

**Determining the Relationship Between Perceptions of HIV Susceptibility and HIV
Status of Women Who Have Sex with Women**

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Thesis Submitted in Fulfilment of the Requirements for the Degree of Master of Arts by

Thesis in Psychology

Rhodes University

June 2024

Abstract

Background: Adolescent girls and young women (AGYW) who have sex with women (WSW) are at potential risk for HIV, contradicting the common belief that WSW have low HIV susceptibility, a misperception persists despite evidence to refute it.

Objective: This study examined the relationship between perceived HIV susceptibility and actual HIV status among South African AGYW WSW, focusing on those reporting at least one same-sex sexual experience, using data from the DREAMS Evaluation survey.

Methods/Design: An archival study employing the Expanded Health Beliefs Model (EHBM) analysed secondary de-identified data from the DREAMS Evaluation Survey with a multistage stratified cluster sampling design. The sample comprised 18,296 AGYW aged 12-24 across four districts in South Africa, including 1,362 identified as WSW. ANOVA was conducted using SPSS 28 to explore the relationship between perceived HIV susceptibility and actual HIV status.

Results: WSW's perceived HIV susceptibility was low (38.5%) to very low (25%), while HIV prevalence in this sample/group was 15.9%. No significant relationship was found between perceived HIV susceptibility and actual HIV status ($p = 0.126$).

Conclusions: WSW do not perceive themselves as being susceptible to contracting HIV despite the high prevalence of the virus in this group. Public health interventions should focus on raising awareness about risk factors, such as low use of barrier protection, substance use, and other behaviours highlighted in the literature, to better inform and protect this population.

Keywords: Adolescent Girls and Young Women, Women who have sex with women, perception of HIV susceptibility, HIV status, Expanded Health Beliefs Model

Authors Note

This DREAMS Evaluation Survey primary study was supported by the President's Emergency Plan for AIDS Relief (PEPFAR) through the Centers for Disease Control and Prevention (CDC) under the terms of FOA GH11-1154/Award GH000372. Its contents are solely the responsibility of the authors and do not necessarily represent the official position of the funding agency.

Declaration of Originality

I, the undersigned, hereby declare that the work contained in this thesis is my own work unless otherwise referenced. It has not been previously submitted at any other university for the purposes of fulfilment of a degree.

Aimee Zuccarini
16/09/2024

Table of Contents

Abstract	2
Table Of Contents	Error! Bookmark not defined.
List Of Figures	8
List Of Tables	9
List Of Appendixes	10
List Of Abbreviations	11
Definitions Of Terms	14
Chapter 1 Introduction	20
1.1 Background Of The Study.....	20
1.1.1 Overview Of The Larger Study	23
1.2 Problem Statement	24
1.3 Purpose Of The Study	28
1.4 Research Questions	30
1.4.1 Main Research Question	30
1.4.2 Sub-Questions	30
1.5 Research Objectives	30
1.6 Research Hypothesis	30
1.7 Thesis Structure.....	30
Chapter 2 Literature Review	32
2.1 Introduction	32
2.2 HIV & WSW In South Africa	34
2.2.1 An Overview	34
2.2.2 History Of WSW And HIV.....	35
2.2.3 WSW South African HIV/AIDS Policy	36

2.3 HIV Prevalence And Risk For WSW In South Africa	38
2.3.1 HIV Prevalence Of AGYW Wsw In South Africa	38
2.3.2 HIV Risk Of AGYW Wsw In South Africa	39
2.3.3 Factors That Exacerbate The Hiv Risk Of Wsw.....	41
2.3.4 Risk Of HIV Infection During Female-To-Female Sexual Intercourse.....	46
2.4 Research Theoretical Framework: The Expanded Health Belief Model	47
2.4.1 Concepts Investigated In The Expanded Health Belief Model.....	48
2.5 Conclusion.....	51
Chapter 3 Methodology	54
3.1 Introduction	54
3.2 Research Hypotheses.....	55
3.3 Study Methodology	55
3.3.1 Setting	56
3.3.2 Sampling	60
3.3.3 Instruments.....	62
3.3.4 HIV Counselling And Testing	63
3.4 Procedures	64
3.4.1 Community Consultation	64
3.4.2 Training Of Study Staff	65
3.4.3 Household Visits And Interviews	65
3.4.4 Laboratory Procedures	66
3.4.5 Sample Collection.....	66
3.5 Reliability And Validity	66
3.6 Data Analysis	68

3.6.1 Statistical Analysis Overview	68
3.6.2 Statistical Analysis Rational	68
3.6.3 Categorisation & Grouping.....	70
3.7 Ethics.....	70
3.7.1 Compensation	72
3.8 Conclusion.....	72
Chapter 4 Results	74
4.1 Introduction	74
4.2 Descriptive Epidemiology Findings.....	75
4.2.1 Male Sexual Partner History.....	77
4.3 Core Result Findings.....	79
4.3.2 Analysis Of Research Question 1	84
4.4 Conclusion.....	86
Chapter 5 Discussion And Conclusion	88
5.1 Introduction	88
5.2 Discussion Of Results	88
5.3 EhbM Theoretical Framework Insights	92
5.4 Limitations Of The Study.....	94
5.5 Strengths Of The Study	94
5.6 Recommendations For Further Research	95
5.7 Main Contribution Of The Study	96
5.8 Conclusion.....	97
References.....	102

List of Figures

Figure 1: Flow Diagram of The Expanded Health Belief Model for WSW’s Health Decisions
.....48

Figure 2: Map of the DREAMS Evaluation Districts.....57

List of Tables

Table 1: Study Population in Four DREAMS Implementation Districts 2011–201759

Results Tables

Table 1: Demographic Characteristics Of Women Who Have Sex With Women (WSW) Enrolled In Four Districts In Gauteng And Kwazulu-Natal (N=1362)76

Table 2: History of Male Sexual Partners Among Women Who Have Sex with Women (WSW) Enrolled in Four Districts in Gauteng and KwaZulu-Natal (N=1362)78

Table 3: Perceptions of HIV Susceptibility and HIV Status Among Women Who Have Sex With Women (WSW) Enrolled in Four Districts in Gauteng and KwaZulu-Natal (N=1362) 80

Table 4: Levene’s Test for Homogeneity of Variances^b in Perceptions of HIV Susceptibility by HIV Status Among Women Who Have Sex With Women (WSW).....82

Table 5: Descriptive Statistics Of Mean, Std. Deviation, Std Error, Lower and Upper Bound & Range of Perceptions of HIV Susceptibility and HIV Status Among Women Who Have Sex With Women (WSW)83

Table 6: ANOVA Results for Differences in Perceptions of HIV Susceptibility by HIV Status Among Women Who Have Sex With Women (WSW).....85

Table 7: RQ1 Hypothesis Test Summary85

List of Appendixes

Appendix A: Data Use Agreement	122
Appendix B: Original DREAMS Evaluation Survey Ethical Approval	125
Appendix C: Rhodes University Human Research Ethics Committee Waiver	127
Appendix D: Informed consent for AGYW 19 and 17-12	128
Appendix E: Cross-Sectional Study Questionnaire	142
Appendix F: Table 1 and Figure 2 Release Form	145
Appendix G: Syntax.....	147

List of Abbreviations

AGYW	Adolescent Girls and Young Women
AIDS	Acquired Immunodeficiency Syndrome
ANOVA	Analysis of Variance
APA 7th	American Psychological Association, Seventh Edition
CDC	Centers for Disease Control and Prevention
CHW	Community Health Worker
DREAMS	Determined, Resilient, Empowered, AIDS- Free, Mentored and Safe
EHBM	Expanded Health Beliefs Model
GBV	Gender-Based Violence
GPS	Global Positioning System
HCT	HIV Counselling and Testing
HBM	Health Beliefs Model
HHS	Department of Health and Human Services
HIV	Human Immunodeficiency Virus
HSRC	Human Sciences Research Council
Lag AI EIA	Limiting Antigen Avidity Index Enzyme Immunoassay
LGBT	Lesbian, Gay, Bisexual and Transgender
LGBTQ+	Lesbian, Gay, Bisexual, Transgender, Queer and Plus

LGBTQI	Lesbian, Gay, Bisexual, Transgender, Queer and Intersex
MSM	Men who have Sex With Men
MSW	Men who have Sex With Women
NDOH	National Department Of Health
NGO	Non-Government Organization
PCR	Polymerase Chain Reaction
PEPFAR	President Emergency Plan for Aids Relief
PLHIV	People Living With HIV
SANAC	South African National AIDS Council
SD	Standard Deviation
SE	Standard Error
SGBV	Sexual and Gender-Based Violence
SHRS	Sexual Health and Reproductive Services
SOP	Standard Operating Procedure
SPSS28	Statistical Package for the Social Sciences version 28
STI	Sexually Transmitted Infection
SV	Sexual Violence
USA	United States of America
VCT	Voluntary Counselling and Testing
WSM	Women Who Have Sex with Men
WSW	Women Who Have Sex with Women

WSWE	Women who have Sex with Women Exclusively
WSWM	Women Who Have Sex with Women and Men
YW	Young Women

Definitions of Terms

Adolescent Girls and Young Women (AGYW): This demographic refers to females aged 12 to 24 years. AGYW are characterised by distinct needs and vulnerabilities, which increase their risk of HIV infection (George et al., 2020). These include biological immaturity, limited access to healthcare, education, age-disparent relationships and economic resources (George et al., 2020). In sub-Saharan Africa, including South Africa, AGYW face a disproportionately high HIV incidence, underscoring the need for targeted interventions to support this population and reduce their HIV risk (George et al., 2020).

Age Disparent Relationships: These are relationships with significant age differences between partners, usually of 5 or more years (George et al., 2020). This impacts power dynamics and vulnerability to HIV, particularly amongst AGYW (George et al., 2020).

Archival Study Design: This study design uses existing data to answer new research questions (Das et al., 2018). This is relevant to HIV research and prevention among WSW in South Africa as it can use readily available data without the high cost that would otherwise be expected (Das et al., 2018).

CDC: This federal agency works under the Department of Health and Human Services, also known as HHS (U.S. Department of Health & Human Services, 2019). The primary goal of this organisation is to protect public health and safety (HHS, 2019). The CDC played a significant role in the DREAMS Evaluation Survey and DREAMS Programme, providing technical expertise, guidance, support, funding, and capacity-building assistance (Cawood et al., 2021). The CDC has impacted WSW health policy in South Africa through its research, guidelines, and recommendations (Allanise et al., 2011). While the CDC is headquartered in the United States of America (USA), its work and expertise have global implications, including influencing health policies in other countries (Allanise et al., 2011; HHS, 2019).

De-Identified Data: This refers to data that has been processed so that it can no longer be linked to an individual (Garfinkel, 2015). This is done by hiding identifying information, such as names, ID numbers, contact information, and other direct identifiers (Garfinkel, 2015). This is particularly relevant to WSW as obscuring this information protects this vulnerable population from being personally stigmatised due to this study (Okanlawon et al., 2012).

DREAMS Evaluation Survey: This cross-sectional survey assessed the DREAMS programme's impact on AGYW aged 12-24 across four districts in South Africa from March 2017 to July 2018 (Cawood et al., 2021). It aimed to evaluate the programme's influence, HIV incidence, sexual risk behaviours, and access to educational and healthcare services in the AGYW population of this area (Cawood et al., 2021). Key measures included changes in HIV status confirmed by blood tests, shifts in sexual behaviour, and improved access to schooling and health services (Cawood et al., 2021).

DREAMS Programme: The DREAMS programme was started by the US President's Emergency Plan for AIDS Relief (PEPFAR) (Cawood et al., 2021). They aimed to reduce HIV incidence among AGYW in 10 sub-Saharan African countries, including South Africa (Cawood et al., 2021). This programme was launched in April 2016, DREAMS stood for Determined, Resilient, Empowered, AIDS-free, Mentored, and Safe, and was rolled out in high-HIV-burden districts in South Africa, including the City of Johannesburg, Ekurhuleni, eThekweni, uMgungundlovu, and uMkhanyakude (Cawood et al., 2021; Oguntomilade, 2020).

Epicentre Health Research: Epicentre was employed to conduct fieldwork for the DREAMS Evaluation Survey (Cawood et al., 2021). This organisation has over 20 years of expertise in conducting epidemiological studies, surveillance, and programme evaluations, particularly in HIV prevention and treatment (Cawood et al., 2021). This positioned Epicentre well for collecting high-quality data for this survey (Cawood et al., 2021). Known for their experience

in infectious diseases and operating in resource-limited settings, Epicentre's involvement ensured high-quality, evidence-based data collection, which is crucial for formulating practical public health recommendations and interventions (Cawood et al., 2021).

Expanded Health Beliefs Model (EHBM): The EHBM extends the traditional Health Belief Model by including social, cultural, interpersonal, and structural factors influencing health behaviours (Carpenter, 2010). It is particularly pertinent for young women and the LGBTQ community to acknowledge how societal norms around gender and sexuality can impact their healthcare access and utilisation (Carpenter, 2010). In HIV research, the EHBM helps in understanding respondent's perceptions of HIV risk, the effects of stigma, and the importance of supportive relationships (Carpenter, 2010). It provides a holistic framework for addressing the diverse factors affecting health outcomes in these populations (Carpenter, 2010; Rosenstock et al., 1994; Tarkang & Zotor, 2015).

Health Beliefs Model (HBM): This theoretical framework explains and predicts health-related behaviours based on individuals' beliefs and perceptions (Rosenstock et al., 1994). This model's components include (a) perceived susceptibility, (b) perceived severity, (c) perceived benefits, and (d) perceived barriers (Carpenter, 2010; Rosenstock et al., 1994). In the context of HIV research among AGYW WSW in South Africa, the HBM is relevant as it helps understand their beliefs and perceptions related to HIV prevention (Rosenstock et al., 1994).

HIV Prevalence: This refers to the proportion of individuals in a population who are infected with HIV when tested (Cawood et al., 2021).

HIV Status: HIV status is identified in individuals according to their blood test results as either HIV-positive or HIV-negative (Cawood et al., 2021). HIV incidence was assessed in the DREAMS Evaluation survey, which collected whole blood through dried blood spots and plasma tests (Cawood et al., 2021).

Inclusion Criteria: In a study, individuals must possess these specific characteristics or criteria to be eligible for participation in a research study or survey (Cawood et al., 2021).

Lesbian: There is not one accepted definition of 'lesbian.' The term has been applied to women who engage in sexual relationships with other women, either exclusively or alongside relationships with men (behaviour), women who identify as lesbian (identity), and women who have a sexual preference or attraction to women (desire or attraction) (Institute of Medicine, 1999). This definition is further complicated by people's experience of gender identity (Tate, 2012). Tate (2012) highlighted the complexity of defining lesbian identity, noting that this term also encompasses transgender and genderqueer individuals who identify as female at any point in their lives. This emphasises the importance of current and past gender identities in shaping a person's choice of self-identification (Tate, 2012).

Multistage Stratified Cluster-Random Sampling: This sampling method is used to study extensive and diverse populations efficiently and representatively in the DREAMS Evaluation Survey (Cawood et al., 2021; Eichhorn, 2022). A multistage approach to stratified cluster-random sampling in this survey involved treating the four districts under study as the primary layers of stratification (Cawood et al., 2021; Eichhorn, 2022). These stratified layers were used to divide the study population by age and gender to establish clusters of households with AGYW present (Cawood et al., 2021; Eichhorn, 2022). AGYW households were then randomly chosen for visitation (Cawood et al., 2021; Eichhorn, 2022).

PEPFAR: The President's Emergency Plan for AIDS Relief (PEPFAR) is a U.S. initiative started in 2003 to combat the global HIV/AIDS epidemic (U.S. Department of State, n.d.). It supports countries heavily affected by HIV/AIDS, focusing on prevention, treatment, care, and support services (U.S. Department of State, n.d.). In this study, PEPFAR is crucial as it funds and supports the DREAMS programme aimed at reducing HIV infections among AGYW in

sub-Saharan Africa, including South Africa (Cawood et al., 2021). PEPFAR's role underscores the significance of international collaboration in enhancing health outcomes and reducing HIV incidence among this vulnerable group (Cawood et al., 2021).

Perceptions of HIV Susceptibility: This component of the EHBM refers to an individual's subjective assessment of their likelihood or risk of contracting HIV (Rosenstock et al., 1994). In this study, perceptions of HIV susceptibility are measured through a specific question in the survey that asks participants if they agree with the statement, "My chances of getting HIV are high." Responses are captured on a scale from 1 (strongly agree) to 4 (strongly disagree). This translates this data on subjective levels of agreement into quantifiable data representing participants' perceived HIV susceptibility (Rosenstock et al., 1994). This is an appropriate substitution for risk perceptions as there is a precedent of 'perceptions of susceptibility' being used as a synonym for 'risk perceptions' within published psychology research (Ferrer & Klein, 2015)

Perceptions of Severity: This component of the EHBM is linked to an individual's belief about the seriousness and potential negative consequences of a health condition such as HIV (Rosenstock et al., 1994).

Perceptions of Threat: This component of the EHBM relates to an individual's overall assessment of the potential negative consequences of a health condition (Rosenstock et al., 1994). Together, perceptions of severity and susceptibility contribute to a person's perception of risk and motivate them to engage in health-related behaviours (Rosenstock et al., 1994).

Primary Study: The primary study was the DREAMS Evaluation Survey. This secondary research utilised the data from this survey to answer its research questions.

Risk: A broad and comprehensive term that refers to the chance that something will affect or harm an individual's health (National Institutes of Health, 2016).

Risk Perception: This is a subjective assessment that an individual makes about the likelihood that they will be affected by an adverse event (e.g., injury, illness, disease, and death) (Paek & Hove, 2017).

Secondary Study: Also known as secondary analysis or secondary research, this kind of research analyses and interprets existing data collected by other researchers or organisations to answer new research questions (Chandola & Booker, 2022).

South African National AIDS Council (SANAC): This multi-sectoral body was established by the South African government to coordinate the national response to HIV/AIDS (SANAC, 2023). SANAC's relevance to HIV and WSW relates to its role in shaping policies, strategies, and programmes that address the specific needs and challenges faced by this population about HIV/AIDS (SANAC, 2023).

SPSS28: SPSS Statistics is a statistical software suite developed by IBM that is a comprehensive system for analysing data (IBM Corp, 2023).

Women Who Have Sex with Women (WSW): This term is used instead of or alongside labels such as lesbian or bisexual because it includes a broader range of sexual identities (SANAC, 2013). This includes not only those who identify as lesbian or homosexual but also bisexual women and those who identify as heterosexual but engage in sexual activities with women (SANAC, 2013). This term was preferred for this context as it encompassed all women who may be at risk for HIV, regardless of how they identify (SANAC, 2013).

Chapter 1 Introduction

1.1 Background of the Study

Globally, 39 million people are living with the human immunodeficiency virus (HIV), and approximately 7 to 8.2 million of those individuals reside in South Africa (Matebeni et al., 2021; UNAIDS, 2023). This virus has disproportionately affected women and girls, with 53% (4.5-5.2 million) of South Africa's people living with HIV (PLHIV) belonging to this demographic (South African National AIDS Council, 2023; UNAIDS, 2022, 2023). It has been estimated that approximately 4,400,000 adolescent girls and young women (AGYW) are living with HIV in South Africa (UNAIDS, 2019). This high prevalence suggests that South Africa is at the epicentre of the HIV pandemic, as it arguably has been since the 1990s (Gona et al., 2020; SANAC, 2023). Within the context of the HIV crisis, specific populations have been understudied, and their HIV risk has been underestimated (Cloete et al., 2011; Nyeck et al., 2019).

Among these are South Africa's AGYW, who have sex with women, a diverse and heterogeneous population with intersectional vulnerabilities to this virus (Armisen, 2013). According to the South African National AIDS Council or SANAC (2013), women who have sex with women (WSW) include "not only women who self-identify as lesbian or homosexual and have sex only with other women but also bisexual women and those who self-identify as heterosexual but who have sex with other women" (p.7). While both WSW and lesbians may engage in same-sex relationships, the term WSW encompasses a broader group, including those who identify as bisexual or heterosexual (Institute of Medicine, 1999; SANAC, 2013). In contrast, lesbian specifically refers to women whose primary sexual attraction and identity is centred on women (Institute of Medicine, 1999). Despite the wide range of women who can be classified or labelled as 'WSW', in the context of this study, Black South African AGYW

WSW are the primary focus. The recent increased awareness in mainstream HIV discourse, recognising this population's elevated risk for HIV acquisition, was the catalyst for focusing on this group (Centers for Disease Control and Prevention (CDC), 2021).

