain on its implementation as part of combination prevention given that women still need to negotiate condom use with their partners to ensure maximum protection.

The practice of younger women partnering with older men is common throughout southern Africa, and is often thought of as the "sugar daddy" or "*blesser*" phenomenon (Harrison *et al*., 2015). Thus, perceptions of risk for *blesser* relationships were assessed among AGYW and men participating in the current study. Age disparate relationships with older men are a key contributing factor to the prevalence of HIV in South Africa (Zuma *et al*., 2016). Data presented in Chapter Five shows that 10% of AGYW participating in the current study believed that having a *blesser* relationship presents a low risk of HIV infection compared to 30% of male participants. 90% of AGYW believe that having a *blesser* is a high risk scenario compared to just 30% of male participants. 40% male participants reported that there was no risk of HIV in *blesser* relationships.

Whilst perception of risk was high among AGYW in the current study, 10% of these participants perceived having a *blesse*r as low risk of HIV. On the other hand, 30% of male participants believe there is low risk of HIV in this scenario with an additional 40 percent of male participants stating that there was no risk of HIV infection in *blesser* relationships. This suggests that male participants do not deem *blesser* relationships as a high risk of HIV infection.

Finally, participants' perceptions of risk for taking an HIV prevention pill (oral PrEP) to reduce their risk of infection were assessed in this study. Oral PrEP has proven to have consistent rates of up to 75% protection benefits in numerous settings and populations (Baxter and Abdool Karim, 2016). Furthermore, if taken daily as prescribed, oral PrEP has high efficacy as an HIV prevention strategy (Auerbach *et al*., 2015). Although participants were informed that oral PrEP was highly effective when taken regularly, some participants expressed doubt. Data in Chapter Five shows that 60% of AGYW who participated in the current study believed that taking a pill daily to prevent HIV infection was low risk compared to 30% of the male participants. . However, 70% of male participants believe that taking a pill to prevent HIV presents no risk of HIV infection compared to 40% of AGYW. This data suggests a low perception of oral PrEP among AGYW in this study when compared to men participating in this study.

Perception of HIV prevention methods is influenced by many factors, including beliefs' about the efficacy of the product and the person's ability to use the product, among many others (Frankis *et*

al., 2016). This establishes the importance of exploring potential users' perceptions of oral PrEP as these will be a determining factor in acceptance and uptake.

Objective 2: To establish the key influences under which adolescent girls and young women in Vulindlela, South Africa are willing to use oral PrEP

There is a clear need to understand the factors that might facilitate the effective use of oral PrEP (Young and McDaid, 2014b). Awareness knowledge of oral PrEP is one of the factors that can influence oral PrEP acceptance and use. Intended users of oral PrEP cannot use the product if they have no knowledge or awareness of it. Studies suggest that oral PrEP awareness is influenced by proximity to HIV (Frankis *et al.,* 2016). Further, literature suggests that women in countries such the United States of America were concerned that they had not been hearing about oral PrEP even though it was approved for use in 2012 (Auerbach *et al*., 2015). This is consistent with findings in this study. Just fewer than half the total number of participants in this study reported to have heard about oral PrEP.

This finding suggests poor knowledge of oral PrEP among the participants. Even the participants who had said they had heard about oral PrEP had neither enough nor correct information about it. Some participants indicated that they had heard about a pill that prevents HIV, but they did not know what it was called. It was surprising to learn that not a lot of people were aware of oral PrEP in Vulindlela, considering that this area is the location of the CAPRISA research site.

Furthermore, even though some people said they had heard about oral PrEP, they did not have in-depth information about this new HIV prevention method. These findings also point to inconsistencies in information about oral PrEP. For example, while side effects of oral PrEP such as nausea and renal problems are noted in literature (Karim *et al*., 2010), there is no mention of the pill being "rejected" by the body. Additionally, tended to associate oral PrEP with the emergency contraceptive pill and assumed oral PrEP was to be taken at exactly the same time every day, just like the contraception pill. Further, none of the participants were aware that oral PrEP was to be used with condoms as combination prevention.

The lack of information about oral PrEP contributes to barriers to acceptability of oral PrEP among participants. A highly effective HIV prevention method does not benefit the key population group for which it is intended if they have little to no knowledge of it. Further, lack of information plays

a role in reducing self-efficacy among participants. Again, if intended user groups have no idea about how to use a product, then it is unlikely to help them. Health communication is highlighted as a key factor in creating demand for oral PrEP (Tomori *et al.*, 2014). Thus, this finding suggests that more needs to be done by health communicators to ensure that the message about oral PrEP reaches key user populations. There is a need to ensure that demand is created before full implementation of oral PrEP to generate demand (Celum *et al.*, 2015).

Acceptability of oral PrEP

Literature suggests that people's perceptions of oral PrEP may play a role in its acceptability (Casale *et al*., 2011). An individual can form perceptions about oral PrEP based on information he/she hears about the product. However, perceptions can also be shaped by interpersonal relationships and the views of people around them about this new HIV prevention method. The tone of participants suggested a moralistic stance. While oral PrEP is meant to allow AGYW to protect themselves from HIV without having to negotiate condom use if they are unable to due to challenges such as being involved with older men or other unequal relationships, participants seemed to disassociate themselves from the use of oral PrEP and made it clear that it was for 'other' people who practice irresponsible sex.

