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Understanding young people's experiences and perspectives on HIV prevention in four communities in Zambia

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DECLARATION

I, Madalitso Mbewe, declare that "*Understanding young people's experiences and perspectives on HIV prevention in four communities in Zambia"* is my own work that has not been previously submitted for any degree or examination at any other university, and that all sources I have used or quoted have been acknowledged.

Madalitso Mbewe **07/12/2020**

Signed:

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ABBREVIATIONS

AIDS – Acquired Immunodeficiency Syndrome

ANC – Antenatal Care

ART – Anti-Retroviral Therapy

ARV – Anti-Retroviral

CHiPs – Community Healthcare Providers

EMTCT – Elimination of Mother-to-Child Transmission

HIV – Human Immunodeficiency Virus

HPTN – HIV Prevention Trials Network

HRB – Health-Risk Behaviour

NGO – Non-Governmental Organisation

P-ART-Y – PopART for Youth

PEP – Post-Exposure Prophylaxis

PLHIV – People Living with HIV

PMTCT – Prevention of Mother-to-Child Transmission

PopART – Population effects of Antiretroviral Therapy to reduce HIV transmission

PrEP – Pre-Exposure Prophylaxis

SSA – Sub-Saharan Africa

STI – Sexually Transmitted Infection

TasP – Treatment as Prevention

TB – Tuberculosis

UNFPA – United Nations Fund for Population Activities

UNAIDS – United Nations Programme on HIV/AIDS

UNICEF – United Nations International Children's Emergency Fund

UTT – Universal Testing and Treatment

VCT – Voluntary Counselling and Testing

VMMC – Voluntary Medical Male Circumcision

YPLHIV – Young People Living with HIV

YPNLHIV – Young People Not Living with HIV

YPNTHIV – Young People who have Never Tested for HIV

WHO – World Health Organization

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ABSTRACT

Background

The HIV incidence among young people aged 15 to 24 years remains a global health concern. Sub-Saharan Africa (SSA) is the home of approximately four million young people living with HIV, and young people in the region account for about 70% of new infections annually. Over 85% of HIV infections among young people in SSA is sexually transmitted. Therefore, the aim of the study was to understand young people's experiences and perspectives on HIV prevention in four communities in Zambia.

Methodology

A qualitative cohort of 23 young people aged 15 to 24 years was sampled from four communities in Zambia. Participants were young people living with HIV (YPLHIV) young people not living with HIV (YPNLHIV) and young people who have never tested for HIV (YPNTHIV). At three-month intervals, data was collected through participant observations, individual in-depth interviews, and participatory workshops involving focus group discussions. Visits were conducted every fortnight to maintain contact with the participants, between the three-monthly intervals. Observation notes were written-up, and the recordings from the interviews and focus group discussions were transcribed and managed using ATLAS ti. All the data was thematically analysed.

Results

HIV prevention was not a novel concept to young people. Participants' experiences and perspectives on HIV prevention were closely linked to age, gender and knowledge of HIV serostatus. Young people living with HIV had more knowledge about HIV and atiretroviral therapy compared to not living with HIV or young people who had never tested for HIV. Health-risk behaviours, such as multiple sexual partners, sexual violence, alcohol and drug use were prevalent among young people. Treatment as prevention was not a well-known concept among young people, including YPLHIV. Community narratives, attitudes and value systems influenced young people's uptake of existing HIV prevention and sexual and reproductive health services. Young people's social networks influenced their health decisions.

Conclusion

Knowledge of one's HIV status was critical in the way that young people experienced and perceived HIV prevention. Young people's health-risk behaviours and decisions on HIV prevention were influenced positively and negatively by multilevel environmental factors, including friends, family and community structures. Therefore, HIV prevention strategies must holistically consider young people's experiences and perspectives on existing HIV prevention methods, taking into account their differences in serostatus, before scaling up or rolling out services.

CHAPTER ONE: STATEMENT OF THE PROBLEM

1.1 Introduction

On a global scale, HIV/AIDS-related deaths are said to have declined by about 33% since 2010 (Avert, 2019). Although the HIV incidence has significantly declined from 2.9 million in 1997 to 1.7 million in 2019, current achievements remain far off track from the United Nations General Assembly (UNGA) 2020 target of reducing the HIV incidence to less than 500 000 (UNAIDS, 2018, 2019, 2020). Consequently, HIV/AIDS remains a major global health problem, even after decades of health programming and interventions (Avert, 2019, UNAIDS, 2018). The United States Department of Health and Human Services (U.S-DHHS) (2019) indicated that the global HIV prevalence was approximately 38 million in 2019, and over 70% of the people living with HIV (PLHIV) domiciled in sub-Saharan Africa (SSA), with eastern and southern Africa accounting for about 20.6 million (57%) of PLHIV, and western and central Africa accounting for about 5.0 million (13%) PLHIV. Asia and the Pacific account for 5.9 million (16%) PLHIV, and 2.2 million (6%) PLHIV are in western and central Europe, and North America (Avert, 2019; UNAIDS, 2017; U.S-DHHS, 2019, 2020).

Global health research has delved further to disaggregate HIV prevalence by age, sex, and gender (Avert, 2019; U.S-DHHS, 2019). Because of these classifications, populations at risk can now be viewed within specific demographic categories (Nakazwe et al., 2019). The United Nations Fund for Population Activities (UNFPA) identified young people as a population at risk, and defined young people as persons between the ages of 15 and 24 years of age (UNFPA, 2010) .

Research has highlighted that the last two decades have seen a steady rise in HIV prevalence among young people, indicating that about 39% of the HIV global burden of disease is borne by young people (Avert, 2019; Govender et al., 2018). Sub-Saharan Africa (SSA) is the home of approximately four million young people living with HIV (YPLHIV), and young people in the region account for about 70% of new infections annually (Price et al., 2018; Ssewanyana, Mwangala, van Baar, Newton, & Abubakar, 2018)

In SSA, Zambia has an HIV prevalence of 11.3%, which is considered among some of the highest in the region (UNAIDS, 2020). The HIV prevalence and incidence among young people in countries like Zambia is said to be on the rise, and the majority of young people are reported to acquire HIV sexually (Lary et al., 2004; Maman, Katebalila, & Mbwambo, 2018; Maticka-Tyndale et al., 2005). Zambia reports an HIV incidence of over 50% among young people (UNGASS, 2018; Linyaku et al., 2017; Nakazwe et al., 2019; Zimba-Chisashi, 2019). A relatively high number of YPLHIV in the age group 15 to 24 years were perinatally infected (Slogrove et al., 2018) at a time when elimination of mother-to-child transmission (EMTCT) methods had not been developed (Slogrove et al., 2018). Young people who were not perinatally infected were victims of high-risk sexual behaviours, which was either consensual or non-consensual, and often generational and intergenerational, thereby, increasing the rate of transmission (Carnevale et al., 2011; Price et al., 2018; Ssewanyana et al., 2018). Young people, for social and economic reasons, find themselves in sexual networks that predispose them to either contracting or transmitting HIV (Bhana & Pattman, 2011; Price et al., 2018; Rogers et al., 2019; Ssewanyana et al., 2018; Viljoen et al., 2017).

In 2015, the United Nations (UN) called for joint global health efforts in order to reduce the HIV incidence among young people, especially in SSA (UNAIDS, 2016a). Targeted areas were identified, listing HIV prevention as key to reducing the HIV incidence among young people (UNICEF, 2018). Understanding HIV prevention for young people was considered critical on the global health agenda (UNICEF, 2018).

Previous research in Zambia indicated that strategic frameworks in the country did not adequately cover the HIV prevention needs of young people on a large scale (Hodgson, Ross, Haamujompa, & Gitau-Mburu, 2012; Mburu et al., 2014a; 2013). The traditional forms of HIV prevention identified through existing programmes and interventions included condom use, abstinence, monogamy, and the use of sterile sharps and syringes (National AIDS Council, 2017). Voluntary medical male circumcision (VMMC) was another form of HIV prevention that received much attention in the last decade (Chandra-Mouli et al., 2015; Mburu et al., 2013; National AIDS Council, 2017). Research showed that HIV testing was key to HIV prevention (Denison et al., 2012; 2015; Hayes et al., 2014; 2019; Hodgson et al., 2012), highlighting that HIV testing or one's knowledge of their serostatus was the starting point for the utilization of antiretroviral therapy (ART) to reduce or eliminate horizontal and vertical transmission (Alexio et al., 2019; Bond et al., 2016, 2018; Evidence for HIV Prevention in Southern Africa, 2018; Shanaube et al., 2017).

1.2 Statement of the Problem

Previous research in Zambia showed that strategic frameworks in the country still needed to build a variety of HIV prevention strategies for young people (Hodgson et al., 2012; Mburu et al., 2013, 2014). Research further suggested that relevant HIV interventions for young people ought to be pitched with the idea that young people were a unique group with unique needs (Pettifor et al., 2013). ‘What works for a single group of young people may not suit another’(UNAIDS, 2016a).

Not many qualitative studies have investigated young people’s HIV experiences and HIV prevention practices or behaviours (Linyaku et al., 2017; Mackworth-Young et al., 2020; Mburu et al., 2014b; Philbin, 2014). The P-ART-Y study conducted in 9 communities in South African and 10 communities in Zambia included a qualitative component that provided an opportunity to understand young people’s experiences and perspectives with regard to HIV prevention. Understanding of the various HIV ‘pathways’ (i.e., being HIV positive, HIV negative or never having tested for HIV) in which young people find themselves, can be critical for understanding how they navigate through their HIV service needs (Hoddinott et al., 2018).

The HIV incidence among young people, particularly in Zambia, has been on the rise, despite the global focus on HIV prevention over the last three decades (Govender et al., 2018; Mavedzenge et al., 2011). This situation is partly as a consequence of the fact that HIV services for young people are offered in different places and spaces depending on what the community has to offer (Kielmann & Cataldo, 2017). The experiences and perspectives of young people specifically have not been strategically integrated currently within existing HIV prevention practices and programmes of the country (Denison et al., 2015; Hodgson, Ross, Haamujompa, & Gitau-Mburu, 2012; Mburu et al., 2013). With the growing call to involve and understand the voices of young people in public health discourse that is focused on alleviating the public health burden of HIV, the present study was undertaken and aimed to explore the lived experiences and perspectives of young people of different HIV serostatuses regarding HIV prevention.

1.3 Aim of the Study

The aim of the study was to understand young people’s experiences and perspectives on HIV prevention in four communities in Zambia.

1.4 Objectives of the Study

The objectives of the study were the following:

- To understand the experiences and perspectives regarding HIV prevention of young people who tested positive for HIV (YPLHIV).
- To understand the experiences and perspectives regarding HIV prevention of young people who tested HIV negative (YPNLHIV).
- To understand the experiences and perspectives regarding HIV prevention of young people who had not tested for HIV and who did not know their HIV serostatus (YPNTHIV).

1.5 Significance of the Study

In SSA, Zambia has an HIV prevalence of 11.3%, which is considered among the highest in the region (UNAIDS, 2020). In 2015, the United Nations (UN) called for joint global health efforts to reduce the HIV incidence among young people, especially in SSA (UNAIDS, 2016a). Previous research in Zambia indicated that strategic frameworks in the country did not adequately cover the HIV prevention needs of young people on a large scale (Hodgson et al., 2012; Mburu et al., 2014a, 2013).

Therefore, this study will contribute and build on existing literature with regard to strategies involving young people on HIV prevention, as well as report on the experiences and perspectives of young people on current HIV prevention strategies. Through this study, health policy-makers, public health programmers and ministerial decision-makers may understand how young people view and reason on matters of existing HIV prevention strategies. It will also provide critical insights into some of the narratives that may affect the behaviours of young people of serodiscordant status who are confronted by various HIV challenges. Currently, there is an urgent focus on the need for evidence-based HIV prevention programmes and services for young people in Zambia (Ministry of Health, 2017). The findings of the present study, therefore, can be instrumental in informing or reshaping the existing modes of HIV prevention programmes and service delivery strategies for serodiscordant young people who are confronted by various HIV challenges in Zambian communities.

1.6 Delimitations of the Study

1.6.1 Inclusion Criteria

Young people with the following characteristics were included in the study:

- Aged 15 to 24 years and resident in the main PopART study catchment area.

- In the category of YPLHIV, an eligible participant had to be tested as HIV-positive and placed on ART for ≥3 months, at the time of recruitment.
- In the category of YPNLHIV, a participant had to be tested HIV-negative for ≥3 months, because the seroconversion period is three months approximately.
- In the category of YPNTHIV, a participant was never tested for HIV and did not know their HIV serostatus at the time of recruitment.