AGYW in South Africa are already defined as a population with a high risk for HIV based on their high prevalence and incidence (UNAIDS, 2019; 2023). In 2022, AGYW made up 77% of all new HIV infections in sub-Saharan Africa, with 4,000 AGYW infected with HIV in this area each week (UNAIDS, 2023). Furthermore, directly within South Africa, the George et al. (2020) study found that the country's highest HIV incidence rate (1.5%) was among AGYW between 15 and 24 years old. Based on AGYW's high prevalence and incidence results, this population in this setting continues to be perceived by researchers and policymakers as a critical priority population (George et al., 2020; UNAIDS, 2023). More focus on these young WSW is necessary as strengthening interventions amongst at-risk AGYW has been labelled a priority by policymakers and several key organisations (SANAC, 2023; UNAIDS, 2019; 2023)

However, WSW in any age group were not labelled a priority population until recently (CDC, 2019; 2021). From the early 1990s until the '2021 update', the CDC categorised WSW as a population with a very low risk for an HIV infection (CDC, 2019; 2021; Richardson, 2000; Silverberg et al., 2022). This categorisation was predominantly based on the low risk for HIV acquisition during oral sex as measured in clinical studies amongst heterosexual couples (Logie & Gibson, 2013; Michigan Department of Health and Human Services; Pat et al., 2014). However, in the '2021 update', WSW's low-risk categorisation for HIV was acknowledged by the CDC not to be supported by clinical and social study findings (CDC, 2021; Silverberg et al., 2022). This change in perceptions of the urgency of WSW HIV risk has also been reflected in South African policy (SANAC, 2023). The 2023-2028 iteration of SANAC's strategic plan

has identified lesbians as an ‘other priority population’ that is particularly vulnerable to HIV in specific settings (SANAC, 2023).

This is positive as contemporary studies have indicated that the HIV rates for WSW are at high levels, comparable to WSM (CDC, 2021). This high prevalence is particularly problematic amongst WSW who are Black, women who have sex with women and men (WSWM), or AGYW (CDC, 2021). These WSW sub-populations may be at increased risk for sexually transmitted infections (STIs) such as HIV (CDC, 2021). This increased risk is linked to their reported risky sexual behaviours, such as low sexual barrier use (e.g. male/female condoms or dental dams) during sexual encounters with both men and women (CDC, 2021). AGYW WSW, like their AGYW WSM counterparts, are in areas that are known as ‘high incidence settings’ (CDC, 2021; George et al., 2020; UNAIDS, 2023). This means that these participants are in geographical locations where there is a persistently high rate of infection with HIV (Kharsany et al., 2019). This increases the risk of infection for HIV amongst AGYW WSW as they are exposed to many of the same biological, structural, and behavioural HIV risk factors as their WSM counterparts (CDC, 2021; George et al., 2020; UNAIDS, 2023).

Furthermore, due to their youth, AGYW WSW also face a heightened risk of HIV infection because of biology compared to both the general South African populace and their male peers (CDC, 2021; George et al., 2020). It was found in 2022 that in sub-Saharan Africa, AGYW are more than three times as likely to acquire HIV than their male counterparts (UNAIDS, 2023). This increased vulnerability stems from a combination of factors. However, a critical vulnerability lies in their biology; AGYW have immature cervical canal walls and a higher incidence of bacterial and viral STIs (Fethers et al., 2012; George et al., 2020). Structurally, they face challenges such as low education levels, poverty, and experiences of sexual abuse, whilst behaviourally, they are exposed through practices like transactional sex

and engaging in multiple partnerships (Bajunirwe et al., 2020; George et al., 2020; Tat et al., 2015). These biological and structural factors mediate much of AGYW WSW's behavioural-based risk for HIV, as these vulnerabilities substantially increase the risk of their sexual behaviour (CDC, 2021; George et al., 2020).

It is therefore arguable that, based on these biological, structural, and behavioural factors, HIV risk may be heightened amongst the AGYW sub-population of WSW in South Africa in comparison to WSW over 25 years old (George et al., 2020; Logie & Gibson, 2013; Tat et al., 2015). A recent Southern African study found that the HIV prevalence among Black WSW stands at 9.6%; however, this study was based on WSW over 18 years old (Sandfort et al., 2013). Whilst the CDC (2021) has reported on the heightened risk of this age group of WSW, Evans et al. (2016) found that there is a prevalent perception of low HIV susceptibility in this population. This perception conflicts with the available evidence, specifically for AGYW WSW in high-incidence settings in South Africa, as they face an intersection of risk for HIV due to their gender, race, sexual partner history, and socioeconomic status (George et al., 2020; Logie et al., 2011). In addition to the structural risk posed to WSW by the high incidence of homophobia resulting in gender and sexual-based violence in South Africa (Brown, 2012; Govender et al., 2019). It is, therefore, arguable that biological, structural, and behavioural factors unique to AGYW may exacerbate the HIV risk of this age group of WSW. Thus, more research is needed on the health beliefs of this population, as this misperception relating to HIV susceptibility may have an impact on health decisions and the prevalence in this population.

1.1.1 Overview of The Larger Study

This study uses quantitative data that was collected by The Determined, Resilient, Empowered, AIDS-Free, Mentored, and Safe (DREAMS) Evaluation Survey focused on

young and adolescent women aged 15 to 24 years (Cawood et al., 2021; Oguntomilade, 2020). This survey aimed to evaluate the DREAMS programme conceived under the U.S. President's Emergency Plan for AIDS Relief (PEPFAR) in South Africa (Cawood et al., 2021; Oguntomilade, 2020). This programme adopted an all-encompassing strategy to navigate and dismantle the complex barriers to HIV prevention faced by these young women (Cawood et al., 2021; Oguntomilade, 2020). To evaluate the DREAMS programme, this survey targeted the same five districts in which the DREAMS Core Package of services was rolled out (Cawood et al., 2021; Oguntomilade, 2020). Namely, in Ekurhuleni, eThekweni, uMgungundlovu, and the city of Johannesburg (Cawood et al., 2021; Oguntomilade, 2020). Due to the aims of the DREAMS programme, this evaluation collected data on predominately Black AGYW, a population with a notably high prevalence and incidence of HIV (Cawood et al., 2021; Oguntomilade, 2020).

1.2 Problem Statement

Despite the HIV risk posed to AGYW WSW in South Africa due to situational and intersectional-based risk, there is a widespread misperception that this population is 'susceptibility-free' (Cloete et al., 2011). This perception can be understood as the belief that this population has a low likelihood of acquiring an HIV infection (Cloete et al., 2011; Rosenstock et al., 1994). Cloete et al. (2011) highlighted this as a potentially dangerous oversight, while Evans et al. (2016) noted the lack of supportive evidence for this perceived 'low' susceptibility. However, this problem is exacerbated by this population's relative invisibility in HIV research and policy, which has real consequences for sexual health reproductive services (SHRS), as it limits their ability to address the unique needs of WSW (Logie & Gibson, 2013). Correcting this misconception is crucial, as South African AGYW

WSW have unique needs and vulnerabilities to HIV that require intervention (Brown, 2012; Poteat et al., 2015).

Over a decade ago, Cloete et al. (2011) argued that WSW are a potentially under-recognized high-risk population for HIV infection in South Africa. Although there is a widespread perception amongst South Africans, including amongst WSM themselves, healthcare professionals, health researchers and policymakers, that WSW face little to no susceptibility to HIV, this perception does not appear to be supported by empirical evidence (Evans et al., 2016; Patel et al., 2014). It is assumed that WSW's sexual activity only includes oral sexual intercourse with women, which was found amongst heterosexual couples to be low or very low risk for HIV infection (Michigan Department of Health and Human Services, 2023; Patel et al., 2014). However, research suggests that WSW sexual behaviour is varied and goes beyond female-female oral sex (Mendoza-Pérez et al., 2019). Notably, many WSW have both male and female partners, which carries an increased risk for HIV infection (Mendoza-Pérez et al., 2019; Tat et al., 2015). These risk factors are particularly problematic when viewed against the common misperception that WSW are a unique, 'HIV-susceptibility-free' population (Evans et al., 2016).

This is a difficult misperception to correct because of the way that transmission risk categories have been structured (Logie & Gibson, 2013). Contemporary HIV transmission categories lack the option to indicate that transmission occurred due to female-to-female sexual intercourse (Logie & Gibson, 2013). This has real consequences for the HIV infection rate in this population (Evans et al., 2016; Logie & Gibson, 2013). Without statistical evidence of these transmissions, there is little pressure to improve SHRS for WSW (Logie & Gibson, 2013). This is substantiated by reports in South Africa and internationally that WSW experience barriers to care, especially amongst WSWM and WSW who are Black and AGYW

(CDC, 2021; SANAC, 2023). This invisibility in transmission categories restrains WSW-focused HIV research/policy discourse, placing WSW at increased risk for HIV (CDC, 2021; Logie & Gibson, 2013).

The lack of WSW-focused SHRS and a low perception of personal susceptibility to HIV has left a noticeable gap in knowledge and motivation among WSW regarding how and why they should reduce their risk for STIs such as HIV (CDC, 2021; Tat et al., 2015). This is supported by study findings that a low perception of HIV susceptibility among WSW impacts this population's motivation to take preventative actions against HIV (Tsui et al., 2012). WSW have been reported to engage in avoidable risky sexual behaviours that increase their risk of contracting HIV; this includes sharing sex toys and engaging in sexual activities during menstrual cycles (Chan et al., 2014; Wilton, 2012). Issues exacerbated by the finding that the use of barrier protection during sexual activity with female and male partners is infrequent, as highlighted by the studies reviewed by the CDC (2021). AGYW who have sex with women are not living in separate enclaves but are instead in a high-incidence setting for HIV and are subpopulations of a community that is highly at risk for this virus (Cloete et al., 2011). Thus, the lack of WSW-focused SHRS and low perception of personal susceptibility to HIV have important and concerning implications for this population's self-efficacy to take protective measures (Cloete et al., 2011; Rosenstock et al., 1994).

Despite the urgency of investigating low perceptions of HIV susceptibility amongst AGYW WSW in South Africa, this is challenging to explore in the literature. There is a dearth of information on this population in this setting - especially in quantitative research. Further research on this population, particularly in the South African setting, is worthy of exploration. This country has a unique socio-political and cultural context, which places it at the centre of the HIV epidemic (Gona et al., 2020; SANAC, 2023). South Africa's high prevalence of HIV,

combined with complex social dynamics, including gender inequality and stigma against the lesbian, gay, bisexual, transexual and queer (LGBTQ) community, provides a critical backdrop for investigating the perceptions of HIV susceptibility among WSW (SANAC, 2023). However, it is essential to recognise the potential limitations of this focus. Firstly, the scope of existing information on WSW and HIV in South Africa is limited, with most studies concentrating on the risk of WSM. This gap in the literature restricts this study's ability to fully understand the nuances of HIV risk among AGYW WSW, potentially overlooking factors specific to this population. These limitations may affect this study's conclusions and need to be acknowledged.

The indications are that AGYW WSW are not a unique, 'HIV-susceptibility free' population. Instead, they are a part of the broader AGYW population, a population which has been identified in South Africa and elsewhere in sub-Saharan Africa as experiencing persistently high HIV incidence rates (CDC, 2021; Lewis et al., 2022; SANAC, 2023). There is an urgent call to develop tailored strategies to address the unique needs of AGYW (UNAIDS, 2019). This is particularly important in high-risk sub-populations like WSW, whose sexual health needs show evidence of being inadequately addressed in South Africa (CDC, 2021; Cloete et al., 2011; SANAC, 2023; Tat et al., 2015). Developing effective interventions for this population requires more research on the pervasive misperceptions that this population is affected by (Evans et al., 2016). This study aims to bridge this gap in knowledge by examining the relationship between WSW's perceptions of HIV susceptibility and HIV status. By adopting the framework of the Expanded Health Belief Model (EHBM), this research will offer nuanced insights into the subjective assessments WSW make about their HIV risk, thereby informing more effective public health strategies and interventions tailored to their unique needs (Rosenstock et al., 1994).

1.3 Purpose of the Study

The primary purpose of this study is to determine if there is a relationship between WSW's perceptions of HIV susceptibility and their HIV status. The objective is to measure and analyse perceptions of HIV susceptibility and assess the effect of this variable on participants' HIV status. An objective reflected in recent research on other at-risk populations for HIV, such as the study by Khani Jeihoon et al. (2018), examined the effect of an educational program based on the Health Belief Model (HBM) on HIV/AIDS knowledge, attitudes, and behaviours among high school students. However, this study also seeks to go beyond studying the broader concept of risk for HIV in this population. Instead, using the framework of the EHBM, this study aims to comprehensively analyse the more nuanced concept of perceived susceptibility to address a gap in HIV research on WSW (Rosenstock et al., 1994).

Initially, the variable of 'perceptions of HIV susceptibility' was termed under the DREAMS Evaluation Survey questionnaire as 'risk perceptions' (Appendix E). To better incorporate the themes of the Expanded Health Belief Model (EHBM) framework, this study used the term 'perceived susceptibility' (Rosenstock et al., 1994). This is an appropriate substitution as a precedent of 'perceptions of susceptibility' being used as a synonym for 'perceived risk' within published psychology research (Ferrer & Klein, 2015). Using the EHBM framework, this research will distinguish between the broader concept of risk—which encompasses a variety of external and behavioural factors—and the more personal and subjective concept of perceived susceptibility (Paek & Hove, 2017; Rosenstock et al., 1994). Therefore, this study aims to shed light on the internal cognitive processes influencing health behaviour decisions among WSW (Adams et al., 2014; Blumenthal et al., 2019). This objective is critical for understanding health decisions in this population (Rosenstock et al., 1994).

However, the concept of ‘perceived susceptibility’ has suffered from a lack of comprehensive quantitative research on this component of WSW (Cloete et al., 2011; Rosenstock et al., 1994). There is a wealth of qualitative research on this component regarding men who have sex with men (MSM), men who have sex with women (MSW) and WSM (e.g., Haruna & Ago, 2014; Noorman et al., 2024). However, due to the decades of messaging reinforcing low perceptions of HIV susceptibility in this population, this is a crucial area of WSW health decisions requiring further research (Logie & Gibson, 2013; Matebeni et al., 2013; Rosenstock et al., 1994). Therefore, it is hoped that through improving knowledge of perceived susceptibility and its relationship to HIV status, this study will positively impact the development of tailored HIV policies and interventions for this population.

This study provides data on nuanced personal assessments that inform cognitive health decisions amongst WSW (Rosenstock et al., 1994). This would be invaluable to policymakers constructing prevention strategies and programmes, as these results could be used to build on the foundation created by this study to assist decision-makers in meeting the unique needs of the WSW community. This study, therefore, hopes to enhance the understanding of perceptions of HIV susceptibility and HIV status among WSW for other researchers to build upon in future studies. To achieve this study’s expected outcomes and purpose, one main and two sub-research questions were designed to measure and evaluate the relationship between perceptions of HIV susceptibility and HIV status. It should be noted that secondary data was used and analysed at both provincial and district levels; this information was employed to guide the researcher in understanding this complex issue better.

1.4 Research Questions

1.4.1 Main Research Question

1. Is there a relationship between the perceptions of HIV susceptibility and the HIV status of WSW?

1.4.2 Sub-Questions

2. What are the perceptions of HIV susceptibility of WSW?
3. What is the HIV prevalence of WSW?

1.5 Research Objectives

1. To measure both the HIV prevalence and the perceptions of HIV susceptibility among WSW.
2. Evaluate the relationship between perceptions of HIV susceptibility and HIV status.

1.6 Research Hypothesis

There is no relationship between WSW's perceptions of HIV susceptibility and their HIV status.

1.7 Thesis Structure

The structure of this thesis consists of several chapters that follow the standard progression for a master's thesis. It begins the current section, Chapter 1, which introduces the study, provides background information, and states the problem this study seeks to address. Additionally, this chapter provides the research questions, objectives, and hypotheses. Chapter 2 is a literature review that explores the relevant literature on AGYW WSW, HIV, and perceptions of WSW's HIV susceptibility. Chapter 3 outlines the methodology, including the study setting, sampling, instruments, procedures, and ethical considerations. Chapter 4 presents

the study's results, and an analysis of the data related to the research questions. Finally, Chapter 5 provides a discussion of the findings and a conclusion. Overall, the structure of this thesis allows for a comprehensive exploration of the research topic.

Chapter 2 Literature Review

2.1 Introduction

The purpose of this chapter is to review contemporary empirical studies on perceptions of HIV susceptibility among WSW in South Africa. This is done to support the aim of this study, which is to explore and understand the complex dynamics between perceptions of HIV susceptibility and HIV status among this subpopulation of AGYW. By synthesising the findings from these studies, the chapter aims to demonstrate the need for the current research and highlight the gaps in knowledge in this area.

A consistent finding in the literature is that WSW tend to underestimate their individual HIV susceptibility, regardless of their perceptions of WSW collective HIV susceptibility and their own actual HIV status (Evans et al., 2016). This means that WSW have been found to often underestimate their personal likelihood of being infected with HIV (Evans et al., 2016; Rosenstock et al., 1994). This pattern has been observed in South Africa (Cloete et al., 2011), as well as in Canada (Logie & Gibson, 2013) and the United States (McCune et al., 2017). This discrepancy between individual and collective perceptions of susceptibility is a key area of concern (Evans et al., 2016), highlighting the need for further research to understand how these perceptions are formed and how they impact HIV prevention behaviours.

The reviewed studies also highlight the complex social and structural factors that contribute to the gap between perceptions of HIV susceptibility and actual HIV risk among WSW (Evans et al., 2016; Logie & Gibson 2013; Cloete et al. 2011). For instance, WSW often face institutionalised exclusion from the dominant HIV categorising framework, which leads to a lack of recognition and inaccurate recording of HIV infections among this population (Logie & Gibson, 2013; Wikramanayake et al., 2020). This exclusion not only hinders the estimation of HIV prevalence but also perpetuates the misperception that WSW are a

‘susceptibility-free’ population (Cloete et al., 2011; Evans et al., 2016). This misperception is reinforced by healthcare providers who may lack access to accurate information on infections between women and may inadvertently contribute to WSW’s false sense of security against HIV (Mkhize & Maharaj, 2020; Richardson, 2000).

The literature highlights the necessity for ongoing research and the development of targeted interventions and tailored sexual health strategies that specifically address the unique needs of WSW. Current HIV education programs may not effectively reach or educate this population, as their perceptions of susceptibility are influenced by misinformation and a lack of access to specific health education (Matebeni et al., 2013; Mkhize & Maharaj, 2020). Therefore, it is crucial to develop interventions focused on increasing HIV knowledge that is LGBTQ-focused and aimed explicitly at shifting WSW’s perceptions of HIV susceptibility (Evans et al., 2016; Matebeni et al., 2013; Mkhize & Maharaj, 2020). By addressing these gaps in knowledge and understanding, future interventions can be designed to better meet the needs of WSW and reduce HIV transmission within this population.

Studies by Tsui et al. (2012), Chan et al. (2014), and Wilton (2012) highlight the low perception of HIV susceptibility among WSW and the pressing need for further research in this area. Understanding this gap in perception is critical, as it directly impacts the effectiveness of current HIV prevention efforts. Addressing these perceptions is an essential step toward developing health interventions that will effectively address the HIV prevention needs of this population. The present study aims to contribute to this body of knowledge by examining the relationship between perceptions of HIV susceptibility and HIV status among AGYW WSW in South Africa. By building upon existing literature and utilizing the framework of the EHB, this review seeks to provide insights into the complex factors that shape health beliefs and decision-making processes among WSW.

2.2 HIV & WSW In South Africa

This section provides an overview of the existing research and knowledge regarding the intersection of HIV and WSW in the South African context both historically and contemporarily. This is done through an exploration of the unique challenges and vulnerabilities faced by WSW in relation to HIV prevention, transmission, and access to healthcare services. The section aims to contribute to a better understanding of the specific needs and experiences of WSW in the context of HIV.

2.2.1 An Overview

HIV is a medical and social disease that disproportionately affects marginalised communities within South Africa (Myburgh et al., 2021; Simbayi et al., 2021). According to Patel et al. (2014), HIV transmission occurs in the most intimate parts of human life; this list, ordered from greatest to lowest risk (excluding sexual exposures), includes blood exposure through transfusions (9,250/10,000), contaminated sharp objects (63/10,000), ‘parenteral’ or needle stick exposure (23/10,000), and ‘vertical’ or mother-to-child exposure (1700–2900 /10,000) (CDC, 2019; Myburgh et al., 2021; Patel et al., 2014; Sperling et al., 1996). Sexual exposures range from anal sex that is receptive (138/10,000) to insertive (11/10,000), followed by insertive penile-vaginal sex (8/10,000) and receptive (4/10,000) and finally oral sex, both receptive and insertive (0–4/10,000) (CDC, 2019; Patel et al., 2014). The remaining ranked parenteral exposures are biting, spitting, throwing body fluids, and sharing sex toys; these exposures are ranked as negligible (CDC, 2019; Patel et al., 2014).

Patel et al. (2014) findings are used by the CDC (2019) to estimate the per-act probability of acquiring HIV. These findings have informed policy, research, funding, and medical treatment, which means that they have influenced the advice for what and the missed opportunities for preventative HIV SHRS for WSW in countries like South Africa (CDC, 2019;

Maughan-Brown & Venkataramani, 2018). The perception that WSW have a very low susceptibility to HIV infection is based on this 'low' (0-4/10,000) risk of transmission during oral sex (CDC, 2019; Patel et al., 2014). However, WSW sexual behaviour may be riskier for HIV than previously thought (CDC, 2021). Research indicates that this population's sexual acts range beyond oral sex and include acts that can increase female couples' vulnerability (Chan et al., 2012; Mendoza-Pérez et al., 2019). Although not the focus of this current study, additional research to determine an accurate and focused evaluation of this population's risk of infection is worthy of further exploration.