This finding suggests that participants have negative perceptions of oral PrEP. This is evident in participants' suggestions that oral PrEP is for people who are 'loose' or likely to practice irresponsible sex. Again, it is important to observe that participants point to "other" people as likely candidates for oral PrEP yet they also practice similar risky sexual behaviours. This finding suggests that oral PrEP is associated with casual sex and perceived as a licence to cheat by both male and female participants. The idea that oral PrEP is associated with irresponsible sex seemed predominant among all participants.

Partner knowledge in oral PrEP use

Literature has documented the numerous challenges that women face in relation to HIV prevention (Dellar *et al*., 2015; Naicker *et al*., 2015). One such challenge is often that women have to depend on their male partners' willingness to use condoms as their primary prevention strategy. Thus, oral PrEP has the potential to address the problem of lack of agency and control among women when it comes to HIV prevention methods by allowing them to take oral PrEP without their partner's

knowledge if they so wish (Baxter and Abdool Karim, 2016). Thus, in cases where male partners refuse to use condoms for any reason, AGYW would still have some level of protection against HIV infection. AGYW were asked if they would use oral PrEP covertly and the general view was that they would want their partners to know that they were using this method to prevent HIV infection. This finding seems to disrupt the notion that using oral PrEP covertly empowers women. For women participating in this study, a sense of empowerment came from the idea of informing their partners about oral PrEP use and not seeking permission.

Strong emphasis was made on the fact that AGYW would not be seeking permission from their partners, rather they would be informing them of their decision to use oral PrEP. The men seemed surprised at the idea that their partners might initiate oral PrEP without informing them. They stated that they did not expect women to seek permission, but they did expect to be informed. All participants seemed to associate covert use of oral PrEP with mistrust. Further, covert use of oral PrEP is associated with stigma of being HIV positive.

The men participating in the study were asked what they thought about women using oral PrEP covertly. Only one participant said that he would not mind his partner using oral PrEP secretly because he would be protected as well. Other participants did not agree and stated that they did not expect women to seek permission; however, as a partner in the relationship, they felt that they needed to know the steps that their partners were taking to prevent HIV infection. This finding is important because it brings up a perspective of changing gendered behaviour among participants and an evolving culture in Vulindlela. In African culture, men tend to expect women to seek permission for anything they intend to do, even if it relates to contraception (Harrington *et al*., 2016). Thus, it was interesting to hear men say they only wanted to be informed, and not asked for permission to use oral PrEP.

Establishing user profiles for oral PrEP

In 2015 the World Health Organization (WHO) released guidelines for oral PrEP (WHO, 2015). The guidelines recommend the provision of oral PrEP as an additional prevention choice for people at high risk of HIV infection (Baxter and Abdool Karim, 2016). These guidelines combined with the approval of oral PrEP for HIV prevention by several countries including France, South Africa and Kenya, has made the use of PrEP for HIV prevention a possibility (Karim *et al*., 2010). PrEP is a particularly important HIV prevention option for women, as it is one of the few strategies that

can be directly controlled by a woman(Baxter and Abdool Karim, 2016). However, challenges in oral PrEP implementation remain; particularly among populations that would benefit most from the use of oral PrEP. Participants suggested that party girls, *blessees*, girls who have more than one sexual partner, girls who abuse alcohol and then have unprotected sex, boys who party too much as well taxi and truck drivers would benefit most from the use of oral PrEP. Participants stated that these were high risk scenarios and that anyone who was exposed to these situations needed access to oral PrEP.

Using these suggestions from participants, the researcher explored possible scenarios that could lead to exposure to risk of HIV infection. Thereafter, the link and level of risk were established according to each category of potential users, particularly high risk groups such as adolescents and youth. Thus, the findings of this study have contributed to the establishment of the following profiles user profiles for oral PrEP among AGYW and men in Vulindlela, South Africa.

Table 6.1 User profiles for oral PrEP

Category	Opportunity	Link to risk	Profile
Adolescents	Establishing relationships with boys/girls their age for the first time Victims of peer pressure in school or community setting	• High risk; HIV status between partners has not been established	• Male and female • 15- 18 years • Attending high school • Ready to become sexually active
Adolescents	Involved in relationships with older men/ women for status or economic reasons	• High risk; Age disparate relationships often do not allow for condom negotiation	• Male and female • 15-18 years • Attending high school • Sexually active
Young women	Involved in relationships with older men for status or economic reasons	• High risk; Age disparate relationships often do not allow for condom negotiation	• 19-25 years • Sexually active • With one or more children • Abuse alcohol
Young women	Early stage of sexual relationships with men in similar age range	• High risk; HIV status between partners has not been established	• 19- 25 years • Sexually active
Young men	Involved in multiple concurrent partnerships	• High risk; HIV status between partners has not been established;	• 25-35 • Sexually active; abuse alcohol & engage in unplanned, unprotected

Table 6.1 illustrates categories of potential users and potential situations where oral PrEP use may prove beneficial for use.