1.6.2 Exclusion Criteria

Young people with the following characteristics were excluded from the study:

- Young people resident outside the main PopART study catchment areas.
- Persons that were younger than 15 years and older than 24 years.

1.7 Definitions of Terms

Health-risk behaviours refer to activities carried out by people with an intensity and frequency that increases one’s susceptibility to injury or disease (Ssewanyana et al., 2018).

Intergenerational sex is a once-off or repeated sexual encounter between a young person and a person ten or more years older (Dellar, Dlamini, & Karim, 2015; Subedar et al., 2018).

HPTN 071 (PopART) refers to the HIV prevention trials network trial number 071, also known as PopART - population effects of antiretroviral therapy to reduce HIV transmission (Hayes et al., 2014).

Post-exposure prophylaxis (PEP) is short term antiretroviral (ARV) treatment that is given to a person who is HIV negative within 72 hours of potential exposure to HIV to prevent them from getting HIV (Avert, 2016).

Pre-exposure prophylaxis (PrEP) is a long term ARV treatment method by which people who are HIV negative and at risk of getting HIV, take a prophylactic pill is every day to prevent infection (UNAIDS, 2016b).

Prevention of mother-to-child transmission (PMTCT) is a combination of effort services to reduce and eliminate the chances of a woman who is HIV positive from passing on the virus to her infant before and after birth (Avert, 2018a).

Sexual violence is forceful non-consensual sexual attempts or acts that can be physical or verbal (WHO, 2012).

Transactional sex is a once-off or continuous sexual relationship, where sex is exchanged for material support, financial and/or other benefits (UNAIDS, 2019).

Treatment as prevention (TasP) is the use of antiretroviral therapy (ART) to prevent HIV transmission (Avert, 2019; Bekker & Hosek, 2015; UNAIDS, 2019).

Voluntary counselling and testing (VCT) is a process through which a person who voluntarily decides to get an HIV test, goes through counselling before and after getting an HIV test (Avert, 2017; Denno, Hoopes, & Chandra-Mouli, 2015).

Voluntary medical male circumcision (VMMC) is a medical procedure in which part of the foreskin of the penis is removed by a trained health care professional to reduce a male's susceptibility to HIV by 60% (Avert, 2018).

Young people refers to persons between the ages of 15 and 24 years (UNFPA, 2010).

CHAPTER TWO: LITERATURE REVIEW

2.1 Introduction

Young people, especially in SSA, are a population at high-risk for HIV infection (Bekker & Hosek, 2015; UNAIDS, 2018, 2019). Existing statistics indicate a high HIV disease burden among young people in SSA (Lary et al., 2004; Rogers et al., 2019; Sani, Abraham, Denford, & Ball, 2016; Sutcliffe et al., 2020; UNAIDS, 2019, 2020) suggesting the need for HIV prevention strategies that are specific to the needs of young people (Anyanwu, Akinsola, Tugli, & Obisie-nmehielle, 2020; Lary et al., 2004; Maticka-Tyndale et al., 2005; Sani et al., 2016).

2.2 HIV and Young People in SSA

Although young people, as a population in SSA, are alarmingly affected by HIV, their level of HIV risk varies according to their subgrouping within the population (Mustafa, 2018; Nakazwe et al., 2019). For instance, there exists a discrepancy in risk levels between young men and women (Govender, 2018; Hayes, 2019; Hosek, 2016; Viljoen, 2017). Specifically, young women aged 15to 24 years are more vulnerable to HIV infection compared to young men their age (Nakazwe et al., 2019). UNAIDS (2019) reported that young women aged 15 to 24 years were at 60% higher risk of contracting HIV compared to their male counterparts.

Some of the key HIV risk factors in SSA include poverty, economic stress, gender inequality, social norms and rigid constructions of masculinity and femininity (Sani et al., 2016; UNAIDS, 2019). One common mode of transmission that has been associated with these risk factors is sexuality (Sani et al., 2016). Statistics showed that about a quarter of the infections in SSA were among young people under the age of 25 years, and these were usually as a result of unprotected sex (Mustafa, 2018; UNAIDS, 2018). Previous research named sexuality as a centripetal force for HIV transmission, with over 90% of HIV infections among young people in SSA occurring as a result of sexual (both consensual and non-consensual) activity (Bhana & Pattman, 2011; Campbell, 2001; Phail & Sani et al., 2016; Stevenson et al., 2003). Sexually transmitted HIV infection among young people has often been linked with limited sexual and reproductive health (SRH) knowledge, and a lack of awareness of health services (Pettifor et al., 2005; Price et al., 2018; Ssewanyana et al., 2018). Young people in the region are said to engage in high-risk sexual practices (Govender et al., 2018; Pettifor et al., 2005; Price et al., 2018; Ssewanyana et al., 2018). Ssewanyana et al. (2018) classified high-risk sexual practices to be among the top health-risk behaviours (HRBs) of young people in SSA, stating that high-risk sexual behaviour was often common among young people in the age range of 15 to 24 years. Additionally, high-risk sexual behaviour among young people was also linked to adventure and curiosity associated with puberty and growing-up (Price et al., 2018; Ssewanyana et al., 2018). Health-risk behaviours among young people in SSA were often said to be amplified by limited knowledge levels that were mostly fuelled by a culture of silence, especially linked to sexuality (Govender et al., 2018; Lary et al., 2004; Price et al., 2018; Ssewanyana et al., 2018)

Research in SSA emphasized that a culture of silence and taboo existed around issues of sexuality (Eaton, Flisher, & Aar, 2003; Lundgren & Amin, 2015). Culture, social norms, and gender roles and patterns were highlighted as significant influences on young people’s sexual choices

(MacPhail & Campbell, 2001; Maticka-Tyndale et al., 2005; Viljoen et al., 2017; Yllequist, 2018). Previous research explained that cultural and social norms influenced how young men and women were ‘expected’ to behave in sexual relationships (Edin et al., 2016; Haberland & Rogow, 2015; Mburu et al., 2014; Viljoen et al., 2017; Yllequist, 2018). These ‘expectations’ significantly impacted young people’s choices around sexuality and, eventually, HIV prevention. Lary et al. (2004) highlighted culturally acceptable practices and experiences, such as non-consensual sex in a relationship, among the factors that rallied against safe sex and condom use among young people. Because of this, most young people were more likely to engage in unsafe sex, and young women were often more vulnerable than young men. For this reason, the gender lens cannot be overemphasized in analysing HIV risk (Berer, 2004; Maticka-Tyndale et al., 2005; Rogers et al., 2019; Sani et al., 2016; Sohn et al., 2019; Ssewanyana et al., 2018; Tolli, 2012).

Sexually transmitted HIV infection is often interlocked with gender issues that are key to understanding young people’s health-risk and HIV prevention behaviours (Lary et al., 2004; Lundgren & Amin, 2015; Ssewanyana et al., 2018; Viljoen et al., 2017). Gender imbalances, propelled by African societal norms, tend to make young women more vulnerable to contracting HIV from their partners (Rogers et al., 2019; Yllequist, 2018). Most African traditions prohibit young women from resisting violent partners, and this makes young women remain in high-risk situations or relationships (Dellar et al., 2015; Eaton, Flisher, & Aar, 2003; Lary et al., 2004; Lundgren & Amin, 2015). Apart from abusive relationships, young women often fell prey to sexual abuse from not only their partners, but also from other members in their communities, such as family members, including uncles and older men (MacPhail & Campbell, 2001; Maticka-Tyndale et al., 2005; Stephenson, 2009; Villa-Torres & Svanemyr, 2015).

2.2.1 HIV and Young People in Zambia

Only 43.9% of young people in Zambia aged 15 to 24 years have correctly identified ways of preventing sexual transmission of HIV (UNAIDS, 2019). Previous research in Zambia reported low knowledge among young people and a lack of access to HIV and SRH services that can support the reduction in HIV transmission (Kalibala, Samuel, & Mulenga, 2011). Zambia has committed to the global target to "ensure that 90% of young people have the skills, knowledge, and capacity to protect themselves from HIV infection, and experience reasonable access to sexual and reproductive health services by 2020 in order to reduce the number of new HIV infections among adolescent girls and young women to below 100 000 per year" (UNAIDS, 2019).

In 2014, the HIV prevention trials network (HPTN) launched trial number 071 in 21 communities, twelve in Zambia and nine in South Africa. The HPTN 071 is also known as the population effects of ART to reduce HIV transmission (PopART). The PopART project was a three-arm, cluster-randomized trial, whose purpose was to determine the impact of a combination HIV prevention intervention package on HIV incidence in Zambia and South Africa (Hayes et al., 2019; 2014; Musheke et al., 2012). A few months into the study, investigators realized that there was a need to deliver PopART with a particular focus on young people. In this regard, an ancillary study called PopART for youth was added to the research project. It aimed to determine the impact of PopART on young people - PopART for youth (P-ART-Y) – over a period of 26 months.

With the UNAIDS 90-90-90 targets in mind, PopART was conducted in conjunction with the existing public health system (Hayes et al., 2019; Musheke et al., 2012; Shanaube et al., 2017).

Partnerships with existing local government health facilities were established and utilized throughout the study in order to provide sustainable HIV care in the long run (Hayes et al., 2014, 2019; Musheke et al., 2012; Shanaube et al., 2017).

The PopART intervention was delivered by a team of community HIV care providers (CHiPs) who went from door-to-door in all intervention communities providing HIV services (Hayes et al., 2014; 2019; Shanaube et al., 2017). The intervention package included voluntary HIV counselling and testing (VCT) and established a referral linkage to HIV care in local health care facilities for persons diagnosed HIV positive (Hayes et al., 2014; 2019; Shanaube et al., 2017). Men who tested HIV negative were encouraged to go to the local health facility for voluntary medical male circumcision (VMMC). Pregnant women were referred for antenatal care (ANC), and those who tested HIV positive were referred for prevention of mother-to-child transmission (PMTCT) services (currently called elimination of mother-to-child transmission - EMTCT). During the door-to-door visits, condom use was promoted and provided to all residents. In addition, tuberculosis (TB) and sexually transmitted infection (STI) screening were conducted. In all screening processes, formal referrals for follow-up care at the local health facility were provided for all positive cases.

In the P-ART-Y study, the same interventions as the main study were offered to young people, with a few adjustments to suit the interventions to young people (Hayes et al., 2019; Shanaube et al., 2017). In addition to the main PopART package, young people also had community health day events, school-based VCT, and the revamping of youth-friendly spaces in some communities. There were also youth counsellors who provided escort services to health care services for young people who either had difficulties linking to health care services or had defaulted on their treatment. The youth counsellors also provided counselling services to young people, as and when needed.

2.3 Young People’s Experiences and Perspectives on HIV Prevention

Previous research in SSA has captured some young people’s experiences and perspectives about HIV prevention (Denison et al., 2015; Hodgson et al., 2012; Mburu et al., 2013). Young people’s experiences of HIV prevention usually centred on the choices and preferences of protective methods, HIV service provision, access to health facilities and an awareness of the relevant stakeholders offering HIV prevention services (Hodgson et al., 2012; MacPhail & Campbell, 2001; Mburu et al., 2013; Viljoen et al., 2017). Phail and Campbell (2001) shared young men’s experiences and perspectives that indicated inconsistent condom use either by choice or to conceal other sexual affairs. Young people sometimes expressed that they preferred certain preventive methods over others, and that pleasure sometimes tended to supersede protecting themselves from contracting HIV (MacPhail & Campbell, 2001; Rogers et al., 2019; Yllequist, 2018).

HIV prevention choices sometimes varied by gender (Nakazwe et al., 2019.) On the one hand, more often than not, young women rarely took up the responsibility of looking or even suggesting condom use for various reasons, including fear of breaking up relationships or losing potential marriage partners, fear of losing financial or material resources (in the case of transactional sex), inability to negotiate safe sex, little knowledge of risk behaviour because of premature age, and fear of community stigma, if spotted accessing or seeking SRH services for the purpose of accessing condoms (Govender et al., 2018; Lary et al., 2004; Viljoen et al., 2017). On the other hand, previous research indicated that the ‘responsibility’ to access and decide upon protective methods was often given to young men (MacPhail & Campbell, 2001; Rogers et al., 2019; Viljoen et al., 2017; Yllequist, 2018). Some scholars indicated that often young men made ‘the request’ or initiated sex in the relationship, which sometimes also meant they had to figure out whether or not protection would be necessary, and how to get access to condoms, for instance (Lary et al., 2004; Nakazwe et al, 2019; Ssewanyana et al., 2018).

