An exploration of the social-cultural factors that influence oral pre-exposure prophylaxis uptake and integration into Sexual and Reproductive Healthcare services for young women in KwaZulu-Natal.

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DECLARATION

I hereby declare that the work presented in this thesis entitled: *An exploration of the social-cultural factors that influence oral pre-exposure prophylaxis uptake and integration into Sexual and Reproductive Healthcare services for young women in KwaZulu-Natal* was submitted at the Centre for Communication, Media and Society, the University of KwaZulu-Natal from February 2016 to December 2019 under the supervision of Professor Eliza Govender. This work has not been submitted in any other institution. The work presented herein is solely my work unless specific references and acknowledgements as taken from sources have been provided.

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Abstract

In the past, HIV prevention efforts have disappointingly focused on reducing individual risk, with insufficient attention to socio-cultural, economic, structural, and other contextual factors that increase vulnerability to HIV. However, public health efforts towards HIV prevention now focus on combination strategies. This strategy recognizes that the integration of biomedical, social and structural interventions in mitigating the HIV and AIDS epidemic will translate to population-level impact. In Southern Africa, young women are disproportionately vulnerable to HIV infection, with women between the ages of 15 to 24 twice more likely to be infected than men. However, the licensure of oral pre-exposure prophylaxis (PrEP) and the South African National Department of Health policy on the integration of oral PrEP in sexual reproductive health (SRH) services creates renewed hope for young women who are often unable to negotiate safe sex practices.

Nevertheless, the effectiveness of biomedical technologies is influenced by socio-cultural, structural and economic factors. This underscores the need to understand; (a) Populations that will consider using oral PrEP, (b) The likely socio-cultural challenges or opportunities that will influence acceptance, uptake and adherence of oral PrEP, and (c) How to integrate oral PrEP in already existing SRH services in a manner that ensures optimal adherence to oral PrEP to key population groups. This study sought to find effective ways in which oral PrEP can be integrated into SRH services in South Africa, KwaZulu-Natal (KZN).

To attain an in-depth understanding of this topic, participatory visual methodologies in the form of journey mapping workshops and one-on-one interviews with 15 young women taking oral PrEP were facilitated. The participatory approach to this inquiry created an enabling space for young women to engage in dialogue about oral PrEP. Young women need to be placed at the centre of the response to HIV and AIDS in a meaningful way that will facilitate sustainable interventions in the fight against HIV and AIDS. Two nurses from both research sites were also interviewed to yield healthcare providers perspectives into the study inquiry. The study has the potential to inform policymakers on how existing SRH services can be improved to multi-dimensional systems that support oral PrEP uptake and adherence by young women at high risk of HIV.

Findings of this study support the conclusion that oral PrEP needs to be integrated into already existing SRH services in ways that are context-specific and culturally relevant for communities. The young women in this study explicitly shared the various social and cultural factors that will influence them accessing oral PrEP in SRH services within their local clinics. Issues related to the structure, services offered and healthcare provider's attitudes will affect acceptance, uptake and adherence of oral PrEP by young women in rural and urban KZN communities.

Keywords: Sexual and reproductive healthcare services, HIV prevention, oral pre-exposure prophylaxis, young women, cultural competence, participatory visual methodologies.

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Acronyms

ABC	Abstinence, Be Faithful, Condom use
AGYW	Adolescent Girls and Young Women
AIDS	Acquired Immunodeficiency Syndrome
AR	Action Research
ART	Antiretroviral Therapy
ARV	Antiretroviral Drugs
CCMS	Centre for Communication, Media and Society
CFPD	Communication for Participatory Development
GBV	Gender-Based Violence
HIV	Human Immunodeficiency Virus
HSRC	Human Sciences Research Council
KZN	KwaZulu-Natal
MCP	Multiple and Concurrent Partnerships
NGO	Non-Governmental Organisation
PAR	Participatory Action Research
PEP	Post exposure prophylaxis
PR	Participatory Research
PVM	Participatory Visual Method
PrEP	Pre-exposure prophylaxis
SRH	Sexual and reproductive health
STI	Sexually Transmitted Infection
UKZN	University of KwaZulu-Natal
UNAIDS	Joint United Nations Programme on HIV and AIDS
UNICEF	United Nations Children's Fund
VCT	Voluntary Counselling and Testing
VMMC	Voluntary Medical Male Circumcision
WHO	World Health Organisation

Definition of key terms

Participatory Visual Methodology (PVM)- Participatory visual methodologies (PVM) refer to a range of approaches that allow research participants to express themselves through drawings, images, or dramatizations to share their own lived experiences or opinions towards social issues (Black et al., 2018, Mitchell et al., 2011).

Oral Pre-exposure prophylaxis- Oral pre-exposure prophylaxis (PrEP) is the use of ARV drugs by people who are not HIV positive to prevent the acquisition of HIV (WHO, 2016). Oral PrEP is intended for people at substantial risk of acquiring HIV (UNAIDS, 2016)

Vulnerable populations- These are groups of people who are vulnerable to HIV infection because of their situations or contexts**.** The populations may also face social and legal barriers to access HIV prevention and treatment. Each country should define the specific populations that are vulnerable to HIV infection, as these groups vary from country to country (WHO, 2016).

Key populations- These are groups that are at high risk of HIV infection and are disproportionately affected by HIV in all epidemic settings. These population groups usually face legal and social challenges that increase their vulnerability, as well as limited access to HIV prevention, treatment and care (WHO, 2016).

Antiretroviral (ARV) - This refers to drugs used to treat HIV (WHO, 2016)**.**

ART- Antiretroviral therapy refers to the use of three or more ARV drugs for the treatment of HIV (WHO, 2016). ART involves lifelong treatment that people who are HIV positive subscribe to.

Combination prevention- This refers to the combination of biomedical, behavioural and structural approaches to HIV prevention to effectively reduce HIV transmission in diverse contexts (WHO, 2016). The combination prevention approach is based on the notion that there is no single intervention, or method has the ability to reduce the HIV

and AIDS epidemic, but rather a combination of approaches and interventions can prove to be more effective. Combination prevention emphasises the point that different setting and populations will require different combinations of interventions (UNAIDS, 2016).

Adherence- This refers to a person's behaviour in taking medication, or changing lifestyle according to recommendations given by a healthcare worker (WHO, 2016).

Prologue

I remember the excitement that stirred in me as I realised that I was going to attend my first "international" conference in July 2016. After months of waiting for the grand event, it was finally here, the 21st International AIDS Conference in Durban, South Africa. Little did I know that this would be the beginning of my research journey. The theme of this conference was "*Access, Equity, Rights now*". It became clear during this conference that there have been great advancements made in biomedical field that promise to alleviate and even end the HIV and AIDS epidemic, including ongoing research on HIV vaccine. However, the recurring and underlying subject in the conference was how do we (as scholars, scientists, activists and government) get these biomedical technologies to the people who need them the most? It became clear in this conference as I attended several sessions that while advancements in the HIV and AIDS field were being made, there was still another mountain to face; *Access, Equity, Rights* to the populations that need these interventions the most.

I was particularly astonished to learn that the novel oral pre-exposure prophylaxis (PrEP) for HIV prevention was now available in some parts of the world and that it had been available for the past few years. But in South Africa, this biomedical intervention had only received licensure at the end of 2015, and it was not made available to the general population nor vulnerable population groups. This did not make sense. Being a South African, and well aware of the fact that we face the highest HIV and AIDS rates in the world, it did not make sense to why oral PrEP was not available in the country. This sparked inquiry and several questions that began this research journey.

Chapter one: Introduction to study

"While it is up to biomedicine to produce efficacious prevention technologies, it is up to social scientists to guide the uptake and use of these efficacious prevention technologies in the real world and to ensure that they are effective and, on the basis of their research, inform prevention and policy response. It is not the case that an efficacious prevention method will work simply because public health officials or clinicians tell people to embrace them."

(Kippax and Stephenson, 2016:2)

Why this study?

This study was inspired by several insights, some of these have been highlighted in the prologue. The most academically sound of these inspirations is the devastating HIV and AIDS rates in South Africa that have not decreased significantly since the epidemic began three decades ago. There were an estimated 1.9 million new HIV infections in 2017 globally, with over 1 million from sub-Saharan Africa (Ward et al., 2019). At the centre of this epidemic lies vulnerable populations that have little or no means to protect themselves against HIV infection. Specific to the Southern African[1] region, young women are disproportionately vulnerable to HIV infection, in Africa young woman account for approximately 25% of new HIV infections globally, and have unmet needs for HIV prevention (Celum et al., 2019). Female vulnerability to HIV infection is exacerbated by various factors including socio-cultural, economic and biological factors (Mansoor et al., 2019). Factors contributing to HIV and AIDS vulnerability, particularly in South Africa among young women are multi-layered and interconnected. While some women are in intergenerational relationships that place them at higher risk of HIV infection, some young women face gender-based violence that places them at high risk of HIV infection (Dunkle et al., 2004, Kim and Motsei, 2002, De Oliveira et al., 2017).

[1] Defined here as including eight countries: Botswana, Lesotho, Malawi, Namibia, South Africa, Swaziland, Zambia, and Zimbabwe.

HIV prevention plays a critical role in alleviating the HIV and AIDS epidemic. While HIV and AIDS treatment and care are also very important in the epidemic, preventative measures have the potential to halt new infections. The HIV and AIDS landscape needs to move beyond treating and taking care of people with HIV and AIDS to also prioritise preventing those who are HIV negative from becoming infected. This is more urgent for vulnerable populations groups. HIV incidence has remained intensely high among young South African women, particularly those in rural contexts (Kharsany et al., 2015, Shisana et al., 2014). Even though there is a plethora of HIV prevention methods available in South Africa, there is not enough prevention interventions that have demonstrated effectiveness in reducing new HIV infection in vulnerable populations.

HIV prevention calls for social transformation and not an exclusive focus on the individual for behaviour change, this social transformation will come in understanding social practices, norms of communities and sexual networks that perpetuate the epidemic (Kippax, 2017). Therefore, there is a need for comprehensive[2] HIV prevention interventions that account for all the multi-layered contributing factors in the HIV and AIDS epidemic in South Africa. Moreover, there is a need to pay particular attention to population groups that face extreme vulnerabilities towards HIV and AIDS, such as young women given the disproportionate rates of infection in the South African context.

Oral pre-exposure prophylaxis (PrEP) is a novel approach to HIV prevention that has the potential to empower young women at high risk of HIV infection to protect themselves without their male partner’s initiation (Mansoor et al., 2019, Celum et al., 2019). Several studies have established oral PrEP to be an effective HIV prevention intervention for young women, however, PrEP success in terms of HIV incidence reduction depends on acceptance, uptake and adherence among vulnerable population groups (Ahmed et al., 2019). Therefore efforts to support oral PrEP acceptance, uptake and adherence are critical. Healthcare facilities where oral PrEP is made available for vulnerable population groups is one of the sites that needs to be explored and strengthened to ensure success of this intervention within communities.

The current study seeks to find effective ways in which oral PrEP for young women in South Africa can be integrated in sexual and reproductive healthcare (SRH) services, as recommended by the South African Department of Health (2016). Currently, there is very little knowledge on the effectiveness and impact of integrating oral PrEP into SRH services as recommended by the Department of Health (Mansoor et al., 2019). More importantly, there is no knowledge on how oral PrEP can be integrated into already existing SRH services within clinics in ways that will be contextually relevant (Milford et al., 2018). Therefore, this study sought to explore how oral PrEP can be integrated into SRH services in ways that are socially and culturally relevant.

This study explored this research inquiry through participatory research with young women to generate knowledge that can inform the integration of oral PrEP in SRH services. Gaining insight into young women's perceptions on the social and cultural factors that act as barriers or enablers to accessing oral PrEP in SRH services is critical. Therefore, as South Africa sets out to upscale oral PrEP in SRH services, the social and cultural contexts in which vulnerable populations are situated needs to be understood for optimal population-level impact. The main concern here is how HIV prevention interventions such as oral PrEP can be made available in SRH services in a manner that will encourage uptake, acceptance and adherence,

This study suggests that a blanket approach to integrating oral PrEP in SRH services will not be feasible in the South African context. Different settings and populations require different HIV prevention interventions, carefully tailored to address the contextual needs (Govender et al., 2017). The most effective HIV prevention intervention is a comprehensive package that suites the population and setting (UNAIDS, 2016). Culturally sensitive, socially relevant and structurally appropriate HIV prevention packages are necessary. This thesis set out to find ways in which oral PrEP for young women in South Africa can be effectively integrated in SRH services in ways that account for their socio-cultural contexts. Such an integration is hoped to ensure access, acceptability and appropriateness of PrEP for the key population that the product is designed for, such as young women in KwaZulu-Natal.

Background to this study

This study comes at an intersection in South Africa when HIV prevention has advanced with biomedical technologies, namely the licensing of oral PrEP Truvada in December 2015. The country continues to be the hub of the HIV and AIDS epidemic with young black women being disproportionally affected by the pandemic (UNAIDS, 2016). The present situation of the epidemic depicts the urgent need for efficient and effective prevention methods. More specifically, the province of KwaZulu-Natal (KZN), South Africa has recognised to be the epicentre of HIV and AIDS with high prevalence rates among young women (Kharsany et al., 2015, Shisana et al., 2014, Rehle et al., 2007).

The study population in this study refers to two populations; the first is young black women in Vulindlela, rural KwaZulu-Natal, the second is young black women in eThekwini urban KwaZulu-Natal. The study focuses on young black women because this population group in the South African context are more vulnerable to HIV infection than other race (Shisana et al., 2014, Shisana et al., 2017). Vulindlela is a sub-district in the uMgungundlovu Municipality within KwaZulu-Natal. This area comprises of farmlands and traditional settlements, informal and peri- urban living (Kharsany et al., 2015, Frohlich et al., 2014). The Vulindlela area is characterized by high burdens of poverty and HIV incidents (Kharsany et al., 2015). Rural women were enrolled for this study at the CAPRISA Vulindlela Research Clinic right next to a comprehensive primary health care clinic in Vulindlela.

The second research site; eThekwini District, is a Metropolitan Health District comprising of 103 wards that are urban, rural and peri-rural in nature. The CAPRISA eThekwini Clinical Research site (urban area) is located in central Durban adjacent to a large public-sector primary-care clinic designated for the diagnosis and treatment of sexually transmitted infections (STIs) and tuberculosis. The eThekwini area has 5 regional hospitals, 2 district hospitals 4 specialised hospitals, 8 Community health centers (CHC) and 110 clinics including 57 clinics under local authority. Participants for this study are recruited at the eThekwini Clinical research site, this site is in the middle of one of the busiest taxi ranks in the Durban Central Business District (CBD), the clinic contains two sections, a Treatment Clinic for HIV-TB co-infected patients and

a Prevention Clinic that cares for high risk clients infected with sexually transmitted infections (CDC, 2014). I selected these two research sites because of the high HIV and AIDS rates in these contexts, moreover because the young women who were part of this study were enrolled from an oral PrEP demonstration project that was facilitated in these two research sites.

Conceptualising oral PrEP introduction

This research comes on the back of the recent National Policy on HIV PrEP and, Test and Treat (T&T) which prescribes that PrEP must be made available as part of a comprehensive HIV prevention package and integrated in already existing SRH services (Department of Health, 2016). The policy is guided by the World Health Organization (WHO) recommendations on providing people with antiretroviral therapy upon diagnoses with HIV regardless of their CD4 count (Camlin et al., 2016), and the use of oral PrEP as an additional prevention measure for people at substantial risk of acquiring HIV (Department of Health, 2016). Young women in South Africa have been identified as a key population, highlighting their impending need for oral PrEP as an HIV prevention method. It is in this context that this study will investigate the facilitating enablers or barriers to integrating SRH services and HIV prevention looking at how communities, particularly key populations are likely to receive this integrated service. This study aims to develop a model that will enable the effective integration of oral PrEP.

Framing the study: mapping our experiences

Meaningful HIV and AIDS-related research cannot be conducted among young people without a truthful and holistic picture of what is going on in the lives of young people. There is a need to understand the contributing factors that increase the risk and vulnerability of young women to HIV, and identify the key barriers to HIV prevention before proposing solutions, and new interventions.

Biomedicine must give attention to the cultural contexts surrounding oral PrEP implementation in sexual and reproductive healthcare services, particularly the socio-

cultural factors that will affect the effectiveness of this HIV prevention method for young women in South Africa.

It is important to understand the underlying philosophical assumptions, and propositions of a particular study in order to understand the values that the researcher has subscribed and appreciated in a study.

The theoretical underpinnings that inform this study are premised in the culture-centered approach which advocates the active participation of those directly affected by the phenomenon under inquiry. The culture-centered approach (Dutta, 2011) has three pillars (structure, culture and agency) that will assist in understanding how oral PrEP can be integrated into SRH services in a sustainable and locally relevant manner.

In addition, this study makes use of the cultural competence approach. Cultural competency in health refers to the ability for health care systems to provide appropriate care for patients with diverse values, beliefs and behaviours, the goal is to meet the patient's social, cultural and linguistic needs (Betancourt, Green & Carrillo, 2002). Calzada and Suarez-Balcazar (2014), propose a model of cultural competency which outlines how health care facilities (structures) and service providers can become more culturally competent. Within this model cultural competence at the organisational level promotes ongoing awareness and skills development among staff which in turn will facilitate the delivery of culturally appropriate services and programs that serve the needs of patients (Calzada and Suarez-Balcazar, 2014).

The culture competency approach assists in understanding how structures (as explained by Dutta) can become appropriate for patients from various cultural backgrounds, and within this study, SRH services are the structures that need to be aligned with young women's socio-cultural needs in order to facilitate smooth roll-out of oral PrEP. Furthermore, cultural competence in SRH services will afford young women's values, beliefs and behaviours to be considered when making oral PrEP available. The cultural competency approach provides enlightenment on the concept of "structure" as proposed by Dutta (2011) which is the locus of this study.

In terms of the methodology that mobilised this study, participatory visual methods (PVM) were used. PVM's have the potential to facilitate discussion, collaboration and inclusion of young women in HIV prevention research. Through participatory research methods, this study creates space for young women to practice a level of agency by being actively involved in the research process. Participatory workshops were facilitated, these included journey mapping as form of participatory visual method. Using a participatory approach to this study created an enabling and safe space for young women to engage in dialogue about their sexual health and SRH services in their communities. This research methodology was effective in addressing the research question, and meeting the research objectives.

Principal questions of inquiry

1. In what ways is the current structure and organization of SRH services an impeding or facilitating environment for young women assessing biomedical products?
2. What are the likely socio-cultural challenges or opportunities that will influence acceptance, uptake and adherence of oral PrEP in SRH services among young South African women KZN?
3. In what ways can the current structure and organization of SRH services be realigned to meet the needs of young women in order to ensure acceptance, immediate uptake and adherence to oral PrEP?

The objectives of this study are to:

Explore the current structure and organization of SRH services an impeding or facilitating environment for young women assessing biomedical products.

Examine the likely socio-cultural challenges or opportunities that will influence acceptance, uptake and adherence of oral PrEP in SRH services among young South African women KZN.

Investigate how the current structure and organization of SRH services be realigned to meet the needs of young women in order to ensure acceptance, immediate uptake and adherence to oral PrEP.

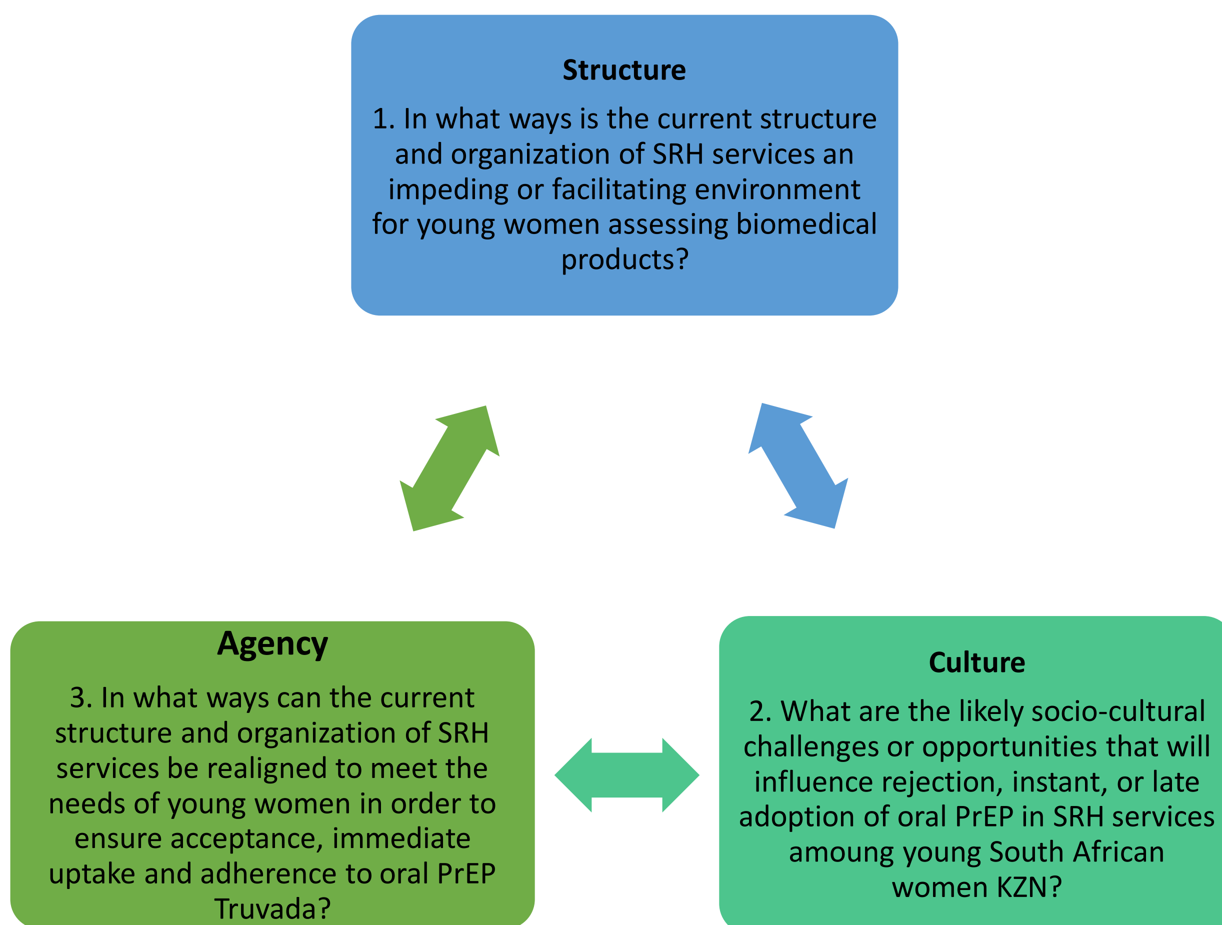


Figure 1.1: The interactions of research questions and theoretical principles

This study set out to explore the socio-cultural enablers and barriers to oral PrEP acceptance, uptake and adherence when this prevention technology is integrated into SRH services in KZN. Furthermore, this study sought to explore how these barriers can be addressed when integrating PrEP into SRH services. In effect, this study suggests a model that will assist develop culturally sensitive and contextually relevant ways of integrating oral PrEP in SRH services.

Structure of the thesis

Chapter one offers an introduction into the research topic, the possible integration of oral PrEP in already existing sexual and reproductive healthcare services for young women in KwaZulu-Natal. This chapter gives a background to the HIV and AIDS prevention cascade, with an emphasis that even after three decades, HIV and AIDS

is still a public health challenge. The chapter proposes that social scientists play a critical role in the HIV and AIDS field, even in the introduction and facilitation of biomedical technologies that promise to change the HIV and AIDS landscape. This chapter also contextualises the study by explaining the overarching research questions, and objectives. The guiding theoretical principles in this study are also presented alongside the methodological map that guided the study.

Chapter two gives a conceptual map of the research problem by presenting the global and local context of the HIV and AIDS epidemic. A timeline depicting the various biomedical advances that have been made in the past three decades towards HIV and AIDS prevention, care and treatment is presented.
The concept of "socialising the biomedical" is critically discussed with an emphasis of the multilayers of influence towards the HIV and AIDS epidemic. It is within these multilayers that biomedical interventions need to be introduced and made available to high-risk population groups. This chapter demonstrates some of the contributing factors towards the HIV and AIDS epidemic which cannot be ignored when biomedical interventions are developed for populations that are most vulnerable to the epidemic. Various contexts around the world have different key population groups that are more vulnerable to HIV and AIDS. In the South African context, young women have been identified as a key population group that is at high risk of HIV and AIDS. In this chapter, I make an argument that young women need access to HIV prevention methods that can give them control over their sexual health.

Chapter three expounds on the theoretical pillars in this study. The culture centered approach as conceived by Dutta (2011) and the cultural competence approach are used in this study to understand the acceptance, uptake and adherence to oral PrEP when this biomedical technology is integrated in SRH services. This chapter discusses how the culture centered approach helps to make sense of a biomedical technology that needs to be made available to population groups that are situated within cultural contexts that influence their health-related behaviour. This section looks at the culture-centered approach as a theory that has been applied to explain and understand the creation of knowledge and social norms regarding health-related issues within a community or society.

Chapter four presents the methodological framework that guided this study. This section looks at the methods used to collect data and the philosophy that has informed those methods. The central discussion in this chapter is around the use of participatory research.

Chapter five is a reflection of the ethical considerations and dilemmas that were involved in this study. Working with young women through participatory methods, and discussing sensitive issues related to their sexual health and SRH services can raise multiple ethical dilemmas that require specific ethical precautions to be taken in research. In this chapter, I discuss the ways in which I addressed and negotiated ethical dilemmas in the research process. My experiences as a researcher demonstrate that PVM fosters environments of inclusion and cultural sensitivity through dialogue, for young women where they felt comfortable and safe to share their opinions and experiences concerning sexual and reproductive health matters.

Chapter six presents the data that was collected in this study. This chapter comprises of three sections; visual data from the workshops facilitated, and textual data from the workshop and one-on-one interview with the young women. Lastly, textual data from the one-on-one interviews with the nurses is presented. The data is presented according to the developed themes for systematic layout.

Chapter seven gives an account of the data analysis. This chapter offers a critical analysis and discussion of what the data collected means in relation to literature and the theoretical framework adopted in this study.

Chapter eight presents the unique knowledge contribution of this study into the field of HIV prevention, giving a social science perspective in oral PrEP integration into SRH services. This chapter concludes with a proposed model of how oral PrEP can be integrated in SRH services in a manner that is context specific and culturally relevant. It provides the conceptual model developed from this study, with a proposal that oral PrEP must be integrated in SRH services in a manner that is context specific and culturally relevant.

Chapter nine is the final chapter, which concludes by summarising the key findings of this study in relation to the research questions, and stating the conceptual and methodological contributions of this study.

Chapter Two: Literature review

Introduction

This chapter presents the literature in the field of HIV prevention, treatment and care by presenting the global and local context of the HIV and AIDS epidemic. A timeline is presented, which depicts the various biomedical advances that have been made towards HIV and AIDS prevention, treatment and care. This chapter presents the concept of "socialising the biomedical" which emphasises the importance of acknowledging the multilayers of influence within this epidemic. One of the central arguments in the chapter is that young women in South Africa need to be prioritised in the HIV and AIDS epidemic as they have been identified as a vulnerable population group.
Moreover, in this chapter, an argument is presented that young women need access to HIV prevention methods that can give them control over their sexual health.

There has been great advancements in the proven efficacy of HIV prevention technologies available; with voluntary medical male circumcision (VMMC), treatment as prevention (TasP), post-exposure prophylaxis (PEP), and pre-exposure prophylaxis (PrEP) recently being added to the already- existing toolbox of condoms, lubricant, behavior change interventions, harm reduction, structural interventions and advocacy programs (Ward et al., 2019). However, despite these significant advances in treatment and prevention strategies, HIV and AIDS remains one of the leading public health challenges in the world with 2.1 million people newly infected with HIV in 2015, and 1.1 million deaths from AIDS-related illnesses in the same year (UNAIDS, 2015). In 2017 it was estimated that 1.9 million new HIV infections were recorded globally (Ward et al., 2019). While there is a slight decrease in new HIV infections on a global scale, these figures depict strides of success in the HIV and AIDS field.

After three decades of multi-disciplinary efforts to alleviate the HIV and AIDS epidemic, the spread of the virus has been escalating at a steady rate with 36.9 million people reported to be infected with HIV in 2019 (Ensor et al., 2019).

It is evident that the world is not on track with the ambitious goals of ending the epidemic by 2030[3], however, there is progress in new HIV infections number of people who know their HIV status, and an increase in the number of people accessing HIV prevention methods (AVAC, 2019). This highlights the advancements in the HIV prevention landscape, however, this is not sufficient when considering the HIV and AIDS global goals.

Globally, HIV and AIDS-related illnesses are the leading cause of death among adolescents, and almost a third of HIV infections are among young people aged 15 to 25 years (MacQueen, 2017). Young women bear a disproportionate burden of HIV infection in the South African context, in 2016 the number of new HIV infections among young women was 44% higher than young men (Dellar et al., 2015, MacQueen, 2017), and these young women acquire HIV infection at least five to seven years earlier than their male counter parts (De Oliveira et al., 2017). Furthermore, it has been reported that women in sub-Sahara Africa account for 56% of new HIV infections in 2015 (Agot et al., 2019). Adolescent girls and young women (AGYW) remain significantly more vulnerable to HIV infection, according to the UNAIDS 2016 estimates, young girls between the ages 15-24 make up 70% of new infections among young people. In South Africa, young women have been identified as a key population group that needs to be prioritised in the HIV prevention agenda (UNAIDS, 2015, Venter et al., 2015, Celum et al., 2019). Young women need to be placed at the centre of the response to HIV and AIDS in a meaningful way that will facilitate comprehensive and sustainable interventions.

[3] UNAIDS has welcomed the new goals, targets and commitments of the 2016 United Nations General Assembly Political Declaration on Ending AIDS. Countries have agreed to a historic and urgent agenda to accelerate efforts towards ending the AIDS epidemic by 2030.

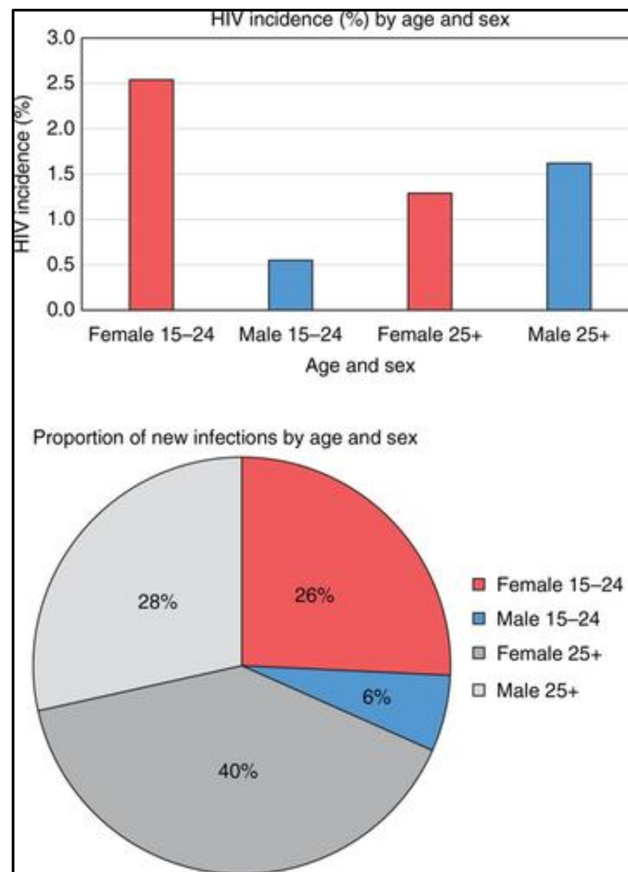


Figure 2 .1: Disproportionate HIV incidence in young women in South Africa

Adopted from Dellar et al. (2015)

Figure 2.1 above depicts the skewed spread of HIV in South Africa, with young women clearly over burdened by HIV incident rates and new infections. Young women in South Africa contribute almost 30% of new infections in age groups 15-24 (Dellar et al., 2015), this is unacceptably high when considering that their male counterparts in the same age group contribute almost 10% of new HIV infections. These estimates represent 2015 figures, however this disproportionate spread of HIV has not changed significantly up to date (Celum et al., 2019). In this thesis, young women are positioned as a key population group that needs to be included in HIV and AIDS research.

In this chapter, I offer an outline of the global HIV and AIDS landscape, highlighting the advancements made in HIV and AIDS prevention, treatment and care. Thereafter I point to young women as a key population group in the HIV and AIDS epidemic within the South African context and discuss how this population groups needs to be prioritized for effect HIV and AIDS prevention. This chapter offers a social science

perspective to HIV and AIDS, proposing that this is not just a biomedical disease but it is also a social disease requiring multifaceted and social development interventions. The role of health communication is then discussed in relation to the introduction, implementation and integration of oral PrEP into sexual and reproductive health care services for young women in KwaZulu-Natal.

Mapping a social disease: HIV prevention, treatment and care

Thirty years into the HIV and AIDS epidemic brings lessons that teach us that past interventions that set out to alleviate the epidemic have failed to adequately address the drivers of this epidemic. To demonstrate this, I provide a concise timeline of the complex HIV and AIDS epidemic on a global and local scale.
AIDS was first documented in the United States of America among homosexual men in 1981, it is not clear how long before this discovery HIV and AIDS was affecting people around the world (Kippax and Stephenson, 2012, Beck and Mays, 2006). Some researchers and scholars suggest that HIV and AIDS may be traced back to the 1920s (Kippax and Stephenson, 2016). Since this time of discovery, HIV and AIDS has spread exponentially around the world, being defined as a public health challenge (Baxter and Abdool Karim, 2016, Celum et al., 2015, Mojola, 2014). What this means is that the spread of this virus has shown to be complicated, with some areas around the world being more burdened by the epidemic than other parts of the world (Mojola and Wamoyi, 2019). In recent years, researchers have established the fact that some regions have displayed spatial concentration of hyper-endemics, which refers to settings with high HIV incidences, or high prevalence rates (UNAIDS, 2016a, Mojola and Wamoyi, 2019). These hyper-epidemic characteristics in the HIV and AIDS field show the social, cultural, structural complexities of this public health challenge that need to be explored.

The epidemic has drawn attention and caused alarm in research spaces and government institutions, and as a result, exuberant amounts of funding have been invested into this field as an attempt to explore how this epidemic can be eradicated (Kelly et al., 2018). Initially, the most reported mode of transmission was largely engaging in sexual intercourse and risky drug injection practices, mothers to child transmission during child birth, breastfeeding, unsafe blood transfusions (Kippax and

Stephenson, 2016). However, over the years, HIV and AIDS has displayed more complicated means of spreading which include; biological, social, economic and contextual factors that have been identified in the field (Pettifor et al., 2009, Reddy, 2010, Shefer, 2005, Naranbhai et al., 2012).

In 1987 one of the biggest initiatives to address HIV and AIDS as an epidemic was launched, the World Health Organisation (WHO) initiated The Global Program on AIDS to raise awareness; generate evidence-based policies; provide technical and financial support to countries; conduct research; promote participation by NGOs, and promote the rights of people living with HIV[4]. Then in that same year, 1987 the first drug for AIDS was developed, zidovudine (AZT) (Esté and Cihlar, 2010). However in 1989, there was an estimation of 400 000 AIDS-related cases reported by the WHO, showing a lack of success in the initiatives being implemented to address HIV and AIDS (Esté and Cihlar, 2010). This was just the beginning of evidence to show that HIV and AIDS was not just a biomedical disease, but also a social disease, as termed by Kippax and Stephenson (2016). So even though there was treatment available for people living with HIV and AIDS, AIDS-related deaths were still rising and the spread of the disease was not relenting. This means that there were some social, structural and economic aspects that needed to be considered in availing biomedical interventions. Essentially, AZT did not prove to be an effective in the overall alleviation of HIV and AIDS epidemic, but its development encouraged HIV testing and gave hope to people already living with HIV (Kippax & Stephenson, 2016).

Evidence from clinical trials

While behaviour change interventions were being developed, some showing success, and some limited efficacy (Mwale and Muula, 2017), the next years in the HIV and AIDS landscape witnessed tremendous advancements in biomedical technologies with several clinical trials displaying efficacy in prevention technologies. In 2010 the Centre for the Aids Programme of Research in South Africa (CAPRISA) 004 microbicide clinical trial was hailed successful for a virginal gel that established a 36 % protection against HIV infection for women (CAPRISA, 2010). In the same year 2010, the iPrEx clinical trial established a reduction in HIV infections among men who

[4] CDC Global HIV/AIDS Milestones: On the Path to an AIDS-Free Generation'

have sex with men (MSM) of 44% by taking oral PrEP (Grant et al, 2010). Following this, in 2011 results from the HPTN 052 trial[5] established that early initiation of antiretroviral use among serodiscordant couples reduces the chances of HIV infection by 96% (Cohen et al., 2011). This meant that in a sexual relationship where one person is HIV positive and they are on antiretroviral therapy, they decrease the chances of infecting their partner with HIV by 96%.
Several clinical trials including TDF2, iPrEx, Partners PrEP, PROUP, IPERGAY and the Bankok tenofovir study have proven that oral PrEP is effective in reducing HIV transmission when used consistently (UNAIDS, 2016). Most importantly, these clinical trials also found that oral PrEP effectiveness is dependent on adherence to the product and failure to adhere to the product will result in low effectiveness (Idoko et al., 2015).

The findings recorded above were a critical milestone as they recognized the possibility of antiretroviral treatment (ARV)- based prevention options. The results from the HPTN 052 trial supported the use of antiretroviral treatment as a part of a public health strategy to reduce the spread of HIV (Cohen et al., 2011). In the same year 2011, a second option for an all-in-one combination ARV tablet was approved and made available, this was in efforts to expand HIV treatment options for people living with HIV (AVERT, 2017). For the first time in history, in 2012 FDA[6] approved PrEP for HIV-negative people to prevent sexually transmitted HIV, what this meant was that adults who were at high risk of HIV infection now had another option of HIV prevention (U.S. Food and Drug Administration, 2012).

Global goals in alleviating the HIV and AIDS epidemic

The HIV and AIDS landscape saw success in 2013 when UNAIDS reported a 30% fall in AIDS-related deaths since 2005, this success was largely due to ART uptake which prolonged the life span of HIV positive people (UNAIDS, 2013). ART enables HIV positive people to live normal healthy lives if they adhere to the treatment regimen which they need to keep for the rest of their lives. In 2014 UNAIDS set out to make ambitious goals to alleviate the HIV and AIDS epidemic by launching the 90-90-90 goals which aim for 90% of people living with HIV to be diagnosed, 90% of those

[5] http://www.nejm.org/doi/pdf/10.1056/NEJMoa1105243
[6] https://www.fda.gov/ForConsumers/ConsumerUpdates/ucm311821.htm

diagnosed to be accessing antiretroviral treatment and 90% of those accessing treatment to achieve viral suppression by 2020 (UNAIDS, 2014). Part of the efforts to reach the 90-90-90 goals is the “Fast-Track” targets which aim for scale-up of HIV prevention and treatment programs to stop 28 million new infections by 2030 (UNAIDS, 2014).

With the “Fast Track” targets, treatment and HIV prevention programs were stated to be critical and it was strongly suggested that in ending the HIV and AIDS epidemic prevention and treatment need to be prioritised. Progressively, in 2015 UNAIDS announced that the Millennium Development Goal (MDG) concerning HIV and AIDS had been reached with 15 million people receiving antiretroviral treatment (UNAIDS, 2015). In the same year the WHO launched the new treatment guidelines which recommended that people with HIV should be given antiretroviral treatment regardless of their CD4 count, and this should be as soon as they are diagnosed with HIV, this has become known as “test and treat” (WHO, 2015).

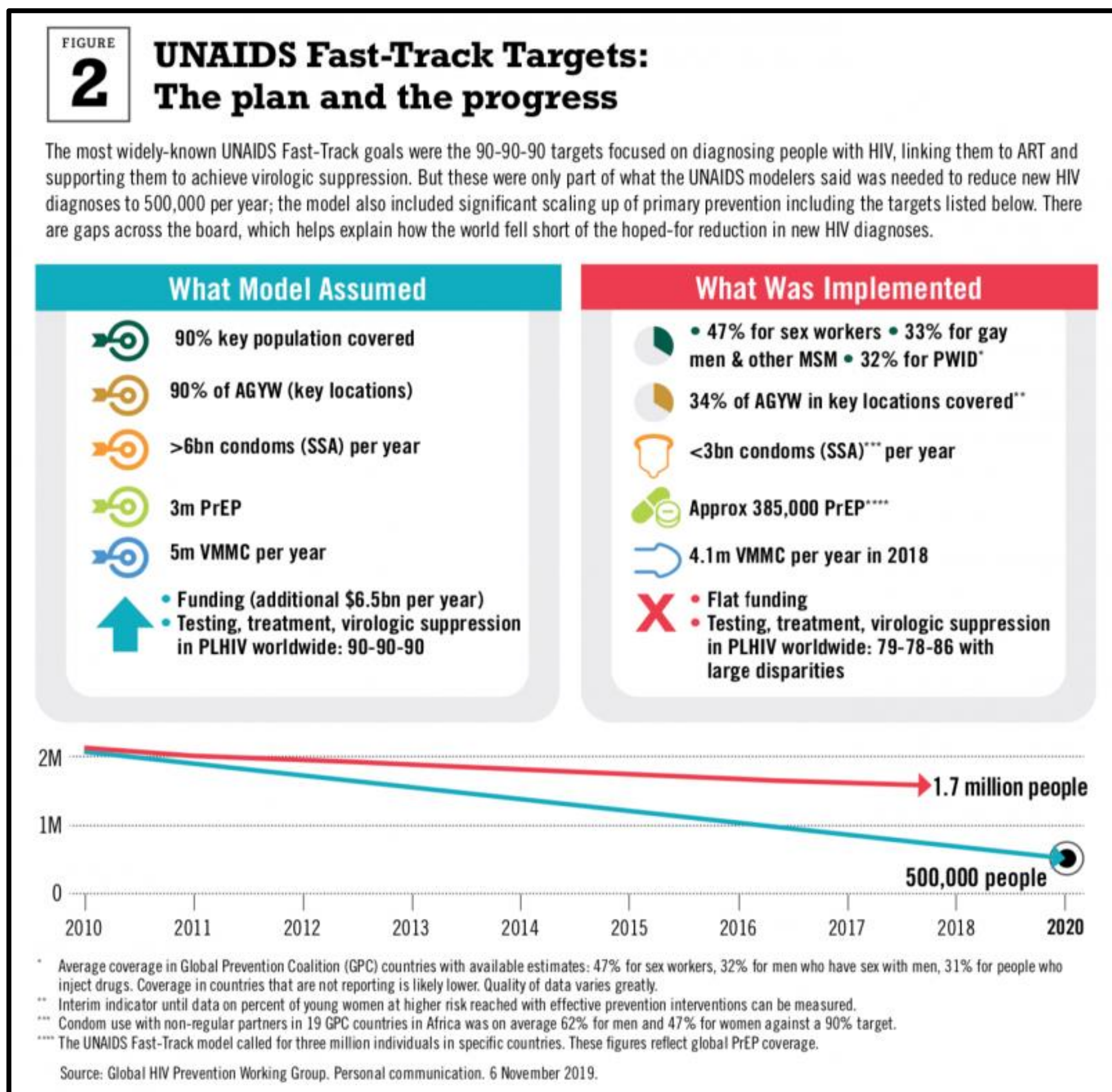


Figure 2.2: UNAIDS Fast-Track Targets: The plan and the progress[7]

The figure above is a depiction of the UNAIDS Fast-Track global goals, and the progress that has been made to date. The UNAIDS global goals are not on track, as depicted in the figure above, across the various goals depicted on this diagram, there is obvious lagging. Ensuring that 90% of key population groups know their status, and upscaling of oral PrEP, is also not on track, with approximately 385 000 people reported to be on PrEP instead of the goal of ensuring 3 million people on oral PrEP

[7] Image used with permission from AVAC: https://www.avac.org/infographic/unaids-fast-track-targets-plan-and-progress

by 2020 (AVAC, 2019). Even though the goals illustrated on this figure are for the year 2020, it is already evident that the targets set will not be reached.

Despite all the intense labour to halt the HIV and AIDS epidemic for the past 30 years, empirical research and interventions focusing on the individual level have proved not to be as effective as expected (Kaufman et al., 2014, Auerbach and Hoppe, 2015, Auerbach et al., 2011). In essence any attempts to alleviate the HIV and AIDS epidemic must move from the notion of simply recommending uptake and adherence to biomedical interventions such as condoms, PrEP, TasP and PEP. Rather, it must be acknowledged that HIV risk and AIDS care involve complex behaviors influenced by contextual factors.

Therefore, there is a need to look at interventions designed to alleviate the HIV and AIDS epidemic and consider why the world is still facing high HIV incidence. It is evident then that the availability of condoms, the recommendation of VMMC, the availability of PrEP, and the availability of antiretroviral therapy does not necessarily translate to population-level impact in curbing the HIV and AIDS epidemic. More needs to be done that goes beyond availing biomedical interventions which prove to be efficacious in clinical trials and demonstration projects but lack effectiveness in real-lived settings.

The urgency for advancing HIV prevention is emphasized by the asymmetrical spread of the virus. Some areas around the world are more burdened than others, Eastern and Southern Africa have 6.2% of the world's population, but this region accommodates close to half of the world's people living with HIV (Bekker and Gray, 2017). In this region, 46% new HIV infections were reported in 2015 (UNAIDS, 2016b). What this means is that while on the global scale new HIV infections are decreasing, in some regions new infection rates are grossly high. The cycle of new infections in these regions need to be halted and prevention interventions must lead the progression. Recent evidence proposes that the most effective approach to eradicating HIV and AIDS is a combination of biomedical, behavioral and structural interventions that will focus on reducing vulnerability and supporting prevention methods (Isbell et al., 2016). HIV prevention must be prioritized in strategies to end the epidemic.

Prevention cascade

Evidence from research strongly suggests that the most effective method of reducing new HIV infections is developing combination approaches that take into cognizance biomedical, behavioural and structural interventions that will address vulnerability enhancers and then drive uptake of prevention options (Godfrey-Faussett, 2016, Hargreaves et al., 2016, Isbell et al., 2016). The HIV prevention cascade has emerged as an approach and framework that considers multiple perspectives in order to halt new HIV infections, the combination approach underscores the HIV prevention cascade (Hargreaves et al., 2016).

The HIV prevention cascade suggests that there is a need to understand the multi-determinants of HIV incidence such as multiple sexual partners, access to biomedical prevent products and lack of healthcare facilities. Baxter and Abdool Karim (2016) give an example of an HIV prevention option that operationalizes the combination approach, these would consist of: oral PrEP, counselling on avoiding early sexual debut, access to SRH services, social protection interventions, e.g., cash transfers, gender-based violence education, male and female condoms, Treatment of STIs, medical male circumcision for partners and PMTCT when pregnant.

The integration of oral PrEP in SRH services needs to consider structural, behavioural and biomedical interventions. This research is situated within this context of the prevention cascade, therefore the integration of oral PrEP into SRH services is an important part of the prevention cascade.

Having highlighted and traced some of the successes and challenges in HIV and AIDS prevention, treatment and care, the UNAIDS programme is still committed to endorsing the global 90-90-90 goals by 2020 (Huerga et al., 2018). Part of the goals to end AIDS as a public health threat by 2030 is to ensure that 3 million people at risk of HIV are accessing PrEP by 2020 (AVAC, 2019). Furthermore, new consolidated guidelines from the World Health Organisation (WHO) stipulate that without addressing the needs of key populations, the response to HIV will not be effective

(WHO, 2016). Therefore, developing comprehensive[8] HIV prevention strategies that are tailored for vulnerable population groups is crucial, and in South Africa young women are a vulnerable populations group.

However, for the past three decades, the most effective means of HIV prevention are dependent on men, leaving women with little or no autonomy over their sexual health. The male condom in particular is the most effective HIV prevention method: though, its effectiveness depends largely on the male's willingness and ability to use the condom correctly (Baxter and Abdool Karim, 2016, Kelly et al., 2015). There is a growing understanding that key population groups in the HIV and AIDS epidemic need to be prioritised in the HIV prevention agenda. Specific to Africa, and Southern Africa, Adolescent girls and young women (AGYW) are a key population group in the HIV and AIDS epidemic, accounting for approximately 25% of new HIV infections globally, and have may unmet needs for HIV prevention (Celum et al., 2019, Celum et al., 2015).

In order for this biomedical product to be effective, we need to address critical questions that consider various social, economic and cultural influences that make HIV prevention a complex phenomenon for key populations. The research problem is premised in the understanding that oral PrEP as an HIV prevention technology will not be effective if these biomedical technologies are not integrated into health care services in ways that are socially and culturally sensitive; in essence, the implementation of oral PrEP in SRH services in South Africa must show cultural competence. Cultural competence refers to "a set of congruent behaviours, attitudes, and policies that come together in a system, agency, or among professionals and enables that system to work effectively…" (Cross, 1989: iv). In other words, cultural competency speaks to public health interventions taking into cognisance the dynamic contexts situated amid localised and cultural experiences of key populations.

[8] Combination & comprehensive prevention programmes are "rights based, evidence-informed, and community owned programmes that use a mix of biomedical, behavioural, and structural interventions, prioritised to meet the current HIV prevention needs of particular individuals and communities, so as to have the greatest sustained impact on reducing new infections." UNAIDS, 2010

The female condom is an example of an HIV prevention technology that did not show cultural competency resulting in low acceptance, uptake and adherence to this product (Gollub, 2000). Programming the female condom, providing post-exposure prophylaxis (PEP), delivering sterile needles and scaling up MMC provides examples in the HIV prevention landscape of slow and low acceptance, uptake and adherence to a prevention product or intervention (Hankins et al., 2015). Therefore, developing culturally competent approaches to engage key populations at high risk of HIV infection remains a paramount priority in the current HIV prevention cascade[9] (Hargreaves et al., 2016). These are some of the issues that need to be considers as oral PrEP becomes available for high-risk population groups in South Africa.

Oral PrEP- agents of transformation in the HIV prevention landscape?

Oral PrEP is an additional HIV prevention technology within the 2020 Fast-Track strategy towards ending AIDS as an epidemic by 2030 (UNAIDS, 2016). Oral PrEP for HIV prevention refers to a biomedical prevention method that involves the use of antiretroviral (ARV) medication to reduce the risk of HIV infection for those who are HIV negative (AVAC, 2015). Various clinical trials have confirmed that oral PrEP is both efficient for HIV prevention in both men and women when adherence is optimal (Idoko et al., 2015, Van Damme et al., 2012, Choopanya et al., 2013, Marrazzo et al., 2015, Thigpen et al., 2012, McCormack et al., 2016, Celum et al., 2019). UNAIDS (2016) has prioritized raising public demand for PrEP, suggesting inclusion of PrEP in national strategies, supporting access to PrEP, advancing strategies for optimal PrEP delivery and uptake, especially for key population groups, as well as supporting funding towards inclusion of PrEP in HIV programmes. These priorities are driven by the ambitious goal of enrolling 3 million people on PrEP by 2020 (UNAIDS, 2016).

Several independent clinical trials on the effectiveness of oral PrEP have been successful with serodiscordant couples, heterosexual men, women, men who have sex with men (MSM), people who inject themselves with drugs and transgender women (Baeten et al., 2012, Grant et al., 2010, Heffron et al., 2017, Baeten et al.,

[9] The HIV prevention cascade is emerging as a new approach to guide the design and monitoring of HIV prevention programmes in a way that integrates these multiple perspectives. The prevention cascade starts with the recognition of risk…identify the population at risk for whom their prevention product, approach, or technology is designed.

2018). Furthermore, a systematic review and meta-analysis of PrEP trials clearly demonstrated that PrEP is effective in reducing the risk of HIV infection (WHO, 2016). Importantly, it was observed that the level of protection did not change by age, sex or regimen (TDF or FTC + TDF), the only distinct factor that influenced efficacy of the biomedical product is adherence (WHO, 2016). When all the studies were analysed all together, it was established that adherence is a key determinant of the effectiveness of oral PrEP as an HIV prevention intervention. The WHO (2016) has recommended that support for PrEP adherence should be included when potential patients are being informed about this HIV prevention method. Furthermore, PrEP users should be advised that PrEP reaches levels of protection after 7 doses, and that PrEP is only recommended to be used during periods of high risk.

Global and local policy for oral PrEP

The WHO (2012) released its first recommendation of oral PrEP in 2012 for MSM and serodiscordant couples in demonstration projects, then in 2014 the WHO recommended PrEP for MSM as an additional prevention option. More recently, in September 2015 the WHO recommended offering PrEP for all populations at substantially high risk of HIV infection (Koechlin et al., 2017). The UNAIDS 2016- 20 has set a goal of ensuring 3 million people are put on PrEP (UNAIDS, 2015 fast track). South Africa's Medicines Control Council (MCC) ruled that oral PrEP- Tenofovir disoproxil/emtricitabine (TDF/FT3), commonly known as Truvada is safe and effective. Truvada was licensed in South Africa in December 2015, and in May 2016 a national policy on HIV PrEP and T&T was released. The South African Department of Health is working towards PrEP being available for those people at high risk of HIV infection, the policy states that the integration of PrEP and T&T in SRH services is one of the main objectives in reducing the incidence of HIV infection (National Policy, 2016).

Further, the HIV PrEP and T&T policy in South Africa emphasizes that while PrEP is a highly effective prevention method, access should be prioritized to key populations as part of a combination of HIV prevention tools and services. Oral PrEP success in terms of incidence impact depends on high rates of acceptance, uptake and adherence by key population groups. With the Department of Health policy to oral PrEP, SRH services need to be strengthened and prepared for facilitating oral PrEP to communities. In the South African context, there is a need for preliminary research

to depict what are the enablers or barriers of integrating SRH services and HIV prevention; we need to understand what will facilitate immediate uptake, late uptake or rejection of oral PrEP in SRH services by young women.

Oral PrEP as an HIV prevention technology raises questions that must be explored in order to translate biomedical and clinical findings to acceptance, uptake and adherence of oral PrEP for key populations to ensure population-level effectiveness (Auerbach and Hoppe, 2015). Studies have suggested that there is a need for social scientists to investigate factors that may contribute to the acceptance, uptake, and adherence to PrEP, and while there are several studies that have made these explorations, more needs to be done (Kelly et al., 2015, Auerbach and Hoppe, 2015, MacQueen, 2017, Kippax, 2012). Oral PrEP demonstration projects with African AGYW indicate the discontinued use of oral PrEP in the first few months after oral PrEP initiation were approximately 50% (Celum et al., 2019). This means that a significant among of AGYW who start using oral PrEP in demonstration projects, discontinue using the biomedical product, even though they have been informed by the risk of non-adherence to the product. AGYW adherence support for oral PrEP is therefore critical, there is need for further research to be done to establish how adherence among key population groups such as AGWY can be encouraged.

There is an urgent need to enhance understanding of PrEP among young women who are high risk of HIV infection that will encourage adherence to the product once available. Baxter and Abdool Karim (2016:111) state “The challenge now is to determine how best to implement PrEP in the populations that would benefit most, while still maintaining high levels of adherence”. The integration of oral PrEP in SRH services must facilitate environments that will encourage adherence as this will determine product effectiveness, translating clinical trial efficacy to population level impact. While other PrEP formulations such as injections and vaginal rings are still under clinical trials, there is a demand for interventions that will be designed to support oral PrEP adherence. These are some of the broader research problems that must be considered in the integration of oral PrEP in SRH services in South Africa, therefore this study will take a look at this issues as part of the broader research problems.

Oral PrEP integration in SRH services

Clinics providing SRH services within communities are one of the structures that can contribute to oral PrEP adherence, as this will be the locus of access to oral PrEP for AGYW. This study is interested in the social and cultural dynamics that will affect oral PrEP integration in SRH services, this inquiry is premised on the notion that biomedical technologies that are offered in SRH services must be made available in ways that are contextually relevant to community members.

Existing research on PrEP suggest that acceptability of PrEP use will also be determined by many interconnected factors such as country-setting, ethnic group, education level, gender, age and socio-economic group (Ramjee, 2011, Cáceres et al., 2015, Dutta, 2013, Underhill et al., 2010, Celum et al., 2015). Therefore, it is critical that we understand the implementation of PrEP within the South African context. A large body of literature stresses the significant role of culture in relation to public health issues, as people understand and manage their health under specific socio- cultural prescriptions (Mojola, 2014, Slabbert et al., 2015, Petersen, 2009, Mantell et al., 2005, Singhal, 2013). Decisions to adopt specific health behaviors such as accessing and adhering to PrEP in SRH services will take place within complex interconnected and localised cultural settings (Baxter and Abdool Karim, 2016, Dutta, 2011, Dutta, 2013). This necessitates a culture centered approach in the exploration of enablers or barriers of PrEP implementation. Further, research also shows that the implementation of PrEP will require a nuanced understanding of how individuals and communities comprehend this HIV prevention method (Auerbach and Hoppe, 2015). We cannot hold the assumption that integration of PrEP in SRH services will be feasible, this calls for a critical investigation into PrEP implementation, by exploring the socio-cultural enablers or barriers to PrEP acceptance, uptake and adherence.

Integrating PrEP into SRH services for young women will encompass more than availing a biomedical product to those at high risk of infection, but rather it will involve the taking into cognisance the socio-cultural narratives that influence individuals' conceptualisation of health. The field of cultural studies offers theoretical opportunities to explore contemporary social issues, and to understand how people make sense of health issues within their cultural contexts.

There is also a need for us to define and distinguish the terms “efficacy” and “effectiveness” to understand why biomedical interventions have not yielded optimal success in HIV and AIDS reduction. Aral and Peterman (1998) define efficacy as the improvement in health achieved within research settings, in expert hands, under ideal circumstances and measuring individual level effect. Typically, biomedical HIV technologies are regarded as successful if the outcomes of randomized control trials (RCT’s) demonstrate efficacy (Kippax, 2012). However, effectiveness refers to the impact an intervention achieves in the real world, and in entire populations or subgroups (Aral and Peterman, 1998). To reach effective HIV and AIDS prevention, treatment and care, and efficacious tools need to be made available to populations, must be accepted by communities and made part of people’s everyday lives (Kippax, 2012). What is critical then is not only the availability of efficacious tools for HIV and AIDS interventions, but also the means to make sure that people in communities accept and adhere to the technology in a sustainable manner.

An effective response to HIV and AIDS calls upon social change. Attempts to alleviate the HIV and AIDS epidemic worldwide has led to an understanding that the struggle against this epidemic is not simply finding biomedical solutions that prevent or treat HIV, but rather HIV and AIDS involves complex behaviours influenced from multiple levels (Kaufman et al., 2014). The complex interplay of individuals knowledge, attitudes, emotions, and risk perception; power relations between sexual partners; economic inequalities; access to healthcare services; and policies that make HIV a priority in health care, all influence HIV and AIDS prevention, treatment and care. These factors cannot be ignored when developing epidemic control interventions. HIV and AIDS prevention, treatment and care involves people and people are social beings in social relations and practices.

> *“Since the beginning of the pandemic, the focus of discourse and policies throughout the world solely on the medical aspects of the illness, and since the beginning of the South African controversy, solely on the availability of drugs, has made the social issues (both carried and revealed by AIDS) practically inexpressible.”* (Fassin, 2007:189)

As insinuated in the quote above, an overemphasis has been placed on the biomedical aspect of HIV and AIDS with neglect of the contextual drivers of the epidemic. While

it is important that HIV prevention interventions such as oral PrEP are made available for vulnerable groups, social contexts in which these vulnerable population groups exist need to be understood.

After the global roll out and expansion of treatment as prevention[10] (TasP), global efforts to provide access to HIV treatment were also raised. The public health structures and expertise to test, counsel, and treat people who are HIV positive, and those at risk of becoming HIV positive became a priority as well (Kippax and Stephenson, 2016). All these developments resulted in the clinic becoming the setting to host and give HIV prevention to the general population and those at high risk of HIV infection, the clinic has become a place where expertise in HIV prevention could be implemented. Therefore, global funding has focus on the expansion of clinics, facilities and infrastructures that promised to alleviate the HIV and AIDS pandemic, however, after three decades, Kippax and Stephenson (2016) argue that the clinic has become the major, if not only site of promoting HIV prevention strategies, testing and counselling. For instance Beck and Mays (2006) state that the starting point for all HIV programming begins with HIV counselling and testing. Kippax and Stephenson (2016) on the other hand state that what this does is take prevention from everyday life where people have sex and inject themselves with drugs, to the world of the clinic, a shift which can be said to be intensified by the recent push to expand “test and treat”- the danger here is to focus on the individual, excluding the social context in which they live.

The test and treat program has been proven to be effective in that it promotes early detection of HIV infection and results in early treatment, the public health argument then in this is that people are rational being, who make decisions based on their autonomous views, i.e. if you know that you are HIV positive, you will not engage in unsafe sex practices (placing others at risk) and if you are HIV negative, you will strive remain so. However, while testing and counselling may work well to reinforce HIV

[10] Treatment as prevention (TasP) refers to HIV prevention methods and programmes that use antiretroviral treatment (ART) to decrease the risk of HIV transmission. https://www.avert.org/professionals/hiv-programming/prevention/treatment-as-prevention

prevention programmes. The clinic does not provide the context for effective HIV prevention because exclusive counselling as prevention reinforces the notion that HIV transmission is an individual matter. This focus can discredit the social context in which people make their health related decisions and even increases issues of stigma, particularly in context where there is a lack of social understanding of the epidemic (Kippax and Stephenson, 2016).

As oral PrEP is being made available in SRH services in South Africa for vulnerable population groups as recommended by the Department of Health policy for PrEP implementation, it is important to first understand the SRH services that PrEP will be integrated into. The SRH services where oral PrEP will be made available must be culturally competent and contextually relevant to the community it is serving. If for instance young women in a community do not feel safe attending the local clinic for SRH services, then they will be discouraged from accessing healthcare in that clinic. The clinic as point of provision for healthcare services needs to be culturally competent and meet the needs of the local community members it serves. The phase of oral PrEP integration into SRH services in South Africa needs to come in conjunction with structures and services that will promote acceptance, uptake and adherence to oral PrEP. However, we need to consider that the clinic must provide combination prevention measures, and take into consideration the contexts where they are serving, tailoring services to meet the needs of community members.

Kippax and Stephenson (2016) give an interesting view towards the clinic, stating that placing the clinic as the major site of HIV prevention has led to the individualisation and even "privatising" prevention leading to undermining collective efforts to prevention. Therefore the community must be given an opportunity to work in conjunction with the clinic in HIV prevention. Milford et al. (2018) argue in their work that community engagement and involvement even in the integration of HIV prevention in SRH services must be informed by community members. Most of the time, prevention efforts in the clinic are individualistic, and as a result the impact of these prevention efforts within the clinics have been limited (Kippax and Stephenson, 2016).

The role of communities in HIV prevention

There is a need to explore further how the community can be engaged and included meaningfully in HIV prevention interventions. HIV counselling, as a services provided in the clinic for instance does not in itself address the social norms shaping a person's lifestyle, but rather offers a space to discuss issues affecting the patient. Furthermore, in the clinic HIV and AIDS related information is usually delivered in a "top-down" manner, where people are addressed as patients receiving relevant information from experts. This positioning is disempowering (Kippax and Stephenson, 2016).