The first category comprises male and female adolescents aged 15– 18 years. At this stage of their lives, adolescent boys and girls are likely to be initiating relationships with others in the school setting or communicationg, possibly due to peer pressure. 10% of adolescent girls participating in this study stated that they were in a relationship and having unprotected sex. Thus, this is a high

risk scenario because first, they are likely to not have taken HIV tests, hence have no knowledge of their partners' HIV status.

The second category of potential users comprises both adolescent girls and boys aged 15 – 18 years who are engaged in age disparate relationships. While literature of often refers to the "sugar daddy phenomena", adolescent boys men are also likely to get involved with older women (Idele *et al.*, 2014). Age disparate relationships often result in the younger partners being unable to negotiate condom use with older sexual partners (Zuma *et al*., 2016).

The third category of users is young women who are aged 19 – 25 years who may be involved with older men for economic or other reasons. This scenario presents high risk of HIV because women in unequal relationships often are unable to negotiate condom use (Brady *et al.*, 2015). The fourth category features young women aged 19 – 25 years who may be initiating relationships with partners in their age group. Risk is identified in the stage before partners test for HIV. The fifth category comprises men ages 25– 35 years. Exposure to risk in this scenario involves low perception of risk for multiple sexual partners, serially or concurrently. Such potential users would also be those with a tendency to abuse alcohol, which further excerbates risk (Shuper *et al*., 2016).

3. ***To understand barriers and enablers that influence the acceptability of oral PrEP among adolescent girls and young women and men in Vulindlela, South Africa***

Enablers affecting acceptance of oral PrEP

i. Perceptions of oral PrEP among health care providers

Literature suggests that health providers' beliefs, perceptions and own cultural beliefs could influence willingness to promote oral PrEP as an HIV prevention strategy (Krakower and Mayer, 2016). The HCT counsellor and clinic nurse at the local clinic in Vulindlela were asked what they thought of the idea of oral PrEP and if they would recommend this HIV prevention method to patients. The HCT counsellor and the nurse both had positive perceptions and stated that they highly recommend oral PrEP to patients in the area. This study found that primary health care providers in Vulindlela have a positive perception of oral PrEP. They stated that the use of PrEP was a good idea and alluded to fact that people in the community were dying, thus any new HIV prevention method that promised efficacy was welcome and they would encourage people to take it. This finding suggests that positive perceptions by health care providers in Vulindlela can be seen as an enabler that could influence acceptance of oral PrEP. This is because primary care

providers are the first point of contact for patients who come to the clinic for sexual reproductive health, thus they are in a good position to recommend oral PrEP as a new HIV prevention method.

Barriers influencing oral PrEP acceptance

i. Structural issues in public health system

Studies suggest that public health system in South Africa is over – burdened (Eyles *et al*., 2015). Research into structural issues in HIV prevention have tended to focus on issues such as empowerment, social structure, and inequality (Padian *et al.*, 2011). However, there is a need for studies that examine the ability of the South African health system to deliver on PrEP implementation in its current state. This is an important finding that participants alluded to when they asked to state barriers to acceptance of oral PrEP. Participants said making return trips to the clinic because different services are accessible on different dates would prove to be a challenge when they were asked to describe challenges that would be a barrier to them accepting and using oral PrEP.

Further, the HCT counsellor stated that gaps in the current system were already visible at Vulindlela. This is because only patients who come to the clinic for HIV testing are informed about oral PrEP. She said in the current system, patients who come to the clinic for sexual reproductive health services are not referred to the designated oral PrEP nurse. This finding supports the growing calls for integrated HIV health care services and sexual and reproductive health services in South Africa (Brady *et al*., 2015).

ii. Knowledge, attitudes and perceptions of parents

When AGYW participating in this study were asked whether they would prefer to use oral PrEP covertly, inform their sexual partners or seek permission from them to use oral PrEP, an important point was raised in the focus group with adolescent girls. The participants in this focus group stated that parental consent would be a prerequisite for them to take oral PrEP, however, they observed that parents may not be willing to let their daughters take oral PrEP. Participants stated that parents may be misinformed about oral PrEP, may not know about it or may perceive acceptance of oral PrEP as a licence for their daughters to engage in unprotected sex with many men.

This finding is very important when considered in the context of South Africa where oral PrEP is targeted primarily to AGYW. Adolescent girls may still require parental consent for a number of things, however, in terms of the law in South Africa, a child does not require consent of a parent or guardian if they are aged 12; such action is considered to be in their best interest, the child is deemed to 'demonstrate maturity' and has undergone pre- and post-counselling (Strode *et al.*, 2010). Similar requirements need to be met for a legal minor to access contraception thus; similar categorisation needs to be clearly communicated about oral PrEP. This is because parents' negative perceptions of oral PrEP may play a role in adolescent girls' acceptance and utilisation of oral PrEP. This is particularly important because oral PrEP is expected to be implemented as part of combination prevention intervention. However, educating parents may result in them informing and educating their children about the product.

iii. Perceived barriers of oral PrEP

Participants indicated that oral PrEP was a good idea and stated that, in theory, they would not mind taking it as long as they were protected. However, they expressed concern over the need to take PrEP on a daily basis, stating that this would not be possible. There was a marked difference in responses between men and women, with men being more open to the idea of taking oral PrEP. Adolescent girls and young women said they did not have boyfriends, hence they had no need to take oral PrEP.