Previous research has often linked SRH practices and HIV risk to young people’s ability or inability to access appropriate SRH services (Denno et al., 2015; Govender et al., 2018; Price et al., 2018; Ssewanyana et al., 2018; Villa-Torres & Svanemyr, 2015). Challenges regarding appropriate SRH services for young people can be understood in the dual contexts of provision and accessibility (Denno et al., 2015; Dickson, Ashton, & Smith, 2007; Mburu et al., 2013; Zimba-Chisashi, 2019). Both these contexts are often punctuated by human and material resource issues (Lary et al., 2004; Nakazwe et al., 2019; Sani et al., 2016; Ssewanyana et al., 2018; UNAIDS, 2018; 2019). Access to information and material resources, such as condoms, has sometimes been reported as difficult for young people who live in traditional, rural settings (Lary et al., 2004; Mburu et al., 2014; UNAIDS, 2019; Villa-Torres & Svanemyr, 2015). Research has also reported that there were occasions when young people had access to condoms from a wide range of sources, but did not know how to use them correctly (Denno, Hoopes, & Chandra-Mouli, 2015; Pettifor et al., 2005).

2.3.1 Experiences of Young People Living with HIV

Global health action has acknowledged that HIV prevention and SRH services for young people need to take into account the unique needs of young people (Kielmann & Cataldo, 2017; Shanaube et al., 2017; UNAIDS, 2018; 2014). The UN in 2014 recognized that the HIV service needs of YPLHIV were central to HIV prevention among young people for both the present and future generations (UNAIDS et al., 2014). Previous research involving YPLHIV in SSA showed that their experiences regarding HIV prevention were usually linked to access to SRH services (Denno et al., 2015; Hodgson et al., 2012; Mburu et al., 2014b; Ssewanyana et al., 2018; Subedar et al., 2018).

In 2011, a situational assessment of HIV prevention programming for young people in Zambia was conducted (Kalibala & Mulenga, 2011). It showed that YPLHIV had special HIV prevention and SRH needs that had not been taken into consideration in HIV prevention programmes in the country (Kalibala &Mulenga, 2011). Like other studies, the assessment pointed out that young people were misplaced in the service provision picture in the sense that most health facilities had not figured out whether to attend to them at paediatric or adult clinics (Kalibala & Mulenga, 2011; Mburu et al., 2014b). The assessment also showed YPLHIV experienced stigma when they sought HIV prevention at SRH services, especially for obtaining condoms (Kalibala &Mulenga, 2011). One of the key outcomes of the assessment was that YPLHIV were stigmatized by adults of their communities (Kalibala & Mulenga, 2011). Apart from stigma, previous research also showed that YPLHIV often struggled to access appropriate HIV services, because they sometimes did not understand what was available (Cataldo, Lettow, Coats, Musandu, & Mulumba, 2014; Ssewanyana et al., 2018).

Creating a supportive environment for young people, including YPLHIV, was considered foremost among the recommendations for HIV prevention service provision (Damulira et al., 2019; Kalibala & Mulenga, 2011; Kielmann & Cataldo, 2017; Napierala Mavedzenge et al., 2011). Further research highlighted that the support needs for YPLHIV were key for their SRH choices, and this was largely dependent on their experiences at home, at the clinic and in the community at large (Denison et al., 2012; 2015; Denno et al., 2015).

One of the key issues was how young people related to HIV prevention efforts in their respective communities (Shanaube et al., 2017; Yllequist, 2018). Previous research in SSA has highlighted some key perspectives and experiences that young people had with HIV prevention (Linyaku et al., 2017; Price et al., 2018; Yllequist, 2018). There existed a distinctive and dramatic interaction between sex, gender, and power relations in the HIV epidemic in SSA, especially in southern Africa (Maticka-Tyndale et al., 2005; Maughan-Brown et al., 2018; Rogers et al., 2019; Yllequist, 2018).

2.3.2 Young People’s Perspectives on Intergenerational Sex and HIV Prevention

Previous research in SSA often highlighted some stereotypes in the HIV epidemic among young people (Viljoen et al., 2017). HIV was sometimes referred to as ‘an epidemic of wealth’, which often emphasized that intergenerational sex created an opportunity for young women to get access to wealth that they desired or wanted (Mustafa, 2018; Nakazwe et al., 2019; Viljoen et al., 2017). In most cases these studies revealed that oftentimes young women acquired wealth from much older men and not from their fellow young peers (Mustafa, 2018; Yllequist, 2018). These relationships were often characterised by unequal power relations that not only increased young women's risk of contracting HIV, but also made it difficult for young women to negotiate safe sex with their much older partners, whose chances of carrying HIV were many times higher than those of sexually active young men (Govender et al., 2018; Lary et al., 2004; Mustafa, 2018; Price et al., 2018; Viljoen et al., 2017; Yllequist, 2018).

2.3.3 How Young Women are Perceived to Transmit HIV

In some studies reported in SSA, the power relations that existed, related to sex and gender, often made young women experience high-risk sexual situations that often stemmed from how men were set on a pedestal in their society, as if they had a biological privilege or natural entitlement to acquire sex from women, regardless of the woman's desire (Edin et al., 2016; Lary et al., 2004; Lundgren & Amin, 2015; Maughan-Brown et al., 2018; Price et al., 2018; Viljoen et al., 2017; Yllequist, 2018). This was said to not only fuel the disparaging practice of intergenerational and condomless sex, but also made HIV prevention difficult, especially for young women who were often considered weak, physically, intellectually, regarding safe sexual practices (Eaton, Flisher, & Aar, 2003; Maughan-Brown et al., 2018; Nakazwe et al., 2019; Viljoen et al., 2017; Yllequist, 2018). In spite of this, more often than not, women were still heavily blamed for the spread of HIV, especially young women (Mustafa, 2018; Rogers et al., 2019; Subedar et al., 2018; Viljoen et al., 2017; Yllequist, 2018). Scholars often argued that this biased view of women as 'spreaders' of HIV, obscured their vulnerability to the existing, but unwritten, power relations that disempowered them from making appropriate HIV prevention choices (Govender et al., 2018; Subedar et al., 2018; Viljoen et al., 2017).

2.4 Experiences of HIV Testing and HIV Prevention

Previous research in southern Africa has shown that although HIV testing and knowing ones HIV status have been purported to hold great promise as a starting point for HIV prevention, it was equally important to understand the different social consequences of knowing or finding out one's HIV status, especially for young people (Shanaube et al., 2017; Yllequist, 2018).

A study in Zambia showed that HIV counselling and testing services in the country did not offer adequate information to lessen stigma against PLHIV (Mutombo, 2014). People who had undergone HIV testing still believed in the prevailing myths and misconceptions and, sometimes, this was also true for PLHIV, because they did not fully understand what they were living with (Mutombo, 2014). Other studies in SSA indicated that in spite of the increase in HIV programming in the region, myths and misconceptions were still prevalent and they left very little room for well-informed HIV prevention choices (Damulira et al., 2019; Haffejee et al., 2018; Linyaku et al., 2017; Maticka-Tyndale et al., 2018).

Previous research has highlighted that the onus was on HIV prevention service programmers to understand what young people knew and understood about HIV prevention (Damulira et al., 2019;

Nakazwe et al., 2019; Sohn et al., 2019). Previous research has shown that sometimes young people perceived HIV prevention efforts as emphasizing that a particular HIV serostatus was more desirable than another (Bernays et al., 2015; Denison et al., 2015; Yllequist, 2018). While this may be true for public and global health purposes, research in SSA showed that young people sometimes felt that having an HIV positive status attracted blame, regardless of how it was acquired, and this oftentimes served to misplace YPLHIV and their role in the national HIV prevention strategy (Govender et al., 2018; Ssewanyana et al., 2018; Yllequist, 2018). The Perspectives from YPLHIV often indicated that HIV prevention efforts and campaigns sometimes created a form of stigma against them by focusing more on YPNLHIV as key decision-makers in the process of HIV prevention (Yllequist, 2018).

Previous research has shown that the afore-mentioned biased emphasis on HIV negative young people, as being key role-players in HIV prevention, made it harder for communities to openly talk about how HIV could be prevented at various levels (Haffejee et al., 2018; Mburu et al., 2014b; Rogers et al., 2019; Viljoen et al., 2017; Yllequist, 2018). A study in South Africa showed that young people avoided talking about HIV in the community, because they feared being stigmatized as an HIV positive individual (Yllequist, 2018). HIV was often misunderstood as ‘a family thing’, if one person had it, then everybody in the household had it (Yllequist, 2018). Additionally, research in SSA showed that in most cases there was a pervasive silence about HIV in most communities in the region (Mbereko et al., 2019; Hodgson et al., 2012; Linyaku et al., 2017; Mburu et al., 2014b).

2.4.1 Young People and not Testing for HIV

HIV testing was often mentioned as a key strategy for HIV prevention efforts (Bekker & Hosek, 2015; Denno et al., 2015; Haffejee et al., 2018; Shanaube et al., 2017; Vermund & Hayes, 2013). Previous studies in SSA showed that not testing for HIV was a common practice among young people (Shanaube et al., 2017; Yllequist, 2018). A study in South Africa showed that young people who did not want to test for HIV were reported to be very defensive over their decision not to test (Yllequist, 2018). For some young people, not testing for HIV was often tied to not wanting to discover their HIV positive serostatus or entertaining the false perceptions about HIV testing, based on the prevailing myths and misconceptions (Haffejee et al., 2018; Shanaube et al., 2017; Yllequist, 2018). A study in Zambia showed that young people under the age of 18 years did not want or were unable to test for HIV, because of a health policy that required them to obtain parental consent in order to get an HIV test (Evidence for HIV Prevention in Southern Africa, 2018; Kalibala & Mulenga, 2011).

2.4.2 Myths and Misconceptions About HIV Testing

Studies in SSA revealed that young people sometimes feared getting an HIV test, because they did not trust the health care system (Denno et al., 2015; Haffejee et al., 2018; Shanaube et al., 2017; Vermund & Hayes, 2013). A qualitative study in SSA showed that some young people believed that they would get a positive result, because the nurse testing them for HIV would use a needle that was already contaminated with HIV (Yllequist, 2018). Studies that focused on young people also highlighted that the lack of trust in the health care system was sometimes linked to the perception that if the young person turned out to be HIV positive, in one way or another, the nurse would disclose the young person's HIV positive status to others in the community (Haffejee et al., 2018; Mburu et al., 2014b; Shanaube et al., 2017). Myths about HIV were said to be perpetuated by the invisibility of HIV in most communities (Linyaku et al., 2017). Scholars often attributed myths about HIV to the silence about living with HIV (Haffejee et al., 2018; Yllequist, 2018), without the right mix of knowledge and insights from actual experiences, people’s imaginations were constantly at liberty to breed myths and misconceptions (Yllequist, 2018).

2.5 Pervasive Silence About HIV and the Implications for HIV Prevention

Previous research in SSA revealed that young people were ignorant about the prevalence of HIV in their age-group (Price et al., 2018; Ssewanyana et al., 2018; Stephenson, 2009; Yllequist, 2018). For instance, a study in South Africa revealed that in a national survey, 79.2% of young people aged 15 to 24 years did not perceive that they were at risk of getting HIV (Yllequist, 2018). Research in SSA presented evidence that issues of HIV were rarely discussed among young people, and this often was said to be as a result of communities being pervasively silent about HIV (Akintola, 2011; Bernays et al., 2015; Yllequist, 2018). Researchers sometimes highlighted that it was almost as though HIV was considered a “medical” condition, and that the only place it could be discussed freely was at the clinic ‘with the medical people’ (Alli, Maharaj, & Vawda, 2013; Hodgson et al., 2012; Yllequist, 2018).

Research in southern and eastern Africa highlighted that this silence about HIV made it difficult for young people to make HIV prevention choices (Conner et al., 2019; Eaton, Flisher, & Aaro, 2003; Stephenson, 2009; Yllequist, 2018). Qualitative research in SSA showed that discussions about HIV were said to be difficult, and young people sometimes indicated that talking about HIV was awkward, because it was linked to sex, and sex was often a difficult topic to talk about, even when sexually active (Edin et al., 2016; Emmanuel et al., 2015; Gwanzura-Ottemöller & Kesby, 2006; Kielmann & Cataldo, 2017; Maughan-Brown et al., 2018; Mburu et al., 2014b; Ssewanyana et al., 2018; Yllequist, 2018). Research further highlighted that HIV discussions were dependent on people's interest in talking about it (Bernays et al., 2015; Haffejee et al., 2018; Linyaku et al., 2017; Mburu et al., 2014b; Philbin, 2014). Their lack of interest and desire to talk about it, not only increased the risk of transmission, but also preserved a culture of silence about sex and HIV (Maticka-Tyndale et al., 2018; Yllequist, 2018).