2.2.2 History of WSW and HIV

The dominant contemporary perception held by the general public in South Africa, including among healthcare professionals, health researchers and policymakers is that WSW have a low susceptibility to HIV (CDC, 2021; Evans et al., 2016); historically, this was not a common assumption (Richardson, 2000). In the early to mid-1980s, the 'beginning' of the acquired immunodeficiency syndrome (AIDS) crisis, public health policy focused on 'risk groups' rather than 'risk behaviours' (Richardson, 2000). This meant that those who were perceived as most susceptible to contracting HIV were injecting drug users and homosexual people, both WSW and MSM (Richardson, 2000). This past perception of high susceptibility resulted in the American Red Cross advising 'gay' men and women not to donate blood (Richardson, 2000). Medical researchers assumed that this virus was associated with the lifestyles and behaviours of 'homosexuals' regardless of their gender identity (Richardson, 2000). This view was echoed by the public media, who labelled HIV/AIDS the 'gay disease' (Richardson, 2000). This association with homosexuality resulted in intense stigma, public indifference, and governmental inaction (Gil et al., 2021). This was demonstrated in America

when the president at that time, Ronald Reagan, did not publicly acknowledge HIV and AIDS until 1985, four years after people began to die of the virus (Gil et al., 2021).

It was only when research and epidemiological data from many countries showed that HIV/AIDS affected individuals and communities in a variety of different ways that HIV health education policy shifted (Richardson, 2000). For example, data from African countries at the time showed almost equal numbers of men and women living with HIV (Richardson, 2000). This led to the assessment that heterosexual intercourse was a key transmission route for the virus, resulting in a shift in HIV/AIDS health education policies from emphasising 'risk groups' to 'risk behaviours' (Richardson, 2000). A consequence of this shift was that WSW were no longer perceived as highly susceptible to HIV infection based on the presumed low risk of HIV transmission during oral sexual intercourse between women (Richardson, 2000).

2.2.3 WSW South African HIV/AIDS Policy

HIV/AIDS health policies and programming in South Africa have shown a lack of consistency in the country's national HIV/AIDS strategic plans for WSW. The 2007-2011 strategic plan made by SANAC (2007) included HIV prevention and treatment programmes for MSM, lesbians, and 'trans persons'. This strategic plan also committed to providing an incremental roll-out of a comprehensive customised HIV prevention package for lesbians (SANAC, 2007). A package that included voluntary counselling and testing (SANAC, 2007). Despite these promises, these plans were never followed through, nor were any concrete goals relating to WSW included in the subsequent 2012 or 2017 strategic plans (SANAC, 2012, 2017). In the 2012-2016 national strategic plan, the term WSW was defined, and the phrase 'Lesbian, Gay, Bisexual, Transgender and Intersex' (LGBTI) was included and labelled as a vulnerable population (SANAC, 2012). However, no corresponding goals or plans were made for WSW (SANAC, 2012).

Only over a decade later, in the most recent 2023-2028 strategic plan, lesbians have been specifically identified and included in several goals (SANAC, 2023). In this iteration of the strategic plan, lesbians have been labelled an ‘other priority population’ who are seen as “particularly vulnerable to HIV, TB and STI infections in certain contexts and who might have reduced access to healthcare and social services” (SANAC, 2023, p. 25). This acknowledgment of vulnerability and their inclusion under ‘other priority populations’ provides hope that WSW’s HIV/AIDS prevention and care needs will be a part of the promised four goals of the National Strategic Plan (NSP) (SANAC, 2023). These goals include breaking down barriers to achieving outcomes for HIV, STIs and TB; maximising equitable and equal access to health services; fully resourcing and sustaining an efficient NSP that is more inclusive and accountable; and building more resilient and integrated systems to address HIV, TB, and STIs (SANAC, 2023). This is promising and provides a degree of hope that the unique needs of this WSW population will be addressed.

This latest iteration of the strategic plan shows considerable promise for several reasons. The repeated mention of Lesbian, gay, bisexual, transgender, intersex queer and questioning (LGBTQ+) individuals throughout the document does seem promising, as lesbian is mentioned in the title of this acronym (SANAC, 2023). Furthermore, in this strategic plan, LGBTQ+ have several concrete goals with accountable partners, which may substantially increase the likelihood of action being taken to address this population’s unique health needs (SANAC, 2023). These goals include enhancing legal protection against hate and sexual and gender-based violence (SGBV) crimes directed at them, supporting the addressment of human rights violations, and using community organisations to strengthen this population while reducing stigma and discrimination (SANAC, 2023). This at least shows evidence of an understanding of the challenges faced by WSW (SANAC, 2023).

2.3 HIV Prevalence and Risk for WSW in South Africa

The expressed purpose of this section is to discuss pre-held perceptions of the HIV susceptibility of AGYW WSW. Research suggests that the perception that WSW are an HIV susceptibility-free population is not limited to WSW themselves but a problem that extends to the general population of South Africa (Evans et al., 2016). These perceptions about WSW's susceptibility are often not based on the actual risk factors affecting the HIV prevalence in this population (Evans et al., 2016). Instead, Evans et al. (2016) found that both the general public and healthcare professionals, health researchers, and policymakers in South Africa hold the belief that WSW's sexual identity is protective against HIV infection. This misconception was highlighted in their mini-review of empirical research, which aimed to identify barriers to HIV testing and disclosure among WSW in South Africa (Evans et al., 2016). Thus, in the current study, it is essential to examine what factors impact this population's risk in detail and demystify the gap between WSW's risk behaviours and perceptions of susceptibility using the available facts and statistics.

2.3.1 HIV Prevalence of AGYW WSW in South Africa

The population size and HIV prevalence of AGYW WSW are challenging to estimate with accuracy. This has important implications for intervention effects aimed at curbing HIV infections in this population (Mkhize & Maharaj, 2020). Although two studies, Sandfort et al. (2013) and Daly et al. (2016), suggest a prevalence of 9.6% and 9%, respectively, for sub-Saharan WSW. These prevalence estimations need to be viewed cautiously due to the lack of reliable data on the size of the WSW population in South Africa (Cloete et al., 2011; Nyeck et al., 2019). Currently, there is no definitive or accurate estimation of HIV incidence and prevalence amongst WSW in South Africa (Mkhize & Maharaj, 2020; Nyeck et al., 2019). This is primarily due to the limited research explicitly conducted on WSW (Mkhize & Maharaj,

2020). In addition to an absence of disaggregated data on gender, sexual orientation, or age in population estimates making it difficult to assess the proportion of AGYW WSW (Nyeck et al., 2019). By extension, estimations of 9% or 9.6% prevalence of HIV lack proportional context within South Africa (Daly et al., 2016; Sandfort et al., 2013).

The estimated size of South Africa's LGBTQI population is approximately 634,000 adults (Nyeck et al., 2019). This estimate includes individuals who self-identify as lesbian, gay, bisexual, or "other than heterosexual" (Nyeck et al., 2019, p. 35). This figure was derived from an analysis of secondary data from various sources, including the South African Social Attitudes Survey 2015/2016, the 2011 South African Census survey, and a national survey targeting LGBTQI individuals in South Africa (Nyeck et al., 2019). However, these sources do not include disaggregated data on the proportion of males and females in this population, individuals' sexual orientation or age (Nyeck et al., 2019). It is, therefore, impossible to accurately estimate how many of these individuals are WSW or the proportion of AGYW WSW. By extension, this also makes it extremely difficult to assess what a figure like 9% or 9.6% HIV-positive WSW means proportionately in the context of South Africa (Daly et al., 2016; Sandfort et al., 2013).

2.3.2 HIV Risk of AGYW WSW In South Africa

A further challenge is that several factors may influence HIV risk and the prevalence of different sub-populations of WSW in South Africa. Racial categorisation is a pertinent consideration as it is a proxy indicator for socioeconomic factors affecting HIV risk (Mabaso et al., 2019; Wabiri & Taffa, 2013). The legacy of apartheid has entrenched structural inequalities, contributing to a higher risk of HIV infection among marginalised groups (Mabaso et al., 2019). Socioeconomic status is closely connected to HIV risk, with poorer individuals, including AGYW, facing heightened vulnerability due to factors like economic dependency on

men, which reduces autonomy in health and welfare decisions (Mabaso et al., 2018). This dynamic frequently results in risky sexual behaviours such as not using condoms, engaging in concurrent or multiple sexual partnerships, transactional and intergenerational sex, and an increased likelihood of experiencing SGBV (Mabaso et al., 2018).

The correlation between HIV risk and education further compounds this issue. Studies have shown that a high level of education enables individuals to make informed decisions about their health, while lower education attainment increases AGYW's vulnerability (Mabaso et al., 2018). Lewis et al. (2022) conducted a cohort study with 2,710 AGYW in KwaZulu-Natal (KZN) on HIV incidence and risk factors. This study found that participants aged 20-24 who failed to complete secondary school were more likely to engage in risk behaviours linked to an increase in HIV incidence (Lewis et al., 2022). In addition, substance use, particularly binge drinking, is associated with risky sexual behaviours, increasing HIV risk among AGYW (Singer et al., 2023). Singer et al. (2023) conducted a cluster-randomised trial with 500 South African young women (YW) to assess an intervention targeting substance use behaviours and HIV risk (Singer et al., 2023). The study found that YW who reported frequent binge drinking (n=177) were significantly less likely to use condoms during their last sexual encounter compared to those who did not report binge drinking (Singer et al., 2023).

Amongst WSW, a similar and even exacerbated barrier to sexual health has been found in substance use (Hibbert et al., 2019). Evidence suggests that not only do WSW report higher levels of drug use than WSM, but substance use was also found to be a critical factor in risk-taking amongst this sub-population of AGYW (Hibbert et al., 2019). It was found that among 591 South African WSW, substance use was prevalent, as 50.1% had used recreational drugs, whilst 2.1% had used intravenous drugs (Tat et al., 2015). Similarly, in a cross-sectional anonymous online survey conducted amongst 1501 WSW in the United Kingdom, it was found

that 94% of participants had consumed alcohol in the previous 12 months, and 67% of these WSW had engaged in sex under the influence of alcohol (Hibbert et al., 2019). It was also found that individuals who reported participating in sexual activities while under the influence of substances were more likely to engage in behaviours they would not typically do when sober (Hibbert et al., 2019). These results suggest that substance use is a concerning issue for WSW and the broader population of AGYW and that this behaviour can increase their risk for HIV exposure.

SGBV is another significant risk factor for HIV amongst WSW. Studies by Sandfort et al. (2013) and Daly et al. (2016) indicated that SGBV, whether occurring with or without substance use, exacerbates South African WSW's vulnerability to HIV infection. Among UK's WSW in Hibbert et al. (2019) survey, 7% reported instances of SGBV, with a significant association found between these experiences and substance use. This indicates that SV and substance use, as seen in Hibbert et al. (2019), whether occurring together or separately, is a vulnerability for WSW that increases their risk of exposure to HIV. Given these intersecting risk factors, any assessment of AGYW WSW's risk for HIV infection needs to acknowledge their unique vulnerabilities within the broader context of AGYW. As with other AGYW sub-populations, WSW engage in risky behaviours such as transactional sex, limited condom use, and having multiple sexual partners, which are strongly associated with HIV acquisition (Tat et al., 2015). In summary, the available evidence indicates that AGYW WSW in South Africa may have an increased HIV risk than their older counterparts in the general population. Socioeconomic inequalities, substance use, and experiences of SGBV shape this risk profile.

2.3.3 Factors that Exacerbate the HIV Risk Of WSW

WSW face unique challenges that exacerbate their risk of HIV compared to the general population of WSM and AGYW. These factors include sexual-risk behaviours (Tat et al.,

2015), barriers to care (Govender et al., 2019; Logie & Gibson, 2013), lack of accurate health information (Cloete et al., 2011; Wilton, 2012), institutionalised exclusion (CDC, 2021; SANAC, 2023), lack of LGBTQ-focused sexual health information (Bautista et al., 2016; Tat et al., 2015), marginalisation and invisibility (Sandfort et al., 2013), intersectional stigma (Logie et al., 2011; Nel & Judge, 2008), lack of accurate population estimates (Nyeck et al., 2019), lack of recognition of female-to-female HIV sexual transmission (Logie & Gibson, 2013; Mendoza-Pérez et al., 2019), and limited research and data (Evans et al., 2016; Patel et al., 2014). Understanding these factors is crucial for developing targeted interventions and tailored sexual health strategies to reduce HIV transmission within the WSW population effectively. In this section, the research on these risks is discussed, as well as their implications for the perceived HIV susceptibility among WSW compared to the general population of WSM AGYW.

2.3.3.1 Incidence of Sexually Transmitted Infections. Cloete et al. (2011) found that 73% of HIV-positive WSW had a history of STIs. This high prevalence is reflected in other research at different time points (Bautista et al., 2016; Tat et al., 2015). Pinto et al. (2005 cited in Tat et al. 2015) found that up to one-third of the 145 WSW participants were experiencing at least one STI. Additionally, findings from five studies conducted with WSW between 1995 and 2014 found a high prevalence of bacterial vaginosis (BV), ranging from 25-50% of the study populations (Tat et al., 2015). BV is a condition caused by an overgrowth and imbalance of normal vaginal flora, and its presence has been found to increase the risk of HIV infection, as it allows the adherence and survival of the virus (Bautista et al., 2016; Kairys & Garg, 2022). A study by Fethers et al. (2012) which pyrosequenced the vaginal micro-biome of 454 WSW and WSM, found that WSW may be a high-risk population for BV. These findings, particularly the relationship between BV and HIV demonstrated by Bautista et al. (2016), highlight the

heightened vulnerability of WSW to HIV infection due to the high prevalence of STIs in this population.

2.3.3.2 Sexual and Gender-Based Violence and Risk of HIV Infection amongst WSW. South African studies have highlighted the impact of SGBV as an exacerbating HIV risk factor for WSW (Govender et al., 2019; Sandfort et al., 2013). Sandfort et al. (2013) found that 31.1% of the WSW participants reported forced sex by either a man or a woman, with younger victims at higher risk of HIV infection (Sandfort et al., 2013). This association between SGBV, youth and HIV transmission is concerning as South Africa has a high incidence of recorded SGBV cases (Brown, 2012). In the early 2010s, South Africa had the highest recorded rape rate per capita in the world; research found that approximately 115 rapes were being reported per 100,000 inhabitants each year (Brown, 2012). This issue has only worsened in the last decade, with South Africa referred to by some as the rape capital of the world (Govender, 2023).

Homophobia-motivated SGBV, known as ‘corrective’ or ‘curative’ rape, disproportionately affects Black WSW, especially those in townships (Brown, 2012; Govender et al., 2019). This SGBV is perpetrated by heterosexual men against WSW to ‘correct’ or ‘cure’ what they perceive as their ‘unnatural’ sexual orientation (Brown, 2012). In a study of 20 WSW couples in Limpopo province, Govender et al. (2019) documented frequent experiences of harassment and underreported instances of homophobia-driven rape. It should be noted that research on WSW elsewhere has also obtained similar findings (e.g., Burkina Faso, Ghana, and Nigeria - Okanlawon et al., 2012; USA – Tilley et al., 2020). WSW face intersecting risks to SGBV and HIV infection due to a combination of factors that increase their vulnerability, arguably placing them at a greater risk for HIV than WSM.

Nel and Judge's (2008) framework on intersectionality explains how factors such as physical appearance, racial categorisations, socioeconomic status, and gender identity of LGBTQ individuals exacerbate HIV risk amongst WSW. These factors influence the probability of individuals experiencing prejudicial speech and actions, particularly within impoverished communities (Nel & Judge, 2008). In short, they argued that such social discrimination is not shared uniformly within the LGBTQ population (Nel & Judge, 2008). Wells et al. (2006) also noted that Black WSW had a greater risk of sexual assault than white WSW due to cultural and socioeconomic disparities. For many Black WSW, 'coming out' is dangerous rather than empowering; they often face the threat of social exclusion and even SGBV if their sexual orientation is exposed (Mkhize & Maharaj, 2020; Okanlawon et al., 2012).

WSW's vulnerability to SGBV not only increases their risk of HIV but also affects their perceptions of that risk (Govender et al., 2019). This context is important to understand because the lived realities of WSW are highly relevant to explaining why there might be a discrepancy between perceived and actual HIV risk among WSW. The threat and experience of homophobic SGBV is a daily experience for many black WSW in South Africa, which increases their risk of HIV (Govender et al., 2019; Sandfort et al., 2013). The vulnerability posed by SGBV interacts with layers of marginalisation, including discrimination based on gender, sexual orientation, and sometimes race or socioeconomic status (Mkhize & Maharaj, 2020). Whilst these intersectional vulnerabilities can compound the risk of HIV, the complex nature of these overlapping risks may not be fully recognised or understood by WSW themselves (Matebeni et al., 2013; Mkhize & Maharaj, 2020). As a result, Matebeni et al. (2013) suggest that WSW might not connect their experiences of violence and discrimination

with their HIV risk. Thus, this complex context is critical in understanding the heightened risk and the gap in perceived versus actual risk for HIV among WSW.

2.3.3.3 Poverty, Employment and Social Discrimination against WSW. Poverty is an important explanatory variable in South Africa's HIV epidemic generally and in individual risk of HIV infection (Kim et al., 2021). In comprehensive terms, poor and YW are more likely to be living with HIV due to their engagement in more risky sexual behaviour than wealthier women (Kim et al., 2021). This is pertinent for WSW, as relatively recent research has shown how social discrimination against WSW in South Africa correlates with economic prejudice against them (Nyeck et al., 2019). For example, an analysis of data in South Africa's 2011 national census record found that women perceived to be 'masculine' were less likely to be employed than gender-conforming individuals (Nyeck et al., 2019). Thus, WSW in South Africa are more likely to experience poverty and unemployment (Nyeck et al., 2019).

Taking this issue further, this study also reported on the results of the 2013 national census, which found that most South Africans (70%) felt strongly that homosexual sex and individuals who broke gender dressing norms were "disgusting" and "wrong" (Nyeck et al., 2019, p. 31). It was also reported that workplace bullying, prejudicial stereotyping, discriminatory management policies and procedures, and sexual harassment were central themes in reports from South African WSW about their workplace experiences (Nyeck et al., 2019). Similar results were obtained previously from a small South African exploratory study involving five lesbian employees who had disclosed their sexual orientation to their colleagues (Lötter, 2015). Research on WSW elsewhere in Africa has yielded similar findings with negative implications for HIV prevalence in these populations (Okanlawon et al., 2012; Poteat et al., 2015). This has important implications for the socioeconomic status of WSW and their vulnerability to HIV.

2.3.4 Risk of HIV Infection during Female-to-Female Sexual Intercourse

Culturally dominant ideas about what sexual activity constitutes as intercourse have led to the dismissal of female-to-female sexual practices as low-risk for HIV transmission (Richardson, 2000). WSW sexual activity includes manual stimulation, oral sex, and the use of sex toys (Mendoza-Pérez et al., 2019). In an online survey of 1139 self-identified WSWE (67.4%) and WSWM (32.6%) in Mexico, nearly all participants reported using their hands or fingers for stimulation (Mendoza-Pérez et al., 2019). A notable proportion of WSWE (70.6%) and WSWM (75.3%) also continued sexual activities during menstruation, increasing HIV risk (Mendoza-Pérez et al., 2019). These sexual behaviours pose risks for HIV transmission (Curlin et al., 2013; Mendoza-Pérez et al., 2019). However, as they exclude penile insertion, it is easily dismissed as not ‘real sex’, making the risk of these acts easy to ignore (Richardson, 2000).

Although some studies, such as Patel et al. (2014), indicate that the risk from oral and shared sex toys is negligible, Chan et al. (2012) documented a case of female-to-female HIV transmission supported by genetic analysis. The CDC investigated a transmission case where a WSW contracted HIV, with her only risk factor being her HIV-positive female partner during the six months before her seroconversion (Chan et al., 2012). The couple routinely had rough unprotected oral and vaginal intercourse, used insertive sex toys and occasionally had sexual contact during menstruation (Chan et al., 2012). The CDC found that both women tested positive for HIV-1 with a very high degree of genetic similarity (Chan et al., 2012). This, in addition to the high viral loads present, suggested that transmission occurred during sexual contact (Chan et al., 2012). This case challenges the perception that female-to-female sex is HIV risk-free, showing that this behaviour poses a real risk infection risk (Chan et al., 2012; Mendoza-Pérez et al., 2019).