In the year 2000, UNAIDS acknowledged the limitations of an individualistic approach to HIV prevention in the World AIDS Report;

> "Individuals do not live and make decisions in a vacuum. After years of focusing on personal choices about lifestyle, by the early 1990s AIDS prevention programmes were giving renewed attention to the social and economic context of people's daily lives[…] Recognition of the factors that fuel the HIV epidemic prompted the development of new programmes for reducing vulnerability – in the civil, political, economic, social and cultural arenas -that would work in synergy with more traditional prevention approaches aimed at diminishing risk-taking behaviour." (UNAIDS, 2000, 37).

It is therefore important that we understand the real-lived experiences of HIV infection among young women in various geo-spatial settings in South Africa, types of sexual encounters and sexual choices at various stages of their live. Alleviation of HIV incidents among young women will be achieved through the combination of interventions that include behavioural, structural and biomedical elements. Culture can be seen as an enabler to understand the diverse preferences and acceptability of HIV prevention options. The concept of culture will be discussed elaborately in the next chapters, and we will see how from there how culture can offers a nuanced understanding of how women experience and encounter HIV infection, where socio-cultural adjustments can facilitate the uptake, acceptability and adherence to biomedical interventions by young women as vulnerable population groups.

Vulnerable population groups vary across countries, and the multiple factors that contribute to vulnerability to HIV infection also varies across settings (Ward et al.,

2019, Mojola and Wamoyi, 2019). It then becomes fundamental to identify vulnerable population groups at the local level, then detect risk factors within communities where these vulnerable population groups are situated. This will contribute to the development of context specific and effective interventions towards HIV and AIDS alleviation. In the South and East African regions for example the risk factors associated with young women being vulnerable to HIV infection include; age-disparate relationships, transaction sex, multiple concurrent sexual partners, having sexual partners that are not circumcised (Ward et al., 2019). Therefore, it will be important to identify a mix of HIV prevention technologies and interventions that will meet the needs of this these young women at high risk of HIV infection. The UNAIDS (2010) has established that there is no single HIV prevention method or approach that will be effective, but rather a combination of prevention approaches and technologies will be effective.

Kippax and Stephenson (2016) give an interesting argument that suggests that there is a need to understand that no one mode of HIV prevention can be generalisable from country to country, and from time space to another. This means that what is successful in Australia may not necessarily be successful in South Africa, and what worked in 1997 may not work in 2020, the issue of HIV prevention is one of working with contingency. Secondly, Kippax and Stephenson (2016) state that HIV prevention interventions that prove efficacy at clinical trial level do not simply result in a reduction in HIV incidents. Prevention methods cannot be assumed to simply work because public health officials tell people to take them. There is a dire need to focus on the social drivers that influence specific practices that make people vulnerable to HIV and AIDS, these practices (which are usually referred to as 'risk-behaviours') are largely socially organised and culturally determined (Auerbach et al., 2011). If South Africa will see progress in the HIV and AIDS prevention cascade, then we need to focus on key population groups and investigate how social, economic, and contextual drivers to HIV incidences can be addressed effectively.

Concerning health services, the following questions must be explored; do health services take into account people's health needs that are embedded in their diverse social contexts? How do health services enable people to identify factors increase

their vulnerability to disease? Do they provide ways by which individuals and communities can respond to contexts of vulnerability? In South Africa, young women have been identified as a key population group as face greater vulnerability to HIV infection. Often, key population groups experience structural barriers and even discrimination in society that can increase their vulnerability to HIV infection by limiting their access to healthcare services (Mayer and Allan-Blitz, 2019a). Key population groups refer to populations that are among the most likely to be exposed to HIV and stigmatization (UNAIDS, 2015).

The Structural factors can affect susceptibility to HIV infection through lack of access to HIV testing, care and treatment, it can also influence health-related behaviours and sexual networks by being socially marginalized, and therefore determining sexual partners choice (Mayer and Allan-Blitz, 2019a). Moreover, key population groups may have increased risk to HIV infection because of lack of access to HIV prevention methods such as condoms or sterilized syringes (Ward et al., 2019). The inability to negotiate safe sex practices that many young women face in South Africa is also one of the greatest challenges in vulnerability for this key population group, and this is discussed in more detail below.

Vulnerable population in South Africa: Adolescent Girls and Young Women

Ayres et al. (2010) defined vulnerability as a set of conditions that make individuals and communities more susceptible to disease or disability. The focus on vulnerability population groups allows for attention to be drawn to social factors, structures and contexts. Before vulnerability became a meaningful term in public health, the focus was on the term ‘risk’, which epidemiologists determined through probability studies that determined which populations would be more susceptible to a disease, but failed to explain what brought this risk, and what influenced this distribution of diseases (Ayres et al., 2010). Moreover, terms such as risk were identified to increase stigma and discrimination, leaving people affected and infected by HIV more unprotected (Ayres et al., 2010). Focusing on vulnerability of populations in alleviating diseases

has caused public health experts to shift their focus on the social context in which people are embeded and find themselves vulnerable.

This study sets out to explore how oral PrEP can be integrated into SRH services for young women as vulnerable population group. Even though oral PrEP has been given merit for being an effective HIV prevention method, population level effectiveness will be determined by several interacting components.

Unfortunately, young women in Sub-Saharan are commonly referred to be the face of the HIV and AIDS epidemic (Poulin et al., 2016). Even though this may seem to be cynicism is substantiated by statistics that display the high burden that young women in Sub-Saharan Africa face, this has been extensively discussed in the introduction of this chapter. Having said this, we now need to establish and understand what some of the social, cultural and contextual factors that perpetuate HIV risk and infection among young women in Sub-Saharan Africa. The next section will now take a look at the social, cultural and economic factors contributing to young women's vulnerability to HIV infection.

The chosen definition of young women in this thesis includes all those falling within the ages of 18-35 years (Atujuna et al., 2018). As such, most epidemiological data, and much of the discussion here, is presented in terms of this age stratification. Research has established the fact that women are disproportionately infected with HIV in the Sub-Saharan context because of several contributing factors. Women are biologically more vulnerable to HIV (Naranbhai et al., 2012), and this is exacerbated by various behavioural, contextual, and structural factors (Celum et al., 2019, Shefer, 2005, Patton, 2004, Ngubane, 2010); younger age of sexual debut (Pettifor et al., 2004); older and concurrent sexual partners (Pettifor et al., 2009, Halperin and Epstein, 2004); transactional sex for survival or to achieve high-class lifestyles (Scott et al., 2005, Leclerc-Madlala, 2003); limited access to education or increased school drop-out rates (Reddy, 2010); and social norms that deny women healthy sexual practices and control over their sexuality (Jewkes, 2009). The vulnerability, lack of agency, and marginalisation that many African women encounter suggest that strategies of abstinence, be faithful, and male and female condom use alone is insufficient to significantly reduce their vulnerability to HIV risk.

The significant imbalance in HIV prevalence rates between men and women that exits in Southern Africa demands for attention if the HIV and AIDS epidemic will be curbed effectively. Statistics show that the rate in which adolescent girls and young women (AGYW) are becoming infected with HIV goes beyond the biological factors that make this key population vulnerable. The social drivers of this disproportionate spread of HIV include; relationships with older men, transactional sex, violence, lack of access to health care services, and limited access to education. Age -disparate relationships are common in Southern Africa, and research suggests this is one of the key drivers of the epidemic in the AGYW population (Dellar et al., 2015, Akullian et al., 2017, Celum et al., 2019). These relationships are characterised by a lack of consistence in condom use, and a lack of negotiation in other safe sex practices. Studies show that as little as four years in age differences increases the risk of HIV transmission, and as the age gap widens, risk of infection increases. The age- disparate relationships are motivated by various social norms or expectations from both the young women and older men (Baxter and Abdool Karim, 2016).

Transactional sex

Transactional sex has received growing attention in the HIV and AIDS literature as it is considered to be an prominent causal factor to the high HIV infection rates among young women in South Africa in the region (Wamoyi et al., 2019).
The concept of transactional sex is understood to be a response to modernity, economic stress, and inevitably a key driver to HIV transmission (Lawson, 2008). Women is relationships characterised by monetary benefits or any form of material benefits from their male partner have less opportunity to negotiate for safe sex practices (Wamoyi et al., 2019). While young women may enter into sexual relationships in order to gain basic needs such as shelter, food and education, it is becoming more common for young women to enter into sexual relationships for a luxurious life style (Lawson, 2008; Leclerc-Madlala, 2003; Quarry & Ramirez, 2009). Research also highlights that young women involved in transactional sex become more vulnerable to HIV infection because they tend to have more sexual partners, and the partners are usually older, they are more likely to have sex under the influence of alcohol, also women who are financially dependent their male partners find themselves vulnerable to sexual abuse (Dunkle et al., 2004, Fielding-Miller et al., 2016).

Gender-based violence

Gender based violence is also a key social driver of high HIV prevalence rates in young women. Research has established the link between intimate partner violence (IPV) and HIV infection, with statistics showing an increase in HIV infection for women who experience violence from their partners (Mannell et al., 2019). Young women's vulnerability to HIV has a positive correlation to their male partner's risky sexual behaviour; men who are violent to their female partners often have other high-risk behaviours including substance abuse, and multiple and concurrent sexual partners, and even more likely to be living with HIV (Mannell et al., 2019)
The risk of HIV infection in these relationships is marked by the fact that abusive men are more likely to have more multiple and concurrent sexual partners, and inconsistent use of a condom (Kim and Motsei, 2002). Young women in South Africa are confronted with these social factors that cannot be ignored when developing relevant and effective HIV and AIDS interventions. It is critical that we have an insight into these social factors because any intervention that does not take these factors into consideration will be ineffective, even biomedical interventions.

Access to SRH services

Lack of access to sexual and reproductive services for young women is also a social driver for young women who are vulnerable to HIV infection in South Africa (Holt et al., 2012, Pillay et al., 2019). Globally, the challenge of inadequate access to good services for young women is a problem that is perpetuating the HIV epidemic because young women lack sexual and reproductive information and services that can prevent unwanted pregnancy and sexually transmitted diseases including HIV (Bearinger et al., 2007). Research has established the fact that women become more vulnerable to HIV infection as they progress from youth to adulthood (Karim et al., 2012, Kharsany et al., 2015). Therefore ensuring access to sexual and reproductive healthcare services to young people is critical if the HIV and AIDS prevention agenda will make significant progress. Providing young women with effective sexual and reproductive health services prior to sexual debut is therefore crucial in reducing HIV incidence in this population group.

These social, structural and economic contributors to the high HIV rates among young women are just a few of the many factors that can be discussed, these were simply discussed to show how the epidemic has been particularly hard felt by young women in South Africa. Even though several interventions have been developed to address these social drivers to HIV rates, there has been little improvement. The questions that still linger then are; how can intervention outcomes be improved? How can young women be significantly empowered to protect themselves from HIV infection and have control over their sexual health? What interventions can be implemented that will be contextually and culturally relevant for young women in the HIV prevention agenda?

As discussed earlier in this chapter, incredible progress has been made in providing a plethora of biomedical HIV prevention technologies available to young people in South Africa, and other part of the world. People living with HIV (PLHIV) and on antiretroviral therapy can now reach viral suppression, meaning undetectable levels of HIV, this prevents them from transmitting HIV to their sexual partners (Skovdal, 2019). We also now have the provision of oral PrEP which significantly reduces the risk of becoming infected, VMMC. Most of these biomedical technologies, except VMMC, are dependent on the user making adherence critical for effectiveness of the product.
However, all biomedical interventions that have been established to be effective rely on behaviour change in one way or another, this is often accompanied with the requirement of adherence. Oral PrEP for example requires adherence by persons who are HIV negative, and the use of ARV's requires adherence by people who are HIV positive. These biomedical interventions will fail if adherence is not maintained.

This thesis is not in any way trying to discount biomedical interventions in the HIV prevention field and promote behavioral and structural approaches. Rather, I am proposing the idea that whether prevention technologies or interventions advocate delayed sexual debut, condoms use, clean needles and syringes, PrEP or PEP, all prevention requires behavior change (Kippax and Stephenson, 2012). For effective HIV prevention, people need to change their social practices, and these changes must be supported by broader social change. The uptake of oral PrEP for example will require changes in practices that can only be sustained if they are supported by widespread social change; regular HIV testing is important, a combination of other HIV prevention option such as condom use, and adherence to oral PrEP are critical for

those who decide to use oral PrEP. HIV testing needs to be normalized in social contexts to remove the stigma that often comes with this practice, these are social issues that need to be explored and understood as biomedical technologies such as oral PrEP are being made available for key population groups.

Questions that become important to tackle as oral PrEP becomes available to key population groups are; how can this biomedical intervention be made available in ways that are socially and culturally relevant? What are some of the social issues that we need to explore and understand in order for young women as a key population group accept, take up, and adhere to oral PrEP for HIV prevention? What are the social and structural support systems that need to be strengthened to encourage young women at high risk of HIV? How can oral PrEP be integrated in already existing SRH services in ways that communities will respond to positively?
One of the starting points in these questions lies in effective health communication. Usually when biomedical technologies are proposed as effective, many do not fully communicate that for user effectiveness at the population level, behaviour change is necessary. Effective health communication is then vital as part of HIV prevention combination strategies. In the next section, we will discuss health communication within the HIV prevention continuum.

Social Change and Health Communication for HIV prevention

Health promotion is the process of enabling people to increase control over their health as well as factors influencing their health. It goes beyond focusing on the individual, but rather locates wellness within an individual's environment (WHO, 2017). Communication is a critical pillar of health promotion, it is the driver in effective health promotion as it can catalyse behaviour change at the individual and societal level. Earlier years in the field of health communications focused primarily on psychology, and social marketing theories that target people's attitudes, beliefs and behaviours (Lewis and Lewis, 2014). However, recently literature and practices has seen health communication move from its roots in individualised, medical models towards socio-ecological approaches that now underpin health promotion (Lewis and Lewis, 2014). This shift is explained in the work of Syme (2004: 3):

> “[w]e rarely identify and intervene on those forces in the community that cause the problem in the first place…if we can move away from a singular focus on diseases and risk factors and begin to think about community and social forces, we can also relate to the community in a more meaningful way.”

The WHO (1986), also affirms this notion by stating that community empowerment is essential in health promotion and health communications, their ownership and control of their health trajectory is critical in sustainable health promotion. It is important to develop health communication initiatives that carry social justice, community empowerment and capacity building in order to empower in becoming agents of their own development (Lewis & Lewis, 2016).

Dutta (2011) on the other hand argues that effective health communication should facilitate participation in social change. This notion involves creating platforms for marginalised communities to be agents of change that promotes health within their everyday lives.

In the previous sections we have clearly argued that HIV and AIDS is not exclusively a health issue, the occurrence of this epidemic is influenced by multifaceted socio-economic, cultural and ecological determinants. Social change communication is an inclusive way of responding to HIV and AIDS as a social challenge, it focuses on addressing the drivers of gender inequality, stigma, discrimination, violation of human rights and cultural misconceptions (O. Airhihenbuwa, 2000, Vermund et al., 2014). Within the context of this study, some of these social, contextual and cultural issues will influence the acceptance, uptake and adherence to oral PrEP by young women, and these partly the interest of this study.

For oral PrEP to be successful at population level, individuals must get tested, know their status, seek care, and adhere to the oral PrEP use. Communication plays a role in each of these steps, as communication can be used to create awareness for health-seeking behaviour and also increase support in healthcare services at the clinic and community level (Storey et al., 2014). From the demand side, communication has played a role in convincing people to get tested and obtain their results, in ensuring treatment access, linking those infected to care, and addressing stigmatizing attitudes

that may prevent individuals from taking these actions (Kaufman et al., 2014). On the healthcare side, communication has been shown to mobilize community care and support and increase the quality of patient-provider interaction, which in turn can improve adherence (Vermund et al., 2014). Health communication has a critical role to play in encouraging HIV testing, creating oral PrEP awareness, effective integration into SRH services, and adherence to oral PrEP.

As it has been highlighted earlier, oral PrEP is both efficient and effective for HIV prevention in both men and women when adherence is optimal (Idoko et al., 2015, Van Damme et al., 2012, Choopanya et al., 2013). Adherence to oral PrEP had been highlighted as a challenge for younger populations, and poor adherence is associated with decreased efficacy of the biomedical technology (Hosek et al., 2016). Therefore, even though this study aims to investigate how oral PrEP can be integrated in SRH services in a manner that will ensure access, acceptability and appropriateness for the young women, I am interested in the socio-cultural factors that could prohibit or support uptake and adherence of oral PrEP. Effective health communication between patients and healthcare providers is not only associated with greater patient satisfaction, it is also relevant to higher adherence to treatment regimens (Martin, 2013). Among many other contributors to adherence support for young women that should be strengthened for oral PrEP effectiveness, health communication is one of the factors that needs to be studied further.

If PrEP will change the HIV prevention landscape in this generation, it must make use of social change and health communication strategies for effective health communication that considers the social and cultural context of key populations. In regions of high concentrations of the HIV and AIDS epidemic, comprehensive and tailored response looking into aspects of prevention, care and treatment must be developed. The HIV and AIDS epidemic has proven to be a social condition rather than an individual problem, requiring a more social approach for alleviation.
Therefore, as South Africa transitions into making oral PrEP for HIV prevention available in SRH services, there is a need to explore the social, cultural and contextual factors that will affect young women's acceptance, uptake and adherence to this biomedical intervention. We need to also understand how SRH services in South

Africa can effectively make HIV prevention methods available for vulnerable population groups in a manner that accounts for their contextual needs.

SRH services lie at the heart of the provision of healthcare for young women, as they face several sexual and reproductive health challenges such as high maternal deaths, sexually transmitted diseases, unplanned pregnancies and high HIV prevalence rates (Milford et al., 2018, Braeken and Rondinelli, 2012, Govender et al., 2019, Smith et al., 2018). Access to SRH services for young women is therefore important for this vulnerable population group. However, literature shows that even though young women want to access to SRH services, they are faced with perceived and real barriers (Smith et al., 2018).
Moreover, the high HIV prevalence rates among young women, and the escalating unplanned teenage pregnancies illustrate that there is a need for the integration of SRH service and HIV prevention (SANAC, 2017, Cooper et al., 2015, Milford et al., 2018). Access to integrated services in SRH services and HIV prevention has the potential to result in young woman making more informed choices about their sexual health.

If oral PrEP integration into SRH service is going to result in population level success, then government needs to consider SRH services as structures that must meet the needs of young women in communities. SRH services need to be structures that young woman can rely on to receive assistance that will help them practice safe and informed sexual choices. The South African National Strategic Plan (2017–2022) and other policies in South Africa have been advocating for integrated services, however policy recommendations are received slowly (Cooper et al., 2015, Department of Health, 2016, Health, 2017).

In the South African context access to SRH services has been characterized by several challenges including healthcare provider negative attitudes, long waiting times, stigma and discrimination (Mulaudzi et al., 2018, Pillay et al., 2019, Jonas et al., 2018). However, the South African healthcare system is one that has experienced challenges and with the initiation of Anti-retroviral therapy (ART), the system has experienced a great capacity demand. Below I discuss this further, with the intention

to draw out some of the strains that may bring challenges to effectively integrating SRH services with HIV prevention.

ART was initiated by the South African government in 2005, and as of 2017, approximately 4.4 million South Africans were on ART (HSRC, 2018).
This shows the remarkable success that has been reached in initiating people on ART, however, this large scale of people on ART in South Africa is stressful for the country's healthcare system. The ongoing provision of ART has placed great service demands to an already strained public health infrastructure (Duncombe et al., 2015, Dookie and Singh, 2012). This has presented challenges for the public health sector in South Africa, resulting in weakening service delivery.

Conclusion

The overarching message I set out to give in this literature review is that the HIV and AIDS epidemic is more than a disease resulting in public health challenges, but rather this epidemic is a social challenge. Therefore, social scientists have a critical role to play in the HIV and AIDS epidemic globally. As advancements are being made in the biomedical field with HIV prevention options, and potential vaccines in clinical trials, social scientists need to respond to the challenge of understanding how best to make these biomedical interventions available to vulnerable population groups.
This chapter offered a concise timeline of the developments and advancements made in the HIV prevention, treatment and care continuum, highlighting this epidemic as a "social disease" which has resulted in hyper-epidemics where parts of the world experience concentrated HIV incident rates.

Through relevant literature I stressed how sub-Saharan Africa has the highest HIV rates and incidents in the world, and even within these settings, young women are disproportionally affected with HIV compared to their male counterparts.
However oral PrEP for HIV prevention has proven efficacy in clinic trials and demonstration projects, and this biomedical intervention offers renewed hope for vulnerable population groups such as young women.

However, as we enter into the fourth decade of the HIV and AIDS epidemic, it is becoming obvious that the efficacy and provision of biomedical interventions goes beyond “getting drugs into bodies” as Auerbach and Hoppe (2015) terms it. Rather, there are social, cultural and contextual complexities that surround vulnerable population groups such as young women in South Africa within the HIV and AIDS epidemic.

These complexities have the potential to influence acceptance, uptake and adherence to biomedical interventions such as oral PrEP for HIV prevention. This means that we need to understand young women’s lived experiences so as to make oral PrEP available in SRH services as prescribed by the DoH *HIV PrEP and Test and Treat* policy in South Africa. Therefore, combination prevention approaches that consider biomedical, social and structural factors are important as oral PrEP becomes available in SRH services. For optimal population-level effectiveness, oral PrEP must be made available in combination with biomedical, social and structural interventions that take into consideration the localised dynamics that affect vulnerable population groups in the HIV and AIDS epidemic.

The overall objective of this study is to explore the socio-cultural enablers and barriers to oral PrEP acceptance, uptake and adherence when this prevention technology is integrated into SRH services in KZN. Moreover, this study explores how these barriers can be addressed when integrating PrEP into SRH services.

This section of the thesis addressed the contextual issues surrounding the research topic, and the next section will present the theoretical framework adopted in this study that helped me to study the possible social and cultural enabler and barriers to oral PrEP integration into SRH services for young woman.

Chapter Three: A Culture Centered Approach to HIV Prevention

“*Understanding the cultures of those we serve requires more than words and good intentions. The journey toward cultural competence requires the willingness to learn from ones experiences and act.” (Hanley, 1999:1)*

This chapter explores culture as one of the key social drivers in public health opportunities and challenges. More specifically in this chapter I discuss the theoretical underpinnings informing my inquiry into the integration of oral PrEP in SRH services for young women. The theoretical framework informing this study is the culture-centered approach as proposed by Dutta (2008), and cultural competency approach (Betancourt et al., 2002).

In this chapter, I critically conceptualize the need to develop biomedical HIV prevention technologies that are culturally and contextually relevant and acceptable for vulnerable population groups. Moreover, I explore the need for SRH services to be culturally competent and socially relevant to those whom the health intervention is designed to benefit. The first section discusses at the culture-centered approach framework that has been applied to explain and understand the creation of knowledge and social norms regarding health-related issues within a community or society. The characteristics that differentiate the culture-centered approach from other cultural theories are; (1) voice and dialogue, (2) structures, (3) context and space, (4) values and (5) criticism. These characteristics are discussed in this section with direct reference to oral PrEP introduction, implementation and integration within the South African context for vulnerable population groups. The culture-centered approach is premised on three key tenants that interact to create space for marginalized communities to engage in meaningful dialogue; structure, culture and agency. These tenants can be used to understand the construction of health-related meanings and the experiences of the marginalized communities. The second section explores the concept of cultural competence, and how healthcare settings and healthcare practitioners can be culturally competent in order to be effective in their relative communities and societies in which they serve.

Cultural dynamics in this study

This study set out to explore the experiences of young women accessing oral PrEP in SRH services, with the intention to understand how SRH services can be made culturally competent for effective integration of oral PrEP for young women. This thesis takes the stance that oral PrEP implementation strategies must go further than offering a biomedical intervention to young women at substantial risk of HIV infection, to offering interventions that are also culturally competent. A central argument in this thesis is that a blanket approach to integrating oral PrEP in SRH services will not be feasible in the South African context. Different cultural and social settings and populations require different HIV prevention interventions, or interventions carefully tailored to address the contextual needs of the community (Pettifor et al., 2015).
The most effective HIV prevention intervention is a comprehensive package that suites the population and setting (UNAIDS, 2016). Culturally sensitive, socially relevant and structurally appropriate HIV prevention interventions are necessary in public health if interventions are expected to be effective at the community-level. Culture has become recognised as an important component that contributes to peoples behaviours, particularly health related behaviours (Airhihenbuwa, 2010, Airhihenbuwa et al., 2014, Dutta and Thaker, 2016).

This thesis is interested in HIV prevention and making HIV prevention available in the most effective ways for key population groups that need it the most. The terrain in which this study is situated is one that has been dominated by biomedical science driven scholarship where the HIV and AIDS epidemic has been understood and studied from a biomedical perspective. The initial response to the HIV and AIDS epidemic was grounded in the biomedical narrative, and it has played a dominant role in the HIV and AIDS prevention agenda (Kippax and Stephenson, 2016, Kippax, 2017). For instance, the biomedical narrative was primarily focused on diagnosis, HIV testing and treatment, and the search for a vaccine (Kippax and Stephenson, 2016). This came with the assumption that health, and health-related behavior is exclusively situated at the individual level, disregarding the social and cultural context that individuals are situated. However, over the past three decades scientist, scholars and advocates have recognized that this is not an effective means of address the HIV and

AIDS epidemic. Rather, HIV and AIDS prevention must involve communicative interaction, especially talking with community members. Dialogue with community members must results in efforts to develop social practices to adopt, rework or reject particular techniques of HIV prevention (Kippax and Stephenson, 2016). Therefore, effective HIV prevention resides within the scope of acknowledging the social and cultural contexts that people are situated. HIV prevention strategies are inherently social, and the social worlds in which they operate cannot be reduced to biomedical.

Culture and Marginalisation

'Culture' is a term that is referenced frequently in healthcare literature, it is usually used to refer to non-western cultures (Lupton, 2012). However, the term 'culture' transcends the definition of 'non-western', culture is universal. It is a collective consciousness of both measurable and unmeasurable components which can be seen, heard or silently revealed through history, language or customs (Betsch et al., 2016). Culture is not static, but rather reinforced through social norms that people develop as a collective, Betsch et al. (2016) states that culture can be reinforced by structures in a society which are not always visible. Culture therefore can be reinforced in visible structures or invisible structures that exist in a society. An example of this would be religious beliefs that are taught from generation to generation, these religious beliefs prescribe behaviour to people, reinforcing culture. Moreover, there are physical structure such as healthcare systems that are in place in a society where culture is reinforced daily. People are part of cultural groups that influence their behaviour consciously and unconsciously. Culture then becomes an essential component of meaning construction related to health in a social context and also when constructing personal understanding of health and illness (Betsch et al., 2016).

Culture can therefore be defined as a framework of people within a community that is a learned/learning experience, a process of evolving, living, and adapting (Ford and Yep, 2003). Culture therefore plays a critical role in determining the level of health of an individual or community at large, this is even more relevant in the African context where the behaviour and attitudes of family and the community influence an individual's behaviour (Airhihenbuwa and Webster, 2004). Culture has been identified

as factor contributing to nature of the HIV and AIDS epidemic, cultural beliefs around sexual practices have a direct effect on HIV prevalence (Airhihenbuwa and Webster, 2004). Literature in HIV and AIDS research highlight the importance of understanding the epidemic within the social and cultural context in which it exits (Airhihenbuwa et al., 2014, Kaufman et al., 2014, Kippax and Stephenson, 2012, Auerbach et al., 2011). It is this argument that forms the theoretical pillars of this study, and herein we will discuss the significant role of culture in health, specifically culture as a critical component in oral PrEP integration into SRH services for young women. Culturally appropriate interventions in alleviating HIV and AIDS in South Africa, particularly to key populations groups is a fundamental prerequisite if we want to see an 'AIDS-free generation'.

Marginalisation is a concept that is used frequently in this chapter, therefore a working definition of this term is necessary. One of the elements of the culture centered approach is the study of marginalised contexts (Dutta-Bergman, 2004). Marginalisation refers to being at the side line of the dominant system, it is a state of in access to resources in society (Dutta, 2008) .
Therefore marginalisation in the context of this study refers to individuals or communities that usually face limited or no access to healthcare resources. One of the main characteristics of being marginalised is being "voiceless". In health communications, being marginalised usually speaks to in access to healthcare resources and the concept of being rendered voiceless in discursive spaces in society where policy-informing dialogue takes place (Dutta, 2008). This is the position of not having a voice in the state of affairs that affect the individual or community. For instance key population groups in South Africa who are more vulnerable to HIV infection, are those who are usually marginalised. These population groups normally do not have platforms to meaningfully engage in dialogue that informs social and health-related policies.

A culture centered approach to HIV prevention

The development of the culture centered approach by Dutta (2008) builds on the criticism offered by Airhihenbuwa (1995) and Dutta-Bergman (2004) towards the

dominant models of health communication. The culture centered approach to health communication draws its principles from critical theory which places emphasis on critically questioning power relations and the production of knowledge (Dutta, 2008). Critical theory studies show how structures can constrain the life experiences of the under privileged classes (Dutta, 2008), drawing attention to questioning who is developing knowledge, who is setting the status quo and who has the power to set the agenda in society i.e. the public health agenda? Power reflects the way in which access to structures creates relationships of dominance and subordination in society (Dutta, 2007). This implies that those who have power and access to structures determine the lives of those without access, subordinating them through power relations. Therefore, critical theory questions these power relations and propagates for the inclusion of those who are marginalised and subordinated through power relations in society. Critical theory questions the values of biomedicine, advocating for the identification of historical, political and economic factors that shape a culture's responses to and concepts related to health, illness and treatment issues (Lupton, 1994).

The work of Lupton (1994) argues that efforts of health promotion and all health-related interventions are often based on the universal logic of scientific inquiry, that draw upon individualistic assumptions about what constitutes health risks and hence are ignorant of social and cultural contexts. These health promotion efforts are therefore unresponsive to the social, cultural and economic contexts within which individuals health experiences are located.

The work of Lupton (1994) calls for a critique of approaches and theories that inform health-related interventions that inspired scholars such as Airhihenbuwa (1995) to call for culture centered approaches to health promotion. This led to two streams of research with the common goal of centralising the concept 'culture'; the culture centered approach and the cultural sensitivity approach.

Culture is the main concept that drives the culture centered approach, foregrounding the participation of community members in social issues, and in the construction of meanings. Culture is constituted through the act of participation of local community members, and it is therefore continually constructed by its members (Dutta, 2008). Central to the culture centered approach is that the construction of health-related

meaning which involves the negotiation of shared meanings through active participation from community members (Dutta, 2018). It is through this active participation that community members create and reaffirm values, practices and meanings. According to the culture centered approach, culture is comprised of traditions that are passed on from one generation to the next, and also from changes that are introduced from members actively participating and contributing to meanings within a community. Therefore, culture is simultaneously stable and dynamic, in that it draws from what is being passed on from generation to generation, and also taking from contributions from the active participation of community members.

A study conducted in South Africa explored community members perceived relevance of HIV prevention and care interventions implemented in their communities established that community involvement in designing the HIV prevention and care interventions is critical (Naidoo et al., 2017). Key findings in this study proposed that traditional and cultural beliefs about sexual practices need to be re-examined in order to develop effective HIV prevention and care programmes (Naidoo et al., 2017). Several studies in South Africa have established similar finding that lead us to believe that culture and social cohesion has a critical role in the HIV and AIDS prevention cascade.

The culture centered approach stresses the need to develop interventions that are consistent with the community's culture (Airhihenbuwa, 1995, Dutta, 2008, LeClerc-Madlala, 2009). The culture centered approach is of the stance that people in marginalised communities have the capacity and capability to define their own health needs and develop possible solutions to their needs. This agency is activated through meaningful dialogue with relevant stakeholders. In this context, the researcher does not come in as an expert bringing knowledge to people about their social challenges. By doing this, the voices of the marginalised then becomes important in the search for social challenges and possible solutions, not just the researchers. This notion takes us out of the realm of offering people solutions, changing people and teaching people how to get out of their problems; offering a one-way transmission model to alleviate social challenges. Rather, the culture centered approach proposes a two-way process that begins with understanding people, and understanding their cultural context (Dutta, 2008, Airhihenbuwa, 2010).

Therefore the culture centered approach suggests a shift in the role of the researcher, from being the interventionist who plans and develops an intervention which they introduce and facilitate in a community to one where the researcher engages with community members through dialogue and a listening attitude (Dutta, 2003). The researcher then needs to take off the “expert cap”, and take up on a “listening cap” where they genuinely seek to hear the views of the community members. According to Freire (1970), engaging in dialogue involves a fusion of identities, based on dismissing subject-object distinctions. Moreover Freire (1970) argues that being dialogical is not invading, not manipulating, and not imposing orders. This is the notion that has informed the culture centered approach. The methodological approach in this study adopted culture centered approaches to interacting with participants, the young women involved in this study were given an opportunity to engage in meaningful dialogue through a workshop setting that was developed to make the young women comfortable to share their experiences.

Fundamental to the culture centered approach is the understanding that members of a community actively participate in dialogue about the structures that are within their social context (Dutta, 2008). Cultural members actively engage in dialogue to identify critical issues in their community, this results in problems being identified by the community members instead of external entities. In such scenarios, the community members gain an opportunity to learn from each other, and the researcher or scholar also gain an opportunity to learn through dialogue. However, communities may not have structures that provide platforms for cohesion and dialogue.
Dialogue and listening are the foundations for meaningful community engagement, not only as a means of providing people with health related information, but also on implementation strategies, and participation in the consideration of solutions, and strategies (Dutta, 2013).

Application of the culture centered approach in this study

In the context of this study, the culture centered approach takes the assumption that the introduction, implementation and possible integration of oral PrEP in SRH services

must be informed by community members through the process of dialogue. Moreover, community members for which oral PrEP is being made available for must inform and even subscribe what manner this HIV prevention technology must be made available for them. In the realm of oral PrEP implementation, the action of engaging in dialogue with community members calls for a commitment to create participatory spaces where community members can continually share evidence of effectiveness, risks, side-effects and costs involved in accessing oral PrEP. The concept of participatory spaces that promote meaningful dialogue with community members is not a "once-off" encounter, but rather a continuous exercise if effectiveness of any intervention with succeed.

Even though oral PrEP is a biomedical product that was initiated and developed in science-driven contexts, and proposed as a possible solution to a public health challenge (the HIV and AIDS epidemic), the involvement of community members at the introduction, implementation and integration level is critical. The inclusion of key population groups in the introduction, implementation and integration of biomedical products such as oral PrEP must be centralised in the HIV prevention cascade. Vulnerable population groups such as young women, and other vulnerable populations must be given the opportunity to engage in dialogue that will inform policy and provision related to oral PrEP in order for this HIV prevention technology to be effective at the community level.

The culture centered approach suggests that the effectiveness of oral PrEP for a particular marginalized community needs to be placed in the hands of the community members in conversation with healthcare stakeholders, and on the basis of evidence (Dutta, 2013). Therefore, it is important that local capacities for community participation towards scientific decision- making are developed. This is particularly important in South Africa where young women who form a vulnerable population group in the HIV and AIDS epidemic are contextualized in rural environments where they are often marginalized from implementation and policy-informing decisions.

This understanding suggests that as oral PrEP is being introduced, implemented and integrated in healthcare structures in South Africa, there is a need to develop mediums for community members and key healthcare stakeholders to engage in a reflexive

process through dialogue. This exercise has the potential to result in effective roll-out of oral PrEP as an HIV prevention method for vulnerable populations because those accessing oral PrEP and using it will have the opportunity to engage in a reflective process with key healthcare stakeholders. This can facilitate oral PrEP introduction, implementation and integration to be constantly enhanced to suite the cultural values and needs of a particular community. Taking this notion into consideration will result in context-specific interventions that will in effect serve the needs and values of a particular communities. The culture centered approach in essence proposes is that a blanket approach toward oral PrEP in SRH services cannot be adopted across several contexts.

Tenets of the culture centered approach

In trying to understand the culture centered approach, there are key characteristics about this theoretical framework that cannot be excluded from a conversation on the critical role of culture when theorising about health. These characteristics include; voice and dialogue; structure, context and space, values and criticism (Dutta, 2003). Figure 3.3 below offers a summary depiction of all the characteristics of the culture centered approach:

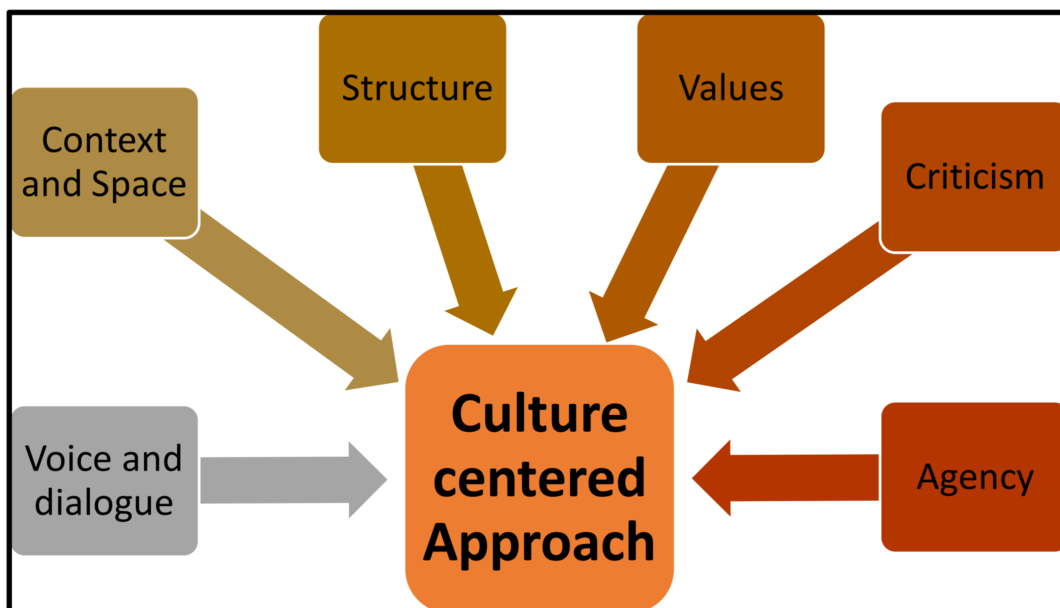


Figure 3.3: Tenets of the culture centered approach (Dutta, 2011)

The first characteristic of the culture centered approach is one that has been discussed above, and that is *voice and dialogue*. The culture centered approach seeks the recognition, and inclusion of the voices of local community members in social issues for the purpose of social change and development (Dutta, 2003). Central to this characteristics is that marginalised communities must be given the platform to engage in meaningful dialogue to define social challenges and develop possible solutions. In health related issues, this is critical in that this understanding eliminates the concept of having an external "expert" defining social challenges and proposing solutions for cultural members.

Voice refers to the articulation of views from community members, Dutta (2008) usually refer to the 'voices of the subaltern", which is the marginalised population group that usually has "no voice" in platforms where social change decisions are being made. The concept of voice speaks to the ability to actively make contribution to decision making in society through dialogue, it is the capacity of community members to express their views and opinions on issues that affect them. Moreover, the concept of voice and dialogue relate to those who are usually excluded from discursive spaces, and are marginalised. Being marginalised results in being silenced, even on issues that directly affect community members, being marginalised also speaks to being absent from the dominant discourse in society. Therefore, the culture centered approach privileges the voices of those who are usually marginalised from discursive spaces.

Campbell et al. (2009) argues that social spaces for critical thinking are important in the HIV and AIDS prevention landscape in South Africa. Their argument is that people do not lack information about HIV and AIDS prevention, but rather people often lack safe 'social spaces' where they through discussion, start to collectively look at ways in which they can use this information in their own lives, renegotiating individual and social norms that undermine their own and others' health and well-being (Campbell et al., 2009). With the recent licensure of oral PrEP and roll-out policy to inform oral PrEP introduction in SRH services, it is important that social spaces are created for people to engage in dialogue about challenges and opportunities in using oral PrEP. This will allow for community member to gradually taking ownership of medical facts about PrEP, airing any doubts, confusions or stigmatisation there may be. Moreover, it is

important that population groups that are the most vulnerable to HIV infection are given spaces to negotiate how biomedical interventions can be made available and accessible to them in effective ways.

Key population groups in the HIV and AIDS epidemic in South Africa for instance have in the past been excluded from decision-making, policy-informing dialogues even though they are at the centre of the epidemic. Instead, external “expert” stakeholders would be given platforms to engage in dialogue and make decisions about keep population groups. This over the years has proved to be inappropriate and plays a disadvantage in the HIV prevention agenda as it limits the voices of those who needs preventative measures.

The diagram below developed by Wilson and Neville (2009) depicts some key elements that can be adopted when creating space for dialogue with vulnerable populations. Researchers or external stakeholders must understand the vulnerable population group that they are interacting with is premised in traditions, values, epistemologies, worldviews, socio-cultural and historical politics that inform their health behavior, and their understanding of health related issues (Wilson and Neville, 2009). This requires that the researcher or external stakeholder to have a sense of humility, an attitude of listening and observing before talking, and having a willingness to consider and include aspirations and needs of the vulnerable population group in their protocol or policy developments (Wilson and Neville, 2009). The researcher must be conscious of the fact that the community members where research is facilitated, are people who have a particular worldview that is informed by traditions and social norms, of which are a product of historical, contemporary and political realities.

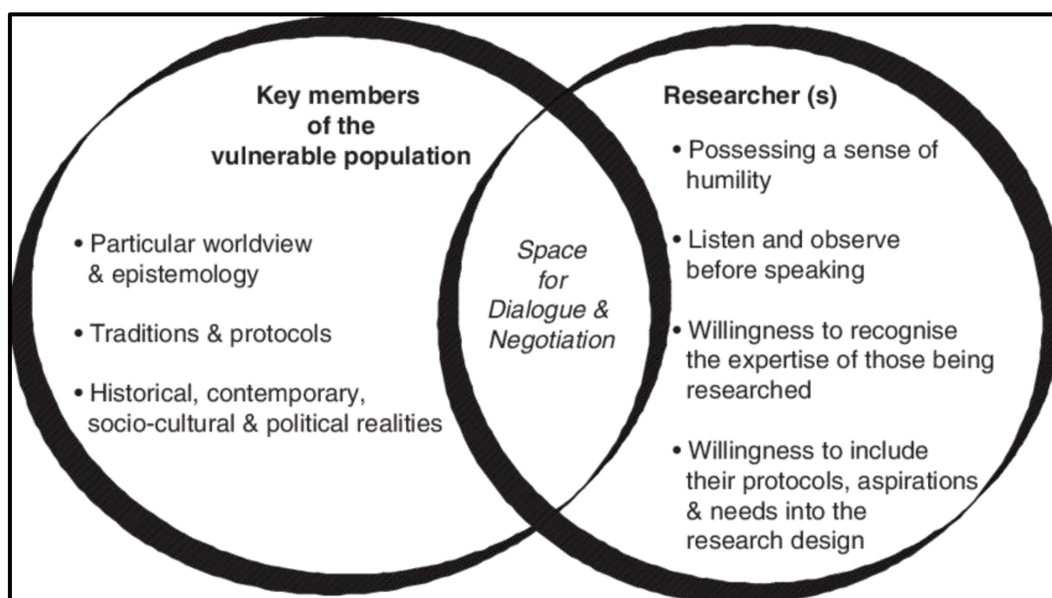


Figure 3 1: Creating the Space for Dialogue and Negotiation

Adapted from Wilson and Neville (2009)

Structures refer to organisations, systems and processes that determine how society is organised, how it functions, and how members of that community relate to one another through those structures. Structures within the HIV prevention cascade include policies, healthcare facilities, healthcare practitioners, community based organisation structures and the like. The HIV combination prevention approach proposed that in order to alleviate HIV and AIDS globally, a combination approach in addressing HIV prevention must be adopted. This approach highlights “structures” as one of the three pillars of combination prevention (UNAIDS, 2010).

Combination HIV prevention is an approach developed by the United States in the President’s Emergency Plan for AIDS Relief (PEPFAR), this approach proposes a combination of biomedical, behavioural, and structural interventions to meet the HIV prevention needs of community members for sustained impact. (UNAIDS, 2010).

> *Combination prevention programmes are: “...rights-based, evidence-informed, and community owned programmes that use a mix of biomedical, behavioural, and structural interventions, prioritized to meet the current HIV prevention needs of particular individuals and communities, so as to have the greatest sustained impact on reducing*

> *new infections. Well-designed combination prevention programmes are carefully tailored to national and local needs and conditions; focus resources on the mix of programmatic and policy actions required to address both immediate risks and underlying vulnerability; and they are thoughtfully planned and managed to operate synergistically and consistently on multiple levels (e.g. individual, relationship, community, society) and over an adequate period of time. They mobilize community, private sector, government and global resources in a collective undertaking; require and benefit from enhanced partnership and coordination; and they incorporate mechanisms for learning, capacity building and flexibility to permit continual improvement and adaptation to the changing environment."* (UNAIDS, 2010: 8)

It is evident from the statement above from UNAIDS that global structures are gaining recognition as key contributors to the HIV prevention cascade. Structure as highlighted earlier have the potential to enable people to enact agency concerning issues related to social or their health. Therefore, there is a level of priority that should be placed in making structures more enabling for community members to be agents of their own transformation even in the HIV and AIDS epidemic.

Empowering women and girls, as a key population group for example with the agency to claim their rights, receive quality education, giving access to resourceful healthcare facilities, and having access to accurate healthcare information for HIV prevention is an indispensable structural component in the combination prevention approach.
Structural interventions for HIV prevention among injecting drug users involves for example can be addressed by the creation of a policy allowing syringe and needle exchange (Des Jarlais, 2000). Syringe exchange and provision programmes, which are part of a larger harm reduction approach, are structural because they commonly require a shift in policy in contexts where this is illegal (Gupta et al., 2008).

Structures at the macro-level refer to policies, political actors, or corporations that influence structures at the micro level such as local clinics in communities (Dutta, 2011). An example of this tandem relationship would be the licensure of oral PrEP in South Africa. The South African Department of Health is working towards PrEP being

available for those people at high risk of HIV infection, the policy states that the integration of PrEP and T&T in SRH services is one of the main objectives in reducing the incidence of HIV infection (National Policy, 2016). Further, the policy emphasizes that while PrEP is a highly effective prevention method, it should be made available to key populations as part of a combination of HIV prevention tools and services. This structure at the macro level will directly affect structures at the micro levels i.e. SRH services delivering oral PrEP in local communities. The emphasis for the culture-centered approach is gaining a sense of understanding of these structure (which inhibit people from gaining access to health-related services) from the experience of the local members. A policy for instance may disregard the needs of people at the grass roots level, thereby creating structural barriers for people at the local level. The culture-centered approach suggests that in such a case, local members must be given a platform to be agents of their own transformation by raising social challenges and possible solutions.

By emphasising dialogue among community members, the culture centered approach creates a space where community members can share how structures within their communities constrain their agency, or enacts agency (Dutta, 2003). What this means is that structures have the capacity to constrain human agency or enact human agency. Therefore agency exits in relationship with structures, agency being made possible by structures. Dutta (2003) states that structures defines the limit of human action, and also create the opportunity for human agency (Dutta, 2003). The concept of structures will be discussed below with more relevance to health, and the healthcare-setting.

Figure 3.2: Combination prevention strategy

Adapted from Shepherd (2016)

The figure 3.2 above gives an example of a combination prevention strategy that is developed for young women between the ages of 15 to 24 from southern Africa. The various coloured shapes represent three different interventions; orange represents biomedical intervention, pink represents behavioural interventions and green represents structural interventions. This figure displays how the combination prevention strategy combines several structural, biomedical and behavioural interventions in order to provide context-specific HIV prevention measures. This strategy speaks to the need to develop interventions that address structural factors in every community because structures can either impede or facilitate access to healthcare that is needed by community members. Oral PrEP will be ineffective if structures are not in place to facilitate the accessibility of this biomedical intervention to young women who need it to protect themselves from HIV infection. The right policy's must be in place for young women to access oral PrEP, there must be

provision for healthcare structures that will facilitate the availability of oral PrEP to young women, there must be healthcare workers and other structures in place to make the introduction, implementation and integration of oral PrEP in SRH services effective for young women. Structures within the culture centered approach have an interconnected relationship with context and space (these are concepts that the culture centered approach centralises), structures usually function within local communities context and space.

Context and space in the culture centered approach refers to immediate surroundings, and local setting where cultural members are located (Dutta, 2003). These spaces are part of the everyday life that cultural members live, and make decisions. Localised contexts encompass how health meanings, health beliefs, health practices and health understanding are developed among community members. Local contexts include language, cultural practices, religious practices, and access to healthcare. Contexts are inclusive of the day to day experiences of local community members, these spaces influence and inform how cultural members make sense of health-related issues, and how they make sense of social issues.

Contexts are important when studying public health issues because interventions can only be effective when they have been developed in such a manner where they are contextually relevant. Health-related behaviour cannot be studied outside of an understanding of the context in which the behaviour is enacted. For instance adolescent girls and young women who are a key population group in the HIV and AIDS epidemic in South Africa are mostly located in contexts where they are faced with social and economic factors that contribute to their vulnerabilities (Mojola and Wamoyi, 2019). Recent years in the HIV prevention cascade, research has established hyper-epidemics where HIV incidence rates are disproportionately high compared to other settings (Kharsany et al., 2015, Shisana et al., 2014, Mojola and Wamoyi, 2019). Research suggests that carefully studying contexts where HIV prevalence rates are perpetually rising due to contextual factors is important in order to develop effective intervention to alleviate the hyper-epidemic[11].

[11] Settings with persistently high HIV incidence, and/or HIV prevalence exceeding 15% of the adult population. Mojola, S. A. & Wamoyi, J. 2019. Contextual drivers of HIV risk among young African women. *Journal of the International AIDS Society,* 22**,** e25302.

“The context specificity and dynamic nature of the social factors that can drive HIV risk and vulnerability requires that we gather adequate information about local situations in order to make recommendations about interventions that may have a meaningful impact on HIV epidemics” (Auerbach et al., 2011). Context are central factors in the HIV and AIDS epidemic, and intervention that aim to bring a halt to HIV prevalence rates in a particular population, must understand the contextual drivers of the intervention. Public health practitioners and researchers have often abandoned, or ignored, this social perspective, by ignoring the complexity and contexts where epidemics are imbedded does not make them go away.

Dutta (2008) is of the opinion that the health experiences of the marginalised communities are often located at the geographical margins of healthcare systems. In South Africa, rural communities are usually characterized by being isolated from large economic activities, having little or no health-related resources, unemployment, lack of sanitation and poverty (Rispel, 1992). It is these contextual characteristics that often place young women in vulnerable positions with little or no means to employ safe sex practices. Therefore, initiatives that aim to alleviate the HIV and AIDS epidemic will come about through a comprehensive HIV responses that include responses to contextual factors that affect HIV risk and vulnerability among key population groups.

The culture centered approach suggests that *values* are central in the manner in which community members define problems, social problems or health-related problems. The way in which something is seen as a problem depends on the lense that is being used, the problem is “never free from this cultural lense” (Dutta, 2003:64). The way in which we define a social or health problem is dependent on the lens through which we see it. West- centric values for instance promote weight loss for obese people, while many African and Asian cultures promote obesity as a sign of wealth and good health.

Cultural values not only lead us in what we define as problems, but they also help up develop possible solutions to those problems or challenges. Therefore ‘values” are an important characteristic of the culture centered approach to health. If values of a particular community are not understood, interventions that are developed and implemented in that community can sometimes be points of contestation in that people with different cultural values have different intentions and interests when solving a

particular social issue. In the context of health for example, a cultural community may reject the proposal of having condoms available for teenagers as an HIV prevention intervention because the community may see abstinence from sexual intercourse as the only option that teenagers must be offered for HIV prevention. Another example is the issue of obesity and weight control, cultural values influence body Image (Anderson et al., 1990, Liburd, 2003, Patt et al., 2002). While some cultures value the idea of being overweight, and see it positively, other cultures see it as a health threat. This means that healthcare practitioners or intervention experts must seek cultural competence when seeking to assist communities with health-related issues (Airhihenbuwa et al., 1995).

Criticism refers to the critical framework for interrogating the dominant paradigm, this is done by suggesting that we need to look at the values that inform the dominant paradigm. The culture centered approach is a critical framework for questioning dominant theories and practices that have been the driving force in the field of health communication.

The dominant paradigm is firstly critiqued for the assumption that "experts" have all the necessary tools and knowledge to examine the beliefs, values and practices of those "being researched", and as a result the "experts have the ability to develop solutions and interventions to help the "researched" (Dutta, 2008). These relationships based on the "researcher" and the "research" are predicted by who has the power, it is those who have power who can construct conceptual maps, investigate problems, and then develop possible solutions. Dutta (2008) refers to this as the "expert-object relationship", stating that this divide is often even geographical. For instance, most research and scholarship in health are centralised in Europe and the West world, and as a result interventions, champagnes are typically conceptualised, designed and implemented in the First Word and inherited by the Third World (Dutta, 2008).

The culture centered approach brings a critique that this power divide must be interrogated and revised if healthcare practitioners, policy makers, governments and other key stakeholders in the health field desire for community level effectiveness. There is a need to give marginalised communities the benefit of defining their own social problems, and giving them the platform to develop possible solutions that can be implemented for them.

Secondly, the dominant paradigm in health is rooted in the individual level focus when studying health (Airhihenbuwa, 2010). Western cultures value the study of health on the individual level with the understanding that any health problem or challenge can be located in the individual, and therefore any intervention or medical solution ought to focus on the individual in order for effectiveness. Theories and practices in health that place emphasis on the individual level may be effective and meaningful in Western contexts, but they are not relevant in African, Asian, Latin America and Caribbean, where social cohesion and family orientation is upheld (Obregon, 2000). Moreover, the HIV and AIDS epidemic has proved over the past three decades that health and illness are not located within the individual, but rather contextual factors have great contribution. Kippax and Stephenson (2016) argue in their book "Socialising the biomedical Turn in HIV prevention" that people are social beings, and people's health-related behaviour is a result of collective actions that become norms in a particular society. For example, in the 1980s and early 1990s condom use in the gay community was endorsed as a means of 'safe sex', and condoms were also used to demonstrate one's responsible behavior towards others and one's belonging to the gay community. Therefore, if condom use became the norm within a particular group, it may be difficult to engage in unprotected sex (Kippax and Stephenson, 2016). This is simply an example of how the individual-level bias that characterizes the dominant paradigm is limiting when developing interventions.

Moreover, Kippax and Stephenson (2016) strongly propose in their work that even HIV prevention is effective when grounded in communities, such as gay communities, social networks, and friendship groups. It is by working with collective agency that social practices are changed, that healthier and safer health related behavior is adopted.

There are debates that have come to question if the HIV and AIDS epidemic is a health issue or if it is a development issue, and this is because the epidemic has over the past decades displayed characteristics that go beyond the individual level (O. Airhihenbuwa, 2000, Airhihenbuwa et al., 2014)
Looking at the HIV prevention landscape, remarkable progress has been made in the expansion of biomedical HIV prevention technologies available to young women (Skovdal, 2019). However, the effectiveness of these biomedical interventions at the

community level is questionable as HIV prevalence rates are not decreasing as expected, and this is a result of neglecting the social and contextual factors that influence individual behavior change.

Agency refers to the ability of cultural members to actively participate in negotiating with the structures in which they find themselves, and to enact their choices (Dutta, 2008). In other words, agency refers to the concept of being able to meaningfully engage with the structures that can impede or facilitate access to health care, it also encompasses the ability of people to be able to have control over their choices in life, i.e. having access to HIV prevention, and therefore being able to take control of one's sexual health. Marginalized communities usually face challenges in practicing agency, being voiceless renders them unable to challenge the structures that impede their access to healthcare services. Therefore, agency becomes meaningful in relation to the structures that community members find themselves in. For instance, rural areas in South Africa are usually characterized by poverty, and limited healthcare resources, moreover the community members in these contexts do not have access to platform to question and challenge their lack of resources, this means that the community members in these contexts are limited in practicing agency.

Agency speaks to the ability of the cultural members to portray their preferences in the structures which they find themselves i.e. SRH services (Dutta, 2011).
Therefore, cultural members should be able to practice agency by challenging the structures that impede them from accessing healthcare resources, and ideally, structures should also provide platforms for community members to practice agency. For instance, even as oral PrEP is being made available in SRH services in South Africa, key population groups must be centralized in this process by giving them the agency to inform how these biomedical interventions are being introduced, implemented and integrated. Key population groups must be given the agency to enact what they believe is best for them, they must be included in a meaningful way at every stage of oral PrEP integration into SRH services.

Placing communities at the centre of research

The cardinal point of the culture centered approach to research strategies is the commitment to the articulation of the voices of cultural members and the emphasis on dialogue as an avenue for local members to make meaningful contribution toward knowledge creation (Dutta, 2008). The researcher becomes an active participant in the co-construction of knowledge with the participants.
The culture centered approach promotes the use of community-based participatory methods to research in addressing healthcare disparities by emphasizing the central role of the community in defining the health problem and corresponding health solutions

The theoretical framework in this study informed the methodology of this study. In this study, I adopted a participatory visual methodology (PVM) called journey mapping in a workshop setting. This participatory research method, draws upon the life experiences of local community members who are participants in the study to develop maps that portray their experiences about a particular phenomenon. PVM enables community members to define their own challenges through art-based methods of expression such as painting, drawing, drama creation etc. and express their own possible solutions to their problems. The significance of PVM is that it represents what would not have been easily expressed in words (Mitchell and Sommer, 2016). PVM gives participants the control in the research process by allowing them to generate data, present the data and also be involved in the analysis process. This in practice gives research participants a level of agency because they are not just seen as "objects" in the research process, but rather, they are seen as co-creators of knowledge.

This study sought to give the young women involved in this research the opportunity to share through dialogue and art what their experiences of accessing oral PrEP from the clinic was like, and from this make suggestion on how the SRH services can be improved for young women within their communities. I selected this methodology because participatory research is distinctly differentiated from conventional research in power dynamics. PVM sets out to diffuse the power imbalances between the "researcher" and the "researched", this approach invites participants to practically take

the research process into their own hands, develop the research data, be involved in the analysis process, and participate on how the data can be actioned to see practical social changes in their contexts.

The culture-centered approach prescribes that research must go beyond the involvement of the local community in the formative research step of defining a problem and developing potential solutions, but to also locate the locus of decision-making in the realm of the community (Dutta, 2008). This is done so that decision-making capacities are shifted into the hands of the community members. Therefore, researchers and healthcare stakeholders become resources that help build the capacities of the community toward achieving specific goals that are raised by community members. The community is seen as the appropriate owner of the problem configuration and the corresponding solutions (Dutta, 2011). Therefore, the motive is on creating platforms where the community members make decisions about possible solutions to social challenges.

Workshops form core elements of the culture-centered approach and are directed toward developing contextually relevant solutions through community participation (Dutta, 2018). The workshops include the broader community and ensure that key stakeholders are brought to the table in the development of solutions. Through the principles of dialogue, workshops are purposed to bringing to surface community voices in shaping the issues and agendas that are pertinent to the community. Whereas community workshops in many instances, constitute small groups of communities that are invited for the dialogues, other examples of community workshops involve open meetings where the entire community is invited for participation in the development and finalizing the possible solutions (Dutta, 2018).

This study places emphasis on the concept of vulnerable population groups, and therefore advocates that these groups be prioritized in the HIV prevention research agenda. However, research with vulnerable populations needs to be sensitive and considerate of the fact that this population group often experiences inequalities in their health experiences and health outcomes. More often, vulnerable population groups also experience being subjected to researcher's agenda when participating in research (Wilson and Neville, 2009). Hence why this study adopted a participatory

approach to working with young women, this approach facilitated an inclusive atmosphere because the young women were actively involved in the research process.

Vulnerable populations are exposed to risk when researched by those who belong to the dominant paradigm and experience privilege, unconsciously 'undermine' their traditions and social norms in a way that reinforces negative viewpoints or discrimination (Bishop, 2005, Smith, 2005). Research with vulnerable populations has been challenging and problematic, especially research brought by researchers with their own agendas. Therefore, this study sought to mobilize PVM in workshop settings, this fostered an environment of inclusion and cultural sensitivity through dialogue.

Wilson and Neville (2009) give a framework in their work on how to go about working with vulnerable population groups in research, they propose that the researcher must be aware of these principles and follow them if the research being conducted will be accommodative, sensitive, relevant and beneficial for the research participants. The principles underscoring this framework of working with vulnerable population groups are; partnership, participation, power and protection. These principles are always in a process of self-reflection, where the researcher reflects on their own world views and epistemologies influence understanding and interpretation.

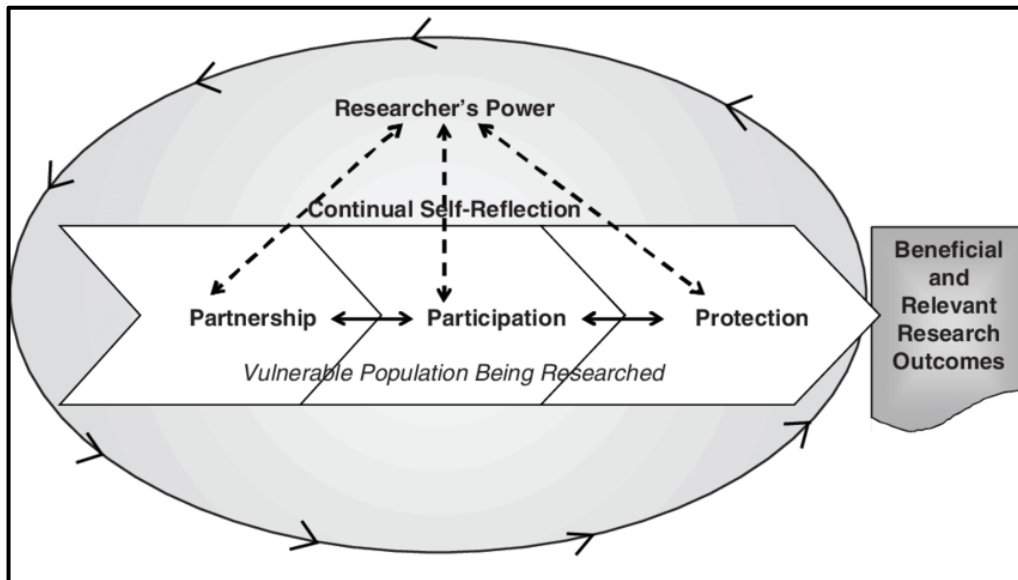


Figure 3.4: the 4 Ps of Research with Vulnerable Populations (Wilson and Neville, 2009)

Wilson and Neville (2009) propose the four "P's" that outline principles to follow to optimize the outcomes of the research be both beneficial and relevant for the vulnerable population being researched. These principles are closely related to those discussed above from the culture-centered approach. Partnership refers to researchers creating a space where the building of meaningful and ongoing relationships with those being researched can be established and maintained throughout the research process (Wilson and Neville, 2009). This concept is closely related to the core characteristics of the culture-centered approach which reinforce working "with" community members, as appose to working "on" community members.

The culture-centered approach is interested in creating community-academic partnerships that facilitate the participation of the community members in the definition of problems and solutions, and in the generation of knowledge (Dutta and Thaker, 2016). In health communication and health promotion, the culture-centered approach states that interventions are most effective when the origin of knowledge production is located in the community from which the intervention is designed for (Dutta and Thaker, 2016). The concept of partnership is also critical in the aspect of introducing biomedical interventions into a community, the community members need to be involved in a meaningful way, in the process of developing models of introduction and integration of a biomedical intervention. Those for whom the product has been

developed need to inform how these products can be made available in the most effective manner.