Discussions about sex and HIV prevention were sometimes coupled with issues of masculinity (Edin et al., 2016; Lary, Maman, Katebalila, & Mbwambo, 2004; Maticka-Tyndale et al., 2018; Ssewanyana et al., 2018; Viljoen et al., 2017). Previous research findings showed that young people followed unwritten rules that empowered men to 'take the lead' in issues dealing with or engaging in sex and, as such, if a man did not start the discussion, it was not 'a woman's place' or prerogative to start the conversation (Emmanuel et al., 2015; Haffejee et al., 2018; Hallman, Kenworthy, Diers, Swan, & Devnarain, 2015; Maticka-Tyndale et al., 2005; Maughan-Brown et al., 2018; Nakazwe et al., 2019; Rogers et al., 2019; Ssewanyana et al., 2018; Viljoen et al., 2017). The disempowerment of young women was often evident in some of the explanations young women gave for not engaging in conversations about HIV prevention (Emmanuel et al., 2015; Maughan-Brown et al., 2018; Viljoen et al., 2017; Yllequist, 2018). Researchers highlighted that discussions about HIV were largely dependent on what young people were taught or made to believe, as they grew-up (Lundgren & Amin, 2015; Maticka-Tyndale et al., 2005; Maughan-Brown et al., 2018; Viljoen et al., 2017). Some young women in a study in South Africa, when asked why they never started conversations about HIV prevention and sexual choices with their sexual partners, highlighted that ‘they had never been taught to do so’ (Yllequist, 2018).

Studies in SSA also showed that because sex and HIV were difficult topics in most communities, having discussions about HIV and sex were sometimes difficult, even for people offering HIV prevention services (Govender et al., 2018; Yllequist, 2018). A study in South Africa showed that young people who worked for an initiative offering HIV prevention services, sometimes found it challenging to start and sustain discussions about sex and HIV prevention with their clients who were also young people aged 15 to 24 years, and this made it more difficult to correct or disseminate correct information about HIV, even at peer level (Yllequist, 2018).

2.6 Young People’s Experiences in Acquiring Information About HIV Prevention

Previous research in SSA acknowledged the concerted efforts that existed to ensure that young people were informed about HIV (Berer, 2004; Chandra-Mouli et al., 2015; Denno et al., 2015; Doyle et al., 2012; Michielsen et al., 2013; Sani et al., 2016). Studies in SSA indicated that some of the key players and disseminators of HIV prevention information for young people were non-governmental organisations (NGOs) (Denno et al., 2015; Nakazwe et al., 2019; Yllequist, 2018). Non-governmental organisations were often named among some of the common sources of comprehensive information for young people (Denno et al., 2015; Kalibala & Mulenga, 2011). Apart from NGOs, young people also obtained HIV prevention information from schools, the television, radio, the SRH clinic, and friends (Stephenson, 2009; Yllequist, 2018). From the different studies, young people’s perceptions about HIV prevention sources were based on the level of detail they received, and the health clinics and NGOs were often said to offer 'more details' about HIV (Denno et al., 2015; Dickson et al., 2007; Mburu et al., 2013; Stephenson, 2009; Yllequist, 2018). Some studies took a step further to highlight that the type of information received at the clinic was sometimes dependant on who was receiving the information (Denison et al., 2015; Linyaku et al., 2017; Yllequist, 2018). Young people mentioned that sometimes 'you get more information once you are a victim of a particular disease' (Yllequist, 2018). In this regard, researchers felt that YPLHIV received more detailed information about HIV, which YPNLHIV were not privileged enough to receive, because of their negative HIV status (Denison et al., 2015; Haffejee et al., 2018; Mburu et al., 2013; Yllequist, 2018). For example, details about antiretrovirals were often limited to YPLHIV (Bernays et al., 2015; Denison et al., 2015; Yllequist, 2018).

Research also showed that some of the older youth were able to highlight the differences they saw in the type of HIV prevention information they received, from the time that they were young (Yllequist, 2018). Young people often indicated that when they were young, HIV prevention emphasis was placed on avoiding HIV transmission by avoiding contact with another person's blood, and not sharing razor blades or needles (Vermund & Hayes, 2013; Yllequist, 2018). In some studies, young people highlighted that they only heard about HIV being sexually transmitted, when they were much older and had already had unprotected sex (Eaton, Flisher, & Aaro, 2003; Edin et al., 2016; Haffejee et al., 2018; Hallman et al., 2015; MacPhail & Campbell, 2001; Ssewanyana et al., 2018; Svanemyr, Amin, Robles, & Greene, 2015). A study in Zambia showed that HIV prevention messaging was quite contentious in a school-setting, where only abstinence messaging was allowed (Kalibala et al., 2011). A study in South Africa advocated promoting HIV prevention information, especially in school-settings that were sometimes labelled as promoting sexual activity among young people (Yllequist, 2018).

2.7 HIV Prevention for Young People

Michielsen (2012) indicated that there was a need to understand the different focus areas in HIV prevention interventions for young people in SSA, and to explore them further. Previous research has categorized HIV prevention efforts as comprising biomedical, behavioural and structural or contextual (Michielsen, 2012). These categorizations were linked to HIV key risk factors, and within each category, there were specific interventions identified for implementation (Bekker & Hosek, 2015; Pettifor, 2014; UNAIDS, 2019).

2.7.1 Biomedical Methods of HIV Prevention

Biomedical forms of HIV prevention included some of the most common forms of HIV prevention, such as male and female condoms, and VMMC (Avert, 2019; Pettifor, 2014). Biomedical HIV prevention strategies have been stepped up to include SRH services and TasP in the form of post-exposure prophylaxis (PEP) and pre-exposure prophylaxis (PrEP) (Bekker & Hosek, 2015; Avert, 2019; UNAIDS, 2019). In the past, most interventions commonly promoted condom use and VMMC, however, recent research in biomedical techniques were said to have exhibited some promise with regard to HIV prevention among young people in SSA (Bekker & Hosek, 2015; Rogers et al., 2019; Slogrove et al., 2018). Further research and inquiry among young people in SSA have shown that promotion of SRH services, including SRH rights, and TasP can help advance HIV prevention efforts (Avert, 2019; Bekker & Hosek, 2015; Pettifor, 2014; UNAIDS, 2019).

In a review of different HIV prevention strategies in SSA, Pettifor et al. (2013) explained that PrEP had different successes for young people, recommending further investigation and replication in different settings among young people, especially in high incidence regions like SSA (Pettifor et al., 2013). The implementation of ART or TasP for young people is still under review in Zambia (Zimba et al., 2019). Interest in TasP, such as PrEP, is one approach that has recently been perceived to possess great promise in reducing the risk of HIV transmission (Bekker & Hosek, 2015; Zimba et al., 2019).

2.7.2 Behavioural Methods of HIV Prevention

Current behavioural methods included some of the oldest forms of HIV prevention strategies that centred around preventing sexual transmission of HIV through behaviour change (Dellar et al., 2015; Pettifor et al., 2011). Behavioural approaches, such as delaying sexual debut, applying the ABCs (abstinence, being faithful, and using a condom), reducing multiple concurrent sexual relationships, limiting partner-change, and avoiding substance use were promoted in order to reduce HIV risk (Pettifor et al., 2011). Since its advent in the 1990s, these were some of the popular methods of HIV prevention (Doyle et al., 2012; Pettifor et al., 2013; Yllequist, 2018). However, in the mid-2000s, research indicated that there was a need to take into account underlying socio-cultural, economic, political, legal and other contextual factors of HIV prevention (Avert, 2019; Pettifor, 2014).

2.7.3 Structural and Contextual Methods of HIV Prevention

Context has been highlighted as the bedrock for underlying factors that increase HIV risk among young people in SSA (Rogers et al., 2019; Yllequist, 2018). Some of the important drivers of HIV risk among young people included poverty, gender and power inequities, stigma and discrimination, and limited health spaces that focused specifically on young people (Nakazwe, 2019; UNAIDS, 2018, 2019). Structural interventions also sought to empower and propagate poverty reduction in order to reduce risky behaviour, such as transactional sex among young people (Mavedzenge et al., 2011; Michielsen, 2012; Nakazwe, 2019; Pettifor, 2014; UNAIDS, 2018; 2019).

Ho et al. (1995) indicated that in most developed countries, the lessons learnt from patient experiences helped improve HIV management. Only a few studies have been conducted in developing countries that explored the experiences and perspectives of HIV prevention among young people (Pettifor et al., 2005; Price et al., 2018; Ssewanyana et al., 2018). There is need for more literature that presents and explains the experiences and perspectives of young people in particular (Doyle et al., 2012).

2.8 Theoretical Framework on HIV Prevention

HIV prevention is one of the key areas in the fight against the spread of HIV (Ministry of Health, 2017). Some of the dominant theories in designing HIV prevention interventions and programmes include the Social Cognitive Theory (SCT), the Stages of Behaviour Change (SoC), the Social

Ecological Model (SEM), the Theory of Reasoned Action (TRA) or Theory of Planned Behaviour (TPB), and the Health Belief Model (HBM) (Michielsen, 2012; Michielsen et al., 2012).

The results or effects of theory-based studies have often produced a rise in knowledge and instilled positive attitudes, but yielded very little change in the sexual behaviour of young people (Michielsen et al., 2012). Therefore, it has been suggested that because HIV prevention is heavily dependent on sexual behaviour, sexuality can take different contexts and have no uniform behaviour (Mburu et al., 2014b; Ssewanyana et al., 2018).

2.8.1 Theoretical Framework of the Study

Robson (2011) highlighted ethnographic methods among other approaches used in exploratory designs. Baum (1995) explained that the exploratory design provides the opportunity for study participants to share experiences and perspectives that can provide an in-depth and rich understanding of young people's experiences and perspectives on HIV prevention. In this study, ethnographic methods were used to understand HIV in the context of the study communities. Wilson and Chaddha (2009), in their description of ethnography in theory and practice, underlined that ethnography allowed the researcher to uncover various meanings of social behaviour through the lens of the subject under investigation. It is in light of this that the research team of the main study sought to understand how young people contextualized HIV within the PopART study communities.

In order to understand how the study participants interpreted their world, the study employed seven dimensions that were covered in four modules. The seven dimensions included the cast of characters, space, how they got by, power relations, sex and love, horizons and ambitions/fears, and meta-structural.

The cast of characters dimension entailed looking at an individual in a familial context, using a genogram and other social network diagrams. These were used to understand how the study participants related with their family. Social network diagrams were also used in this dimension to understand various aspects of physical and emotional closeness or distance, and how these were tied to HIV issues.

Space was another dimension that was explored to understand how participants made use of their space, and their interactions within various spaces, at home and in the community. This dimension was deemed necessary to get a sense of how young people chose to use space, and how this linked to HIV. It was also through this dimension that researchers were able to highlight different spaces in the community that were linked to HIV by the participants and through certain observations.

How they 'got by' was a dimension focused on understanding the socio-economic situation of the study participants. Because HIV is often linked to economic issues, this dimension sought to understand how participants survived and managed to 'get-by' on a daily basis. The power relations dimension was used to create an understanding about decision-making, confidentiality and manipulation in the lives of the study participants and the community. This dimension was meant to help researchers understand how HIV was linked to the different power relations that existed among participants and their community.

‘Sex and love’ was another dimension that was explored. This dimension was explored because of the close link that HIV has with issues of sex and love. The ‘horizons and ambitions/fears’ dimension was deemed useful to understand how participants situated themselves at present and in the future, regardless of their HIV status. This dimension was explored to understand how HIV fell into play with the different views that participants had of themselves, and how their personal views related to the choices they made concerning HIV presently, and how this translated into their future perspectives.

The meta-structural dimension looked at the family or individual and their place in politics. It focused on policies, contextual factors, both positive and negative, and how these affected the participants and their families in relation to HIV. These seven dimensions guided the inquiry at different stages of the study. It is was based on these concepts that the interview guides and other study tools and activities were designed.