This finding showed low acceptance of oral PrEP despite participants agreeing that the concept of this new HIV prevention pill is a good one. Some participants find it difficult to believe that oral PrEP is effective in preventing HIV infection despite numerous studies published on the efficacy of oral PrEP. This finding shows that the people on the ground for whom the product has been developed and who are expected to use have scant information about it. This affects acceptability of oral PrEP. Additionally, participants' reluctance to take oral PrEP daily already showed a possible future challenge with acceptance and adherence.

Theoretical implications

The findings in this study relate to the HBM and SEMCHB, which are the conceptual frameworks underpinning this study.

Perception of low personal risk

The HBM stress the importance of perceptions about the seriousness of a health threat, perceptions about one's perceived susceptibility to a health threat, and one's perceived ability to reduce one's risk as key determinants of health behaviour (Rimer, 2008). Low perceived personal vulnerability is a risk factor because it reduces the motivation to take the necessary precautions. While perceptions of risk were high among AGYW in this study, perceived susceptibility was found to be unrealistically low despite high rates of sexual activity, alcohol abuse and low condom use. According to the HBM when perceived susceptibility and perceived severity are high, individuals are likely to consider adopting measures to prevent HIV (Champion and Skinner, 2008). This is relevant for oral PrEP implementation because it potential users need to have a high perception of risk to consider oral PrEP as a useful and relevant HIV prevention method for them to use.

Perceived susceptibility, perceived severity and perceived self-efficacy

The HBM posits that an individual's likelihood of adopting a health behaviour is located in perception. In the current study, perceived susceptibility denotes the AGYW and men's perceptions of their own vulnerability to HIV infection while perceived severity denotes their assessment of how likely they are to be exposed to HIV infection. Studies have identified perception of risk as an important factor that can influence candidacy for oral PrEP (Frankis *et al*., 2016; Young *et al*., 2014a). On the other hand, an individual must have confidence in their ability to adopt preventive behaviour (Bandura, 1997). This is called perceived self -efficacy.

Findings in this study revealed that relations between perceived susceptibility and perceived self-efficacy were subjective among AGYW. Female participants in this had a high perception of risk for condom-less sex, and their perceived susceptibility and perceived severity was high. However, this did not translate to self-efficacy, which proved to be very low. This presents a challenge for oral PrEP introduction because it shows that participants are engaging in high risk behaviour although they aware of severity. Further, this finding shows that participants are not using existing HIV prevention methods that have been proven to be effective, despite knowing about them. Male participants, on the other hand, stated that they did not perceive condom-less sex as high risk for HIV. Further, male participants' perceived susceptibility was low in this study although perceived severity was high.

One reason for these findings could be attributed to gender dynamics in heterosexual relationships. Literature suggests that condom use is stigmatised in long term relationship as such requests imply

a lack of trust in the partner (Zuma *et al*., 2016). Other misconceptions contribute to low rates of condoms, the most common being the perception that condoms make sex less pleasurable (Guerra *et al.*, 2016). Perceived risk, susceptibility and severity for drinking alcohol were high among at the shebeen and then having unprotected sex were high among all participants, however, this this not improve self-efficacy as it was found to be low.

The Health Belief Model posits that adoption of preventive behaviour can only occur if perceived risk and perceived susceptibility are high. Additionally, perceived severity and perceived self-efficacy must be high. Further, benefits to taking up the preventative behaviour must outweigh the barriers (Bandura, 1997). Thus, while perceived severity is general high among participants, there is a need to raise perceived risk, perceived susceptibility, perceived self-efficacy and perceived benefits of oral PrEP to encourage acceptance and uptake among the intended key user groups participating in this study.

Perceived enablers and benefits

The HBM posits that people consider positive and negative features of preventive behaviours and the balance will influence their behaviour (Rimer, 2008). Barriers seem to outweigh the enablers to acceptance of oral PrEP in this study. While positive perceptions of oral PrEP among health providers in Vulindlela are encouraging, factors such as structural issues affecting the public health system as well as negative associations and perceptions of the product may prove significant.

SEMCHB

Contrary to other studies that report women's interest and willingness to try oral PrEP (Eisingerich *et al.,* 2012; Fisher *et al.,* 2017), findings in this study suggest that acceptability is influenced by numerous factors. While a number of participants in this study are fairly accepting of oral PrEP, some challenges remain.

One of these challenges is the lack of belief in oral PrEP's effectiveness. Literature states that the efficacy of oral PrEP has been consistent in various settings and contexts since 2010 (Baxter and Abdool Karim, 2016; Karim *et al.,* 2010). However, this finding suggests that some participants were unaware of the efficacy of oral PrEP possibly due to the fact that they have not had any experience with it, due to its limited availability or lack of information on the product. Further, these participants' response emphasises the influence of interpersonal relationships in influencing

acceptability of new HIV prevention methods. Therefore, the interpersonal level of the SEMCHB is a viable construct to inform understanding of the role of social relationships in influencing acceptance of new HIV prevention methods. The SEMCHB posits that behaviour is influenced by multiple levels of intrapersonal, interpersonal, community, and policy contexts (Glanz *et al*., 2008).