Participation on the other hand involves the meaningful inclusion of members of the vulnerable population in the planning phases of the research (Wilson and Neville, 2009). The concept of participation speaks to the idea of inclusiveness for the community members in the research process, and also in knowledge production. Community members must be placed not only in the center of the research, but they must also be given a platform to partner with researchers, or external stakeholders that promise to bring health related improvements. The culture centered approach prioritises creating processes and spaces where local voices can be heard and play an important role in developing solutions that are specific to the community needs (Dutta and Thaker, 2016). The research participants must be given the agency to actively engage in the research process so that they have a sense of ownership in research and possible health-related solutions within their communities.

The concept of protection entails safeguarding vulnerable populations from the potential for exploitation in the research process, this entails abiding in the necessary ethical principles in research.

Chapter five highlights all the ethical principles that were taken in this study, the chapter also explains some of the ethical dilemmas I faced when working with young women from both rural and urban areas who have been accessing oral PrEP. Researchers should take the responsibility of employing a 'power with' rather than a 'power over' approach (Wilson and Neville, 2009). This is exercised by the researcher by taking deliberate steps to melt away the walls of power that can make the research participants intimidated in the research process. Wilson and Neville (2009) emphasis this point by stating that researchers must be willing to engage in power sharing, which can be facilitated by the process of partnership and participation of vulnerable populations.

All these principles discussed above for working with vulnerable population groups are also prominent features in the culture-centered approach, they are premised in the notion that effective research must centered around marginalized population groups, allowing these groups to define the research agenda and actively participate in the

research process for effective social change, making them agents of their own transformation.

In the context of this study, the involvement of young women in the introduction and integration of oral PrEP in SRH services is critical. More so, it is important that we come to understand how the integration of oral PrEP can be effective for the key population groups that this intervention is designed for. Below is a diagram that depicts the interplay of three pillars from the culture-centered approach; structure, culture and agency.

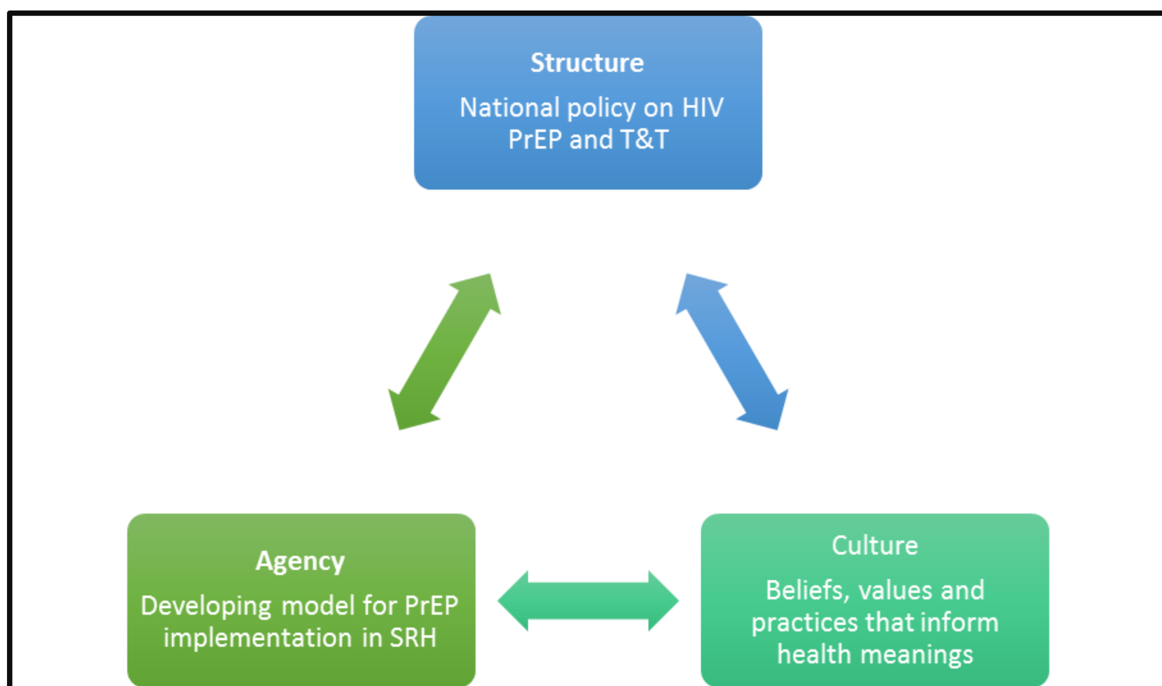


Figure 3.5: Interplay of structure, culture and agency

Adapted from Dutta (2011)

As figure 3.5 depicts, the culture-centered approach is built on three key concepts; structure, culture and agency. The intersection of these three concepts creates space for marginalized community members to be heard, breaking through into discursive spaces that interrogate impeding structures in marginalized settings. This interplay results in the co-creation of knowledge for research and policy informing decisions. It is the interplay of structure, culture and agency that results in marginalized communities.

The Culture Competency Approach in Public Health Care Services

Culture impacts health; therefore, health providers need to be aware of the cultural imprints among community members that can create challenges for healthcare providers. This is why cultural competence is important, it provides overall excellence in healthcare and health systems (Ihara, 2004). Public health providers need to have cultural insight and understanding in developing health interventions that will accommodate cultural issues without reinforcing any tradition of inequality or discrimination.

Cultural competency in health refers to the ability for health care systems to provide appropriate care for patients with diverse values, beliefs and behaviours, the goal is to meet the patient's social, cultural and linguistic needs (Betancourt et al., 2002). Kardong-Edgren and Campinha-Bacote (2008), on the other hand states that cultural competence in the healthcare setting refers to the process in which the healthcare providers continuously strives to work effectively within the cultural context of a client, individual, family and community. In concurrence, Giger and Davidhizar (2002) define cultural competence as a dynamic, fluid, continuous process where an individual, system, or health care agency has meaningful and useful care delivery based on the cultural heritage, beliefs, attitudes, and behaviours of people whom they provide healthcare care services. Therefore, cultural competence encompasses an array of processes, systems, attitudes, beliefs and provided services that accommodate and comply with the cultural contexts in which they are situated. The concept of cultural competence in this study makes reference to the ability of healthcare services such as SRH clinics to provide services that are sensitive to the cultural attributes of the community it serves. We study the SRH services as a structure where community member's access health services for HIV prevention. Cultural competence is also conceptualised in this study as the proficiency of healthcare providers to relate with clients in a culturally sensitive manner, this is inclusive of linguistic ability to communication.

Calzada and Suarez-Balcazar (2014), proposed a model of cultural competency which outlines how health care facilities (structures) and service providers can become more culturally competent. Within this model, cultural competence at the organisational level

promotes ongoing awareness and skills development among staff which in turn will facilitate the delivery of culturally appropriate services and programs that serve the needs of patients (Calzada and Suarez-Balcazar, 2014). The culture competency approach assists in understanding how structures as explained by (Dutta) can become appropriate for patients from various cultural backgrounds, and within this study, SRH services are the structures that need to be aligned with young women's socio-cultural needs in order to facilitate effective roll-out of oral PrEP. Furthermore, cultural competence in SRH services will afford young women's values, beliefs and behaviours to be considered when making oral PrEP available, which will most likely result in acceptance, uptake and adherence to the biomedical product.

The cultural competency approach provides enlightenment on the concept of "structure" as proposed by Dutta (2011) which is the locus of this study. The word "culture" is used in this study is inclusive of the pattern of human behaviour which includes thoughts, social norms, customs, actions, beliefs and values. the word "competence" is used because it implies having the capacity to function well, therefore a culturally competent system acknowledges and incorporates the critical role of culture.

Cultural competence in SRH services

Terms such as 'culturally competent' or 'culturally appropriate' health care have emerged in a popular manner as an umbrella concept that recognise the importance of health-care facilities, healthcare services and healthcare workers being sensitive to the disparities of health status in the quality of health care experiences between social class, racial and ethnic groups (Lupton, 2012). These terms are usually raised to bring awareness and overcome inequalities and disparities experiences across ethnic groups, racial groups and social classes (Lupton, 2012).

The NDoH operational guidelines for HIV, STI, and TB programmes in South Africa, for key populations recognises the need for healthcare provider training in sensitisation in order to better support public healthcare services and adolescent friendly services for priority populations (SANAC, 2017). Both the services provided in primary

healthcare clinics, and the actual structure where people access health care treatment, and care need to be aligned to the social and cultural needs of the community. There is a need for the structure and services provided in the structure to be culturally competent so that the local community members can benefit maximally from the services provided for them. The NDoH operational guidelines recognise this and therefore commit to training healthcare providers to be proficient in serving community members.

Campinha-Bacote (2002) writes about the delivering healthcare services in a manner that displays cultural competence, in his work, he emphasises that cultural competence is an on-going process in which the healthcare provider always strives towards with the aim of effectively working within the context of the client (individual, family and community). *The Process of Cultural competence in the Delivery of Healthcare Services* proposed by Campinha-Bacote (2002) is a model that views cultural competence as a progressive process, the model requires that the healthcare providers view themselves as becoming culturally competent, and not having already attained cultural competence. This concept is important because it encourages healthcare providers with an attitude of continuous learning towards the social and cultural contexts where they are serving.

There are five main assumptions of *The Process of Cultural competence in the Delivery of Healthcare Services Model* (Campinha-Bacote, 2002): (1) Cultural competence is a process, not an event; (2) Cultural competence consists of five constructs: Cultural awareness, cultural knowledge, cultural skill, cultural encounters, and cultural desire; (3) There is more variation within ethnic groups than across ethnic groups; (4) There is a direct relationship between the level of competence of healthcare providers and their ability to provide culturally response health care services; (5) Cultural competence is an important component in rendering effective and culturally responsive services to culturally and ethnically diverse clients.
Important to note here is the fact that cultural competence cannot simply be achieved through training, or any once-off activity, but rather it is a continuous process that the healthcare provider should strive to engage.

Within this model, cultural awareness refers to the process of self-examination and exploration into ones cultural and professional background (Campinha-Bacote, 2002). It is important that the healthcare provider is aware of their own cultural orientation so that they are aware that this can influence their understanding of other cultures. This causes the healthcare providers to be sensitive to any bias or discrimination that they may unconsciously relay to people outside of their cultural orientation. Cultural awareness involves recognition of one's biases, prejudices and assumptions about others (Campinha-Bacote, 2002). When a healthcare provider is not aware of their own cultural and professional values, they risk imposing their beliefs, values and behaviour on others i.e. a patient receiving counselling and treatment (Campinha-Bacote, 2002).

Cultural knowledge on the other hand is the process of obtaining knowledge about diverse cultural groups or more specifically the cultural group that they are serving (Campinha-Bacote, 2002). Gaining this understanding of patients' health related beliefs and values also entails considering their world views. The patient's world views will explain how they makes sense of illness and how it guides their seeking for medical care. This becomes essential when giving diagnosis, explaining health-related issues, explaining illness and wellness to patients. Worldviews influence people's values, and values in turn lead people to understand health and illness differently, while some cultures may attribute obesity as a health-risk, other cultures may view this as wellness. Therefore, healthcare providers must understand the cultural orientation of the community in which they are serving in order to share health-related information effectively. This notion is critical in the HIV prevention landscape in South Africa, as oral PrEP becomes available in SRH services, there is a need for healthcare providers to understand the cultural orientation of populations that are accessing the biomedical HIV prevention method so that they are able to effectively communicate the importance of uptake, acceptance and adherence to oral PrEP. If the healthcare practitioners fail to understand the cultural orientation of the population groups accessing HIV prevention methods in the clinics, then there may be failure to encourage uptake, acceptance adherence to oral PrEP by those and substantial risk of HIV infection.

Cultural skill refers to the ability to collect data concerning the patients, part of this includes being able to perform a cultural assessment (Campinha-Bacote, 2002). This is the ability of healthcare providers to get access to useful information about the cultural orientation of patients that come to access health services.
Cultural encounters on the other hand refer to the process where the healthcare provider deliberately engages in cross-cultural interactions with clients from diverse backgrounds (Kardong-Edgren and Campinha-Bacote, 2008), however, healthcare providers should be aware that interactions with two or three persons from a cultural does not make them an expert in that culture. It could even be possible that those individuals do not represent their cultural values and beliefs because of intra-culture variation, this is why cultural competence needs to be viewed as a continuous process.

Cultural desire is the motivation that the healthcare workers have to want to engage in becoming culturally competent. Healthcare workers must have a desire for cultural componence, rather than doing it by obligation, they must have a genuine care about wanting to know and understand the cultural and contextual background of those they are assisting (Campinha-Bacote, 2002). The healthcare providers must desire to attain cultural knowledge, cultural awareness, and cultural skill and also desire to engage in cultural encounters. Campinha-Bacote (2002) states that within this model, these five constructs have an interdependent relationship with each other, therefore all these constructs must be experienced by the healthcare provider in order for healthcare services provided to be culturally competent. The figure below provides a visual description of the interplay of the five constructs, the process of cultural competence in healthcare delivery.

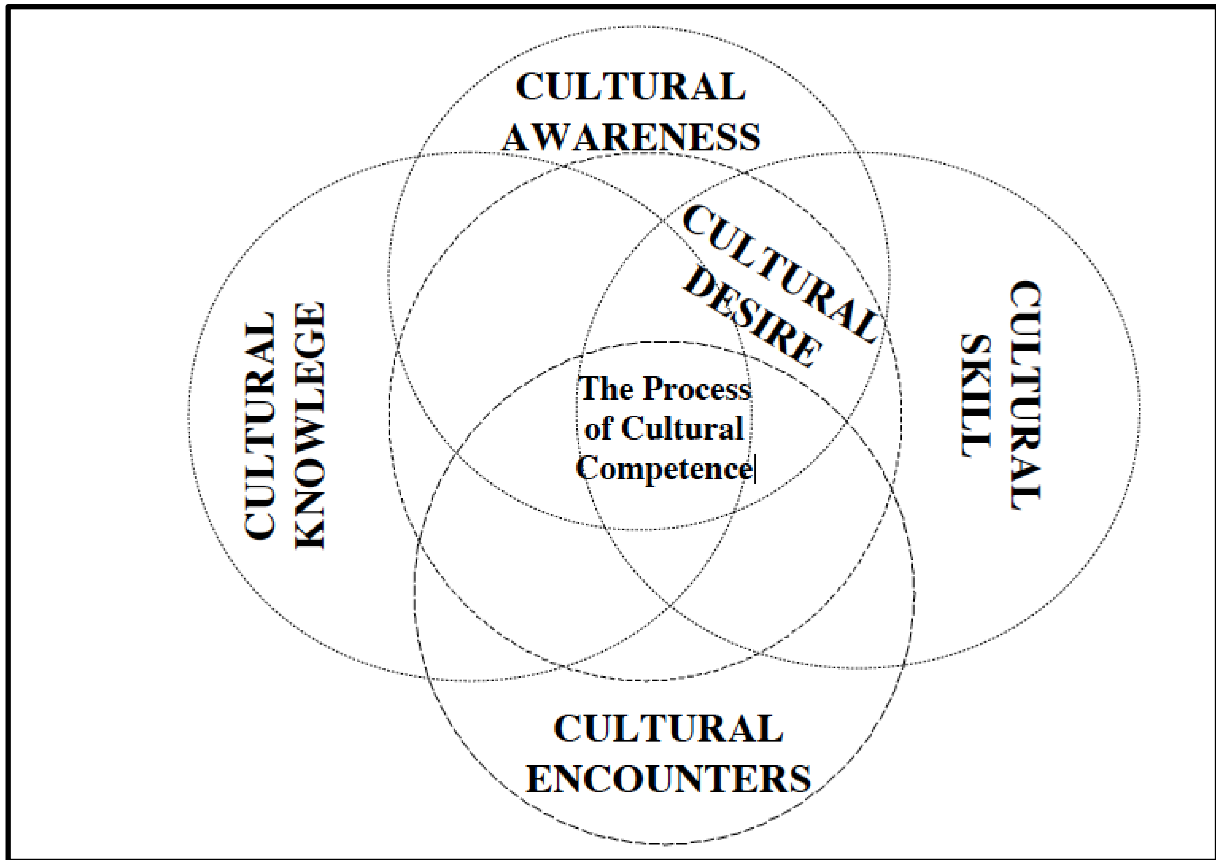


Figure 3.6: The process of cultural competence in the delivery of healthcare services (Campinha-Bacote, 2002)

A systematic review was conducted by Betancourt et al. (2002) exploring sociocultural barriers to healthcare, and cultural competence efforts that address these barriers. The study identified barriers to healthcare on several levels; organisational (leadership), structural (process of care), and clinical (healthcare provider and patient encounters). Clinical barriers have to do with interaction between the healthcare provider and patient, these barriers occur when there are sociocultural differences between the healthcare provider and the patient. These differences may be based on beliefs relating to medical practices, understanding of illness and diseases, attitudes towards medical care and levels of trust in doctors or nurses (Betancourt et al., 2002). For instance if a patient believes that having multiple concurrent sexual partners is a normal social practice which is reinforced by their cultural orientation, then the healthcare provider will need insight into the cultural values of the patient that inform their views about have multiple concurrent sexual partners so that they can effectively inform the patient about the health risk involved in their sexual behaviour. Furthermore, this study found that communication between the patient and healthcare provider has

a direct link to patient satisfaction, adherence to treatment or medication and therefore the patients overall health outcomes (Betancourt et al., 2002). Communication between healthcare providers and patience then becomes a critical aspect in the healthcare encounter.

In the healthcare context, healthcare providers and the patients they are seeking to assist must make sense of each other's meanings and assumptions related to health so that meaning is not lost. Healthcare providers often find that their patients come to access health services with beliefs and concepts about their illness from their own culturally informed views that are incongruent with medical understandings (Lupton, 1994). This then underscores the need for healthcare providers to be culturally competent, by having knowledge and understanding of the cultural orientation of their patience in order to help patience effectively.

Clinical barriers arise when patients experiences challenges in accessing healthcare due to complex, underfunded systems of care (Betancourt et al., 2002). Cultural competence interventions intended to address structural barriers focus on ensuring culturally and linguistically appropriate health education materials, improving the medical referral process (Betancourt et al., 2002). However, structural barriers encompass more than language relate issues, but also the design, and functioning of the healthcare system, including; the intake process, waiting period for appointments, referral methods, and continuity of care. This is an important aspect in this current study, as one of the research questions explores how the SRH services as structures that are culturally competent.

Conclusion

Culture plays a significant role in an individuals' understanding of health, wellness and illness, culture shapes patients' personal beliefs towards illness, and therefore their health behaviors too. Culture also influences healthcare delivery, clinical communication and the patient-physician expected relationship. If any health-related intervention seeks to be effective in any community it targets, then concepts of the

culture-centered approach must be considered; voice and dialogue, structure, culture, agency, and criticism in order for that intervention to be culturally competent.

To reach a point where health-related interventions are successful in communities, community members must be centralized in the process of defining the social challenges and possible solutions towards those challenges. Community members must be empowered by giving them the right to be agents of their own transformation, practicing agency. In this chapter, I have proposed the emphasis of cultural members' voices being heard by providing platforms for meaningful dialogue concerning health challenges and possible solutions.

The integration of oral PrEP in SRH services will call for the voices of key population groups in the HIV and AIDS epidemic to inform oral PrEP introduction, implementation and integration. It is these population groups that face greatest vulnerabilities in the epidemic and must therefore be prioritized and given platforms to express what they believe increases their vulnerability and inform how these vulnerabilities can be addressed. Oral PrEP as a biomedical intervention must be implemented and integrated in healthcare services in communities in ways that will be consistent with the cultural and contextual needs of community members.

Moreover, healthcare workers and the structures in which they operate must show cultural competence in order for community members to respond to the offered services positively. What this means for oral PrEP integration into SRH services in South Africa, is that in order for adherence to be encouraged among young women, healthcare workers and the SRH services must be culturally competent.

There are several examples of successful interventions that have considered culture as an important factor, but future interventions must continue to incorporate cultural elements in a way that will result in structures that are culturally relevant in communities. Even the introduction of biomedical interventions must consider social environments as well as the organizational culture of the healthcare system and community members' beliefs and attitudes. Researchers alike must be sensitive to the concept of culture when conducting research by recognizing and appreciating the significant role that culture plays when facilitating.

Chapter Four: Methodological Framework

"the gendered, multiculturally situated researcher approaches the world with a set of ideas, a framework (theory, ontology) that specifies a set of questions (epistemology) that he or she then examines in specific ways (methodology, analysis)…Every researcher speaks from within a distinct interpretive community that configures, in its special way, the multicultural, gendered components of the research act (Denzin and Lincoln, 2011:21).

Introduction

This study elicits the views of South African women previously involved in a demonstration project called CAPRISA084 that set out to assess the feasibility, acceptability, uptake and patterns of use of daily oral pre-exposure prophylaxis (PrEP) (tenofovir disoproxil fumarate + emtricitabine) as part of sexual and reproductive healthcare (SRH) services to young women and men at risk of acquiring HIV in urban and rural KwaZulu-Natal.

This study explores the attitudes, preference and acceptance levels of African young women towards oral PrEP, as well as views on how oral PrEP can be integrated into the already existing SRH services for young black women in KwaZulu-Natal South Africa. Based on Interpretive Social Science (ISS) paradigm, this research is premised on the belief that people acquire meaning in a social context, and that context influences how people make meaning of the world. Furthermore, the philosophy that guides ISS believes that social reality is what people perceive it to be, it exists as people experience it and give it meaning. The ISS provides an interpretive explanation of people's social reality by revealing the meanings, values, attitudes and rules of daily living (Neuman, 2003).

In this chapter, I critically discuss the ontological and epistemological values that inform this study. As a scholar in the Social Sciences, my methodological perspectives are premised within this discipline which utilises empirical methods that explain the causality of events (Janesick, 1994). This method can be expressed in either a

quantitative or qualitative design This study was guided by a qualitative research design, which gives emphasis to understanding social phenomena through direct observation, communication with participants, or analysis of texts, and may stress contextual and subjective accuracy over generalisability (Denzin and Lincoln, 2011, Neuman, 2011, Bless et al., 2006, Struwig and Stead, 2013). Therefore the findings in this study cannot be generalised, nor can they be said to be a reflection of a larger population group from a different context.

In previous chapters, I offer a critical discussion on how the HIV and AIDS epidemic is not exclusively a health challenge, but it is also a social phenomenon that requires multidisciplinary approaches to search for ways in which this epidemic can be alleviated. HIV and AIDS is a social and development challenge that calls for context-specific methods of research, where appropriate research methods for each setting are employed (Alali, 2014). Methodological soundness in this study is not complete without considering the key population group, their social setting, their interaction with the healthcare facilities and the socio-cultural variables that influence their health-related behaviors. HIV and AIDS research in Africa has not seen enough advancements in addressing the epidemic, and the number of AIDS-related deaths counted annually demonstrates this. There have been debates regarding the appropriateness of research methods used in Africa, perhaps researchers have not explored the right methodologies (Alali, 1997). The HIV and AIDS epidemic is a multifaceted social and development challenge, and in some cases, conventional research methodologies may not be sufficient when making inquiries into this epidemic. Therefore, this study proposes that a participatory approach is more appropriate when making inquiries on complex social issues since it accommodates reflexivity and flexibility.

This research is positioned in cultural studies and development communication. As a researcher, I am interested in the lived experiences of my research population group. Consequently, I relate with the research participants as co-creators of knowledge and not necessarily objects in the research process. This study argues that participatory approaches to research are more appropriate when working with young people and exploring sensitive or complex topics such as HIV and AIDS. Participatory methodology has emerged as a paradigm in its own right, advocating that people

cannot be engaged by consciousness and knowledge other than their own (Loewenson et al., 2014). Cultural studies has been informed by an interest in emancipation, equity and democracy, and also driven by attempts to radically contextualize cultural processes (Flick, 2013). The cultural studies approach has informed the participatory investigations into the following research questions;

1. In what ways is the current structure and organization of SRH services an impending or facilitating environment for young women assessing biomedical products?

2. What are the likely socio-cultural challenges or opportunities that will influence acceptance, uptake and adherence of oral PrEP in SRH services among young South African women in KZN?

3. In what ways can the current structure and organization of SRH services be realigned to meet the needs of young women in order to ensure acceptance, immediate uptake and adherence to oral PrEP?

The idea is to generate empirical data that will assist in facilitating the integration of oral PrEP in SRH services that is representative of the localized and cultural context in which these services will be offered. This study has made use of this stance through participatory research with young women to generate knowledge that is to inform the integration of PrEP in ways that account for their cultural values. Gaining insight into young women's perceptions on the social and cultural factors that can work as barriers or enablers to accessing PrEP in SRH services, as the this study sought to do, will be a significant initial step to the realization of this objective.

This study draws principles from participatory research with methods to review and validate the experiences of those directly involved in issues studied to learn from experiences. The research design of this study is premised in phenomenology. The phenomenological approach provides a rich and complete description of human experiences and meanings (Creswell et al., 2007). The phenomenological approach aims to develop a complete, accurate, clear description and understanding of particular human experience or an experiential moment (Flick, 2014, Creswell et al., 2007). This normally entails gathering "deep" information through interviews,

discussions and participant observations with individuals sharing their perspectives on a phenomenon (Lester, 1999). "Phenomenological studies are highly dependent on individuals. Individuals, either through interviews or their cultural products, i.e. what they write, paint, etc., are used to draw out the experiences of a particular phenomenon" p122 (O'leary, 2004). This chapter outlines the research methodology employed to address the above objectives and execution of the proposed research inquiry. The table below provides an outline of the methodological map followed in this study:

Ontological Assumption	Nominalist
Epistemological Assumption	Interpretive Social Science (ISS)
Research Approach	Qualitative
Research Design	Participatory research
Selection of participants	Non-probability Sampling Purposive sampling
Data Collection	Journey mapping workshops In-depth Interviews
Data Analysis	Thematic Analysis

Table 4.1: Methodological map

Epistemological and ontological underpinnings

All scientific inquiry rests on assumptions and principles that guide the researcher, whether the researcher acknowledges it or not, the research that they conduct is influenced by specific assumptions that influence how they make scientific inquiry and how they make sense of their findings (Neuman, 2011, Della Porta and Keating, 2008). Competing approaches in social science differ in their ontological base and

epistemological base. The importance of defining and clearly outlining the methodology in any study is that the researcher establishes the philosophy behind the chosen methods utilized in their study. Della Porta and Keating (2008) state that methods are the ways in which data is collected, while methodology refers to the way in which methods are used and the justification of making use of those methods.

The ontological roots in this research is referred to as the nominalist stance, which states that our experience of the world (physical and social) is shaped and determined by our social and cultural interpretations (Neuman, 2011). Ontology refers to the philosophy of what exists; it is concerned with the nature of being, whereas epistemology is the understanding of how we know the world around us, how people come to understand reality (Neuman, 2011). According to the nominalist stance, subjective cultural beliefs determine how we experience our day to day encounters and how we define reality and truth. It is through this lens that I will be making an inquiry of young women's experiences of accessing oral PrEP in SRH services in KwaZulu-Natal.

This study is premised in ISS. Neuman (2011), defines ISS as an approach towards natural science that believes that people acquire meaning in a social context, and this context influences how people make sense of the world. ISS states that social reality is what people perceive it to be, it exists as people experience it and give it meaning. Furthermore, ISS provides an interpretive explanation of people's social reality by revealing the meanings, values, attitudes and what influences their of daily living (Neuman, 2011). This approach to research is appropriate for this study because the inquiry seeks to understand the attitudes, preference and acceptance levels of young women towards oral PrEP, as well as investigate how oral PrEP can be integrated into the already existing SRH services for young black women in rural and urban contexts. Crotty (1998) elucidates that within ISS, the researcher is concerned with the culturally derived and historically situated interpretations of the social world. This definition emphasises the philosophical foundation of this thesis which makes an inquiry into the cultural and social factors that influence women's conceptualisation of oral PrEP within SRH services.

Qualitative Research

This research deals with subjective variables such as attitudes, preferences, perceptions and notions from several women from different backgrounds. On this account, it is appropriate to utilize qualitative methods of research. Janesick (1994) argues that a researcher must first ask themselves “what do I want to know in this study?” before choosing the most appropriate methodology, in other words, one cannot simply want to conduct a qualitative study without a question. Qualitative researchers must design their studies with particular people in mind, with social issues in mind, and must to some degree prepare themselves to be exposed to the social setting under inquiry so that they understand the study population’s social setting (Janesick, 1994). There are several definitions of qualitative research, most of which share similarities, in this study the working definition of qualitative research is:

> *Qualitative research is a form of long-term first-hand observation conducted in close proximity to the phenomena under study. The research is, ideally, performed in a naturalistic setting with emphasis on everyday behaviour and is often descriptive in nature*.
> (Jankowski and Wester, 1990:44)

The social context of the phenomenon under investigation is significant in qualitative research; in qualitative research, the researcher is not only concerned with the data collected, but also with the context in which the data is collected. This study employed qualitative methods of research to collect in-depth data on female perceptions towards the integration of oral PrEP into SRH services to find out what are the social and cultural barriers or enablers that young women could face in accessing oral PrEP.

The research design is critical in any study, research design can be understood as the bridge between the research questions and the execution of the research, it is the map and plan that the researcher adopts in an attempt to address a set of objectives and questions (Durrheim, 1999). The qualitative research design that I have developed for this study must be understood in view of the research questions and the people it involves. Firstly, the inquiry at hand is interested in young women within the South African, rural and urban KZN setting. To some degree this population can be

categorized as marginalized. In the literature review I discuss how young women in the South African (especially rural) setting are a key population in the HIV and AIDS epidemic. Young women are one of the most vulnerable groups in the epidemic (Mayer and Allan-Blitz, 2019b). Secondly, I make an inquiry into healthcare systems positioned in social settings where people access basic healthcare needs. Thirdly, this research explores perceptions, attitudes and acceptance levels toward biomedical interventions. It is therefore important that the research design considers spatial, and socio-cultural context.

Significance of qualitative research: Cultural Studies and Social Change Communication

> *"Participatory communication in research implies, at the most basic level, that researchers are not solely responsible for generating the research or communicating about it. Research participants, local citizens, or those traditionally referred to as 'the researched' are able to participate in creating and expressing their own knowledge and, in so doing, empowering themselves to effect social, political, economic, and cultural change that is appropriate for them"*

(Cornish and Dunn, 2009:666)

Experience is central to cultural studies (Pickering, 2008). What this means is that exploring the experiences of people and how they have made sense of these experiences, is important in cultural studies. Furthermore, Pickering (2008) states that experience is a key category of analysis within cultural studies, and has also become a recognised dimension of research practice. As highlighted in the quotation above from Cornish and Dunn (2009), the research participants must participate and create their own knowledge.

When talking about 'lived' experience, it is important to note that experience always involves interpretation of what happens in life, this is influenced by our perceptions, feelings, and actions, this then makes the issue of "experience" complex (Winter, 2014). This was a key consideration for me as a researcher who sought to understand

young women's experiences in accessing an HIV prevention interventions in SRH services. In chapter five, I explain in more detail how I worked around the issues of experiences being subjective, making meaning and understanding what the young women were portraying in the workshops and interviews. Cultural studies also reveals that research questions, and methods are influenced by social, political and historical contexts (Winter, 2014). The knowledge gained in the research process is therefore localised and context specific, in such a way that the same study can yield different data, and experiences reported on reality. This then calls the researcher to be critical in the analysis process and in conceptualising the data collection.

The process of research is usually one of dialogue, but this does not mean that cultural studies researchers should assume that knowledge simply derives from experience or that experience simply validates what is said (Pickering, 2008). While it is important to respect what participants report on and share, this is only one-sided. The other side is that the researcher must bring balance by critically engaging the kind of evidence given and how this evidence relates to the structural location of the research subject (Pickering, 2008). In this study, the matter of "rurality" and "urban" was explored before going into the research sites because, it is within these context that young women who were part of this study are situated. Therefore, as a researcher, it is critical to know and understand that experience must be examined critically. As highlighted in the quotation in the previous section by Cornish and Dunn (2012), participatory communication entails researchers collaborating with research participants in the process of knowledge production. So while participants provide in-depth reflections on their experiences, the researcher collaborates by interrogating and studying what is being proposed by the participants to make sense of the data collected. From this we can see that one of the distinguishing features of cultural studies is its focus on subjective aspects of social relation.

The emergence of participatory research

This study borrows methodological principles from participatory research (PR). PR has a variety of practices which has led to several labels, some prefer "praxis research", or "action research", or "collaborative research", or "activist research", or "participatory action research", or "participatory research" (Stoecker and Bonacich, 1992). While all

these names may sound different they all hinge on the same fundamental values. As Stoecker and Bonacich (1992) state in their work, PR has two basic aims; the first aim is democratisation of knowledge creation, simply put this refers to the process of actively involving people in communities who usually “do not have a voice” in defining their social challenges and also contributing to possible solutions to their social challenges (Stoecker and Bonacich, 1992, Wright et al., 2018). The democratisation of knowledge also includes engaging people from oppressed communities in the research processes which are usually conducted by external stockholders. In effect, this places those who are usually marginalised in spaces where they can make meaningful contributions to research that is conducted in their social spaces. Stoecker and Bonacich (1992) also highlight that this kind of knowledge production is linked to empowerment, not only are the marginalised involved in the research process, but they are empowered through the research process.

The second aim of PR is social change (Stoecker and Bonacich, 1992). The democratisation of knowledge must then result in practical social change, as the marginalised (powerless) grow in knowledge production, there must be tangible social changes that enhance social living. PR is guided by a political and social change perspective which will lead to breaking inequality and result in a restructuring of society that will enhance social justice (Wright et al., 2018, Aldridge, 2016, Chevalier and Buckles, 2013). In the HIV and AIDS field, women have played a critical role in both prevention and treatment, whilst they have also been emphasised as a vulnerable group in the epidemic (Tallis, 2012). There has been a great emphasis on young women being a vulnerable population group within the HIV and AIDS epidemic in South Africa, placing them at the centre of the HIV and AIDS response. However, the persistent incidents rates of HIV among women show that more needs to be done in involving women. Women who are most vulnerable to the epidemic must be identified and involved in HIV and AIDS research in a more meaningful way. In this study, I included young women as co-creators of knowledge in the research process by adopting a PR stance. This means moving away from the notion of conducting research “on” participants to conducting research “with” participants. This was achieved this through an interactive process which is discussed further in the next sections in this chapter.

The aim of participatory research methodology is to empower participants to take action in improving conditions in their lives and communities (Parker, 2006). PR emphasizes a “bottom-up” approach that aims to prioritize the locally defined social challenges (Cornwall and Jewkes, 1995). The driving element in PR is the involvement of local community members in the research process, allowing these community members to gain a sense of agency. The involvement of community members needs to result in transformative learning which refers to the way people see the world, and how they see themselves (Mezirow, 1990).

One of the strengths that PR is known to have is in exploring local knowledge and perceptions (Cornwall and Jewkes, 1995). This was a central point for me in this research process, the young women involved in this study were invited to contribute to this research because I sought to understand the local knowledge and perceptions of these young women towards oral PrEP as a new HIV prevention intervention. Participatory research is usually characterised by interactive, reflexive and flexible processes, in contrast to the rigid and linear processes in conventional research (Wright et al., 2018). Participatory methods in research enabled the young woman to define their own social challenges and develop their own possible solutions in the context of a workshop.

While conventional research usually focuses on generating knowledge for understanding, PR focus on knowledge for action (Cornwall and Jewkes, 1995). Characteristics of PR include; participation, addressing practical problems, generation of knowledge and enacting change. Moreover, PR is distinctly differentiated from conventional research in power dynamics within the research process, the explicit aim of PR is to empower people who are usually powerless, poor, or marginalised in society to bring about needed social change (Wright et al., 2018, Baum et al., 2006).
In this study, the research participants are young women, as argued previously, this population group within the HIV and AIDS epidemic have been identified as a vulnerable group that needs to be empowered. Tallis (2012) states: “AIDS moves far beyond being simply a ‘disease’, necessitating more than a public health response…demanding our responses to be up to the challenges posed, beyond a simple health approach and to address multiple and complex inequalities”. It is in this context that this study makes an inquiry into women’s perceptions towards HIV

prevention technologies that have the potential to empower young women. One of the objectives of this study includes exploring SRH services, this makes the research methodology more appropriate because health care systems are social institutions that reflect inequalities, and can also confront inequalities (Loewenson et al., 2014). Healthcare systems can facilitate social empowerment through the involvement of marginalised and vulnerable groups in decision making.

Three approaches to participatory research inquiry

In his work, Reason (1994) explores three approaches to participatory research; *co-operative inquiry, participatory research and action inquiry*. These three approaches stand together in contrast to orthodox research that is characterised by a narrow world view which monopolises “knowledge” to an elite few, the “privileged” so to be. At the same time, these three approaches emphasise different aspects of participatory research. For the purpose of this study, I will discuss these three approaches so as to bring out the principles of participatory inquiry that this research adopted. Thus study adopted principles from these approaches.

Co-operative inquiry:

The co-operative inquiry comes from humanistic psychology which promotes the idea that people can choose the way they live without being conditioned by restrictive social influence, emphasising free-will and positive human potential (Reason, 1994). The advocate of co-operative inquiry was John Heron, who stated that orthodox research utilises inadequate methods for the study of people because people are (to some degree) self-determining (1971; see also Heron, 1981, reason, 1988). Heron suggested in his work that orthodox social science research excludes the recognition that people have the ability to think, and exclusively make their decisions without external influences, therefore this orthodox stance treats people as less than self-determining. Reason (1994) postulated that for this approach, the researcher can facilitate research on people in an appropriate manner when they address persons as self-determining. Therefore, in co-inquiry, all those involved in the research are seen as co-researchers contributing to the generation of knowledge, designing and managing the research and drawing conclusions. People involved in the research are

also seen as “co- subjects” actively participating in the research (Reason, 1994). Co-operative inquiry argues to be a valid approach to conducting research on people because it emphasises “a collaborative encounter”. Research participants’ experiences are highly valued.

Participatory Action Research:

Participatory action research (PAR) is perhaps the most widely recognised of the three approaches discussed in this section. PAR is important because it emphasises the political aspect of knowledge creation. While there are several communities of PAR, the key principles of this approach are what follows. Since the term “action research” was coined by Kurt Lewin in the 1940’s participatory research has used social science to advance this process of “action”. Fals-Borda and Rahman (1991) place the roots of PAR in liberalist movements which strived for radical transformation in society. The essence of PAR is to “awaken and enlighten common peoples”, therefore PAR tradition concerns itself with power relations; the powerful and the powerless (Baum et al., 2006, Chevalier and Buckles, 2013).

The aim of PAR is to confront the way in which the powerful and influential hold and define the creation of knowledge in society. In PAR the knowledge and experiences of the oppressed are valued because it is believed that through the experience of something, we may come to understand its essence, in other words, we feel, enjoy and make sense of something as reality through our experiences (Reason, 1994). Therefore, the three major concerns of PAR are; to produce knowledge and action that is useful to a group of people (the marginalised, powerless) through research, the second matter of concern for this approach is to empower people (the marginalised, powerless) through the process of creating knowledge from their own experiences. A third important point in PAR is the value of genuine collaboration. Researchers working with those who are oppressed must adopt the stance of working with the value of collaboration (Minkler, 2000, Wright et al., 2018). The key driver here is dialogue, those who are usually marginalised and powerless are given the platform to share their experiences and thoughts about a phenomenon through meaningful dialogue.

Denzin and Lincoln (2011) also state that PAR is the ‘enlightenment and awakening of people, empowering the ‘powerless’. Therefore, PAR is recognises the lived

experience of people who are often oppressed (Denzin and Lincoln, 2011). Other key principles in PAR are; the recognition that research participants must not be treated as data sources but as human beings with the purpose of helping them improve their quality of life (Rodríguez and Brown, 2009). Research participants are invited to bring their personal experiences and understandings to define social challenges and to also be part of developing possible solutions towards those challenges.

Gibbon (2002) states that using PAR in doctoral studies that make inquiries in health care settings involves managing conflicts, and the researcher must be prepared for this. However, in this study, we will be borrowing principles from PAR for the purpose of eliciting appropriate information from the research population.

Action inquiry:

The third approach to PR is referred to as, action inquiry. Action inquiry is concerned with the development of effective actions that will result in beneficial transformations and justice in society. Torbert (1991) argued that research and action are interwoven in practice, he states that knowledge is always gained in action and for action, therefore, the two cannot be separated even though they are analytically different. Reason (1994) highlights that action inquiry is concerned with conducting research about everyday life with the aim of effectively solving social issues facing people. Unique to this approach is the identification and use of theories that are said to guide the behaviour of people (Reason, 1994).

The ontological assumption of these three approaches is cited below (Reason, 1994:332)

> *"For me, the concrete reality is something more than isolated facts. In my view, thinking dialectically, the concrete reality consists not only of concrete facts and (physical) things, but also includes the ways in which the people involved with these facts perceive them. Thus for me…the concrete reality is the connection between subjectivity and objectivity, never objectivity isolated from subjectivity."*

In participatory research, people's values, views, perceptions and experiences are highly honoured because the inquiry is viewed to be more than a means to an end,

but rather as a process whereby persons involved may define their social problems and practice agency through the research conducted. The three approaches mentioned above emphasis experiential knowing, highlighting the fact that research participants can learn to be self-reflexive. This self-reflexive process is one of the principles adopted in this study as I explore young women's perceptions of the integration of oral PrEP in SRH services. I wanted young women who are part of this study to go through this self-reflexive process so as to share their experiences of receiving oral PrEP in SRH services. It is these young women's experiences that have the potential to inform oral PrEP policy (and relevant stakeholders) what is important for PrEP implementation so that these biomedical products are effective at the population level. These approaches stress different aspects of participatory inquiry that underpins this study; Collaborative encounter; Valuing the knowledge and experience of the marginalised; the interconnectedness of action and research. I have carefully adopted these principles so as to address the research questions.

Challenges in participatory research

There are several challenges that the researcher may face when conducting participatory research. Firstly, the researcher may fail to understand a community's cultural and social reality, and therefore fail to reach out to participants in a manner that is acceptable and appropriate (Loewenson et al., 2014). If the researcher fails to gain trust from participants because of being naive to the social and cultural context in which the participants are embedded, the aim of the research may not be reached. Authentic participation from participants cannot be expected when there is no trust.

Secondly, community members may refuse to participate in the research project. This may be caused by various issues which include; language barriers, cultural beliefs that perpetuate gender dynamics (female researchers may not be accepted in a community because of their gender). If the researcher cannot gain access to community members that are specifically needed in the research project, they will fail to collect data that will help in addressing the research questions. Another challenge that may arise in PR is the issue of people bringing different experiences, which can be contradictory when analysed (Loewenson et al., 2014). Because PR values people's experiences and emphasises focus on knowledge generated through

personal perceptions and experiences, the researcher may have challenges making sense of the different perceptions and views concerning the phenomenon under inquiry, especially when the experiences presented by the participants is contradictory. The researcher may also experience conflicts and threats that arise in the data collection phase of the study because sharing personal experiences may invoke unpleasant emotions in the participants (Loewenson et al., 2014).

The researcher may need preparation and support in managing these challenges, and in addition to basic research skills that one must have, researchers and academics in PR need to display the following competencies, see Loewenson et al. (2014); (a) An ability to adopt mutual respect to participants who express views that are contrary to the researcher's beliefs; (b) Ability to draw on different knowledge, even when it is abnormal for the researcher; (c) Sensitivity to diverse value systems, and affirmation of the cultural beliefs in a community; (d) Emotional intelligence, the ability to be aware of and also handle emotions that arise during the research process among the participants. In chapter five, I explain in detail how I addressed some of these challenges in the research process.

Research Population

The study population in this study refers to the two populations; the first is young black women in Vulindlela, rural KwaZulu-Natal, the second is young black women in eThekwini urban KwaZulu-Natal. The reason this study focuses on young black women is that there is sufficient literature that black women in the South African context are more vulnerable to HIV infection than other races (Shisana et al., 2014, Shisana et al., 2017). Vulindlela is a sub-district in the uMgungundlovu Municipality within KwaZulu-Natal. This area comprises of farmlands and traditional settlements, informal and peri-urban living (Kharsany et al., 2015). Vulindlela is a rural community with a population of about 150 000 Zulu-speaking people, there are sixteen primary healthcare clinics (PHC) in this area and 60 community-based organizations that are interested in providing HIV prevention home-based services (Kharsany et al., 2015). The Vulindlela area is characterized by high burdens of HIV incidents, in 2012 it was estimated that HIV prevalence in this area was close to 40% in women aged 20-24

years and exceed 50% in women aged 25-34 years (CAPRISA, 2015). Rural women were enrolled for this study at the CAPRISA Vulindlela Research Clinic right next to a comprehensive primary health care clinic in Vulindlela.

eThekwini District is a Metropolitan Health District comprising of 103 wards that are urban, rural and peri-rural in nature. The CAPRISA eThekwini Clinical Research site (urban area) is located in central Durban adjacent to a large public-sector primary-care clinic designated for the diagnosis and treatment of sexually transmitted infections (STIs) and tuberculosis. The eThekwini area has five regional hospitals, two district hospitals, four specialised hospitals, eight Community health centers (CHC) and hundred and ten clinics including fifty-seven clinics under local authority. Participants for this study were recruited at the eThekwini Clinical research site, this site is in the middle of one of the busiest taxi ranks in the Durban Central Business District (CBD), the clinic contains two sections, a Treatment Clinic for HIV-TB co-infected patients and a Prevention Clinic that cares for high-risk clients infected with sexually transmitted infections (CDC, 2014). In this study, young women were enrolled from this study at the CAPRISA eThekwini Clinical Research site.

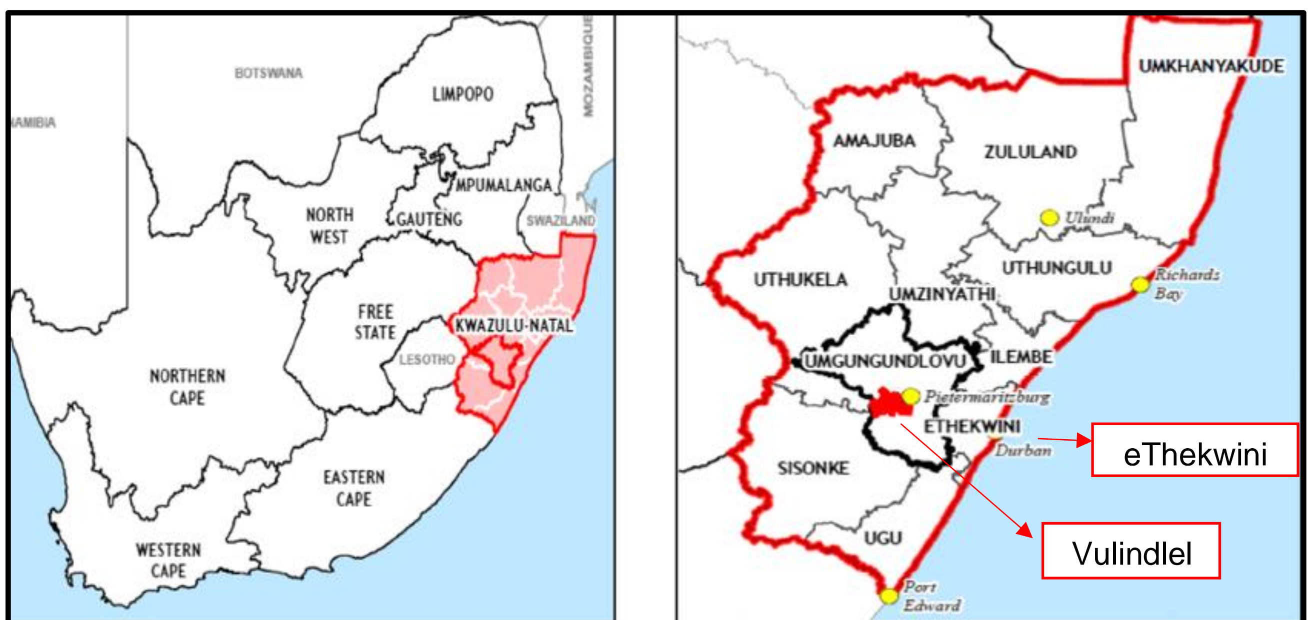


Figure 4.1: Research site in KwaZulu-Natal, South Africa

Source: (Kharsany et al., 2015)

In June 2016 the South African National Department of Health (NDoH) rolled out oral PrEP to select sex workers sites (Eakle et al., 2017). The guidelines have now been updated to include other target populations, including adolescent girls and young women. However, oral PrEP is not available in all national clinics but is available at the demonstration project level. Therefore, it was only relevant to consider participants in this study who were part of a demonstration project where they were accessing oral PrEP. Understanding the perceptions of young women who are already accessing oral PrEP in SRH services as a key objective. Participants for this study were therefore recruited from a demonstration project; CAP084 entitled "*A demonstration project of daily, oral tenofovir disoproxil fumarate + emtricitabine pre-exposure prophylaxis (PrEP) as part of sexual reproductive health services for young women at high risk of acquiring HIV in KwaZulu-Natal: Informing policy and practice for PrEP scale-up*". The aim of this demonstration project is to assess the feasibility, acceptability, uptake and patterns of use of daily, tenofovir disoproxil fumarate + emtricitabine (oral PrEP) provided as part of SRH services to young women and men at risk of acquiring HIV in urban and rural KwaZulu-Natal. The demonstration project was implemented at the following CAPRISA clinics in partnership with the adjoining public health facility:

• Rural: CAPRISA Vulindlela Clinical Research Site, KwaZulu-Natal, South Africa
• Urban: CAPRISA eThekwini Clinical Research Site, Durban, South Africa (STI Clients)
• Peri-Urban: CAPRISA Umlazi Clinical Research Site, Umlazi, Durban South Africa (Peri- and post-partum cohort)

Sampling and sample size

Qualitative and quantitative studies have different aims, in quantitative studies there is usually a hypothesis that is tested on a representative so that the results are generalizable (Bless et al., 2006, Neuman, 2011, O'leary, 2004). In qualitative research, the goal is to deepen our understanding about a process, relationship, or social scene, and this is not done with the intention to generalize the findings (Neuman, 2011). When sampling in qualitative research, it is participants relevance to the research topic rather than their representativeness which determine the way in which

the people are selected for the study (Flick, 2014). Participants in this study were purposively sampled.

There are several ways of employing purposive sampling, these include; maximum variation sampling, homogeneous sampling, typical case sampling, extreme deviant sampling, critical case sampling, total population sampling and expert sampling (Etikan et al., 2016, Palinkas et al., 2015). This study employed homogeneous sampling, which entails focusing on candidates who share specific characteristics, the idea is to focus on the specific similarities that the candidates share (Palinkas et al., 2015, Etikan et al., 2016). The participants in this study were selected on the basis of their age, their race, their access to oral PrEP, and their participation in the CAP084 demonstration project.

Participants were recruited using a recruitment screener (see appendix 6). I used this recruitment screener to ensure that participants were recruited according to a clear inclusion and exclusion criteria.
The criteria prioritised was, therefore, based on demographic characteristics, for instance, age, and gender. I recruited thirty young women from the eThekwini CAPRISA clinic, and thirty young women from the Vulindlela CAPRISA clinic. In total sixty young women were recruited in this study. The number sixty represents a relatively small sample size which, however, cannot be described as being too small. From the recruitment screener eight young women from each research site were selected and called to be part of this study. In total sixteen young women were called and invited to be part of the journey mapping workshops and one-on-one interviews. Therefore, from each research site there were eight young women invited for the workshops and interviews. However, over all fifteen young women arrived for the workshops and interviews. One of the young women who had confirmed availability did not arrive for the workshop and one-on-one interview.

The sample size was restricted by budgetary constraints and, to a lesser extent, time available for conducting workshops and interviews was limited. Ultimately, the size of the sample, whether large or small, it is not an issue in the context of qualitative and interpretive investigation. Statistical representativeness was not a core aim in this study. Kumar (2019:192) states that “the sample size in qualitative research does not

play any significant role as the purpose is to study only one or a few cases in order to identify the spread of diversity and not its magnitude". This explains the sample size in this study, as large numbers were not an objective that I sought to reach because of the study design.

In this study three arbitrary 'rules' of qualitative sample size stratification justified my small sample size. Sixteen as a total sample size is still a definite number, and there are reasons the researcher arrived at that number. Ellsberg and Heise (2005:35) point out that "a sample population of fifteen units is a good average for short term qualitative studies". Ritchie et al. (2013), on the other hand, regard twenty to fifty one-to-one interviews to be standard. The recommendations by Ellsberg and Heise (2005) and Ritchie et al. (2013) constituted the first arbitrary rule the researcher utilised in choosing the number of respondents for her study. The second rule was that the smaller the sample, "the better the quality of the interaction with the research participants" (Crouch and McKenzie, 2006:483). Sampling, usually defined as "the selection of a part to represent the whole" (Peil, 1995:23), does not necessarily yield better data by including everyone. The third and final rule utilised was that sample sizes are typically smaller anyway in qualitative research (Huberman and Miles, 1994). In total, fifteen participants participated in the workshops, following one-on-one interviews. To reiterate the second rule of qualitative sampling mentioned above, that the smaller the sample, "the better the quality of the interaction with the research participants" (Crouch and McKenzie, 2006:483). I further divided the journey mapping workshops into two groups of four ladies (see table 4.3).

The table below displays the sample size of this study:

	Number recruited	Number invited	Number participated	Journey mapping workshop	In-depth Interviews
eThekwini Clinic	30	8	8	8	8
Vulindlela Clinic	30	8	7	7	7

Table 4.2: Study sample

	Journey Mapping Workshop (Group 1)	Journey Mapping Workshop (Group 2)	Number of Participants in each group
eThekwini Clinic	4	4	4
Vulindlela Clinic	3	4	3 and 4

Table 4.3: Workshop composition

There were inclusion and exclusion criteria that this study adopted. The table below depicts the inclusion criteria used to recruit and enroll participants for this study.

Female	Male
Persons enrolled in the CAP084 Demonstration project	Persons not enrolled in the CAP084 Demonstration project
Persons between the ages of 18 and 35.	Persons below the age of 18, or over the age of 35.
Able and willing to provide first person informed consent for participation in this study.	Any mental health condition which would impede comprehension of the study.
HIV negative.	Patients who are not willing to provide written informed consent.
	HIV positive

Table 4.4: Inclusion and Exclusion criteria

The recruitment screener assisted in ensuring that potential participants had a good idea on what this study entailed. The recruitment screener included a brief introductory section to assist the researcher in explaining the study to potential participants. Making use of a recruitment screener added value to the validity and reliability of the research methodology, see aappendix 7: Recruitment screener.

In addition to the young women, it was important for me to conduct in-depth interviews with the nurses that were in charge of the demonstration project in the two clinics. These nurses were part of the process of dispensing oral PrEP to the young women for a period of 2 years and more. They occupied a beneficial position to highlight some of the socio-cultural barriers that young women face at the CAPPRISA clinics when

collecting oral PrEP. The two nurses were recruited upon recommendation by the principle investigators of the CAP084 demonstration project.

Participatory research: application in this study

Participatory research is achieved through “critical examination of action” in order to understand the participant’s social problems and possible social interventions (Govender, 2013). Through PR principles young women contributed to the generation of knowledge that has the potential to inform the integration of oral PrEP in SRH services, in ways that account for their cultural values. This study set out to explore the likely social and cultural challenges or opportunities that will affect the use of oral PrEP by young women. It offered the participants a platform to define the social problems they faced when accessing oral PrEP at the clinic. Gaining insight into young women’s perceptions on the social and cultural factors that can work as barriers or enablers to accessing PrEP in SRH services is critical in the HIV prevention field.

Loewenson et al. (2014) explains health systems as complex social systems that reflect, affect and build social values. Therefore, there is a need to investigate the social dimensions that influence availability, access and uptake of health services, especially in low-income countries like South Africa. For oral PrEP to be effective as an HIV prevention technology at the population level, there is a need to explore influencing social and cultural factors to PrEP availability, access and uptake. This is discussed in more detail in chapter three.

Experiential knowledge can be a key mobilizer into this complex social phenomenon. There is also a stance that states that when people are involved in decisions about how health services are delivered they are more likely to trust, use and respond positively (Wright et al., 2018, Koch and Kralik, 2009). Therefore, as we actively involve young women in research such as this one, they may gain a sense of agency. Having been recognized as a vulnerable population in the HIV and AIDS epidemic, this study involves a group of young women who have previously had access to PrEP in SRH services. As the researcher, I wanted the participants to go through a reflective

process of their experiences of accessing PrEP in SRH facilities, it is from their experiences that knowledge production is developed in this study.

This study made use of a participatory research method called journey mapping in the context of workshops. Data was also collected through follow-up one-on-one interviews with the young women involved in the workshops. Through the journey mapping workshops, the research participants were given the opportunity to be significantly involved in this research. Through the journey mapping, participants were given the platform to define challenges and problems they face in society and within the SRH services specifically. It is here that the participants were addressed as self-determining agents, participants were therefore part of the collaborative encounter of this research process. I allowed the participants to identify, define and make sense of their experiences with accessing PrEP in SRH services within clinics. When people who are often marginalized are given a space to share their opinions, they do experience some level of emancipation because this reflective process that they are part of makes them know that they are significantly contributing to the development of knowledge. This research is premised on the notion that when participant's perceptions are considered, there is a greater opportunity to improve primary healthcare services.

The transmission of HIV is the outcome of particular sets or patterns of social and cultural practice. Patterns of social and cultural practice give rise to the spread of the epidemic therefore when exploring effective HIV prevention methods such as oral PrEP, we must understand that the reduction of HIV transmission lies in the hands of those affected and infected. This study has focused on actively involving young women who have been identified as a vulnerable population. I specifically worked with women from rural and urban KwaZulu-Natal as these two groups are the most vulnerable to HIV infection. As these young women are involved in the research process through their experiential knowledge, they become agents of their own social transformation by generating knowledge that will be disseminated and hopefully results in social change.

Below is a table with a comprehensive comparison between participatory and conventional research by Cornwall and Jewkes (1995):

	Participatory research	**Conventional research**
What is the research for?	Action	Understanding with perhaps action later
Who is the research for?	Local people	Institutional, personal and professional interests
Whose knowledge counts?	Local people's	Scientists'
Topic choice influenced by?	Local priorities	Funding priorities, institutional agenda's, professional interests
Methodology was chosen for?	Empowerment, mutual learning	Disciplinary conventions, 'objectivity' and 'truth'
Who takes part in the stages of the research?		
Problem identification?	Local people	Researcher
Data collection	Local people	Researcher, enumerator
Interpretation	Local concepts and framework	Disciplinary concepts and framework
Analysis	Local people	Researcher
Presentation of findings	Locally accessible and useful	By researcher to other academics or funding body
Actions on findings	Integral to the process	Separate and may not happen
Who takes action?	Local people, with/without external support	External agencies
Who owns the results?	Shared	The researcher
What is emphasised?	Process	Outcome

Table 4.5: Participatory and conventional research

Data collection methods: Journey mapping and Interviews

Art-based methods and interviews were used in this study to collect data that would help address the research questions and reach the research objectives. The overarching objective of this study is to find out how oral PrEP can be integrated

into already existing SRH services in ways that account for young women's social and cultural values. This will be achieved by;
Establishing how the current structure and organization of SRH services is an impeding or supporting environment for young women accessing biomedical HIV prevention products; Exploring the likely socio-cultural challenges or opportunities that influence acceptance, uptake and adherence of oral PrEP in SRH services for young women in KZN; Outline ways the current structure and organization of SRH services can be aligned to meet the needs and social-cultural values of young to ensure acceptance, immediate uptake and adherence to oral PrEP.

Art-Based Inquiry: mapping as a tool

Emergent methods in research have come as a means of answering complex research questions which usually reveal hidden and difficult to access knowledge (Hesse-Biber and Leavy, 2010). Art-based research falls within the spectrum of emergent methods in research, there is a growing recognition in the qualitative paradigm that art is a form of expression that can yield knowledge which would not have been yielded using orthodox means of inquiry. This study explores the social and cultural factors that influence women's decisions to access HIV prevention methods in SRH services, therefore, I have adopted the use of arts-based methods to collect data so that I could dig deep into the experiences and perception of young women. The social phenomenon under investigation is one that can be complex in nature, requiring research methods that will go beyond what participants may say at face value. Using an integrated approach that involves both visual and word-based research methods allows for the opportunity to explore both the diversity and complexity that is the base of much social research interested in human experience (Guillemin, 2004).

McNiff (2008:29) gives a comprehensive definition of arts-based research: "[It] can be defined as the systematic use of the artistic process, the actual making of artistic expression in all of the different forms of the arts, as a primary way of understanding and examining experience by both researchers and the people that they involve in their studies".

Important to note in this definition is that art-based methodologies are systematic, these procedures must follow a systematic process in order to ensure experimental consistency. One may be tempted to assume that art-based research is haphazard in nature because it is flexible and different from conventional data collection methods but this is not a true reflection of the method. Arts-based methodologies are effective means of meaning-making through creative arts, though it is full of complexity, the art products are themselves texts that can be read and interpreted by their research participants and the researcher (Mitchell et al., 2011). However, when a researcher makes use of drawings as a methodological tool, the process involves more than engaging participants in making drawings, the researcher's analysis of these art pieces becomes critical in knowledge creation (Hankins et al., 2015). Art-based techniques in research often require research participants' drawing and talking or drawing and writing about the meaning of what they have drawn (Hankins et al., 2015). The process of art-based research is therefore engaging, requiring for participants to dig deep in their thought process and for them to be reflective about their experiences related to the social phenomenon under inquiry.

Maps as art-based research methods have been used in participatory rural appraisal to understand ecological and social features that people may perceive as enabling or impeding in their communities (Cornwall, 1992). This study made use of journey mapping and interviews for data collection, journey mapping falls within the spectrum of art-based research as it probes participants to participate through drawing and writing. In journey mapping process, the participants draw one or more maps of their area or of the setting for the research study and particularly noting the physical conditions (Loewenson et al., 2014). This process of journey mapping may be used to identify problems in an area, to analyse service access and benefits by social groups, and to identify proposals for change in condition services (Loewenson et al., 2014). Maps may be added to at different stages of the research process, with the aim to present new, substantiating information, to support implementation and to monitor and evaluate action and remodelling. Drawing maps is a form of art-based inquiry that research participants to express their experiences and views on a particular phenomenon in a systematic manner.

The art-based journey mapping aims to create this atmosphere. Another important characteristic is to use probes as a researcher in order to ensure that the research questions can be answered once the interview is addressed. The success of the interviews lies largely on the researcher. The role of the researcher is similar to that of a facilitator, the aim is to always steer the participant back to the topic. This means that the researcher will exercise judgement, whether or not a point has received important information or not. In qualitative research, it is crucial that the researcher learns to probe and to be interactive with the participants.

Journey mapping in this study

The journey mapping workshops were designed to explore young women's experiences of clinic visits for SRH services to access oral PrEP, and also to explore what the young women in this study believe is needed to improve clinic visits for other young women in their communities. The journey mapping workshops involved several participatory activities, with journey mapping as the main participatory visual method of data collection. During the workshops, the young women created two journey map charts. The first chart was the depiction of the young women's experience of attending the SRH services to access oral PrEP (a step-by-step map of the clinic visit process), this first journey map was labelled the "reality clinic". The second journey map that the participants created was a journey map that depicts participants desired experience in the clinic, this journey map was labelled the "dream clinic". Both the journey maps developed by each of the young women in the workshop displayed a clear outline of all the steps and processes that are involved in the SRH clinic visit when collecting oral PrEP.