HIV can survive in vaginal fluid and menstrual blood, making sexual intercourse during menstruation particularly risky (Curlin et al., 2013; Mendoza-Pérez et al., 2019). Menstruation's hormonal and associated changes can increase genital and viral shedding (Curlin et al., 2013). This can be understood in terms of a woman's uterine wall, which contains viral particles, being evacuated during menstruation (Curlin et al., 2013). These risks are heightened if one partner has a high viral load (Doull et al., 2018; Wilton, 2012) and if the partner performing oral sex act has mouth infections (Campo et al., 2006). However, many of these proposed risk factors need further study in this population, as they are drawn from research that is dated (e.g., Campo et al., 2006) or not specifically studied amongst WSW (e.g., Curlin et al., 2013; Doull et al., 2018).

Further research is needed as despite evidence showing that female-to-female sex carries some risk, many WSW perceive themselves to be at low or no risk of an HIV infection (Matebeni et al., 2013; Evans et al., 2016). This leads to a false sense of security and lower adoption of safer sex practices (Matebeni et al., 2013; Evans et al., 2016). According to Matebeni et al. (2013), "women who report a positive HIV status and exclusive sexual relations with female partners believed that they are 'safe'" (p. S43). This indicates a significant gap in awareness and education about HIV transmission risks among WSW (Matebeni et al., 2013). The misperception that WSW is prevalent both among WSW and healthcare providers in South Africa, further exacerbating this issue (Evans et al., 2016).

2.4 Research Theoretical Framework: The Expanded Health Belief Model

The EHBM, as discussed in this chapter, forms the theoretical groundwork to explore the intricate relationship between knowledge, attitudes, and behaviours concerning HIV in the AGYW WSW population. The base of the EHBM is the *Health Belief Model* (HBM), a well-established psychosocial framework which has been extensively used for over four decades to

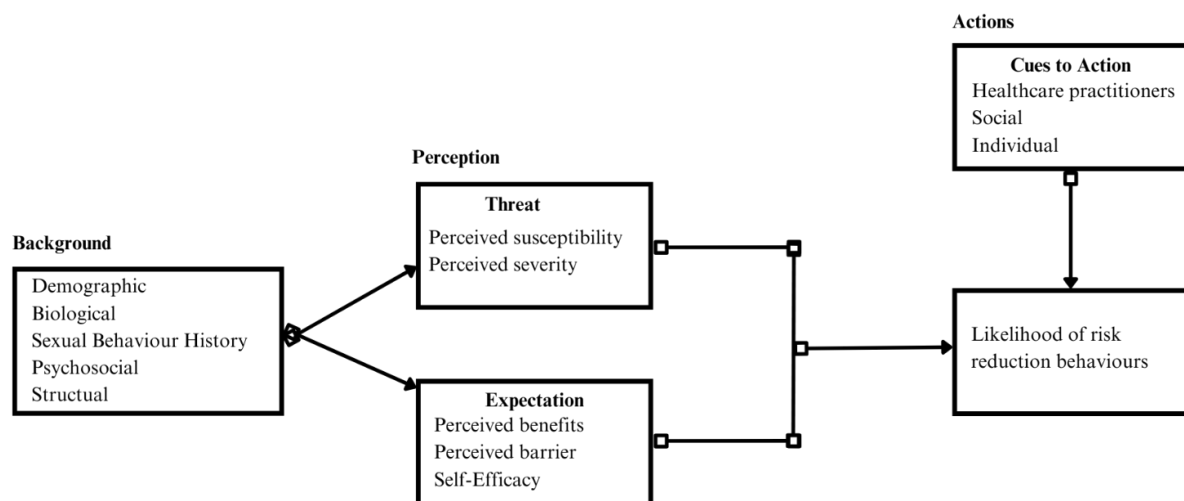
understand health perceptions (e.g., Bokolo & Govender, 2022; Janz & Becker, 1984; Pletzer, 2000). The continued use of HBM can be partly attributed to its history as one of the first theories in behavioural science (Glanz & Bishop, 2010). However, its effectiveness is a fundamental explanation for the HBM's enduring predominance as a conceptual framework in preventive health research (Jones et al., 2014; Green et al., 2020).

A primary argument of the HBM is that people's perception of susceptibility to an adverse health outcome motivates them to act in healthier ways (Carpenter, 2010). This model proposes that a person will not work to prevent an adverse health outcome if they believe they are unlikely to be affected (Carpenter, 2010). Secondly, the HBM predicts that the stronger a person's perception of the severity of an adverse health outcome, the more they will be motivated to avoid that outcome (Carpenter, 2010). However, in total, the HBM investigates four concepts: (a) *perceived susceptibility*, (b) *perceived severity*, (c) *perceived benefits*, and (d) *perceived barriers* (Carpenter, 2010).

2.4.1 Concepts Investigated in the Expanded Health Belief Model.

Figure 1

Flow Diagram of The Expanded Health Belief Model for WSW's Health Decisions



Note. Figure 1. The Health Belief Model. Adapted from “The Health Belief Model and Drinking and Driving: A Theoretical Discussion,” by T. E. Tucker, 1994, *Journal of Alcohol and Drug Education*, 44(3), p. 4. Retrieved from <https://scholarworks.gvsu.edu/cgi/viewcontent.cgi?article=1206&context=theses>

^a Work was open source; according to American Psychological Association, Seventh Edition (APA 7th) guidelines, no release is needed.

This study chose to investigate one key concept of the EHBM: perceived susceptibility. The concept of perceived susceptibility relates to how likely the person believes a target behaviour will produce negative health outcomes, such as HIV (Carpenter, 2010). However, it should be noted that the researcher utilised the expanded form of the HBM known as the EHBM due to its inclusion of the concept of perceived threat (Rosenstock et al., 1994). This concept was not investigated in the results, but it is necessary to understand the importance of this study’s findings on perceived susceptibility. The framework provided by this model was, therefore, helpful in interpreting and explaining how AGYW WSW’s perceptions of HIV susceptibility impact their HIV status. The concept of perceived susceptibility was then contextualised through the understanding of perceived threat provided by the EHBM.

This use of the HBM and the EHBM as a framework for the analysis interpretation of WSW participants’ beliefs about their personal HIV susceptibility and how they impact their preventive behaviour is supported by the literature (Montcalm & Myer, 2000). Several studies have used this model to comprehend the health perceptions of young people in South Africa (Chetty-Makkan, 2021; Earnshaw et al., 2018; Ndabarora, 2009). Additionally, this model has been effectively used to interpret intersectional vulnerabilities for HIV and how these challenges impact health behaviour, as demonstrated in recent research by Mkhize and Maharaj

(2020). The application of this framework has been found to highlight how these challenges are intricately linked with factors such as age, gender, and the social and cultural contexts in which individuals exist (Mkhize & Maharaj, 2020). This demonstrates the effectiveness and appropriateness of the HBM and its expanded form as a framework for interpreting the results of this secondary study.

2.4.1.1 Perceived Susceptibility. This concept refers to an individual's subjective assessment concerning their risk of contracting a particular health condition (Rosenstock et al., 1994). In the context of HIV, perceived susceptibility relates to participants' beliefs about their personal likelihood of being infected with the virus (Rosenstock et al., 1994). Rosenstock et al. (1994) reviewed empirical evidence for the variables of the HBM and their association with HIV preventive behaviours. This research is regarded as a seminal text on the EHBM as it introduced the revised and expanded form of the HBM and provided a framework for understanding this model in the context of HIV (Carpenter, 2010; Rosenstock et al., 1994).

2.4.1.2 Perceived Severity. Although this study does not measure this concept, it warrants attention. Perceived severity is crucial to understand in conjunction with its relationship with perceived susceptibility, as together, these variables shape individuals' perceptions of HIV as a threat (Rosenstock et al., 1994; Tarkang & Zotor, 2015). Perceived severity involves individuals' understanding of the seriousness of contracting HIV. In constructing their perception of severity, individuals assess the potential health repercussions and the broader social impacts of living with the virus (Rosenstock et al., 1994; Tarkang & Zotor, 2015). This dimension is influenced by one's beliefs about the medical outcomes and social consequences associated with HIV (Rosenstock et al., 1994). Concerns range from fears of death and loss of functionality to pain and the effects on relationships and social standing (Rosenstock et al., 1994). This concept is a crucial piece of the health decision puzzle because,

despite a high perception of susceptibility, not everyone is necessarily moved to take preventive steps to ensure that they do not place themselves at risk of contracting HIV (Tarkang & Zotor, 2015). The recognition of HIV's severe implications, in both physical and social domains, is essential in driving individuals towards adopting protective measures (Tarkang & Zotor, 2015). This highlights the complex interplay between understanding the gravity of HIV and the motivation to engage in preventative behaviours.

2.4.1.3 Perceived Threat. The EHBH hypothesises that perceived susceptibility and severity create the additional variable known as 'perceived threat' (Rosenstock et al., 1994). The perceived threat in the context of HIV/AIDS is believed to relate to the fear of HIV infection (Tarkang & Zotor, 2015). Rosenstock et al. (1994) asserted that the perception of threat from an illness is a crucial initial cognitive step in embarking on a course of action to reduce that threat. Rosenstock et al. (1994) also suggested that this additional variable was important in another way; if individuals had a high perception of threat, their perceptions of benefits and barriers would be more predictive of behaviour change. Essentially, Rosenstock et al. (1994) asserted that the constructs of cues to action and perceived benefits and barriers had a greater influence on health behaviour in situations in which HIV is perceived as a high threat. Thus, the relationship between perceived susceptibility and severity is essential because it is hypothesised that a high perception of threat increases an individual's sensitivity to the other variables of the EHBH (Rosenstock et al., 1994).

2.5 Conclusion

This literature review underscores the critical need to explore the complex dynamics of perceptions of HIV susceptibility among WSW, guided by the EHBH. HIV disproportionately impacts marginalised communities in South Africa, a reality that starkly encompasses WSW. Historically, WSW have been overlooked by national HIV/AIDS health policies and

programming, reflecting a broader trend of intersectional stigma and invisibility. This oversight has perpetuated a narrative of low perceived HIV susceptibility among WSW despite emerging evidence that this population may face a much greater risk for HIV than previously perceived.

The review strongly suggests that WSW often underestimate their HIV susceptibility, regardless of their actual HIV status. Complex social and structural factors, including institutional exclusion from mainstream HIV categorisation and misinformation, influence this discrepancy. The EHB framework has found a gap in large-scale quantitative research on WSW, particularly regarding the nuanced vulnerabilities this sub-population faces in the context of HIV.

The research suggests that WSW face significant barriers to accessing appropriate SRHC and HIV education, contributing to their low perceived susceptibility. Current HIV education programs are not effectively reaching WSW, highlighting the need for targeted, LGBTQ-focused interventions to bridge this knowledge gap. The EHB framework emphasises the critical role of perceived susceptibility in health-related decision-making. A recurring theme in the literature is WSW's perception of low HIV susceptibility, which weakens their inclination towards taking preventive measures.

However, this review is not without its limitations, primarily stemming from the relative invisibility of WSW in South African research and the assumptions made about this population's sexual and reproductive health by policymakers. Consequently, accurate population estimates for WSW and AGYW WSW remain elusive, as does a baseline for their HIV prevalence. This is further complicated by the absence of a recognised HIV transmission category for female-to-female sexual intercourse, making it challenging to conclusively determine the impact of this transmission route both locally and globally.

In conclusion, the literature review highlights the urgent need for more comprehensive studies to accurately assess the HIV risk and prevalence among AGYW WSW and WSWM. This study aims to bridge these literature gaps, employing the EHBM as a theoretical foundation for understanding perceptions of HIV susceptibility among WSW. By exploring this connection or lack thereof, this study aims to enrich the existing body of knowledge, leveraging a critical review of the literature and the well-recognized EHBM framework to navigate and clarify the complex landscape of perceptions of HIV susceptibility among WSW.

Chapter 3 Methodology

3.1 Introduction

This study was designed to assess if a relationship exists between HIV status and perceived HIV susceptibility among AGYW in South Africa, focusing on those with a history of same-sex sexual partners. To achieve this aim, this study leveraged data from the extensive DREAMS Evaluation survey, which used a cross-sectional design to survey 18,707 AGYW aged 12-24 years, including a subset of 1,362 WSW. This provided a unique opportunity to examine this population of AGYW in South Africa from a new perspective. Unlike most existing research involving small cohorts, this study's use of the DREAMS Evaluation survey dataset offered a rare chance to add additional data on the perceptions of HIV susceptibility of WSW at a much larger scale.

As an archival study, this research leveraged existing quantitative survey data from the DREAMS Evaluation survey, which evaluated the impact of HIV prevention programmes on AGYW across four districts in South Africa. By analysing this secondary data, the study positioned itself within the archival research study design domain, drawing from a pre-existing, large-scale data set to investigate the nuanced perceptions of HIV susceptibility among WSW within the AGYW population. This methodological approach allowed for a focused examination of a critically underrepresented population, in addition to an efficient and cost-effective avenue to bridge large gaps in the current understanding of HIV susceptibility and prevention in South Africa's WSW community.

The decision to utilise an archival research methodology was made to investigate the relationship between perceptions of HIV susceptibility and HIV status among AGYW WSW in South Africa. Archival data was used because it was available, and the hypothesis had not yet been tested within the data. Using a quantitative research design with representative

sampling, validated instruments, and appropriate statistical analysis techniques, this study was able to address the research questions and objectives directly. This design ensures reliable and valid primary data collection by incorporating contextual factors, participant perspectives, and ethical considerations while acknowledging potential limitations. The approach aimed to provide valuable insights into the relationship between HIV susceptibility perceptions and HIV status among AGYW WSW.

This data analysis concentrated on a subset of the DREAMS Evaluation survey data, employed both descriptive and inferential statistical techniques to address one main and two sub-research questions:

3.2 Research Hypotheses

RQ1: Is there a relationship between perceptions of HIV susceptibility and HIV status?

Null Hypothesis (H0): There is no relationship between perceptions of HIV susceptibility and HIV status.

Alternative Hypothesis (H1): There is a relationship between perceptions of HIV susceptibility and HIV status.

3.3 Study Methodology

Social science research systematically studies human behaviour, social structures, and cultural phenomena using qualitative and quantitative methods to generate reliable and valid insights into complex social issues (Chakraborty, 2019). This approach generally includes techniques such as surveys, interviews, ethnography, and statistical analysis to collect and analyse data (Chakraborty, 2019). Thus, social science research provides a comprehensive understanding of social phenomena (Chakraborty, 2019).

In this study, the focus was on investigating the relationship between perceptions of HIV susceptibility and HIV status among AGYW WSW in South Africa (Chakraborty, 2019). The research design was centred on using secondary data, specifically archival data from the DREAMS Evaluation Survey, to address the research questions (Chakraborty, 2019). The decision to utilise secondary data was justified due to its availability and the relevance of the existing data to the research hypothesis, which had not yet been tested within this context or data set (Chakraborty, 2019).

This research design allowed for the collection and analysis of primary data that directly addressed the research questions (Chakraborty, 2019). Using quantitative methods, including representative sampling, validated instruments, and appropriate statistical analysis techniques, ensured that the findings were scientifically rigorous and generalisable (Chakraborty, 2019). Compared to qualitative methods, which provide in-depth insights but may lack generalizability, this quantitative research design was more appropriate for establishing patterns and relationships across a larger population (Chakraborty, 2019). Therefore, this methodology was suitable for this study as it aimed to provide valuable insights into the perceptions and realities of HIV susceptibility among AGYW WSW, ultimately contributing to targeted HIV prevention and educational initiatives (Chakraborty, 2019).

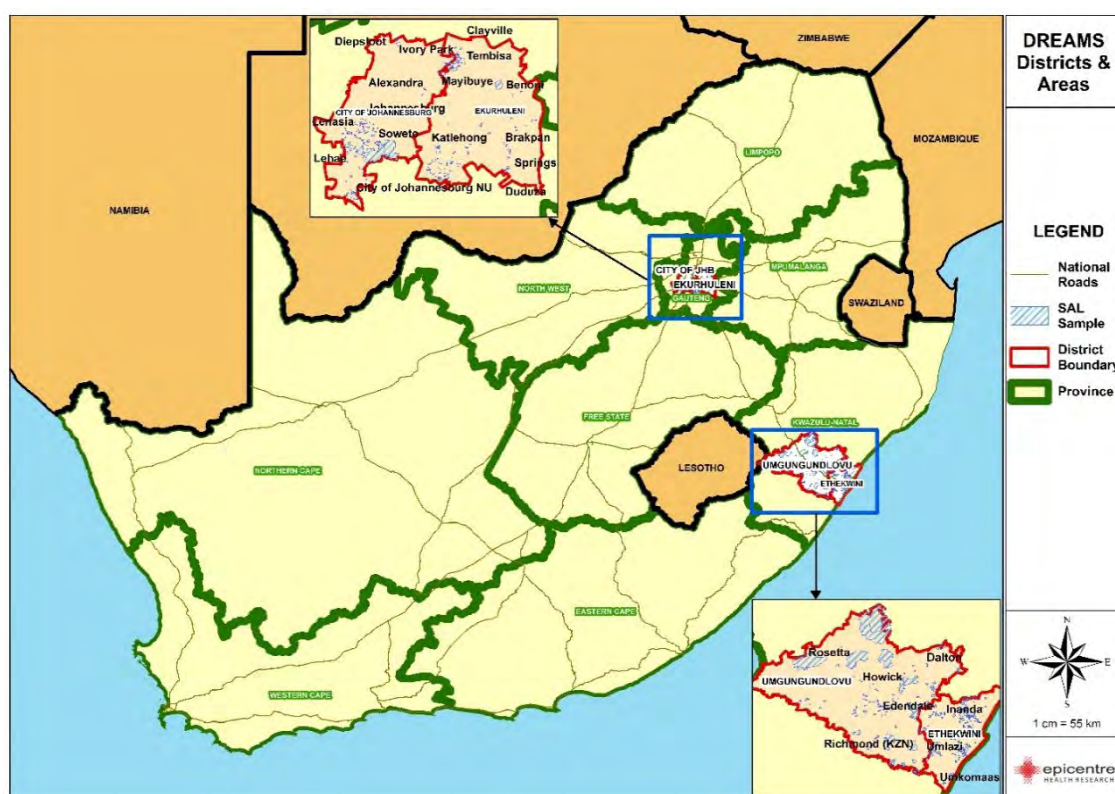
3.3.1 Setting

The DREAMS Evaluation survey enrolled 18 296 AGYW in four selected districts in South Africa (Cawood et al., 2021). These participants were recruited from households where the DREAMS programme was implemented, including the districts of Ekurhuleni and the City of Johannesburg (COJ) in the Gauteng province (GP) and the districts of uMgungundlovu and eThekweni in the province of KZN (Cawood et al., 2021). The four study districts had an estimated population of 12 073 421 individuals (Cawood et al., 2021).

In 2016, CDC South Africa and its partner, the President's Emergency Plan for Aids Relief (PEPFAR), initiated plans to implement a DREAMS programme in selected areas of the districts mentioned above (Cawood et al., 2021). Epicentre, an independent organisation, was contracted to conduct the baseline surveys in these four districts. Epicentre collected data from participants in GP (Ekurhuleni and the city of Johannesburg) and in KZN (eThekweni and uMgungundlovu) (Cawood et al., 2021).

Figure 2

Map of the DREAMS Evaluation Districts



Note. Figure 2. Map of AGYW study districts 2018. Adapted from “An Evaluation of Adolescent Girls and Young Women’s Exposure to HIV Prevention Programmes within the four DREAMS Implementing Districts in South Africa: A Cross-Sectional Study. By Cawood et al., 2021, Epicentre. P. 4. Retrieved from <https://epicentre.org.za/wp->

[content/uploads/2021/09/E-Report-Cross-Sectional-Survey-of-Adolescent-Girls-and-Young-Women-in-Selected-DREAMS-districts-.pdf](#)

^a See Appendix F for the DREAMS Evaluation survey principal investigator's permission for use.

3.3.1.1 KwaZulu-Natal Province. This province had the highest prevalence of HIV in South Africa; according to Simbayi et al. (2019), approximately 27% or 1 in 4 PLHIV (aged 15-49 years old) are in KZN. In 2016, the KZN district of uMgungundlovu was found to have a prevalence of 20%, whilst the district of eThekweni had a slightly lower rate of 16.7% (Simbayi et al., 2019). eThekweni is a district with the busiest port on the African continent (Municipalities of South Africa, n.d.). It is mainly rural (68%) but has a significant urban area (Municipalities of South Africa, n.d.). uMgungundlovu was the second-largest district in KZN; it included traditional, informal, rural, and urban settlements (Municipalities of South Africa, n.d.). Pietermaritzburg was this district's largest city and is the capital of KZN (Municipalities of South Africa, n.d.).

2.3.1.2 Gauteng Province. Although this was the smallest geographical province, it was also the most densely populated region in South Africa (Alexander, 2019). GP had an HIV prevalence of 17.6% (Human Sciences Research Council, 2018). When it was measured in 2017, GP had the fifth highest HIV prevalence for people between 15–49 years old (HSRC, 2018). The City of Johannesburg and Ekurhuleni, the two districts studied in GP, had an HIV prevalence of 12.9% and 15.0% in 2017 (HSRC, 2018). Both districts were densely populated and featured high levels of industrialisation (Alexander, 2019).