This finding suggests that health communication will be imperative in ensuring positive perceptions and possible uptake of oral PrEP. Participants agreed that making oral PrEP available without sufficient educational and awareness campaigns would cause a lot of confusion and misinformation. Thus, the finding suggests a need for communicators to put a 'face' to future communication about oral PrEP. Future public health communication may benefit from leveraging relatable women in the communication and promotion of oral PrEP.

Conclusion

This chapter analysed and discussed data collected through focus group discussions and interviews. The analysis sought to understand perceptions of risk among adolescent girls and young women (AGYW) and men in Vulindlela, South Africa. The chapter explored acceptability and possible barriers and enablers that affect acceptability of oral Pre-Exposure Prophylaxis (PrEP) among these key user groups. Additionally, the chapter explored data in relation to the study's research questions and objectives as well as the conceptual framework on which this inquiry rests. Finally, user profiles of oral PrEP and links to risk which were generated from the data were presented and discussed in this chapter. The next chapter is the conclusion to the study which summarises the key points of the study, limitations and recommendations for future research.

CHAPTER 7: CONCLUSIONS AND RECOMMENDATIONS

Introduction

This study explored perceptions of risk and the acceptability of oral PrEP among adolescent girls and young women (AGYW) and men of Vulindlela, South Africa. The study further examined barriers and enablers that influence acceptability of oral PrEP as a new HIV prevention method among these key user groups. Constructs of the Health Belief Model (HBM) and the Interpersonal level of the Social Ecology Model for Communication and Health Behaviour (SEMCHB) were used as conceptual frameworks underpinning the current study. These constructs were useful in understanding how AGYW and men in Vulindlela perceived oral PrEP and how these perceptions inform their acceptability of oral PrEP.

The SEMCHB was particularly useful in considering how social relationships influence perception and acceptability of oral PrEP among AGYW and men in Vulindlela. Thus, these models were appropriate in the study because they provided a lens through which the researcher could assess the likelihood of AGYM and men in Vulindlela were likely to adopt oral PrEP based on their perception of risk.

Literature reviewed in this study reveals that AGYW aged 15-25 years are more vulnerable to HIV infection compared to their male counterparts (Karim *et al.*, 2017). In fact, AGYW are said to be eight times more likely to contract HIV than males in the same age group (Naicker *et al*., 2015). However, AGYW's heightened vulnerability goes beyond physiology, it is intricately associated with deep-rooted gender inequalities, harmful gender norms, and structures of patriarchy that limit women and girls from reaching their full potential and leave them vulnerable to HIV infection (Dellar *et al*., 2015). Complexities of current HIV prevention methods have been broadly explored in this study and the relevance and urgency of new HIV prevention technologies such as oral PrEP has been established. However, before oral PrEP is widely implemented in South Africa, it important to gain an understanding of the various users who are willing to use this HIV prevention method research for tailored and targeted HIV prevention efforts.

Therefore, this study sought to address questions of awareness, perceptions and acceptability of oral PrEP among AGYW in Vulindlela. To establish the relevance of oral PrEP, it was necessary to explore participants' perceptions about their risk with contracting HIV. This is important because it initiates conversations about measures that participants can take to protect themselves. Thus, if participants believe that they are at risk for HIV infection and consider HIV as a serious enough to avoid; then they are more likely to consider new HIV prevention options. Participants were aware of their risk and susceptibility to HIV as well as the severity of the virus. Hypothetically, AGYW were found to be more cautious than men in relation to undertaking risky behaviour. However, this finding did not translate to practical behaviour as young women admitted to not always practising safe sex. Thus, while the current study found that perceived susceptibility and perceived severity to HIV infection is high among participants, acceptability of oral PrEP was quite low.

The low acceptability could be credited to lack of awareness and negative perceptions of oral PrEP. This study found that very few participants knew about oral PrEP. Even those who had heard about oral PrEP had scant information about what it is and its intended purposes. This was evident in the responses from participants, with some giving inaccurate information about the product. An important point to note is that none of the participants were aware that oral PrEP was to be used with condoms as an additional prevention option. This will be an important message for health communicators to focus on because oral PrEP has improved effectiveness if used as part of combination prevention.

In keeping with the World Health Organization's (WHO) findings that oral PrEP is not for everyone, participants identified potential user profiles for key user groups who can benefit maximally from the use of oral PrEP. Thus, this provides a baseline on which health communicators and health promoters can create messages to communicate oral PrEP to targeted audiences.

According to the HBM, an individual is likely to adopt a new behaviour if perceived susceptibility and perceived severity are high, there are perceived benefits to adopting the behaviour and self-efficacy is high. Therefore, there is a need for heath communicators to raise self- efficacy for users of oral PrEP. This is particularly important because participants in this study indicated that taking PrEP on a daily basis would not be possible, with others stating that they had a hard time ingesting

any kind of tablet, and by extension oral PrEP. Participants also noted that taking oral PrEP daily would be a challenge. This suggests a low level of self- efficacy, which could impede acceptance, uptake and adoption of oral PrEP. Consequently, lack of knowledge about oral PrEP coupled with negative perception and slow self-efficacy becomes a barrier to the acceptance and adoption of oral PrEP.