All the young women in the workshops had an opportunity to present their journey map charts, each explaining what the images and expressions used in their journey maps meant. The presentation of all the journey maps by the young women were all recorded and transcribed. This presentation process was the first step in data analysis, as the participants each expressed through verbal presentations the meaning behind the images and drawings on their journey maps. This ensured that the researcher would not loose meaning through interpretation of the journey map charts.

Journey mapping process

The first step in the journey mapping activity was to brief the young women on the art-based activity they were about to participate in. An opportunity for questions and answers was provided to ensure that the young women understood what journey mapping is and what the purpose of this activity is during the workshop.

The young women were then given all the material needed for the activity; charts, color papers, scissors, crayons, Koki's, markers, pens, pencils, stickers, magazines, glue and more stationary for create their journey maps. Each young woman during the workshop had their own set of stationary and necessary artifacts to creatively develop two journey map charts.

Thereafter, the young women were prompted through guiding questions in developing the journey map charts. The first journey map that the young women were asked to develop was a journey map that depicts their lived experiences of visiting the clinic to access oral PrEP in SRH services. This journey map was entitled the "reality clinic". Here the young women outlined the step-by-step process they follow when visiting the clinic to access oral PrEP. I made use of prompting questions such as *"Reflecting on all your clinic visits, draw a step to step map of what you do and what you encounter from the moment you enter the clinic".* Several other questions were proposed to the young women to ensure that they depict on their chart how they felt in the process of visiting the clinic. See figure 4.1, the journey map guide. The young women were given sufficient time to develop their charts to their own contentment. As the researcher, I avoided rushing the young women through this process as I sought to get the young women in spaces where they could reflect, think and decide how to depict their clinic visit experience on a chart.

After the young women completed their first journey map, they were given the opportunity to present their charts to the small group of young women in the workshop. This allowed for the young women to explain in detail what each picture, drawing, texts and other artistic forms on the chart meant for the. The young women were free to share as much details that they wanted to present from their charts. All these presentations were recorded and transcribed.

After a break, the young women were then asked to develop their second journey map. The second journey map was developed to depict the 'ideal' experience that the young women desire to experience when visiting the clinic to collect oral PrEP. The second journey map was entitled the "dream clinic". Again, the young women were given prompting questions to help them develop their journey maps. The same procedure for the "reality clinic" was used at this phase, but the emphasis in this second journey map was that the young women depict what they desire to experience when they go to the clinic. After the young women completed their first journey map, they were given the opportunity to present their charts to the small group of young women in the workshop. All these presentations were recorded and transcribed.

Figure 4.2: Participant presenting journey map

(Photograph by author, taken 28 July 2018)

In this study, journey mapping was used with the aim of understanding young women's experiences in accessing oral PrEP in SRH services. The first goal of using journey mapping as a data collection tool is participation. I wanted the young women in this study gain a sense of participation in the research project. The journey mapping

exercise afforded the participants an opportunity to explicitly share their experience of clinic visits without talking directly to me as a researcher. This process created a sense of liberty to share what participants perceived to be enabling or impeding in accessing PrEP. Through this exercise, the participants could reflect on their experience and highlight problems, challenges and opportunities in the actual clinics where they accessed their oral PrEP.

Through the journey mapping exercise, this study sought to understand ways in which the current structure and organization of SRH services are impeding or supportive environments for young women accessing oral PrEP. One of the research questions in this study sought to explore what ways the current structure and organization of SRH services be realigned to meet the needs of young women in order to ensure acceptance, immediate uptake and adherence to oral PrEP.

See table below for a brief journey mapping guide that was followed in the workshop process in this study:

Journey mapping guide
The facilitator introduces this activity to participants as a reflective exercise where they get to creativity externalize their step by step journey of visiting the SRH clinic. Each participant will be given a poster size sheet and drawing material. Participants may use symbols to mark their experiences of their visit to the SRH clinic. Facilitator prompts the participants through several questions in order for guide them in the development of their journey maps. Questions: 1. Reflecting on all your clinic visits, draw a step to step map of what you do and what you encounter from the moment you enter the clinic. (show sample of map) 2. What did you do in these different steps? E.g. taking blood tests, waiting room 3. On your journey map, mark any steps in your clinic visit that were most easy for you. Think about what made this step easy. Write this within your map. 4. On your journey map, mark any stages in your clinic visit that were most difficult for you. Think about what made this so difficult. Write this within your map. 5. If you had to change anything about your clinic visit, what would this be and at which step in your map would this fit in? 6. Do you think the information you receive at the SRH clinics on contraceptive options and HIV prevention are sufficient and helpful?

7. Reflect back on the experiences that you have had with the health care workers, were those helpful encounters? What would you change about these? Write this on your journey map, anywhere on your poster sheet.
8. Are there any things that you believe need to be included in the clinic visit that you believe will encourage you to come regularly?

Figure 4.3: Journey mapping guide

The journey mapping guide presented above gives a clear outline of what was used to steer and facilitate the workshop. Though this was not a rigid guide, it gave the researcher an outline of questions to help the participants develop journey maps that addressed the scope of this study. The journey mapping guide also contributed to ensuring validity and reliability of the research method, in that it provided structure to the journey mapping activity.

Journey mapping in a workshop context

Workshops are defined as a place where things are made or repaired (Merriam-Webster, 2016). However, several definitions of the term “workshop” have emerged, today workshops refer to meetings whereby a group of people learn new knowledge, perform creative problem-solving, and/ or innovate in relation to a context-specific issue (Ørngreen and Levinsen, 2017). Ørngreen and Levinsen (2017) conducted a literature review of the use of workshops as a research methodology, their work established that workshops are an effective means of understanding complex social issues in a participatory manner. Workshops can be a platform where issues are presented, experimented with, played out, and discussed, therefore Ørngreen and Levinsen (2017) state that workshops are a place where meanings are negotiated and defined. Moreover, workshops can be a place where new factors relating to social issues are identified, these may be factors that the participants and researcher were not aware of prior to the workshop.

Participation from participants is central in workshops, the inclusion of ideas, opinions and perceptions from those involved in the workshop is very important (Wakkary, 2007). Unlike other participatory settings of data collection, workshops provide a platform where the participants and the researchers/ facilitators actively learn together and negotiate meanings. What becomes critical in this setting is openness from both

the researcher and the participants. From the researchers' position, openness speaks to the ability to allow the participants to influence the course of the workshop and allow for unexpected findings. The researcher must also create a supportive environment, where participants feel safe to participate and share candidly. Openness from the participants speaks to the involvement of participants where they find themselves being able to express themselves honestly and freely. The significance of workshops is the collaborative element that it brings to the research process, where the researcher and the participants are coming together to learn about social issues.

Figure 4.4: Journey mapping workshop

(Photograph by author, taken 28 July 2018, eThekwini)

Figure 4.2 above depicts one of the journey mapping workshops facilitated during this study. Using workshops as a research methodology requires that the researcher outlines a basic set of research questions and objectives (see, journey mapping workshop guide, appendix 5). While the researcher/ facilitator is open to unexpected findings, it is important to have objectives to ensure relevant data collection. Workshops are specifically designed to fulfil pre-defined objectives, however, the data collection is not predictable or restricted in nature (Ørngreen and Levinsen, 2017). When planning to conduct a workshop, is important to plan well, Steinert (1992) gives

us 12 tips on how to successfully plan and conduct workshops (Öberg and Hernwall, 2016).

It is important to emphasise the notion that workshops are conducted by people with experience within the field of research inquiry. The young women within the workshop must be limited to a small number (5- 10) to allow everyone personal attention and the chance to be heard. In this study, the number if research participants in each workshop was four young women, this small number was intentionally selected to allow for more in-depth interaction. The small numbers in the workshops also allowed for an environment where participants can feel more comfortable to share their experiences. The young women were expected to actively participate and influence the workshop's direction, as well to as practice the relevant techniques, skills, situations, and so forth. Additionally, workshop participants and organisers expect an outcome (e.g. the generation of new insights, suggestions, or (re)designs of a product, process, or innovation).

Art based methods of data collection are often used to collect data which extend beyond the use of interviews, focus groups and questionnaires to explore a range of development or public health issues (Chamberlain et al., 2018). Participatory approaches aim to generate knowledge and information, from different cultural groups and communities. The emphasis is on generating knowledge from the perspectives not only of the researcher, but also of those who are being researched. Journey mapping was adopted to promote meaningful participation that can contribute to authentic discussions from young women that will assist in highlighting challenges and solutions related to HIV prevention and SRH services. Journey mapping enabled participants to identify daily barriers or enablers which their experiences of visiting SRH services. Each of the young women who were part of the journey mapping workshop had an opportunity to present to the groups their "reality clinic" and their "dream clinic". Here the young women are presented with an opportunity to share and explain as they feel comfortable to do so some of their experiences of visiting the clinic to access oral PrEP.

Data collection was conducted through the use of journey mapping workshops and interviews with young women attending SRH services. Interviews were conducted to

collect thick-descriptive data to further elaborate on the issues discussed during the workshop (Neuman, 2011) on young women's perceptions of the availability of oral PrEP in SRH clinics. This data collection method gives the opportunity to get to know people and how they conceptualize reality and their decision making (Terre Blanche et al., 2006). One-on-one interviews were conducted with all the woman who participated in the journey mapping workshop. Interviews were conducted at each research clinic with eight women between the ages of 18 to 30. Eight participants in each clinic sufficient since the research questions require in-depth input from participants, having more than eight ladies present could obstruct in-depth responses. Interviews are discussed below in more detail,

The age group outlined in the data collection (18-35) is significant to this study because adolescent girls and young women are disproportionately vulnerable to HIV infection and could therefore benefit from the availability of PrEP as an HIV prevention method.

Interviews

To debrief on the journey mapping session, the next phase of data collection was one-on-one interviews. Interviews in this study serve a critical role in the data collection process even though they are conducted at the second phase of data collection. I decided to use interviews for this study because it gives a platform for discussing some issues that participants may not feel comfortable sharing in a group setting. Moreover, interviews were preferable for this study as appose to participants filling out a questionnaire, or perform an experimental task (Kelly, 2006).

Interviews are usually defined as a form of conversation, a conversation with a purpose (Ritchie et al., 2013). Interviews are structure and flexibility, allowing the researcher to follow an interview guide yet also allowing for space for the discussion to go beyond the prepared questions (Ritchie et al., 2013). While the researcher is open to dialogue with the participant, the researcher comes with a guideline of questions that will help them to answer the research questions. Another characteristic in the interview process is the interactive element that the researcher must insist on in order to get the participant to share more freely (Ritchie et al., 2013). It was my intention as the researcher to ensure that the participants in this study feel comfortable

and free to share their personal experiences in SRH clinics. Being interactive with the participants is critical for me, as this causes them to feel free to share their personal lived experiences.

Through one-on-one interviews, the young women involved in the workshops had an opportunity to further discuss the issues that were raised during the workshops. The interviews with the young women were designed to allow the young women to share more discretely their personal encounters and experiences in the clinic. HIV prevention and sexual and reproductive health are topics that can be sensitive in nature, therefore it was necessary that interviews are facilitated so that they can discuss personal issues in a private setting. It was interesting however to note that the young women engaged in the workshops freely and disclosed of personal encounters related to using oral PrEP and colleting oral PREP at the clinic. As a researcher, I had preconceived thoughts that the young women would not disclose of personal issues during the workshop sessions, but this was not the case.

I made use of an interview guide that had questions related to; uptake, acceptance and adherence to oral PrEP; services provided in the SRH within clinics; perceived community and family perceptions towards oral PrEP. See appendix 3: participant interview guide.

Data analysis

In qualitative research, the data analysis process begins while gathering the data, analysis is a continuous and iterative process, however, two key stages characterise its course (Neuman, 2011, Ritchie et al., 2013). The first step is to manage the data and the second involves making sense of the evidence through descriptive or explanatory accounts (Ritchie et al., 2013). To analyse data entails a systematic process of organising the data collected on the field, it includes the examining and integration of different findings (Neuman, 2011, Terre Blanche et al., 2006). When analysing data, we need to connect particular concepts, and identify broad patterns or themes (Neuman, 2011).

Analysing data enables the researcher to improve their understanding, expand on theory and to advance already existing knowledge in the field of study. While the researcher is going through this process, they look for patterns and relationships among the “raw data” collected. Ritchie et al. (2013) states that 'raw' data may come in diverse forms, for example; verbatim transcripts of interviews or discussions, observational notes taken by the researcher, or any written documents taken during the data collection process. Whatever form the data takes, the material in qualitative research is rich in detail. The fact that the data collected in qualitative research is rich and detailed requires the researcher to have a systematic and reliable data management strategy. The data needs to be organised in such a way that the researcher can make meaning from it.

The analytical framework embraced for this study this study is influenced by the culture centered approach and cultural competency approach. The culture centered approach seeks to develop an understanding of culture that explores questions such as: How do cultural members communicate with one another about health issues? How do they develop meaning about health (Dutta, 2015)? The culture centered approach prescribes qualitative data collection methods to explore such questions, the researcher applies the interpretive or “exploratory” approach to seek understanding on how members of a community make sense of health related issues (Dutta, 2015). Therefore, this study takes the participants local realities seriously, exploring their experiences through art-based methods and dialogues. Guest et al. (2011) state there are two main approaches to data analysis; exploratory, which is adopted in this study, and confirmatory. The difference between the two is that in an exploratory study, the researcher carefully reads and rereads the data before to identify the emerging themes.

In contrast, confirmatory studies are hypothesis driven, and the researcher already has predetermined “themes” or categories of analysis (Guest et al., 2011). Exploratory analyses acknowledges the critical role of theory in research, and theory (however implicit) gives direction to what will be examined, and how it will be examined (Guest et al., 2011). In the context of this study, the culture centered approach as discussed above gave perspective to the research inquiry in this study. See table below, this is a summary of the differences between the two approaches.

Exploratory (“content” driven)	Confirmatory (“hypothesis-driven)
Ask question: “What do x people think about y?”	Hypothesizes: “x people think z about y”
Specific codes/ analytic categories NOT predetermined	Specific codes/ analytic categories predetermined
Codes derived from data	Codes generated from hypotheses
Mostly uses purposive sampling	Generally employs random sampling

Table 4.6: Differences between exploratory and confirmatory approaches to qualitative data analysis. Adopted from Guest et al. (2011)

All the data that was collected in this study was divided into two sets; the first set comprises of data collected from the journey mapping workshops, and the second set of data collected was from the one-on-one interviews. The journey mapping sessions and the interviews were recorded and transcribed.
The female participants taking oral PrEP in this study created two journey maps that represented their current experience of the SRH services, and their ideal experience of SRH services when they collect their oral PrEP. All the participants were given the opportunity to present their journey maps. This was the first process in data analysis, as the participants each had the chance to explain to the researchers and other participants what they were illustrating through the imagines and phrases used on their journey maps. This process allowed the researcher to understand what each participant wanted to depict on their journey map posters without losing or misinterpreting meaning.

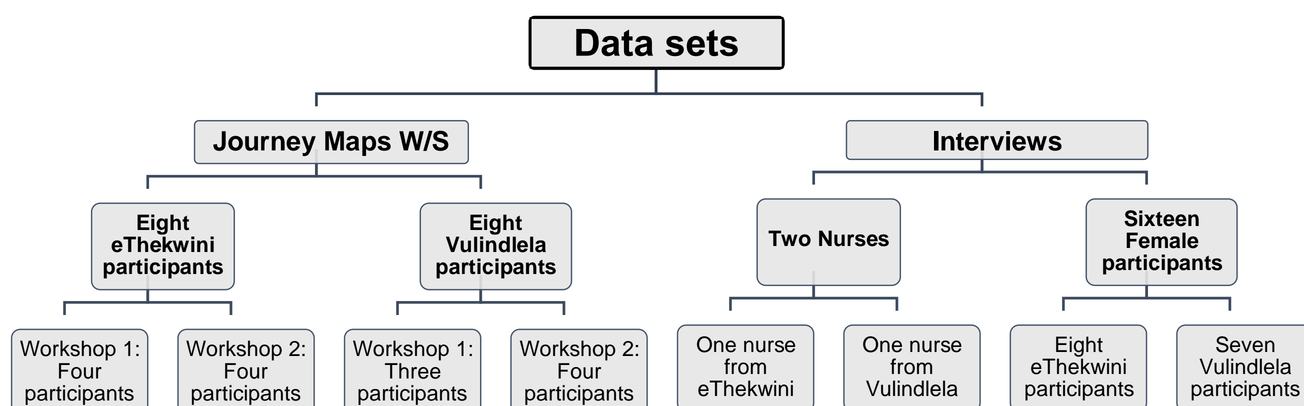


Figure 4.5: Data sets

All the data collected in this study was analysed through thematic analysis. Thematic analysis as a qualitative descriptive approach is usually used to identify, analyse and report patterns (themes) within data (Guest et al., 2011, Braun and Clarke, 2006). Thematic analysis are suitable for answering questions such as: "what are the concerns of people about an event?" "What reasons do people have for using or not using a service or procedure?" (Vaismoradi et al., 2013). Generally, thematic analysis is the process of searching for and identification of common threads that extend across an entire interview or set of interviews (Vaismoradi et al., 2013, Braun and Clarke, 2006). Moreover, this process of analysis does not only care on the frequency of themes in the data, but also their relationship, thematic analysis is more than finding patterns in the data. The themes that are identified must be analysed.

Thematic analysis is was used to organise the data collected, below are six stages in the thematic analysis process as proposed by Braun and Clarke (2006). I followed these steps as a guide to organising the data I would have collected from the journey mapping session and interviews.

Phases of thematic analysis	
1. Familiarizing yourself with your data.	Transcribing data (if necessary), reading and re-reading the data, noting down initial ideas.
2. Generating initial codes	Coding interesting features of the data in a systematic fashion across the entire data set, collating data relevant to each code.
3. Searching for themes	Collating codes into potential themes, gathering all data relevant to each potential theme.
4. Reviewing themes	Checking if the themes work in relation to the coded extracts (Level 1) and the entire data set (Level 2), generating a thematic 'map' of the analysis.
5. Defining and naming themes	Ongoing analysis to refine the specifics of each theme, and the overall story the analysis tells, generating clear definitions and names for each theme.
6. Producing the report	The final opportunity for analysis. Selection of vivid, compelling extract examples, final analysis of selected extracts, relating back of the analysis to the research question and literature, producing a scholarly report of the analysis.

Table 4.7: Phases of thematic analysis

In phase one, I spent time in familiarizing themselves with the data by listening and readings the recoded interviews, and workshop sessions facilitated. I also continuously took down notes and making key points in a research journal. This process was continuous and reflexive because the researcher also kept referring to notes made in the research field as data was being collected. So even though Braun

and Clarke (2006) present a linear process, in reality, this is a continuous and flexible process. I went through a process of continuously familiarize themselves with the data, even at each phase if necessary.

In the second phase, I started to develop codes according to the frequency of a key point in the data collected data, and also according to the interesting points. Once several codes were developed from the data, these codes were grouped and analyzed to develop themes, this was the third phase.
In the fourth phase of thematic analysis, I went through a process of reviewing the themes to see if they make sense, and to create a map of analysis. In this phase I had to look at my own work critically. In the case of this study, I also sought supervision guidance and peer-review on the themes I generated from the data.

In phase five, I started to clearly name and define each theme that was developed from the data so that it makes sense even in the context of the study.
Lastly, phase six entailed analyzing the data in a manner that addresses the research questions and objectives. It is at this point where I also had to go back to read what literature and the theory used in this study say in relation to the emerging findings. This phase needs critical engagement so as to establish what us substantiated by literature, and what is contrary to literature. This phase is interesting as it pulls together all the sections in the thesis.

Limitations and challenges encountered

Generalisability and Participation

This study is limited in that the data collected is not generalisable. As with qualitative studies, the data reflected in this study cannot be generalised for other population groups within South Africa as the real-lived experiences of the young women involved in this study are particular to the context in which they were studied. While I highlight this as a limitation, this has also been the main argument of the thesis; oral PrEP integration into already existing SRH services cannot adopt a “blanket approach”.

Rather various context needs to be studied in such a way that will lead to culturally sensitive and contextually relevant oral PrEP roll-out.
Furthermore, the research interests within this study was the lived experiences of young women who have been accessing oral PrEP from SRH services through a demonstration project that was facilitated by a research institute (CAPRISA). Having been part of a demonstration may result in bias, in that the participants have had previous experiences of being involved in research that required them to reflect on their experiences of accessing oral PrEP.

Due to logistical constraints and the fact that participation of this study was voluntary, some participants that indicated interest in this study did not arrive for the actual journey mapping workshops and interviews. Some participants indicated on the day of the workshops and interviews that they could no longer be part of the study. This was a great limitation in that the study sample size was carefully tailors to achieve desired out comes. The workshops for instance were designed to accommodate four participants, and in cases where a participant could no longer attend resulted in a workshop with three participants.

Conclusion

The guiding theory in this thesis is premised in the notion that participation and inclusion of research participants is critical in knowledge production. In this study, the researcher adopted the role of the active participant in the co-construction of knowledge along with the research participants. In this chapter the concept of participation is proposed and argued to be critical in meaningful qualitative research. Young women were purposively sampled in KwaZulu-Natal from both rural and urban contexts, these young women were involved in the participatory visual methodology process and one-on-one interviews in order to understand how oral PrEP integration in SRH services can be facilitated in a contextually and culturally relevant manner. The study is descriptive, as the participants described their experiences of clinic visits, their encounters of accessing oral and their experiences of using oral PrEP for HIV prevention. Through thematic analysis the researcher developed themes that would

assist in addressing the research questions that are premised in the culture centred-approach (structure, culture and agency).

In the next chapter I provide a personal reflection of the research process as the researcher and discuss some of the ethical dilemmas that were faced in this study, and how those were addressed.

Chapter Five: Participatory Visual Methods as ethical research practice

Participatory visual methods (PVM) have the potential to facilitate discussion, collaboration and inclusion of young women in HIV prevention research. However, the use of PVM such as journey mapping have been limited in application with South African young women, particularly on topics such as sexual and reproductive health (SRH) and HIV prevention.

In this chapter, I reflect on the ethical considerations and dilemmas that were involved in this study. I employed a participatory approach with the direct involvement of young women to engage in dialogue about inclusion of oral PrEP as part of the SRH services. Working with young women through participatory methods, discussing sensitive issues related to their sexual health and SRH services, can raise multiple ethical dilemmas that require specific ethical precautions to be taken in research. In this chapter, I offer a discussion on ways of addressing and negotiating ethical dilemmas in the research process from my own experiences from this study. These experiences suggest that PVM fosters environments of inclusion and cultural sensitivity through dialogue, for young women where they feel comfortable and safe to share their opinions and experiences concerning sexual and reproductive health matters. This study established that journey mapping as a PVM is a contextually and culturally relevant research method in the engagement of young women about SRH issues.

Introduction

In South Africa, young rural and Indigenous women are often disproportionately vulnerable to HIV infection due to social, cultural and economic factors that place them in vulnerable and marginalised positions. Scientific health advances such as oral PrEP as a new HIV prevention technologies provides rural and urban young women with opportunities of agency and empowerment to make informed sexual health decisions despite gender-based constraints enabling autonomy in HIV prevention. The use of PVM has unearthed a number of ethical issues in research when working with girls and young women, and there is limited literature that reflects on these in significant ways.

With 7 million people are estimated to be living with HIV in South Africa, young women accounting for 36% of new infections, here is an increasing need for young women to be involved in HIV and AIDS-related research as they represent one of the key population groups in the HIV and AIDS epidemic (AVERT, 2018). Poverty, disparities in social and economic opportunities, gender-based violence, cultural and biological factors have all been cited as key contributors to the high HIV and AIDS rates that girls and young women face in South Africa (Dellar et al., 2015, Venter et al., 2015, Naranbhai et al., 2012, Shefer, 2005). Therefore, there is a need for research methods that are ethically appropriate and safe for young women, yet also cognisant of the social and cultural contexts in which these young women make SRH decisions. The need for ethical research methods that are appropriate for girls and young women is well established (Singh et al., 2006, Bekker et al., 2014, Emanuel et al., 2004).

In this chapter, I draw on my experiences of employing journey mapping as a participatory approach with young women in rural Vulindlela and urban eThekwini, KwaZulu-Natal, South Africa. While PVM has been employed for a few decades in the social sciences to engage communities on public health issues, its use in HIV prevention programs that utilise biomedical technologies has been limited. Recent studies have advocated for the need to explore the potential of PVM for community engagement in biomedical research (Black et al., 2018). This study made use of PVM to understand the possibilities of oral PrEP integration in SRH services, for young women in rural and urban KwaZulu-Natal. However, with the use of PVM has emerged a number of ethical issues, particularly in research that focuses on marginalised groups in institutions and communities, including girls and young women. Research that reflects on these is only just emerging.

As highlighted in the previous chapter, this study is located within cultural studies, and resists perpetuating discourses that speak for all women, but rather proposes the interactions with individuals and communities to understand social and cultural experiences by listening to local voices. Therefore, in this study PVM was utilised as a contextually and culturally relevant research approach that aids in the meaningful engagement and inclusion of vulnerable and marginalised populations such as young

women in rural and urban contexts, we see PVM as an ethical approach to research, particularly around sensitive issues that relate to SRH.

Even though the study population for this study included young women from both rural, and urban settings, this chapter focuses more on the novelty of making use of PVM among young women from rural setting Because of their peculiar vulnerabilities in the HIV and AIDS epidemic.

Young women in rural communities face greater challenges in the HIV and AIDS epidemic in South Africa with multiple social and cultural factors that marginalize them, creating a vicious cycle of vulnerabilities which include; intimate partner violence, discrimination, sexism, lack of sexual and reproductive healthcare services (Kim and Motsei, 2002, Dunkle et al., 2004, Jewkes, 2009). Rural communities are usually characterized by being isolated from economic activities, having little or no health-related resources, unemployment, lack of sanitation and poverty (Rispel, 1992). According to Sauvageot and Da Graça (2007), rurality may be defined in various ways and no universal definition has been adopted. However, most rural dwellers work in agriculture, often for very low rates of compensation, there is also a high dependence on social grants (Council et al., 2005). It can be argued that an individuals' income or the family's income determine the access to health relate resources they can have.

Young women in rural contexts that are poor can face challenges of access to healthcare by virtue of their economic status; a young girl in a rural village may not afford to travel to the clinic to access basic healthcare. Moreover, not only do poor people have lower levels of access to basic healthcare services compared to other segments in the population, but their healthcare infrastructures are usually under resourced (Dutta, 2011). In poor rural areas in South Africa, there is a serious shortage of skilled medical personnel, the government healthcare system continues to deteriorate, with the private healthcare sector only providing services for a minority of the country's population (Kim and Motsei, 2002, Coovadia et al., 2009). This is the context that young women in rural communities find themselves as they seek for HIV prevention methods that will protect them from HIV infection.

The vulnerability, lack of preventative measures for women, lack of agency, and marginalisation that many African women encounter suggest that strategies of abstinence, be faithful, and male and female condom use alone is insufficient to significantly reduce their vulnerability to HIV risk (Sen and Östlin, 2008) .

A large body of literature emphasizes the significant role of culture in relation to public health issues; how people manage and maintain their health is dominantly influenced by their socio-cultural context (Slabbert et al., 2015, Petersen, 2009, Mantell et al., 2005, Singhal, 2013). Understanding how cultural prescriptions can influence acceptance of oral PrEP in various contexts is key for effective implementation and product uptake by young women who need oral PrEP to protect themselves against HIV infection. Oral PrEP implementation and acceptability studies need to include culture-sensitive approaches to HIV prevention options that include discussions with young women, particularly in the African context (Tanner, 2008, Severy and Newcomer, 2005, Weeks et al., 2004, Stirratt and Gordon, 2008). Moreover, there is a need to conduct research with populations that are usually marginalised, there is also a need to conduct research in contexts that are highly affected by the HIV and AIDS epidemic. There is a need for us to conduct research that will help understand the real, lived experiences of young women in rural settings, who engage in various sexual encounters at different stages of their lives in an ethically appropriate manner.

Of particular relevance to our work is the fact that young women in rural communities face the bulk of the challenges related to the HIV and AIDS epidemic. The high rates of HIV infection among this population intersect with multiple social and cultural factors that marginalize them, including poverty and unemployment, as well as gender-based violence (e.g., intimate partner violence, sexual assault and rape), discrimination, and sexism (Kim and Motsei, 2002, Dunkle et al., 2004, Jewkes, 2009). Rural communities are usually characterized by being isolated from large economic activities, having little or no health-related resources, including sexual and reproductive healthcare services, and sanitation (Moletsane and Ntombela, 2010). It is these characteristics that often place young women in vulnerable positions with little or no means to negotiate safe sex practices, often exposing them to the risk of SITs, including HIV. It is for this reason that the study we reflect on used journey mapping, a participatory visual method, to

explore the merits of including oral PrEP as part of SRH services in order to reduce HIV infection among young women.

To allow for maximum participation from the young women, the workshops were structured around several participatory activities with journey mapping as the main data generation method. Journey mapping is a participatory visual method that involves participants reflecting on their lived experiences and particular encounters that can be depicted on large scale paper in a 'map-like' diagram. This process allows participants to carefully and freely express their experiences through drawing or mapping (Dutta and Thaker, 2016). Mapping as a research method fits within a broader framework of PVM that engages communities in the generation of information, where they have control over the process (Maman et.al, 2009:370). In this study, participants were encouraged to create a map on a large-scale paper that depicts their experiences of going to the clinic to access their oral PrEP supply. The participants were given materials including poster paper, colored paper, scissors, glue, crayons, colored markers, etc., to create a map that depicted their typical clinic visit when they are going to the clinic to collect their oral PrEP. The prompt for the journey mapping was:

> *Reflecting on all your clinic visits, draw a step by step map of what you do and what you encounter from the moment you enter the clinic. What do you do in these different steps? (e.g., taking blood tests, sitting in the waiting room, etc.).*

Probing questions to assist participants develop journey map that described their clinic visit experience were prepared. The questions were flexible so as to allow for change depending on how the women responded and what information they felt comfortable providing. With the assistance of a bilingual research assistant, we were engaging with women who were comfortable speaking isiZulu, we interacted in their native language. We alternated between the two languages depending on the participants preferred language, if a participant interacted and asked questions in isiZulu, we would change from English to speak isiZulu. In some encounters, we found that the participant's asked that we explain the prompting questions more and then we would alternate to isiZulu from English in order to explain some concepts more clearly. The workshops were audio-recorded and transcribed and translated by the researcher and an assistant to ensure data intercoder reliability.

Below is a schedule that guided the facilitation of the workshops on day one and day two comprised of one-on-one interviews with all the participants who were part of the workshop the previous day. The workshop schedule below depicts what was done in all four workshops on day one.

Time	Activity	Facilitators	Materials	Outcome
Day 1				
08h00-08h30	Arrival, Set up,	Facilitator 1 & Facilitator 2	All Stationary	Facility set-up for participants
09h00-09h30	**Phase One:** **Introduction** - Welcome. - Who we are. - What we are doing. - Why we are doing this. - Clear understanding of participations. - Questions and Answers - Sign consent form	Facilitator 1 (Facilitator 2 to be taking down notes)	Flipchart Marker Consent forms Pens	Participants understanding of the research study. Signed consent forms.
09h30-10h00	**Phase Two:** **Introduction to Participatory visual methodology (PVM)** - What is PVM? - Creativity and thinking out the box	Facilitator 1 (Facilitator 2 to be taking down notes)	Chart Markers	Establish an understanding of PVM with participants.
10h00-10h30	**Picture-me exercise** In a pile of printed-out images, participants must select a picture that they would like to use to share something about themselves, "picture-me" in this image.	Facilitator 1	Pictures	Ice-breaker Participants introduced to one another in a way that gives insight into their lives. Allow participants to share and open up about their personal lives.
10h30-12h30	**Phase Three:** **Journey Mapping** - What is journey mapping? - How can journey mapping help us? The participants will draw two journey maps, one of their current visit ("reality")to the clinic and the other of their "ideal" journey map.	Facilitator 1 (Facilitator 2 to be taking down notes and photographs)	Paper, colour paper, magazines, koki pens, scissors, markers, glue.	Establish an understanding of journey mapping. The journey maps complete.
12h30-13h15	**Phase four:** **Journey map discussion** - Debrief of journey maps.	Facilitator 1 (Facilitator 2 to be taking down notes)	Chart Markers	Understand participants experience of the exercise and understand overall findings.
13h30-14h00	LUNCH			
14h00-14h15	Wrap up & explain next day workshop			

Table 5.1: Workshop schedule

All the young women worked on their own "clinic journey map" on large scale paper to provide enough space for privacy and creativity. During this process, the young women determined what to share/not to share and were reassured of their right to withdraw from the workshop process at any point if they felt uncomfortable. In addition, to enable participants to elaborate on the issues they raised during the journey mapping exercise, as well as to raise new ones they did not feel comfortable raising in a group setting, I conducted one-on-one interviews with all the young women in the group.

Ethical dilemmas emerging from the journey mapping workshops

Research on oral PrEP as an HIV prevention method is important for understanding young women's SRH needs. However, paramount importance should be placed on the safely and well-being of participants who are part of research projects conducted in their communities. Ethical principles and standards are therefore important to ensure that participants are protected, particularly vulnerable groups in rural contexts in developing countries. Research in developing countries can create risks of exploitation on participants and communities where these studies are conducted (Emanuel et al., 2004).

That all research must be regulated by ethical principles that ensure that participants involved in the study are not placed in risk by their participation in the research study is common knowledge. This study sought to implement ethical principles that would protect young women involved in this study. As discussed above, young women in South Africa have been identified as a key population within the HIV epidemic. They are faced with a number of socio-economic challenges that increase their vulnerability to HIV infection, as well as limited access to HIV prevention, treatment and care. Through journey mapping, we attempted to provide the young women in the study with safe spaces to express themselves about the barriers to accessing oral PrEP in SRH services in the clinic. However, a number of ethical dilemmas emerged from my use of PVM. These, and the strategies we used to address them, are discussed below.

Participation as the driver of inclusion

The principles of participatory research that informed this study emphasize a "bottom-up" approach in the research process that aims to prioritize locally defined social challenges (Cornwall and Jewkes, 1995). The driving element in participatory research is the involvement of the local community members in the research process, allowing these community members to gain a sense of agency. This gives participants in the study a sense of involvement and ownership of the developed knowledge in the research. Similarly, in this study, my aim was to involve the young women in knowledge production, and to make a meaningful contribution in research that is about that them and for them. For example, ideally, the young women in this study should have been given the platform to develop the research agenda by contributing to the development of research questions and objectives. However, this study could not be inclusive of community members at every stage in the research process. Instead, as researchers, I went into the research field with predetermined research questions and objectives.

The young women who were part of this study were involved in the data collection process and, to some extent, in the data analysis. To circumvent this, my use of PVM, and journey mapping in particular, promoted participation, in which the young women were given a platform for effective meaning-making and knowledge production. Utilising journey mapping as a methodological tool enabled participant engagement, from production to analysis, in which participants openly shared their perspectives through the art they produced (Hankins et al., 2015). The visual artefacts they produced (journey maps), were read and interpreted with them in the workshops (Mitchell et al., 2011).

The process of PVM is engaging, requiring participants to dig deep in their thought process and to be reflective about their experiences related to the social phenomenon under inquiry. As a researcher, I created a space where we continuously engaged participants on what they meant in the maps they produced by asking questions and listening to the answers. The use of PVM in this study, specifically journey mapping, was employed to give the young women a sense of control and inclusion in the research process. It provided them a space to voice their perspectives on a sensitive

issues they would otherwise not be able to freely discuss in conventional research methods: their sexual and reproductive health and rights.

‘Safe spaces’ as ethical considerations in research with young women

As discussed above, in this study, I sought to create safe spaces in which the young women could discuss their needs vis-à-vis accessing oral PrEP in SRH services in the clinic. This meant that I needed to employ research methodologies that were safe, contextually relevant and accommodative of young women and their sexual health and needs. In the South African context, where young women often find themselves in abusive relationships characterised by gender-based violence (Dunkle et al., 2004, Gerntholtz et al., 2010, Ackermann and Klerk, 2002), including rape; there is a greater call for researchers and scholars to provide safe platforms for engagement, sharing and dialogue in the research process. Such research is also necessitated by the marginalisation of girls and young women that occurs at both the individual and community level, in which they are rendered voiceless and invisible in mainstream discourse, and are sometimes are structurally deprived of materials and resources (Dutta, 2008).

The journey mapping workshops not only created spaces for young women to express their experiences and opinions through art, they also created a place where young women could discuss issues that they would not have discussed in conventional research contexts. In this study I created “safe spaces” by carefully selecting venues for the workshops that would provide privacy for the young women within their communities. I specifically chose spaces where young women recognised that I respected their privacy and created an environment that was safe and offered an opportunity for them to freely talk about their lived experiences, and to express their views on such sensitive issues as their SRH. I used spaces that were being rented out by the local community library. The space was free from distraction and secluded from activity that could disrupt the workshop process. Of particular relevance to us was what Wilson and Neville (2009) refer to as ‘culturally safe spaces’ for conducting research. These encompass respecting the worldviews of those being researched, recognising their culturally-driven differences, and including these in the design and

location of the research. Creating culturally safe spaces requires commitment to respect the rights of the research participants as human beings and to genuinely 'work with' them (Wilson and Neville, 2009).

For the above reasons, I selected the venue adjacent to the community library. All the participants could easily walk to the venue or take a taxi. This was informed by my belief that taking participants away from their familiar everyday contexts to conduct research may make them feel intimidated or alienated, and therefore, further silenced. Even though orthodox research methodologies provide spaces for research participants to feel safe, sometimes they fail to develop contextually relevant and culturally sensitive ways of engaging with research participants. The history of research in Africa is typified by scientists from outside of the continent researching and writing about Africans. African people were largely never in the development and analysis of research done "on them", and therefore has limited involvement in what questions were asked, and what conclusions were reached (Bless et al., 2006).

Listening and learning from participants

A key ethical principle that drove this research was the need to listen to the young women's voices. Listening to women's voices at the local level is imperative, as it interrogates the stories from their perspectives, and challenges narratives of their helplessness, low self-efficacy, and backwardness that have historically been portrayed in dominant discourses in mainstream social change initiatives (Dutta, 2011). Vanner (2019) is of the opinion that providing opportunities for girls to speak, and listening to them has become a key element of girlhood studies, and should hold a prominent place in transnational understandings of girlhood.

As South Africa transitions into the phase of oral PrEP upscale and integration into SRH services, there is a need to engage and converse with key populations to whom this product is being targeted (i.e. young women) without making them feel even more vulnerable. In this context, young people must be able to share their views around their vulnerabilities to HIV infection, what prevention options they see as viable for them to access in safe spaces that will protect them. In this study, listening to the

voices of the young women through journey maps enabled us to hear these perspectives. I deliberately opened spaces for discussion among the young women during the workshops so that I as the researcher could listen and learn from their lived experiences.

Obtaining and Re-establishing Consent

Informed consent has received recognition as a critical ethical principle in any research, regardless of the context and population (Wasunna et al., 2014). In this study, consent from young women who would be involved in this study was fundamental, as the foreground of inclusion. I had to ensure that the young women felt comfortable to be part of this study, and not feel that they were coerced in any manner. In this study, I was informed by the notion that allowing people the opportunity to understand what they are agreeing to participate in (informed consent) is critical. As the researchers, I communicated with potential participants in both English and isiZulu, their home language. Consent forms were also made available to the participants in both languages.

The workshops were also conducted in both English and isiZulu to ensure that the participants were able to express themselves. This was to ensure that participants had a clear understanding of what the study entailed and what their rights were, for example, to anonymity, autonomy and to refuse to participate, as the research process unfolded (Bekker et al., 2014). The concept of gaining consent with this particular group was critical because young women in South Africa are cited as a vulnerable and key population group in the HIV and AIDS epidemic, therefore any research conducted with young women should consider their already existing vulnerabilities, and provide points of withdrawal. Therefore, what is critical here is that research participants are not put at further risk of harm or their vulnerability exacerbated by the research processes. Moreover, the fact that they are a group whose permission for anything is seldom sought, ensuring that they gave informed consent to participating in the study was particularly important.

Discussion

In this study, I used journey mapping with young women to solicit their views about accessing oral PrEP in SRH services within clinics in their rural communities. My aim was to use this participatory visual method to facilitate their active participation in the research, particularly in research related to sexual and reproductive health, a topic that is regarded as taboo in rural communities. Journey mapping as a process engaged the young women in a collective process of understanding their own needs, in the context of broader HIV prevention options for women. The PVM blurred the boundaries of art, research and conventional forms of data collection and enabled the inclusion of women as knowledge producers.

As discussed above, a number of ethical issues emerged in the study. These included obtaining consent from a group that is normally regarded as powerless (young women), expecting young women to speak out, when they are usually silenced and expected to be silent on important issues in their community, and ensuring that their participation was sustained throughout the research process. To address these, I used PVM, and in particular, journey mapping. For example, I conducted the research in the form of workshops to create an interactive learning space for us and the participants. I believe that the workshops promoted participation, enabled learning for us and the young women regarding oral PrEP and SRH, and contributed to a strong sense of agency and self-efficacy. For the participants in this study, the workshops communicated a sense that I as the researcher truly desired to hear their views.

Participatory research methodologies are effective means of meaning-making and knowledge production through creative arts, though it is full of complexity, the art products are themselves texts that can be read and interpreted by their research participants and the researcher (Mitchell et al., 2011). The essence of visual methodologies is that they represent what would not have been easily expressed in words (Mitchell and Sommer, 2016). My experiences of using PVM in this study proved to be an effective approach in engaging young women about sensitive issues such as SRH and HIV prevention. PVM allowed us to create an interactive, co-learning environment that enabled young women to speak freely about challenge they face

when they go to SRH services to collect their oral PrEP. This methodology allowed us to understand the young women's experiences of the clinic that would not have been easy to express in an interview setting. PVM allowed the young ladies in this study to reflect, interrogate and make suggestions toward the SRH services in their communities.

Conclusion

Young women in rural communities are both marginalised and vulnerable in the HIV epidemic. If we are to address their vulnerability, we need research that takes their perspectives on HIV prevention and SRH issues seriously. This will enable the development and implementation of carefully tailored intervention that address their contextual needs. In this context, culturally sensitive, socially relevant and structurally appropriate HIV prevention packages are needed.

Therefore, as South Africa sets out to upscale oral PrEP in SRH services, the social and cultural contexts in which vulnerable populations are situated need to be understood for optimal population-level impact. This study suggests that to do this, there is a need to further engage young women to explore how oral PrEP can be integrated into SRH services. In the HIV prevention field, we need to understand that new HIV prevention tools such as oral PrEP will not be easily embraced because they are needed by communities. It is only through a better understanding of the social and structural contexts in which these innovations are introduced that we can perhaps facilitate the successful integration of oral PrEP in SRH services for vulnerable populations. To gain this understanding, such populations need to be engaged in ethically considerate methods such as PVM. In this study, I established that journey mapping as a PVM is a safe, contextually and culturally relevant research method in the engagement of young women about sexual and reproductive healthcare issues. This methodology engaged young women in exploring their access to oral PrEP as an HIV prevention method, and the possibilities of integration it in SRH services in an ethical way.

The following chapter will present the data collected from the journey mapping workshops and the one-on-one interviews with the young women. Data derived from nurses interviews is also presented in the next chapter to give a healthcare providers perspective towards this research inquiry.

Chapter Six: Data Presentation

Introduction

This chapter presents the data collected in this study. As described in chapter five, the data collection in this study was in two phases; the first phase was the journey mapping workshops that the young women were involved in, and the one-on-one interviews with all the female participants who participated in the journey mapping workshops. Two nurses from both the rural and urban CAPRISA research clinics were also interviewed, see also Figure 4.3: data sets in chapter four that depicts the data collected.

Structure of chapter	
Section 1	Visual Data from journey mapping workshops.
Section 2	Textual data from one-on-one interviews with the young women taking oral PrEP.
Section 3	Textual data from one-on-one interviews with nurses.

Table 6.1: Structure of data presentation chapter

The first section of this chapter presents the visual data from the journey mapping workshops. All the visual data presented is clearly labelled with participant pseudo name, code and location. The second section of this chapter presents data from the transcripts from the journey mapping workshop and one-on-one interviews with the young women. The third section of this chapter presents the data from the one-on-one interviews with the nurses from both the eThekwini CAPRISA clinic and the Vulindlela CAPRISA clinic. The data collected from the nurses is presented according to the themes developed.

Thematic analysis

As it has been stipulated in the methodology chapter, the data in this study was analysed using thematic analysis. The process of thematic analysis as a qualitative descriptive approach is usually used to identify, analyse and report patterns which are

referred to as themes within data (Guest et al., 2011, Braun and Clarke, 2006). This form of analysis is the process of searching for and identification of common threads that extend across an entire interview or set of interviews (Vaismoradi et al., 2013, Braun and Clarke, 2006). Moreover, this process also considers the relationship between the themes identified, meaning that thematic analysis is more than finding patterns in the data. The data within this chapter; both visual data and interview data is analysed through this approach.

The prompting questions that were used in the workshop and one-on-one interviews were guided by the main research questions in this study, which are discussed more in chapter one:

1. In what ways is the current structure and organization of SRH services an impeding or facilitating environment for young women assessing biomedical products?
2. What are the likely socio-cultural challenges or opportunities that will influence acceptance, uptake and adherence of oral PrEP in SRH services among young South African women KZN?
3. In what ways can the current structure and organization of SRH services be realigned to meet the needs of young women in order to ensure acceptance, immediate uptake and adherence to oral PrEP Truvada?

Also see appendix 3 (participant interview guide), appendix 4 (nurse interview guide), and appendix 6 (journey map guide) for more details on the research instruments that informed the data collection process.

Biographical Information: Young women

In order for the information obtained to relate to its context and provide more understanding, it is necessary to be aware of the biographical information of the young women who were involved in this study. Below two tables are displayed to depict the biographical information of the young women who were part of this study:

Date of interview	Respondent Pseudo name	Age	Employment status	Place	Duration of using oral PrEP
16-11-2018	(P1) Amanda	31	Unemployed	eThekwini CAPRISA clinic	7 months
16-11-2018	(P2) Zandi	29	Unemployed	eThekwini CAPRISA clinic	10 months
16-11-2018	(P3) Zoleka	34	Unemployed	eThekwini CAPRISA clinic	8 months
16-11-2018	(P4) Akhona	23	Unemployed	eThekwini CAPRISA clinic	13 months
27-07-2018	(P5) Phakama	28	Unemployed	eThekwini CAPRISA clinic	8 months
27-07-2018	(P6) Yolanda	23	Employed	eThekwini CAPRISA clinic	25 months
27-07-2018	(P7) Lihle	25	Unemployed	eThekwini CAPRISA clinic	No data provided
27-07-2018	(P8) Zinhle	31	Unemployed	eThekwini CAPRISA clinic	7 months

Table 6.1: Biographical Information- Urban Young Woman

Date of interview	Respondent Pseudo name	Age	Employment status	Place	Duration of using oral PrEP
17-08-2018	(P9) Liyema	21	Unemployed	Vulindlela CAPRISA clinic	7 months
07-08-2018	(P10) Mzamo	29	Unemployed	Vulindlela CAPRISA clinic	4 months
17-08-2018	(P11) Lethu	23	Unemployed	Vulindlela CAPRISA clinic	1 month
07-08-2018	(P12) Yummy	24	Unemployed	Vulindlela CAPRISA clinic	3 months
07-08-2018	(P13) Ndalo	28	Unemployed	Vulindlela CAPRISA clinic	6 months
07-08-2018	(P14) Qondi	20	Unemployed	Vulindlela CAPRISA clinic	6 moths
17-08-2018	(P15) Thando	21	Unemployed	Vulindlela CAPRISA clinic	5 months

Table 6.2: Biographical Information- Rural Young Women Group

In terms of age disparities, only four participants were in their thirties, and most of the young women involved in this study were in their early and mid-twenties. As we can see from above, majority of the young women involved in this study were unemployed during the study period. As mentioned in chapter two, young women are a key

population group in South Africa that is considered to be at high risk of HIV infection (Celum et al., 2019). The young women involved in this study fit into this vulnerable population group because of their age, gender, and employment status that characterize some of the factors that contribute to their vulnerability to HIV infection.

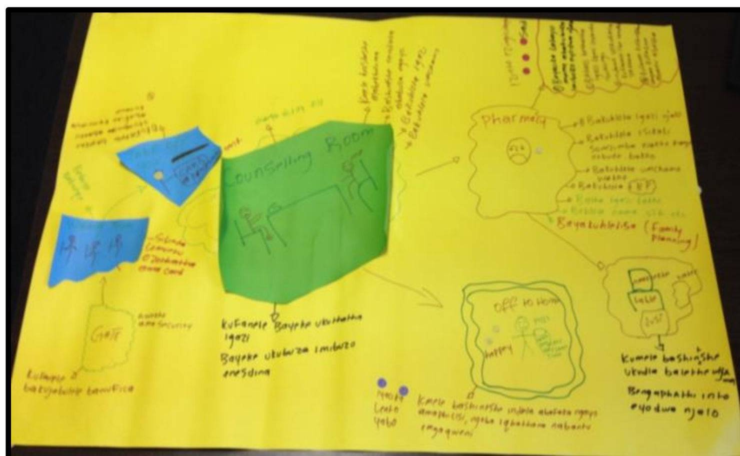
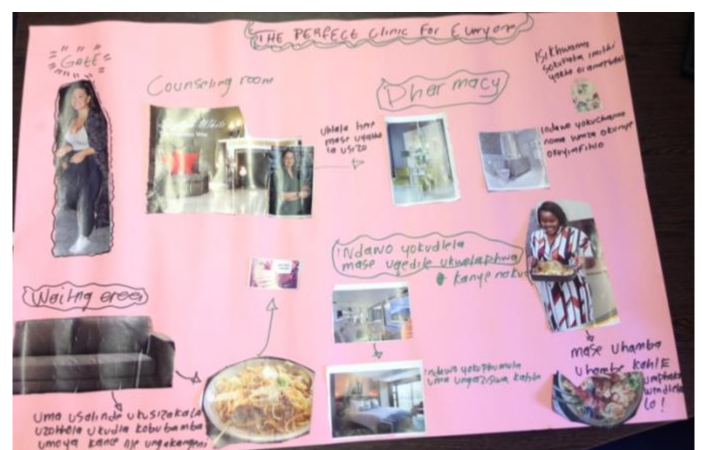
Visual data: Journey mapping workshop

In this section, charts from the journey mapping workshops are presented. The first set of journey maps, which are 14 in total (2 journey maps per person) are from rural Vulindlela and the following 16 journey maps (2 journey maps per person) are from urban eThekwini. Key points from each chart that were visible to identify and read, are presented to depict the statements that the young women clearly shared on their charts. Some of the texts on the charts were written in isiZulu, which was the predominant home language among the young women. These texts were translated and presented by the researcher where necessary. A short description of the text and illustrations on the charts is also provided below every set of the journey maps created by the young women.

While most of the young women wrote clearly on their charts, some of the young women did not use texts as much, but rather made use of images. This did not in any way bring obscurity to what the charts represented because all the young women had the opportunity to verbally present their journey map charts. The data from the verbal descriptions of the charts was transcribed and is thematically presented in the next section of this chapter.
A short description of the journey map charts is also given below the two charts for each young woman to give readers further details about what the young women illustrated on the charts.

What was interesting to note from the visual data, which is also a note of caution is that most of the young women preferred to outline the current problems they faced in the clinic by using solution-based language or terminology. In the first journey map labelled on the tables below as “Reality Clinic”, most of the young woman gave a clear depiction of the various steps and processes involved when going to the clinic to collect

oral PrEP, however, most of the young women made recommendations on what can be improved in the clinic. This does not limit or disadvantage the data presented as the points raised on the journey map charts, the journey maps still reflect the lived experiences of these young women as they go to the clinic.

<table>
<tr><th colspan="2">Liyema, Vulindlela (P9)</th></tr>
<tr><th>Reality Clinic</th><th>Dream Clinic</th></tr>
<tr><td>
</td><td>
</td></tr>
<tr><td colspan="2">Key points from the charts

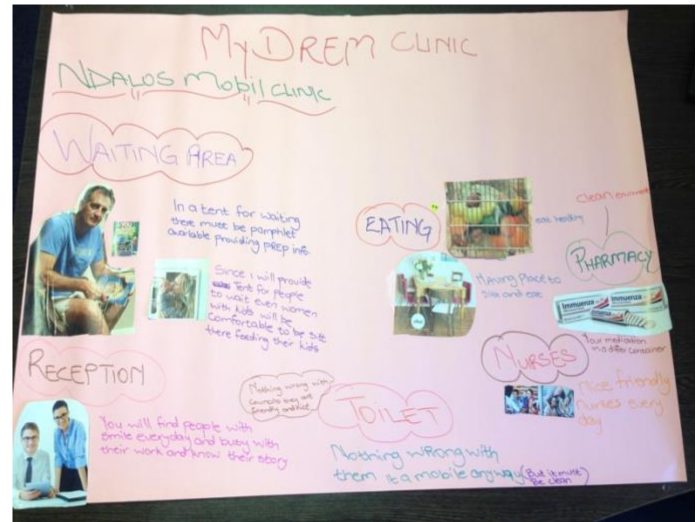
Reality clinic: “They must be fast when attending to us…”
“They must not ask us irritating questions…”
“They must change the packaging of the pills…”
Dream Clinic: “While waiting to be attended, you must get food to eat…”
“ A package to carry your treatment…”
“A place to rest while you are waiting…”</td></tr>
</table>

P9 made a clear depiction of her journey through the clinic when collecting oral PrEP. The texts, expressions, and images used in the "reality" clinic are mostly negative with most of the texts giving recommendation of what the healthcare providers "must do". The reality clinic presented here is recommendation- based, with comments showing dissatisfaction of services provided at the clinic, particularly dissatisfaction with healthcare providers. As depicted in the text box above, P9 wrote "they must not ask us irritating questions", this suggests that P9 has been asked "irritating questions" during the counselling sessions. A sad face was drawn on the chart in the pharmacy section, this could be a depiction of dissatisfaction of services. Even though there is clear dissatisfaction of the clinic experience on this chart, the journey map end off with a positive point. An image of a smiling person is depicted on the "reality clinic", and this is labelled "off to home".

The dream clinic depicted by P9 is entitled "The perfect clinic for everyone", and places emphasis on friendly services through images of three people smiling. This young woman highlights the importance of the oral PrEP packaging by mentioning on first chart that the pill packaging must be changed, and on the second one that they must be given a pack to carry treatment. In the dream clinic journey map, food and comfort in the waiting area are depicted as important in the clinic visit. A clean and sophisticated bathroom and bedroom are included in the chart showing that these are some facilities that the "dream" clinic they envision would have. The step to step process in both the charts is very similar, with no major changes to the original process undertaken in the clinic.

Most of the journey maps depicted the same process involved in collecting oral PrEP from the clinic within the SRH services. However, the young women expressed different opinions about the services provided with some of the young women expressing dissatisfaction with the services provide at the clinic, and some expressing satisfaction in the services provided.

Ndalo, Vulindlela (P13)

Reality Clinic	Dream Clinic
	

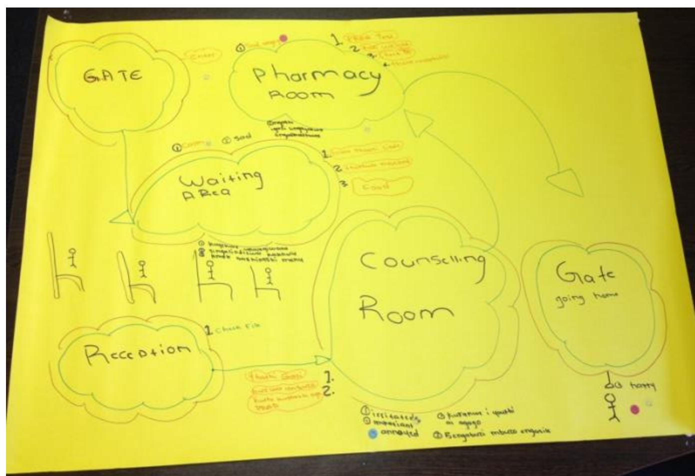
Key points from the charts

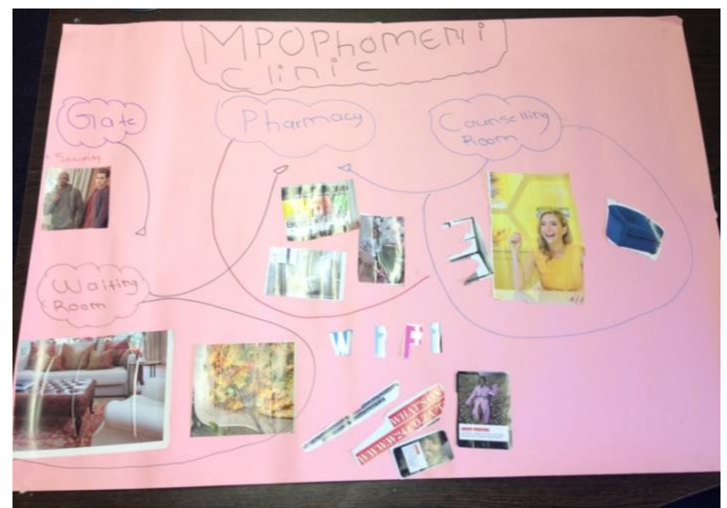
Reality clinic: "They should get us a tent so we that we do not get a sun…
and it become a problem when it raining…"
"I am happy with it counsellors are friendly…"

Dream Clinic: "In a tent for waiting there must be pamphlets available providing PrEP info…"
"You will find people with smile every day and busy with their work…"
"But it must be clean…"
"Have a place to sit and eat…"
"Your medication in a differ…"
"Eat healthy…"

A clear step-to-step process of the clinic visit is given by P13, however, little expression shown in each of the steps. P13 inserted two sad faces on her journey map, the first one being at the very beginning of the process in the waiting area. The second sad face was labelled “see a nurse”, showing that when it is time to see a nurse, it is an unpleasant encounter.

The dream clinic journey map gave a clear depiction of what the ideal clinic would look like. This dream clinic was entitled “Ndalo’s mobile clinic”, making it more personal for the participant. P13 depicted that her clinic would have pamphlets giving further information about PrEP. The point of healthcare providers being friendly is depicted twice on this dream clinic chart, and the issue of having clean spaces in the clinic is depicted twice in the dream clinic chart. This emphasis of these points highlight the that to this young woman, friendliness and cleanliness are important in a clinic.

<table>
<tr><th colspan="2">Qondi, Vulindlela (P14)</th></tr>
<tr><th>Reality Clinic</th><th>Dream Clinic</th></tr>
<tr><td>


</td><td>


</td></tr>
<tr><td colspan="2">

Key points from the charts

Reality clinic: “We are made to wait for long…”
“Irritated, impatient, annoyed…”
“put in youth: not grannies…”
“We must not be asked irritating questions…”
Dream Clinic: “Wifi…”
</td></tr>
</table>

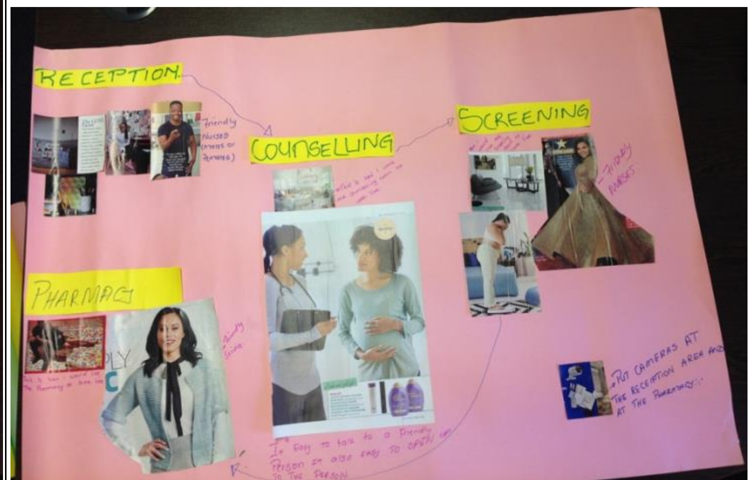
The reality clinic depicted here is clear and simple with little description of all the steps involved in the clinic visit. P14 depicted negative points concerning the clinic visit with little clarification of these points on the chart. Significantly, P14 highlighted the aspect of the nurse’s age, stating that younger must replace the older nurses. Within the

counselling area, the labels “irritating, impatient and annoyed” were placed, describing the counselling sessions.

The dream clinic for P14 had very little words, but rather made use of images to describe the “ideal” clinic visit. The only descriptive text on the chart is “WiFi”. The images used in this chart largely depicts the kind of healthcare workers that will be in that clinic, and the setting in the clinic. For example, P14 used an image of a couch in the waiting area to show comfort that must be experienced in this section on the clinic.

<table>
<tr><th colspan="2">Mzamo, Vulindlela (P10)</th></tr>
<tr><th>Reality Clinic</th><th>Dream Clinic</th></tr>
<tr><td>

</td><td>



</td></tr>
<tr><td colspan="2">

Key points from the charts

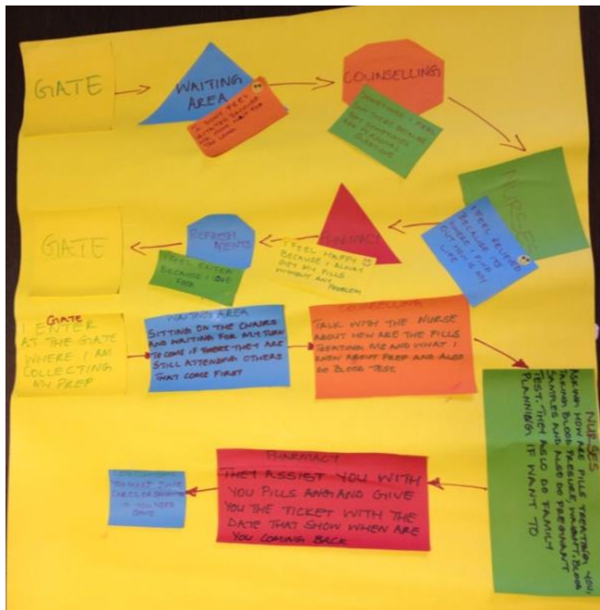
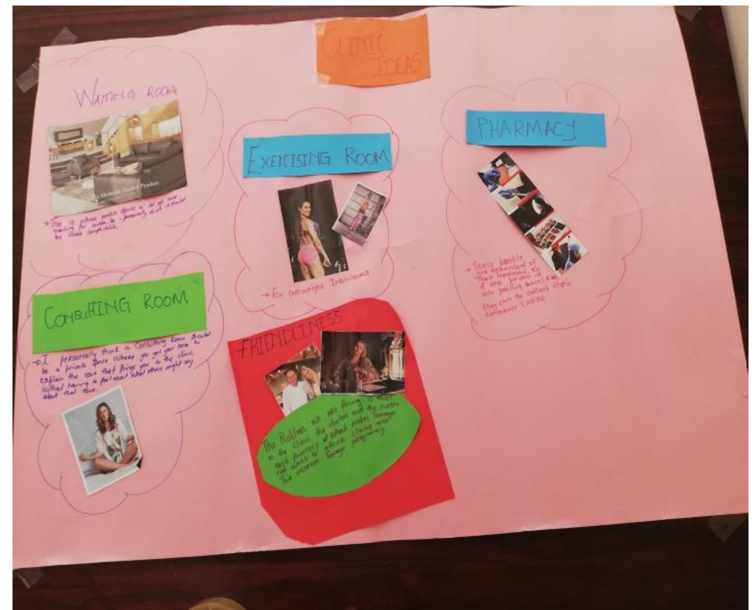
Reality clinic: “Things to be improved…unfriendly nurses…judgemental nurses…”
“Collecting medication…over the moon…”
“things to be improved… late coming of the mobile…”
Dream Clinic: “Friendly nurses, male or female…”
“Friendly service…”
“it is easy to talk to a friendly person…”
“Put cameras in the reception and at the pharmacy…”

</td></tr>
</table>

P10 describes her clinic visit journey clearly, with detailed descriptions of her feelings in each step in the clinic visit. Unlike most of the reality journey maps depicted by the

other young women, the overall impression of this journey map is a positive one. This chart has clear smiling faces and positive texts are evident such as “happy”, “excited” and “over the moon” on the chart. P10 depicts on her journey map that her clinic visit to collect oral PrEP is a pleasant one, with the exception of improvements being made at some points in the clinic. However, like many of the other young women, this chart depicts the counselling session as an unpleasant encounter. On this chart, the counselling session is labelled as “sad”. It was striking here to note the consistency with this perception, and the one-on-one interviews elaborated further on this point of the counselling session being unpleasant. However, this data will be presented later in this chapter. In their depiction of their typical visit to the clinic, P10 states on her chart that nurses must be friendlier, and they must not be judgemental.