2.8.1.1 The Social Ecological Model

In this study, the social ecological theoretical framework, otherwise referred at as the social ecological model (SEM) was used to understand the interaction between and within these seven dimensions, and how meanings could be derived from young people’s experiences and perspectives of HIV prevention (Glanz, 2005). The SEM identifies and explains how behaviour is shaped by ones environment (Banks et al., 2020; Baral et al., 2013; Busza et al., 2012; Dyson et al., 2018; Glanz, 2005; Michielsen et al., 2012; Musheke et al., 2012; Svanemyr et al., 2015). The SEM postulates that behaviour cannot be shaped singularly by the individual themselves, but rather is a result of a complex relationship between different players at different levels in one’s environment (Banks et al., 2020; Davis et al,. 2015; Dyson et al., 2018; Frew et al., 2016; Glanz, 2005; McLean et al., 2017).

Previous public health research that has used SEM to explain individual health behaviour and choices emphasized that although the individual was the final actor in any given health scenario, their choices were contrived by experiences and perspectives that they encountered at different levels in a sequential or haphazard manner throughout their life course (Banks et al., 2020; Davis et al,. 2015; Dyson et al., 2018; Frew et al., 2016; Glanz, 2005; McLean et al., 2017). The social ecological framework contextualises human behaviour using the following levels: individual, interpersonal and community levels (Banks et al., 2020; Davis et al., 2015; Dyson et al., 2018; Frew et al., 2016; Glanz, 2005; McLean et al., 2017; Michielsen et al., 2012). In applying this theory, this study grouped the seven dimensions according to these three levels and tried to explain some of the results based on SEM theory. Figure 2.1 below is an illustration of how the seven dimensions employed in this study have been classified into the different levels of SEM.

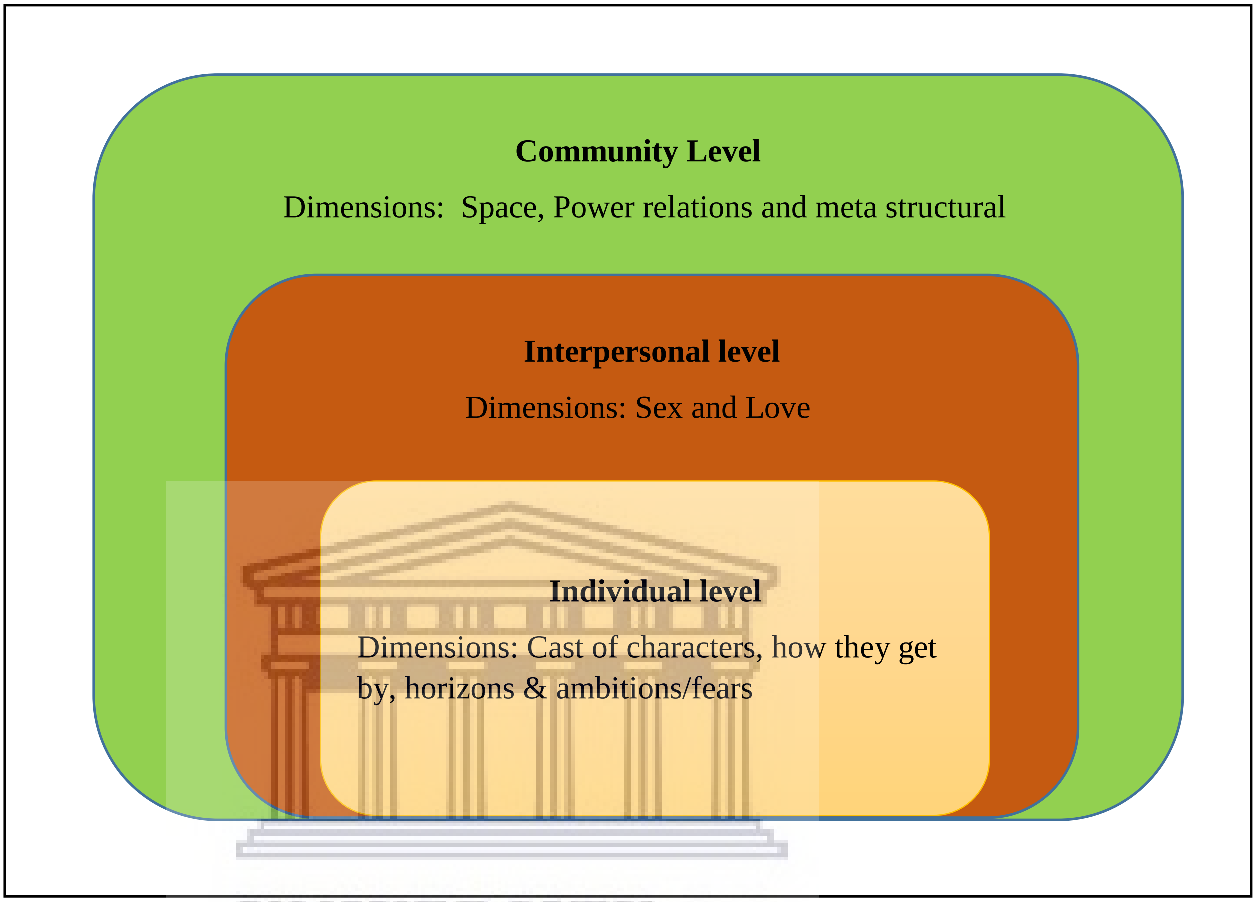


Figure 2.1: Classification of the seven dimensions according to the three levels of the Social Ecological Model

CHAPTER THREE: RESEARCH METHODS

3.1 Introduction

This chapter is a description of the research methods and procedures employed in the study. It presents the study design, instruments and procedures. It also gives a description of the study population, and how study participants were sampled or recruited for the study. Additionally, it also gives a breakdown of how data was collected and analysed. Also presented are the efforts taken to maintain data quality, and the ethical considerations.

3.2 Study Design

This study entailed a secondary data analysis of research data that was originally collected in the P-ART-Y study. In the original P-ART-Y study, a qualitative exploratory design, was used to follow a cohort of young people.

3.2.1 Study Setting

The P-ART-Y study was conducted in four communities in four provinces in Zambia, namely, Lusaka, and the Central, Northern and Southern provinces of Zambia. Out of the four communities, three were PopART intervention sites and one was the control site. Generally, the four PopART communities were low-income, high-density urban residential settings, comprised of multilingual ethnic groups (Musheke et al., 2012). Nyanja and Bemba are the most commonly spoken languages throughout Lusaka and the Northern and Central provinces, whereas Tonga and Nyanja are spoken in the Southern provinces. Most of the residents in these provinces live in poverty, and this is reflected in the type of housing (Musheke et al., 2012). The healthcare needs in all PopART communities are serviced by one government clinic, which provides both in- and out-patient services. The health facilities were initially designed (and built in the post-colonial period) for smaller populations, but with time the populations and catchment areas have grown, due to migration from rural and informal settlements to urban areas (Musheke et al., 2012).

3.3 Study Population and Sample Size

3.3.1 Description of the Study Population

The study population comprised a total of 23 young people aged 15 to 24 years. They were purposively recruited from four PopART study sites, with six recruited from each site, except for one site where only five were recruited. Two participants were recruited from each of the following three categories, i.e., young people living with HIV (YPLHIV x 2) and were on ART for ≥3 months at the time of recruitment and, next, were young people (who tested negative) not living with HIV (YPNLHIV x 2) and, lastly, were young people who were never tested for HIV (YPNTHIV x 2). A period of not less than three months of testing for HIV was picked as the eligibility criterion for YPNLHIV, because of the three-month window period for HIV seroconversion (Avert, 2017). In all three HIV categories, the researchers sought a gender balance of participants. This mix of participants was considered appropriate for gaining a deeper understanding of the experiences and perspectives of young people of HIV categories (Patton, 2003). Young people were recruited with the help of community HIV care providers (CHiPs), youth counsellors and clinic lay health workers.

3.4 Data Collection

In the P-ART-Y study, an ethnographic approach was used to collect data from the cohort of 23 young people. The 23 participants were followed over an 11-month period (from February 2017 to January 2018). Qualitative researchers applied different techniques to explore and understand the participants' ways of life, experiences and perspectives (Robson, 2011). Each participant was involved in four main data collection activities, conducted at two-to-three-month intervals, i.e., participant observations, individual in-depth interviews (IDIs), participatory workshops and focus group discussions (FGDs). Within these activities, visual tools were used, which included social and disclosure network diagrams that explored young people's networks, and how these linked to HIV prevention. Drop-in visits were made every fortnight, in-between the four main visits, in order to maintain contact with the participants.

Open-ended questions of an exploratory nature were used in the IDIs and FGDs to collect data in the original P-ART-Y study. This allowed the participants to provide unanticipated responses, which enabled an in-depth understanding and interpretation of the participants' experiences (Baum, 1995).

3.4.1 Participant Observations

At the beginning of each round of activities, the researchers visited the participants to make appointments for when they could spend a day with them. On an agreed day and time, the researchers would visit a participant and observe them in their natural setting, as they carried out their daily activities in order to gather natural facts about the participant (Creswell, 2014; Genzuk, 2000; Robson, 2011). Researchers sometimes accompanied and walked around the community with participants, as they carried out various routine tasks. During these observations, the participants engaged in various conversations and discussions about different topic areas. In the process of the observations, notes were taken by the researchers of all the participant's daily interactions within their social network.

3.4.2 In-Depth Interviews

During the first, second and fourth visits, each participant took part in an individual in-depth interview (IDI) for about 30-to-60 minutes, at a convenient time and in a private venue in order to ensure participant confidentiality and integrity. A semi-structured interview guide was used to conduct the interviews. Probes were incorporated into the interviews to aid data collection and provide meaningful depths and breadths of information that created a better understanding of the phenomena from the participant's experience and perspective (Legard, 2003; Robson, 2011). Probes were sometimes generated from observations in order to gain more clarity and understanding of occurrences. The IDIs were recorded, with the participant's consent.

3.4.3 Participatory Workshop and Focus Group Discussions

In the third round of data collection, a participatory workshop was held in each study site, and all the participants within the site were invited to attend, regardless of their HIV serostatus. The workshop lasted just over half-a-day. Participatory activities and FGDs were conducted as part of the research protocol. Robson (2011) and Creswell (2014) highlighted that FGDs were very useful for collecting data about the larger community. Community members shared experiences and perspectives that reflected community-based norms. Other participatory activities included vignettes and collages. Young people used vignettes to tell true life stories about what happened in their communities. Each participant also made a collage ‘about me’, using pictures from magazines to describe themselves. All the participants explained their vignettes and collages to the researcher, who captured the explanations on an audio recorder with each participant’s consent.

3.5 Data Analysis

In the P-ART-Y- main study, the audio recordings of all the interviews were transcribed verbatim, then translated into English, and further cleaned of any form of identifiers, such as names of individuals, and places in the communities. Observation notes were written-up, and visual data scanned as part of data collection. In this study, the data was analysed with computer-aided data analysis (CADA) software called ATLAS ti., a qualitative data management programme (Pope, Ziebland, & Mays, 2000).

An inductive approach to thematic data analysis was used (Saldana, 2016). This involved exploring (reading and re-reading) each individual piece of data, whether textual and visual, in order to identify relevant codes (Robson, 2011; Saldana, 2016). The codes were put into a coding framework, where they were defined, so that they did not lose meaning during the analysis process. The codes were subsequently used to select segments in the text or visual data with similar meaning. Portions identified to have a similar code were grouped into potential themes. The themes were reviewed and compared across sources to generate meaning, and analytic memos were generated during this process (Robson, 2011; Saldana, 2016). The data was then interpreted, which involved understanding and explaining the thematic networks or links in the data in order to generate an understanding of the concepts, based on the participants HIV categories, and HIV prevention experiences and perspectives (Robson, 2011).

3.6 Research Rigour

3.6.1 Prolonged Engagement

Given the ethnographic nature of the original study, the cohort of 23 young people were followed in their respective communities at prearranged intervals between February 2017 and January 2018. According to Robson (2011), the researcher's relationship with the respondent tends to become a trusting one over time, when an ethnographic mode of enquiry is used. Over time, the respondents progressively build trust in the researcher, and this is said to increase the credibility of the data collected (Creswell, 2014; Forero, 2018; Robson, 2011). It was hoped that by the researchers spending a prolonged period of time with the participants, it provided the researchers sufficient time to build trust with the participants in order to collect credible data.