Another barrier identified in this study was the disconnection of HIV prevention and sexual and reproductive health in the public health system. Thus, there is a need to streamline health services to ensure that people have access to an efficient public health system. Further, participants in the focus group with adolescent girls raised an important point regarding possible need for parental consent for adolescents to access oral PrEP. This needs to be clearly defined before national implementation of oral PrEP is undertaken.

Further considerations and directions for future research

Oral PrEP has the potential to significantly reduce new HIV infections among AGYW (Karim, 2016). However, oral PrEP can only be effective if it accepted and used by the intended user population. This study has found that there are a number of issues that need to be addressed to ensure user acceptability and uptake before oral PrEP roll-out. First, there is an urgent need to involve men in the promotion of women-initiated HIV prevention methods such as oral PrEP. While the idea of oral PrEP is to enable women to initiate HIV prevention without having to negotiate with their male partners if the need arises, power dynamics and gender roles entrenched in African culture may prove a barrier to this. Thus, taking advantage of this culture may lead to greater gains in oral PrEP implementation. Therefore, there is a need for studies that explore the notion of women empowerment in HIV prevention. Situating women empowerment as more than providing tools for women in HIV prevention, but using all available resources (including using male voices) to ensure women are educated and informed about their choices in HIV prevention may lead to the development of theories and interventions that go beyond providing tools as empowerment.

There is also a need to mobilise health communication strategies for new product introduction before the full implementation of oral PrEP. Communication about it has been lacking. It is important to ensure that information about the product is shared and interest is generated before a national roll-out to ensure that intended users are aware of the product; they know its efficacy rate

and know where to access it and how to use it. This study uncovered confusion regarding whether oral PrEP is another name for the contraceptive pill as well as side effects. Health communication in this aspect is very important because it contributes to raising the self-efficacy of users. Absence of communication about oral PrEP could result in the product being stigmatised, given that it is ARV based as shown by perceptions of participants in this study.

Findings in the current study have contributed to the generation of user profiles for oral PrEP. Thus, there is a need to develop targeted communication strategies for oral PrEP promotion. Targeted communication is more effective because provides relevant information to the targeted group. That way, users are not bombarded with blanket statements that may not apply to their context, leading to low perception of candidacy for oral PrEP. Targeted communication also assists with the vehicles through which messages about oral PrEP can be sent to different audiences.

Limitations of the study

There are several limitations that must be noted in this study. Firstly, the sample size was too small to allow for the generalisability of findings. Secondly, the findings and conclusions of this study reflect the awareness, perceptions and acceptability of oral PrEP among the AGYW and young men in Vulindlela, South Africa who took part in this study. Thus, while offering insight into how key populations perceive oral PrEP the findings and conclusions from this study cannot be generalised to apply in other settings. However, the transferability of the study cannot be dismissed as this research was carried out according to the methodology explained in detail in Chapter Four. Thirdly, it was difficult to ascertain informed perceptions of oral PrEP when the product is not readily available for use; hence none of the participants in this study has real experience with it. Thus it is important to note that perceptions could have been different if the participants had been speaking from an informed perspective.

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APPENDIX 1: Discussion Group Guidelines for Men and Women groups

1. Women: Aged 15-25
2. Men: Aged 24-35

Main Research Focus:

- What are the barriers and facilitators of oral PrEP acceptability with AGYW and young men in Vulindlela?.

Research Aim:

- Analyse perceptions of risk and, awareness and acceptability of oral PrEP with AGYW accessing ANC and FP services in 6 primary health clinics.

Understanding Risk:

Risk Games

1. Level of Risk

    - Using two colours of candy/sweets that are separated in two bowls/containers, pretend that the one colour is poisonous and the other is a normal candy/sweet.
    - Ask participants if they are willing to eat the bowl of good candy with one poisonous candy in the bowl
    - Gradually increase the number of poisonous candies in the bowl, and reduce the good candies each time until you have more poisonous candy in the bowl.
    - Each time ask the participant if they are willing to eat the candy with the additional poisonous candy in the bowl

    Outcome: explain to participants that we all have different levels of risk which we are ok with and which we accept, and its important to know your risk, and what risk you are willing to accept.

    Time allocation [10 minutes]

2. Risky Scenarios
    Ask the participants to pair up together.
    Place tape/or chairs in the floor to divide the area into three zones: NO risk, low risk and HIGH Risk.
    Ask participants to stand in the various zones that they relate too for each of the five scenarios.
    Scenario 1: having sex without a condom
    Scenario 2: drinking lots of alcohol at the shebeen and having sex
    Scenario 3: having more than 1 sexual partner
    Scenario 4: having a blesser relationship
    Scenario 5: Taking a pill everyday to prevent HIV infection

    Time allocation [10 minutes]

Risk mapping activity to understand the perceived susceptibility and perceived severity (first two steps of HBM).

AM I AT RISK? (Perceived susceptibility)

Hand out A4 sheets of paper.

Ask participants to document/draw or write down situations that make them feel at risk. This can be any situation.

Ask participants to document/draw or write down if they are at risk of HIV infection?

Time allocation: [5 minutes]

HOW LIKELY IS MY RISK? (Perceived Severity)

Ask participants to document/draw or write down if they feel they are at high or low risk of HIV infection?