The dream clinic chart has several images depicting the healthcare providers, images of people smiling, and labels “friendly nurses”. The word “friendly” is mention four times in this journey map, emphasising the importance of healthcare providers being friendly. In the dream clinic, the step-to-step process in the clinic is the same as the reality clinic. P10 did not change the process, but rather made changes to the way services are provided in the clinic.

<table>
<tr><th colspan="2">Yummy, Vulindlela (P12)</th></tr>
<tr><th>Reality Clinic</th><th>Dream Clinic</th></tr>
<tr><td>
</td><td>
</td></tr>
<tr><td colspan="2">

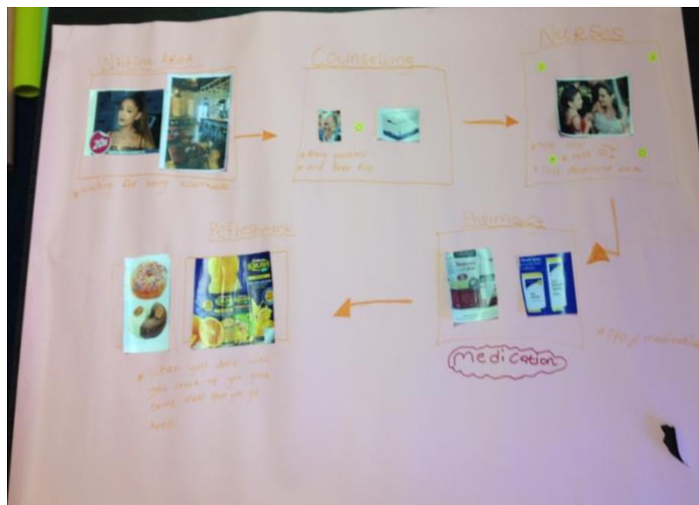
Key points from the charts

Reality clinic: "I do not feel irritated because we do not have to wait for long…"
"Counselling…I sometimes feel shy there because they sometimes ask personal questions…"
" I feel happy because I always get my pills without any problem…"
"Refreshments… I feel excited because I love food…"
Dream Clinic: "Exercise room for overweight individuals"
" I personally think that a consulting room should be a private space where you get your time to explain the issue."
" Some people are ashamed of their treatment."
</td></tr>
</table>

A clear depiction of the step-to-step process involved in collecting oral PrEP at the clinic is given in this reality clinic chart. Positive texts are made on the chart, interestingly, this journey map is very different to the accounts given by the other women. Through the various steps involved in the clinic, P12 states clearly that she is

“happy”, “excited”, and “relieved”. The overall impression of this journey map is that P12 is pleased with the process and services provided at the clinic.

The second chart, the ideal journey in the clinic developed by P12 shows the importance of health, and having health facilities such as “exercise rooms” in the clinic. In the ideal clinic journey map, friendliness is highlighted as an important feature, friendliness from healthcare providers. The waiting area is illustrated as a comfortable space with couches. P12 did not spend time showing a clear illustration of the process involved in this “dream clinic” when collecting oral PrEP, but rather shows particular features that must be in the clinic.

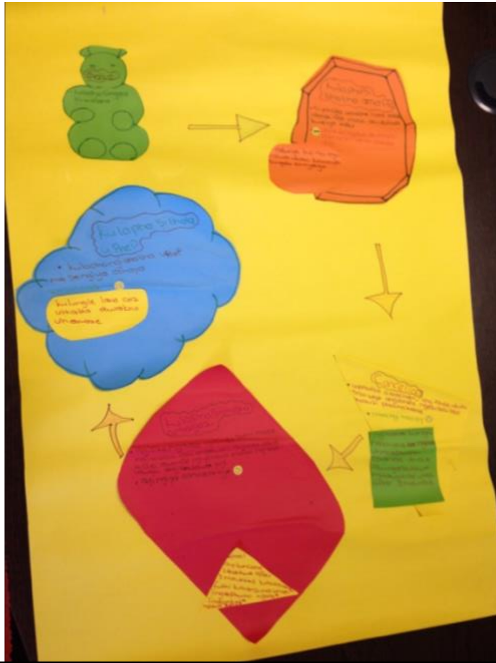
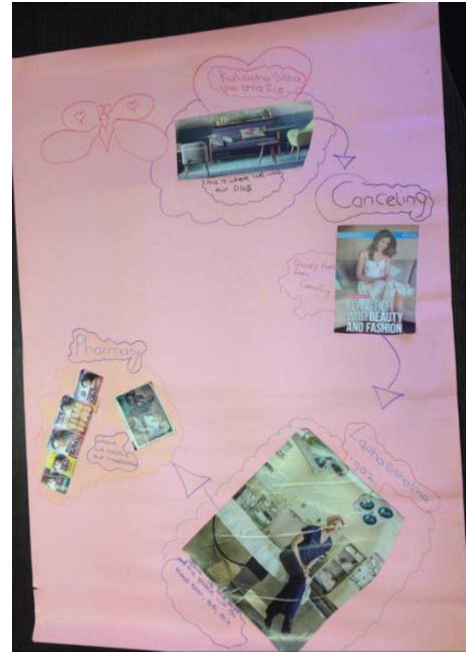
Lethu, Vulindlela (P11)	
Reality Clinic	**Dream Clinic**
	

Key points from the charts

Reality clinic: "We must have house with table and chairs to wait for counselling…"
"Go back home with a big smile and grab some juice…"
Dream Clinic: "When you are done with your check up, you grab some meal and you go home…"

P11 depicts her experience of attending the clinic to collect oral PrEP in a straight forward manner with little description of the process. However, the last stage of the journey map which is entitled "Go back home", is labelled "big smile", which insinuates that this young woman is satisfied with the services at the clinic at the end of the process. There is no negative feedback in this journey map, P11 did not express any negative points in her experiences.

The dream clinic depicting the ideal journey experience in the clinic illustrates an experience that is pleasant, with friendly healthcare providers. Again, there is an emphasis on friendliness from healthcare providers, this is illustrated through the smiling faces and images of people smiling on the chart.

Thando, Vulindlela (P15)	
Reality Clinic	**Dream Clinic**
	

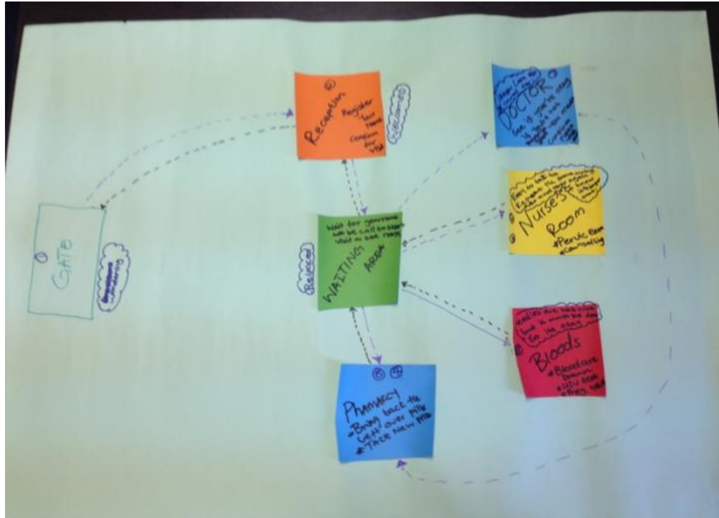
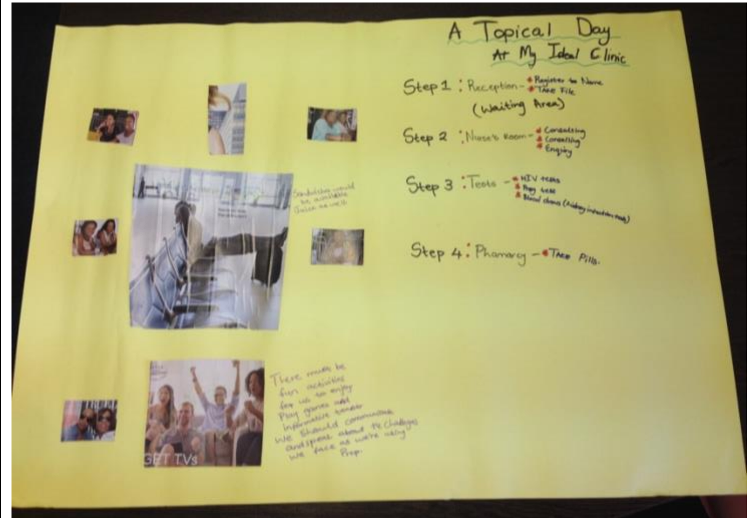
Key points from the charts

Reality clinic: “Counselling… I am happy…”

Dream Clinic: “Friendly nurse from counselling.”

P15 depicted her clinic visit experience in a clear map of the step-to-step process that leads to receiving oral PrEP. This journey map is not descriptive but offers a clear illustration of what is involved at each step in the process of collecting PrEP at the clinic. The dream clinic that P15 developed is largely with a mixture of images with key words to describe all the steps in the clinic.

The same step-to-step process depicted in the reality clinic journey map is followed in the ideal journey map, P15 did not change the process in the clinic visit, but rather added a description of what she would like to experience during a clinic visit. Descriptive words such as “friendly nurses”. The rest of the text on the chart consists of labels of the various steps in the clinic.

Zandi, eThekwini (P2)	
Reality Clinic	**Dream Clinic**
	

Key points from the charts

Reality clinic: “Needles are not nice, but it must be done…”

“Nurses room…easy to talk to…”

Dream Clinic: “Sandwiches would be available… Juice as well…”

“ There must be fun activities for us to enjoy…”

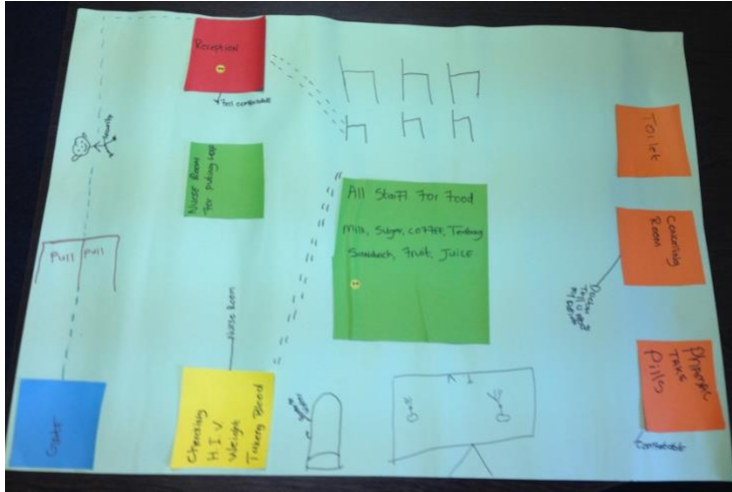
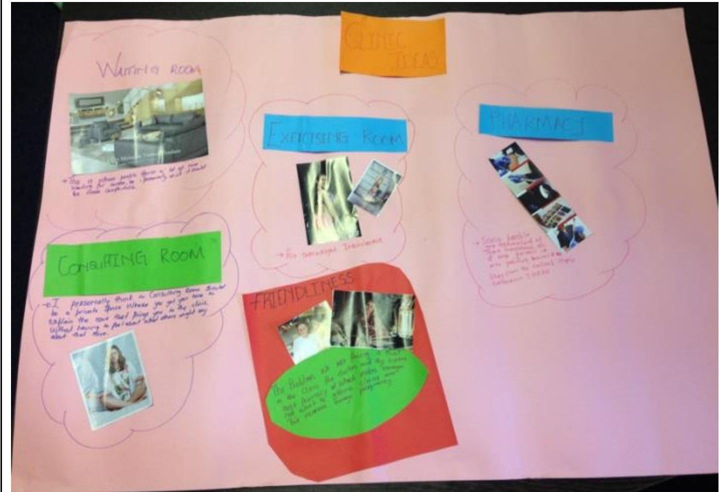
“We should communicate and speak about the challenges we face as we’re using PrEP”

The journey map depicting the experience of P2 when she goes to the clinic is a clear depiction of the step-to-step process involved when collecting PrEP at the clinic. P2 did not provide a description of her personal opinions of each step which was part of the prompts provided for all the young women during the workshops. No images were used in this journey map, and the text on the chart is limited to explaining what each step at the clinic involves.

The ideal journey map in the dream clinic chart is a creative illustration of what P2 would like to experience when they go to the clinic to collect oral PrEP. She made use of images, and texts on the chart to describe what an “ideal” clinic visit would look like.

The four steps that this P2 illustrated here is similar to the steps depicted in the reality clinic chart. This ideal journey map of the clinic is characterised with friendly faces, images depicting a comfortable and relaxed space, and descriptions of what this young woman desires to see in the clinic. On the chart P2 states that there must be "fun activities".

Amanda, eThekwini (P1)

Reality Clinic	Dream Clinic
	

Key points from the charts

Reality clinic: "Pharmacy…take pills. Comfortable"

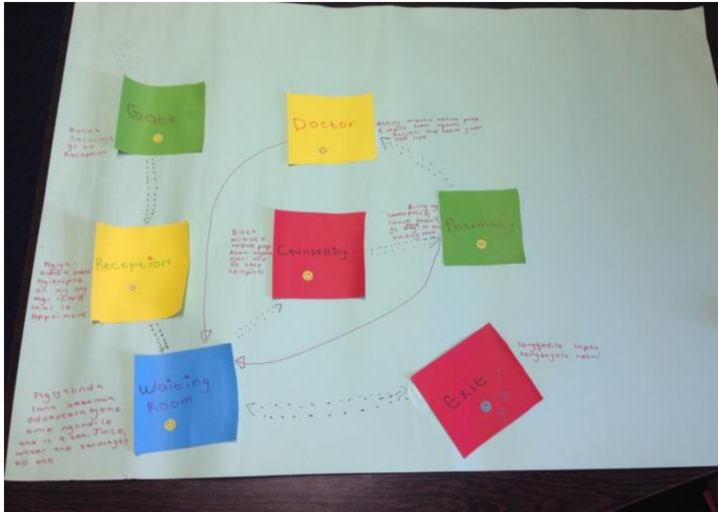
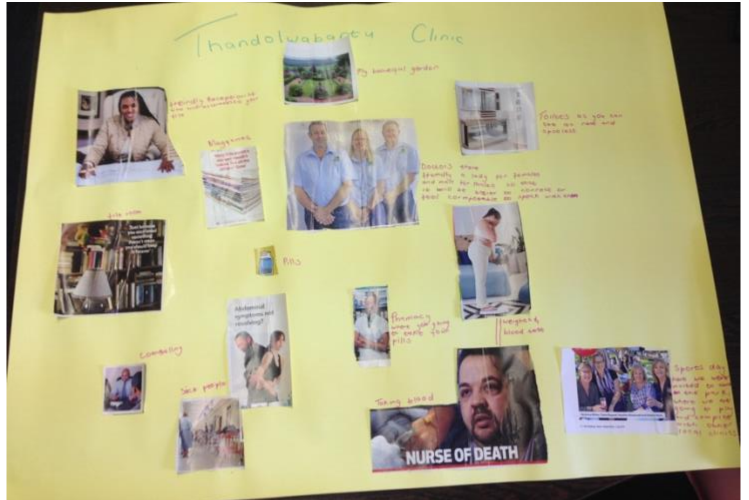
Dream Clinic: "Waiting room… this is the place where people spend time waiting for nurses, so I personally think it should be more comfortable."

"I personally think that a consulting room should be a private space where you get your time to explain the issue that brings you to the clinic. Without having to think about what others might say about the issue."

"Friendliness…the problem we are facing in the clinic the doctors and nurses are not friendly at which teenagers do not want to attend clinics and this increases teenage pregnancy."

The journey map developed by this young woman is a creative depiction of the process involved when going to the clinic to collect oral PrEP. There is no clear depiction of the various steps involved and how one step leads to the next, as the other young women depicted their journey map. However, P1 clearly showed through texts on colourful blocks the various steps involved when going to the clinic. The chart does not provide description of how P1 feels about the various steps at the clinic. The dream clinic chart

depicting the ideal journey through the clinic visit provides depictions of what characterises this ideal journey at the clinic, however, there is no clear step-to-step process. Friendliness is emphasised on this journey map, with a brief description of the challenges that young women face when they go to the clinic. There is also a short description of what the counselling room should be like, P1 believes that the counselling room should be a private space where patients can freely engage with healthcare providers about challenges or problems.

<table>
<tr><th colspan="2">Akhona, eThekwini (P4)</th></tr>
<tr><th>Reality Clinic</th><th>Dream Clinic</th></tr>
<tr><td></td><td></td></tr>
<tr><td colspan="2">Key points from the charts

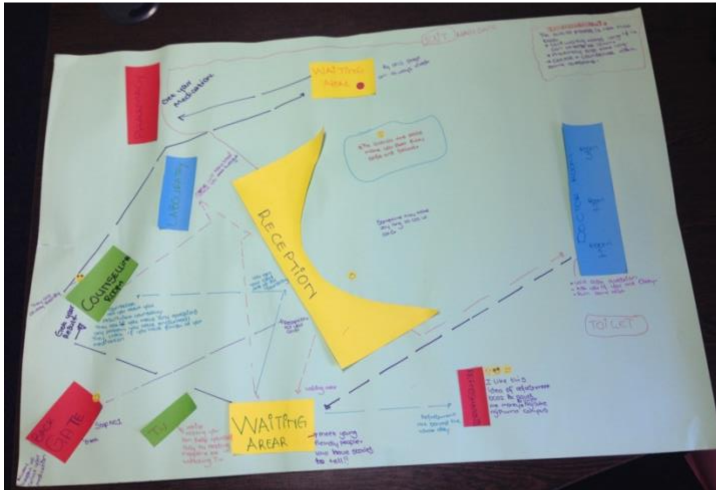
Reality clinic: “Doctor…asking questions about PrEP…and about your sex life.”
“Counselling… ask questions about PrEP, about how it is treating you and all about life issues.”
Dream Clinic: “Friendly receptionist…”
“Doctors there are friendly, a lady for female and a man for males. It will be easier to connect or feel comfortable to speak with them.”
“Toilets as you can see its neat and spotless.”
“Sports day. Here we were invited to come to the park where we are going to play and compete with other local clinics.”</td></tr>
</table>

P4 depicted her journey map clearly with arrows pointed to the various steps and processes involved in visiting the clinic to collect oral PrEP. A short description of each step in the clinic visit is provided on the chart. However, P4 was not descriptive about her personal experiences on the clinic visit on the chart. The second journey map that depicts the ideal clinic visit is entitled “thandolwabantu clinic”, this translated into

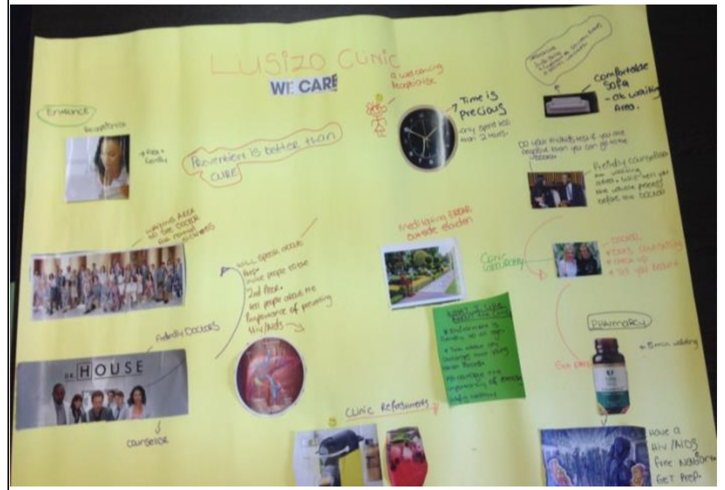
English is “people’s love clinic”. This journey map depicts a pleasant clinic visit with several people in the clinic displaying friendliness. The first image on the chart is a picture of lady smiling, and a caption next to this image reads “friendly receptionist”. There is also another picture on this chart with three people smiling, and the caption next to this image is “doctors there friendly. A lady for the females, and man for males”. There is an image of magazine. There is an image of women, and the caption next to this image is “sports day…” There is a picture of a bathroom that is clean and the caption next to this bathroom is “toilets as you can see it’s neat and spotless”. There is an image of a man smiling, and the caption next to this image is “pharmacy”. The overall impression with this journey map is that this clinic visit if filled with people who are friendly, people with big smiles. The point of friendliness from healthcare providers is consistent.

Zoleka, eThekwini (P3)

Reality Clinic



Dream Clinic



Key points from the charts

Reality clinic: “Counselling room… they are always friendly.”

“Overall the place make you feel, safe and secure.”

“Sometime they take very long to call your card.”

“While waiting, you can keep yourself busy by reading magazine or watching TV.”

“The overall process is not that bad.”

Dream Clinic: “Receptionist… fast and friendly. A welcoming receptionist”

“Friendly Doctors…”

“Clinic refreshments…”

“Meditating area outside garden…”

“Talk about challenges that young women face.”

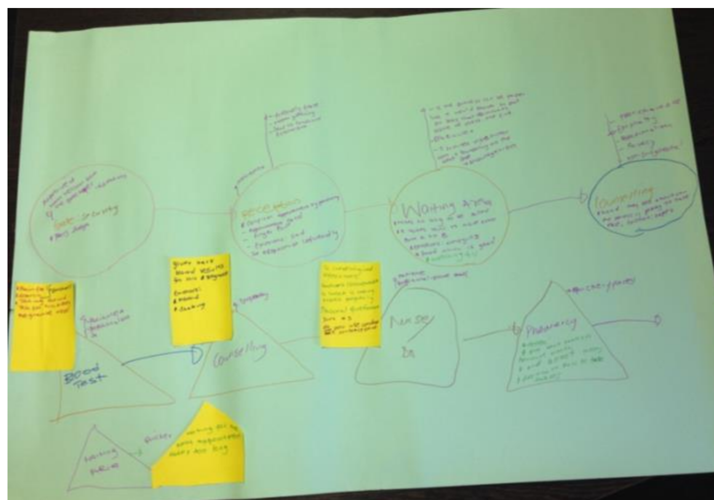
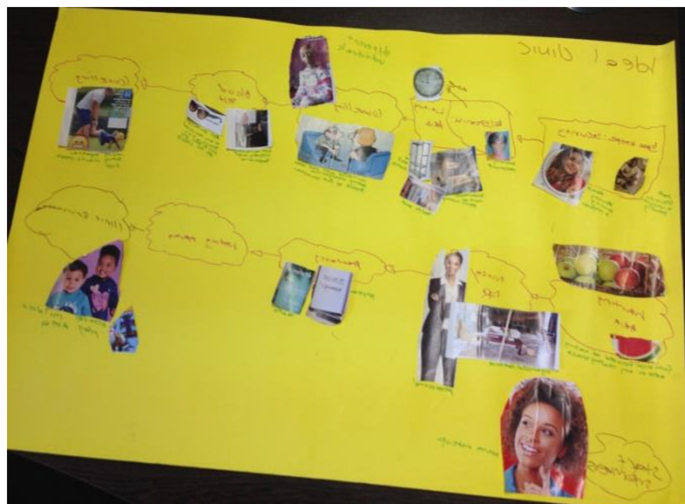
“Environment is friendly to all ages.”

“Time is precious. Only spend less than 2 hours.”

P3 provided a clear journey map chart with an outline of the various steps and processes involved when going to the clinic to collect oral PrEP. On this chart, smiling faces are used in several places. There are five smiling faces on the chart, indicating that P3's experience of clinic visits are usually pleasant, and her overall impression of clinic visits when she collects oral PrEP is often pleasant. The texts on the chart also reflect that this young woman was pleased with the clinic visits.

The second chart of the ideal journey map of the clinic when collecting oral PrEP is a descriptive account. The chart is entitled "Lusizo clinic", which means "help or helpful clinic", then there is a caption beneath that "we care". Even though there is no clear indication of the order of processes or steps that patients following when colleting oral PrEP on this chart, a clear description of the various places and processes in the clinic, such as the pharmacy. On the chart, the various healthcare workers a described, nurses, doctors, and the clinic staff members like the receptionist. There is a clear indication that the staff members and the healthcare workers must be friendly and welcoming.

A striking point to note on this chart, that there is a garden in this ideal clinic for the purpose of meditation. There is a picture of a clock, and a description below this picture stating, "time is precious, only spend more than 2 hours". The waiting area is described to be comfortable in this ideal clinic visit, a picture of a "sofa" is placed on the chart with a short description that this area is comfortable. The overall impression of this journey map is one where the clinic is a space that is welcoming, with friendly healthcare providers, and comfortable spaces with little waiting times.

Phakama, eThekwini (P5)	
Reality Clinic	**Dream Clinic**
	

Key points from the charts

Reality clinic: “Painful, scary. Taking bloods…”

“Waiting for the next appointment takes too long.”

“Receptionist improvement…friendly face, proper greeting, lead to conducive environment.”

“Waiting area…takes too long to be called. It takes hours to move om point A to point B. Emotions: annoying…”

“If the process can be faster, spacious…”

“Counselling…Transparency, empathy, professionalism, privacy, non-judgemental.”

Dream Clinic: “Male security in uniform friendly.”

“Friendly receptionist.”

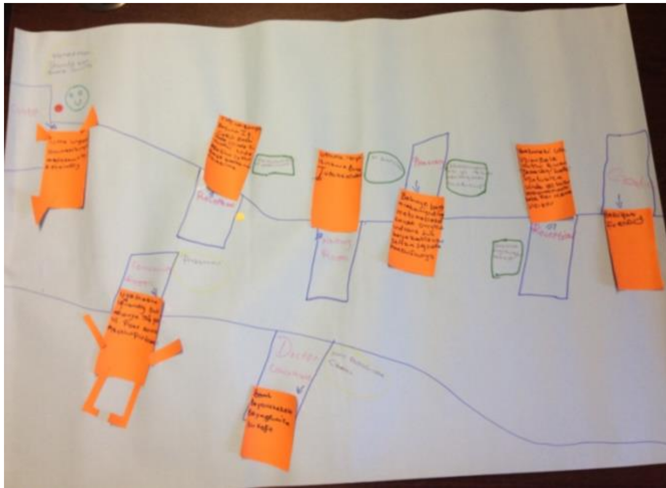
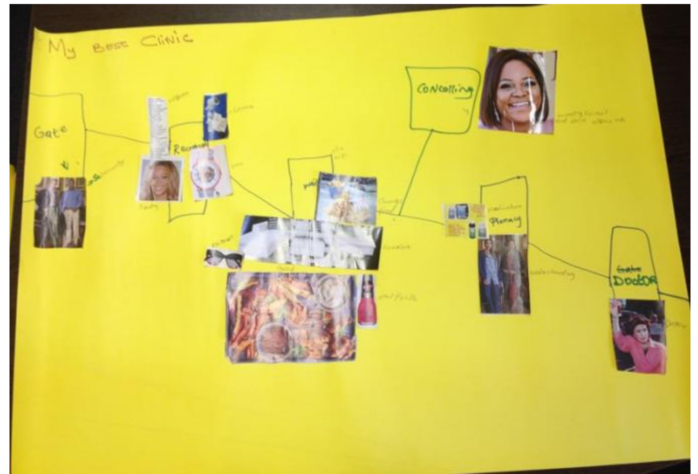
“Accommodate children, play area”

“Working together…”

P5 developed a clear depiction of her ideal clinic visit when she collects oral PrEP. Even though there are no images on the first chart, she drew shapes and wrote down

descriptive texts. In the waiting area depicted on the chart, there is a text there that states, “quicker time”. In the area where the counselling area is labelled, there is a text there that states, “afraid, shocking”. This is a description of emotions she feels at this particular point in the clinic visit. In the area for “blood tests, there is a text that states, “painful, scary”. In the section where the pharmacy is depicted there is a descriptive text, “quicker and faster”. This is written as a recommendation to what needs to be improved in this area. The overall impression of this journey map chart is that P5 usually has an unpleasant experience of going to the clinic. There is no positive expression of the clinic visit on this chart, but rather description of the various processes and recommendation on what can be improved.

The second, the dream clinic journey map is presented in an unclear manner with unclear texts. However, there are several images on the chart depicting what this young woman would prefer to experience when collecting oral PrEP in the clinic. The chart has several pictures of people smiling, laughing and expressing being happy. Like most of the charts that the other young women developed, this dream clinic journey map places emphasis on friendliness and a space where people are welcoming in the clinic.

<table>
<tr><th colspan="2">Lihle, eThekwini (P7)</th></tr>
<tr><th>Reality Clinic</th><th>Dream Clinic</th></tr>
<tr><td></td><td>
</td></tr>
<tr><td colspan="2">Key points from the charts

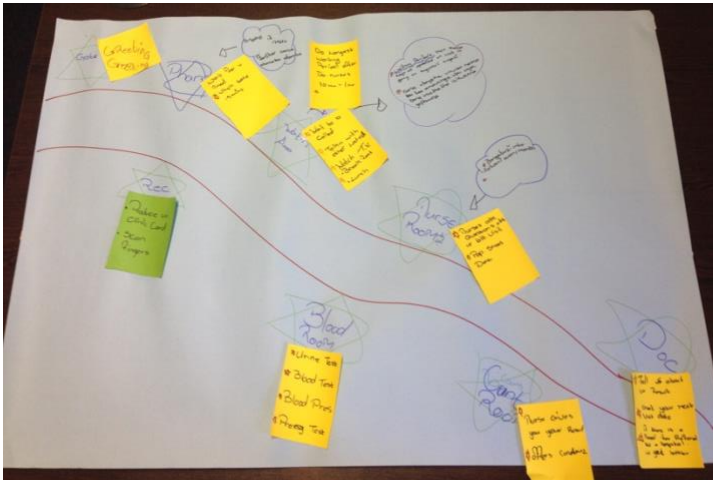
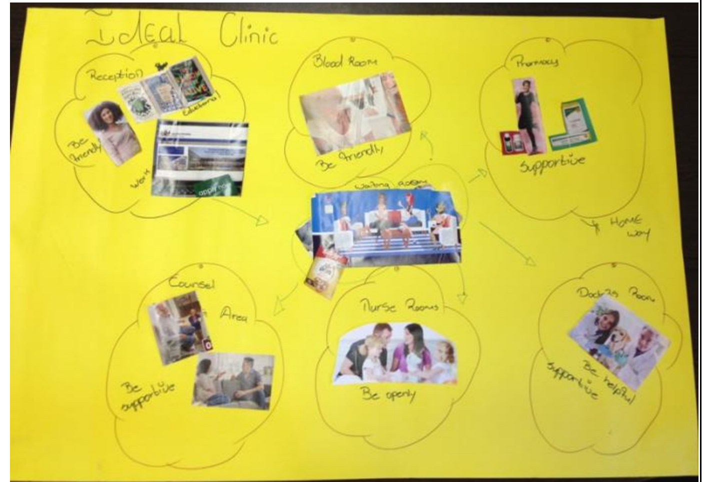
Reality clinic: “It is quick, friendly. But others give us poor service.”
“They are fine, friendly.”

Dream Clinic: “Friendly counsel and more welcome.”</td></tr>
</table>

P7 developed a journey map chart depicting a typical clinic visit to collect oral PrEP. Even though the chart does not have pictures, the journey map mostly comprises of texts that describe what happens at each point during the clinic visit. The “journey” through the clinic as depicted on this chart starts at the gate. P7 drew a smiling face, expressing being happy to go to the clinic. There is also another smiling face on the journey map near the waiting area that is depicted on the chart. There are no negative points describes on this journey map. The overall impression of this journey map is that this young woman is pleased with her clinic visit, as there is no indication of negative encounters during the clinic visit, and there is no recommendation of what should be changed in the clinic visit.

The second chart of the ideal clinic journey map depicts a simple outline of the various steps or processes involved when one goes to the clinic to collect oral PrEP. P7

provided several images to describe how this ideal journey through the clinic should be. All the images of people used in this chart, are images of people smiling, which is similar to what the other young women during the workshops depicted in their ideal experiences in the clinic. There is a picture of a camera near the reception area, and an image of a watch near the waiting area, and an image of a lady smiling at the reception area.

<table>
<tr><th colspan="2">Zihle, eThekwini (P8)</th></tr>
<tr><th>Reality Clinic</th><th>Dream Clinic</th></tr>
<tr><td></td><td>
</td></tr>
<tr><td colspan="2">Key points from the charts

Reality clinic: “Longest waiting period…”

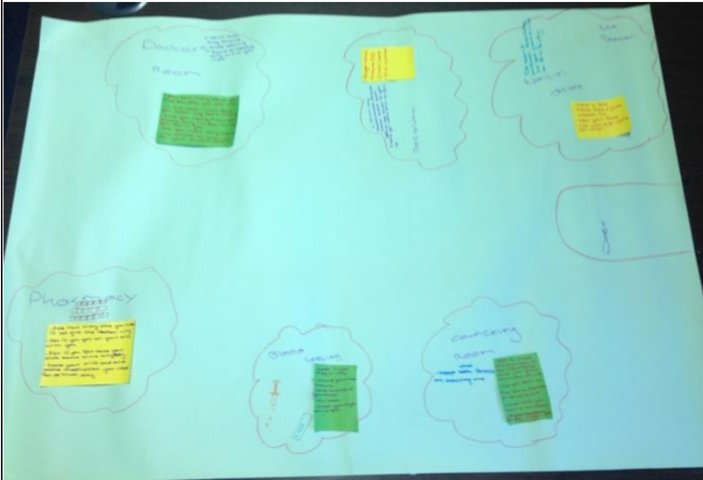
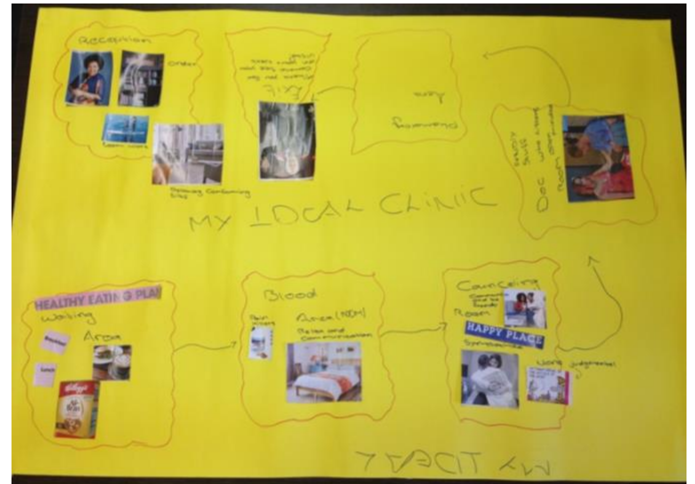
Dream Clinic: “Receptionist… be friendly, work.”
“Counselling area… Be supportive.”
“Doctors room, be helpful, supportive.”</td></tr>
</table>

The journey map developed by P8 gives a clear outline of the various steps when collecting oral PrEP at the clinic, however, this chart is not descriptive in expressing how P8 felt about the various steps. This chart focuses more on highlighting and labelling the various steps involved when going the clinic to collect oral PrEP. The steps are highlighted and labelled with no description of the personal experience.

The second chart depicting the ideal journey through the clinic is depicted in a more expressive and colourful manner. The chart is has a large heading with the text, “ideal clinic”. The several images on the chart are of people smiling, talking and working. There is a section on the chart depicting the reception area, with a picture of a woman smiling, with a picture of books, and a picture of a computer. Then there are text

describing this reception area, these texts state, “receptionist, be friendly, work and educational”. Then there is a section that is labelled as waiting area with a picture of young women having a discussion on a couch. It was interesting to see that this young woman also highlighted the counselling area, and added a text stating, “be friendly”. There is also an area labelled as the “doctors room”, with a text stating “be helpful and supportive”. The overall impression of this ideal journey through the clinic when collecting oral PrEP is similar to that which the other young women depicted, and that is a space that is characterised by friendly and supportive healthcare providers, and comfortable spaces.

Yolanda, eThekwini (P6)

Reality Clinic	Dream clinic
	

Key points from the charts

Reality clinic: "I think they should stop asking some questions when you visit.."
"Do some physical activities while waiting…"

Dream Clinic: "Reception… order."
"Waiting area…Healthy eating plan."
"Counseling…happy place, non-judgemental."
"Friendly staff who listen…"
"Relaxing seats…"

P6 developed a journey map that gave a basic outline of the various steps involved when collecting oral PrEP at the clinic. Even though this journey map does not have images or expressions, P6 gives a clear outline of the steps and processes involved when collecting oral PrEP at the clinic. The text on the chart is limited to a description of what is dome at each step or process in the clinic, with do description of personal experiences. However, when the young women all had an opportunity to present their journey map charts, more expressions and descriptive experiences came out, bringing more insight into what was illustrated on the journey map charts.

The second journey map depicting P6's desired experience of the clinic visit is presented in a creative manner. with images and texts used to illustrate the ideal clinic visit, this young woman entitled her chart, "my ideal clinic". On this chart there are several images of people, some are smiling, another image shows people hugging, another image is of people hugging. Similar to what the other young woman depicted on their ideal journey maps, this chart emphasis a clinic space that is welcoming, with friendly healthcare providers. In the reception area illustrated on the chart, there is an image of a woman smiling, and a text that reads, "order, team work". In the waiting area illustrated on the chart there are images of cereal boxes, and coffee, with a text that reads, "healthy eating plan". In the counselling room illustrated on the chart, there is an image of people hugging, and young woman talking, then there are texts that read, "happy place, sympathise, and non-judgemental.

Summary of visual data

The visual data across both research sites, rural Vulindlela and urban eThekwini share consistent similarities. It was interesting to identify that the experiences of these young women in the clinic when collecting oral PrEP was similar. The processes that the young women are not pleased with, or steps during the clinic visit that made them feel uncomfortable were more often similar. This was also evident for the second journey map, the "dream" clinic, more similarities than differences were evident in the second journey maps.

Below is a table that offers a summary of the data presented according to the two journey maps created by each of the young women; the "Reality Clinic" and the "Dream Clinic":

Summary of visual data	
Reality Clinic	**Dream Clinic**
Waiting period in the clinic when accessing oral PrEP is too long.	Healthcare providers including nurses, doctors, counsellors and other clinic staff need to be friendly.
Packaging of PrEP pills must be changed.	Waiting periods in the clinic need to be more efficient; shorter waiting periods.
Counselling sessions make the young women uncomfortable.	Clinic waiting area must be a comfortable space, with entertainment such as book, magazines, WIFI etc.
Going for blood tests is uncomfortable	Counselling spaces must be comfortable spaces with healthcare providers that are friendly.
The nurses at the clinic are reported by most of the young women to be unfriendly, and judgemental.	
The young women who in this study reported being asked too many questions by healthcare workers at the clinic.	
The young women mostly illustrated being happy to receive their oral PrEP at the end of the process of being at the clinic.	
The young woman illustrated positive expressions about receiving refreshments at the clinic.	

Table 6.4: Summary of visual data

This section presented the visual data from the journey mapping workshops. All the charts are presented above with brief points taken directly from the charts so as to amplify important words that the young women used on their charts. All the charts presented above were individually presented by the young women during the workshops with in-depth discussion on what they were portraying and illustrating on their charts.

All the charts presented above were accompanied by a thick description from the young women, as most of the content on the charts is in the form of images and not texts.

Interview data

The next section of the data presentation will offer a more in-depth discussion of the visual data which were supported by follow-up interviews. The interview data is presented below where the main themes developed from the data are informed by the main research questions and the theoretical framework guiding this study, as explained in chapter three. The themes below are related to one another, and there was an overlap even in discussion where participants would engage in a discussion with more than one theme at a time (see Figure 6.1 below).

However, the themes were divided up so as to present the data in a systematic manner and elaborate on the key points raised by the participants in both the workshops and the one-on-one interviews. The themes developed are:

1. Nurses attitudes in the clinic.
2. Waiting times in the clinic.
3. Access to resources in the clinic.
4. Privacy and confidentiality.
5. Family and partner influence and support to oral PrEP uptake.
6. Attitudes towards oral PrEP.
7. Community perceptions and understanding of oral PrEP.

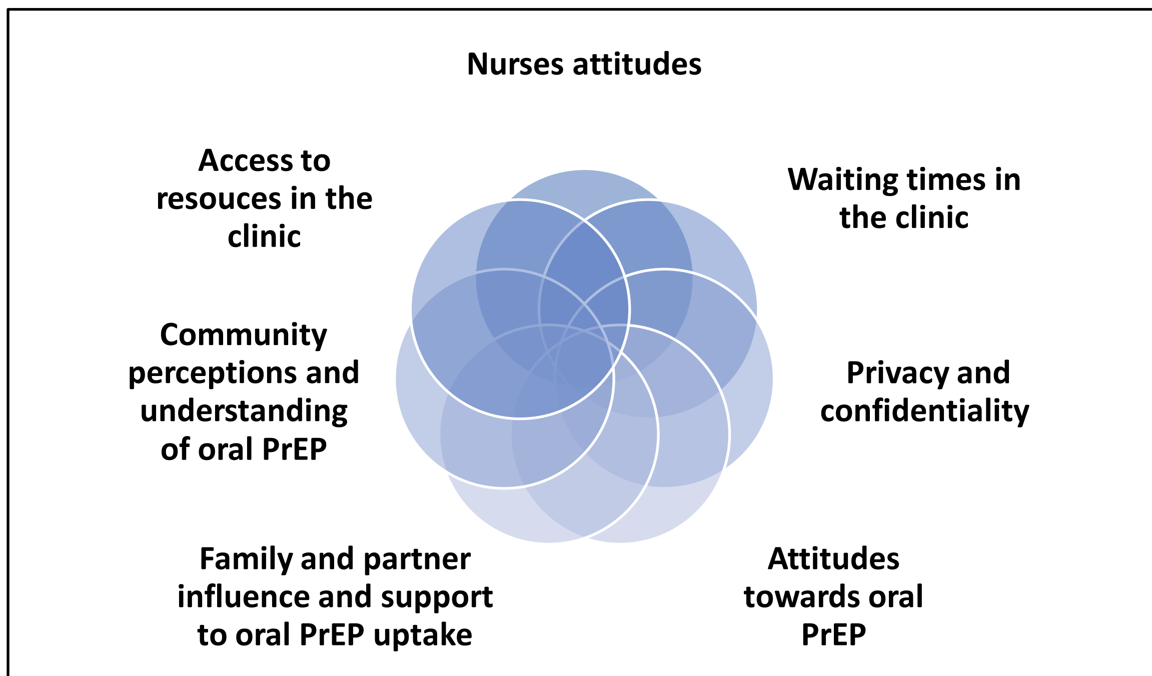


Figure 6.1: Overlapping themes from the data

It was not possible to present all the data that this research accumulated due to the scope that this thesis aims to cover (Nowell et al., 2017). Therefore, I will present some of the views expressed by these young women, and the presentation of data below has been presented according to the themes developed from the data collected.

Short quotes from the young women and two nurses are presented to aid in understanding key points that were raised in the journey mapping workshops and one-on-one interviews. Longer quotes are also included to provide the reader with the context of the discussion. Braun and Clarke (2006) emphasise the importance of using quotations, extracting from the raw data to illustrate the complex story that the data presents. In this chapter this recommendation is followed to convince the reader of the validity of the data presented, setting a foundation for the data analysis in chapter seven.

All quotes are accompanied by a clear label of participant, date, place and data collection method to demonstrate that various participants were represented across the results (Nowell et al., 2017).

This section also presents a comprehensive summary of the findings in line with the research questions and the theoretical framework of this study. These three

summations presented, give the reader an overview of the relation and alignment of research questions, theoretical framework and the research findings. See figure 6.3, figure 6.4 and figure 6.5

Nurses attitudes in the clinic

Nurse's attitudes and behavior towards the young women in the clinic was a reoccurring topic in the workshops and the one-on-one interviews. The young women in this study expressed that nurses' attitudes were important to them, and affected their clinic visit experience when they collected their oral PrEP or when they went to the clinic for other healthcare services. The young women in this study raised certain attitudes and behaviors from the nurses that they felt were negative and discouraged them in their clinic visits. There were also specific attributes, attitudes and skills that the young women cited to be critical for all nurses to have in the clinic.

The young woman below raised the point that when the nurses are not patient with them, it makes the process of being examined more "difficult". This highlights the fact that consulting, and examining with nurses is difficult, but the nurse's attitude makes this process even "more difficult".

> ***They are like not patient*** *because I am not used to doing tests like putting something in your vagina so, they are not patient when it comes to those things. It's so uncomfortable because even though it's not painful but it's uncomfortable. They must get used to understanding that we are not used to all these things because we don't go to the clinic just to check if we have infections or not unless you see something wrong.* ***They are not patient with us*** *when we get nervous and ask to be given some time … It's the instruments that are uncomfortable in your vagina,* ***but the nurses are making it even worse*** *because they are not patient with you, we want to finish and attend someone else, put this in, you see, they are making it more difficult.*
>
> (P5, 28 July 2018, eThekwini Workshop)

The young women in the workshops and interviews also repeatedly stated that nurses in the clinic were judgemental, and the young women received this in a negative and disheartening manner. The point of nurses being judgemental was brought up as something that made the young women feel "humiliated". The following discussion depicts this:

> ***Black nurses are so judgmental,*** *and they sometimes speak things that humiliate you and don't understand how it makes you feel, someone of a different race from you knows how to talk to you appropriately and make you feel comfortable.*
> (P14, 7 August 2018, Vulindlela Workshop)

Another lady in the same workshop stated:

> *They ask how many partners you have, when last you had sex, uhm did you use protection, if no why.*
>
> Researcher *: How do those questions make you feel?*
>
> *Uncomfortable sometimes because* ***there are judgemental nurses****, you can tell her that you have one partner and she'd say you are lying, why don't you use a condom, such questions.*
> (P13, 7 August 2018, Vulindlela Workshop)

Some of the young women in the workshop stated that nurses often judge them and also accuse them for lying when they are consulting or in counselling at the clinic. This was expressed several times by different participants during the workshops and interviews. The statement below further depicts this point:

> *It's the way they disagree with you when you tell them something, like I said when they ask how many boyfriends you have, and you say one, how many time have you had sex this month, if you say no you haven't* ***they say you are lying****. You can just see that.*
> (P12, 8 August, Vulindlela interview)

Another participant further elaborated on the point of nurses being judgemental and accusing them of “lying”:

> *There are those who do tell you that it’s okay even if you don’t have one partner, a lot of people do it, she says that to make you feel comfortable and free to talk. Then you’ll get another who will ask you how many partners you have, she’s already annoyed then you answer that you have one partner, **she’d just say you all like lying**. Then you start getting nervous because of that and you even feel like telling her that she must go read the previous pages, and then she says even writing one thing all the time is irritating for her. I’m sure after you leave she says you are rude so, someone of a different race won’t criticize you like that nurse.*
>
> (P14, 7 August 2018, Vulindlela Workshop)

In an interview, one of the young women stated that the nurses actually “question” what you say to them and they often do not accept what you are saying.

> *If only the nurse can understand your answers and not question them. **The problem is that she questions your answers and disputes it,** she doesn’t want to accept what you tell her. When you tell her to go back and look at what you said in the beginning, it’s like you are being rude to her. You have to respect her because she’s older and always have to be beneath her.*
>
> (P10, 7 August 2018, Vulindlela Interview)

In another workshop one of the ladies stated that nurses must be “non-judgemental”:

> *I think they should empathize and **be non-judgemental** and they don’t. You mention something, and the facial expression shows they’ve completely judged you, even though they haven’t used any words.*
>
> (P5, 27 July 2018, eThekwini Workshop)

The young women expressed the fact that nurses must be “friendly”, the point of being friendly was a reoccurring point within the workshops and the one-on-one interviews.

Moreover, this point of healthcare providers and clinic staff being friendly was evident in most of the journey map charts that the young women developed. Below, a young women depicts this point further;

> *And then* ***the sister you'll find at counselling must be friendly*** *because it's easy to talk to a friendly person. You can open up to them and talk, you can see how this lady is dressed talking to the doctor, it's easy to talk to the doctor because she's friendly.*
> (P10, 7 August 2018, Vulindlela workshop)

Another young woman from a different workshop raised the importance of having friendly staff in the clinic:

> ***I think it's important for people to be friendly .****You know we go there firstly because we know the pills work for us, arriving in an environment where people are not happy like they not fine, you even greet the security and say hello and they don't eve pay attention to you, it's depends on their attitude on the day you came. But I think the security is a gatekeeper, the first person you see wherever you are going so, I think it's very important for that person to be friendly. The receptionist too, as a receptionist you need to put on a friendly face because you are the face of that company or organization, she has to politely greet people so that we see that we are welcome, and that the environment is conducive here for, she just has no time for us…*
> (P5, 28 July 2018, eThekwini Workshop)

The young women in the workshops and interviews also characterised the nurses in their local clinics as being "rude". Several of the young women explicitly stated that they will not access oral PrEP from their local clinics being the nurses are "rude";

> *If PrEP is made available at the clinic and we are told to get it there with the clinic staff behaving the way it is, we won't. One,* ***they are rude*** *secondly, they don't work. They treat a person anyhow and you can't say anything because they are older, you just need to walk away or wait for*

> *those hours she tells you. If it's four hours or five, you'll wait just to get PrEP.*
> (P10, 7 August, Vulindlela Interview)

Another young women in an interview stated that even though she likes PrEP, once it is made available in the local clinic, she will no longer use PrEP because of the nurses attitudes and behaviour at the local clinic:

> *I like PrEP at the mobile,* ***when it goes to the clinic I won't go there****. I don't want to lie if they put it in at the clinic I won't go. I and PrEP will break up on that day except if I personally go to CARISA not this clinic. Some say the nurses here shout, if you make a mistake like maybe you are coming from another area when you are here you have to take the treatment here, the nurse will tell you to go back to where you usually take it or bring some things, referrals, and such things. Fine give me the treatment then tell me to go fetch those things, but they don't give you anything whereas I'm sick, they don't have time for anyone.*
> (P13, 7 August 2018, Vulindlela Interview)

One of the young women reported that the point of nurses shouting in the clinic during the journey map workshop. This young woman raises multiple issues that are in the quote below, these will be presented in more detail in the next section. This is an example of the over lapping themes that was discovered in the raw data:

> *The problem is,* ***nurses at the clinic are always shouting*** *and they don't have time, a person can die there like one elderly person who died there. They don't have time to work but, are always going up and down, you arrive in the morning and only leave late afternoon.*
> (P15, 16 August 2018, Vulindlela Workshop)

A few of the young women commented on the nurse's behaviour, stating that the nurses are lazy:

*Because **the nurses here are very lazy and they don't care about you** so, at CAPRISA they know your job, at the clinic they give you ARV's and only do tests after 3-6 months and they don't check if the kidneys are fine or things like that, they don't car. Like for instance with my sister, the doctor changed ARV's and gave her some other pills, it turns out when she went to Grey's because she was pregnant, the doctor told her that the pills she's taking are affecting her kidneys, who then must she blame? The doctor gave her wrong medication.*
(P10, 8 August 2018, Vulindlela workshop)

This view was echoed by another young women who said:

*I see **they are lazy because it's not all of them who are busy with patients,** you see some walking around, but they arrived for a while and they would've attended to many people by then or maybe two...*
(P6, 7 July 218, eThekwini Workshop)

One of the young women during an interview expatiate on how the nurse's attitudes and behaviours in the clinic make them feel. She stated that going for counselling with the nurse's makes her feel nervous:

*The challenge is like I said is at counselling, **I just get anxious thinking** about what kind of nurse I'll come across today when I go to counselling. When I get there I'm afraid to talk, I don't know what to say to her. That's the challenge I face and also, sometimes when you go there maybe I had sexual intercourse and didn't use protection, I think I'm pregnant or something.*
It's these questions they have of how many boyfriends you have, when you tell them you have one they don't agree with you and judge you. Maybe also coming across a nurse you are afraid off, and you can't talk to her…
(P12, 7 August 2018, Vulindlela Interview)

Significant statements about nurses' attitudes:

1. They are like not patient.
2. Nurses are so judgmental.
3. They say you are lying.
4. They are rude.
5. The nurses here shout.
6. I think it's important for people to be friendly
7. The nurses here are very lazy
8. I just get anxious thinking about what kind of nurse I'll come across today

Table 6.4: Summary of significant statements: nurses' attitudes

Waiting times in the clinic

During the workshops and the one-one-one interviews, it became clear from both the rural and urban research sites that the young women did not like the waiting periods in the clinic. The data depicts that time spent at the clinic is long due to several factors such as long ques and slow assistance by the nurses as presented above. Waiting times at the clinic was a predominant theme that the young women expressed as something that they found to affect their experience of collecting oral PrEP in SRH services in the clinic. Majority of the young women involved in this study cited waiting times in the clinic to be long, they stated that this will affect PrEP acceptance, uptake and adherence.

The quote below depicts one of the young women's' feelings towards the waiting times in the clinic, she stated that this will have on her continuing to use oral PrEP. The young women shared the challenges of the waiting time and working:

> *Those waiting areas…**I just wish the process could be quicker** because like I said sometimes we sit and wait for hours just to be called. From the counsellor to the nurse it's takes maybe an hour so, we'd like*

for the process to be quicker. I don't think once I'll start working I'll be able to continue taking PrEP especially if I must take it monthly because that will require for me to ask for off days at work, obviously that won't be right even though we like taking PrEP and would like to continue taking it for those employed. It was good for me because I'm unemployed but since I've started at Welfare I'll have to constantly ask but it won't matter for now because I'm doing voluntary work. When I start working, I even told…

(P5, 28 July 2018, eThekwini Workshop)

Another participant in the same workshop raised the point that people may not take PrEP because of the long waiting period at the clinic for PrEP collection:

A lot of people won't take PrEP *because they'll realize they'll have to be there for a very long time, some have to go to work…*

(P6, 28 July 2018, eThekwini Workshop)

The young women stated that the waiting period in the clinic is too long, and this may lead to people not taking oral PrEP. The quote below expressed the process in the waiting time at the clinic and the implications this could have on people accessing oral PrEP at the clinic:

Each and every stage there's waiting *more especially after you've done all the processes. You are only waiting for the next appointment for an hour, just to receive a card with your next date visit. One other time I almost left it, I told them I'm leaving because I had been waiting for so long and I had a short course I was doing so I had to go and revise because I had an exam, so I want to go.*

And some don't feel like they have to take PrEP, people got to the clinic and wait for a long time because they have T.B, they have HIV and it's now compulsory for them to take it so that they get better. But if they are not sick…

(P5, 27 July 2018, eThekwini Workshop)

The same young woman in the interview further emphasised the fact that she believes that people will not use PrEP because of the time that is required for one to collect PrEP at the clinic:

> *If the process would be much quicker people would go to the clinic for PrEP and other things... If the service delivery can be much quicker then people would go.*
> (P5, 28 July 2018, eThekwini Interview)

When talking about the services provided in the clinic where the young women collect oral PrEP in the eThekwini CAPRISA clinic, this lady stated that time is the only issue she has with their service delivery:

> *Even when you are done and have to get your appointment card that says when you have to come back, you have to sit and wait for another hour when you are supposed to be leaving but you are waiting.* ***Time is the issue. It the main issue that I only have.***
> (P8, 27 July 2018, eThekwini Interview)

In another interview, one of the young women clearly stated the steps and processes to collecting oral PrEP in the clinic that they do not like waiting when they go to the clinic:

> ***I don't like waiting*** *especially waiting for someone you see right in front of you going up and down while you are waiting and end up being assisted by someone who's been available from the beginning. Maybe also if you wouldn't have to go to a counsellor and then wait for another one to take blood samples, after getting counselling the same counsellor should take the blood samples right there instead of talking to the counsellor and then going back to the waiting area, going back for blood tests and again to the waiting area before seeing the doctor. If you can see one person, talk to them and do whatever needs to be done and wait for the results.*
> (P3, 16 November 2018, eThekwini Interview)

In an interview, one of the young women elaborated on the point of the waiting times in the local clinic by stating that this shows "poor service delivery". This young woman stated that there should be a CAPRISA research clinic in every community for PrEP to be made available to community members:

> ***There is poor service delivery,*** *they would say that they open at 8 am and then patients arrive at the clinic in order to be attended first. They first start with gossiping and when you complain about waiting they tell you that the waiting period is 3 hours. I think that there should be a CAPRISA in every township, city, rural area because if I take it from the clinic I am pretty sure that people will not get it. I am one of the people that do not go to the clinic quite often even when I was pregnant I would go to the gynaecologist because I wanted to prevent to stand in the long lines. Even people who don't have money would borrow money so that they can buy painkillers because the service delivery at the clinic is very poor.*
>
> (P5, 27 July 2018, eThekwini Interview)

In an interview, when one of the young women was asked what they think about their local clinic, and what their perceptions are towards the local clinic they stated the following:

> *I don't like it because whether you got there in the morning or noon it's the same, you all leave at the same time. They like going for long tea-break, you go there and get only one thing and give their friends many. While you are seated you have to put up your feet or move because they are now cleaning, you wait for a long time, go to the window, go check your B.P, and go to many places, it would better if you check your B.P you also do other things. You have to queue at different places for many things before seeing the doctor, it would be better if you did all those things in one place.*
>
> (P11, 17 August 2018, Vulindlela Interview)

The issue of the clinic being "full", and having large numbers of patients was raised several times. This was raised as an overlapping point with healthcare workers being "very slow" and shortages of healthcare workers. Below is just one of the comments from a young women during an interview:

> ***The clinic is always full****, and they take a long time to attend to patients, they are very slow and there's also people who are not from our area who come to the clinic which makes it even more full. When you go to our clinic you need to know that you'll be spending the whole day there, sometimes you'll find that it's only two nurses on duty.*
> (P1, 16 November 2018, eThekwini Interview)

Similar views were echoed by a young woman who stated that nurses play a role in the clinic ques being long and slow:

> *The space in the clinic here is too small, I prefer when coming to the clinic to be there for less than an hour, but here you stay too long, there's a few nurses, the space is small, they move too slow and they are lazy.*
> (P12, 8 August 2018, Vulindlela workshop)

Again, young women in this study attributed the problem of waiting times in the clinic to nurses pace in attending to patience and working efficiently. Interestingly, this young woman alluded to the fact that clinics are not sufficiently staffed:

> *The clinic is always full, so one person can do one thing because everyone else is absent from work. You'll find that there is only three nurses and you haven't seen others for a long while. Then there's also a long process there, going to the window, going to check your B.P, it must all be in one place then you go when you collect your pills only. But, at the clinic you start at the window then go join another queue for the B.P, then again joining another queue, you end queueing three times.*
> (P15, 16 August 2018, Vulindlela Workshop)

Significant statements about waiting times in the clinic:
1. I just wish the process could be quicker. 2. Each and every stage there's waiting. 3. Time is the issue. It the main issue that I only have. 4. I don't like waiting. 5. You have to queue at different places for many things. 6. The clinic is always full. 7. You'll find that it's only two nurses on duty.

Table 6.5: Summary of significant statements: waiting times in the clinic

Access to resources in the clinic

Some of the young women raised the issue of limited access to resources in their local clinics. All the comments and discussions around access to resources that were raised by the young women referred to their local clinics, and not to the CAPRISA research clinic where they were currently accessing oral PrEP. Several young women boldly stated that their local clinics usually have a shortage or no access at all to some medications. Some of the young women stated that the nurses influenced the limited resources by not fairly distributing medication. The quotations below depict these points, and a variety of comments from the one-on-one interviews and the workshops are presented below.