Table 1

Study Population in Four DREAMS Implementation Districts 2011–2017

Characteristics of the population within South Africa DREAMS implementation districts (2011–2017)	eThekwini	uMgungundlovu	City of Johannesburg	Ekurhuleni
Population size: 10–24 years AGYW	500 214	153 722	584 104	395 866
Population density per square km	1 501.9	113.9	2 695.9	1 652.0
HIV Antenatal Care Prevalence (%)	41.1%	42.5%	27.5%	33.5%
People living with HIV (PLHIV)	516 167	225 284	533 960	468 521
Number of AGYW 10–19 years receiving grants	64 716	84 942	189 845	155 135
Number of orphans	86 734	42 000	61 634	55 261
Number of girls in schools Ages 10–20 years	238 544	74 602	276 185	161 182
Teenage pregnancy (deliveries at facility in women under 18 years and not terminations) (%)	7.0%	8.5%	3.6%	6.2%
Number of households	956 713	272 666	1 434 856	1 015 465

Note. Table 1. Study population in four DREAMS implementation districts 2011–2017.

Adapted from “An Evaluation of Adolescent Girls and Young Women’s Exposure to HIV Prevention Programmes within the four DREAMS Implementing Districts in South Africa: A Cross-Sectional Study. By Cawood et al., 2021, Epicentre. p. 5. Retrieved from <https://epicentre.org.za/wp-content/uploads/2021/09/E-Report-Cross-Sectional-Survey-of-Adolescent-Girls-and-Young-Women-in-Selected-DREAMS-districts-.pdf>

^a See Appendix F for the DREAMS Evaluation survey principal investigator’s permission for use.

3.3.2 Sampling

The secondary study leveraged a subset of data from the broader DREAMS Evaluation survey, explicitly focused on AGYW WSW. This targeted approach aimed to evaluate and analyse the specific perceptions of HIV susceptibility in this sub-population of AGYW, contributing to the wealth of information on their health beliefs, potentially improving HIV prevention and care efforts.

The DREAMS Evaluation survey utilised a sophisticated stratified cluster-based random sampling design (Cawood et al., 2021; Eichhorn, 2022). This design treated the four districts as the primary layers of stratification (Cawood et al., 2021; Eichhorn, 2022). Sample size allocation across these districts was meticulously calculated to mirror the distribution of AGYW in the areas targeted by DREAMS interventions, with contributions from PEPFAR partners on intervention locales (Cawood et al., 2021; Eichhorn, 2022). These sites were then precisely mapped onto the census small areas layer (SAL), which outlined the sampling areas to ensure extensive coverage of the targeted regions (Cawood et al., 2021; Eichhorn, 2022). The sampling frame for each district was constructed using 2011 census SALs (Cawood et al., 2021). It was validated through a rigorous process involving aerial photography, Geo Terra Image counts, district council estimates, and the latest midyear population estimates from Statistics South Africa (Cawood et al., 2021).

Within the sampling frame, detailed data from each SAL on households, gender, population group, and age informed the sampling calculations (Cawood et al., 2021). To achieve a representative sample of 18,500 AGYW aged 12–24 years, the study proposed the systematic random selection of 55 households per SAL (Cawood et al., 2021). This strategy anticipated a non-response rate of $\leq 20\%$, aimed at engaging at least 18 AGYW from each selected SAL. 1,050 SALs were chosen randomly, with 450 in KwaZulu-Natal and 600 in

Gauteng, reflecting strategic considerations of population density and the geographical distribution across these regions (Cawood et al., 2021).

This methodological precision in the DREAMS Evaluation survey's sampling strategy provided a robust framework from which the secondary study could draw a focused subset of AGYW (Cawood et al., 2021; Eichhorn, 2022). By concentrating on participants in same-sex relationships, the secondary analysis aimed to illuminate the underexplored facets of their perceptions of HIV susceptibility, informing more nuanced interventions within the scope of the DREAMS initiative and beyond (Cawood et al., 2021; Eichhorn, 2022). However, a limitation of this sampling strategy was the overwhelming proportion of Black Africans in the sample population. Consequently, this AGYW WSW sample may under-represent Indian and Coloured WSW and omits White WSW.

3.3.2.1 Participant Eligibility. This secondary analysis specifically focused on participants from the DREAMS Evaluation survey who reported engaging in same-sex intercourse. Eligibility for this subset was based on affirmative responses to the question, "Have you ever had sexual intercourse with a woman?" This question aimed to identify AGYW within the DREAMS cohort with an experience or 'history' of at least one sexual relationship with another female. This marked a distinct focus shift from the broader DREAMS Evaluation survey's parameters.

The DREAMS Evaluation survey set broader inclusion criteria, targeting female household residents aged twelve to twenty-four years within selected intervention areas (Cawood et al., 2021). These criteria were multifaceted: eligible participants between twelve to eighteen years of age needed to provide assent and guardian consent; moreover, an adult household member needed to complete a household composition form and consent (Appendix D) (Cawood et al., 2021). Eligible participants between eighteen and twenty-four years old

were asked to provide informed, written consent to participate (Cawood et al., 2021). Participants were required to be present in the household, willing to consent in writing to partake in the survey and prepared to engage with the study's data collection efforts (Cawood et al., 2021).

Conversely, the DREAMS Evaluation survey delineated a series of clear exclusion criteria that disqualified individuals facing cognitive or mental challenges that would hinder their understanding of the study (Cawood et al., 2021). This included those who were deaf or mute, non-speakers of English, IsiZulu, Sotho, or Afrikaans, individuals unavailable during specified data collection hours (8 a.m. to 9 p.m.), or residents in the district for less than a year (Cawood et al., 2021).

3.3.3 Instruments

The DREAMS Evaluation survey utilised an electronic data collection system, where participants electronically acknowledged consent and were provided with detailed information sheets (Appendix D) (Cawood et al., 2021). These sheets explained the study's goals, biological testing processes, and how to access test results, alongside contact information for further queries (Cawood et al., 2021). Data collection was facilitated using Samsung tablets equipped with Mobenzi researcher software®, ensuring the digital input of all questionnaires directly at the point of collection (Cawood et al., 2021). It is crucial to note that the process safeguarded participants' anonymity and privacy; rather than collecting personal identifiers, each respondent was assigned a unique identifier (Cawood et al., 2021). This measure effectively linked participants' responses to their questionnaires and biological samples without compromising confidentiality (Cawood et al., 2021).

This secondary study harnessed a selected subset of items from the comprehensive Individual AGYW questionnaire, explicitly focused on the segments relevant to understanding

the experiences and perceptions of WSW. The meticulous approach undertaken during the original DREAMS Evaluation survey provided a robust foundation for the current research. Thus, the researcher was able to measure and analyse the nuanced perspectives of WSW, maintaining data integrity while exploring critical aspects of perceptions of HIV susceptibility among this subgroup.

The following scales were utilised by this study to answer the research questions: (See Appendix D: Individual AGYW Questionnaire)

1. The Demographic information, included age, gender, population group and location, describing the ‘sociodemographic characteristics’ of WSW.
2. AGYW’s perceived susceptibility to contracting HIV was assessed, which was one item, and a higher value on this measure indicated a lower perceived susceptibility to contracting HIV. Values range from 0–4. This was used to answer question 1 and to measure the levels of perceived HIV susceptibility in the population. In addition, this scale was used to answer the question, “Is there a relationship between perceptions of HIV susceptibility and HIV status?”
3. Sexual behaviour information, included partner biological characteristics, were used in the study’s inclusion criteria. Only participants who answered yes to a history of sexual intercourse with at least one woman were included in this secondary study.

3.3.4 HIV Counselling and Testing

After collecting socio-demographic data, the DREAMS Evaluation survey field workers offered the AGYW a rapid HIV test, adhering to the National Department of Health (NdoH) HIV testing protocols (Cawood et al., 2021; National Department of Health, 2015). For AGYW below 18 years old, written consent from caregivers was obtained to disclose HIV results at the end of the survey, and they gave assent for HIV counselling and testing (HCT)

(Cawood et al., 2021). Among AGYW, 66.2% received HCT, 2.3% declined testing due to existing antiretroviral treatment, 22.4% declined citing prior knowledge of their status, and 9% expressed fear of testing (Cawood et al., 2021). The HIV testing procedure occurred in a private room within the household, taking approximately 30 minutes and involved the HIV rapid test and pre-and post-test counselling (Cawood et al., 2021). AGYW testing positive for HIV were promptly referred to care, support, and treatment, with detailed records maintained for individuals directed towards test results, treatment, and care (Cawood et al., 2021).

3.3.4.1 Biological Measures. In the DREAMS Evaluation survey, trained phlebotomists collected two micro-containers of whole blood, obtained through finger pricks, for dried blood spots and plasma specimens (Cawood et al., 2021). These specimens were crucial for determining the HIV status, HIV incidence, treatment drug levels, and viral load levels of all AGYW participating in the study (Cawood et al., 2021). The collected blood was stored in sterile containers and meticulously logged onto a laboratory tracking sheet (Cawood et al., 2021). The blood collection followed the Standard Operating Procedure (SOP), aligning with the protocols outlined by the South African National Department of Health (NdoH) for drawing blood for the HIV Polymerase Chain Reaction (PCR) test (Cawood et al., 2021; National Health Laboratory Service, 2020). The calculation of HIV incidence relied on the Limiting Antigen Avidity Index Enzyme Immunoassay (Lag AI EIA) (Cawood et al., 2021). These results were used in the secondary study to analyse HIV status.

3.4 Procedures

3.4.1 Community Consultation

Before starting the data collection for the DREAMS Evaluation survey, the communities in each district were informed about the study (Cawood et al., 2021).

Communication with stakeholders included traditional leaders, partners implementing the DREAMS programme, and public, private, and NGO service providers within the study districts (Cawood et al., 2021).

3.4.2 Training Of Study Staff

The DREAMs Evaluation survey employed only young female field staff aged 20 to 25 to enhance relatability with study participants (Cawood et al., 2021). These staff underwent comprehensive training covering study rationale, methodology, assessment, and data collection techniques (Cawood et al., 2021). Specialised training focused on interviewing AGYW with sensitivity to sexual issues and violence (Cawood et al., 2021). Additionally, staff received training in Good Clinical Practice, Human Subjects Protection, HCT, biological sample collection, safety protocols, and ethical guidelines (Cawood et al., 2021). Continuous refresher training was conducted throughout the study period to maintain proficiency (Cawood et al., 2021).

3.4.3 Household Visits And Interviews

The DREAMs Evaluation survey staff utilised global positioning system (GPS) coordinates to identify households, visiting approximately 55 randomly selected households from each selected SAL (Cawood et al., 2021). If a chosen household was ineligible, abandoned, refused participation, or members were away for an extended period, the next household on the sampling frame was approached with supervisor approval (Cawood et al., 2021). Visual maps and a mobile application with Mobenzi® software facilitated the location of sampled households, providing GPS coordinates and questionnaires (Cawood et al., 2021). After introducing themselves, the staff obtained verbal consent for household participation and invited eligible AGYW for interviews (Cawood et al., 2021). Those who declined to participate

were encouraged to provide feedback, while consenting participants selected a private location for survey administration and confidential biological sample collection (Cawood et al., 2021).

3.4.4 Laboratory Procedures

The DREAMS Evaluation survey utilised the Global Clinical & Viral Laboratory in Durban to manage sample collection, processing, shipping, and archiving, utilising prepared barcoded sample collection packs (Cawood et al., 2021). These packs included two microtainer blood collection tubes, sterile needles, cotton wool balls, and alcohol gauze (Cawood et al., 2021).

3.4.5 Sample Collection

Samples linked to enrolled participants through unique study numbers were transported daily to the Global Clinical & Viral Laboratory in Durban and then processed according to a laboratory algorithm for weekly delivery to the HIV Surveillance and Sero-Molecular Diagnostic Section in Johannesburg (Cawood et al., 2021).

Epicentre permitted the secondary study to utilise the DREAMS Evaluation survey dataset for this thesis (Appendix A). Access was granted to the entire survey data set. The dataset had previously been delinked of any identifying information. The researcher then filtered for individuals who reported same-sex partners, creating a sub-set of AGYW who had reported a history of female same-sex intercourse. This process produced a sample of 1,362 WSW included in this study.

3.5 Reliability and Validity

The DREAMS Evaluation survey's research methodologies gave the researcher access to robust and reliable data. The DREAMS Evaluation survey utilised the Mobenzi® electronic data collection system for a comprehensive range of tasks, including data gathering, fieldwork

oversight, and seamless integration for real-time analysis (Cawood et al., 2021). This advanced system facilitated meticulous monitoring of research activities and strict adherence to the study's SOP (Cawood et al., 2021). To further ensure the integrity of the data, field supervisors employed tracking software for spot checks and shadow visits, while daily automated reports highlighted any discrepancies or missing elements in the data collection process (Cawood et al., 2021). Additionally, a dedicated quality control team revisited a random 10% of households to confirm the accuracy of the collected data, maintaining a rigorous standard of data verification and compliance (Cawood et al., 2021).

However, utilising secondary data had inherent biases, including publication and researcher bias, which could have influenced the outcome and interpretation of studies (Baldwin et al., 2022; Stebbins & Ritchie, 2021). Publication bias arises when a researcher's results or conclusions influence the selection of studies for analysis, potentially sidelining research that deviates from prevailing narratives (Stebbins & Ritchie, 2021). Similarly, researcher bias refers to the potential distortion of study findings due to the subjective influences of the researcher, whether intentional or not (Baldwin et al., 2022). These biases could have impacted the reliability and validity of secondary research findings (Baldwin et al., 2022; Stebbins & Ritchie, 2021). However, this survey's data set was not chosen based on whether its' results supported the secondary study's conclusion. The DREAMS Evaluation survey's focus and its' sample population were substantially different, so the researcher could not have predicted the results of this secondary study in advance. Furthermore, by applying the EHB, researchers adopted a uniform approach to exploring the health behaviours of this population, enabling a broader comparison and validation of findings across its diverse settings (Hambolu et al., 2013). This structured application of the EHB and its lack of bias in

choosing this study ensured that its insights contributed meaningfully to the existing body of knowledge despite the challenges inherent to secondary research.

3.6 Data Analysis

This secondary study utilised a statistical software called the 28th version of IBM Statistical Package for the Social Sciences (SPSS28). SPSS28 was used to both code and classify the respondent's data. The HIV status data was categorical, and the perception scores were ordinal; this was influenced by the design of the survey questions.

3.6.1 Statistical Analysis Overview

The statistical analysis for the secondary study mainly utilised descriptive statistics and a one-way Analysis of Variance (ANOVA). First, descriptive statistics were used to summarise the demographic characteristics of the WSW. Before conducting the ANOVA, Levene's test for homogeneity of variances was used to confirm that the assumption of equal variances was not violated (Field, 2009). ANOVA was then conducted to explore the relationship between perceptions of HIV susceptibility and actual HIV status among WSW participants (Field, 2009). Descriptive statistics of perceptions of HIV susceptibility survey responses and HIV status were also provided to contextualise the results (Field, 2009). The focus of this statistical analysis was to determine whether perceived susceptibility to HIV differed significantly between HIV-positive and HIV-negative groups.

3.6.2 Statistical Analysis Rational

The main statistical test used to analyse the relationship between perceptions of HIV susceptibility and actual HIV status was a one-way ANOVA. ANOVA was used because this kind of test was designed to compare the means of more than two groups (Field, 2009). This fits the secondary study's objective of examining whether there are significant differences in

the mean perceptions of HIV susceptibility between those who are HIV-positive and those who are HIV-negative (Field, 2009). ANOVA tests for overall group differences by comparing the systematic variance between groups to the unsystematic variance within groups (Field, 2009). Thus, using ANOVA allowed for the analysis of how perceptions of susceptibility vary between HIV status groups.

Before conducting the ANOVA, the assumption of homogeneity of variances, which is crucial for ANOVA, was checked using Levene's Test (Field, 2009). Levene's Test assesses whether the variance across the groups is equal (Field, 2009). If the p-value from Levene's Test is greater than 0.05, it suggests that the assumption of equal variances is met, thus validating the use of ANOVA with this data set (Field, 2009). In this case, Levene's Test indicated that the assumption was not violated, allowing the analysis to proceed (Field, 2009).

In this analysis, descriptive statistics were chosen to provide a thorough summary of participants' perceptions of HIV susceptibility and their actual HIV status. Specifically, measures such as the mean, standard deviation (SD), standard error (SE), and 95% confidence intervals were used to describe the central tendency and variability of the data (Field, 2009). The SD quantifies the variation or dispersion in the scores, reflecting how much the individual participant's responses deviate from the mean (Field, 2009). While the SE represents the accuracy of the mean as an estimate of the actual population mean (Field, 2009). Confidence intervals provide a range in which the actual population mean is likely to lie with 95% certainty, offering insight into the precision of the estimated mean perceptions of HIV susceptibility (Field, 2009). Including confidence intervals enhanced the interpretation of the results by quantifying the uncertainty surrounding the mean estimates and offering a clearer understanding of the variability in the data (Field, 2009).

3.6.3 Categorisation & Grouping

Using EHBMs, the researcher identified and analysed participants' perceived HIV susceptibility to answer the research questions. Participants' answers to the question, "I feel that the chances are high that I can get HIV" (see Appendix D), were analysed and categorised into four levels. The rationale for selecting and grouping categories for the secondary analysis was based on the original intentions of the primary researchers who designed the survey question that asked participants if they strongly agreed, agreed, disagreed or strongly disagreed with the supplied statement. The researcher adjusted the responses into levels to improve the readability of the answers to the secondary study question. Those who strongly agreed were placed in the 'very high' level, while those who agreed were categorised as part of the 'high' level. Those who disagreed with the statement were categorised into the 'low' level, and finally, those who strongly disagreed were placed in the 'very low' level of perceived HIV susceptibility.

Finally, it should be noted that to improve the data set visual representation in table form, the researcher recorded the variable HIV status away from 0. HIV status was recorded so that one was equal to HIV negative and two was equal to HIV positive. This ensured that when giving information on descriptive statistics, the minimum, maximum, mode and mean were represented understandably in the visual format of a table. Similarly, to improve readability perceptions of susceptibility, the researcher recorded 'very-low' to 1, 'low' to 2, 'high' to 3, and 'very-high' to 4.

3.7 Ethics

The use of de-identified secondary data ensured that participants' confidentiality was protected. During this secondary study, care was taken to ensure that participants voluntarily participated and provided informed consent (Appendix D) and that this data remains de-

identified. The researcher conducting the secondary study confirmed that further data analysis was appropriate. Permission was granted to access this data set for secondary data analysis by the DREAMS Evaluation survey principal investigator (Appendix A), who had permission to allow secondary analysis of this data set. This data was temporarily stored on the researcher's computer and was protected by a password. After this study, this data was deleted from their hard drive.

To ensure confidentiality, the DREAMS Evaluation survey team recorded no personal identifiers on data collection tools (Cawood et al., 2021). A unique study barcode linked the sample and to the corresponding questionnaire (Cawood et al., 2021). Informed consent was obtained from individuals aged 18 and above, and for those under 18, parental or guardian consent and individual assent were required (Cawood et al., 2021). Moreover, questionnaires were administered in the participants' languages of choice (Cawood et al., 2021).

Given the age of participants and the sensitive nature of specific survey questions related to topics like sexual behaviour and HIV status, participants may have experienced discomfort during interviews. The survey staff underwent comprehensive training to effectively manage any potential stress or unease from study participation and were taught how to work with vulnerable populations (Cawood et al., 2021). While no adverse events were expected, a protocol was established to document and promptly report any unforeseen occurrences to the principal investigator (Cawood et al., 2021).

The DREAMS Evaluation survey protocol, informed consent and data collection forms were reviewed and approved by the University of KwaZulu-Natal Biomedical Research Ethics Committee (BFC 198/16) and the Provincial Department of Health in both KZN and Gauteng (Govender et al., 2021); as seen in Appendix B. In addition, the Human Research Ethics

Committee and the Humanities Faculty Research Ethics Committee of Rhodes reviewed and approved this secondary research (Appendix C).

3.7.1 Compensation

AGYW were compensated for their time and any discomfort they may have felt with a gift valued at R50 (Cawood et al., 2021).

3.8 Conclusion

The methodology section of this study was crucial to understanding the rigorous approach employed to quantify and analyse the intricate dynamics of perceptions of HIV susceptibility among WSW in South Africa. Access to expansive, high-quality data from the DREAMS Evaluation survey was also instrumental. This strategic use of archival data, collected through a methodologically robust cross-sectional design, facilitated a deeper understanding of a high HIV-risk WSW population while safeguarding them from potential research-related harm. The application of the EHBm enabled a standardised exploration of health behaviours, enhancing the comparability and validity of the findings across diverse contexts.

Nevertheless, this study navigated inherent limitations of secondary research, including potential biases such as publication and researcher bias, which, although addressed, may, to a limited degree, have swayed study outcomes and interpretations. As noted earlier, these limitations were addressed through the researcher's lack of knowledge about the study conclusions for WSW and the strategic application of the EHBm, which provided a consistent and comprehensive framework for analysing and evaluating health beliefs in this population. Despite this, it should be noted that this study's focus on Black South African AGYW participants limits its generalizability to other locations, racial groups, and older WSW.