In pairs, discuss why they believe they risk is high/no for contracting HIV?

Feedback to the wider group

Time allocation; [10 minutes]

Awareness of HIV prevention options

Introductory

- Can you tell me about HIV prevention?
- What do you know about preventing HIV infection?
- What are the prevention options available to reduce your risk of getting HIV?
- What are the most commonly used HIV prevention methods?
- Have you heard about PreP? Can you explain further?
- Have you heard about the oral prevention pill? Can you explain further?

Time allocation: [10 minutes]

Introduce oral PrEP (look for a simple introduction)

Time allocation: [5 minutes]

Acceptability

- How do you feel about taking PrEP every day?
- How would it affect your daily life?

- Do you believe PrEP can lower your risk of HIV? Will you feel more protected? Why?
- How do you believe PrEP would benefit your life? Young women generally?
- Who do you think oral PrEP is aimed at?
- What are the first words you think of when someone says he/she is taking PrEP?
- Do you think PrEP will be acceptable with your partner? With your family?
- Do you believe people would react negatively towards oral PrEP?
- How do you think your partner will feel about you taking oral PrEP?
- Do you think your partner will be willing to take oral PrEP?
- What can we do to make PrEP more acceptable?

Time allocation [10 minutes]

Perceived benefits

- What are some of the benefits of taking oral PreP?
- What are some of the actions you will need to take to start on PrEP?
- What will prevent you from taking PrEP?

Time allocation [10 minutes]

*******THE END********

APPENDIX 2 – CONSENT FORM

UKZN HUMANITIES AND SOCIAL SCIENCES RESEARCH ETHICS COMMITTEE (HSSREC)

APPLICATION FOR ETHICS APPROVAL
For research with human participants

INFORMED CONSENT

Note to researchers: Notwithstanding the need for scientific and legal accuracy, every effort should be made to produce a consent document that is as linguistically clear and simple as possible, without omitting important details as outlined below. Certified translated versions will be required once the original version is approved.

There are specific circumstances where witnessed verbal consent might be acceptable, and circumstances where individual informed consent may be waived by HSSREC.

Information Sheet and Consent to Participate in Research

Date:

Greeting: (Choose a greeting appropriate for the setting – not "Dear Participant", as this assumes enrollment).

My name is Nqobile Ndzinisa, a registered student at the University of KwaZulu-Natal (UKZN) in the Centre for Culture, Media and Society (CCMS). My email address is 216073982@stu.ukzn.c.za and my cellphone number is 063 532 8197.

You are being invited to consider participating in a study that involves research into understanding young women's ideas and beliefs about the use of anti-retroviral drugs by HIV negative people to prevent HIV infection (called oral Pre-Exposure Prophylaxis).

The aim and purpose of this research is to explore whether young women would consider using Pre-Exposure Prophylaxis as a method to prevent HIV infection. The study is expected to enroll 32 participants in total. This will include 10 adolescent girls and young women aged 15-25 accessing ante-natal services at Mafakathini Clinic; 10 men aged 25 -30 accessing voluntary and testing services at the clinic; 10 adolescent girls from Ncemhlophe High school as well as 1 nurse and 1 HIV counsellor at a community hall in Vulindlela community. It will involve allowing potential participants to sit in focus group discussions and indepth interviews with the counsellor and nurse. The duration of your participation if you choose to enroll and remain in the study is expected to be 1 hour long.

The study will provide no direct benefits to participants however, your participation is likely to help the researcher find out more about the beliefs of young girls about HIV in general and PrEP in particular.

This study has been ethically reviewed and approved by the UKZN Humanities and Social Sciences Research Ethics Committee (approval number__ HSS/0909/017M ___).

In the event of any problems or concerns/questions you may contact the researcher at 063 532 8197 or the UKZN Humanities & Social Sciences Research Ethics Committee, contact details as follows:

HUMANITIES & SOCIAL SCIENCES RESEARCH ETHICS ADMINISTRATION
Research Office, Westville Campus
Govan Mbeki Building
Private Bag X 54001
Durban
4000
KwaZulu-Natal, SOUTH AFRICA
Tel: 27 31 2604557- Fax: 27 31 2604609
Email: HSSREC@ukzn.ac.za

Participation in this research is voluntary and participants may withdraw participation at any point. In the event of refusal/withdrawal of participation, you will not incur penalty or loss of treatment or other benefit to which you are normally entitled.

Children will take consent forms home to their parents/ guardians and parents will be requested to sign consent forms if they agree to let their children participate in the study. The informed consent form will clearly explain that involvement in the study is completely voluntary and respondents have the right to withdraw from the study at any point. This will ensure that participants will make an informed, un-coerced decision in terms of their involvement in the study. Signed forms returned to the researcher will be taken as consent to participate. However, in cases where parental consent cannot be provided, potential participants will be excluded from the study. To prevent harm to potential participants resulting from exclusion from the study, the researcher will encourage potential participants to participate in educational HIV prevention programmes at the school. The researchr will explain that exclusion is only limited to this study, not to participation in current and future HIV prevention programmes in the school and in the community. Further, a child assessment form will be given to learners so they may assent to participate. Potential participants can withdraw at any time. If a child withdraws from the study, their parents will be contacted.