> *When you take a child there,* ***they will tell you they don't have panado****, they will only give the child a dose, they'll take the bottle out and take it back inside the cupboard once the child has drunk it….*
> ***The Mpophomeni clinic is a disgrace.***
> (P10, 6 August 2018, Vulindlela Workshop)

Another young lady in an interview stated that at their local clinic the nurses talk to patience in a discouraging manner. This young lady went on to state that the nurses will tell patients that there are no pills in the clinic:

> *What would discourage them is how the nurses talk back at you when collecting the pills and the way they don't attend to people. Sometimes you'll get there to collect pills and they say there don't have the pills. It also happens that when you've missed a date like for HIV pills, they give you a portion of it and extend your date. They say since you didn't come yesterday you'll only get this portion, you'll get other pills on your next date or say you've defaulted and make you restart classes* ***. I think that what would discourage people.***
> (P12, 7 August 2018, Vulindlela Interview)

In an interview, another young woman from Vulindlela stated that they are informed by the nurses that there is no medication in the clinic. The young woman in this interview like the previous young lady quoted above states that the nurses are rude. When talking about a lack of resources, both these young woman raised the issue of nurses' attitudes. These are two important points:

> *I can say the clinic we have it's the same as if we don't have one, you stay there for a long time without getting any help. Secondly, there's no medication, they tell you to come back the following day, when you do come back there's a story that's going to come up.* ***The nurses are rude****…Some don't work, they don't have clock in time or clock off time. They come in at work at whatever time they want if that's at ten they leave at one.*
> (P10, 7 August 2018, Vulindlela Interview)

During the one-on-one interviews the young women elaborated extensively towards the issue of limited resources in the clinics and the nurse's attitudes and behaviour in this. The quotation below highlights several issues related to limited resources in the clinic, the first point that this young lady raises is that the nurses are using their work time for relating with family. Secondly, this young lady states that the nurses in the

clinic will prescribe an alternative method to treating a particular illness or ailment because there is no medication. This young lady further states that medication is not dispensed accurately, with pill containers being opened and closed to take pills. The issue of losing files and entering inaccurate information in the files was raised by this young lady. Lastly, this young lady raises the point that this lack of resources and the nurse's attitudes towards patience:

> ***Sometimes when you go to the clinic you'll find them with their relatives****, you get in and tell them the issues, maybe the child has a feverish temperature, vomits after eating, they'll just tell you to make glucose,* ***there's no Panado or allergex but you can see it in the drawers.*** *You ask how because you can see it, they take it and give it to their relative and you don't get it while you need it and they just taking it for any future need they might have then they use it. Like with the pills ARV's, when you go collect them because I usually collect for my aunt, it has happened three times. When I went there for the first time the file was missing and they made a missing file, they took the pills, opened them, and gave me pills for twelve days then said she'll have to come after those twelve days. I looked at that because you'd be waiting for the pills and someone would get in and say Thembi give me some pills and they would take out maybe four from the box and give it to them, different pills. Then for someone else too they take out the pills and they say they will write it on the files and give them their next visit date, but you get counted pills. The grandmothers can even faint while waiting for their pills because they are told the pills are finished and they say it's their fault because they are not drinking the pills as prescribed which is false.* (P15, 7 August 2018, Vulindlela Interview)

The statement below form one of the ladies in the workshops emphasises that there is usually a variety of medication that is inaccessible in the clinic:

> *Then when you get there,* ***there's say it's not available****. It happens with ARV's as well. Even heart and diabetes medication run out, they sometimes don't get their medication when they go there…Or*

sometimes they give you a portion of the medication not the whole so, I don't know about PrEP being at the clinic.
(P9, 18 August 2018, Vulindlela Workshop)

Lack of access to resources in the clinic is not limited to medication, but it also include lack of access to information in the clinic. Another young female raised the point that there is also lack of medical information at the clinic. This young lady during an interview stated that the burses at the clinic can at time even refer a patient to research for information instead of providing that information:

They must give you time to ask and answer you, if you don't understand something they must explain again and not tell you to get data and google it. It's not all of us who have data to go to google, when you get to the clinic you need information because you can't leave from home to the clinic to ask information about something you don't need?
(P10, 7 August 2018, Interview)

The same young women stated during the interview that the structure is not too bad, but the "staff" in the clinic "make it bad". This highlight the overlapping relationship between the clinic services and the nurses in the clinics, this emphasises the importance of nurses in the clinic:

The clinic is not too bad, the only thing that's making it bad is the staff. They don't respect their jobs and even the management doesn't care about what's happening, they sit in their office and do their work. The cleaning staff also fails to do their work, the toilets are dirty, you can't even use them, the equipment is broken so, if those things can be changed and the staff, the clinic won't be as bad as we think it is if those few things are removed.
(P10, 7 August 2018, Interview)

Some of the participants raised the point that they do not trust their local clinics, because in the clinics, files get lost. This young lady in a workshop raised the issue

that files in the local clinic usually get lost, and she makes a suggestion that the CAPRISA research clinic needs to continue administering oral PrEP:

> *That's why I was suggesting that CAPRISA continues with it testing services, at CAPRISA they don't lose results. There's a challenge of the loss of results at the clinics, T.B results gets lost, children's results when a child was born, and they do those tests they normally do after birth if the mother is positive, those tests get lost. So, the clinic…*
> (P13, 6 August 2018, Vulindlela Workshop)

Significant statements about access to resources in clinic:

1. They will tell you they don't have panado,
2. The Mpophomeni clinic is a disgrace.
3. I think that what would discourage people.
4. They say there don't have the pills.
5. I can say the clinic we have it's the same as if we don't have one.
6. They'll just tell you to make glucose… no panado or allergex.
7. Even heart and diabetes medication run out.
8. The only thing that's making it bad is the staff.

Table 6.6: Summary of significant statements: Access to resources in the clinic

Privacy and confidentiality

Closely related to access to resources within the clinic is the theme of privacy and confidentiality in the clinics. The young women who were part of this study raised the point that they need a clinic that can protect their privacy, and also keep confidentiality. The theme of privacy and confidentiality was an overlapping theme with access to resources because some of the young women stated that files go missing in the clinic, and this also speaks to the issue of confidentiality.

More specific to this theme however, is privacy and confidentiality in the structure and services provided from the clinic.

> ***They should emphasize confidentiality maybe if they put up posters on the walls like "do not disturb"*** *for when you are talking to a counsellor, so that no one will enter.*
> *I think privacy as well,* ***while you inside with the counsellor someone just walks in without knocking,*** *how do you get in while we are inside? Transparency, empathy, and privacy we don't have…*
>
> (P5, 26 July 2018, eThekwini Workshop)

Talking about this issue in an interview, one of the women said:

> ***There must be privacy at the counselling rooms*** *as Phakama mentioned and we must only talk about what we came for there, since we came for PrEP like how's it treating you, any changes, the importance of preventing against HIV, they must stop asking us about changed contact details…*
> (P6, 27 July 2018, eThekwini Interview)

It was interesting to note that one of the young women during an interview raised the point that nurses are unprofessional because of the lack of privacy during the counselling sessions:

> *I think we've mentioned before I feel like they are unprofessional …So being unprofessional of the counsellors as well as nurses, we've mentioned before that* ***they like to be judgemental counsellors don't give as privacy*** *knowing there are challenges that we face every day. Nonetheless we go because we want help as much there are challenges but at the end of the day we find help*
> (P5, 27 July 2018, eThekwini Interview)

The majority of participants were greatly concerned with the issue of confidentiality and privacy, below is a depiction of these concerns:

There must be privacy and they need to understand that when I go to talk to them I go there because I want our talk to be confidential. ***So I think it is careless that a person can go and shout out that, even if it something small but to me it is confidential.*** *To me it is huge, if you are going to say "Sthembile here are your results, you have nothing". You see, it not confidential and there is everyone. Like, if I was sick you would have called me aside. So everyone would know now that since you have called me aside it means that there is something wrong with me cause I've seen that in some other clinics or whatever. It becomes obvious that "since they are calling this person aside like this, there's something wrong". Even though you don't know what exactly is wrong but there's something wrong. You also start thinking to yourself "I wonder what is wrong, what do they have?" You see nje.*

(P6, 27 July 2018, eThekwini Interview)

Significant statements about Privacy and confidentiality
1. They should emphasize confidentiality maybe if they put up posters on the walls like "do not disturb". **2.** While you inside with the counsellor someone just walks in without knocking. **3.** There must be privacy at the counselling rooms. **4.** So I think it is careless that a person can go and shout out that, even if it something small but to me it is confidential.

Table 6.7: Summary of significant statements: Privacy and confidentiality

The theoretical framework guiding this study is the culture centered approach, and in this framework there are three pillars that have been used to categorise the data collected; structure, culture and agency. The diagram below is a summary of the findings in a spider diagram depiction. The findings in this diagram are grouped according to the first pillar within culture centred approach- structure, with the aligning research question.

Structure

Research Q1. In what ways is the **current structure and organization of SRH services** an impeding or facilitating environment for young women assessing biomedical products?

(Note; participants expressed the impeding factors, indicating that there were no facilitating factors)

7. **Lack of medication** in the local clinics was raised as a point that oral PrEP will be effective once it available in the local clinics.

4. **Entertainment** in the waiting room in the clinic was raised as important; books, wifi etc

5. **Language** barriers noted as a challenge when collecting medicines at the pharmacy.
(a) The young women from the eThekwini clinic stated that it is important to have healthcare works that speak Zulu.

3. The **waiting period** in the waiting room is too long.
(a) Something should be done to reorganise the system on how one takes PrEP to make the process quicker.

Findings

1. **Nurses attitudes** are cited to be impatient and judgemental to young women in the clinic.

6. Nurses were cited to be rude. Therefore, **professionalism** was raised several times by participants as an important attribute for healthcare givers and clinic staff to have.

2. More **privacy** is needed in the clinic; the urine samples that are needed are not done in **privacy in the mobile clinic**.
(a) In the mobile clinic privacy is a problem for the young women.
(b) In the eThekwini SRH clinic, privacy was a problem too- during the counseling sessions young women felt that they did not have privacy.

Figure 6.2: Comprehensive summary of themes related to structural issues

Family and partner influence and support to oral PrEP uptake

In the workshops and one-on-one interviews, it became evident that the young women were concerned about family and partner support towards their accessing oral PrEP. Some of the young women shared the misconceptions people in their communities and family had towards oral PrEP. Some of the young women strongly stated that family support is important when taking oral PrEP. However, a few of the young women believed it was not important to have family or partner support when taking oral PrEP. The issue of partner disclosure of PrEP use and support was also a reoccurring point that several of the young women raised. It was interesting to note from the workshops and one-on-one interviews that none of the young women stated that they used oral PrEP in confidentiality.

Several young women shared that they started using oral PrEP because they did not trust their partners. One of the young woman in the workshops openly that she was motivated to start taking oral PrEP because she did not live with her partner:

> ***I took it because I don't live with him****, it can be fun while we together, but you can't trust what they do when you are not around, gone all these months, you don't know what they get up to. So, I thought it's better if I just take the pill, whatever he does will be on him.*
> (P9, 16 August 2018, Vulindlela Workshop)

Another young lady in the same workshop stated that she also started taking oral PrEP because she did not trust her partner, and furthermore, she stated that she told her partner that she is taking oral PrEP:

> *Okay,* ***I didn't trust my child's father****, if he came home he would come back with open condoms. So, I wasn't sure if he was using them or not so, I thought it would be better if I had a way of protecting myself. Even though I doubted but, I said let me just try and see if it works out, to protect myself, I even told him that there is a pill that I will take because*

> *I don't trust him and him going to someone who will not disclose to him that they are sick…*
> (P15, 16 August 2018, Vulindlela Workshop)

One of the young women in the workshop stated that she started taking oral PrEP because she was in a long distance relationship, this young lady also stated that she informed her partner that she is taking oral PrEP:

> ***The reason why I decided to take PrEP is, I'm in a long-distance relationship*** *so, I don't see my partner often. I don't know what he gets up and what he'll come back with and infect me with. So, I decided to take PrEP and I informed him about the pill, he said he doesn't have an issue with it.*
> (P11, 16 August 2018, Vulindlela Workshop)

The young women were passionate and highly opinionated about family support when taking oral PrEP. The point of family support was raised again and again in the workshops and one-on-one interviews. Some of the young women believed that family support is important when taking oral PrEP. The young lady quoted below states that her family knows that she is taking oral PrEP and they support her. She expressed that she does not hide the fact that she is taking oral PrEP:

> ***They know and support me*** *even my sister's children who are around 13-tears, I send them to get my pills because children today that age are very curious, they want to know why are you taking these pills every day at the same time. You sit them down young as they are and tell them about these pills and what they are for as they grow up. It's easy for me because I live with open-minded people, even if I go to a friend's party or to restaurants I don't hide my pills. I'm not ashamed of it because they even remind me if I have my pills because they know, I told them about PrEP. If we are not ashamed we can even educate others about it too.*
> (P5, 26 July 2018, eThekwini Workshop)

The young lady quoted below also shared that her family and partner know that she is taking oral PrEP, she also shared the fact that her partner reminds her to take oral PrEP, and refers to it as "ARV's":

> ***Everyone at home knows, even my partner knows*** *like I said when my alarm goes off at 8, he says it's time to take your ARV's, can I get you water, he supports me.*
> (P8, 26 July 2018, eThekwini Workshop)

One of the ladies during a one-on-one interview stated that it is important to have family support when taking oral PrEP daily. She stated that they encourage her to take oral PrEP, and also visit the clinic to collect the oral PrEP. Several young women also stated that having family support you, and even remind you to take oral PrEP is encouraging:

> *Yes, it's important because like what I mentioned about my sister, she doesn't want us to be in the same situation as her. She's the one who told me to go take PrEP, even when she takes her pills at 9, she reminds me to also take mine maybe if my phone is not with me.* ***They encourage me in every way, even with the visit date they remind me.***
> (P12, 6 August 2018, Vulindlela Interview)

During the one-on-one interviews with a young lady, she shared how her mother even knows that her partner is HIV positive. She stated that she told her mother that she is taking oral PrEP, she expressed in the discussion that her family and her boyfriend are supportive:

> ***My mother knows*** *that my boyfriend is HIV positive so when I told her that there is something like PrEP, I read and I want to know where I can find it. Because I didn't know that there was a place called CAPRISA and that there is PrEP. I thought that you get Prep at the doctor, I didn't know that it was available at CAPRISA. My mom and I spoke about my boyfriend's status bout him having HIV so I decided to go to CAPRISA and then besides one of my sister's is HIV positive. I think that they are*

open, they don't want me to use ARVs. They know that what I am taking is good and it will help me at the end of the day. So they know it and are very supportive, my boyfriend is also supportive and he takes ARVs.
(P5, 27 July 2018, eThekwini Interview)

Majority of the young women expressed that family support is important, and a few of the young women clearly stated that they receive support from their mothers to take oral PrEP for HIV prevention. The quote below depicts the fact that there are young women who do want support from family even if other people may not support them:

> ***My mother knows and is supportive****, she doesn't want me to get sick in the future. She's fine with it and tells me to take it because people my age are sick. And people talk even though it's become a normal thing but they say this one is sick…*
> (P11, 17 August 2018, Vulindlela Interview)

Largely, the issue of family support being important was a central point for the young women. The quote below if from an interview with one of the young women in Vulindlela who vividly stated that family is important and that support needs to start at home:

> ***Family is important because you can't take PrEP unless you are getting support from home, support starts from home, you need to be open.*** *Because if you take it in hiding one day your mother might be cleaning and find the container. The first thing that would come to her mind is that it's ARV's, because she doesn't know what it is. It's better if you sit down with her and tell her about the pills and what's it's for. Make them understand that I've decided to take it because of one and two.*
> (P10, 7 August 2018, Vulindlela Interview)

> ***At home they support me even though it's not all of them, my friends know I'm taking PREP as well.*** *Some ask me if I've taken the pill when it's time then if I have I tell them yes, I've taken the pill, others just ask me if taken the "food for my life" then I answer them. For me it's*

important that they know because if they are not aware and something happens to me, maybe I get sick and they find my pills and think all along I've been taking ARV's.
(P15, 17 August 2018, Vulindlela Interview)

While some of the young women stated that they received family support when they disclosed that they were using oral PrEP, some young women expressed the fact that family did not understand. One of the young women in the one-on-one interviews shared that her family was doubtful and asked her if taking oral PrEP would not infect her with HIV:

When I told my family that I'm taking PrEP, some were doubtful of this pill that one knows about. *They were asking if I don't think this pill will infect me with HIV so, I decided to take the risk those who were asking me couldn't take it anyway because they are already infected. I told my friend about this pill because I saw the type of lifestyle she was living, I told her since she's living in the fast lane, she's going to need this pill and she asked me to explain to her about the pill. I explained to her that this pill helps against the infection of HIV, I told her you have a lot of partners and you don't protect yourself so, she needs it. She said she's still going to think about it and it's been some time now because even yesterday I asked her if she's still thinking about it and she said if she's destined to be infected with the disease so be it, some accept it some don't.*
(P15, 17 August 2018, Vulindlela Interview)

During a workshop, one of the ladies stated that when she disclosed the fact that she is taking oral PrEP to her partner, he was sceptical and even thought that she was taking ARV's. Several young women stated that people close to them and in the community often think that oral PrEP is an ARV drug:

When I first told him, he was a bit sceptical *but, I sat down with him and explained to him that I'm taking the pill I don't trust him, we don't see each other for months and I often find open condoms in his pants, I don't*

know if he uses them every day or not so, I don't know if he uses them or not. It is my way of protecting myself and he said he doesn't trust it, he thought it was ARV'S. I gave him a form and he ended up understanding and he didn't even want to test but, after I explained to him about the pill and him seeing it after I collect it, he ended up testing.
(P15, Vulindlela Workshop)

By contrast, one of the young women expressed during an interview that she does not have a problem about what people think. This young woman shared during the one-on-one interview that people think that taking PrEP means that you are immoral:

Like I said I don't have a problem because I know no matter what a person may think they must know one, that I'm not sick, two I'm protected. I don't have a problem, I can do something like that but there's another thing that people often talk about. They ask why are you taking PrEP. ***If you are taking PrEP it means you are immoral****. If someone would see me in different cars they'd say, "you supposed to do this because you know that you are taking PrEP, that's why you are taking it." So, it's those kinds of things that would make me be reluctant to do it, other things I don't care about.*
(P13, 6 August 2018 Vulindlela Interview)

Significant statements about family and partner influence and support to oral PrEP uptake:

1. Okay, I didn't trust my child's father.
2. Everyone at home knows, even my partner knows.
3. They know it and are very supportive, my boyfriend is also supportive, and he takes ARVs.
4. They encourage me in every way, even with the visit date they remind me.

5. Family is important because you can’t take PrEP unless you are getting support from home, support starts from home.
6. Some were doubtful of this pill that one knows about.
7. He thought it was ARV’S.
8. If you are taking PrEP, it means you are immoral.

Table 6.8: Summary of significant statements: Family and partner influence and support to oral PrEP uptake

Community perceptions and understanding of oral PrEP

Community perceptions and understanding towards oral PrEP was a reoccurring theme in the data. The young women expressed in the workshops and one-on-one interviews that there was a variety of perspectives that community members have towards oral PrEP and towards them taking oral PrEP. To a great extent the young women shared that there was a lack of understanding in their communities about what oral PrEP is and what is does. The young women from eThekwini and Vulindlela also stated that there are many people in their communities that believe that oral PrEP is an ARV drug. The use of oral PrEP was also associated with a particular lifestyle, the young women stated that some people in their communities believed that people who take oral PrEP are promiscuous.

The quote below was extracted from a discussion where this young lady is sharing how one of her neighbors had a misconception that oral PrEP is ARV drugs:

> *There was an old lady who saw me at CAPRISA and asked me what I was doing there, I explained to her that I’ve come to collect my pills and she said there is no such thing. After collecting my pills, she asked me to pass by her house to explain because what she’s been told is different from what I told her. I agreed and went pass her house and showed her the pills,* ***she said I’m lying this is an HIV pills****, I asked her to bring an ARV if she has it so that we can look at both look and see if they are the same. She said when you are starting your ARV’s you get the pills like*

those I had. So, I saw that she doesn't understand this, so yesterday, when was this? Yes, yesterday it was Monday I went to collect pills for my aunt and the old lady was there too, the mobile as well. We went there, and I told her I'm with this old lady and she understand the difference between this pill and the ARV, she said she heard I'm taking an ARV so, she explained to her and she eventually understood and said the people that told her didn't explain the way she did, now she believes the pills are not the same.
(P14, 6 August 2018, Vulindlela Workshop)

There were a few young women who shared that they did not like disclosing the fact that they are using oral PrEP to people because people think that they are "immoral". The two quotations below were taking from one-on-one interviews with a young woman from Vulindlela and the other young lady from eThekwini:

Protecting yourself is a good thing but I don't like people knowing that I take PrEP because ***people think when you are taking PrEP it is because you have no morals****.*
They think you are not well-behaved because you know that you are fine so, you'll go sleeping around which is not true, I don't like it.
(P9, 17 August 2018, Vulindlela Interview)

But when you tell some people about PrEP ***they think it's for immoral ladies.***
(P8, 26 July 2018, eThekwini Workshop)

During a workshop in eThekwini, one of the young women raised the point that people taking PrEP should not be ashamed of using PrEP. This young lady expressed that people must be encouraged and motivated to take PrEP by those who are already using it. She then pointed to the fact that people associate oral PrEP with HIV:

It starts with us people who are taking PrEP. We must not be ashamed with PrEP and we should encourage people through our actions to take PrEP. This will encourage and motivate them, we take PrEP for

ourselves, we should not be afraid of it. ***People tend to associate PrEP with HIV*** *but as I said before it all lies with the person taking PrEP, they shouldn't be ashamed because that will make people who don't know what PrEP is, fear taking PrEP.*
(P5, 26 July 2018, eThekwini Workshop)

Across the workshops and interviews, the young ladies who were part of this study kept raising the point that there is a misconception about oral PrEP being and ARV drug, and also a misconception that taking PrEP can cause one to become HIV positive. The quote below depicts these misconceptions:

She asked me if I'm taking PrEP and I said yes, she asked me if I was 100% sure of what they say it does and I said yes, that's what they tell us, but I won't say much because I started taking PrEP while HIV negative. So, they are saying what if this thing in the upcoming years causes me to be ill, am I not afraid … I said I don't know I'll see when it happens on that day… It's what they think, they say since you take it if you don't have HIV they infect you with it that way. How can possibly infect you because they do blood tests and everything right in front of you. There's no way they can do that, but people say there's no such thing. But I…
Sometimes I think I'm wasting my time and ***they say it's no different from someone taking ARV's*** *because you also take it daily at the same time. It would be better if it's taken monthly, but then again those who take ARV'S…I didn't have side effects like having bad dreams which is what they say ARV's do, have certain things growing on the body, losing body shape and all that.*
(P9, 17 August 2018, Vulindlela Interview)

One of the young women vividly stated that when she takes her oral PrEP daily, her neighbour judges her. Again, this young lady shared the point that there are some people say that PrEP looks like ARV drugs:

> *It makes a lot of noise, so she judges me, when someone comes to me in the room I'm renting I would tell them when it's time for me to take my pill. I'd take my PrEP and they would ask me what is it and I explain to them, but my neighbour would always* ***judge me and say it's pills that look like ARV's****, how are they different and so on.*
> (P4, 16 November 2018, eThekwini Interview)

Another young lady shared during a discussion in an interview that some of her friends did not that there is HIV prevention method like oral PrEP, and they said that oral PrEP are ARV drugs:

> *In my family I've told my sister I have two sisters and I told both of them. I don't know if I can say they are reluctant or what, they said it's fine but when you called at CAPRISA and I told them to go get it they said they don't have time because they are working. When I told some of my friends they didn't believe me, they said there is no such pill to prevent HIV infection I'm lying to them. I came back with it and showed them, and they told me it's ARVs, but some do believe me. Another one said I'm gaining weight and it might be due to the PrEP I'm taking and that I must stop taking it because it's making me weigh more.*
> *They said they are similar to ARV's and one of friends even said her mother is taking ARV's and the colour is the same as that of PrEP. I said the only ARV I know is the pink one and they said there is a blue and white one too. I don't know ARVs that much, I just know the pink one only from someone who has it.*
> (P1, 16 November 2018, eThekwini Interview)

During an interview, there was young lady who stated that she was comfortable in sharing that she is taking PrEP even though some people will state that an "HIV pill":

> *Yes, I'm comfortable because I want others to be helped too, I tell them that there's such a pill and what's it for then it's up to a person if they decide to take it or not.* ***Some people will judge you*** *and say you are*

taking an HIV pill when you are not, but if a person wants to know more they'll go to the clinic.
(P12, 7 August 2018, Vulindlela Interview)

An interesting point was raised by one of the young ladies during a workshop, she stated that people need to be educated about PrEP, about the difference between oral PrEP and ARV drugs:

> *That's the problem, people think that if they take* ***PrEP people will think it's ARV's.*** *That's why I'm saying it's very important to educate them, because in my family there is someone who is taking ARV's, but they know how to distinguish them from PrEP.*
> (P5, 26 July 2018, eThekwini Workshop)

In an interview, a young lady raised a similar point to the one above about educating people, and informing them about PrEP. This young lady stated that people who are already using oral PrEP, should inform other people:

> ***I said it needs to be explained by someone who takes PrEP*** *and show them. All my friends know that I'm taking PrEP, at home they know as well, my friends also tell their friends and I'd get WhatsApp texts from them asking me to explain to them about the pill and I explain to them. They ask if there's nothing bad that I'm experiencing or any changes in my body since I'm taking it and I say no.* ***Some say they are scared and others say they need professionals to explain*** *to them further about the pill. I don't know what a person like that would be putting their trust on but, the way I explain to them some eventually change their mind and want to use it. Some ask to go with me when I go to collect my PrEP, maybe that I've told are now taking it but, some they'll give us six months to see what issues we'll have by taking PrEP.*
> (P15, 17 August 2018, eThekwini Interview)

Significant statements about Community perceptions and understanding of oral PrEP:

1. She said I'm lying this is an HIV pills.
2. People think when you are taking PrEP it is because you have no morals.
3. They say it's no different from someone taking ARV's.
4. They say since you take it if you don't have HIV they infect you with it that way.
5. It's very important to educate them.
6. I said it needs to be explained by someone who takes PrEP

Table 6.9: Summary of significant statements: Community perceptions and understanding of oral PrEP

The theoretical framework guiding this study is the culture centered approach, and n this framework there are three pillars that have been used to categorise the data collected; structure, culture and agency. The diagram below is a summary of the findings in a spider diagram depiction. The findings in this diagram are grouped according to the first pillar within culture centred approach- culture, with the aligning research question

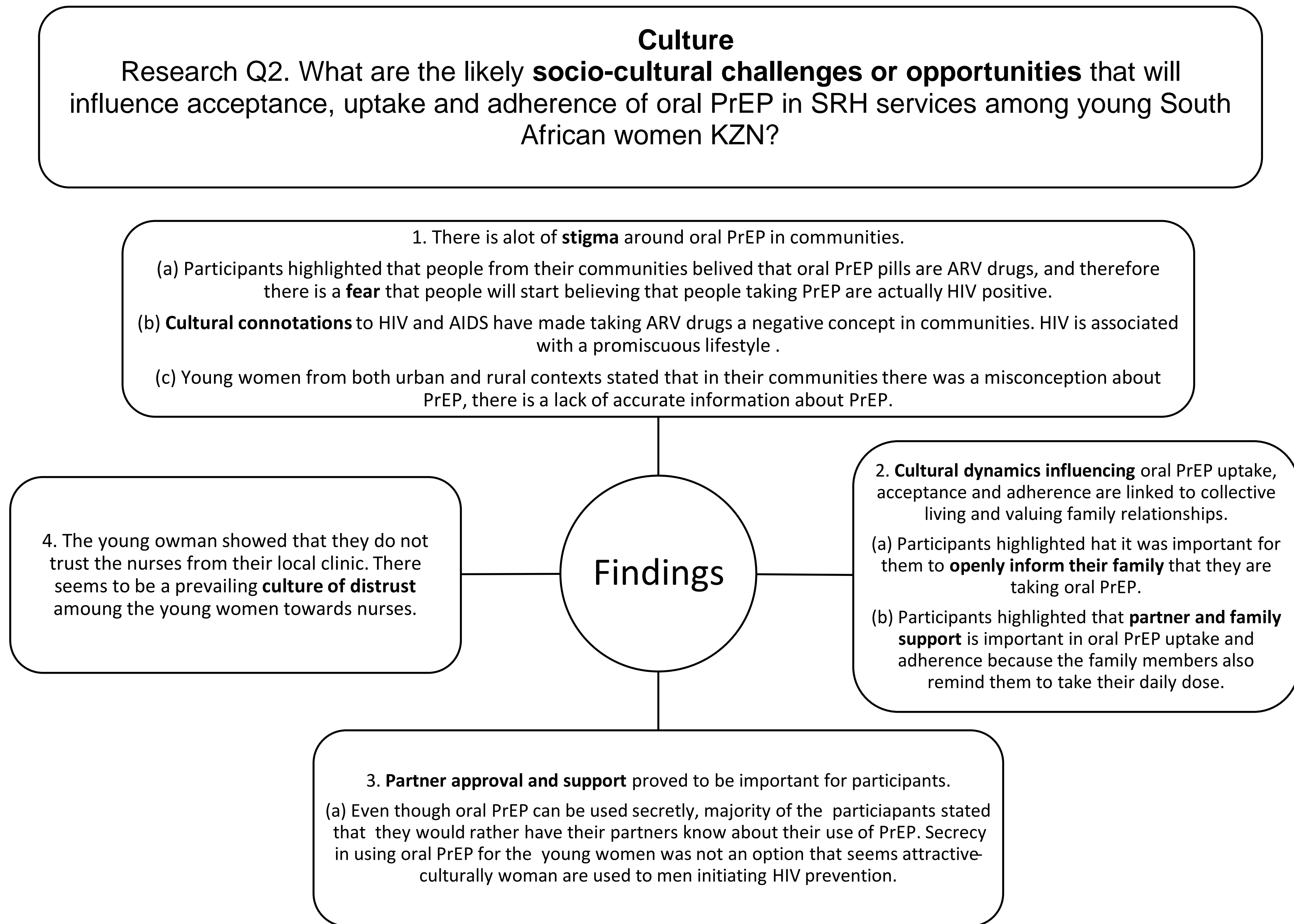


Figure 6.3: Comprehensive summary of themes related to cultural issues

Attitudes to oral PrEP

Several issues were raised by the young women about oral PrEP, but one of the most reoccurring issues that the young women raised in discussions concerning oral PrEP was the issue of taking the drug every day. This was raised by the young women as a challenge. The issue of taking oral PrEP daily was consistently raised as an issue in the workshops and the one-on-one interviews.

The quotation below depicts one of the attitudes that the young women had towards oral PrEP, this young lady states that she sometimes considers not taking oral PrEP anymore because it is "annoying":

> ***Sometimes you even think about quitting****, I take mine at 6 but sometimes when it's time I just ignore it and take them another time, it's annoying. When maybe you not at home maybe in town and the time to take your pills is near you get stressed out as to when you'll arrive at home and take the pills.*
> (P9, 17 August 2018, Vulindlela Interview)
>
> *The fact that every day at a specific time you will take pills is not child's play.*
> (P7, 27 July 2018, eThekwini interview)

In another interview, the young woman stated that when one starts using oral PrEP it is not easy, but you get used to it as you keep taking the pills, she stated that sometimes you may forget to take the medication:

> *It's not a problem because you get used to is as time goes on, you know at 7 you take your pill, you don't even pay much attention to it.* ***But at the beginning it's a problem because you sometimes forget.***
> *But it's not easy, it's irritating but it's better once you are a regular because you get pills for three months. It's annoying if you still get pills for a month and knowing you have to come back the following month.*
> (P14, 7 August 2018, Vulindlela Interview)

Another young lady stated something similar to what is quoted above, she said that taking oral PrEP is not easy but you get used to it. She further elaborated that after some time, taking oral PrEP daily becomes a norm, moreover this young lady stated that she is motivated when she sees family taking ARV's:

> ***It's not easy but you get used to it.*** *When you've missed a dose, you don't feel good so, taking it every day becomes a normal. Even though it takes time, but you get used to it and it's not a pill that you must take for the rest of your life, when you don't want it anymore you stop. It's not easy taking a pill every night at 8 but, what motivates you is seeing someone from your family taking their ARV's, it also motivates you to take yours since you don't want to be where they are.*
> (P10, 7 August 2018, Vulindlela Interview)

One of the young women stated that people ask her what the difference is when one is taking oral PrEP and when one is taking ARV's:

> ***Taking it every day, how is it different from a person who is already HIV positive****, that's what people say. You also think really what the difference is because I take it when I want to, and don't take it if I don't feel like it. I always think once I stop nothing will put me at risk.*
> (P13, August 2018, Vulindlela Interview)

One of the young ladies shared in an interview that a friend advised her to hide her oral PrEP, however this young women did not see the need for her to hide her use of oral PrEP:

> *Yes, I remember this one time when my friend the one who doesn't want to get tested came to my house and saw my pills, She, asked me if this was my pills and I said yes.* ***She then said "you must hide this"*** *but from me I don't see why I should hide anything if you come into my room you'll the pills on top of the table. What will people I don't care really because they are sick too like everyone else in the world, so, if a person*

is taking their treatments or medication, let them be. I thought to myself she must be scared of what people will say when they see her when going into that door and this is because of lack of information but I don't know why because I always tell her. She wouldn't have thought that people will say she's sick when she's carrying that container.
(P13, August 2018, Vulindlela Interview)

The issue of using oral PrEP secretly was a reoccurring point in the workshops and one-on-one interviews, with one of the young ladies strongly suggesting that young women taking oral PrEP should not "hide it". This young woman expressed the fact that she believed that getting support when taking oral PrEP is important:

> ***They must not hide it, support is very important and needed even from your partner****, but people are not the same. Some hide it from their partner, I don't, and he doesn't have a problem. I even told him that we must come here at CAPRISA together but he's lazy to because he works every day.*
> (P1, 16 November 2018, eThekwini Interview)
>
> *I think once people are aware of PrEP and what's it for and where it's available it will be more like women taking charge of their health. Especially young people they want to be in charge of their health, like young women under 35-years in the universities. If they approach PrEP like that. As a way of giving women charge of their health even us who are taking it won't be ashamed, because that's where it starts, if a person who is taking it is ashamed, then others won't take it too.*
> (P5, 26 July 2018, eThekwini Workshop)

The young women during the interviews mostly, shared some of the side effects they experienced when taking oral PrEP. The young woman quoted below shared how they experienced side-effects when she started taking oral PrEP:

> ***At the beginning of PrEP, you lose your appetite** then go there and tell them the side effects of the pills then they give you something, after that you don't experience any side effects.*
> (P9, 17 August 2018, Vulindlela Interview)

When asked what oral PrEP is during the one-on-one interviews, most of the young women shared the side-effects that one may experience when taking oral PrEP:

> *PrEP is a pill that you take daily for the prevention of HIV infection when having sexual intercourse with your partner whether it's one or multiple partners. **The pill has side effects** but they don't last for long, if there's something bothering you, you can contact them and let them know so that they can help you. When you want to stop taking it, you can do that.*
> (P11, 17 August 2018, Vulindlela Interview)

It was very interesting to hear from the young women that most of them felt that the period of side-effects was not too long, and all of them shared how they endured the period of having side effects. None of the young women shared that they stopped using oral PrEP because of the side effects:

> *There are side effects but for only one to two weeks after you start taking it. It's not that bad because it's juts nausea and over-eating. After two weeks it's ends then you go back to normal so, it's not something that can make a person to stop taking pills.*
> (P13, 7 August 2018, Vulindlela Interview)

Significant statements about attitudes to oral PrEP:
1. Sometimes you even think about quitting… it's annoying. **2.** At the beginning it's a problem because you sometimes forget. **3.** Taking it every day, how is it different from a person who is already HIV positive. **4.** … "you must hide this" **5.** They must not hide it, support is very important. **6.** It will be more like women taking charge of their health. **7.** At the beginning of PrEP, you lose your appetite.

Table 6.10: Summary of significant statements: attitudes to oral PrEP

Comprehensive services in clinics

Most of the young women who were involved in this study clearly stated that oral PrEP must be made available in SRH service where they can receive healthcare that combines HIV prevention with family planning. All the young women in this study stated that what they enjoyed the most about accessing oral PrEP at the CAPRISA research clinic was the fact that they received healthcare provision for family planning and other SRH services that they needed. The young women in this study vividly stated that receiving combined services was encouraging for them to even go to the clinic to receive their oral PrEP. This point was also raised in the previous theme, it is evident that in some communities, the use of oral PrEP is associated with promiscuity and immorality.

The quote below depicts one of the statements made by the young women regarding the provision of other healthcare services when going to the CAPRISA research clinic. This quotation depicts what most of the young women shared in both the interviews and the workshops. It became clear through these discussions that the young women

appreciated receiving other healthcare services when collecting their oral PrEP, even going through tests:

> *… **the most exciting part for me was when I had to do tests that I don't normally do.** If I wasn't at the clinic I would be at home I wouldn't be doing them. So, I get to do those tests and the results had to come back and they tell me in terms of the tests they had these are my results, if there's anything isn't okay they will give me treatment, or they will give me advice on what to do next.*
> (P2, 16 November 2018, eThekwini Interview)

When asked about the combination of family planning and HIV prevention methods such as oral PrEP, the young women expressed that they would want to receive multiple services at the clinic in combination; HIV prevention and family planning:

> Researcher: *Do you think it's important for family planning to be combined with PrEP?*
>
> *Yes, **it's important because you know when you go for PrEP you'll get everything else** you need in one place, without having to do one thing here and then to the clinic for something else.*
> (P9, 17 August 2018, Vulindlela Interview)

When asked further about the integration of oral PrEP and SRH services, one of the young women shared that it is encouraging to go to the clinic and receive healthcare for several issues instead of just one:

> Researcher*: Do you think such things encouraged you as a person to keep going to the clinic? The fact that they were offering other services.*
>
> *Yes, I believe PrEP should be at clinic where there's everything, if you are sick, **if you want family planning or anything of that sort you should just get it here, where everything is there.** At the clinics*

there's mothers there for children vaccination and that sort of thing, it must there so that they may easily have access to it.
(P2, 16 November 2018, eThekwini Interview)

Significant statements about comprehensive services in clinics:
1. The most exciting part for me was when I had to do tests that I don't normally do.   **2.** …it's important because you know when you go for PrEP you'll get everything else.   **3.** …if you want family planning or anything of that sort you should just get it here, where everything is there.

Table 6. 11: Summary of significant statements: Comprehensive services in clinics

Attitudes to oral PrEP and SRH services

Research Q3. In what ways can the current structure and organization of SRH services be realigned to meet the needs of young women in order to ensure acceptance, immediate uptake and adherence to oral PrEP?

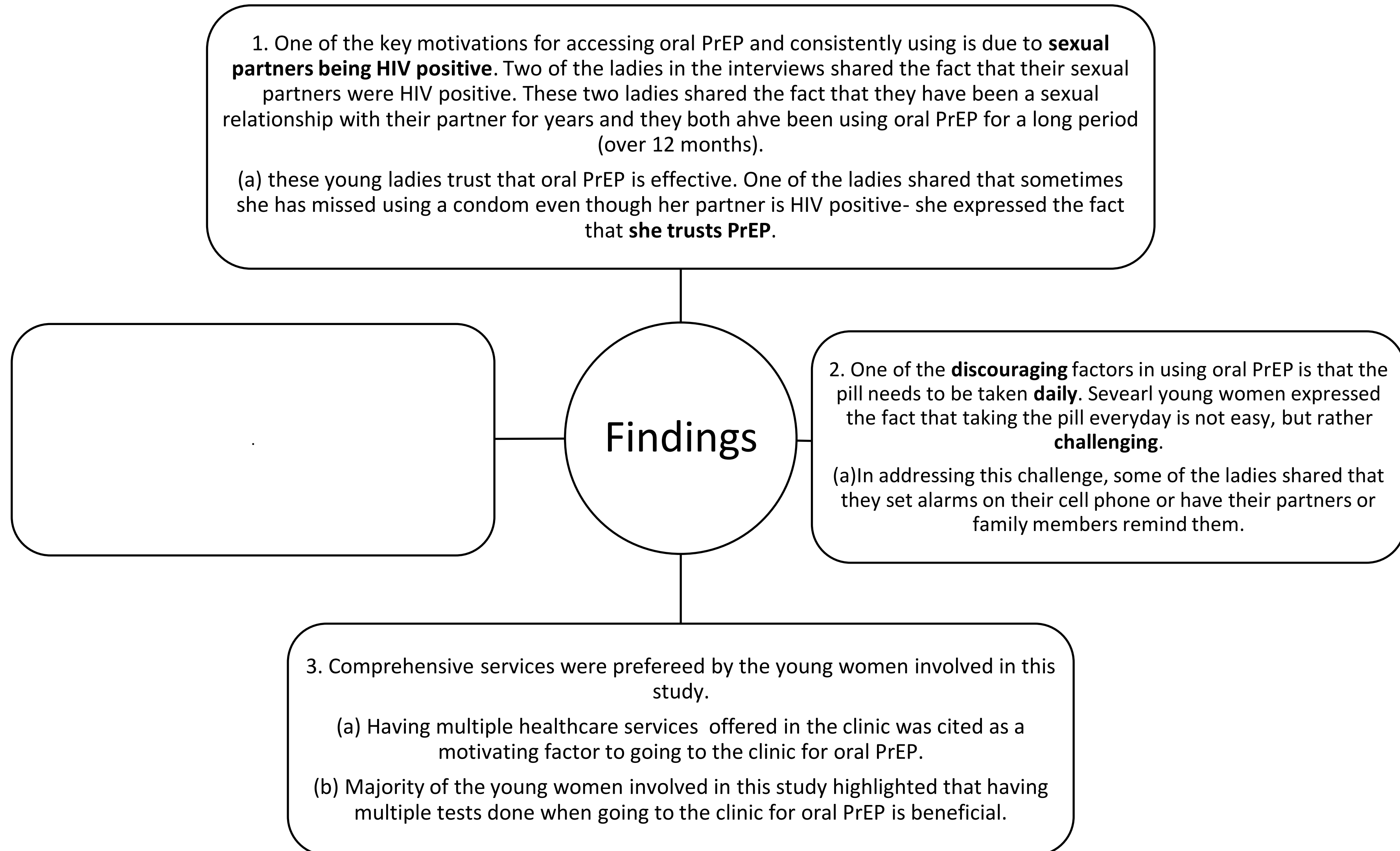


Figure 6.4: Comprehensive summary of themes related to attitudes towards oral PrEP and SRH services

This section has presented data from both the journey mapping workshops and the one-on-one interviews with the young women involved in this study. The data is systematically presented according to the themes that were developed from the raw data. Each theme is succinctly presented in a textbox with significant statements from the young women.
Section one which is the visual data and section two above are interlinked in that the data presented in section two elaborates and gives more light into the data presented in section one. The visual data is enriched and gives off more meaning when viewed alongside the quotations in the subsequent section.
The following section will now present the perspectives and views of nurses directly involved in making oral PrEP available for the young women in this study within the SRH services.

Summary of data presented

Most of the young women involved in this study spoke strongly about nurses' attitudes, behaviors and skills in the clinic. It became evident through the workshops and one-on -one interviews with the young women that the nurse's attitudes in the clinic had a direct effect on the young women's experiences of going go the clinic for oral PrEP or any other medical services. The young women in this study felt that the nurses in the clinic are not patient with them, making the process of examination and consultation uncomfortable. In addition, the young women also expressed that nurses usually depict being judgmental towards them, this was echoed in more depth during the one-on-one interviews as the young ladies shared on their experiences of clinic visits. One of the indications that the nurses were judging them was due to the fact that the nurse would accuse the young women to be lying about health-related information that the young women were asked to disclose during counseling.

Several of the young women explicitly shared that they have had an experience in the clinic where the nurse would ask them questions, and upon responding, the nurse would state that they are lying. The young women shared that this was discouraging.

A common view among the young women in this study was that the nurses from their clinics are rude and unfriendly. This point was raised without the researcher asking a direct question related to this.
The nurses interviewed shared that it is important for nurses to be trained on dealing with patients.

Waiting times in the clinic was raised as an alarming point by the young women. Across both research sites, eThekwini and Vulindlela, the young women stated that the waiting times in the clinic are too long. A few of the young women believed that people will be discouraged form starting to use oral PrEP because if the long waiting times in the clinic when one goes to collect their oral PrEP. The young women attributed the long waiting times in the clinic to several factors such as the clinic being over crowded, shortage in nurses on duty and nurses being lazy to work.

The young women involved in this study repeatedly shared that there was a lack of access to resources in the clinic. Majority of the young women shared personal experiences of how they visited but they were informed that the medication they needed was not available. This point was also attributed to nurses distributing medication unfairly. This was raised as discouraging.

Privacy and confidentiality were raised as being important in the clinic. The young women felt that they needed to know that what they share with nurses and counselors was held confidentially. Moreover, the young women shared that they should be offered privacy when consulting in clinics because the lack of privacy they face when going to the clinic makes them feel uncomfortable.

The young women involved in this study cited family and partner influence support to oral PrEP uptake as necessary. Most of the young women in this study shared that they disclosed the fact that they were taking oral PrEP to their partners and family members. It was interesting to note here that most participants did not like keeping their use of oral PrEP a secret. A few of the young women boldly stated that support in taking oral PrEP must start at home. Misconceptions regarding oral PrEP by family members and partners was cited by the young women as something that could be discouraging in continuing to take oral PrEP.

Overall, the young women in this study felt that taking oral PrEP for HIV prevention is important. To the point that when the young women were sharing their challenges with taking oral PrEP daily, they stated that they still continued to take PrEP. Some of the challenges of taking oral PrEP that was cited by the young women included the side effects that they experienced and the issue of remembering to take the pill every day. One of the young women even stated that when she started taking oral PrEP she would even contemplate just discontinuing the use of PrEP

Community perceptions and understanding of oral PrEP was raised as an important issue. In both the interviews and workshops, the young women shared the fact that there were several misconceptions about oral PrEP in their communities. The most common point raised in both research sites was that there were misconceptions that oral PrEP pills were ARV drugs. Majority of the young women raised the point that family members, partners and neighbors believed that PrEP was an ARV drug.

The next section presents data from one-on-one interviews from the nurses involved in this study. The data is arranged according to the themes developed and represented in the previous section.

Biographical information: Nurses

Date of interview	Code	Age group	Employment status	Place	Duration of working for CAPRISA research clinic
30-07-2018	(N1)	20-30	Professional nurse and team leader on the CAPRISA084 demonstration project.	Vulindlela CAPRISA clinic	13 Months
19- 11-2018	(N2)	50-60	Research nurse on the CAPRISA084 demonstration project.	eThekwini CAPRISA clinic	11 years

Table 6.12: Biographical Information of Nurses Interviewed

Both the nurses that were interviewed were involved in making oral PrEP available for all the young women who were part of this study. The nurses played key roles in the

clinic where SRH services were provided, these nurses were involved in making provision of oral PrEP and other SRH services that the young women needed. The nurse's perspective in this study are important as they had close contact with all the young women enrolled on the CAPRISA084 demonstration project.

The following quotations depict the views and perspectives that the nurses shared during the one-on-one interviews. This data is presented according to the themes developed and presented in the previous section.

Nurses attitudes in the clinic.

The nurse from the CAPRISA eThekwini Clinic raised the point that it is important for nurses to get trained and develop certain skills. The quotation below depicts one of the nurse's views on nurses' attitudes in the clinic, this nurse highlighted training and gaining practical experience in dealing with patience with adherence issues as important. This nurse cautioned that it is not good to "pre-judge" a patient:

> *Besides training nurses, the nurses also need to be like confident in handling patients not participants. So, uhm they also need to gain a lot of knowledge, experience, like they need to practice. So, academic knowledge is good but practical knowledge is also important. So, you need to deal know how to deal with somebody who's having adherence problems like missing tablets. So, the thing is* ***you can't like be biased and pre-judge somebody, you know****.* ***So, you've got to be open minded.***
> (N2, 19 November 2018, eThekwini Interview)

Access to resources in the clinic.

During the interview, one of the nurses raised the issues of the importance of having a clinic that is well run when providing oral PrEP to patients in need. This nurse referred to the structure, the services provided and functioning of the clinic:

> *Exactly, so the thing is* ***you've got to have a well-run clinic****. People must know exactly what's happening in the clinic. Others are going to have like you going to have poor adherence right, people are not going to come to the clinic. And*

then if somebody comes with a side effect of PrEP, you've got to treat that person. You can't you know what listen I don't have uhm let's see one side effect is headaches, I don't have Panado's in the clinic. You know what I'm saying, those are all deterrent factors. So, you not going to have adherence. This person will say you know what, and the thing is uhm you've got to counsel the participant properly. So, you can't say you know what, okay you've got a headache take this Panado. You have to explain you know what okay at the onset of taking PrEP you will might have the side effects for a couple of days and it will go away. You know what I'm saying, so, it all comes like all in one. Counsel the participant properly, provide treatment, and then say okay listen uhm if it continues come back or call me or you know things like that and follow up, so all that promote adherence.

(N2, 19 November 2018, eThekwini Interview)

Family and partner influence and support to oral PrEP uptake.

Both nurses from eThekwini and Vulindlela raised the issue of family support. The nurses raised some issues that can surround taking PrEP secretly by reference to patience experiences. It is interesting to note that the nurses suggested that there are some patients who prefer not to tell people or even their families that they are using PrEP. This is contrary to what the young women involved in this study shared about the importance of disclosing to family and partner that they are using oral PrEP.

There were some negative comments about the issue of taking PrEP secretly. The quotation below depicts some of the challenges that people can face when taking oral PrEP secretly:

So, we had a participant who had a problem taking PrEP uhm so, that is why it's so important to talk to a participant. So, she couldn't take PrEP because she used to hide her bottle in her mom's room, so they never had like a room as such. Yes, they don't have individual rooms, it's like where she was sleeping and sitting room area right, they use to make beds over there. So, the thing is a couple of times her mom was not well, so she would go sleep and lock the

door, so she couldn't take her PrEP. And because there was younger kids in the house, so, she couldn't keep PrEP anywhere even in her bag.
(N2, 19 November 2018, eThekwini Interview)

One of the nurses shared that she has experienced patience discontinuing the use of oral PrEP because their partner was not supportive of her taking the pill. This particular example that the nurse made was making reference to a married young woman:

With the ones that are married, I'll just put it like that. There will be issues of partners complaining to when the partner wants to take PrEP comes to us and then they go back and explain to the partner. There will be issues like, 'are you not trusting me, that is why you want to take this pill?' Some of them they will come back and say 'ei I won't be able to enrol because my husband didn't allow me'. Or they will say I'm cheating because he is working far and I'm here and I want to take PrEP to be protected from HIV, what HIV cause it's me and you.
(N1, 30 July 2018, Vulindlela Interview)

The point of family influence on a person taking oral PrEP was echoed by the other nurse who made reference to a mother who brought her daughter to the clinic so she can decide if she would like to start taking oral PrEP. What was interesting here was the fact that this nurse also highlighted the importance of community influence:

Community influences, family influence, partner influence. So, it will totally depend on that. The thing is uhm if you can empower a woman, a young woman that would be such an awesome thing. So, she can make decisions for herself in future, and say "This is my life, If I can't protect my life no one else will". We actually had a mom uhm that was taking PrEP, and the daughter and uhm it was such a good thing because like the mom used to like empower the daughter and I thought that was so amazing. She brought her daughter
(N2, 19 November 2018, eThekwini Interview)

The nurse from Vulindlela shared how the young women in the community were often discouraged by their parents from taking oral PrEP, questioning why they would want to start taking PrEP:

With the younger ones, they'll come back and say mom said am I having sex now? Why am I deciding to take PrEP? I think that also affect with family planning…

(N1, 30 July 2018, Vulindlela Interview)

Attitudes towards oral PrEP

One of the discouraging factors that patients often shared with nurses concerning taking oral PrEP was the issue of taking the pill daily. This is consistent with what the young women involved in this study shared during the workshops and one-on-one interviews. The quotation below is a depiction of this point:

They say they are going to forget to take it and drink it every day, agh its irritating. Some of they are unable to swallow the pill, it's too big. Besides that it is like ARV for HIV positive people, these are the things they mention.

(N1, 30 July 2018, Vulindlela Interview)

Community perceptions and understanding of oral PrEP.

During the interviews with the two nurses, the issue of community perceptions and understanding towards oral PrEP was raised as an important issue. The influence of community perceptions towards young women taking oral PrEP or wanting to start taking PrEP was evident in the discussion with the nurses. One of the nurses suggested that community members do need to be educated regarding oral PrEP.

The nurse from eThekwini shared an example of one of her patients who experienced being judged for taking oral PrEP. People in this instance that the nurse was sharing about were assuming that this patient was taking oral PrEP because they are HIV positive. This is consistent with the perceptions that the young women shared about concerning community members. The quote below depicts this point:

So, they were actually like pre-judging him like saying you HIV positive that's why you taking the tablet. So, educating the community at large is so important

that there is such a thing as PrEP. So, that people will be comfortable to go to the local clinics and say you know what I want this tablet.
(N2, 19 November 2018, eThekwini Interview)

One of the nurses shared the fact that some of the young women usually feel uncomfortable going to the clinic to collect their oral PrEP because they do not want to be seen by their neighbours. Again the issue of oral PrEP being understood to be an ARV drug was raised:

…they will complain and say oh gosh I have neighbours here. They gonna see me here taking longer…like I must not be seen here. Okay, taking PrEP even if you are old, it does have a stigma. Cause when we started we had this issue of participants saying it is not different from taking oral ARVs. Because it is the same. We have participants that have partners that are already taking treatment, on ARV treatment who are HIV positive. So they will come to us and say why, why do we have to take this pill?
(N1, 30 July 2018, Vulindlela Interview)

Using oral PrEP secretly was associated with the misconceptions that the family and community have towards oral PrEP. This nurse stated that educating the community about oral PrEP will result in people using PrEP freely, without hiding it. The nurse depicted this point by sharing the fact that one of her patience was using a Panado bottle to keep oral PrEP pills.

We had this one participant that was taking PrEP and the family members didn't know. So, what she did, she took out the uhm tablets from the PrEP bottle and she put it in another bottle that, I think had Panado in it and she was taking the tablets. You see to what extent do some of them go?
…unfortunately that's what I'm saying we have to better educate the community. We have to have to so, that people are like free to go to there and just access PrEP. People can say you know what they can walk into the clinic and say can I have a PrEP, without even like you know whispering taking the sister to one side and saying can I have this tablet but it's sad…
(N2, 19 November 2018, eThekwini Interview)

This section presented some views from the nurses involved in making oral PrEP available for young women in SRH services within clinics. The issues raised by the nurses were interestingly similar to the issues raised by the young women during the workshops and interviews. The key issues that were raised by both the nurses and the young women relate to the structure of the clinic, the services provided in the clinic, the resources in the clinic, community and family perceptions, and the support of family and the partner in taking oral PrEP.

This full chapter presented the data collected in this study. The data is presented in three different sections; visual data, textual data from the workshops and interviews, and textual data from the interviews with the nurses.
It is now necessary to explain the analysis of all the data presented in this chapter.

Chapter Seven: Data analysis and further discussion

"…if researchers simply report the codes and themes that appeared in the transcripts, the results will only offer a flat descriptive account with very little depth, doing little justice to the richness of the data…" (Nowell et al., 2017:8)

Introduction

In the previous chapter, data from the journey mapping workshops and one-on-one interviews was presented according to the themes that were developed. Selected quotations and all photographs of the journey maps that the young women developed were presented. In this chapter, the data presented in chapter six is analysed and interpreted.

Ideally, when a researcher engages in the analysis process of data, there is a progress from simple presentation and description, where the data is organised and summarised to show patterns, to where the researcher begins to make sense of the significant patterns identified in the data (Braun and Clarke, 2006). In this chapter, I progress from the data presentation to the data analysis and interpretation phase. The data presented in the previous chapter will be interpreted and discussed according to the themes that were developed. In addition, the data that is interpreted in this chapter will also be discussed in relation to literature, and the theoretical principles that informed this study.

Theme 1: Nurses attitudes in the clinic.

Nurses' attitudes are a well-known barrier to young women seeking to access sexual and reproductive healthcare (SRH) services (Slater, 2006, Jonas et al., 2018, Warenius et al., 2006). Several studies have cited healthcare providers, and nurses more specifically to have attitudes that affect patient experiences of accessing healthcare services (Wood and Jewkes, 2006, Atujuna et al., 2018).
However, it was still interesting to note that all the young women involved in this study raised the issue of nurse's attitudes and behavior as an aspect that affected their experiences of clinic visits for SRH services. Even though the young women in this

study were not directly asked about nurses' attitudes, the young women cited nurses' attitudes as having a negative impact on their clinic visits. In chapter six, data from both the journey mapping workshops and interviews depicted that the young women felt strongly about nurses' attitudes and behaviors in the clinic.

Nurse's attitudes are very important in healthcare provision, and there is substantial literature that describes how nurses' attitudes negatively affect access to services in health care facilities (Kennedy et al., 2013, Lince-Deroche et al., 2015, Holt et al., 2012, Nare et al., 1997). Comparison of the findings in this study with those of other studies confirms that nurses in most SRH services are not patient, that nurses are judgmental, rude, unfriendly and lazy (Müller et al., 2016, Jonas et al., 2018).

"Nurses are not patient"

During the workshop and one-on-one interviews, the young women shared that they believe that the nurses in their local clinics and the research clinic are not patient. The quotations presented in the previous chapter clearly showed some examples of what the young women termed as impatient. One of the young women shared in the workshop sessions, that when she goes to the clinic for SRH services, the nurses use instruments to do mandatory tests and check-ups on them. However, according to the young women, nurses often display impatience making the process of examination more challenging. This young lady stated, "*They are like not patient because I am not used to doing tests like putting something in your vagina … It's the instruments that are uncomfortable in your vagina, but the nurses are making it even worse because they are not patient with you, we want to finish and attend someone else, put this in, you see, they are making it more difficult" (*P5, 28 July 2018, eThekwini Workshop).

Healthcare workers need to be patient when working with clients. This participant raised the point that when the nurses are not patient with them, it makes her feel uncomfortable. This young women expressed that the process of being examined is uncomfortable, but the nurse's attitude of not being impatient makes it worse. Apart from the quote mentioned above, the young women shared the concept of nurses not being patient in more detail during the one-on-one interviews. It was interesting to note that one of the young woman shared that even when she asks to be given time during

the examination, the nurses would respond by stating that they have other patients to see. Such nurse's attitudes towards patients should be regarded as a problem, in addition to being unethical.

"Nurses are judgmental"

Another recurring point raised about nurses' attitudes was the issue of being "judgmental". Several of the young women stated that nurses in their local clinics are judgmental. The young women stated that nurses being judgmental made them feel uncomfortable. Leplege et al. (2007) state in their work that healthcare practitioners need to display a non-judgmental attitude to patients by being sensitive to everything that the patient shares and esteeming the patient's feelings and values. Literature has established the fact that nurses' attitudes of being judgmental is a barrier to young women accessing SRH services (Warenius et al., 2006, Wood and Jewkes, 2006). Healthcare providers having a judgmental approach towards patience has a straining result in the healthcare system as this acts as an impediment to the use of a range of healthcare services.

The young women in this study stated that the nurses showed that they were judgmental when they discussed issues related to their personal lives, including sexual health. According to the young women in this study, nurses displayed their attitudes of being judgmental when they questioned what they were sharing with the nurses. One of the young women expressed, *"They ask how many partners you have, when last you had sex, uhm did you use protection, if no why… sometimes because there are judgemental nurses, you can tell her that you have one partner and she'd say you are lying, why don't you use a condom, such questions* (P13, 7 August 2018, Vulindlela Workshop). The same point of having nurses accuse patients in the clinic of lying was raised by several young women during the workshops and one-on-one interviews.

An implication of this is the possibility that nurses attitudes towards young women seeking SRH services is indifferent. The concept of nurses being judgmental can be ascribed to the fact that nurses have their own beliefs and opinions towards young women accessing sexual and reproductive healthcare services in their local clinic (Müller et al., 2016). These beliefs and opinions are informed by culture. As discussed

in chapter three, culture influences the way healthcare providers relate to patience as they unconsciously follow their cultural prescriptions (Campinha-Bacote, 2002). The findings in this study suggest that there is a need for healthcare providers to be culturally competent. When a healthcare provider is not culturally competent, being aware of their own cultural and professional values, they risk imposing their beliefs, values and behaviour on others. Several studies within the South African context have established the fact that nurses often behave and relate to patience according to their personal beliefs and values (Warenius et al., 2006, Jonas et al., 2018, Wood and Jewkes, 2006, Müller et al., 2016). In the provision of oral PrEP in SRH services, it is critical that nurses become culturally competent, being sensitive to any bias or discrimination that they may unconsciously relay to patients.

Most of the young women shared similar views concerning nurses' attitudes in the clinic. However, there was one lady who stated that it is the black nurses that are judgmental. This is a very important point, this young woman believes that it is "black" nurses that are the problem. This may mean that young women do not trust the nurses in their local clinics to the point of stating that the issue is related to their race.

The issue of nurse's attitudes affecting young women negatively can possibly be addressed through initiatives such as the workshop series *Health Workers for Change*, which is a useful healthcare systems development tool (Vlassoff and Fonn, 2001). One of the objectives of this tool is to bring awareness to health workers of sexual and reproductive rights, women's health, and the provision of integrated health services (Vlassoff and Fonn, 2001). This kind of training for nurses may be a key point in making oral PrEP available in SRH services in a manner that is contextually and culturally relevant for the community.

The PrEP and T&T National Policy in South Africa specifies the quality of care needed to roll out PrEP in clinics offering oral PrEP, these include healthcare provider training in providing quality PrEP and Test and Treat (T&T) services (Department of Health, 2016). The national policy recommends that in-service training for healthcare providers must be prioritised, where attitudes, counselling skills and clinical guidelines are developed to enable an non-stigmatised and supportive environment for high risk population groups such as young women (Department of Health, 2016). The findings

in this study show that these recommendations are important as in local clinics needs to be trained to be offer culturally sensitive and competent services.

There is recent literature stating that even after training, nurse's attitudes and behaviours in the healthcare setting do not necessary change (Jonas et al., 2018, Mulaudzi et al., 2018, Lesedi et al., 2011). In the future, further research is needed to explore the kind of training that nurse's need in order for them to have attitudes that are more positive towards patients. With this said, work by Müller et al. (2016) strongly suggests that to mediate nurses values and beliefs in the clinic setting, education and training is paramount. Holt et al. (2012) on the other hand is of the opinion that nurses need to specifically receive training on non-judgemental care and values clarification. The findings in this study support literature that highlight the impact of native nurse-patient relationships. Nurse's attitudes as highlighted above can and often does result in young women not accessing SRH services, therefore the integration of oral PrEP in SRH services may not result in young women accessing these services from their clinics. The data discussed below places further emphasis on this.

A note of caution is due here because in this study, expressions of negative attitudes from nurses were mostly attributed to the nurses from the local clinic, and not the nurses at the CAPRISA research clinics where the young women were accessing oral PrEP. This was interesting to note because it became clear from both the research locations, eThekwini and Vulindlela, that the young women felt that it is the nurses from their local clinics that had attitudes that was discouraging towards them. However, nurses attitudes in public sectors have been highlighted in literature as attributes associated with high workloads, times pressure and limited resources (Jonas et al., 2018). Therefore there may be several factors contributing to nurses negative attitudes in the local clinics as cited by the young women in this study.

Theme 2: Waiting times in the clinic.

Overwhelmingly, the young women expressed great dissatisfaction with the waiting periods at the clinic. The young women articulated that the waiting times at the clinic were too long. This finding was starkly evident in the journey mapping workshops,

where most of the young women clearly depicted on their journey map charts, that waiting in the clinic was unpleasant. This view was raised by the young women as a challenge and discouraging factor when they go to collect their oral PrEP supply from the research clinic, and it was also a concern for their local clinic visits. Even though questions related to waiting times at the clinic were not raised with the young women, it was interesting to see how they all intrinsically shared that the waiting times at the clinic are too long and discouraging during the clinic visits.

Waiting periods in clinic will discourage oral PrEP access

This finding broadly supports the work of other studies in this area linking waiting times, long ques delayed assistance in the clinic setting with reduced patient satisfaction (Jonas et al., 2018, Gerein et al., 2006, Saville et al., 2019). The young women in this study shared the fact that they avoid attending their local clinics because of a combination of factors that include the long waiting periods in the clinic. Another point that was raised by several of the young women in this study, was that even though a person who is ill can bear to wait at the clinic for medical help, a person who is not ill may not have patience and endurance to wait because they are not ill. This point was raised in relation to accessing oral PrEP. The young women stated, "*And some don't feel like they have to take PrEP, people got to the clinic and wait for a long time because they have T.B, they have HIV and it's now compulsory for them to take it so that they get better. But if they are not sick…"* (P5, 27 July 2018, eThekwini Workshop). Taking from this point which was also echoed by a few other ladies, people may not be motivated to sit and wait at the clinic to access oral PrEP in SRH services if the process will entail long waiting periods.

The young women in this study postulated that people may not go to the clinic to access oral PrEP if the process in the clinic requires a long period of waiting, "*If the process would be much quicker people would go to the clinic for PrEP and other things... If the service delivery can be much quicker than people would go"* (P5, 28 July 2018, eThekwini Interview). In an era where oral PrEP is being made available in South Africa in SRH services, for key population groups, the issue of waiting times in the clinic needs to be revised accordingly if product acceptance, uptake, and even adherence will be achieved.