3.6.2 Triangulation

Triangulation of data was one of the key aspects that was included in the design of the study. In this case, robust or varied data collection methods were used, including in-depth interviews, participant observations and participatory workshops (i.e., where young people made visual collages about themselves, wrote vignettes, and participated in FGDs). Data collected through these different data collection methods was triangulated to validate the information (Creswell, 2000; Malterud, 2001; Robson, 2011).

3.6.3 Reflexivity

It is important for researchers to locate themselves within the research (Creswell, 2014; Forero, 2018). It has been suggested that if qualitative research methods are to be trustworthy and confirmable, the researchers ought to reflect on themselves as research entities. Ritchie and Lewis (2003) explained that researchers ought to self-reflect in order to identify and self-report the different physiognomies, assumptions, prejudices, and views about the study. This is said to not only be helpful as a validation technique, but also creates a basis for the reader's understanding of the researcher's viewpoint, and the extent to which the researcher's personal views are separated from the study (Ritchie & Lewis, 2003).

In the P-ART-Y study, a daily reflection tool was used at the end of each day of data collection. The tool was a guide that researchers used to journal their experiences. The researchers documented their reflections of the data collection experience on a daily basis. These included taking note of their thoughts, pre- and post-data collection, challenges faced (what exactly happened and how they were resolved or not), feelings experienced during the data collection process and how these were handled, and ideas generated in preparation for the next data collection round. Researchers also had de-briefing sessions with research assistants, while in the field. In addition, researchers also had debriefing sessions after data collection with the senior researcher. These were sometimes ad-hoc, as and when needed during data collection, as well as at the end of each data collection round. The debriefing sessions helped to keep track and control of the reflexive activities throughout the study period. Reflexivity was not only useful for situating the researcher's personal influence on the study, but was also a monitoring technique for understanding the extent to which the researcher was able to suspend their personal expectations in the study. Notes from reflective journals contributed to analytic memos that were used to refine the analysis process and knit together the discussion of the study findings.

3.6.4 Training in Ethnographic Methods of Qualitative Research

In order to ensure that researchers had the right skills to collect credible data, all researchers, inclusive of research assistants, were trained in ethnographic research methods prior to data collection (Robson, 2011). Refresher meetings and in-house testing of data collection activities were carried out a week or two before data collection in order to strategize and sharpen the researchers' skills, before undertaking the actual field work.

3.7 Ethical Considerations

3.7.1 Ethical Clearance

This study comprised secondary data analysis of research data collected in the original P-ART-Y study. Permission to access and analyse the data was obtained from the principal investigators. Ethical clearance was obtained in the main study from the University of Zambia Biomedical Research Ethics Committee (UNZABREC) (reference number: 011-11-12). The main research study was also granted authorisation from the National Health Research Authority (NHRA) in Zambia. Ethics clearance to conduct the present study was also obtained from the Biomedical Research Ethics Committee (BMREC) at the University of the Western Cape (Ethics reference: BM19/7/19).

3.7.2 Informed Consent

Informed consent is among the key ethical principles that guarantee the safety of the study participants. This means that the participants must be free to decide to participate in the research activities, knowing fully and truthfully what is involved and what their involvement entailed (Creswell, 2014; Forero, 2018; Robson, 2011). In order to understand their (participant) involvement, the researcher had the obligation of truthfully giving the participants full details about the investigation. The researcher had to disclose all manner of data collection tools and materials used in the study. Apart from that, the researcher had to also inform the participants about the purpose of the study, and the possible consequences of taking part in the study (Forero, 2018; Robson, 2011). This meant that the researcher had to inform the participants about any potential harm or discomfort, and the benefits, as well as how the data would be collected and used, and by whom (Robson, 2011). One of the key reasons for obtaining informed consent was to empower the participants to know that they were free or at liberty to take part or not at any point in the study. It was also the bedrock for establishing a truthful and respectful exchange of information between the participant and the investigator (Creswell, 2014; Robson, 2011).

In the P-ART-Y study, participants were taken through an informed consent process, which involved an informing process and a consenting process. At the beginning of each consenting process, participants were given information sheets in English and in local languages (depending on participant preference) containing the purpose, risks, and benefits of the study. When participants were unable to read, the information sheet was read and explained to them in a language they preferred and understood. Only participants who agreed to be part of the study were given consent forms to sign. Participants who declined to participate in the study were also informed that their non-participation would not negatively affect their lives in any way. For example, young people who were benefiting from P-ART-Y interventions at the time of the study, still continued to do so, even if they decided not to take part in the study. In addition, participants who were accessing ART from the clinic, were not affected or infringed from doing so, upon denying consent. For minors, i.e., participants younger than 18 years, the information process was in two parts, one for the participant and another for the parent/guardian. All participants (and their parents/guardians, in the case of minors) were informed that they had the autonomy to stop or withdraw from the study at any point without any penalty or loss of benefit to which they were entitled. For minors, assent was obtained from the participant, and consent was also obtained from their parent(s) or guardian(s). Throughout the data collection activities, participants were reminded of their rights and roles as a participant, and they were also encouraged to take their time during the IDIs, and only to speak when they felt comfortable to talk about sensitive topics.

3.7.3 Confidentiality, Data Protection and Anonymity

It is the role of the researcher to protect the identity of the participant, because research participants have the right to anonymity and confidentiality (Creswell, 2014; Robson, 2011). This meant that the researcher had to ensure that there were no ways of linking the participants to the information they shared. In the case of this study, issues of HIV, and health in general, required the strictest confidence in order to avoid causing harm or discomfort to the participants, either during or after the study. Ensuring confidentiality also meant that the researcher had to be sensitive about discussing certain issues and topics. To ensure confidentiality, participants chose the spaces to be interviewed, and they were also informed that the recordings were strictly for research purposes, and would not be linked to them in any way. All the data collected was cleaned of names regarding community locations, research participants and other identifiers. All the data in the study is kept in a password-protected computer with access allowed to the researcher and supervisors only. The participants were assured that the utmost security would be applied to protect the research data, which will be deleted after a period of 5 years. Should the research results be published, then the participants' personal information will not be disclosed.

CHAPTER FOUR: RESULTS

4.1 Introduction

This chapter is a presentation of the study results. It begins with providing a description of the study participants, and proceeds to give a detailed interpretation of the main themes and sub-themes of the study.

4.2 Description of the Study Participants

The 23 participants were young people aged 15 to 24 years. A description of the personal characteristics of the participants is presented in Table 4.1. A summary of the characteristics of the participants is presented in Table 4.2. Out of the 23 participants, twelve (52%) were male and eleven (48%) were female. Furthermore, eight (35%) were young people living with HIV (YPLHIV), of the eight, four (17%) were young women and four (17%) were young men. Seven (30%) were young people who had never tested for HIV (YPNTHIV), of the seven, four (17%) were young men and three (13%) were young women. Eight (35%) were young people not living with HIV (YPNLHIV), of the eight, four (17%) were young men and four (17%) were young women. A total of seven (30%) were still in school, while two (9%) were recent school-leavers (completed grade 12), five (22%) had dropped out of school, one (4%) was in college, one (4%) did volunteer work, and eight (35%) were in informal employment.

Table 4.1: Description of the personal characteristics of the study participants.

HIV Serostatus	Age (years)	Gender F= female M= male	Marital Status	Occupation
Community 1 (C1) (n = 5)				
YPNLHIV	18	F	Engaged (occasionally living as married)	Out of school (dropped out)
YPNLHIV	17	M	Single	In school
YPNTHIV	21	M	Single	Out of school (dropped out)
YPLHIV	16	F	Single	In school
YPLHIV	21	M	Single	Out of school (completed grade12)
Community 2 (C2) (n = 6)				
YPNLHIV	21	M	Married	Mini-bus conductor
YPNLHIV	18	F	Single	Out of school (completed grade12)
YPNTHIV	24	M	Single	Sole trader
YPNTHIV	17	F	Single	Out of school (dropped out)
YPLHIV	17	F	Engaged	In school
YPLHIV	18	M	Married	Trader (fish, meat, and chickens)
Community 3 (C3) (n = 6)				
YPNLHIV	21	M	Single	Volunteer at the clinic
YPNLHIV	20	F	Married	Out of school (dropped out)
YPNTHIV	16	F	Single	Out of school (temporarily dropped out of school)

YPNTHIV	21	M	Single	Farmer
YPLHIV	21	M	Single	Informal football coach
YPLHIV	17	F	Single	In school
Community 4 (C4) (n = 6)				
YPNLHIV	21	F	Single	In college
YPNLHIV	24	M	Single	Does odd-jobs, i.e., carpentry, building, waiter, etc.
YPNTHIV	16	F	Single	In school
YPNTHIV	21	M	Single	In school
YPLHIV	19	F	Single	Lodge housekeeper
YPLHIV	17	M	Single	In school

Table 4.2: Summary characteristics of the participants.

Variable	Number (n)	Percent (%)
Male	12	52
Female	11	48
YPLHIV	8	35
YPNLHIV	8	35
YPNTHIV	7	30
16-year-old	3	13
17-year-old	5	22
18-year-old	3	13
19-year-old	1	4
20-year-old	1	4
21-year-old	8	35
22-year-old	0	0
23-year-old	0	0
24-year-old	2	9
Single	18	78
Engaged	1	4
Married	3	13
Co-habiting	1	4
In school	7	30
Dropped out of school	2	9

Completed grade 12	5	22
In college	1	4
Employed	8	35
Volunteer work	1	4

Key: YPLHIV - young people living with HIV;
YPNLHIV - young people not living with HIV;
YPNTHIV - young people never tested for HIV.

4.3 HIV Prevention Messaging in the Community

This theme highlights the visual HIV messages that the researchers observed in the community during data collection. A few descriptions of how young people perceived some of the messages will be given in this section.

During the different rounds of data collection, researchers took independent transect walks in the community in order to understand the community dynamics. Researchers also accompanied the young people, while they carried out their daily activities in the community. Throughout the activities and interactions in the community, researchers took note of the different types of messages that were visible in the various study communities. In most cases, community messaging about HIV and HIV prevention was in the form of posters, flyers, banners (seldom used), and writings on walls (commonly at clinics, some schools and places where HIV programmes were being run). In most instances, messages were tailored for the general members of the community. For example, some messages read, "*Know your status, test for HIV today!*" HIV prevention posters used adult models who appeared to be in their late thirties or forties, in most instances, and sometimes even much older.

Some school walls in the communities had writings about HIV prevention. These often emphasised abstinence for young people while still in school in order to prevent contracting venereal diseases, such as HIV and other sexually transmitted diseases. Organisations that were running different HIV initiatives in the community also displayed HIV prevention messaging in the form of posters and writings on their walls.

In the four study communities, each one had a local government health clinic. Out of the four community clinics, only three had spaces designated for young people, which were referred to as the 'youth-friendly corners'. All the youth-friendly corners had HIV and SRH messages on the walls in the form of posters tailored to young people. Most posters used colloquial language that seemed to be preferred by some young people. Young people who had visited youth-friendly corners often referred to some of these posters, during the discussions or interviews about HIV prevention. For example, during an interview, one young man mentioned a poster that he had seen at the youth-friendly corner, where the poster said "one love kwasila" (literally meaning "have only one love"), which to him meant 'stick to one partner'.

In summary, the HIV prevention messaging seen around the various communities promoted VMMC, condom use, safe sex, PMTCT, abstinence, HIV testing and sticking to one partner.