However, these limitations to external validity can be seen as critical potential targets for future research to expand upon this work. Incorporating a broader spectrum of demographics in future studies would enrich other researchers' understanding and help fill in the identified literature gaps.

Despite these limitations to validity and reliability, this study marked a significant advancement in the field by offering a large-scale quantitative examination of WSW in the context of HIV susceptibility in South Africa—a notable departure from much of the existing research on this population. By leveraging the advantages of secondary data, this research paved the way for future investigations to be conducted efficiently and with minimal cost. Hopefully, this methodological foundation has encouraged further studies, using the insights identified here to enhance the understanding of HIV health beliefs and decisions among WSW.

Chapter 4 Results

4.1 Introduction

This research utilised secondary data to measure WSW perceptions of HIV susceptibility and HIV status with the primary aim of analysing their relationship in this population. Assessing these perceptions was vital as they highlighted the complexities of perceptions of HIV susceptibility among AGYW, particularly in contexts of minority sexual identity groups. These results shed light on the discrepancies between perceived HIV susceptibility and actual HIV status, contextualising the vulnerability this population faced and contributing valuable insight to HIV/AIDS prevention efforts.

The results were presented in various formats, which included descriptive epidemiology findings, which provided a breakdown of the WSW sample by age, population group, sex, and location. Descriptive statistics tables were used to summarise central tendencies and variability, Levene's Test was conducted to ensure the assumption of equal variances had not been violated, and cross-tabulations were used to examine relationships between categorical variables. This presentation method enabled the researcher to identify patterns and trends in the data, providing evidence to address the research question, "Is there a relationship between perceptions of HIV susceptibility and HIV status?"

This chapter was structured to align with the research aims. It began by contextualising the intersecting vulnerabilities faced by AGYW WSW through descriptive epidemiology findings, and then it examined the biological determinants by analysing HIV seroprevalence. This approach helped identify patterns and trends, supporting the investigation of the hypothesis that there is no relationship between perceptions of HIV susceptibility and HIV status among WSW. Measurements relating to the population's perceived susceptibility to HIV infection were then presented, which was central to the research questions. Finally, the chapter

confirmed that statistical assumptions and norms were not violated, ensuring the reliability and validity of the findings. This validation allowed for accurate interpretation and meaningful insights into the relationship between perceived HIV susceptibility and HIV status among AGYW WSW.

4.2 Descriptive Epidemiology Findings

This section dealt with the epidemiological findings of the study, focusing on the various statistical tables that highlighted the demographic and behavioural characteristics of the sample population. These tables offered insights into the age distribution, population group, race, geographical location, and sexual partner history of WSW, providing a comprehensive overview of the sample demographics and essential contextual information for potential health implications.

Table 1

Demographic Characteristics Of Women Who Have Sex With Women (WSW) Enrolled In Four Districts In Gauteng And Kwazulu-Natal (N=1362)

Category		Province					Total
		Gauteng		KwaZulu-Natal			
		City of		eThekweni	uMgungundlovu		
Johannesburg	Ekurhuleni						
Age Group	12-14	<i>n</i>	5	7	4	1	17
		%	0.38	0.51	0.29	0.07	1.25
	15-19	<i>n</i>	128	149	131	30	438
		%	9.4	10.94	9.62	2.20	32.16
20-24	<i>n</i>	280	275	293	59	907	
	%	20.56	20.19	21.51	4.33	66.59	
Race	Black	<i>n</i>	400	419	427	89	1335
	African	%	29.37	30.76	31.35	6.53	98
	Coloured	<i>n</i>	13	11	0	0	24
		%	0.95	0.81			1.76
	Indian /Asian	<i>n</i>	0	0	1	1	2
		%			0.07	0.07	0.15
	Other	<i>n</i>	0	1	0	0	1
		%		0.07			0.07
Sex	Female	<i>n</i>	413	431	428	90	1362
		%	48.90	51.10	82.60	17.40	100
	Male	<i>N</i>	0	0	0	0	0
		%					

Table 1 above organised the WSW sample by age, race, population group, and location. The bulk of participants (66.59%) fell within the 20–24 age range, followed by the 15-19 age

group (32.16%), with the 12–14 age group being notably smaller (1.25%). The distribution was predominately consistent across all the districts, except for uMgungundlovu, which only had 6.6% participants. This district may have been underrepresented in this sample population. However, as seen in Chapter 3 - Table 1, this issue was present in the primary study. This table showed that only 153,722 AGYW were surveyed in this district, far fewer than the other district populations. Thus, this potential underrepresentation was a limitation imposed by the primary study.

Most of this sample population were Black Africans (98%), which was consistently spread across the four districts, with smaller percentages of coloured (1.76%), Asian/Indian (0.15%), and others (0.07%). These population group results showed a higher proportion of Black Africans compared to the findings of Statistics South Africa (2023). This was related to the higher concentration of Black Africans in the districts where the sample was drawn. The DREAMS Evaluation Survey chose to concentrate on these regions as they had an elevated HIV risk among AGYW, aligning with the UNAIDS (2023), the CDC (2021) and SANAC (2023) priorities. All participants were female, emphasising the study's specific demographic focus.

4.2.1 Male Sexual Partner History

Table 2 provided information about the sexual partner history of WSW participants, specifically whether they had any male sexual partners. Statistically, this data was essential as it shows the sexual behaviour patterns within the WSW population, indicating an overlap with heterosexual activities.

Table 2

History of Male Sexual Partners Among Women Who Have Sex with Women (WSW) Enrolled in Four Districts in Gauteng and KwaZulu-Natal (N=1362)

Category		Frequency	Percent	Valid Percent	Cumulative Percent
Male Sexual Partner History	No	213	15.60	15.60	15.60
	Yes	1143	83.90	83.90	99.90
	Refused	6	0.40	0.40	100.0
	Total	1362	100.0	100.0	

Table 2 displayed the sexual partner history of participants, indicating that the majority (83.9%) reported having male sexual partners. In contrast, a smaller proportion (15.60%) reported exclusively female sexual partners. Additionally, 0.40% of participants refused to answer this question. These findings highlighted the diverse sexual behaviours within the WSW population and suggested a potential overlap in HIV risk factors between those with male and female partners. The findings suggested that even within a population primarily identified by same-sex behaviour, heterosexual activity was prevalent, which could have influenced HIV transmission risk factors within this group.

Within this table, the 'Percent' heading represented the proportion of participants in each category (No, Yes, or Refused) out of the total sample (N=1362). 'Valid Percent' would normally account for missing data; however, in this case, it was identical to 'Percent' as there was no missing data. 'Cumulative Percent' showed the running total of responses as one moved down the categories, reaching 100%. While 'Percent' and 'Valid Percent' were the most relevant for understanding the distribution of responses, the 'Cumulative Percent' provided a cumulative tally. However, it offered limited additional insight other than to show that there is

no missing data and to maintain the formatting of the descriptive statistical tables in this thesis following the APA 7th guidelines.

4.3 Core Result Findings

This section explored how WSW perceive their HIV susceptibility, offering insights into potential risk perception gaps between perceived and actual HIV risk. Understanding these gaps was important as they may have impacted participants' engagement in preventative behaviour such as regular HIV testing or safer sexual practices.

Various statistical analyses were used, including frequency distributions, Levene's test for homogeneity of variance, descriptive statistics, and a one-way ANOVA. These tests were utilised to illustrate and evaluate the perceptions of HIV susceptibility among the sample population and their corresponding HIV prevalence.

Table 3

Perceptions of HIV Susceptibility and HIV Status Among Women Who Have Sex With Women (WSW) Enrolled in Four Districts in Gauteng and KwaZulu-Natal (N=1362)

Category		Frequency	Percent	Valid Percent	Cumulative Percent
Perceptions of HIV Susceptibility	Very High	178	13.10	13.80	13.80
	High	252	18.50	19.50	33.20
	Low	524	38.50	40.50	73.70
	Very Low	341	25.0	26.30	100.0
	Total	1295	95.10	100.0	
Perceptions Missing System		67	4.90		
Total		1362	100.00		
HIV Status	Negative	1146	84.1	84.10	84.10
	Positive	216	15.9	15.9	100.0
	Total	1362	100.0		

Table 3 showed the results of perceptions of HIV susceptibility among WSW participants and categorised their responses as ‘very high’, ‘high’, ‘low’, ‘very low’, and ‘missing’. The majority perceived themselves to have low (38.5%) or very low (25%) HIV susceptibility, indicating a general trend of perceived low susceptibility (63.5%). A smaller proportion (31.6%) felt their susceptibility was high (18.5%) or very high (13.1%). Additionally, 4.9% of data was intentionally missing, as the original study design excluded those self-reporting as HIV positive to avoid biased perceived susceptibility reflections.

Table 3 also shows the participants' HIV prevalence results. Out of a total of 1362 participants, 1146 (84.1%) tested negative for HIV, and 216 (15.9%) tested positive. In comparison, the DREAMS Evaluation study, which included a larger sample of 18,245 AGYW, found an overall HIV prevalence of 10.4%, with a higher prevalence of 15.1% in KZN and 7.8% in Gauteng (Cawood et al., 2021). The primary study indicated that HIV prevalence was highest among AGYW aged 20-24 years in KZN, at 23.9%, which highlights a significant risk within this subgroup (Cawood et al., 2021). This reflects the higher risk observed in the current study's WSW sample, suggesting that sexually active AGYW, regardless of sexual partner history, particularly in high-prevalence regions like KZN, remain at substantial risk for HIV infection (Cawood et al., 2021).

In this table, 'Percent' is calculated based on the total sample size (N=1362), including participants with missing data. In contrast, 'Valid Percent' excludes the 67 participants with missing responses, providing percentages based only on valid responses (N=1295). For example, while 13.1% of the total sample perceived their HIV susceptibility as "Very High," the 'Valid Percent' for this category is slightly higher at 13.8%, reflecting only those who answered the question. 'Cumulative Percent' adds the valid percentages as one moved through the categories, reaching 100%, and highlights the cumulative distribution of perceptions across the entire valid sample. This distinction between 'Percent' and 'Valid Percent' allows for the missing data to be accounted for and thus presents a more accurate reflection of the responses.

Table 4

Levene's Test for Homogeneity of Variances^b in Perceptions of HIV Susceptibility by HIV Status Among Women Who Have Sex With Women (WSW)

Category		Levene Statistic	df1	df2	Sig.
Perceptions of HIV Susceptibility	Based on Mean	0.17	1	1293	0.68
	Based on Median	0.37	1	1293	0.54
	Based on the Median and with adjusted df	0.37	1	1291.75	0.54
	Based on trimmed mean	0.33	1	1293	0.57

Tests the null hypothesis that the error variance of the dependent variable is equal across groups.

a. Dependent variable: Perceptions of HIV Susceptibility

b. Design: Intercept + HIV Status

The results of Levene's Test in Table 4, with p-values well above 0.05, indicated that the assumption of equal variances had not been violated. This implied that the perceptions of HIV susceptibility were similarly distributed across different HIV statuses. There was no evidence to suggest a significant relationship between these variables based on the variance in perceptions between the different HIV status groups.

Table 5

Descriptive Statistics Of Mean, Std. Deviation, Std Error, Lower and Upper Bound & Range of Perceptions of HIV Susceptibility and HIV Status Among Women Who Have Sex With Women (WSW)

Category		N	Mean	Std. Deviation	Std. Error	95% Confidence Interval for Mean		Mini-mum	Maxi-mum
						Lower Bound	Upper Bound		
HIV Status	Very-Low	178	1.11	0.31	0.02	1.06	1.15	1.00	2.00
Scores (Perceptions of Susceptibility)	Low	252	1.18	0.38	0.02	1.13	1.23	1.00	2.00
	High	524	1.11	0.31	0.01	1.08	1.13	1.00	2.00
	Very High	341	1.10	0.30	0.02	1.07	1.13	1.00	2.00
Perceptions of Susceptibility	Negative	1142	2.81	0.99	0.03	2.75	2.87	1.00	4.00
Scores (HIV Status)	Positive	153	2.68	0.96	0.08	2.53	2.83	1.00	4.00

Table 5 presents descriptive statistics of survey responses. This table had two parts. The first examined participants were categorised by their perceptions of HIV susceptibility. However, the scores related to their HIV status results (1 = HIV negative, 2 = HIV positive). The second section divided participants by their HIV status, but its scores related to their perceptions of HIV susceptibility (1 = very low, 2 = low, 3 = high, 4 = very high).

In the first section, participants who indicated they had very low perceptions of susceptibility had a mean HIV status score of 1.11 (N=178), as this is closer to 1, which is equal to negative. This indicated they had a low prevalence of HIV positivity. Those with low susceptibility had the highest mean score of 1.18 (N=252), suggesting an increase in HIV-positive cases compared to the other perception groups. Participants with high and very high susceptibility perceptions had mean scores of 1.11 (N=524) and 1.10 (N=341). Overall, the data suggested that participants' perceived susceptibility did not impact HIV prevalence.

Regarding HIV status, individuals who tested HIV negative had a mean perception score of 2.81 (N=1142) with a SD of 0.99, indicating they perceived themselves as having a low to very low susceptibility to HIV. HIV-positive individuals had a slightly lower mean perception score of 2.68 (N=153) with a SD of 0.96. The overall mean perception score for all participants was 1.12 (N=1295). A smaller SE indicates more confidence in the sample mean, which is further supported by the 95% confidence intervals, indicating that the range within which the true population mean is likely to fall with 95% certainty (Field, 2009). The 95% confidence interval for HIV-negative individuals' mean perception score is 2.75 to 2.87, providing a reliable estimate of the true mean (Field, 2009). These findings highlighted that HIV-negative individuals generally perceive lower susceptibility compared to HIV-positive individuals.

4.3.2 Analysis of Research Question 1

RQ1: Is there a relationship between the perceptions of HIV susceptibility and HIV status?

Table 6

ANOVA Results for Differences in Perceptions of HIV Susceptibility by HIV Status Among Women Who Have Sex With Women (WSW)

Perceptions of HIV Susceptibility					
	Sum of Squares	df	Mean Square	F	Sig.
Between Groups	2.26	1	2.26	2.34	0.126
Within Groups	1247.69	1293	0.97		
Total	1249,951	1294			

A one-way ANOVA was performed to compare the effect of HIV status on perceptions of HIV susceptibility. The ANOVA results (Table 6) showed that there was no statistically significant difference in perceptions of HIV susceptibility between HIV-positive and HIV-negative groups ($F(1, 1293) = 2.34, p = 0.126$). This indicated that the mean perceptions of HIV susceptibility did not significantly differ based on HIV status, as the p-value was greater than the 0.05 threshold for significance.

Table 7

RQ1 Hypothesis Test Summary

Null Hypothesis	Test	Significance	Decision
There is no relationship between the perceptions of HIV susceptibility and HIV status.	ANOVA	0.126	Fail to Reject the null hypothesis

Table 7 was the hypothesis test for Research Question 1 (RQ1), which examined the relationship between perceptions of HIV susceptibility and HIV status. An ANOVA test was

conducted to test the null hypothesis that there is no relationship between these variables. The test resulted in a significance value of 0.126, leading to the decision to fail to reject the null hypothesis. This indicates that, based on the data analysed, there was no statistically significant relationship between perceptions of HIV susceptibility and HIV status among the participants.

4.4 Conclusion

These results show that there is no relationship between ‘perceptions of HIV susceptibility’ and ‘HIV status’. This finding underscores the gap between WSW’s subjective perceptions of their HIV susceptibility and their actual HIV status. WSW were found to have an arguably high prevalence of HIV; however, their perceptions tended towards a perception of low susceptibility. These results, therefore, suggested that personal perceptions may not always align with clinical realities.

Notably, participants’ responses tended towards low perceptions of susceptibility. Most participants perceived their risk as low (38.5%) or very low (25%), as seen in Table 3. This indicated a general trend of perceived low susceptibility despite an arguably high HIV prevalence of 15.9%. This finding highlights a disconnect between subjective perceptions and actual HIV status, emphasising the need for improved education and targeted communication strategies to align personal risk perceptions with clinical realities.

The results indicated that the study’s null hypothesis cannot be rejected, as no evidence was found of a relationship between HIV status and HIV susceptibility. This can be seen in Table 6, where, through an ANOVA analysis, a p-value value of .126 was found. This indicated that there was no statistical significance found between the results concerning perceptions of HIV susceptibility and the two HIV status groups (positive and negative). These results are valid as Levene’s Test results in Table 4 showed p-values well above 0.05, indicating that the assumption of equal variances was not violated.

The structure of the results sections has methodically addressed each research question, providing detailed statistical analyses to support the findings. Descriptive statistics, normality tests, and variance equality test results confirmed the data's validity and appropriateness for analysis. These findings underscored the disconnection between perceived and actual HIV risk among WSW.

Chapter 5 Discussion and Conclusion

5.1 Introduction

This chapter discusses the key findings of the study on the relationship between perceived HIV susceptibility and HIV status among AGYW WSW in South Africa. The results indicate a disconnect between perceived HIV susceptibility and actual HIV risk, reflecting trends observed in both South African and international studies. This chapter will explore the implications of these findings, compare them with existing literature, and discuss the social and structural factors influencing WSW's perceptions of HIV risk. Additionally, the strengths and limitations of the study will be examined, followed by recommendations for future research and practical interventions.

5.2 Discussion of results

The findings of this study indicate a disconnect between perceived HIV susceptibility and actual HIV status among AGYW WSW in South Africa. Despite low perceived susceptibility, the actual HIV prevalence among WSW was notable, highlighting a disconnect that suggests a need for targeted educational interventions. These findings align with those of Logie and Gibson (2013) in Canada, McCune et al. (2017) in the USA, Evans et al. (2016) in South Africa and Tat et al. (2015) in Sub-Saharan Africa, who all reported a tendency among WSW to underestimate their individual HIV susceptibility. This suggests that the gap between perceptions of susceptibility and actual prevalence of HIV may be related to wider systemic issues surrounding gender, race and sexual minority populations.

A pattern of underestimation in perceptions of HIV susceptibility and high risk of HIV was found among WSW participants. The descriptive statistics provided in Table 5 highlight the perceptions of HIV susceptibility and actual HIV status among the study participants.

Among the surveyed participants, perceptions of HIV susceptibility ranged from very low to very high, yet the actual HIV prevalence did not vary significantly across these categories. This consistency in HIV prevalence despite varied perceived risks suggests a disconnect between perceived and actual risk. Participants generally viewed themselves as being at low to very low risk of contracting HIV, regardless of their actual status. This misalignment could indicate a lack of awareness or understanding of HIV transmission risks among WSW.

The similarity in mean HIV status scores between those who perceived their risk as low and those who perceived it as high underscores this gap in perception. This finding aligns with broader literature suggesting that WSW often underestimate their susceptibility to HIV, possibly due to misconceptions about transmission routes or a lack of targeted health education. These results underscore the need for public health interventions that better educate WSW about their actual risk factors, aiming to bridge the gap between perceived and actual HIV risk.

The perception of low personal susceptibility to HIV in WSW participants mirrors McCune et al.'s (2017) research findings. In this study, a paradox was found amongst their WSW respondents as 30% of participants perceived that they personally were not susceptible to HIV, yet 82% also perceived 'lesbians' at large to be at risk from the virus. This gap between their individual and collective perceptions of susceptibility aligns with broader trends in the literature, such as those discussed by Evans et al. (2016). These South African researchers also highlighted a general tendency among South African WSW to underestimate their HIV risk (Evans et al., 2016). However, Evans et al. (2016) also emphasised that LGBTQ populations have been concerned about HIV in their communities for decades. This secondary study's findings align with existing research by demonstrating the disjunction between perceptions of HIV susceptibility and actual HIV risk in the WSW population (Evans et al., 2016; McCune et al., 2017).

However, it must be acknowledged that studying perceptions of susceptibility is complex, particularly in marginalized populations. Researchers must navigate myths, misconceptions, and the interplay between identity and behaviour to understand this population's perceptions of susceptibility (Logie & Gibson, 2013; Matebeni et al., 2013; Richardson, 2000). Further research on collective susceptibility perceptions would be beneficial to understand how HIV risk perceptions are constructed, especially when these perceptions do not align with the reality of HIV prevalence in high-incidence settings.

Although it was not the aim or purpose of this study, it is notable that the prevalence was higher than what was reported in prior South African studies on WSW (Daly et al., 2016; Sandfort et al., 2013). However, the higher rate of STIs found amongst this AGYW sub-population is supported by reports by the CDC (2021). The CDC (2021) suggested that sexual-risk behaviours (e.g., history of male sexual partners), reduced knowledge of STI risks, and experiences of barriers to care among Black and AGYW WSW place this population at a higher risk of infection for STIs such as HIV. The results of this study and the literature indicate that WSW does not face low to negligible risk for HIV infection (Cloete et al., 2011; CDC, 2019, 2021; Patel et al., 2014)—underscoring the importance of addressing the goals related to WSW in the SANAC's 2023-2028 plan. These goals included breaking down barriers to achieving outcomes for HIV, STIs and TB; maximising equitable and equal access to health services; fully resourcing and sustaining an efficient NSP that is more inclusive and accountable; and building more resilient and integrated systems to address HIV, TB, and STIs (SANAC, 2023). Thus, the results of this study which provide evidence that AGYW WSW face a higher risk of infection, support and highlight SANAC's call for urgent and targeted interventions in this population.