One of the young women stated, "*A lot of people won't take PrEP because they'll realize they'll have to be there for a very long time, some have to go to work"* (P6, 28 July 2018, eThekwini Workshop). A common sentiment that was shared by the young women was that their friends and family in their communities will be discouraged from accessing oral PrEP due to the prolonged waiting periods. The shared response regarding the waiting periods in the clinic was that people will not start using oral PrEP, or even continue when they do start, once it becomes available in the local clinic because of the waiting periods involved. Even though the young women in this study were involved in a demonstration project where clinic service provision is usually at optimal efficiency, they still echoed the point of waiting time being a discouraging factor to oral PrEP access and even adherence.

Waiting times not practical for working class

It is important to note that the young women involved in this study were unemployed during their time of involvement of this study (see table 6.2 and table 6.3 with participant demographics in chapter six). This may be one of the contributing factors for the young women's availability to consistently collect oral PrEP from the SRH services in the CAPRISA clinics. One of the young women expressly shared that once she starts working, she may need to stop using oral PrEP because she will not have time (see chapter six under theme 2 for statement caption). Several of the young women involved in this study also expressed the fact that they believed that young women who work, will not be able to take oral PrEP because of the waiting period at the clinic. Additionally, the various steps and processes involved in the clinic visits when young women go to the clinic to access PrEP is elaborate. All the young women, and the nurses involved in this study gave an account of the steps involved in oral PrEP collection in the clinic. The clinic visit for oral PrEP collection involves taking blood tests, counselling sessions, doctor consultations, and pharmacy consulting

Waiting times and nurse's attitudes

There were several suggestions made by the young women as to why there are prolonged waiting periods in the clinic. The young women referenced their local clinics, and surprisingly shared that the nurses are the cause for the long waiting periods, one

lady expressed, "*they would say that they open at 8 am and then patients arrive at the clinic in order to be attended first. They first start with gossiping and when you complain about waiting they tell you that the waiting period is 3 hours"* (P5, 27 July 2018, eThekwini Interview). However, most of the young women involved in this study also felt that the processes involved when they go to collect oral PrEP at the research clinic take too long. The young women expressed that even the waiting periods between the processes when they collect oral PrEP is too long, for instance the waiting period from the receptionist to when one is called for counselling is a long period. One of the young women specifically state, "*Each and every stage there's waiting more especially after you've done all the processes. You are only waiting for the next appointment for an hour, just to receive a card with your next date visit."* (P5, 27 July 2018, eThekwini Workshop).

However, not all the young women shared this sentiment, which the nurses contribute to the long waiting periods at the clinic. Instead, an interest view was that once oral PrEP becomes available in the local clinic as part of the SRH services, the waiting process involved in going to the clinic to collect PrEP will be too long. Another young woman stated, the long waiting periods in their local clinic was due to the large number of people the clinic was serving. She stated, "*The clinic is always full, and they take a long time to attend to patients…"* (P1, 16 November 2018, eThekwini Interview). Having long ques and high-scale patient intake in clinic is closely linked to the waiting periods in the clinic, this was significant in what the young women involved in this study shared. Perhaps the clinic capacity in various communities needs to be aligned to meet the community needs and numbers.

However, even having highlighted the point above, it was interesting to note here that commonly, young women said that they preferred the research clinic as oppose to their local clinics, with a strong suggestion that oral PrEP provision must continue to be made available in the research clinic. It can therefore be assumed that even though the waiting periods involved in the research clinic when collecting oral PrEP are long, the young women involved in this study still prefer this as oppose to their local clinics.

During the workshops, there was a clear demarcation between the research clinics where the young women were accessing oral PrEP, to their local clinics. It became

very clear that the greatest dissatisfaction with services, particularly related to the long waiting periods in the clinic was associated with the local clinic, and not the research clinic per se. As mentioned above, the young women in this study shared that they would discontinue accessing oral PrEP once the research clinic PrEP becomes available in their local clinics, and no longer in the research clinic. One of the ladies articulated this point, "*I think that there should be a CAPRISA in every township, city, rural area because if I take it from the clinic I am pretty sure that people will not get it. I am one of the people that do not go to the clinic quite often even when I was pregnant I would go to the gynaecologist because I wanted to prevent to stand in the long lines. Even people who don't have money would borrow money so that they can buy painkillers because the service delivery at the clinic is very poor."* (P5, 27 July 2018, eThekwini Interview). There was a common attitude by the young women in this study from both research sites, of dissatisfaction and distrust towards their local clinics, and the healthcare workers within those healthcare systems. This point is evident in all the themes developed from the data collected in this study.

There are several factors that have a direct effect on the waiting periods in the clinic, and sufficient literature has explored these factors, but little has been done to address these in the South African context (Wood and Jewkes, 2006, Gerein et al., 2006, Jonas et al., 2018, Kagee et al., 2011). Some of the identified factors contributing to the prolong waiting times in the clinic include, severe shortage of staff in the clinics, long ques, lack of resources in the clinics, and sluggish attitudes with healthcare workers (Jonas et al., 2018, Ahmed et al., 2019). Some of these cited factors contributing to long waiting periods in the clinic correlate with the views of the young women involved in this study. This further emphasis the fact healthcare services in South Africa, particularly sexual and reproductive healthcare services need to be improved. It is not enough to know about the contributing factors to barriers to access in healthcare services, but meaningful changes need to be made in healthcare services, even at the local clinic level. This is discussed further in more detail in the following chapter. These are some of the structural barriers that will influence oral PrEP acceptance, uptake and adherence as South Africa transitions into a scale-up phase of PrEP in SRH services.

Waiting periods in the clinic are structural issues that need to be addressed as oral PrEP becomes available in SRH services in South Africa. The culture centered approach posits that structures can be an impeding or facilitating factor to local members of a community accessing healthcare services (Dutta, 2011). The emphasis of the culture centered approach is that there is a need to understand these structures within communities that impede access to healthcare services, and this understanding must be derived from community members who are experiencing these impediments (Dutta, 2011). Engaging with community members that are directly affected by structural barriers is critical, the culture centered approach emphasis this by recommending the inclusion of community members in health care services. The integration of oral PrEP into SRH services will call for the inclusion of key population groups that are currently making use of SRH services in their clinics, and community that will also make use of these services. The purpose for this is that these community members have input into healthcare services that they will be available for them. Community members need to be given the platform to identify and outline the various structural challenges that they face in accessing healthcare services in order for these inadequacies become addressed effectively.

Theme 3: Access to resources in the clinic.

The data extrapolated from this study depicts the alarming point that local clinics in some communities face the challenge of lack of resources. It was alarming to hear that the young women shared common experiences around the concept of clinics having limited resources in the clinic. The young women shared that they had experienced several encounters in their local clinics where they did not receive needed medication due to limited resources. In a South African context, the concept of having limited resources in clinics is not a strange notion, several studies have cited this as a challenge even in sexual and reproductive healthcare services (Jonas et al., 2018, Kagee et al., 2011).

Literature points to the facts that South Africa’s healthcare system is characterized by under resourced and overburdened clinics, where facilities often lack the capacity to deliver services to the ever increasing patient demand (Ahmed et al., 2019).

The data collected in this study is consistent to the literature that limited resources in clinics is a challenge in the South African context. The fact that the young women's local clinics usually do not have medication that they need makes the young women to have undesirable perceptions in accessing the clinic for healthcare services.

Access to resources in rural and urban settings

Overwhelmingly, the young women from the Vulindlela rural community expressed concerns regarding the lack of resources in their local clinic compared to the young women from the urban eThekwini. Within this study it became evident that the local clinic situated in the rural setting faced greater challenges in access to resources in compared to a clinic in an urban setting. This finding may be uniquely particular for this study, however, it was an interesting contrast to note. A possible explanation for this might be that low-income context such as rural areas have been highlighted to be disproportionately affected by limited resources in healthcare services (Phiri et al., 2016). While the young women from the urban research clinic also mentioned dissatisfaction in their local clinics due to a lack of resources, there was a great disproportion compared to what the young women from the rural setting. This finding was unexpected and suggests that there is a correlation in lack of resources and contexts where this phenomenon is greater. A note of caution is due here since the study sample size was small and therefore these findings cannot be generalised, these findings however carry merit into concepts that can be further explored.

Basic medication not available

During one of the one-on-one interviews, a young lady explicitly stated that her local clinic is under resourced even in the most basic medication, she said, "*When you take a child there, they will tell you they don't have panado, they will only give the child a dose, they'll take the bottle out and take it back inside the cupboard once the child has drunk it…The Mpophomeni clinic is a disgrace."* (P10, 6 August 2018, Vulindlela Workshop). This experience was common for the young women in rural Vulindlela. Other young women shared instances where they would go to the clinic with a family member who needed to collect their ARV pills, but meet the disappointment of not receiving the pills. The tone of disappointment with the local clinics, and nurses in the

clinic was evident during the workshops and interviews. Most of the young women expressed the fact that they did not trust their local clinics because of personal experiences of not receiving medication that they were in need of. Another young women, as illustrated in the previous chapter stated that when she is ill, she prefers not to go to the local clinic because it is usually under resourced. Repeatedly, the young women expressed the fact that it becomes even more frustrating to go to the clinic, wait for long hours to be assisted, and when one is assisted, patients are told that the medication they need is not available.

However, these findings may be somewhat limited by the fact the young women involved in this study were part of a demonstration project where they were accessing oral PrEP in SRH services within a research clinic setting. Therefore the expressions about dissatisfaction in the local clinic may to some level be a result of comparisons, comparing the local clinic with the research clinic.

Lack of resources and nurses behaviour

The current study found that the manner in which the nurses handled the issue of lack of resources in the clinic is unprofessional. There was an overlap in the themes, nurse's attitudes and limited resources. The young women expressed that they did not trust nurses in the local clinic concerning the lack of medication. One of the young women shared an experienced, "*Sometimes when you go to the clinic you'll find them with their relatives, you get in and tell them the issues, maybe the child has a feverish temperature, vomits after eating, they'll just tell you to make glucose, there's no Panado or allergex but you can see it in the drawers. You ask how because you can see it, they take it and give it to their relative and you don't get it while you need it."* (P15, 7 August 2018, Vulindlela Interview). From this extract, it is evident that nurses are seen to be untruthful about the disclosure of no medication in the clinic. Similar comments were raised by other young women, meaning that this was a problem in the clinics that affected access to resources. According to the experiences and opinions shared by some of the young women, the nurses in clinics lie about the availability of medication in the clinic. Instead of being trusted healthcare providers, nurses are seen as barriers to accessing healthcare services. This is problematic. The incongruity here is that the one who is meant to help, is the one who is seen as a barrier to help.

Even though the issue of limited resources is a separate concept to nurse's attitudes, the young women in this study discussed these themes points jointly. Therefore, it is important that the nurses know how to professionally handle instances where medication in the clinic is not available. Perhaps nurses need training concerning how to address the issue of having limited resources in the clinic. A study conducted exploring the concept of nurse-patient relationships on South Africa discovered that there were several issues contributing to the negative relationships between patients and nurses (Jewkes et al., 1998).

According to Jewkes et al. (1998), nurses verbally abusing patience is a common problem in the South African healthcare systems. This point was evident from the reports that the young women shared about their experiences in their local clinics. Most of the themes that were developed from the data, pointed to the negative treatment that nurses give patients at the clinic. Therefore, it is advisable that as South Africa begins to integrate oral PrEP as an HIV prevention intervention in SRH services, the nurses within these systems need the relevant training and capacity building. Scaling up oral PrEP in South Africa must be inclusive of healthcare workers training, otherwise the provision of oral PrEP may be faced with the challenges of not being accessed in SRH services by those who need this HIV prevention technology the most. There is abundant room for further progress in determining how to address nurses' attitudes towards patients in the healthcare system.

There are also studies that have explored nurse's perspectives towards limited resources and waiting periods in the clinic within the South African context (Jonas et al., 2018, Tsawe and Susuman, 2014, Mulaudzi et al., 2018). In these studies it was raised that nurses usually have several challenges they face that results in their behaviour and attitudes towards patients. According to a study conducted in Cape Town, South Africa, nurses usually face time pressure which may result in negative and rude attitudes towards patients (Jonas et al., 2018). In this same study, nurses expressed that the lack of resources in the clinic is a frustration, as they are unable to best help patient that attend the clinic for healthcare services. In another study conducted in the Eastern Cape, South Africa reported that nurses see shortage of health professionals as a challenge for them to work effectively (Tsawe and Susuman, 2014). This then can influence the quality of services provided by nurses in the clinic.

In another study conducted in Soweto, South Africa healthcare providers raised the point that they are often given limited or no training to help key population groups such as adolescents who seek SRH services (Mulaudzi et al., 2018). From these three studies we can already start to see some of the possible factors that result in nurses attitudes being negative towards patients in the clinic. However, having said all of this, it is not expectable to have nurses give negative attitudes to patients, particularly key populations that need the services.
Several questions concerning nurse's attitudes towards patients in the clinic, particularly towards young women in SRH services. To develop a full picture of the issue of nurses attitudes in the healthcare system in South Africa, further studies are need to understand support systems for nurses that will result in better quality of service provision.

Theme 4: Privacy and confidentiality.

According to the data collected in this study, confidentiality and privacy are important aspects in a clinic context, particularly for sexual and reproductive healthcare services for young women. It was interesting to see that several of the young women in this study depicted the issue of having a clinic, and healthcare providers that respects their confidentiality and privacy, this was clearly portrayed in the "ideal journey map" charts, and even more in-depth during the one-on-one interviews. Confidentiality and privacy were raised as important qualities in the clinic visit particularly during the counseling sessions in the clinic visit. A small number of the young women expressed that there should be protective measures that are placed during the counseling sessions in the clinic to maintain privacy in the clinic.

Lack of privacy and confidentiality in counseling rooms

People walking in and out during consultation sessions in the counseling rooms was cited as disturbing, resulting in feelings of discomfort for the young women. The young women in this study highlighted the fact that they expect that confidentiality is respected in the clinic by nurses because often they go to the clinic to talk about personal and private issues. There are studies that have underscored the merits of

respecting confidentiality in SRH services as a measure of quality (Braeken and Rondinelli, 2012). The findings in this study coincide with this former literature that places emphasis on privacy and confidentiality in the clinic setting (Jonas et al., 2018). The young women involved in this study clearly expressed the impact and importance of confidentiality in sexual and reproductive healthcare services. Confidentiality is at the heart of the code of ethics for medicine, and literature postulates that SRH services must respect confidentiality, particularly for key population groups such as young women (Braeken and Rondinelli, 2012). Therefore, what literature expresses and what this study discovered about the importance of privacy and confidentiality, is a matter of ethics and rights for people accessing healthcare services. It is not a preference by young women but an ethical requirement in the healthcare setting.

The young women in this study felt that they needed to experience privacy during the counseling sessions because it is during these times where they are disclosing personal issues. One of the young women expressed, "*They should emphasize confidentiality maybe if they put up posters on the walls like "do not disturb" for when you are talking to a counsellor, so that no one will enter."* (P5, 26 July 2018, eThekwini Workshop). Several of these young women shared sentiments with this point during the eThekwini workshop. Not having privacy in the counselling sessions made the young women feel uncomfortable. Moreover, the young women felt that there should be measures that the nurses and staff in the clinic take to protect patient's confidentiality and privacy. Similar to the point raised above by this young woman, many other statements from the young women involved in this study centred on how safety precautions can be taken to protect privacy and confidentiality. The comments around the issue of privacy and confidentiality were recommendations- based.

The lack of privacy and confidentiality in the clinic can be a point of discouragement for young women to access SRH services. A study exploring the needs of young people in sexual and reproductive healthcare services suggested that facilities in sexual and reproductive services should comprise of a private and soundproof space so that counselling can be facilitated with confidentiality (Braeken and Rondinelli, 2012). Having sound-proof rooms in the clinic can be one of the several precautions and protective measures that can be taken to conserve patient's sense of privacy. One of the young women expressed during an interview, "*There must be privacy at the*

counselling rooms as Phakama mentioned and we must only talk about what we came for there, since we came for PrEP like how's it treating you" (P6, 27 July 2018, eThekwini Interview). This young woman explicitly shares that the counselling rooms need to be private because these are spaces where they discuss their oral PrEP intake and other private matters.

This point speaks to the clinic structure. The clinic structure needs to be realigned to meet the needs of young women accessing sexual and reproductive healthcare services. One of the needs that young women have in the clinic setting is privacy and confidentiality. Therefore, the structure of the clinic needs to accommodate this need. One of the main research questions in this study focuses on this point, the questions is centred on how sexual and reproductive healthcare services can be realigned to meet the needs of young women.

Nurses role in privacy and confidentiality

Additionally, the young women in this study shared that they valued having privacy in the clinic and confidentiality that would not compromise their integrity. The issue of nurse's attitudes was an overlapping theme here again. The young women shared how nurses must practice confidentiality in the clinic. This recommendation was raised because nurses were reported by the young women in this clinic to openly talk about their confidential information. It was reported specifically by one of the young women that the nurses in their local clinic have the habit of openly sharing her HIV results in a space were other patients can clearly hear. She shared, "*There must be privacy and they need to understand that when I go to talk to them I go there because I want our talk to be confidential. So I think it is careless that a person can go and shout out that, even if it something small but to me it is confidential. To me it is huge, if you are going to say "Sthembile here are your results, you have nothing". You see, it not confidential and there is everyone."* (P6, 27 July 2018, eThekwini Interview). This account reflects how nurse's negative attitudes and behaviours can infringe on patients privacy and confidentiality. The fact that a nurse can talk to a patient about private information in a manner where other patients hear speaks to the nurse's attitudes and lack of ethical practice.

In this study, the lack of privacy and confidentiality was associated with a lack of being professional by the nurses, and also the lack of empathy. The young women expressed the fact that they believe that it is unprofessional for nurses not to give them privacy when they visit the clinic. One of the young ladies shared during an interview, "*I feel like they are unprofessional …So being unprofessional of the counsellors as well as nurses, we've mentioned before that they like to be judgemental counsellors don't give as privacy knowing there are challenges that we face every day."* (P5, 27 July 2018, eThekwini Interview). Several other young women further shared that even though the lack of privacy in the clinic was uncomfortable and demeaning, they continue to attend the clinic because they are in need of the medical services. It is important to understand patients values and beliefs within the healthcare setting because people often make decisions based on their values and beliefs (Auerbach and Hoppe, 2015). Beyond the code of ethics that highlight privacy and confidentiality, in healthcare, when people value privacy and confidentiality in the healthcare setting, then this must be recognised and prioritised.

The culture centred approach frames decisions related to adopting and accessing health care services within dynamic and shifting contexts, which take place in localised experiences (Dutta, 2013). Privacy and confidentiality may be valued concepts within the healthcare setting in a particular community resulting from fear of stigma that is related to accessing health care services, particularly SRH services. In the South African context for example there have been great stigma in young women accessing sexual and reproductive healthcare services, often then in these settings, young women do not continue accessing these healthcare services for fear of being stigmatised in the clinic by the nurses, and also by community members (Pillay et al., 2019). When privacy and confidentiality are not maintained in the clinic, young women may often resolve not to access these services for fear of being identified and stigmatised by community members. Therefore, cultural contexts where access to sexual and reproductive healthcare services is stigmatised necessitates for the confidentiality and privacy to be maintained. The work of Airhihenbuwa (1995) also frames health related behaviour, and even the adoption of health services within social and cultural context that influence peoples behaviours and choices.

The two nurses that were interviewed also shared further on this issue of privacy and confidentiality in the clinic. The nurses shared experiences where young people expressed the fact that they highlight value the issue of confidentiality and privacy in the clinic. The nurse's view on this point are discussed further in the next section of data analysis.

Theme 5: Family and partner influence and support to oral PrEP uptake.

Majority of the young women involved in this study expressed their belief that family and partner support is important in oral PrEP acceptance, uptake and adherence. Overwhelmingly and surprisingly, the young women in this study shared how they believe that family and partner disclosure and support are important for anyone taking oral PrEP. Unlike the presumption that has often been made in literature that oral PrEP can offer young women an HIV prevention method that can be used "secretly", the young women in this study felt that disclosing the use of oral PrEP is important. A study conducted in KwaZulu-Natal established the fact that women from different contexts may prefer various options concerning the disclosure of oral PrEP (Govender et al., 2017). This means that while some young women may prefer to use oral PrEP secretly, others may prefer to disclose their use of oral PrEP.

This study established the fact that a "one-size fits all" approach towards oral PrEP availability and access will not be effective because while some women may refer to use oral PrEP secretly, and a means of practicing autonomy over their sexual health, some women may feel that disclosure of using oral PrEP is empowering, as highlighted in literature (Govender et al., 2017). The current study concurs with this stance as there were various views concerning the issue of family and partner support in the use of oral PrEP. While majority of the young women in this study expressed the importance of family and partner support, there were other young women who were of the opinion that support was not necessarily important when taking oral PrEP.

Family and partner support are "important"

The young women who were of the opinion that family and partner support are important when taking oral PrEP daily substantiated their views by highlighting that having this support system increases adherence. It was a shared opinion that taking oral PrEP came with several challenges including "forgetting" to take the pill daily, however with the support of partner and family, this challenge can be alleviated. The young women expressed that their family or partner would take the initiative daily to remind them to take the pill at the exact time that it is needed. An excerpt from one of the workshops depicts this clearly, "*Everyone at home knows, even my partner knows like I said when my alarm goes off at 8, he says it's time to take your ARV's, can I get you water, he supports me."* (P8, 26 July 2018, eThekwini Workshop). Furthermore, another young lady shared a similar view, "*Yes, it's important because like what I mentioned about my sister, she doesn't want us to be in the same situation as her. She's the one who told me to go take PrEP, even when she takes her pills at 9, she reminds me to also take mine maybe if my phone is not with me. They encourage me in every way, even with the visit date they remind me."* (P12, 6 August 2018, Vulindlela Interview).

Both these opinions were expressed several times in both research sites. The first quotation above related to the issue of having support to remember taking the pill (oral PrEP). It is interesting to note that even though this young woman shares that she has an alarm on her phone to remind her to take the PrEP pill, having someone to also tell her to take her pill at that time encourages her. The second statement above also places emphasis on the point of having a family member help you remember to take the oral PrEP at a particular time. Both these accounts from these young women represent what majority of the young women in this study expressed, family and partner support assists in adherence.

The efficacy of oral PrEP is dependent on adherence. Literature has placed great emphasis on adherence to oral PrEP by young women in clinical trial and demonstration project levels, oral PrEP works, when it is used consistently (Skovdal, 2019, Celum et al., 2019, Moorhouse et al., 2019). Oral PrEP adherence among young African women in particular has shown to be a challenge with a 50% drop off

rate within the first few months of being initiated on oral PrEP (Celum et al., 2019). This means that while young women at risk of HIV infection are being enrolled to start taking oral PrEP, a large percentage of these young women are not continuing to take the pill, making it ineffective. Partner support and family support in oral PrEP adherence may be an important support mechanism for some young women in the African context where communal living and relating is highly valued (Airhihenbuwa, 1995). However, in some contexts, young women may not feel comfortable disclosing to their family or partner. However, it may not be ideal for some people in high risk population groups to start taking oral PrEP because of the inability to adhere to the daily pill regimen and intimate partner violence (Aaron et al., 2018). In some setting in South Africa however, research has brought value to partner support to increase adherence to oral PrEP, with increase in adherence among people who are being supported by their partners (Ware et al., 2012). This is an important issue for future research, the influence of partner and family support on adherence to oral PrEP needs to be further explored.

Male partner involvement discourse suggests that women do encourage the support of men to reduce risk of HIV infection and that some consideration must be given to the role of men as advocates for women initiated prevention such as oral PrEP. During the CAPRISA 004 clinical trial, it was discovered that partner disclosure about microbicide use showed a modest increase in adherence to the clinical product (Mngadi et al., 2014). This findings offers a very nuanced perspective to approaching HIV prevention, particularly of female initiated prevention for the future, by revisiting the current patriarchal role of men in society, and rather using the cultural practices and ideologies as enabler for HIV prevention, men could effectively become advocates for reduce the high infections among women.

Stigma to ARV drugs and oral PrEP use

Another point cited by the young women who declared the important of family and partner support was that this can decrease being stigmatised. The young women expressed how one can explain to their family and partner what oral PrEP is, what it does, and how it is accessed. Having this platform to share and educate the family and partner can remove any misconceptions about oral PrEP that the family or partner may have, removing stigma that is usually associated with oral PrEP. Educating

families and communities is important, and oral PrEP disclosure to family and partner can be a means of educating and sharing accurate information concerning PrEP.

Social acceptability and stigma related issues are important in oral PrEP acceptance, uptake and adherence (Pilgrim et al., 2016), the data collected in this this largely concerns with this. The young women expressed the fact that from their own experiences of using oral PrEP, it is important to inform family and one's partner, educating them about PrEP. Using oral PrEP in secret may result in stigma and misunderstandings regarding what PrEP is and what it does. One of the young women shared, "*Because if you take it in hiding one day your mother might be cleaning and find the container. The first thing that would come to her mind is that it's ARV's, because she doesn't know what it is. It's better if you sit down with her and tell her about the pills and what's it's for. Make them understand."* (P10, 7 August 2018, Vulindlela Interview). This opinion was shared by the other young women involved in this study. Literature has predicted that social acceptance will influence oral PrEP uptake and adherence, particularly family and partner understanding and support will influence young women (Haire, 2015, Pilgrim et al., 2016). By keeping PrEP use a secret may result in further obscurity and confusion towards PrEP as and HIV prevention intervention. This was a key finding in this study, noting that family and partner support are indeed critical in oral PrEP acceptance, uptake and adherence. Therefore willingness of young women to use and adhere to PrEP relies greatly on social understandings.

Several of the young women elaborated on this point by sharing some of the challenges involved in disclosing to one's partner and family about the use of PrEP. Some responses from partners and family were not necessarily supportive, the young women shared that some family members were confused about what PrEP is and even suggested that they are ARV pills. The misconception of oral PrEP being an ARV pill was common when the young women shared their experiences of disclosure to partners and family. Other young women shared that at first, their partners were very sceptical towards the use of PrEP, but over time they understood

In a South African context, where a woman's ability to negotiate safe sex practices with her partner is embedded in cultural discourse, the covert characteristic of HIV

prevention technologies does make product uptake more appealing. However, in other settings is was discovered that women prefer to use microbicides covertly for various reasons including: fear of partner, fear of stigmatization, and fear of appearing untrustworthy (Terris-Prestholt et al., 2013).

As South Africa begins to scale-up oral PrEP in SRH services for young women and other key population groups, further research should be undertaken to investigate the what role the family and partner can play in supporting adherence among oral PrEP users. Future studies on the current topic are therefore recommended.

Theme 6: Attitudes towards oral PrEP

One of the key findings in this study were centered on the challenges of taking oral PrEP daily. The young women involved in this study repeatedly raised the several challenges that they personally face in the oral PrEP daily regimen. In discussing these points, attitudes towards oral PrEP became evident.

Daily oral PrEP regimen discouraging

The young women involved in this study shared that the challenges of taking oral PrEP daily is a great challenge for them that often they even consider discontinuing use. One of the young women shared this point more explicitly during an interview, and this attitude was dominant for most of the young women in this study; "*Sometimes you even think about quitting, I take mine at 6 but sometimes when it's time I just ignore it and take them another time, it's annoying. When maybe you not at home maybe in town and the time to take your pills is near you get stressed out as to when you'll arrive at home and take the pills."* (P9, 17 August 2018, Vulindlela Interview). This is a personal account from one of the young women involved in this study, she expresses that sometimes she does not take the PrEP daily because it is "annoying". As highlighted in the previous section, adherence to oral PrEP is critical if the pill will work. For this particular account, this young women shared how she becomes stressed when she realises that it is almost time to take the pill. This is a depiction of some of the attitudes that the young women involved in this study have towards oral PrEP. It became clear as all the young women shared during the interviews and workshops

that it is the concept of taking the pill daily at the same time that the young women felt annoyed and irritated with.

However, what was also pervasive around this point that even though taking oral PrEP daily is challenging, after some time the process of taking the pill becomes part of the daily routine. So after some time of taking oral PrEP one gets used to taking the pill, this was expressed by most of the young women in this study. An example from this is taken from this young woman, "*It's not a problem because you get used to is as time goes on, you know at 7 you take your pill, you don't even pay much attention to it. But at the beginning it's a problem because you sometimes forget…But it's not easy, it's irritating but it's better once you are a regular".* (P14, 7 August 2018, Vulindlela Interview). This account expresses that taking oral PrEP daily may come with challenges initially, but after some time, the routine of taking the pill daily becomes manageable. This young woman in particular elaborated even more on this point by stating that she is also encouraged to take oral PrEP daily because one of her family members takes ARV pills daily as well.

Side effects from oral PrEP discouraging

Other challenges that were cited by the young women in this study is that oral PrEP has side effects. The young women involved in this study explain that at the point of enrolment to the demonstration project at the research clinic, the possible side effects that come from taking oral PrEP were outlined during the enrolment process. It was during the one-on-one interviews were the young women involved in this study shared their different experiences of the side effects that they experienced when taking oral PrEP. However, even though the side effects were portrayed by the young women as very uncomfortable and even discouraging, all the young women involved in this study also shared that they continued taking oral PrEP until all the side effects subsided. A personal account of this can be seen in this statement, "*The pill has side effects but they don't last for long, if there's something bothering you, you can contact them and let them know so that they can help you. When you want to stop taking it, you can do that".* (P11, 17 August 2018, Vulindlela Interview). Most of the young women shared that even when they did experience side effects they could go to the clinic to receive medical care to stop or relieve the symptoms.

The point of the various side-effects that oral PrEP can have on those who take the pill daily also needs to be a point that is considered as South Africa is making this HIV prevention method available in sexual and reproductive healthcare services. The healthcare systems that will be making this HIV prevention method available must also be ready to assist patients with further medical care needed to address the side effects that using oral PrEP can present.
The young women further shared that they continued taking oral PrEP because they trusted that this HIV prevention intervention works. What was apparent from discussions with the young women in the workshops and one-on-one interviews was that the young women strongly believed that oral PrEP is effective in protecting then from HIV infection when used consistently and in combination with other prevention methods such as condom use.

Taking from the data from this study, it is evident that if young women trust and have confidence that oral PrEP works in preventing HIV these factors can be encouraging for uptake and adherence to oral PrEP. Further research needs to be conducted to explore some of these concepts, particularly research focusing on how to encourage key populations groups towards oral PrEP uptake and adherence.

Theme 7: Community perceptions and understanding of oral PrEP

A key finding in this study is the importance of community perceptions and understanding of oral PrEP. The young women involved in this study shared elaborately how community perceptions and understandings influenced their personal experiences of accessing oral PrEP and continuing to use oral PrEP. Issues of stigma and misconceptions towards oral PrEP were cited by the young women to have a negative impact on their experiences of taking oral PrEP consistently. The young women from both research sites, urban eThekwini and rural Vulindlela shared similar experiences of community perceptions and understandings of oral PrEP.
The young women from both research sites also stated that there are many people in their communities that believe that oral PrEP is an ARV drug. The use of oral PrEP was also associated with a particular lifestyle that carries stigma, the young women

stated that some people in their communities believed that people who take oral PrEP are promiscuous.

Misconception of oral PrEP being ARV drugs

Oral PrEP being misconceived to be an ARV drug was a prevailing misunderstanding in communities that seems to be common. The young women involved in this study shared that family members, and community members associated oral PrEP with ARV drugs, they expressed the misconception that PrEP is an ARV drug. This misconception was because oral PrEP was cited to look like ARV drugs. One of the young women shared, "*After collecting my pills, she asked me to pass by her house to explain because what she's been told is different from what I told her. I agreed and went pass her house and showed her the pills, she said I'm lying this is an HIV pills, I asked her to bring an ARV if she has it so that we can look at both look and see if they are the same. She said when you are starting your ARV's you get the pills like those I had…"* (P14, 6 August 2018, Vulindlela Workshop). This young woman is sharing a personal encounter that she had with one of her neighbors, where her neighbor was persistently telling her that oral PrEP is actually an ARV drug. This experience in particular highlights what many of the people in the Vulindlela community believed oral PrEP is. The comments above also suggests that people in this community know about oral PrEP because this young woman starts off by stating that this neighbor told her that she heard something different from others about what oral PrEP is and what it does.

Several of the other young women expressed the same notions concerning oral PrEP misconceptions with family and the community. Young women from both research sites expressed the same experiences in their communities, and with family.

Encounters such as this one show that vulnerable population groups in an area where people do not understand what oral PrEP is can discourage them from taking oral PrEP. Issues of misconceptions about oral PrEP can create stigma and negative connotations that will in effect discourage people from accessing PrEP in clinics. If misconceptions such as the one cited above are not addressed appropriately in various communities, key population groups in need of oral PrEP may become discouraged from oral PrEP acceptance, uptake and adherence because of the stigma

and misconceptions. This finding has important implications for oral PrEP integration in sexual and reproductive healthcare services. This finding means that more needs to be done to understand community misconceptions, so that this HIV prevention method can be integrated in a manner that addresses stigma. Perhaps oral PrEP integration in local clinics needs to also aim at informing and educating community members about oral PrEP so as to eliminate misconceptions and stigma related to oral PrEP.
The young women involved in this study shared extensively that taking ARV drugs came with stigma and resulted in being "judged" as someone who lives in a particular way. There were vehement comments surrounding the topic of being "judged" by community members for taking oral PrEP, and this was something all the young women shared that they do not like. One of the young women shared this point clearly, "*so she judges me, when someone comes to me in the room I'm renting I would tell them when it's time for me to take my pill. I'd take my PrEP and they would ask me what is it and I explain to them, but my neighbour would always judge me and say it's pills that look like ARV's, how are they different and so on."* (P4, 16 November 2018, eThekwini Interview).

Further research is needed to establish what should and can be done to remove such misconceptions, and possible stigma surrounding oral PrEP for all the communities where oral PrEP will be made available in South Africa.

Literature shows how the use of ARV drugs has a historical negative connotation and stigma in Africa, and particularly so in South Africa where initial introduction of ARV drugs and post exposure prophylaxis was met with resistance by government and society (Tomaselli and Chasi, 2011). This resistance to biomedical interventions in HIV prevention is still experienced in some communities in South Africa and needs further exploration. As Steinberg (2011:150):

> "Indeed, across colonial Africa, medicine was always understood as a vital ingredient in white political power. The needle that penetrates African skin to extract or inject substances into African blood has never been a neutral technology; it is an image that has always been hungry for meaning"

This statement highlights how biomedical technologies are often perceived by Africans as a political mechanism of control that cannot be trusted. Historically, Africans do not easily trust ARV's because of the historical misconceptions around the introduction of biomedicine in Africa (Tomaselli and Chasi, 2011). Some of these notions and beliefs around biomedicine are still evident in some settings in South Africa where ARV's, condoms and even PrEP are seen as interventions that cannot be trusted.
This argument is one of several other factors that may influence negative perceptions even towards ARV's.
The misconception of oral PrEP being an ARV drug may carry implications that will affect oral PrEP acceptance, uptake and adherence. Key population groups may not want to be seen accessing oral PrEP in SRH services, because of stigma, and therefore choose not to use oral PrEP. These issues need further exploration and understanding in research.

Use of oral PrEP use associated with a promiscuous lifestyle

Another interesting finding that the young women shared in this study was that there was a notation that people using oral PrEP live promiscuous lives, or that they have no "morals". This notion was more popular among the young women in the rural Vulindlela area, who shared personal experiences of how some members of the community would ask them questions and share comments when they see them going to the research clinic to collect oral PrEP. These comments and questions suggested that there are community members who believe that people accessing and using oral PrEP live a particular life style. Among several other comments that were shared on this point, these two young women from both research sites stated, "*but I don't like people knowing that I take PrEP because people think when you are taking PrEP it is because you have no morals. They think you are not well-behaved because you know that you are fine so, you'll go sleeping around which is not true, I don't like it."* (P9, 17 August 2018, Vulindlela Interview). This young woman raises two important points, firstly, she is does not like people knowing that she takes oral PrEP, and that this is cause by the fact that many members of her community associate using oral PrEP with a promiscuous lifestyle. Another comment stated, "*But when you tell some people about PrEP they think it's for immoral ladies."* (P8, 26 July 2018, eThekwini Workshop). These two comments are an example of the general notions that some communities,

rural and urban have about oral PrEP. Both these statements depict the stigma that is already attached to oral PrEP use.
However, it is important to bear in mind that the findings in this study was with a small sample group which cannot be used as a representation of a general population, but, these key points carry merit to help us understand some of the social and cultural issues that may affect oral PrEP acceptance, uptake and adherence. These are factors that must be considered in the integration of oral PrEP in SRH services.

There is literature that highlights the importance of further research being conducted to understand stigma and misconceptions surrounding oral PrEP (Celum et al., 2015, Pettifor et al., 2015). One of the ways in which we can understand stigma and misconceptions towards oral PrEP is to first understand the contexts where these issues arise. The culture centered approach places emphasis on the contexts in which people are situated, with an understanding that it is in these contexts where people make health related decisions (Dutta, 2011). Therefore, decision making and contexts are closely related. Dutta (2013:134) shares this point in particular relation to accessing oral PrEP:

> "The decision regarding the adoption of specific health behaviors, including the decisions to engage clinical care to access and use PrEP, take place in dynamic and shifting contexts, situated amid localized experiences of risk and the everyday negotiations of risk among community members."

This statement brings value to the social contexts that people are situated in, and it is in these contexts where oral PrEP acceptance, uptake and adherence will take place. Therefore, it is important that community beliefs, values and understandings around oral PrEP are understood in various settings so that PrEP integration into sexual and reproductive healthcare services offer culturally competent services.
Cultural competency in healthcare services refers to the ability for health care systems to provide appropriate care for patients with diverse values, beliefs and behaviours, and the goal in cultural competence is to meet the patient's social, cultural and linguistic needs (Betancourt et al., 2002). As sexual and reproductive healthcare services begin to make oral PrEP available to high risk populations in South Africa, perhaps cultural competence is one of the commitments that need to be made.

Summary of research findings in relation to the research questions

The table below depicts the research findings in relation to the three main research questions. The three research questions that this study set out to address are;

1. In what ways is the current structure and organization of SRH services an impeding or facilitating environment for young women assessing biomedical products?
2. What are the likely socio-cultural challenges or opportunities that will influence acceptance, uptake and adherence of oral PrEP in SRH services among young South African women KZN?
3. In what ways can the current structure and organization of SRH services be realigned to meet the needs of young women in order to ensure acceptance, immediate uptake and adherence to oral PrEP?

Taking from the results in this study, the integration of oral PrEP in already existing SRH services is important and necessary for effective HIV prevention and provision of sexual and reproductive healthcare services among key population groups. This study noted four important concepts that must be considered in the integration of oral PrEP in SRH services.

Structure and organisation of the clinic

The first research question focuses on the organisation and structure of the clinic. Results from this study indicate that more privacy is needed in the clinic, with several suggestions form the young women involved in this study on how to make some areas in the clinic more private.
The waiting period in the waiting room is too long, it results in long ques. Entertainment in the waiting room in the clinic was therefore raised as important. Having books, magazines and WIFI are just a few of the suggestions made towards making the waiting areas in the clinic.

Clinic staff, nurses and healthcare providers are not necessarily structures, but in this study they are studies as people who are in the healthcare structures, their attitudes were raised as a very important point within the services provided in the clinic.

Specifically, the young women in this study cited, professionalism, kindness, politeness, communicative skills to be important attributes that healthcare providers have in the clinic. Access to medication was cited as a challenge that needs to be considered in local clinic where oral PrEP will be made available. Lack of medication in the local clinics was raised as a point that oral PrEP will be effective once it available in the local clinics.

Social- cultural challenges in the community

The second concept that must be considered in the integration of oral PrEP in SRH services are social and cultural challenges or opportunities within a community that the clinic is serving.
One of the key findings in this study was that there are misconceptions and stigma around oral PrEP in the communities where this study was facilitated, rural Vulindlela and urban eThekwini.
The young women involved in this study highlighted that people from their communities believed that oral PrEP pills are ARV drugs, and therefore there is a fear that people will start believing that people taking PrEP are actually HIV positive.

Cultural connotations to HIV and AIDS have made taking ARV drugs a negative concept in communities. HIV is associated with a promiscuous lifestyle, therefore taking ARV's or taking oral PrEP which is believed to be ARV drugs is stigmatised.
Young women from both urban and rural contexts stated that in their communities there was a misconception about PrEP, there is a lack of accurate information about PrEP.
The data presented and analyzed in this study reveals that there is a sense of cultural collectiveness in the communities where the study was conducted. When looking at how often the young women in this study made several references to their families, partners and community members even when they were not asked directly about them, shows that there is a sense of collectiveness because they did not just view their experiences in isolation. Moreover, the young women involved in this study highlighted that partner and family support is important in oral PrEP uptake and adherence because the family members also remind them and encourage them to take their daily dose. In addition to this point, partner approval and support proved to be important for

some of the young women as depicted in the data, while others did not feel that this is important.
The young women showed that they do not trust the nurses from their local clinic. There seems to be a prevailing culture of distrust among the young women towards nurses.

Attitudes towards Oral PrEP- acceptance, uptake and adherence.

The third concept that must be considered in the integration of oral PrEP in SRH services are young women's attitudes towards Oral PrEP. One of the key motivations for accessing oral PrEP and consistently was found to be sexual partners being HIV positive. Two of the ladies in the interviews shared the fact that their sexual partners were HIV positive. These two ladies shared the fact that they have been a sexual relationship with their partners for years and they both have been using oral PrEP for a long period (over 12 months).
The young women in this study showed that oral PrEP is effective.
One of the discouraging factors in using oral PrEP is that the pill needs to be taken daily. Several young women expressed the fact that taking the pill every day is not easy, but rather challenging.
In addressing this challenge, some of the ladies shared that they set alarms on their cell phone or have their partners or family members remind them.

Structure and organization of SRH services	(a) More **privacy** is needed in the clinic. (b) The **waiting period** in the waiting room is too long, it results in long ques. (c) **Entertainment** in the waiting room in the clinic was raised as important; books, magazines, WIFI etc. (d) **Nurses and healthcare provider's attitudes** were raised as a very important point within the services provided in the clinic; professionalism, friendliness, kindness, politeness, communicative skills. (e) **Lack of medication** in the local clinics was raised as a point that oral PrEP will be effective once it available in the local clinics.
Socio-cultural challenges or opportunities	(a) There is **stigma** around oral PrEP in communities. (b) Participants highlighted that people from their communities believed that oral PrEP pills are ARV drugs, and therefore there is a **fear** that people will start believing that people taking PrEP are actually HIV positive. (c) **Cultural connotations** to HIV and AIDS have made taking ARV drugs a negative concept in communities. HIV is associated with a promiscuous lifestyle. (d) Young women from both urban and rural contexts stated that in their communities there was a misconception about PrEP, there is a lack of accurate information about PrEP. (e) **Cultural sense of collectiveness**- Participants highlighted that **partner and family support** is important in oral PrEP uptake and adherence because the family members also remind them to take their daily dose. (f) **Partner approval and support** proved to be important for participants (g) The young women showed that they do not trust the nurses from their local clinic. There seems to be a prevailing **culture of distrust** among the young women towards nurses.
Attitudes towards Oral PrEP- acceptance, uptake and adherence.	(a) One of the key motivations for accessing oral PrEP and consistently using is due to **sexual partners being HIV positive**.

	Two of the ladies in the interviews shared the fact that their sexual partners were HIV positive. These two ladies shared the fact that they have been a sexual relationship with their partners for years and they both have been using oral PrEP for a long period (over 12 months). (b) These young ladies trust that oral PrEP is effective. One of the ladies shared that sometimes she has missed using a condom even though her partner is HIV positive- she expressed the fact that **she trusts PrEP**. (c) One of the **discouraging** factors in using oral PrEP is that the pill needs to be taken **daily**. Several young women expressed the fact that taking the pill every day is not easy, but rather **challenging**. In addressing this challenge, some of the ladies shared that they set alarms on their cell phone or have their partners or family members remind them.

Table 6.14: Research findings in relation to research question.

Chapter 8: The Socio-Cultural Model to oral PrEP Integration into SRH services

Introduction

Oral pre exposure prophylaxis (PrEP) is at the forefront of novel HIV prevention methods alongside other biomedical interventions that are still under clinic trial level social and behavioural scientists however need to work with biomedical experts to contextualise the accessibility, product uptake and adherence of potential users to ensure population-level effectiveness. What is already evident from literature (as discussed in chapter two) and the findings in this study is oral PrEP needs to be made available as part of a comprehensive combination prevention initiative, taking structural and social issues into consideration. The availability of oral PrEP in sexual and reproductive healthcare (SRH) services within clinics needs to be fostered in a cultural sensitive and contextually relevant manner where healthcare services and healthcare workers show cultural competence.

The previous chapters presented the research findings, and the data analysis that began to show how the findings from this study addressed the research questions and objectives. This chapter presents the unique knowledge contribution of this study into the field of oral PrEP, particularly a social science perspective into oral PrEP integration into SRH services. This chapter will conclude with a proposed model of how oral PrEP can be integrated in SRH services in a manner that is context specific and culturally relevant, highlighting the role of health communication.

A culture centered approach to oral PrEP integration in SRH services

The culture centered approach is a community-based, and dialogically driven participatory framework which is used in this study as a lens for understanding the social and cultural factors that may help facilitate or impede oral PrEP integration into SRH services for young women. In developing an HIV prevention intervention, or program, the culture centered approach advocates that cultural members of a community are prioritized in the process of defining the social challenges, developing possible solutions, and being active agents in facilitating the proposed intervention

(Dutta, 2008). Therefore, in the context of this study, and given the proven efficacy of oral PrEP as an HIV prevention technology in clinical trials and demonstration projects among key population groups, it is even more important to consider its value in real life settings where vulnerable population groups are situated (not just clinical trials and demonstration projects).

The culture centred approach positions the holistic consideration of understanding culture and agency in the context of communities where structural influences act as barriers or facilitators to accessing healthcare (Dutta, 2011). In the context of this study structures refer to clinics, SRH services within clinics, policy related to healthcare services, healthcare providers, resources within and outside of the clinic etc. While agency refers to the ability of cultural members to enact their beliefs, values and suggestions in the structures they find themselves in such as SRH services. Cultural members should therefore be able to practice agency by challenging the structures that impede them from accessing healthcare services and resources. The responsibility of structures in this notion is to provide platforms for community members to practice agency in a meaningful way.

It is imperative that clinics, SRH services, and policies as structures are enabling for potential PrEP users, this was part of the purpose of this study, to explore how oral PrEP can be made available for young women in a manner that will encourage uptake, acceptance and adherence. The findings of this study suggest that there are several social and cultural factors that will affect the choices that young women make in oral PrEP uptake and adherence. These social and cultural factors will vary from setting to setting, as these issues are contextual and localised. The young women involved in this study shared some of their personal experiences of accessing oral PrEP in SRH services, their personal use of oral PrEP, their experiences with family, partners and community members in relation to oral PrEP acceptance, uptake and adherence. The data reflected that there are issues of structure, culture, agency and attitudes towards oral PrEP that need to be considered for services integration. Some of the social and cultural factors that will affect oral PrEP acceptance, uptake and adherence when this HIV prevention technology is integrated in SRH services include; healthcare provider's attitudes, community perceptions and understandings of oral PrEP, partner and family support, and stigma associated with oral PrEP use.

Culture plays a critical role in determining women's health preferences and decisions, particularly in the African context where the family and community influence an individual's health choices (Airhihenbuwa et al., 2014, Woodsong and Holt, 2015). This point was evident in the data collected in this study. When analysing the various themes that were developed from the data, it became evident that the young women involved in this study (from both the rural and urban settings) valued the concept of collectiveness. This was more evident when the young women expressed that family and partner support when taking oral PrEP is important. The value of collectiveness was also evident in the manner the young women shared how uncomfortable they are with community misconception and stigma within the communities related to accessing oral PrEP. The young women shared some of their experiences of accessing oral PrEP at the clinic and taking oral PrEP in a manner that shows that they viewed themselves as part of collectives.

The findings in this study established that there was a general notion in the community that if you go to the clinic to access oral PrEP you are immoral, or you are promiscuous. This was a misconception that was not received well by the young women involved in this study, and they shared how this made them feel uncomfortable. Findings from the nurse's interviews substantiated this point as nurses shared how young women often feel uncomfortable taking oral PrEP in medication packs they receive at the clinic. The nurses shared how some young women change the oral PrEP package containers to avoid people knowing that they are using oral PrEP. These findings illuminate on the dangers of stigma towards oral PrEP that comes from community misconception of the product. Further work is required to establish the viability of these findings in other settings, as various communities may yield different findings.

However, contrary to expectations, findings revealed that felt that it was important to disclose oral PrEP use with family and partner. So even though there was great discomfort in the community knowing about oral PrEP use, majority of the young women felt that partner and family support is critical.

This study established that family, partners, community and social surroundings affect young women's decisions around accessing oral PrEP in SRH services. Though the findings in this study are specific to the research site, the finding carry merit in

highlighting the critical role that social, cultural and localised factors can contribute to the effectiveness of biomedical interventions in population- level impact. While there is literature that establishes the effectiveness of oral PrEP in clinical trials and demonstration level, there is a need for more studies such as this one that explore the social factors that will influence population-level impact.

Culturally relevant and contextually specific model for oral PrEP integration into SRH services

There are limited published studies that explore the integration of oral PrEP into SRH services. There is also very little in literature about the social and cultural factors that could facilitate or impede acceptance, uptake and adherence to oral PrEP when this HIV prevention technology is integrated into SRH services. This study sought to fill this gap and make contribution to the study of oral PrEP integration in SRH services for key population groups. From a social science perspective, this study sought to explore the social and cultural factors that will influence young women's health related behaviour towards oral PrEP for HIV prevention.

Taking into consideration the literature, theory engagement and data from this study, the following model was developed to inform oral PrEP integrated into SRH services in a manner that is culturally relevant and contextually specific. The Socio-Cultural Model to oral PrEP Integration into SRH services as depicted in figure 8.2 below advanced an evidence-based approach to PrEP integration in SRH services. This model can be used mutually with other integration models.

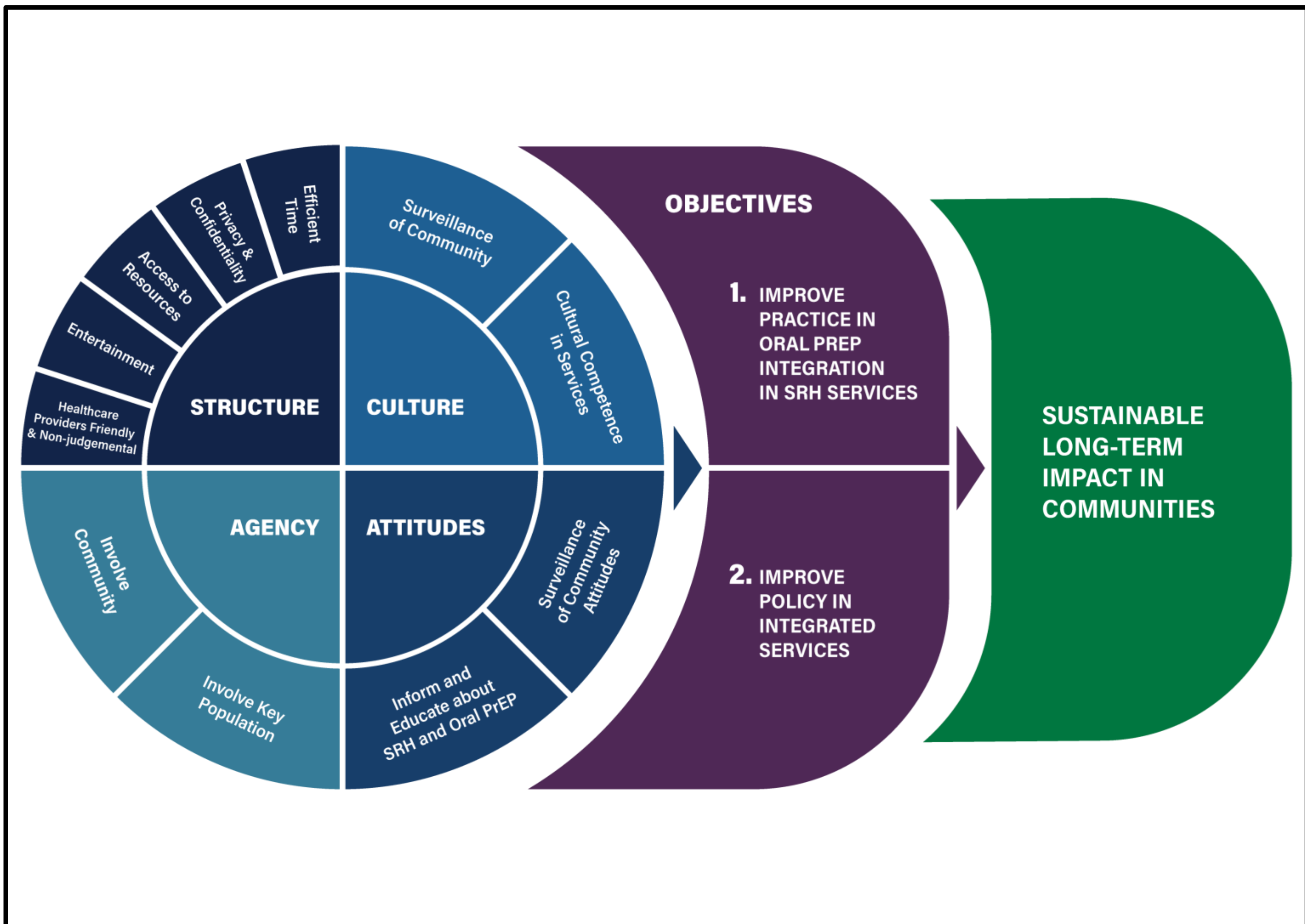


Figure 8.2: Socio-Cultural Model to oral PrEP Integration into SRH services

The socio-cultural model to oral PrEP integration into SRH services consists of four central tenants; structure, culture, agency and attitudes as depicted in figure 8.2 above. This model proposes that these four tenants can considered when integrating oral PrEP into SRH services in various communities. Local contexts are different, and this must be considered when making use of this model, the components should therefore be used in a flexible manner to suit the needs of the community and health system. The overarching principle in this theory is community involvement to inform context specific, and culturally relevant healthcare services for young women as a key population group.

The diagram above depicts some of the localized issues that were discovered in this study, therefore, these can change from setting to setting.
This model was primarily designed to assist oral PrEP integration into SRH services that will result in oral PrEP acceptance, uptake and adherence among young women in KwaZulu-Natal. This model is developed from this study and is proposed as an approach that can facilitate the integration of oral PrEP in SRH services.

Structure:
Structures refers to organisations, systems and processes that determine how society is organised, how it functions, and how members of a community relate to one another through those structures. Structures include policies, healthcare facilities, healthcare practitioners, and community based organisation structures. Structures pattern the distribution of resources, and can be enabling or impeding in accessing healthcare resources and services as explained by Dutta (2008).

The findings of this study raised five specific structural issues that need to be explored in communities and aligned with young women's needs in SRH services when oral PrEP is being offered. These five structural issues are;
(1) Access to resources, (2) Privacy and confidentiality, (3) Healthcare providers that are friendly and non-judgmental, (4) Entertainment, and (5) Efficient time.
The findings in this study reveal that these five structural issues have an impact on young women's experiences of accessing oral PrEP in SRH services, as depicted in the model in figure 8.2. The findings in this study also showed that these factors have the potential to result in low oral uptake and adherence. Continued efforts are needed to understand the structural barriers and enablers in SRH services for young women, further research will be needed in various communities to understand the localized structural challenges.

The young women involved in this study cited the lack of resources in the clinic, unfriendly and judgmental nurses, long waiting times, lack of entertainment and lack of privacy and confidentiality as factors that discourage them from accessing healthcare services from their local clinics. Moreover, majority of the young women from both rural and urban research sites stated that they would not accessing oral PrEP from their local clinics when it is available. Key concerns in structural issues were

largely associated with nurse's behavior and attitudes, this was an overarching theme in the findings of this study. Nurses in the clinic were overwhelmingly cited as impeding in accessing healthcare services. For example, nurses' attitudes were underscored as contributing factors to lack of resources in the clinic, privacy and confidentiality, long waiting periods in the clinic.

Therefore, structures are diverse and often influence each other, however, what is critical is that structures affecting healthcare access for young women in the HIV prevention cascade should be explored and changed so that they are enabling, resulting in improved acceptance, uptake and adherence to HIV prevention methods such as oral PrEP.

The emphasis for the culture centered approach is gaining a sense of understanding of structures which inhibit people from gaining access to health-related services, and this understanding must be informed by local members (Dutta, 2018).

In this study, we sought to explore SRH services as structures where young women access oral PrEP. The findings indicated that the clinic has several factors that have the potential to make this structure impeding for young women seeking to access oral PrEP, these factors include; lack privacy and confidentiality in the clinic, nurses' judgmental and unfriendly attitudes, long waiting periods, and lack of resources in the clinic. The structural factors listed here may be unique to the two research sites because factors such as these ones are context specific and locally peculiar.

Ensuring appropriate healthcare systems, services and support for young women and other key population groups should be a priority in South Africa, therefore further modelling work will need to be conducted in order to understand the implementation of models such as the socio-cultural model of oral PrEP integration in SRH services.

Agency:

Agency refers to the ability to meaningfully engage with the structures that impede or facilitate access to health care services, agency gives people the ability to have control over their choices in life. For example, having access to HIV prevention services as a young woman. Agency includes the ability to challenge structures that limit or impede accesses to health care services or resources. Young women as a key population must be able to challenge structures that are impeding for them in accessing SRH

services. Platforms for this critical interaction of challenging structures must be developed.
In the socio-cultural model to oral PrEP integration into SRH services, community involvement and key population involvement is underscored as the depiction of agency.

In the socio-cultural model for oral PrEP integration into SRH services, the community must be involved in the initial plans towards oral PrEP integration in SRH services. Community members must be prioritized as they understand the nature of social and cultural challenges that perpetuate health related challenges. The model recognizes that community members are not passive recipients of healthcare services, or health-related messages directed at them, but rather community members can practice agency when given the platform to do so.

With the licensure of oral PrEP in South Africa and the roll-out policy to inform oral PrEP integration into SRH services, it is important that social spaces are created for key population groups such as young women to make meaningful contribution through engagement in dialogue about challenges and opportunities in using oral PrEP. Possible results in this is community members gradually taking ownership of medical facts about PrEP, airing any doubts, misconceptions or stigma-related issues.

Key population groups refer to people at high risk of HIV infection and are disproportionately affected by HIV in epidemic settings. These population groups usually face legal and social challenges that increase their vulnerability, as well as limited access to HIV prevention, treatment and care. Key population groups can vary from setting to setting, as expounded by WHO (2018). It is important that key population groups are given platforms to negotiate how biomedical interventions can be made available and accessible to them in effective ways. In the context of this study, this study focused on young women as a key population group. It is evident in the data collected in this study that young women know what they need and want in SRH services for oral PrEP provision that will result in acceptance, uptake and adherence to this biomedical HIV prevention method. Key population groups must be given the agency to enact what they believe is best for them, they must be included in a meaningful way in oral PrEP integration into SRH services.

One of the ways that young women in communities can challenge structures that impeded or limited them from accessing healthcare services, is through dialogical engagement. The culture centered approach postulates that cultural members, in this case, young women should be given platforms where their voices are heard, acknowledged, engaged in a meaningful way (Dutta, 2008). The concept of voice speaks to the ability to actively make contribution to decision making in society through dialogue, it is the capacity of community members to express their views and opinions on issues that affect them.

A key policy priority should therefore be to plan for the long-term interaction with young women and other key population groups in the HIV and AIDS epidemic. Platforms where young women can engage and challenge structures that impede access to healthcare services or resources must exit so that healthcare services will be enabling spaces that will support oral PrEP acceptance, uptake and adherence. This approach will prove useful in expanding our understanding of how SRH services can be culturally relevant and contextually specific to meet the local needs of people accessing the services. If young women can continuously inform how HIV prevention is provided in SRH services, then these healthcare systems will become more and more aligned with young women's needs.

Culture:

Culture refers to the collective consciousness of both measurable and unmeasurable components which can be seen, heard or silently revealed through history, language or customs (Betsch et al., 2016). As discussed in detail in chapter three, the culture centered approach postulates that culture is comprised of traditions that are passed on from one generation to the next, and also from changes that are introduced from members actively participating and contributing to meanings within a community (Dutta, 2008).

The socio-cultural model to oral PrEP integration into SRH services above depicts two important points for the consideration of culture; community surveillance and cultural competence. Firstly, community surveillance refers to community-based observations, the systematic detection and reporting of events of public health significance within a community by community members (Guerra et al., 2019). Additionally, the term "community surveillance" is used in this model as a mechanism to know and

understand the community's cultural values and beliefs that influence health-related behaviour. The process of community surveillance must result in knowledge and understanding of social and cultural prescriptions that affect the individuals and community. Community surveillance has the potential to assist in developing culturally competent healthcare services as healthcare systems will be aligned to the cultural values and beliefs in the community.

Secondly, culturally competent healthcare services and healthcare providers are essential in oral PrEP provision. Cultural competence includes delivering healthcare services in a manner that displays cultural competence, behavior by healthcare workers that shows cultural competence is an on-going process in which the healthcare provider always strives towards with the aim of effectively working within the context of the patient.

Understanding how cultural prescriptions can influence acceptance of PrEP as HIV prevention technologies in various contexts is key for product uptake. This necessitates a new approach towards research on the acceptability of HIV prevention technologies. Lessons are emerging continuously from adherence and acceptability studies of PrEP, which include culture-sensitive approaches, particularly in the African context (Tanner, 2008, Weeks et al., 2004).

Culture is the main concept that drives the culture centered approach, foregrounding the participation of community members in social issues, and in the construction of meanings. Moreover, the culture centered approach explains the construction of health-related meaning as a process involving the negotiation of shared meanings through active participation from community members (Dutta, 2018). It is through this active participation that community members create and reaffirm values, practices and meanings.

Oral PrEP acceptance, uptake and adherence when integrated into SRH services will remain an ongoing challenge if young women's perceptions and accessibility of prevention products are not understood through the socio-cultural predictors of behavioural change and user adoption. While oral PrEP efficacy is clear through clinical trials and demonstration projects, willingness to adopt a new HIV prevention

methods when integrated in SRH services, will determine the effectiveness of this intervention at population level. Most studies on PrEP uptake, acceptance, and adherence neglect the cultural lens in understanding the adoption of biomedical interventions. The findings from this study highlight that there are several social and cultural factors that will influence young women's health-related behaviour towards oral PrEP.

More studies focusing on the role of culture in the introduction of oral PrEP in communities, and the integration of oral PrEP in SRH services is needed. Various settings will yield diverse findings in the role of culture in oral PrEP integration in SRH services as different communities value cultural prescriptions and collectiveness at different degrees. For instance, this study may yield extremely different results when conducting in Western Europe.

Attitudes:

The findings in this study indicate that young women's attitudes towards oral PrEP and SRH services will affect PrEP acceptance, uptake and adherence when this HIV prevention intervention is integrated in SRH services. The young women involved in this study shared their attitudes towards PrEP that resulted in their continuous use of the HIV prevention intervention regardless of structural, cultural and social challenges that they were faced with. Attitudes refer to a person's mind set towards a thing or concept, attitudes also include people's behaviour or tendency to act in a particular way towards something (Pickens, 2005) .

The socio-cultural model to oral PrEP integration into SRH services highlights two concepts that must be considered to address the attitudes of the community and young women's attitudes towards oral PrEP and SRH services; surveillance of community attitudes and disseminating information and educating about SRH services and oral PrEP.