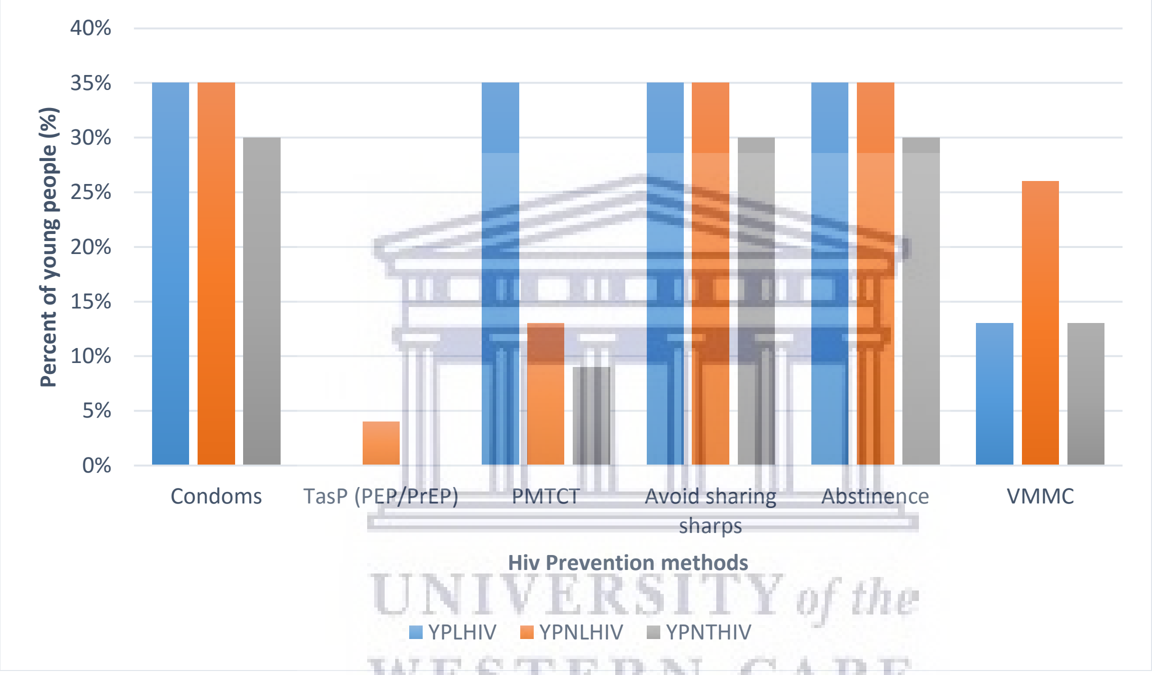
4.3.1 Sources of HIV Prevention Information as Recountered by Young People

In the second interview, young people were asked to do an HIV timeline. Through this exercise, it was possible to gain some understanding of the participants' sources of information about HIV that was recalled from as far back as they could remember. A comprehensive list of sources was used that included school-books, teachers, friends/classmates, health clinics, community health care workers, television shows and adverts, radio adverts, parents (this was very rare, and included mostly mothers), and community talks/rumours. In most cases, young people often stated that they remembered first hearing about HIV when they were in grade one, at an age of about 7 or 8 years. At this age, some young people mentioned that they sometimes heard people talk about HIV and condoms in the community, but they often had a vague understanding of what that meant. Some participants shared how they vividly remembered being told by their parents or guardians never to use other peoples razor blades or sharp objects in order to protect themselves from getting ‘AIDS’. Most young people often mentioned that they started to understand a few concepts about HIV, including HIV prevention, when they were still at school, between the fifth and ninth grades (at an age of approximately 13 to 17 years). Young people often mentioned that the information they received was generally about HIV as a virus, and how to prevent it from spreading. Some young people also mentioned that, as they were growing up, the issue of HIV did not seem like a big problem for young people, which was sometimes evident in their perceptions about HIV and the methods of prevention.

4.4 Young Peoples Perspectives on HIV Prevention

This theme presents the results on how young people perceived HIV prevention. It includes descriptions of what young people did or did not consider to be HIV prevention, and how this shaped their thinking and subsequent actions regarding HIV prevention.

During the second interview, all participants in the study were asked to list the different types of HIV prevention methods they knew. Figure 4.2 shows the HIV prevention methods listed by the 23 young people in the study.



Key: TasP - treatment as prevention
PEP - post-exposure prophylaxis
PrEP - pre-exposure prophylaxis
PMTCT - prevention of mother-to-child transmission
VMMC - voluntary medical male circumcision
YPLHIV - young people living with HIV
YPNLHIV - young people not living with HIV
YPNTHIV - young people never tested for HIV

Figure 4.1: HIV prevention methods listed by study participants.

Condom use (100%), avoiding the sharing of sharps (100%), and abstinence (100%) were the most commonly mentioned modes of HIV prevention by young people. Fewer young people listed PMTCT (57%) as a common mode of HIV prevention. The least common methods of HIV prevention that one participant listed were PEP and PrEP. A few young people also listed 'avoiding kissing' as a method of HIV prevention.

When asked to comment on the HIV prevention methods that they listed, young people often felt that condoms were the most commonly known and used HIV prevention method by both adults and young people:

> *"Because there are people like me who love their lives, so I cannot stop using condoms, even if someone tells me not to use them. I can just ask them that why have you insisted on me to have sex with me without a condom with you. So, if you are weak you can start having sex without a condom and that will lead to HIV contraction."* (YPNLHIV_M_21_C2)

All young people in the study emphasised avoiding sharing sharps, such as razor blades and needles. Although all of the participants listed abstinence as a method of preventing HIV transmission, some argued against abstinence stating that 'some people are born with it':

> *"You can be staying [*abstaining*], but you [already] have it.*"
>
> (YPNTHIV_F_16_C3).

Other young people argued that abstinence was not easy, because people had the option of using condoms. They shared some comments from conversations with fellow young people in the community, who compared condoms to abstinence:

> *"They use condoms, because if you tell many that HIV is a virus whereby for you to prevent it, stop having sex before marriage [then] many disagree. Many refuse. They say no! There are condoms".* (YPLHIV_F_16_C3)

One young man mentioned that he often avoided community health care providers, because on one occasion he was advised by them to abstain from sex. After this encounter, the young man mentioned that he felt guilty, because he felt incapable of abstaining and, so, he decided to run away whenever he saw them:

> *"They told me that really the best way of preventing HIV and AIDS was abstaining from sex. I really didn't want that, because you know people of nowadays, us people of nowadays when someone is telling you the truth, you do not want to accept it, because you know that you have already done the wrong things. So, you are guilty and don't want to do that." (YPNLHIV_M_17_C1)*

Another young man, when asked to comment on HIV prevention methods mentioned that:

> *"Keeping away from girls [abstinence] that can be difficult."*
>
> (YPLHIV_M_21_C3)

4.4.1 Young People's Perception of Their Community in Relation to HIV Prevention

Sometimes, how young people understood HIV prevention issues was closely tied to how they understood their community, and the risk factors therein. Young people sometimes perceived their community in the context of a location, and the population-density as a risk factor for HIV. They often linked these concepts to social and economic factors, which they thought increased the risk of contracting HIV, given the physical location or position of the community and its density. Some young people who lived in high-density areas of the community often felt that 'high-density' locations somehow contributed to the levels of HIV risk among young people. Young people often mentioned that the way in which the community was positioned and arranged made it easy for them to engage in what they defined as risky behaviours, which were said to be common occurrences within the community and its surroundings. For instance, young people shared how high-density areas seemed to have a lot of freedom at night, possibly because of some domestic situations in which the members found themselves. Some young people mentioned that there were some situations where there was not enough space for them to sleep at home, and this created an opportunity for engaging in risky sexual activity:

> *"Sometimes you will find that the house is two rooms, but 15 people live there or even more. The young person will say to the parents, 'I will be going to sleep at my friend's place by the corner there,' and [the] parents will agree, because they know that friend. But when that night time comes, if it is a girl, she will pack a bag and go to the "friend's" house only to go [to] the bars, nightclubs or even a lover's house or a blesser - these "sugar-daddies" - that is what they are calling them now. But at home they know that she has gone to the friend's place to leave more space for others to sleep there."* (YPLHIV_F_19_C4)

Another young man mentioned that:

> *"It is easy to go away at night in our communities, because we are a lot, [and] sometimes your parents won't even notice that you are not there. It's not even*

> *expensive to get into the next community, you just need K5 for transport to go and have a good time."* (YPNLHIV_M_21_C3)

During a focus group discussion in one of the study communities, a young person also made a comparison between high population-density areas and low population-density areas, highlighting that young people from the latter areas often came to high population-density areas to get access to alcohol and other drugs that they could not access in their own (low population-density) residential areas:

> *"Sometimes it is because here people do not have a curfew, and youth from this good compound have curfew. So, they come here to have the freedom to smoke and drink anyhow without restrictions."* (FGD_C6)

Sometimes, the parents' occupations and the time that they spent away from home were linked to young people's opportunity to engage in 'risky behaviour':

> *"Like for me, my father is in Chambeshi and my mother is in Lusaka. They sometimes don't come home even for 3 months. So, when I need to go, I just plan my move and they won't know. I just make sure I take care of myself at least."*
>
> *(YPNLHIV_M_17_*C1)

Another young man mentioned that he took the opportunity, when his father was not around, to go and drink beer and get to smoke weed with friends.

4.4.2 Alcohol and/or Substance Use and HIV Prevention

Young people often associated alcohol and substance use with contracting HIV. They mentioned that drinking was quite common among young people in the community, especially at night-time, and this was when young people engaged in high-risk sexual activities. Narratives and observations indicated that there was a difference in how young men and young women were talked about or viewed in their communities. For instance, during an interview, a young woman, had this to say when she compared young men's behaviours to young women's behaviours *(R = respondent, and I = interviewer)*:

> R: As for the girls, the social life is quite bad, and for the boys it's bad, but I can't complain, but for the girls it's really bad.
>
> *I: I'm a bit interested in knowing how bad?*
>
> R: How bad? [Laughing]
>
> *I: Yes, when you mean bad can you explain to me what you mean by bad?*
>
> R: Well, the girls, they take like it, ummm "Chilepule" (literal meaning: tear it), you go out with a married man who is old enough to be your father and all those stuffs. And, for the guys, its only 'Junta' [spirit with very high alcohol content] and beer that's it.
>
> *I: What does 'Chilepule' mean…?*
>
> R: Yaaa [laughing] it's like break it, expand it, like breaking the rules.
>
> (YPNLHIV_F_21_C2)

In addition, some young people mentioned that young women and girls often went to the bars to get drinks and find themselves 'buyers' or 'blessers'. These were terms used for older men who patronised drinking places and spent money on young girls, in exchange for sex. For young men the story was somehow different. Some young men went to bars at any time they pleased. Based on the group narratives, sometimes this was not really an issue, while other narratives painted scenarios of the bars as being ‘unruly’, and often associated with gangsterism and crime. Community members often attributed these behaviours to the fact that some young people lived on their own, and were not under parental care. Study participants who used alcohol or intoxicating substances, often boasted about this, by sharing how they went to places, far away from home, to drink with friends or smoke marijuana, so that their parents or guardians did not “get in the way”. When a young man was asked why he never drank at home or in the pub, he said that he feared his father, who might find out or that they might even accidentally bump into each other, whilst drinking at the same ‘pub’.

From the observations, it appeared that young people and adults considered some places in the community as ‘notorious’ hangouts for youth, although these places were unique to each community. When asked about such places, common narratives recountered by participants were that some of the young men led gangs and sold marijuana and other drugs in such places. The gangs were often a mix of young men and women who lived together. In one of the communities, the young people mentioned that sometimes young girls would ‘run away’ from home to live in such places, only to go back home, when they fell pregnant.

In one community, the participants explained that sometimes, when they went to a night-club, young men who had money would sleep with any girl they wanted to, because they could afford to buy her a drink or something more. The participants in a FGD mentioned that drinking alcohol made some young people engage in risky sexual behaviour:

> *"Alcohol is worse, because it makes young people have courage to go for prostitutes." (FGD_C2)*

A young man living with HIV mentioned that oftentimes going for drinks was a good starting point to get his partners to have sex:

> *"Because I do not meet with them every day, so I just go visit them by surprise. Then you tell her that let's go we have a drink. Then, while there, you ask if we can have sex, since it has been long. Then she accepts, and we go."*
>
> *(YPLHIV_M_18_C2)*

Young people oftentimes shared situations of when they themselves or people they knew in the community engaged in risky sexual behaviour, because of being either intoxicated or high on drugs. A young woman, who was pregnant at the time of the second interview, mentioned that she and her boyfriend became very comfortable with each other in their relationship, especially when they drank and smoked marijuana. She also mentioned that, at the beginning of their relationship, she and her boyfriend used condoms. But as the relationship progressed, sometimes they did not use protection, especially after smoking marijuana, and that was how she ended up pregnant.

4.4.3 How Young People Perceived HIV Prevention Based on Their Serostatus

Young people perceived HIV prevention differently, which was generally linked to their HIV serostatus. For example, for YPLHIV, HIV prevention was closely tied to what they had been told during their clinical visits. The YPLHIV mentioned that they were often advised 'sternly' to avoid passing on the virus to other people, by adhering to HIV prevention methods in different situations in their daily lives. One aspect of HIV prevention that was raised by YPLHIV was that of ‘getting another type of HIV’.

During the in-depth interviews, YPLHIV often asked a recurring question, which the other young people did not ask. For example, a young woman, when asked to list the modes of HIV prevention, enquired the following:

R: Methods of prevention?
I: yes
R: Like?
I: Any.
R: Like to those who are already infected or those who are not infected?