If you feel uncomfortable at any point during the discussion, you are welcome to calmly leave the group without interrupting other participants. The researcher can remove participants if they refuse to respect other people and their views and not allowing other people a chance to speak.
Potential participants will be reimbursed a total of R25 for transport expenses if they have to travel to the community hall. Refreshments will be provided after the discussion.

The researcher acknowledges that confidentiality is limited in a focus group. However, this study will protect the autonomy of the participants through the particular research methodology. Codes or pseudonyms will be used instead of participants' real names during the

interview, transcription and data analysis stage to protect their identity. Due to the sensitivity of the topic, the researcher recognises the importance of protecting participants from secondary psychological harm. The researcher will ensure all participants know their rights to enclose and disclose what they are comfortable with as a first step to preventing secondary psychological harm. A community developer will also be present should participants need further help. The community developers have access to the school, meaning the participants will know the community developers, ensuring further protection from secondary victimisation. Should the need for further counseling arise during the focus group discussions, considering the sensitive nature of the topic, the community developer will contact one of the chosen referral mechanisms.

ChildLine is understood to be the most appropriate as they have the skills and abilities to deal with a multitude of issues, they are free, they have a 24 hour counseling service, they will be able to give counseling in the participants' language and they provide counseling for physical, emotional and sexual abuse. Once the community developer has contacted the referral mechanism, he or she will follow up with providing transport and the necessary help in order to ensure the participant gets the help they need. Should the participant prefer one of the other referral mechanisms, the community developer will follow the same procedure. Should the participant feel after the research is conducted that they need counseling, the community developer will ensure they will be able to contact a the HCT counsellor to assist further. Toll-free counseling services have been identified as the best method because, should the participant feel they want to contact them in private, they have the ability to do it themselves. However, should they need assistance the community developer will be able to help them.

The data collected in the form of recorded and transcribed interviews will be used for data analysis. The electronic and hard copies of the data will be stored at the Centre for Communication, Media and Society for five years and thereafter disposed of according to the rules and regulations laid out by the University of KwaZulu-Natal.

CONSENT (Edit as required)

I _____have been informed about the study entitled **Understanding user profiles for Pre-Exposure Prophylaxis (PrEP) Uptake: A qualitative study with adolescent girls, young women and men in Vulindlela, South Africa** by Nqobile Ndzinisa.

I understand the purpose and procedures of the study.

I have been given an opportunity to answer questions about the study and have had answers to my satisfaction.

I declare that my participation in this study is entirely voluntary and that I may withdraw at any time without affecting any of the benefits that I usually am entitled to.

I have been informed about any available compensation or medical treatment if injury occurs to me as a result of study-related procedures.

If I have any further questions/concerns or queries related to the study I understand that I may contact the researcher at 216073982@stu.ukzn.ac.za/ 063 532 8197.

If I have any questions or concerns about my rights as a study participant, or if I am concerned about an aspect of the study or the researchers then I may contact:

HUMANITIES & SOCIAL SCIENCES RESEARCH ETHICS ADMINISTRATION
Research Office, Westville Campus
Govan Mbeki Building
Private Bag X 54001
Durban
4000
KwaZulu-Natal, SOUTH AFRICA
Tel: 27 31 2604557 - Fax: 27 31 2604609
Email: HSSREC@ukzn.ac.za

Additional consent, where applicable

I hereby provide consent to:

Audio-record my interview / focus group discussion YES / NO

_____ _____
Signature of Participant **Date**

_____ _____
Signature of Witness **Date**
(Where applicable)

_____ _____
Signature of Translator **Date**
(Where applicable)

APPENDIX 3 ETHICAL CLEARANCE

UNIVERSITY OF KWAZULU-NATAL
INYUVESI YAKWAZULU-NATALI

14 September 2017

Ms Nqobile T Ndzinisa 216073982
School of Applied Human Sciences – CCMS
Howard College Campus

Dear Ms Ndzinisa

Protocol reference number: **HSS/0909/017M**
Project title: **Understanding user profiles for oral PrEP uptake : A qualitative study with adolescent girls, young women and men in Vulindlela, South Africa.**

Full Approval – Full Committee Reviewed Protocol

In response to your application received 27 June 2017, the Humanities & Social Sciences Research Ethics Committee has considered the abovementioned application and the protocol has been granted **FULL APPROVAL.**

Any alteration/s to the approved research protocol i.e. Questionnaire/Interview Schedule, Informed Consent Form, Title of the Project, Location of the Study, Research Approach and Methods must be reviewed and approved through the amendment /modification prior to its implementation. In case you have further queries, please quote the above reference number.

PLEASE NOTE: Research data should be securely stored in the discipline/department for a period of 5 years.

The ethical clearance certificate is only valid for a period of 3 years from the date of issue. Thereafter Recertification must be applied for on an annual basis.

I take this opportunity of wishing you everything of the best with your study.

Yours faithfully

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Dr Shenuka Singh (Chair)
Humanities & Social Sciences Research Ethics Committee

/pm

cc Supervisor: Dr Eliza Govender
cc Academic Leader Research: Dr Jean Steyn
cc School Administrator: Ms Ayanda Ntuli