Surveillance of community attitudes refers to community-based observations of current attitudes towards SRH services and oral PrEP. This process must encompass understanding community attitudes towards oral PrEP and SRH services, this phase may result in stigma-related issues being identified, and misconceptions about oral PrEP and SRH services. The findings in this study illustrated that community attitudes,

and understanding about oral PrEP are important. When there are misconceptions and obscurities about oral PrEP and SRH services, communities may develop stigma and negative connotations towards this HIV prevention intervention. The findings in this study revealed that in both research settings, but more so in the rural research site, there was a common misconception in the community that oral PrEP pills are ARV drugs.

Therefore the socio-cultural model to oral PrEP integration into SRH services advices that disseminating information and educating community members about SRH services and oral PrEP is critical.

Anyone seeking to accessing oral PrEP in SRH services should have access to information, education, and communication materials about PrEP and SRH services that are available in their local clinics. Not only is it important to inform and educate people seeking to access oral PrEP, but the community must also be engaged to address social and cultural barriers that may impede uptake of and adherence to PrEP. A few of the young women involved in this study also elaborated on the fact that in their community people associated oral PrEP use with a promiscuous life style. These findings highlight the importance of knowing and understanding community attitudes towards oral PrEP and SRH services so that information dissemination about oral PrEP and SRH services are appropriately mobilised.

Therefore, health communication has a critical role in addressing stigmatised attitudes that may prevent individuals accessing oral PrEP in SRH services.

Health communication involves the process of multiple function such as, informing people about beneficial health-related behaviours, persuasive or motivating communication about adopting a behaviour change that will lead to improved health, building social support and connections, and fostering an enabling environment (Babalola et al., 2017). Communication has an important role to play in the HIV prevention cascade, and in making oral PrEP available in an effective manner in communities. Firstly, people must be convinced to get tested and obtain their results, in ensuring treatment access, linking those infected to care, making oral PrEP available to those at high-risk of infection so that they remain negative, and addressing stigmatizing attitudes that may prevent individuals from taking these actions (Kaufman et al., 2014). All these stages need communication. On the healthcare side,

communication has been shown to mobilize community care and support and increase the quality of patient-provider interaction, which in turn can improve adherence (Vermund et al., 2014). Therefore, health communication has a critical role to play in encouraging HIV testing, creating oral PrEP awareness, ensuring effective oral PrEP integration into SRH services, and supporting oral PrEP adherence.

Model objectives:

There are two main objectives of the socio-cultural model to oral PrEP integration in SRH services. The first objective is to improve current practice in oral PrEP integration into SRH services. In communities where oral PrEP is already integrated into SRH services, this model can assist in improving integration of these services to suite the local needs of the community that the clinic is serving. In communities where oral PrEP integration is still in the strategizing and planning phase, the model can assist in facilitating a contextually relevant and culturally sensitive integration plan.

The second objective is the possible improvement of current oral PrEP policy. Even though the findings of this study were elucidated from a small sample, the findings carry merit and the recommendations have the potential to inform policy and current practice in this field.

Translating clinical trial success to SRH services success

Biomedical interventions in HIV prevention have made tremendous progress, with a plethora of new technologies that promise to protect key population groups such as young women in South Africa (Skovdal, 2019). However, access and uptake of these new biomedical HIV prevention technologies such as oral PrEP remain low in many settings where clinical trials and demonstration projects have been facilitated (Celum et al., 2019). Key population groups such as young women in South African remain vulnerable to HIV despite the availability of prevention methods because they experience structural barriers that include the lack of services in communities, or lack of knowledge about healthcare services (Smith et al., 2018). SRH services for instance in many rural contexts are characterised by a lack of resources, poor healthcare professional services, and economic challenges that hinder access to primary

healthcare (PHC) and SRH services (Pillay et al., 2019). This point is discussed extensively in chapter two, and the findings in this study also support this point.

Even though biomedical interventions in HIV prevention continue to make major breakthroughs in developing HIV prevention technologies that have proven efficacy, protecting people from HIV infection, making the end of HIV possible, at least in theory (Pantelic et al., 2018, Baeten et al., 2012). Social and structural factors have the potential to limit the potential of new HIV prevention technologies, such as oral PrEP among population groups that need these interventions the most. Women in rural contexts, for instance, are disproportionally vulnerable to HIV infection, yet they are faced with social and structural challenges that restrain their access to biomedical HIV prevention technologies, as well as other SRH services (Smith et al., 2018). These challenges occur and are perpetuated in communities.

> *"The AIDS epidemic begins and ends in the community, with the individuals directly affected by HIV and with those who care for them. Long before the non-governmental organisations (NGOs), governments, donors and multilateral agencies became engaged, those living with HIV, their immediate families and communities work to support and sustain each other and to champion their right to live free from stigma and with full and equitable access to healthcare."* (Simms, 2013:1)

People are members of communities, and therefore act as collectives. This notion is particularly more applicable in the African cultural context where collectiveness is highly esteemed (Airhihenbuwa et al., 2014). People unconsciously adopt behaviours that make sense to themselves, and others in their community (Kippax and Stephenson, 2016). Therefore, communities lie at the heart of meaningful HIV response. As alluded to by Simms (2013) in the quote above, communities are the central spaces where individuals who are HIV infected are situated therefore the appropriate responses to this epidemic must begin in these settings.

In 2019 in commemoration of the World AIDS day, UNAIDS released a document entitled "*Communities make the difference*" (this is the theme for World AIDS day 2019), in this document, there is a global call for the recognition of communities as key

players in meaningful HIV and AIDS response (UNAIDS, 2019). In this document the UNAIDS urges government to invest more in communities by ensuring that there are more community-led organisations that focus on localised HIV and AIDS challenges within the community (UNAIDS, 2019). Communities can make an invaluable contribution to the HIV and AIDS response because it is within these communities that vulnerabilities to HIV infection are perpetuated, and the needs of vulnerable groups can be identified.

Castro et al. (2019), highlight that in the context of upscaling, and making oral PrEP available in SRH services, there is a need to explore the role of community engagement. In this study, the concept of community engagement and involvement in HIV prevention was not the primary interest, however, the findings of this study illuminated the critical role of the community, the family and the partner in oral PrEP uptake and adherence. The culture centered approach as propagated by Dutta (2011) places emphasis on this. As discussed extensively in chapter three, the culture centered approach suggests that the effectiveness of oral PrEP must be placed in the hands of the community, giving community members the agency to bring needed transformation. Nothing must be done for the community without the inclusivity of the community. The findings in this study also place emphasis on this point. Even though this study focused on the clinic setting, the findings reflect that young women often identify themselves as part of a greater collective; the family, and the community.

The factors that make key population groups vulnerable to HIV infection are often localised, and context specific, calling for context-specific and culturally relevant responses to HIV. This study identified several social, cultural and contextually specific issues that have the potential to influence the acceptance, uptake and adherence to oral PrEP when this HIV prevention intervention becomes available in SRH services.

Community perceptions and understanding of oral PrEP was raised as an important issue. Partner and family support were also highlighted by the young women in this study as important factors that affect their adoption and adherence of oral PrEP. In both the interviews and workshops, the young women shared the fact that there were several misconceptions about oral PrEP in their communities. The most common point raised from both urban and rural research sites was that there were misconceptions that oral PrEP pills are ARV drugs. Majority of the young women raised the point that family members, partners and neighbors believed that PrEP was an ARV drug. While this finding may be specific to the study research settings, these notions of misconceptions and stigma towards oral PrEP by community members carry merit for future research. If oral PrEP will be integrated in SRH services in a manner that is context specific and culturally relevant, communities needs to be engaged and informed appropriately about oral PrEP and SRH services. These findings need be scrutinised, but there are some dependable conclusions that can be drawn, and this is the certain influence that the community has towards young women accessing oral PrEP in local clinics.

This study contributes to literature that supports community mobilisation as meaningful HIV responses. The community is needed to enhance the effective oral PrEP integration into SRH services. There is a need to recognise clinics as structures that are situated in communities that directly affect healthcare services.
This study drives the notion that transitioning oral PrEP success from clinical trials and demonstration projects to population-level impact will require nuanced approaches that are led by key population groups in the HIV and AIDS epidemic. Therefore, while integration of oral PrEP in SRH services may result in more accessible services, the availability of this biomedical intervention needs to be accompanied with a contextual

and cultural understanding of the community that the clinic is serving. Those at high risk of HIV infection must be given the platform to inform research, policy and practice.

Community-based and person-centred approach to oral PrEP in SRH services

> "*It's not about everybody getting the same thing. It's about everybody getting what they need in order to improve the quality of their situation."*
> Cynthia Silvia Parker, Interaction Institute for Social Change
> (Grimsrud et al., 2017:1)

The availability of oral PrEP in SRH services cannot be done through a "one-size fits all" framework. From what has already been outlined and discussed above, it is evident that there are contextual and localised factors that contribute to how oral PrEP will be received when integrated into SRH services.

Oral PrEP integration in SRH services needs to be aligned with the community needs, cultural prescriptions and contextual factors. These are all fostered in localised issues that affect the real lived experiences of key population groups at risk of HIV infection. Therefore effective oral PrEP integration in SRH services needs to be preceded by community surveillance that will explore the social and cultural values, and beliefs that will affect oral PrEP acceptance, uptake and adherence.

Moreover, a more specific approach to making oral PrEP available to key population groups needs to consider what has been termed as the person-centred approach. Even though people belong to communities and often adopt health related behaviour that is in congruence with their cultural groups, people also need to be seen as individuals that peculiar needs, and may face unique vulnerabilities. Before proposing a model that can be used to assist in oral PrEP integration in SRH services, I provide a discussion that outlines the key tenants of the person-centred approach which has contributed to the conclusions reached in this study.

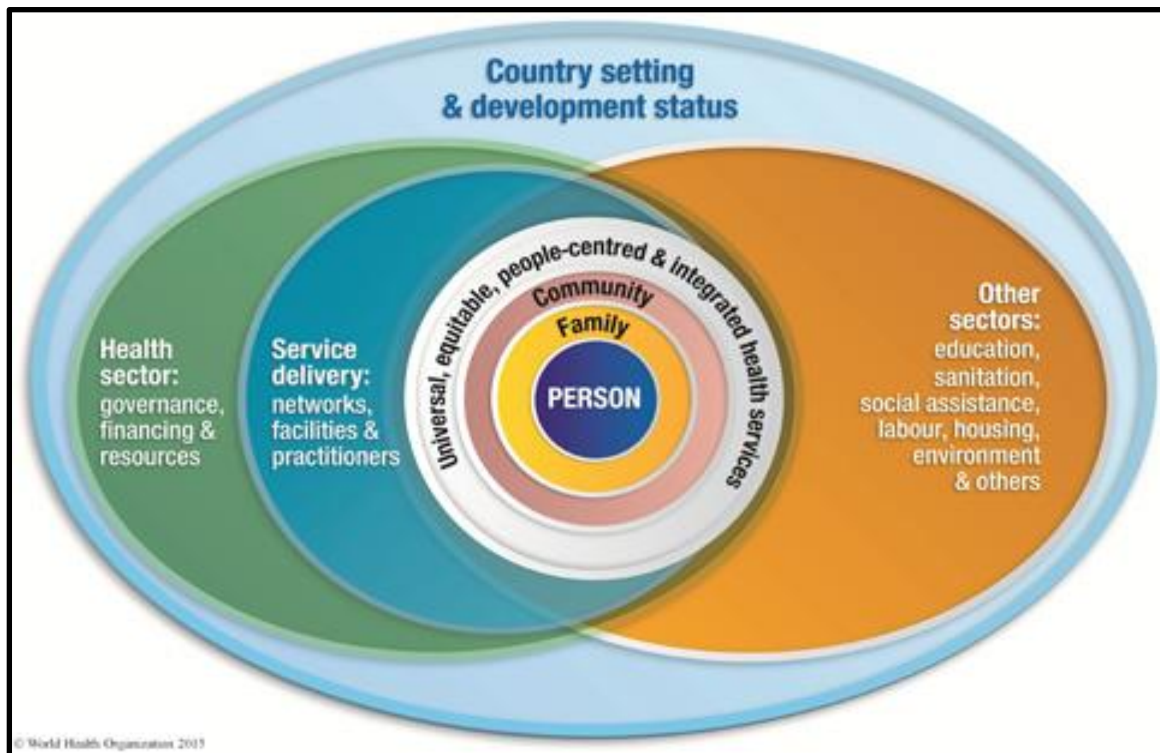


Figure 8.1: Person-centred approach to healthcare services (WHO, 2015)

Figure 8.1 depicts the person-centred approach to healthcare services. This is a model that accounts for the various levels of influence that an individual is imbedded in. As illustrated in this model, people are situated in layers of influence, family, community, healthcare services, facilities, government etc.

Increase cultural relevance of oral PrEP

The person-centered approach has been identified as a means of increasing the cultural relevance, acceptability, applicability of HIV prevention strategies (Cáceres et al., 2015, Olsson et al., 2013). The WHO (2016:2) defines the person-centered approach as "an approach to care that consciously adopts individuals', carers', families' and communities' perspectives as participants in, and beneficiaries of, trusted health systems that are organized around the comprehensive needs of people rather than individual diseases, and respects social preferences"

Giving young women agency in oral PrEP provision

The person-centered approach is distinguished by the principle that people must be recognised by their agency rather than their vulnerabilities (Pantelic et al., 2018, Leplege et al., 2007). This is also the stand point of the culture centred approach that advocates that people, particularly those in marginalised communities can and must be seen as collectives who can practice agency.
People must to be placed in a position where they can be agents of their own needed transformation, instead of being victims to their vulnerabilities. What this means, in reality, is that HIV prevention strategies should not assume people to be powerless to take initiative in defining their needs and developing possible solutions. In the HIV prevention field, people who are at high risk of HIV infection should be prioritized and involved in the development of possible interventions, and the implementation process of those interventions. Young women in the South Africa context should be involved in the upscale of HIV prevention technologies such as oral PrEP by informing how this HIV prevention technology is integrated in SRH services. Nothings must be done for them, without them.

People at the centre of effective HIV response

The person-centered approach advocates that people, and not the intervention be placed at the centre of any response that will have a lasting impact on a community or society (Pantelic et al., 2018). In the HIV prevention landscape, this call for interventions that will place key population groups at the centre of the HIV and AIDS response in a manner that will allow them to define what they need and how to address those needs. In the context of this study, key population groups such as young women need to be involved in significant ways to inform oral PrEP integration into SRH services. The data from this study showed how young women know what they need in the clinic, and they know the social support that is needed for them to use oral PrEP for HIV prevention. However, structures need to create platforms that will give young women the opportunity to inform oral PrEP integration in SRH services.

The person-centered approach values the social, cultural and economic environments that people are situated, believing that these environments affect people response to

an intervention, and the continued engagement in that intervention. In the case of HIV prevention in South Africa, the person-centered approach would recommend that key population groups be placed at the centre of HIV prevention technologies such as oral PrEP to ensure continued adherence.

Responding to needs and competencies

The person-centered approach aims to respond to people's needs and competencies (Leplege et al., 2007). What this mean is that HIV prevention strategies need to look at people's health-related needs in a holistic manner, where people's needs are seen to go beyond the medical level, taking into consideration the social, cultural and economic factors that shape people's health needs. For oral PrEP as an HIV prevention technology to be effective, combination prevention packages that address people's holistic needs are necessary, as highlighted by literature and the findings in this study (Isbell et al., 2016, Hargreaves et al., 2016, Godfrey-Faussett, 2016).

Leplege et al. (2007) identified four principal meanings associated with the concept of person-centeredness: addressing the person's specific and holistic properties; addressing the person's difficulties in everyday life, considering the person as an expert on their own condition and placing emphasis on participation and empowerment; and respecting the person 'behind' the vulnerability, impairment or the disease. Therefore this approach advocates that a "one-size fits all" intervention will not be effective, because this neglects peoples specific needs and the context in people are imbedded.

Conclusion

Oral PrEP integration into SRH services is not as simple as it sounds in theory, several social and cultural issues need to be explored, understood and addressed as oral PrEP for HIV prevention is being upscale and made available in SRH services.
Various settings and contexts will have localised concerns that must be addressed through evidence-based research in communities if the integration of oral PrEP in SRH services for young women will be effective.

Communities need to be placed at the centre of a meaningful response to the high HIV incidents among key population groups. Initiatives such as oral PrEP integration into SRH services need to be placed in the hands of community members by actively involving them in informing the service integration. Community members, and particularly key population groups must not be seen as complacent recipients of healthcare services, but rather as active agents that have the ability to define their own social challenges and contribute to the development of possible solutions.
If oral PrEP integration into SRH services will be successful in various communities, person-centred, culturally relevant and context specific service integration in healthcare services needs to be established.

The socio-cultural model to oral PrEP integration in SRH services give a comprehensive outline of the dynamic issues that must be considered in service integration. Structure, culture, agency and attitudes are the key tenants of this model, and in this chapter, I discussed the utility of this model by explaining how these four tenants operate to influence effective oral PrEP integration in SRH services.

Chapter 9: Conclusions

This chapter offers the overall conclusion of this thesis. The chapter begins with the research aims and objectives, followed by the summary of findings in relation to the main research questions. The methodological contributions of this study which are discussed in greater detail in chapter five are also briefly outlined.

Through the Culture Centered Approach (CCA) and the cultural competence approach, this study critically explored how oral pre-exposure prophylaxis (PrEP) can be integrated into sexual and reproductive healthcare (SRH) services for young women in KwaZulu- Natal. Structure, culture and agency as presented in the CCA are interconnected, and in this study, these concepts are mobalised in an attempt to understand how oral PrEP can be integrated in SRH services for young women in a culturally relevant and meaningful way.

Structure refers to elements such as medical services, medication and transportation services which are essential in health care systems for cultural members, structures can be enabling or constraining -in public health, it is a priority to provide enabling structures (Dutta, 2011). Culture refers to the local context in which people make health-related choices, the emphasis here is the beliefs, values and practices that inform health meanings for communities. In this study we argue that SRH services must be structures that are culturally competent, facilitating acceptance, uptake and adherence to oral PrEP. Agency refers to the ability of the cultural members to portray their preferences in the structures which they find themselves i.e. SRH services (Dutta, 2011). Structure, culture and agency are interconnected, and we mobilized these concepts in an attempt to understand how oral PrEP can be integrated in SRH services for young women in KwaZulu- Natal in a meaningful way.

Aims and objectives of the study

The aim of this study was to explore the social and cultural enablers and barriers to oral pre-exposure prophylaxis (PrEP) acceptance, uptake and adherence when this HIV prevention technology is integrated into sexual and reproductive healthcare (SRH) services. Furthermore, this study sought to explore how possible barriers and

impediments can be addressed when integrating oral PrEP into SRH services. Therefore, understanding the real-lived experiences of young women who are currently accessing oral PrEP in SRH services, allowing them to share what they believe are facilitating or impeding factors in oral PrEP access was what informed the methodological trajectory of this study.

Through the use of participatory visual methodology (PVM) workshops and one-on-one interviews, young women from rural and urban settings were given the opportunity to share their experiences of accessing oral PrEP in SRH services. These young women were given the platform to unveil what they believe would be contextually specific, and culturally relevant for young women in their communities when considering oral PrEP integration into SRH services. Sixty young women who were involved in the CAP084 demonstration project were recruited to be involved on this study, sixteen young women were selected and invited to the workshops and interviews, however, fifteen young women arrived for the workshops and interviews. To allow for maximum participation from the young women, the workshops comprised of four participants in each workshop, with the exception of one workshop that had three participants. Moreover, the workshops were structured around several participatory activities, with journey mapping as the main data generation method. These workshops were followed up by one-on-one interviews with all young women to elaborate on the issues raised during the participatory workshops, as well as raise new issues that the young women may have felt uncomfortable sharing in a group setting.

The combination of PVM workshops and one-on-one interviews was aimed at generating authentic and genuine reflections of young women's experiences and views of accessing oral PrEP in SRH services. Moreover, I sought that the young women share how some of the challenges they faced in the community, with their family, their partners and clinic setting can be addressed so as to promote oral PrEP acceptance and adherence for key population groups in their communities. Two healthcare workers who were research nurses in the CAP084 demonstration project were also interviewed to give a healthcare providers perspective on this topic. At a time where HIV prevention technologies transition from clinical trial and demonstration projects to population level implementation, it is critical to understand the possible

social and cultural factors that will influence acceptance, uptake and adherence of these biomedical technologies.

The findings of this study unearth the great extent to which social, cultural and structural factors influence the acceptability, uptake and even adherence to biomedical technologies such as oral PrEP in SRH services. This study uncovered further what literature has established; HIV prevention is a complex phenomenon and epitomizes the need for a diverse and multi-pronged approach that is context specific, and culturally relevant for key population groups.

This study was premised on the following three research questions:

1. In what ways is the current structure and organization of SRH services an impeding or facilitating environment for young women assessing biomedical products?

2. What are the likely socio-cultural challenges or opportunities that will influence acceptance, uptake and adherence of oral PrEP in SRH services among young South African women KZN?

3. In what ways can the current structure and organization of SRH services be realigned to meet the needs of young women in order to ensure acceptance, immediate uptake and adherence to oral PrEP?

Summary of key findings

This study demonstrated that a context-specific and culturally-relevant model for oral PrEP integration in SRH services will be necessary in local clinics. There are several localized cultural and social factors that will affect oral PrEP acceptance, uptake and adherence in communities, and these factors will vary from setting to setting.
Extrapolating from this study, I can conclude that the availability of oral PrEP in SRH services will not necessary result in acceptance, uptake and adherence to oral PrEP for HIV prevention among young women. Rather there are several factors that will influence oral PrEP acceptance, uptake and adherence. The findings in this study suggest that four main elements that will influence the acceptance, uptake and adherence of oral PrEP when this biomedical intervention is made available in SRH

services; structure, culture, agency and attitudes towards oral PrEP. The socio-cultural model to oral PrEP integration into SRH services that is depicted in chapter eight expatiates on these four elements, discussing their interplay.

Structure and organization of SRH services

The first research question focuses on the structure and organization of the clinic where SRH services are situated. In looking at the structure and organization of SRH services, one of the key findings in this study illustrated that privacy and confidentiality in the clinic are important aspects for young women accessing SRH services. The issue of privacy and confidentiality suggests that the clinic structure must be organized in a manner that will provide a sense of privacy for young women accessing oral PrEP in SRH services.

When attending the clinic for SRH services, young women want to feel that they can consult with nurses and doctors in privacy and in a manner that will protect their confidentiality. Nurses in particular were cited to tarnish young women's privacy and confidentiality in the clinic through verbal disclosure of private information, lack of respect for consulting sessions in the counseling rooms. The young women repeatedly made mention of nurses as being barriers in accessing SRH services in a manner that respects and protects their privacy. These findings, along with current literature suggest that nurses must display behaviors and attitudes towards young women in SRH in a manner that respects and protects their privacy in order to encourage continual access to oral PrEP and clinic visits. Nurses must have additional skills and qualities in addition relevant training in SRH services in order to address young women's needs with cultural competence. Gaining cultural competence, being friendly, non-judgmental and open are some of the skills and attitudes needed by nurses in SRH services.

In addition, the data extrapolated in this study illustrated that lack of resources in the local clinics was a potential barrier to oral PrEP access. Lack of access to resources in the clinic contributes to mistrust of services, which leads to young women not accessing healthcare services in the clinic.

There are several challenges around the lack of medication within clinics, with patients being exposed to encounters where they go to the clinic, wait to be served, and then informed that the medication that they need is not available. Moreover, finding in this study suggest that clinics in rural settings experience lack of resources compared to clinics in urban settings.

In addition to challenges surrounding the structure and organization SRH services within clinics, long waiting periods and the lack of entertainment in waiting areas were cited as areas that need attention in order for the SRH services to be aligned to meet the needs of young women. One of the possible solutions to this challenge was raised, having entertainment in the waiting area in the clinic, can alleviate the frustration of waiting in the clinic for long periods.

Social and cultural challenges or opportunities that will influence acceptance, uptake and adherence of oral PrEP.

The second research question focuses on the social and cultural factors that can result in challenges or opportunities that will influence oral PrEP uptake and adherence by young women.

The community and the family functioned as one of the most important influencers to young women's use of oral PrEP, however, partner support was also cited to be important in oral PrEP use by the young women. The data from this study clearly showed that the young women did not only perceive themselves as individuals, but there was a strong sense of collectiveness in the family and community setting. This concept may vary from setting to setting, as some communities may not value collectiveness compared to other communities. However, oral PrEP integration into SRH services must take these important facts into consideration if these services will be maximally utalised in communities.

This study identified misconceptions and stigma related oral PrEP use in the communities where this study was facilitated; rural Vulindlela and urban eThekwini. The first misconception was that oral PrEP pills are antiretroviral (ARV) drugs. The findings highlighted that people from the communities where this study was conducted believed that oral PrEP pills are ARV drugs, and was also a general fear that oral PrEP use will result in an individual becoming HIV positive.

A note of caution is the small sample size and nature of this study does not allow for the findings in this study to be generalised, however, the findings from this study carry merit that must to be considered in future studies.

Cultural connotations to HIV and AIDS have made taking ARV drugs a negative concept in communities. HIV is associated with a promiscuous lifestyle, therefore taking ARV's or taking oral PrEP which is believed to be ARV drugs results in stigmatization of accessing oral PrEP in SRH services.

The lack of accurate knowledge and understanding of oral PrEP indicates that community members need to be informed and educated about SRH and the use of oral PrEP.

There is a need for information, education and communication (IEC) packages to be developed for various communities to educate and inform people accurately about oral PrEP use and SRH services in a manner that will address stigma and misconceptions. Health communication is therefore important in the trajectory of oral PrEP integration into SRH services.

Health communication will increase community members knowledge and awareness of a particular health issues, problem or solution; therefore health communication about SRH services and oral PrEP provision can influence people perceptions, beliefs, and attitudes resulting in social norms in communities (Freimuth and Quinn, 2004).

Ways that the current structure and organization of SRH services can be realigned to meet the needs of young women.

The third research question focused on how the current structure and organisation of the SRH services can be realigned to meet the needs of young women accessing oral PrEP in SRH services.

This study proposes a model that will assist in facilitating the realignment of SRH services to meet the needs of young women in various communities.

The literature reviewed in this study, the theory engagement and data collected, contributed to the development of the socio-cultural model to oral PrEP integration into SRH services, see figure 8.2 in chapter eight. The model advanced an evidence-based approach to PrEP integration in SRH services. This model can be used mutually with other integration models.

The findings from this study highlight that offering women a space to actively engage in dialogue will catalyse discussions on how to effectively HIV prevention interventions into SRH services by utilising knowledge of the social cultural complexities of a community. Inadequate recognition of the complex interplay of cultural and social factors that shape and prescribe young women's sexual behaviour, and health related behaviour will result in poor acceptance and uptake of oral PrEP when this HIV prevention method is available in SRH services. Beyond access, the availability of oral PrEP in SRH services will require a nuanced understanding of social and cultural values in various communities. Furthermore, this study indicates that oral PrEP provision in SRH services must be context specific and culturally relevant.
Clinics with SRH services where PrEP is made available for vulnerable population groups must be aligned to the community needs and values, creating a non-stigmatised environment where those at high risk of HIV infection can access these biomedical products in the clinic.

Implications for the filed and areas for further research

This study has been one of the first attempts to explore possible social and cultural factors that will impede of facilitate effective oral PrEP integration into SRH services for young women. The findings in this study are therefore novel in the field of integrated services of HIV prevention and SRH.
The study does have several limitations that have been highlighted and discussed in chapter four, the most notable limitation of this study lies in the fact that the sample size is small, and the two research sites cannot be a representation of many settings in South Africa. However, in spite of its limitations, the study certainly contributes to our understanding of the role of social and cultural issues that have an influence on effective oral PrEP integration into SRH services.

The findings in this study have a number of implications for the field, firstly, more studies focusing on the role of culture in the introduction of oral PrEP in communities, and the integration of oral PrEP in SRH services are needed. Various settings with different cultural values and beliefs will yield diverse findings regarding the role of

culture in oral PrEP integration in SRH services. Culturally competent healthcare services must be developed for young women, creating enabling spaces where young women as a key population group in the HIV epidemic can access services that address their needs and are free from stigma.

Ensuring appropriate healthcare systems, services and support for young women and other key population groups in South Africa must be prioritised. As it has been highlighted in chapter eight, further modelling work will need to be conducted in order to understand meaningfully involved key population groups in the development level and implementation level of models such as the socio-cultural model of oral PrEP integration (see figure 8.2 in chapter eight).

A key policy priority should therefore be to plan for the long-term interaction with young women, platforms where young women can meaningfully engage and contribute towards healthcare services that are developed for them. Adopting this approach can result in expanding our understanding of how SRH services can be realigned to meet the needs of young women in various settings across South Africa. Culturally relevant and contextually specific healthcare services are needed in the HIV prevention cascade.

Communication has an important role to play in the HIV prevention cascade, and in making oral PrEP available in an effective manner in communities for key population groups. On the healthcare side, health communication has been shown to mobilize community care and support and increase the quality of patient-provider interaction, which in turn can improve adherence. Health communication has a critical role to play in creating oral PrEP awareness, ensuring effective oral PrEP integration into SRH services, and supporting oral PrEP adherence. This is a factors that must be considered as South Africa transitions into a phase of making oral PrEP available in all SRH services for people at high risk of HIV infection. In order to develop effective health communication messages, the population in which the messages is being developed for must be included, this will result in more relevant and acceptable health communication messages.

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Appendix 1: Informed Consent Form (English)

Information Sheet and Consent to Participate in Research

Date:

My name is Phiwe Nota from the Center for Communications media and Society (CCMS) department at University of KwaZulu-Natal in Durban.

Centre for Communication, Media and Society
Memorial Tower Building |Howard College Campus
University of Kwa-Zulu Natal
4041|South Africa
Phone: +27 031 260 1044
Email: makaulaphiwe@yahoo.com |Website: http://ccms.ukzn.ac.za

You are being invited to consider participating in a study that involves research in exploring the integration of oral pre-exposure prophylaxis in sexual and reproductive healthcare (SRH) services in KwaZulu-Natal. The overall objective of this study is to find out what are the socio-cultural enablers and barriers to oral PrEP acceptance, uptake and adherence when this prevention technology is integrated in SRH services. Furthermore, this study will explore how these barriers can be addressed when integrating PrEP into SRH services. In effect this study will suggest a model that will assist develop culturally sensitive and contextually relevant ways of integrating oral PrEP in SRH services.

The study is expected to enroll 16 female participants from rural and urban areas (Vulindlela and eThekwini). It will involve the taking part in participatory art-based research through journey mapping sessions and one on one interviews. The duration of your participation if you choose to enroll and remain in the study is expected to be a full day for the journey mapping session then the next day will be one on one interviews which will be approximately 1hour.

The study may involve the following risks and/or discomforts; discussing your personal experience of collecting oral PrEP in a sexual and reproductive healthcare (SRH) clinic.

This study has been ethically reviewed and approved by the UKZN Biomedical research Ethics Committee (BE342/17).
In the event of any problems or concerns/questions you may contact the researcher at (provide contact details) or the UKZN Biomedical Research Ethics Committee, contact details as follows:

BIOMEDICAL RESEARCH ETHICS ADMINISTRATION
Research Office, Westville Campus
Govan Mbeki Building
Private Bag X 54001
Durban
4000
KwaZulu-Natal, SOUTH AFRICA
Tel: 27 31 2604769 - Fax: 27 31 2604609
Email: BREC@ukzn.ac.za

Please note that your participation in this interview is voluntary, should you not want to be part of the discussion you may withdraw from this activity at any point in time. Your withdrawal from this interview will not disadvantage you in any way.
You will be reimbursed R200 for your participation in this study, this is to ensure that all your traveling cost for this study are covered and you do not experience any inconveniences regarding this.
With your permission, this interview will be recorded using a sound recorder and photographs will be taken during the workshop. This will be transcribed; however your name will not be used in the written research report. To protect your confidentiality pseudo names will be used during this research.

CONSENT

I ____________________________ have been informed about the study entitled "*An exploration of the social-cultural factors that influence oral pre-exposure prophylaxis uptake and integration into Sexual and Reproductive Healthcare services for young women in KwaZulu-Natal.*" by Phiwe Nota.

I understand the purpose and procedures of the study.
I have been given an opportunity to ask 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 treatment or care that I would usually be entitled to.
I have been informed about any available reimbursement of R200.
If I have any further questions/concerns or queries related to the study I understand that I may contact the researcher makaulaphiwe@yahoo.com or 073 530 4189.
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:

BIOMEDICAL RESEARCH ETHICS ADMINISTRATION
Research Office, Westville Campus
Govan Mbeki Building
Private Bag X 54001
Durban
4000
KwaZulu-Natal, SOUTH AFRICA
Tel: 27 31 2604769 - Fax: 27 31 2604609
Email: BREC@ukzn.ac.za

______________________ ______________________

Signature of Participant **Date**

______________________ ______________________

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

_______________________ _______________________

Signature of Translator **Date**

(Where applicable)

Appendix 2: Informed Consent Form (isiZulu)

Iphepha lolwazi nelemvume yokuzibandakanya ocwaningweni

Usuku:

Ngiyabingelela Mama:

Igama lami nginguPhiwe Nota oseMnyangweni we-Center for Communications media and Society (CCMS) eNyuvesi YaKwaZulu-Natal, eThekwini.

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Uyacelwa ukuba uzibandakanye ocwaningweni oluhlanganisa ukucubungula ukuhlanganiswa kwezinsiza ze-oral pre-exposure prophylasis kwezocansi nezinsiza zokunakekela okuphathelene nenzalo (SRH) KwaZulu-Natal. Inhloso yalo lonke locwaningo kungukuthola ukuthi yiliphi isiko lomphakathi elivimbela nelivumela ukwamukelwa kwe-PrEP efakwa emlonyeni, ukusetshenziswa kwayo nokuyisebenzisa ngokulandela imiyalelo uma lobu buchwepheshe bokuvikela buhlanganiswa nezinsiza ze-SRH. Ngaphezu kwalokho, lolu cwaningo luzobheka ukuthi kungabhekwana kanjani nalezi zithiyo uma kuhlanganiswa i-PrEP ihlanganiswa ne-SRH. Okusempeleni lolu cwaningo luzophakamisa indlela ezosiza ukuthuthukisa izindlela ezibucayi ezimayelana nesiko kodwa ezizobhekana ngqo nokuhlanganiswa kwezinsiza ze-PrEP efakwa emlonyeni nezinsiza ze-SRH.

Kulindeleke ukuthi ucwaningo lubandakanye abantu besifazane abayi-16 abaqhamuka ezindaweni zasemakhaya nezasemadolobheni (eVulindlela naseThekwini). Luzohlanganisa ukubamba iqhaza ocwaningweni olugxile emidwebweni ngokuhlangana kwakhiwa ibalazwe noma umhlahlandlela wokuhlabela phambili nocwaningo bese futhi luhlanganisa ingxoxo phakathi komuntu nomuntu. Isikhathi sokuzibandakanya kwakho uma ukhetha ukuzibandakanya futhi uqhubeke

nokuzibandakanya ocwaningweni kulindeleke ukuthi kube ihora elilodwa nemizuzu engamashumi amathathu esikhathini sokubonana kuhlelwa umhlahlandlela wokuhlabela phambili nocwaningo, bese kuthi ngosuku olulandelayo kube nezingxoxo phakathi komuntu nomuntu okuyothatha cishe ihora elilodwa.

Ucwaningo lungahlanganisa lobu bungozi obulandelayo kanye/noma ukungaphatheki kahle; ukuxoxa ngohlangabezane nakho ngesikhathi ulanda i-PrEP efakwa emlonyeni emtholampilo wezocansi nokuphathelene nenzalo.
Lolu cwaningo selubuyekezwe lwagunyazwa yiKomiti le-UKZN Biomedical research Ethics (inombolo yokugunyaza_____).
Uma kungase kube nezinkinga noma okukukhathazayo/imibuzo, ungaxhumana nomcwaningi ku (nikeza imininingwane yokuxhumana) noma iKomiti le-UKZN Biomedical Research Ethics, imininingwane yokuxhumana nabo imi kanje:

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Email: BREC@ukzn.ac.za

Sicela uqaphele ukuthi ukuzibandakanya kwakho kule ngxoxo kungukuzithandela, uma ungathandi ukubamba iqhaza engxoxweni, ungahoxa kulo msebenzi nanoma yingasiphi isikhathi. Ukuhoxa kwakho kule ngxoxo angeke kukuthikameze nanoma yingayiphi indlela. Uyonikezwa imali engu-R200 (R50 usuku lokhuqala, R150 ngosuku lwesibili) ngokuzibandakanya kwakho kulolu cwaningo, lokhu kungukuqinisekisa ukuthi zonke izindleko zokuhamba kwakho uza ocwaningweni ziyakhokhelwa futhi awuhlangabezani nokungaphatheki kahle mayelana nalolu cwaningo.
Ngemvume yakho, le ngxoxo izoqoshwa kusetshenziswa isiqophamazwi. Lokhu okuqoshiwe kuyobhalwa phansi; kodwa nakuba kunjalo, igama lakho angeke

lisetshenziswe embikweni obhaliwe wocwaningo. Kuyosetshenziswa amagama angewona angempela ukuze kuvikelwe ubumfihlo ngesikhathi kwenziwa ucwaningo.

--

IMVUME (Guqula njengoba kufanele)

Mina u______________________________ngazisiwe ngocwaningo olisihloko sithi: "An *exploration into the social cultural factors to oral pre-exposure prophylaxis (PrEP) uptake and possibilities for integration into Sexual and Reproductive Healthcare (SRH) services in KZN, for young women"* olwenziwa uPhiwe Nota.
Ngiyaqonda inhloso nenqubo yocwaningo.
Nginikeziwe ithuba lokubuza imibuzo ngocwaningo futhi nganikezwa izimpendulo ezinganelisayo.
Ngiyaqinisekisa ukuthi ukuzibandakanya kwami kulolu cwaningo kungukuzithandela futhi ngingahoxa nanoma yingasiphi isikhathi ngaphandle kokuphazamiseka kokwelashwa noma ukunakekelwa kwami engijwayele ukukuthola.

Ngazisiwe ngokukhokhelwa imali engu-R200.
Uma ngiseneminye imibuzo/okungikhathazayo okumayelana nocwaningo, ngiyaqonda ukuthi ngingaxhumana nomcwaningi ku makaulaphiwe@yahoo.com noma ku-073 530 4189.
Uma ngisenemibuzo noma okungikhathazayo ngamalungelo ami njengozibandakanyayo ocwaningweni, noma uma kukhona okungikhathazayo ngengxenye ethile yocwaningo noma abacwaningi, ngingaxhumana ne:

BIOMEDICAL RESEARCH ETHICS ADMINISTRATION
Research Office, Westville Campus
Govan Mbeki Building
Private Bag X 54001
Durban
4000
KwaZulu-Natal, SOUTH AFRICA

Ucingo: 27 31 2604769 - Fax: 27 31 2604609
Email: BREC@ukzn.ac.za

________________________ ________________________

Kusayina ozibandakanyayo Usuku

________________________ ________________________

Kusayina ufakazi Usuku
(Uma kunesidingo)

________________________ ________________________

Kusayina umhumushi Usuku
(Uma kunesidingo)

Appendix 3: Participant Interview Guide

Interview schedule

Research title: An exploration of the social-cultural factors that influence oral pre-exposure prophylaxis uptake and integration into Sexual and Reproductive Healthcare services for young women in KwaZulu-Natal.

Total Participant Time Required: **1 hour 30 Min**

Total interview time: 1 hour 15 minutes

Equipment Needed:

Recording Equipment

Consent Forms

Refreshments

SECTION A – 15 minutes

Introduction (by facilitator)

1. **Warm welcome to the participant.**
2. **Purpose of the interview stated by the facilitator**

The purpose of this interview is to further discuss the issues that we were exploring yesterday in the workshop. This interview aims to find out what woman think the social and cultural issues that will affect PrEP becoming available in sexual and reproductive healthcare (SRH) services. The discussions from this interview will be of benefit in understanding how HIV prevention technologies can be made available in SRH services in a way that is relevant and culturally competent. We are interested in what women want and need to safely and effectively protect themselves from contracting HIV. Everything discussed here will be treated as confidential.

Read out the consent form, and then participant may sign their consent forms.

SECTION B- 20 minutes

PrEP and the SRH services

1. The problem: a brief explanation of the fact that women are the most vulnerable to HIV infection. Present some statistics of HIV prevalence in South Africa, and also in KwaZulu-Natal to contextualise the research problem for the participant.
2. Now I'd like to talk specifically about Pre-exposure prophylaxis (PrEP). What is it? If I had never heard of "PrEP" before, how would you describe it to me?
3. What do you understand about oral PrEP?
   (a) How important is to take the pill daily?
4. When did you start taking oral PrEP?
5. How often do you go to the clinic to collect your oral PrEP?
6. Take me through your clinic visit when you go to collect your oral PrEP?
   (a) What are the various steps you go through?
7. What do you think about the various steps you go through in the clinic visit?
8. What makes your clinic visits easy?
9. What do you enjoy the most about your clinic visit?
10. What are the challenges you face when you go for your clinic visit?
11. If you could, what would you change about your clinic visit?
12. Do you think that the structure and organisation of the clinic is good for you?
13. Besides oral PrEP, what other products do you collect at the clinic?
14. Do you think making oral PrEP available in SRH and family planning services a good idea? Why?
15. What are your specific needs that you think should be provided at the clinic?

(a) What are those needs?

16. Do you think that the nurses and other healthcare providers at the clinic are helpful?
    (a) How are the healthcare providers helpful to you in your clinic visits?

SECTION D- 20 minutes

Discussion on socio-cultural challenges or opportunities that will influence

acceptance, uptake and adherence of oral PrEP

1. Would your close friends in your community be willing to take PrEP?

2. What would be the reason your friends would choose to use PrEP?

3. What would be the reason you and your close friends DO NOT want to use PrEP?

4. Do you think it would be easy to take these pills on a daily basis? Do you believe people would have problems taking oral PrEP daily?

5. What are possible concerns that may discourage you or your close friends from taking PrEP?

6. Do you believe your family and/ or partner are supportive of you taking PrEP?

7. Would you be comfortable telling your friends and family that you are taking oral PrEP?

8. In your own opinion, do you think oral PrEP will be accepted in your community?

9. What are possible concerns about health-care providers that may discourage you or your close friends from taking PrEP?

10. Please take me through the journey maps that you developed yesterday? (Discuss the journey maps that were developed yesterday. Significantly discuss the difference with the current clinic journey and the desired clinic journey).

SECTION E- 20 minutes

Discussion on HIV testing

The National Policy on HIV PrEP and, Test and Treat (T&T) which prescribes that PrEP must be made available as part of a comprehensive HIV prevention package and integrated into already existing SRH services (National Policy on PrEP and T&T, 2016). The policy is guided by the World Health Organization (WHO) recommendations which emphasises the use of PrEP as an additional prevention measure for people at substantial risk of acquiring HIV (National Policy on PrEP and T&T, 2016). Now I would like to find out your opinions about making oral PrEP available in your local SRH clinics.

1. How familiar are you all with HIV-testing? How often do you get tested?

2. How do people decide to get HIV tested in your community? What kinds of things influence your decision of getting an HIV test?

3. What would make HIV-testing more encouraging for people to do regularly?

4. What are some of the influences that might lead young women to make choices about getting an HIV test?

5. How can parents and community influence young women to make positive health choices?

6. What do you think about the clinics offering family planning and sexual and reproductive healthcare in your community?

7. What are your experiences at the clinics in your community? Is it easy to receive help? Explain?

8. Would you recommend that PrEP is made available in your local clinic?

9. What are some of the ways do you think would encourage young women to go to their local SRH clinics to receive PrEP?

10. Do you think your partner, family and community would be supportive of young women who go to SRH clinics to receive PrEP?

11. What are some of the challenges that you think young women like yourself would face in accessing PrEP in these clinics? Please describe.

Conclusion: Thank you for your participation is the discussion, if you have any questions please ask me and I will answer to the best of my ability.

Appendix 4: Nurse Interview Guide

Interview schedule

Research title: An exploration of the social-cultural factors that influence oral pre-exposure prophylaxis uptake and integration into Sexual and Reproductive Healthcare services for young women in KwaZulu-Natal.

Total Participant Time Required: **1 hour**

Equipment Needed:

Recording Equipment

Consent Forms

SECTION A

Introduction (by facilitator)

1. **Warm welcome to the participant.**
2. **Purpose of the interview stated by the facilitator**

The purpose of this interview is to discuss the social cultural factors to oral pre-exposure prophylaxis (PrEP) uptake and possibilities for integration into Sexual and Reproductive Healthcare (SRH) services in KZN, for young women. This interview aims to find out what woman think the social and cultural issues that will affect PrEP becoming available in sexual and reproductive healthcare (SRH) services. The discussions from this interview will be of benefit in understanding how HIV prevention technologies can be made available in SRH services in a way that is relevant and culturally competent. We are interested in what women want and need to safely and effectively protect themselves from contracting HIV. Everything discussed here will be treated as confidential.

Read out the consent form, and then participant may sign their consent form.

SECTION B

Role and responsibilities

1. In which age group do you fall into?

   [20-30], [30-40], [40-50], or [50-60]

2. What is your official role in this demonstration project, the CAP084?
3. How long have you assumed this role?
4. What are your daily responsibilities/ or tasks in this demonstration project?
5. What do you understand this demonstration project, its aims and objectives?
6. Have you been part of any other demonstration projects or clinical trials?

   Can you briefly explain what you were doing in those studies?

   SECTION C

   PrEP in the clinic

7. Now I'd like to talk specifically about Pre-exposure prophylaxis (PrEP). What is it? If I had never heard of "PrEP" before, how would you describe it to me?

8. Would you say that the young women who are part of this demonstration project have a clear understanding of oral PrEP? Do they know how it works and how to take it?

9. Please take me through the process that participants follow to be part of this demonstration project?

10. Once participants are enrolled in this demonstration project, what is the step to step process they go through to access the PrEP here at the clinic? In other words, what characterises a typical clinic visit for a participant?

11. Do you think that the current structure/ facility of the clinic is conducive or ideal for young women to come access oral PrEP?

12. Have there been any complaints about the current structure/ facility of the clinic from the participants?

13. Is the location of the clinic ideal for young women in this community to come and access PrEP?

14. How often do participants come in to collect oral PrEP?

15. How do you monitor adherence to oral PrEP?

16. In this demonstration project, are the adherence patterns? Would you say that women in this demonstration project adhere?

17. How do you follow up and encourage participants to adhere to oral PrEP?

18. Do you think there is more that can be done to encourage women to take oral PrEP for HIV prevention?

19. What do you think are some of the barriers that young women (taking oral PrEP) face that cause lack of adherence?

20. Besides oral PrEP, what other services do you offer young women coming in the clinic?
    Do you think that providing these other services encourages women to take oral PREP for HIV prevention?

21. What do you think about providing oral PrEP in SRH and family planning services?

Time	Activity	Facilitators	Materials	Outcome
Day 1				
08h00-08h30	Arrival, Set up,	Phiwe & Yonela	Sweets, juice All Stationary	Facility set-up for participants
09h00-09h30	**Phase One: Introduction** - Welcome. - Who we are. - What we are doing. - Why we are doing this. - Clear understanding of participations. - Display Biomedical chart . - Q and A - Sign consent form	Phiwe (Yonela to be taking down notes)	Flipchart Marker Consent forms Pen	Participants understanding of the research agenda for the day. Signed consent forms
09h30-10h00	**Phase Two: Introduction to Art Based Research** - What is ABR?	Phiwe (Yonela to be taking down notes)	Chart Markers	Establish an understanding of ARB with participants

	- Creativity and thinking out the box			
10h00-10h30	**Picture exercise**	Phiwe	Pictures	Ice-breaker Participants introduced to one another in a way that gives insight into their lives. Allow participants to share and open up about their personal lives.
10h30-12h30	**Phase Three: Journey Mapping** - What is journey mapping? - How can journey mapping help us? - Show journey maps. - **Journey mapping exercise The participants will draw two journey maps, one of they current visit to the clinic and the other of their ideal journey map**	Phiwe (Yonela to be taking down notes and photographs)	Paper, colour paper, magazines, koki pens, scissors, markers, glue.	Establish an understanding of journey mapping. The journey maps complete.
12h30-13h15	**Phase four: Journey map discussion** - Debrief of journey maps	Phiwe (Yonela to be taking down notes)	Chart Markers	Understand participants experience of the exercise and understand overall findings.
13h30-14h00	LUNCH			
14h00-14h15	Wrap up & explain next day workshop			

SECTION D

Discussion on socio-cultural challenges or opportunities that will influence acceptance, uptake and adherence of oral PrEP

22. How was this mobile clinic established in this community? Who were the stakeholders that were approached to gain access into this community?
23. What programmes or efforts are in place to encourage women to enrol in this demonstration project?
24. In your own opinion, what are some of the social and cultural issues that young women face that would;
    (a) Encourage them to take oral PrEP for HIV prevention, and
    (b) Discourage them to take oral PrEP for HIV prevention
25. In your own opinion, what would influence rejection of oral PrEP by young women in this community?
26. What language is used here at the clinic to communicate with participants? Which language do you prefer communicating with participants, why?

Appendix 5: Participatory Workshop Schedule

Data Collection Participatory Workshops:
Date:
Participants: 8 per site (2 sites)

Introduction to Workshop (30 minutes)

Phase 1: Introducing the researcher and the researchers

Facilitators: Phiwe & Yonela (research assistant) (30 minutes)

- Welcome.
- Who we are.
- What we are doing.
- Why we are doing this.
- Clear understanding of participation.
- Display Biomedical chart.
- Q and A
- What expectations do you have? Do you have any concerns/worries about the workshop?
- Signing of informed consent

Phase 2: Introduction to Art Based Research

Facilitators: Phiwe (30 minutes)

- Explain art based research to the participants:
- ✓ What is Art based research?
- ✓ How does it work?
- ✓ Why is it needed etc.?
- Give participants an understanding the concept of participation and how to use art-based methodologies and participatory methodologies for research.

Phase 2: Picture exercise

Facilitators: Phiwe (30 minutes)

Icebreaker exercise to provide participants with the opportunity to introduce themselves in a way that gives insight into their lives.

- Place cut out pictures on the floor, making sure all of them are visible.
- Ask participants to walk around, looking at the pictures, and to pick any two pictures that they feel represents something about themselves. (This could be a picture that

reminds them of someone in their lives, an event in their lives, their hopes and dreams for the future).

- Once everyone has picked their two pictures, ask participants to sit down in a circle.
- Ask each person to share their two pictures and why they picked them.

Phase 3: Journey Mapping

Facilitators: Phiwe (2 hours)

- What is journey mapping?
- How can journey mapping help us?
- Show journey maps.
- **Journey mapping exercise (Follow journey map schedule)**
- Journey map 1 and journey map 2

Phase 4: Journey map discussion

Facilitators: Phiwe & Yonela (30 Min)

- A short discussion session where participants discuss what their particular journey maps entail, and explain the significance of their journey map.
- Allow two participants who want to share their journey maps to share.
- The discussion session is intended to allow participants to debrief about their journey maps, specifically discussing what they currently experience and what they would like to experience.
- Discuss social and cultural factors highlighted in journey maps that enable or impede the participants oral PrEP acceptance, uptake and adherence.

Close workshop for the day

The researcher thanks for participants for their participation and explains day two of the workshop. Give participants their interview times for the next day.

Time	Activity	Facilitators	Materials	Outcome
Day 2				
08h30-09h00	Arrival, Set up,	Phiwe & Yonela	Sweets, juice, gift packs	Facility set-up for participants
09h00-9h45	Interview 1	Phiwe	Interview guide Recorder	Complete interview
10h00-10h45	Interview 2	Phiwe	Interview guide Recorder	Complete interview
11h00-11h45	Interview 3	Phiwe	Interview guide Recorder	Complete interview
12h00-12h45	Interview 4	Phiwe	Interview guide Recorder	Complete interview
14h00-14h45	Interview 5	Phiwe	Interview guide Recorder	Complete interview
15h00-15h45	Interview 6	Phiwe	Interview guide Recorder	Complete interview
16h00-16h45	Interview 7	Phiwe	Interview guide Recorder	Complete interview
17h00-17h45	Interview 8	Phiwe	Interview guide Recorder	Complete interview

Appendix 6: Journey Map Guide

Journey Mapping Schedule

Equipment Needed:

Recording Equipment; Consent Forms; Flipchart paper; Pencils; Erasers; Sharpeners; Prestik; A3 paper, Markers, Magazines

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Journey mapping

- What is journey mapping? Explain to participants what journey maps are and how they have been used in research before.
- How can journey mapping help us in this study? Explain to participants.
- Show participants journey maps that have been done before.

The facilitator introduces this activity to participants as a reflective exercise where they get to creativity externalise their step by step journey of visiting the Sexual and Reproductive healthcare (SRH) clinic.

Each participant will be given a poster size sheet and drawing material.

Participants may use symbols to mark their experiences of their visit to the SRH clinic. Facilitator prompts the participants through several questions in order for guide them in the development of their journey maps. In the second body map, the participants will make use of magazine cut-outs so as to create their journey maps in a collage.

Questions:

1. Reflecting on all your clinic visits, draw a step to step map of what you do and what you encounter from the moment you enter the clinic. (show sample of a journey map)
2. What did you do in these different steps? E.g. taking blood tests, waiting room. Depict this on your map.

4. On your journey map, mark any steps in your clinic visit that were most easy for you. Think about what made this step easy. Write and draw this within your map.

5. On your journey map, mark any stages in your clinic visit that were most difficult for you. Think about what made this so difficult. Write this within your map.

6. If you had to change anything about your clinic visit, what would this be, and at which step in your map would this fit in?

7. Do you think the information you receive at the SRH clinics on contraceptive options and HIV prevention are sufficient and helpful? You can write this anywhere on your map.

8. Reflect on the experiences that you have had with the health care workers, were those helpful encounters? What would you change about these? Write this on your journey map, anywhere on your poster sheet.

9. Are there any things that you believe need to be included in your clinic visit that you believe will encourage you to come regularly? Write this anywhere on your map.

After participants are done with their first journey map, they will start on the second journey map.

1. Now that you have drawn your current experiences at the clinic on your journey map, now collage your ideal journey map- by cutting out from various magazines, and sticking on your poster size paper.
2. What would you like to experience in your clinic visits when you go to collect your PrEP? Depict this on a journey map.
3. Use the magazines that you have been provided to cut out and paste any images that will assist you in creating this “ideal” clinic visit for your second journey map.

Feedback on Journey mapping

1. Each participant will have an opportunity to share on their journey map. This will allow participants to compare their experiences.
2. A short discussion will be encouraged on the experiences of the participants. This will create a space where critique and engagement in discussion on what makes a best practice for patient experience when getting information, treatment and care.

Appendix 7: Recruitment screener

Recruitment Screener for Young Women

This screener is for recruiting participants for a participatory workshop on oral PrEP implementation in sexual and reproductive healthcare services for young women.

Using this screener: Please keep a record of the number of people in each category who do not end up being selected.

Please recruit:

- Young women
- All participants should be aged 18- 35
- Able to participate using English or Zulu language
- Participants should be drawn from CAP084 study
- All young women must be taking oral PrEP

Note: It is very important to ensure that the participant selected are available and committed to attending the two-day workshop.

Introduction for persons being screened for participation

- Good day. I am ______________________ from the University of KwaZulu-Natal _____________________.
- We are bringing together a small group of young women to participate in a two-day workshop that will take place in the coming weeks.
- I would like to ask you a few simple questions to see if you fall into the category that we would like to invite to participate in the workshop. Do I have your consent to proceed with these questions?

Screener questions

Q1. Are you comfortable participating in part a discussion that is held mostly in English and Zulu?

A	**Yes**	**Continue**
B	No	IF NO, END INTERVIEW: *Thank you, but unfortunately we are looking for people who are with a discussion held mostly in English and Zulu*

Q2. How old are you?

A	**Below 18 years**	**IF <18, END INTERVIEW:** ***Thank you, but unfortunately we are looking for people who are within a different age group***
B	18-35 years	Continue
c	Older than 35	IF >35, END INTERVIEW: *Thank you, but unfortunately we are looking for people who are within a different age group*

Q3. What is the highest level of education you have completed?

A	**Less than a high school leaver's certificate**	**Continue (Select at least 1, maximum 4)**
B	Completed high school	Continue (Select at least 1, maximum 4)
C	Some post-school training	Continue (Select at least 1, maximum 4)
D	Post-school degree/diploma	Continue (Select at least 1, maximum 4)

Q4. What is your current employment status?

A	**Unemployed**	**Continue (Select at least 1, maximum 4)**
B	Student (full or part-time)	Continue (Select at least 1, maximum 4)
C	Employed (part-time)	Continue (Select at least 1, maximum 4)
D	Employed (full-time)	Continue (Select at least 1, maximum 4)

Q5. In the past five years, have you taken part in campaigns or projects that support any of the following?

A	**Local community issues**	**Continue if yes OR no**
B	Employment-related issues	Continue if yes OR no
C	Environmental issues	Continue if yes OR no
D	Gay or lesbian issues	IF 'YES', END INTERVIEW AFTER ASKING QUESTION E.
E	Sex workers	IF 'YES' to D or E, END INTERVIEW: *Thank you, but unfortunately we are looking for people who have been involved in a different combination of issues*

Ensure that you have a contact number and alternate contact for each participant. Enter onto list.

- Where is the workshop and when will it be held?
  Indicate the time and place of the workshop

- How will I get to the workshop?
  You will be reimbursed for travelling to the workshop R200

- *How long is the workshop?*
  Day 1 will be from 8:30am till 2:00pm and day 2 will be (approximately) 1 hour interview and you will be given a time slot. Refreshments will be provided

- *How many other participants will there be?*
  The total number of participants is 8

- *What is the exact purpose of the workshop?*
  The facilitators are interested in understanding how oral PrEP can be implemented in SRH services in a manner that is culturally and socially relevant for young women.

LIST OF PARTICIPANTS

Number	Participant Name	Contact cell	Alternative contacts
1			
2			
3			
4			
5			
6			
7			
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Appendix 8: Ethical Clearance Certificate

03 December 2018

Ms PB Nota (210510013)
Discipline of Public Health Communications
School of Applied Human Sciences
College of Humanities
makaulaphiwe@yahoo.com

Dear Ms Nota

Title: An exploration into the socio-cultural enablers and barriers to oral PrEP uptake and possibilities for integration into sexual and reproductive healthcare services in KZN, for young women. Degree: PhD
REC Ref No: BE342/17 (sub-study of BFC511/16)

RECERTIFICATION APPLICATION APPROVAL NOTICE

Approved:	18 August 2018
Expiration of Ethical Approval:	17 August 2019

I wish to advise you that your response received on 29 November 2018 to BREC letter dated 26 November 2018 has been noted by a sub-committee of the Biomedical Research Ethics Committee (BREC). Your application for Recertification received on 22 November 2018 for the above protocol has now been **approved** for another approval period. The start and end dates of this period are indicated above.

If any modifications or adverse events occur in the project before your next scheduled review, you must submit them to BREC for review. Except in emergency situations, no change to the protocol may be implemented until you have received written BREC approval for the change.

The committee will be notified of the above approval at its next meeting to be held on 11 December 2018.

Yours sincerely

Prof V Rambiritch
Chair: Biomedical Research Ethics Committee

cc Supervisor: eliza.govender@caprisa.org

Appendix 9: Gatekeepers letters

CAPRISA is the UNAIDS Collaborating Centre for HIV Research and Policy

Doris Duke Medical Research Institute (2nd floor), 719 Umbilo Road, Private Bag X7, Congella, 4013, Durban, South Africa
tel: +27 31 2604555 | **fax**: +27 31 2604549 | email: **caprisa@caprisa.org** | **www.caprisa.org**

15 March 2018

Dear Ms Nota

RE: Gatekeeper approval to work with young women for a doctoral research

I have read and understand the request submitted for gatekeeper's permission toward the study entitled "An exploration into the social cultural factors to oral pre-exposure prophylaxis (PrEP) uptake and possibilities for integration into Sexual and Reproductive Healthcare (SRH) services in KZN, for young women."

Your request to work with 8 young women between the ages of 18-30 who are currently using / have used oral pre-exposure prophylaxis (PrEP) whilst enrolled in the CAPRISA 084 study (A demonstration project of daily, oral tenofovir disoproxil fumarate + emtricitabine pre-exposure prophylaxis (PrEP) as part of sexual reproductive health services for young women at high risk of acquiring HIV in KwaZulu-Natal: Informing policy and practice for PrEP scale-up – BREC ref: BFC511/16) has been granted.

These 8 women will be recruited solely for the purposes of your doctoral research under the supervision of Dr Eliza Govender. All women will need to give you permission to participate in your study by signing a written informed consent document.

I wish you well in your doctoral studies.

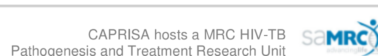
Your sincerely,

Dr Leila E Mansoor
Senior Scientist: CAPRISA
CAPRISA 082 Principal Investigator

T: 27-31-260-1972
F: 27-31-260-4549
E-mail: leila.mansoor@caprisa.org

National Research Foundation

CAPRISA hosts a DST-NRF Centre of Excellence in HIV Prevention



CAPRISA hosts a MRC HIV-TB Pathogenesis and Treatment Research Unit

Partner institutions:

Board of Control: AC Bawa (Chair) • Q Abdool Karim • SS Abdool Karim • R Bharuthram • JM Blackledge (UK) • D Clark • LP Fried (US) • S Madhi • LE Mazwai • CT Montague • B Ntuli • N Padayatchi • M Rajab • DP Visser• ZM Yacoob
Scientific Advisory Board: C Hankins (Chair) • F Abdullah • F Barré-Sinoussi • SM Dhlomo • HL Gabelnick • P Godfrey-Faussett • FG Handley • R Hoff • Y Pillay • T Quinn

Registration number: 2002/024027/08

Doris Duke Medical Research Institute (2nd floor), 719 Umbilo Road, Private Bag X7, Congella, 4013, Durban, South Africa
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CENTRE FOR THE AIDS PROGRAMME OF RESEARCH IN SOUTH AFRICA (CAPRISA)

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719 Umbilo Road

Durban 4041

South Africa

T: +27 (0)33 260 6884 C: +27 (0)74 287 7256

pamela.gumbi@caprisa.org

Dear Ms Nota

RE: REQUEST FOR WRITTEN PERMISSION TO WORK WITH YOUNG WOMEN FOR A DOCTORAL RESEARCH

It is my great pleasure to inform you that your request to work with 8 young women between the ages of 18-30 who are currently using/ have used oral pre-exposure prophylaxis (PrEP) whilst enrolled in CAPRISA 084 study has been granted. These 8 women will be recruited solely for the purposes of your doctoral research project entitled" an exploration into the social cultural factors to oral pre-exposure prophylaxis (PrEP) uptake and possibilities for integration into sexual and reproductive healthcare (SRH) services in KZN, for young women" under supervision of Dr Eliza Govender. As indicated in your request letter, please note that all women will need to give you permission to participate in your study by signing a written informed consent, in addition, you will need to compensate the participating women for their time.

I would like to take this opportunity and wish you well in your Doctoral studies.

Yours Faithfully,

Dr Pamela P Gumbi

CAPRISA hosts a DST-NRF Centre of Excellence in HIV Prevention

CAPRISA hosts a MRC HIV-TB Pathogenesis and Treatment Research Unit

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