A key aspect for targeted interventions to address is the underlying social and structural factors associated with the gap between perceptions and reality of HIV susceptibility, as suggested by this study's results. AGYW WSW demonstrated a predominantly low to very low perception of HIV susceptibility, but this did not align with the reality of their HIV risk, as demonstrated by their relatively high HIV prevalence among WSW. This gap and lack of relationship between these variables may be related to important social and structural factors in South Africa and internationally. On a broad structural level, the perception that WSW are a 'susceptibility-free' population can be linked to the institutionalised exclusion of transmission between women from the dominant HIV categorising framework (Logie & Gibson, 2013; Wikramanayake et al., 2020).

Without recognition or a way to record these infections, it is impossible to estimate the number of lesbian, bisexual and 'queer' women who have been infected with HIV (Logie & Gibson, 2013). This has important implications for policy, funding, and service provision in the risk-saturated world of HIV research (Allanise et al., 2011; Logie & Gibson, 2013). It is, therefore, arguable that this exclusion from transmission categories is an important explanatory factor for this study's perception of HIV susceptibility results. Understandably, WSW's perceptions of susceptibility and HIV status lack a relationship as WSW do not have adequate access to accurate and tailored health information on their risk (Wikramanayake et al., 2020). They, therefore, have a compromised capacity to make informed decisions when addressing their sexual health needs (Wikramanayake et al., 2020).

An important implication of this exclusion from transmission categories is on a social level between healthcare practitioners and their WSW patients. There is a lack of access to facts and statistics on infections among women (Wikramanayake et al., 2020). These infections are

perceived by the public, health practitioners and WSW themselves as rare (Evans et al., 2016; Mkhize & Maharaj, 2020; Richardson, 2000). Research in South Africa indicates that WSW have been exposed to messaging from health providers that reinforce the misperception that WSW are a ‘susceptibility-free’ population (Cloete et al., 2011; Mkhize & Maharaj, 2020). WSW have been found to hold the perception that their sexual identity is protective against HIV infection (Matebeni et al., 2013; Mkhize & Maharaj, 2020; Richardson, 2000). This misperception in which identity is emphasised over behaviour is shared by both health practitioners and WSW and gives many WSW a false sense of security against HIV (Evans et al., 2016; Matebeni et al., 2013). Adjusting and educating healthcare providers’ perceptions about WSW HIV susceptibility to reflect scientific findings more accurately could have far-reaching positive implications for WSW HIV prevalence. Therefore, the results of this secondary study suggest an essential area for further research and intervention, necessitating that interventions focus beyond WSW themselves and include education aimed at health.

5.3 EHBM Theoretical Framework Insights

The EHBM provides a deeper understanding of this study’s findings relating to WSW’s perceptions of low susceptibility. This theory highlights that perceived threat—arising from a blend of perceived susceptibility and severity—is a critical driver of health behaviour (Tarkang & Zotor, 2015). In the context of HIV/AIDS, the perceived threat is closely linked to the fear of contracting the virus (Tarkang & Zotor, 2015). Rosenstock et al. (1994) emphasised that recognising the threat posed by an illness is an essential first step in motivating individuals to take actions aimed at mitigating that threat. Moreover, they argue that a heightened sense of threat enhances the influence of other EHBM components on behaviour change (Rosenstock et al., 1994). Therefore, if WSW do not perceive that they are susceptible to HIV, a critical

piece of the perception of threat puzzle is missing, undermining their ability to accurately assess the threat of HIV, diminishing the likelihood of WSW adopting HIV preventive behaviours (Rosenstock et al., 1994). This postulation is substantiated by Tsui et al. (2012), who found a connection between WSW's low perceived personal susceptibility for HIV and their reduced motivation to take HIV preventive actions. This underscores the importance of increasing HIV knowledge that is LGBTQ-focused, and that is aimed explicitly at shifting WSW perceptions of HIV susceptibility.

Despite AGYW's recognised vulnerability to HIV and the consequent targeting by interventions, in the literature, WSW report feeling sidelined by a system that primarily caters to heterosexual norms (Ochse, 2011; UNAIDS, 2019). The research conducted by Smith (2014) in Cape Town further exemplifies this, as it displays a unanimous frustration among WSW over the lack of accessible and relevant LGTQ-focused sexual health information. The literature indicates that simply having information on HIV has not translated amongst WSW into the ability to practically apply that knowledge to understand personal and perceived HIV susceptibility accurately (Matebeni et al., 2013; Mkhize & Maharaj, 2020). This is clearly illustrated in the report by the CDC (2021), in which WSW were found to have an extremely low use of barrier protection during sexual intercourse with women. HIV education programmes for WSW need to include facts and statistics on WSW and HIV, female condom and barrier use instructions, as well as HIV testing information to increase HIV knowledge and perceived HIV susceptibility (Jacobs et al., 2017; Matebeni et al., 2013; Mkhize & Maharaj, 2020). This highlights an urgent need for strategies to bridge their knowledge-action gap, catering for the nuanced HIV prevention needs of AGYW WSW.

5.4 Limitations of the Study

This study provides valuable insights into perceptions of HIV susceptibility among WSW. However, it is essential to acknowledge a limitation in the data gathered: the presence of intentionally missing data related to perceptions of HIV susceptibility among self-reported HIV-positive participants. This missing data is problematic as it directly concerns a vital aspect of this study, 'perceptions of HIV susceptibility'. However, as shown in Table 3, this only affects a small proportion, 4.9% (67/1362) of the study's participants, and this study was still able to draw responses on perceptions of HIV susceptibility from 11.81% (153/1362) of HIV-positive participants who were asked before learning their HIV status. Additionally, it is possible that HIV-positive participants who knew their HIV status would have given biased responses. Consequently, while this intentionally missing data is a notable aspect of the study's methodology, intentionally excluding these responses did not critically impact the overall results or conclusions. This consideration in the study design underscores the complexity of researching perceptions of HIV susceptibility and highlights the nuanced decision-making involved in gathering and analysing data in such contexts.

5.5 Strengths of the Study

It is also important to acknowledge the strengths of this secondary study and the extensive strengths of the original DREAMS Evaluation survey. These strengths were leveraged to provide a robust foundation for analysing the relationship between HIV status and perceptions of HIV susceptibility among AGYW WSW. Notable strengths of the original dataset include its large sample size and long duration, which enhance the reliability and temporal depth of the findings (Cawood et al., 2021). The geographical diversity covered by the survey in its utilisation of four study districts and its use of multistage stratified cluster-

random sampling design ensures that the results are representative and applicable across different regions (Cawood et al., 2021). The strengths of the primary study therefore provide a solid foundation that strengthens the validity and reliability of the secondary study results.

Moreover, the DREAMS Evaluation survey employed standardised methodologies and electronic questionnaires, enhancing the data collection and analysis consistency (Cawood et al., 2021). This dataset also allowed for the inclusion of multiple data sources and critical indicators, furthering this population's contextual understanding (Cawood et al., 2021). Using weighted percentages and longitudinal analysis further supported detailed assessments, providing insights into trends and changes in behaviour and incidence (Cawood et al., 2021). Critically, the primary study also included objective measures such as blood tests to accurately determine HIV incidence, ensuring the validity of HIV status data (Cawood et al., 2021). The comprehensive focus on the DREAMS programme by Epicentre, backed by support from PEPFAR and CDC, underscores the survey's credibility and alignment with global health standards (Cawood et al., 2021). This alignment allows for meaningful comparisons with other studies and aids in understanding the impact of health beliefs on the targeted population, making this secondary study relevant and exceptionally grounded in high-quality primary research data.

5.6 Recommendations for Further Research

This secondary researcher chose not to include the other components of the EHB. This discussion focused primarily on perceived susceptibility; a conscious choice also necessitated by the limitations imposed by the secondary data drawn from the DREAMS Evaluation survey. By focusing specifically on perceived HIV susceptibility, the researcher examined if relationships existed between the identified variables and used this to explain the

relationships and lack thereof. However, the EHB (illustrated in Figure 1) offers a comprehensive array of important components for delving into health decision-making processes (Rosenstock et al., 1994). Many of these components were not examined in this study, which is an essential area for further research. It is proposed that this secondary study's choice to omit an exploration of the other components of the EHB is not a critical limitation but rather an opportunity for other researchers to build and extend the findings of this research. The focus on perceived susceptibility ultimately provides a key area for improvement in understanding the health decisions of the AGYW WSW population of South Africa.

5.7 Main Contribution of the Study

The results of this study, therefore, have several key takeaways. AGYW WSW in South Africa shows a tendency in their perceptions to underestimate their HIV susceptibility. They also display an arguably high HIV prevalence amongst this population in comparison to the prevalence found amongst the general HIV prevalence of WSW in South Africa. Finally, the lack of a relationship between perceptions of susceptibility and HIV status suggests that current HIV education strategies may not fully meet the needs of WSW. This underscores the need for tailored sexual health strategies built to address the unique needs of AGYW WSW in South Africa. Future interventions could benefit from leveraging the EHB components to design more effective HIV education and prevention programmes for WSW. This is a clear call for additional research to explore the unaddressed components of the EHB and further investigate the health decision-making processes among WSW. These studies could provide deeper insights into the effectiveness of HIV prevention strategies and identify areas for improvement, contributing substantially to the understanding of perceptions of HIV susceptibility and its impact on HIV prevention motivation among AGYW WSW.

5.8 Conclusion

This study sought to measure and analyse the relationship between perceptions of HIV susceptibility and HIV status amongst AGYW WSW. Utilising secondary data, this investigation shed light on critical disparities between these variables with important implications for HIV prevalence amongst AGYW WSW. This population of South African AGYW WSW perceptions of susceptibility were found to be generally low, consistent with other WSW research. Additionally, a multivariate analysis conducted with ANOVA found that there was no relationship between perceptions of HIV susceptibility and HIV status. Therefore, the findings of this study improve the understanding of health beliefs among sub-populations of AGYW, offering insights for developing more targeted HIV prevention and educational initiatives.

However, addressing the misperceptions about perceptions of HIV susceptibility among South African WSW presents unique challenges. The lack of relationship between perceptions of HIV susceptibility and HIV status grounds this analysis in the complex socio-psychological factors that shape health beliefs. The disconnection between perceptions of HIV susceptibility and HIV status highlights that personal assessments of risk are not constructed based on risk behaviours. A consideration that is especially important in the high-incidence setting that this marginalised population is based in. Instead, they are highly influenced by misinformation or the lack of access to the specific health education that this population needs. Indicating that education efforts need to address both the actual risks faced by AGYW WSW and their perceptions of HIV susceptibility. To be effective, interventions must address the specific health needs of marginalised sub-populations such as WSW while ensuring contextual and cultural relevance.

These findings underscore the need for a more nuanced approach to public health amongst the AGYW in South Africa. The lack of correlation between perceived HIV susceptibility and actual HIV status suggests that current HIV/AIDS awareness programmes may not be effectively reaching or educating this population. The uniform perceptions of susceptibility, regardless of HIV status, appear to be more influenced by psychosocial factors than by an understanding of HIV risk factors. This indicates a potential misunderstanding or underestimation of HIV transmission mechanisms in their sexual relationships. Consequently, there is a critical need for targeted educational programmes designed explicitly for WSW. These should aim to deliver tailored and accurate information that also addresses misperceptions about HIV susceptibility in this population.

This supports the conclusions made by SANAC (2023) that WSW face substantial barriers to accessing the SRHC they need. This study suggests that education aimed at correcting misperceptions amongst WSW need to address these structural failings through the promotion of LGBTQ-focused HIV knowledge in this population. However, to achieve an effective promotion of HIV knowledge that could start to close the gap between knowledge in this population, the insights provided by the EHBM must be used. This framework has a direct focus and application potential to correct perceptions of susceptibility amongst WSW. The EHBM provides theoretical explanations on perceptions of susceptibility and how these perceptions fit into threat calculations, suggesting an evidence-based avenue to address how these perceptions interact with health beliefs and behaviour in the context of HIV.

Inversely, insights from these secondary study findings could also contribute to the theoretical understanding of the EHBM framework. The HIV status and perceived susceptibility gap are critical for academic advancement and practical intervention. The results of this study indicate that there is a need for further research using this framework on the

nuances of perceived susceptibility, particularly in how marginalised individuals interpret and internalise HIV knowledge about their risk. Theoretically, this highlights the importance of addressing cognitive biases and enhancing this model's components to better capture the complexity of perception formation in marginalised groups like WSW.

The focus of this study on perceived susceptibility is also an opportunity for further research on the EHB in AGYW WSW. There is a strong need for further inclusive and extensive research on this population that can validate or expand upon this study's findings. Future studies could focus on other components of the EHB, specifically on health decisions concerning HIV in this population. This would expand the range of components utilised to understand how a marginalised population like AGYW WSW make health decisions about this chronic illness. Additionally, it would be valuable if perceptions of the severity of HIV were analysed in this population as it would assist in calculating how WSW cognitively form their perceptions of HIV as a threat. Therefore, what is certain is that WSW are an at-risk group for HIV, and this population is worthy of further study.

However, conclusions drawn from the results of this study may have external validity concerns. Due to this study's reliance on the DREAMS Evaluation survey secondary data, there are potential restrictions on the generalizability of these results. Although the DREAMS Evaluation survey offered an expansive and high-quality data set, the divergence between the objectives of the secondary study and the DREAMS Evaluation survey caused issues that the secondary researcher could not correct. A vital example of this was in the data used to analyse participant's perceived HIV susceptibility. This intentionally missing data from self-reported HIV-positive participants left gaps in the conclusions made by this study. Data on WSW knowingly living with HIV had the potential to give insights into their perceptions of HIV susceptibility that now cannot be analysed.

Despite this, the missing data potentially reduced bias in the study's results, as knowledge of HIV-positive status had the potential to skew perceptions of susceptibility. Additionally, these missing responses comprised a small percentage of the secondary study population. Although the missing data would have provided valuable insights, there is ample evidence to suggest the validity of these results despite the drawbacks inherent in utilising this secondary data, indicating an area for further research, as a quantitative analysis of WSW living with HIV that provides high-quality data on their perceptions of susceptibility may yield valuable findings to assist with intervention efforts.

Another area for additional research lies in the demographic of this study population. The population of the DREAMS Evaluation survey is predominantly comprised of Black AGYW, which limits the generalizability of the secondary study findings. The results of this study may not be valid for other population groups or amongst older adult WSW. This is not inherently problematic as this WSW population (Black AGYW) is particularly at risk for HIV, as supported by the CDC (2021). This focus allows the researcher to concentrate on the highly at-risk population of WSW in a high-incidence setting. Moreover, this study also improved its generalisability by including data from four districts, providing a degree of validity in applying its results to other locations. However, it should be noted that there are limitations to the generalizability of the secondary study; therefore, other researchers viewing these results must be aware of these factors when transferring and utilising these findings in different contexts for intervention opportunities.

This research serves as a part of the pivotal shift in discourse around WSW HIV risk in South Africa and globally. By illuminating the disparities in perceptions of HIV susceptibility and the critical gaps in our current understanding and approach, this study seeks to be a call to action. It advocates for nuanced, inclusive, and informed strategies that resonate with the lived

realities of WSW, paving the way for more effective interventions and reducing HIV transmission within this community. It is hoped that this research will be part of a movement towards a future where the health and well-being of every individual, regardless of their sexual orientation, are prioritised and protected. This demands continued research, advocacy, and policy reform to dismantle the barriers faced by WSW. Confronting and overcoming the marginalisation this group faces in HIV discourse would be a big step towards a future where HIV/AIDS care is not only more comprehensive and accessible but also delivered with the compassion and understanding that every individual deserves.

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Appendix A: Data Use Agreement



Data use agreement

DATA SOURCE

Name of study	DREAMS impact evaluation
Data description	HIV incidence trends among adolescent girls and young women in the eThekweni (KZN), uMgungundlovu (KZN), City of Johannesburg (GP) and Ekurhuleni (GP) districts, South Africa

NAME AND ORGANISATION'S DETAILS OF PERSON REQUESTING DATA

Name	Aimee Zuccarini
Organisation	Rhodes University Masters Student
Email address	aimcaw@icloud.com
Cell number	062 365 9690

DETAILS OF DATA USE

Purpose	Masters thesis via secondary analysis
Period	From 10 / 06 / 2022 to 20 / 06 / 2024
Ethics regulatory authority approving study:	Rhodes University
Study Approval Number:	
Title of study:	The association between HIV risk perceptions and status amongst women who have sex with women.
Aim of study:	To shine a light on HIV risk perceptions and its associations with HIV status amongst women who have sex with women.

CONDITIONS OF USE (TICK EACH ITEM AGREED TO)

<input checked="" type="checkbox"/> I will not attempt any linkage or combination of the study data to identify individuals or for any other purposes that have not been described and agreed with Epicentre CEO Cherie Cawood
<input checked="" type="checkbox"/> I agree to make no attempt to learn the identity of any persons included in these data. If I should discover the identity of a person inadvertently, I will advise Cherie Cawood, of any such discovery in writing within 2 business days.



I agree to utilize data officially received from Epicentre authorized staff person I will also not send data via email attachments.

I will not carry individual-level data on hardcopy listings or forms

I will keep all hard copies of analysis and data runs containing small cells, defined herein as any combination of race, ethnicity, geography, age and/or gender that results in five (5) or fewer cases per cell, locked in a secure location. In addition, for public reporting of results of my analysis of HIPSS data, I agree not to report information on any small cells.

Within seven (7) business days from the end of my authorized period of data use, defined above, I agree in consultation with the Cherie Cawood, to destroy the study encrypted data file and notify the Epicentre data manager that this file has been destroyed.

I agree to notify the Cherie Cawood in writing if I will be changing positions within seven (7) business days prior to my planned change or exit date. I agree not to take copies of the data, data analysis, printouts, runs, graphs, etc with me when I change positions.

I will only access data on secured computers or through secure connections. A computer or connection is considered secure if access is through my site's secure data network, which typically is a VPN (virtual private network) at the institution.

I will review all data documentation provided by Epicentre data manager for the analysis datasets prior to using the data to ensure that I am correctly using the variables in the datasets. I will contact Cherie Cawood, if I have any questions about the correct use of data.

I will promptly inform the Cherie Cawood, of any deviation from these guidelines.

I will acknowledge the contribution of Epicentre by including Cherie Cawood as an author, the PI, the funders and study participants in any publication of this data. (Example below)

The researchers acknowledge the contribution of all study participants and the XXX study team.
Protocol: XXX funded by XXX under terms of the cooperative agreement xxx.

I will not copy data or share data with persons other than those identified in the official proposal.

I will submit all reports based on Epicentre study data to Cherie Cawood for clearance, in accordance with Epicentre and Funder guidelines prior to public release for review and comment.

I understand that I am responsible for agreed upon costs incurred in the preparation and delivery of data and Epicentre will be reimbursed for those costs within 30 days of notification.



This agreement may be amended by mutual written agreement of the Parties. Additionally, this agreement may be terminated immediately upon mutual written consent of both Parties or unilaterally by either Party with sixty (60) days' written notice to the other Party.

Aimee Zuccarini

30/05/2022

Name (Print)

Signature

Date

aimcaw@icloud.com

Mailing address or fax number to receive copy of this signed agreement

List other data user (add list of other users)

Elron Fouten (Masters Supervisor)

Approved by:

Cherie Cawood,

31/05/2022

Epicentre CEO
cheriec@epicentre.org.za

Signature

Date

Please sign in black ink and mail to: Cherie Cawood, Epicentre, 2 Knelsby Ave, Hillcrest, KZN, South Africa

Appendix B: Original DREAMS Evaluation Survey Ethical Approval



Dr K Govender
HEARD
J Block
Westville Campus
govenderk2@ukzn.ac.za

Dear Dr Govender

Protocol: Determine, resilient, empowered, AIDS-free, mentored, and safe programme impact evaluation- HIV incidence trends among adolescent girls and young women in the eThekweni (KZN), uMgungundlovu (KZN), City of Johannesburg (GP) and Ekurhuleni (GP) districts, South Africa
Degree: Non-degree
BREC reference number: BFC189/16

The Biomedical Research Ethics Committee (BREC) has considered the abovementioned application at a meeting held on 12 April 2016.

The study was provisionally approved by BREC pending appropriate responses to queries raised. Your response received on 27 June 2016 to queries raised on 25 July 2016 have been noted and approved by the Biomedical Research Committee at a meeting held on 16 August 2016. The conditions have now been met and the study is given **full ethics approval** and may begin as from 25 August 2016.

This approval is valid for one year from 25 August 2016. To ensure uninterrupted approval of this study beyond the approval expiry date, an application for recertification must be submitted to BREC on the appropriate BREC form 2-3 months before the expiry date.

Any amendments to this study, unless urgently required to ensure safety of participants, must be approved by BREC prior to implementation.

Your acceptance of this approval denotes your compliance with South African National Research Ethics Guidelines (2015), South African National Good Clinical Practice Guidelines (2006) (if applicable) and with UKZN BREC ethics requirements as contained in the UKZN BREC Terms of Reference and Standard Operating Procedures, all available at <http://research.ukzn.ac.za/Research-Ethics/Biomedical-Research-Ethics.aspx>

Pg. 2/...

Biomedical Research Ethics Committee
Professor J Tsoka-Gwegweni (Chair)
Westville Campus, Govan Mbeki Building
Postal Address: Private Bag X54001, Durban 4000
Telephone: +27 (0) 31 260 2486 Facsimile: +27 (0) 31 260 4609 Email: brec@ukzn.ac.za
Website: <http://research.ukzn.ac.za/Research-Ethics/Biomedical-Research-Ethics.aspx>


BREC is registered with the South African National Health Research Ethics Council (REC-290408-009). BREC has US Office for Human Research Protections (OHRP) Federal-wide Assurance (FWA 678).

The following Committee members were present at the meeting that took place on 12 April 2016:

Prof J Tsoka-Gwegweni	Chair
Prof C Aldous	Genetics
Dr R Harrichandparsad	Neurosurgery
Dr M Khan	Obstetrics and Gynaecology
Prof TE Madiba	General Surgery
Dr G Nair	HIV Medicine
Dr S Paruk	Psychiatry
Prof V Rambiritch	Pharmacology (Deputy Chair)
Prof C Rout	Anaesthetics
Prof D Wassenaar	Psychology (Deputy Chair)

We wish you well with this study. We would appreciate receiving copies of all publications arising out of this study.

Yours sincerely



PROFESSOR J TSOKA-GWEGWENI
Chair: Biomedical Research Ethics Committee

Appendix C: Rhodes University Human Research Ethics Committee Waiver



RHODES UNIVERSITY

Where leaders learn

Rhodes University Human Research Ethics Committee

PO Box 94, Makhanda, 6140, South Africa

t: +27 (0) 46 603 7727

f: +27 (0) 46 603 8822

e: ethics-committee@ru.ac.za

NHREC Registration number: RC-241114-045

<https://www.ru.ac.za/researchgateway/ethics/>

15 August 2022

Ms Aimee Zuccarini (Applicant)
Mr Elron Fouten (Supervisor)
Department of Psychology
Rhodes University

Dear Ms Zuccarini,

Re: Ethics Waiver for 2022-5540-6985 The association between HIV risk perceptions and status amongst women who have sex with women.

This letter confirms that the RU-HREC has reviewed your application for ethics approval.

As you will be utilising de-identified secondary data, your research does not involve interaction with human participants, and you are not required to go through the ethics approval process.

You are therefore granted ethics waiver for this study.

Sincerely,

Dr Janet Hayward
Chair of Rhodes University Human Research Ethics Committee

Appendix D: Informed consent for AGYW 19 and 17-12

Title of Study

DREAMS impact evaluation -

HIV incidence trends among adolescent girls and young women in the eThekweni (KZN), uMgungundlovu (KZN), City of Johannesburg (GP) and Ekurhuleni (GP) districts, South Africa

Version 1.0 – 23 February 2016

Informed consent form for enrolment

If the volunteer cannot read, this form must be read to the volunteer exactly as written, in the volunteer's language of choice, and a witness must sign this form to confirm that the correct information was given to the volunteer who freely consents to be in this study.

INTRODUCTION

Good day, my name is _____(Field Staff Name) from Epicentre and we are conducting a research study in collaboration with the NICD, Provincial Department of Health, KwaZulu-Natal and Gauteng and the Centers for Disease Control and Prevention in South Africa (CDC).

The Principal Investigators of the study are:

Dr Adrian Puren, principal investigator	Cherie Cawood, principal investigator
---	---------------------------------------

National Institute for Communicable Diseases	Epicentre Aids Susceptibility Management (Pty) Limited
Private Bag X4	P O Box 3484
Sandringham	Paarl 7620
South Africa	South Africa
Tel: +27-11-3866328	Tel: 0861 482442
Email address: adrianp@nicd.ac.za	Email address: Cheriec@epicentre.org.za

BACKGROUND

You are being invited to participate in a research study that seeks to understand the HIV epidemic in this region. The study is being undertaken to find out whether services that are provided by government and other organizations (DREAMS programme) on HIV information, education, prevention and treatment are having an effect by reducing the number of new HIV infections amongst adolescent girls and young women in this community. To date, we have limited information on HIV in adolescent girls and young women, however, we do know that young girls acquire HIV at a very young age and are also three to five time more likely to be HIV positive compared to boys in the same age group. Knowing more about HIV programmes and whether these have an effect on HIV infection rates will help us improve HIV prevention and treatment programmes. In the case of the individuals who are already infected with HIV, we wish to understand whether they are getting the necessary HIV care and treatment services that they require. For those individuals who are not infected with HIV we will try and understand whether they have received information on HIV and how to protect themselves from becoming infected with HIV.

In each survey we expect to include about 18,500 adolescent girls and young women, 12-24 years, from eThekweni and uMgungundlovu districts in KwaZulu-Natal, and the City of Johannesburg and Ekurhuleni districts in Gauteng. Enrolment will be done in three surveys at different points in time (mid 2016, mid 2017 and mid 2018). Out of those included in the first survey, a smaller group (aged 12-16) will be asked to be followed up approximately 12 and 24 months later to look at changes over time.

PURPOSE OF THE STUDY

The purpose of this research is to understand and know

- The number of adolescent girls and young women who are becoming HIV infected and why
- The number of adolescent girls and young women who are HIV infected and whether they have proper and easy access to care and treatment programmes
- The number of adolescent girls and young women who are HIV uninfected and whether they have proper and easy access HIV prevention programmes

YOUR PARTICIPATION IS VOLUNTARY

Your participation in this study is voluntary and you should not hesitate to ask about anything you are not clear about. Please read (or have someone to read to you) this Consent Form in the language of your choice (English or Isizulu) in order to make sure that you are given enough information about taking part in this research study. If you agree and you qualify to take part in this study, you will be asked to sign this consent form (or make your mark on the form in the presence of a witness). The study staff will then enrol you in this research. They will also give you a copy of this signed consent form to keep. Once you join the study we hope that you

answer the questions truthfully and to the best of your ability. We want to reassure you that none of the information you provide will be shared with anyone in the community or any person outside the study.

PROCEDURES

After you have agreed (**CONSENTED**) and joined the study, staff will:

- Scan your fingerprints. This is done to ensure that all information we collect from you today, and in the future, is correctly assigned to one and the same person, and that we keep all the information in such a way that no one can access it. Should we need to make contact with you in the future, we will confirm your identity through your finger print by comparing it with the finger print taken during this visit.
- Ask for your name, physical address, phone number, and other contact information to stay in contact with you for future visits if needed. This will also help us to provide you with any updates on the study in the future.
- Use a tracking device called Global Positioning System (GPS) to determine the location of your house. Should we need to contact you for a follow-up visit the study staff will use this information to assist in finding you.
- Ask you some general and behavioural questions on your age, who you live with, and what kind of work you do. Whether you have had an HIV test and know your HIV status and some information on your sexual behaviour and sex partners. We will not ask the name(s) of your sex partners. Whether you know of HIV related programmes that are offered in the district and if you have used these services.

- Collect a small amount of blood using a “finger-prick” with a special device (dried blood spots). This will be used for laboratory testing for HIV related and specialized testing to understand the spread of HIV, other sexually transmitted infections and pregnancy.
- Ask you to self-collect a vulvo vaginal swab sample for testing for sexually transmitted infections.
- **If you do not agree to your samples being collected then you will not be able to participate in the study.**

We will not write your name on any of the forms or samples, we will only use numbers, so there will be no way of knowing who the form or sample came from and all this information will be restricted to study staff only. There is no limit on how long the dried blood spots and vaginal samples will be stored and may be tested for other infections. If you do not want us to store the sample then we will destroy the sample as soon as the tests are completed for this study.

We will be happy if you take part in the study, but if you do not wish to, then please just say so and we will not continue. Also if you wish to stop at any time in the interview you will be free to do so and you will not lose your rights to other services. The results of the tests conducted on the sample provided by you will be available from your local Department of Health clinic linked to your barcode. We will provide you with a card with your bar code and the name of the clinic where your results will be sent to enable you to collect your results.

SUSCEPTIBILITY AND/OR DISCOMFORTS

You may feel uncomfortable or anxious about some of the questions you are asked. You are allowed to refuse to answer any question that you do not want to answer. The finger prick may be a little painful for you, but staff members will help you in coping with these.

BENEFITS

Your participation in this research could help us learn more about HIV in your district, especially among adolescent girls and young women, and more importantly about how HIV information, education, prevention and treatment programs are working. We hope that designing interventions/programmes to prevent and control the spread of HIV would benefit young girls and adolescent women in the long term. You could also benefit as it would be possible to know where to access health care. In addition study staff would refer you for the management of HIV, pregnancy or any other minor ailments, if necessary. We hope you benefit from these referrals as you would be able to access care and treatment much earlier.

CONFIDENTIALITY

The study staff will do everything they can to keep your participation in the study private. Access to any information that you provide, the location of your house, your fingerprints and records will be restricted and limited to the study staff. You will be given a study number so that we do not use your name. This number and your name will only appear together on one form. This form will be kept in a locked file to which only certain study staff will have access to. All questionnaires, samples, samples in storage, laboratory result sheets will not contain your name or personal information and will remain confidential. It will not be possible for people looking at any of these forms to know that they belong to you. Any reports or work that will be written and shared with the public will not make it possible for you to be identified

in these reports. We will keep all information from your study records private to the extent allowed by law.

COSTS FOR BEING IN THE STUDY AND COMPENSATION

There is no cost to you for being in the study. You will receive a small gift to thank you for your time and effort.

RIGHT TO REFUSE STUDY PARTICIPATION

It is your choice to be in this study. If you decide not to take part, you will need to inform the study staff and it will not affect your healthcare or any services you are entitled to in any way. If you choose to take part in the study and change your mind at any time, then you can stop being in the study. Should you withdraw from the study, the samples collected from you will be included for all the testing. Your participation is entirely voluntary.

REASONS WHY YOU MAY BE WITHDRAWN FROM THE STUDY WITHOUT YOUR CONSENT

You may be removed from the study without your consent for the following reasons:

- The investigator decides that continuing in the study would be harmful to you.
- The study is cancelled by the University of KwaZulu-Natal (UKZN) Biomedical Research Ethics Committee (BREC).
- Other administrative reasons.

STUDY APPROVAL

This study has been ethically reviewed and approved by the UKZN Biomedical Research Ethics Committee (Approval number: to be inserted once received).

PERSONS TO CONTACT

In the event of any problems / concerns / questions you may contact Cherie Cawood, principal investigator or the Study Field Co-ordinator Mr David Khanile on 0861482442, Epicentre, or

The UKZN Biomedical Research Ethics Administration,
Research Office, Westville Campus, Govan Mbeki Building
Private Bag X 54001, Durban, 4000, KwaZulu-Natal, SOUTH AFRICA
Tel: 27 31 260 4769 - Fax: 27 31 260 4609
Email: BREC@ukzn.ac.za

The study staff will be happy to answer any question or concerns.

Thank you for your time.

**CONSENT STATEMENT AND SIGNATURE PAGE FOR ENROLMENT OF
VOLUNTEERS 18 YEARS AND OLDER**

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 can withdraw should I wish to and it would not affect any of my treatment or care.

I have been made aware of the procedures and that this study has minimal susceptibility.

I have been informed as to who the Principal Investigators are and should I wish to, I could contact

Cherie Cawood, principal investigator or the Study Field Co-ordinator Mr David Khanile on 0861482442, Epicentre, or

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:

The UKZN 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

Volunteer

Volunteer

Date

Name (print)

Signature

Study staff member who

Study staff

Date

Administered consent (print)

Signature

Witness

Witness

Date

Name (print)

Signature

Was a copy of the signed copy given to the volunteer?

Yes

No : If no, why not: _____

DREAMS impact evaluation -HIV incidence trends among adolescent girls and young women in the eThekweni (KZN), uMgungundlovu (KZN), City of Johannesburg (GP) and Ekurhuleni (GP) districts, South Africa

Version 1.0 – 23 February 2016

Parent/guardian/care giver consent form for enrolment of volunteers younger than 18 years

ADMINISTRATIVE PAGE

If the volunteer is younger than 18 years of age, this administrative section must be completed prior to completing the consent / assent forms for enrolment.

1. Has the volunteer's age been verified?
 - Yes
 - No

2. If yes, indicate below how the participant's age has been verified
 - Birth Certificate
 - Identification Document (ID)
 - Other: Specify_____.

3. Who has provided consent for this volunteer, younger than 18 years to participate in this study?
 - Parent
 - Legal Guardian
 - Care giver
 - Other_____

Study staff member

Study Staff signature

Date

(print)

If you have indicated NO to Question 1 or in 3 above there is no adult consent, please do not proceed any further.

**PARENT/GUARDIAN/CARE-GIVER CONSENT STATEMENT AND SIGNATURE
PAGE FOR ENROLMENT OF VOLUNTEERS YOUNGER THAN 18 YEARS**

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

I declare that my child/wards participation in this study is entirely voluntary and can withdraw should I or he/she wishes to and it would not affect any of their treatment or care.

I have been made aware of the procedures and that this study has minimal susceptibility.

I have been informed as to who the Principal Investigators are and should I wish to, I could contact

Principle Investigator Cherie Cawood or the Study Field Co-ordinator Mr David Khanile on 0861482442, Epicentre,.

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

The UKZN 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

 Parent/Guardian/Care giver Parent/Guardian/Care giver Date

Name (print) Signature

 Study staff member who Study Staff Date

Administered consent (print) Signature

 Witness Witness Date

Name (print) Signature

Was a copy of the signed copy given to the volunteer?

Yes

No :If no, why not: _____

HIV Rapid Testing Consent form

Name & Surname: _____

I hereby give consent for the health care worker to conduct an HIV rapid test and provide me with the results.	<input type="checkbox"/> Yes <input type="checkbox"/> No
Please provide me with additional lab results should they be available	<input type="checkbox"/> Yes <input type="checkbox"/> No
I hereby give consent for the health care worker to contact me telephonically to follow-up whether I have been linked to appropriate care.	<input type="checkbox"/> Yes <input type="checkbox"/> No

Volunteer's Signature: _____

Date: _____

Witness: _____

Appendix E: Cross-Sectional Study Questionnaire

The subset of questions used in this study are below.

Section: Participant Criteria	
1.	<p>Eligibility</p> <p>Not eligible if answered yes to any of the following questions:</p> <ul style="list-style-type: none"> <input type="checkbox"/> Younger than 12 or older than 24 years of age. <input type="checkbox"/> Non-resident from the study area. <input type="checkbox"/> Refusal by participant to participate in the study. (No consent.) <input type="checkbox"/> Refusal by participant to provide clinical samples of DBS/peripheral blood and self-collected vulvo-vaginal swab samples. <input type="checkbox"/> Cognitive or mental challenges (based on the assessment of the participant's ability to comprehend the study information provided). <input type="checkbox"/> Deaf or mute. <input type="checkbox"/> Not speaking English, IsiZulu, Sotho, Afrikaans.
2.	<p>Refusal</p> <p>What are the reasons that you do not want to participate?</p> <ul style="list-style-type: none"> <input type="checkbox"/> Participant declined to give a reason(s) for refusal. <input type="checkbox"/> I don't have time to participate in the survey. <input type="checkbox"/> I already know I am HIV positive. <input type="checkbox"/> I don't wish to be retested for HIV. <input type="checkbox"/> I find the topics uncomfortable or embarrassing. <input type="checkbox"/> I don't want my samples taken.

	<input type="checkbox"/> Other (specify) _____
3.	Consent Age of participant <input type="checkbox"/> ≥ 18 years
4.	Consent for study participation <input type="checkbox"/> Individual consent only
5.	Sample collection Barcode <input type="checkbox"/> Scan Barcode

Demographics	
6.	How old were you at your last birthday? ¹ <input type="checkbox"/> (Age of the respondent)
7.	Race of the respondent <input type="checkbox"/> African <input type="checkbox"/> White <input type="checkbox"/> Coloured <input type="checkbox"/> Indian/Asian <input type="checkbox"/> Other

¹ HSRC 2016

8.	<input type="checkbox"/> Risk perceptions
	<p>I feel that the chances are high that I can get HIV [skip if already HIV positive]</p> <p><input type="checkbox"/> Strongly Agree</p> <p><input type="checkbox"/> Agree</p> <p><input type="checkbox"/> Disagree</p> <p><input type="checkbox"/> Strongly Disagree</p>

9.	Sexual Activity
	<p>Have you ever had sex with a boy or man, even if only once?</p> <p><input type="checkbox"/> Yes</p> <p><input type="checkbox"/> No</p> <p><input type="checkbox"/> Don't know</p>
	<p>Have you ever had sex with a girl or women, even if only once?</p> <p><input type="checkbox"/> Yes</p> <p><input type="checkbox"/> No</p> <p><input type="checkbox"/> Don't know</p>

Appendix F: Table 1 and Figure 2 Release Form

Date: 20/02/2024

To Whom It May Concern,

I, Cherie Cawood, in my capacity as the Principal Investigator of the DREAMS Evaluation Survey, hereby acknowledge and permit Aimee Zuccarini, conducting the secondary study titled “Determining the Relationship Between HIV Susceptibility Perceptions and the HIV Status of Women Who Have Sex with Women”, to use data specifically from the following table and figure:

Table 1: Study Population in Four DREAMS Implementation Districts 2011–2017

Figure 2: Map of the DREAMS Evaluation Districts

The use of this data is granted exclusively for academic and research purposes within the scope of the aforementioned secondary study. I understand that the data from this table will be cited appropriately, maintaining the confidentiality and integrity of the data as per the ethical guidelines and agreements under which the DREAMS Evaluation Survey data was collected and managed.

Conditions:

The data will not be used for commercial purposes or distributed to third parties outside the context of the specified secondary study.

Any publications or presentations, including the data from this table and figure, will give full citations to the source.

The researcher agrees to share findings from the secondary study with the DREAMS Evaluation Survey team upon request.

Acknowledgement:

By signing this release form, I grant permission for the use of the specified data under the conditions mentioned above. I affirm that the information provided for the use of data is accurate to the best of my knowledge.

Principal Investigator's Signature:



Cherie Cawood

DREAMS Evaluation Survey Principle Investigator

20/02/2024

Researcher's Acknowledgment:

I, Aimee Zuccarini, acknowledge the permission granted by the Principal Investigator and agree to adhere to the conditions set forth in this release form.

Researcher's Signature:



Aimee Zuccarini

Rhode University

20/02/2024

0623659690

Principal Investigator:

Cheriec@epicentre.org.za

Appendix G: Syntax

* Encoding: UTF-8.

Frequency Of Demographic Distribution of WSW Sub-Sample by Age, Population Group, Sex and Location DATASET ACTIVATE DataSet3.

* Custom Tables.

CTABLES

/VLABELS VARIABLES=agegroup race SEX province_cat district DISPLAY=LABEL

/TABLE agegroup [COUNT F40.0] + race [COUNT F40.0] + SEX [COUNT F40.0] BY province_cat > district

/CATEGORIES VARIABLES=agegroup race province_cat ORDER=A KEY=VALUE EMPTY=INCLUDE

/CATEGORIES VARIABLES=SEX district ORDER=A KEY=VALUE EMPTY=EXCLUDE

/CRITERIA CILEVEL=95.

WSW Male Sexual Partner History FREQUENCIES VARIABLES=sex_man

/ORDER=ANALYSIS.

WSW Perceptions of HIV Susceptibility and HIV Prevalence FREQUENCIES

VARIABLES=recodedchances HIVrecoded

/ORDER=ANALYSIS.

Summary of Homogeneity Tests for Perceptions of HIV Susceptibility by HIV Status Using
Levene's Test of Equality of Error Variances,b

UNIANOVA recodedchances BY HIVrecoded

/METHOD=SSTYPE(3)

/INTERCEPT=INCLUDE

/PRINT ETASQ DESCRIPTIVE HOMOGENEITY

/CRITERIA=ALPHA(.05)

/DESIGN=HIVrecoded.

Descriptive Statistics of Perceptions of HIV Susceptibility Survey Responses & HIV Status

ONEWAY recodedchances BY HIVrecoded

/ES=OVERALL

/STATISTICS DESCRIPTIVES

/MISSING ANALYSIS

/CRITERIA=CILEVEL(0.95).

ONEWAY HIVrecoded BY recodedchances

/ES=OVERALL

/STATISTICS DESCRIPTIVES

/MISSING ANALYSIS

/CRITERIA=CILEVEL(0.95).

ANOVA Results for Differences in Perceptions of HIV Susceptibility by HIV status_partner

ONEWAY recodedchances BY HIVrecoded

/MISSING ANALYSIS

/CRITERIA=CILEVEL(0.95).