(YPLHIV_F_17_C3)

Young people who were not living with HIV or did not know their status did not make this distinction in the discussions about HIV prevention methods, unless probed and, in some instances, they were somewhat clueless. This distinction hinted at some form of extra awareness on the part of YPLHIV, and this may be due to their frequent interaction with the health care system.

When young people expressed themselves about HIV prevention, oftentimes they made reference to the future. Although the young people’s perspectives of the future differed by HIV category (being HIV positive, HIV negative or not knowing one’s HIV status), most of them focused on navigating intimate relationships successfully. Young people living with HIV often had anxieties about navigating through life with a serodiscordant partner (i.e., HIV negative partner) or having children who were HIV negative. Having children who were HIV negative was very central for YPLHIV, especially young women.

For YPNLHIV, as one young man put it, HIV prevention and the future were often about ‘playing it safe’. Some YPNLHIV understood that they needed to protect themselves from opportunistic infections (especially ones that were sexually transmitted). Some young people in this category somehow did not feel that they were at any risk in the future, provided that they continued to be careful with their choices about sex. One young man mentioned that after knowing that he had tested HIV negative that it ‘gave him a ‘job’ to stay negative. For him, this meant only having one girlfriend at a time, and using protection up to a stage when he was sure that they were both HIV negative:

> “*.... at least until I find out their HIV status.*” (YPNLHIV_M_24_C10).

For YPNTHIV, HIV prevention currently and in the future were punctuated by fear, as a young woman highlighted some of her insecurities:

> *“What if when I am ready to be with someone when I grow up, then I find out that I have HIV? I don’t know what I can do, because now I am hearing that you can be born with it.”* (YPNTHIV_F_16_C7)

Another young man also mentioned that it was difficult to think about the future, when being unsure of one’s HIV status. He mentioned that the issue of knowing one’s HIV serostatus was a ‘big issue’, especially when it came to getting married or settling down these days:

> *"I have been with a few girls, sometimes without anything [condoms]. Now, when I find out that I am like that [HIV positive], what can I do? Can you even see yourself getting married like this?"* (YPNTHIV_M_21_C10)

4.4.4 What Young People Did Not Consider as HIV Prevention

Young people sometimes did not consider some forms of HIV prevention as effective. This was because of what they had heard, experienced, understood, or did not understand about the various forms of HIV prevention.

4.4.4.1 Condoms as Prevention

Some young people did not believe condoms were effective or reliable as prophylactics. One young man mentioned that he had experiences where condoms burst, while in use, and this made him lose confidence in their ability to play a preventive role:

R6: A condom can bust, so you do not know?

I: Ok, so what can the guy do?

R6: You just have unprotected sex, since condoms are not safe as well, whatever will happen will happen. I am surprised that these people are emphasising much on the use of condoms, now the problem is, what if it bursts when you are in the act, what are you going to do. So, I suggest that you have unprotected sex, and if you impregnate, you just have to keep it and have a child at home. (FGD_C2)

Some young people also talked about what they had learnt about storage and handling issues related to condoms, and they emphasised that because condoms were not one-hundred percent effective, they were not a good option:

> *"People have a lot of, a lot of belief in those condoms. They say that [it's] perfect, um perfect [practice] makes perfect if you use a condom. But no, sometimes they affect. They affect, you find sometimes the condoms are expired, sometimes you find that they are since condoms they are very funny, they are some which have got holes, they are not proper, where you know in your mind that they are 100%. But for that, I know they are not 100%." (FGD_C3)*

> *"Two things, either becoming infected with HIV or becoming pregnant. Even though a condom is used, it is not a 100%. That's a fact."* (YPLHIV_ F_19_C4)

4.4.4.2 Treatment as Prevention

Out of all the participants in the study, only one young man explained and understood TasP in detail. This could have been partly because he was a volunteer at the clinic working at the ART department.

Two YPLHIV had some understanding about TasP. Some of their responses emphasised having an undetectable viral load and not being infectious. For example, a young man mentioned that he was consistent with taking his ARVs, and believed that the virus in his body was 'sleeping'.

> *"It is because when the virus is sleeping then you have low chances of passing on the disease"* (YPLHIV_M_21_C3)

A young woman mentioned that it was possible to get an undetectable viral load through adherence to treatment:

> *"At times, if you are taking them seriously every day at the given time, you may find that even when you come at the clinic, you might be tested and it may even come out negative, but that doesn't mean that you are cured. They are still in there, but they are just weak and they cannot even stand to fight"*
>
> (YPLHIV_F_16_C1)

For some young people, when asked about TasP, their understanding was about the role of ARVs in 'boosting' the immune system:

> I: *Okay so how about ART, ARVs as prevention, have you ever heard of that?*
>
> R: The only thing I know is that the ARVs they boost the immune system.
>
> (YPLHIV_F_19_C4)

Furthermore, when young people were probed about PEP and PrEP, most of them did not know or even consider 'treatment' as a form of prevention:

> *"ARVs are not for people who are not sick [HIV positive]."* (YPLHIV_M_21_C3)

> *"ARVs, they promote [the] immune system, actually they boost [the] immune system, they don't actually reduce the high chances of a negative person to get*

> *HIV…it doesn't mean that when you drink ARVs, when you go out you go and play [have sex] or dance [that] you won't get AIDS. Yes, you can get [it]."*
>
> *(YPNLHIV_M_24_C4)*

4.4.4.3 Misconceptions About Treatment as Prevention for People Living with HIV

Apart from not knowing about TasP, some young people also had misconceptions about ARVs and how they worked to prevent HIV transmission. A young man mentioned that:

> *"There is, what they say, that if you are on treatment, and you stay for about 1 year on treatment, and you do not have sex with anyone, [then] you can get fine."*
>
> (YPNLHIV_M_21_C2)

When study participants were probed about PMTCT, some of them seemed to have a clear understanding of what this meant, especially young women living with HIV. Other young people mentioned that they knew about PMTCT, but their responses indicated some misconceptions. For example, when a young woman was asked what she understood about PMTCT, she said:

> *"Yeah. That is when they refuse the mothers to breastfeed their children, because they can give them HIV and AIDS."* (YPNLHIV_F_20_C3)

4.5 Young People's Experiences with HIV Prevention

This theme is a presentation of study findings on young people's experiences with HIV prevention. It includes sub-themes that provide descriptions of the different experiences young people had regarding HIV prevention.

4.5.1 How HIV Testing was Linked to HIV Prevention

HIV testing had a critical role to play in the way that young people understood and experienced HIV prevention. For some young people, going through the process of finding out one's HIV status sometimes meant that they could situate themselves in the HIV prevention conundrum. For instance, young people who had undergone an HIV test were able to reiterate or recall some of the HIV prevention methods that they were educated about, before being tested. Young people who had tested for HIV also mentioned that going through an HIV test brought their thoughts about HIV closer to home, in the sense that it was no longer something that they had only heard about in the community, but that it was something they had to deal with in the moment and beyond, depending on the results.

For some young people, it was like the 'starting point for HIV prevention'. Some young people often felt that HIV testing was imperative, especially if one was sexually active. Some young people felt that it would help them make better health choices in order to protect not only themselves, but also others:

> *"Ok, like my friend you found at home, the last time you came, [he] did not want to get tested, but he has a lot of girlfriends. So, one day, there was HIV testing at the ground, and I picked my friend to escort me to the ground. And, when we reached there, I asked Ba Catharine (the adolescent counsellor) to test me. But*

> *she refused [saying] that I always test. So, I suggested that they test my friend, and the guy got tested. The results were negative [and] that is how he said that, since I am fine, I have stopped having so many girlfriends. Before testing, he would even refuse to use condoms. He used to say that I like a complete one [live sex], but now he says that he uses condoms*. (YPLHIV_F_17_C2)

A 24-year-old young man mentioned that before he found out about his HIV status, he was 'reckless sexually'. He also mentioned that going through the counselling and discovering that he was HIV negative made him rethink some of the ways that he was living.

> *"Something changed, from my past. I think I was a little bit careless, [but] after knowing my status, then that reduced… I used to play [have sex] with a lot of girls at school and those from out of campus, whereby we can go out, I go and spend a night that side, [and] early in the morning we come back to school. So, when I received my results, then I was oh, I have to stop, I'm saved."*
>
> (YPNLHIV_M_24_C4)

Young people who had never gone through an HIV test expressed their anxieties about not knowing their HIV status. Three young men mentioned how the questions were endless in their minds. One young man explained the panic he experienced, every time the topic came up. He would ask himself, "could I possibly have HIV?" Other young people who had never tested for HIV, also shared similar anxieties about 'the process' of finding out their HIV serostatus and, hence, they decided not to go through it at all. Being aware of one's HIV status sometimes made young people more aware of the HIV prevention methods being promoted, and the choices that were available to them. Apart from that, the fear of not wanting to know their HIV serostatus caused them to stay away from getting the necessary health care, for fear that they might be HIV positive, and this even when they had other ailments:

> *"The way it feels ok, sometimes when you fall sick, like you have a headache, you start to think that maybe I am just sick of HIV. That's what creates fear, even to test, because you think that if I test, [then] maybe they will catch me with it (the virus). That is just the way it feels. You just have that fear of testing that, maybe, if I test, [then] they will catch me."* (YPNTHIV_M_21_C4)

4.5.1.1 How HIV Testing Sometimes Hindered HIV Prevention

Young people shared their experiences about accessing SRH services that were closely linked to HIV prevention. Young people mentioned that some HIV service providers in the community tied condom distribution to HIV testing. Most of them mentioned that, in some instances, they were only offered condoms, if they agreed to get an HIV test. For some young people, this was not a problem. For instance, a young man in community four mentioned that he tested as often as he could, when it was required of him, especially when he needed to access HIV prevention services. This was not a very popular practice with young people who had never tested for HIV. Because of this, some YPNTHIV and those who had already tested, opted not to access condoms:

> *"They said that you first need to test, that's when they can give you, now…so, I have never tried."* (FGD_C2)

4.5.2 HIV Prevention and Disclosure

One aspect that young people often emphasised was the link between HIV prevention and HIV testing and disclosure. Young people felt that the issue of disclosure was often a problem. Sometimes, young people mentioned that it was not easy to have open discussions about HIV in a relationship. Young people said that they relied on health care workers at a health facility to help them with the issue of disclosure by going for couples testing. This was something that YPNLHIV said was not easy to talk about, even if they already knew their serostatus.

For YPLHIV, HIV prevention was tied to disclosure that was based on some of the advice they obtained from the staff at the SRH facility. A young woman living with HIV mentioned that talking about condoms was difficult, because it presented a high possibility of leading to unintended disclosure. She shared that one time she had to end a relationship with a young man, who questioned her desire to use condoms, when their relationship became sexual. The next time she had a boyfriend, she tried to approach the issue jokingly, but he reacted badly:

> *"Somewhere there at first, I did tell him that I am positive. Then, he answered that I don't want to marry a girl who is positive eeeh…"* (YPLHIV_F_19_C4)

Some YPNLHIV did not see the need to find out the HIV serostatus of their sexual partner, because they did not feel there was any further risk, if they knew their serostatus and used condoms to protect themselves:

> *"I don't think it matters, so long as I can keep myself safe. I use a condom at least."* (YPNLHIV_M_17_C1)

4.5.3 Young People's Experiences in Accessing HIV Prevention Services

Young people shared some of their personal and community experiences with regard to accessing HIV prevention services. Accessing some HIV prevention methods was often considered a difficult process by most young people. For instance, young people sometimes expressed how hard it was for them to access condoms, not because condoms were not available, but because of how they would be viewed by the older community members for accessing condoms at their age. Some young people mentioned that accessing some of the health services sometimes differed for young men and young women:

> *"It is not easy, because if a young girl goes to the clinic to ask … it can be difficult. That is why guys use condoms, because that is a secret, and it is easy to access, because you can ask from your friend that I need some condoms, and you are given."* (YPLHIV_M_18_C2)

A 17-year-old young man mentioned that he was discouraged from accessing condoms by an elderly community health care worker at the clinic. The young man mentioned that he agreed with the health care worker, just to get rid of them. The young man also mentioned that he avoided facing the health care workers, because he was sexually active:

> R: The challenges would be that recently, when I see those people [community HIV care providers] in the community… I feel guilty and run away from them.
>
> *I: Okay, so that is a challenge that you are facing?*
>
> R: Yes, because I know that I am doing something wrong or something I am not supposed to.
>
> *I: Okay.*

R: So, I run away from them?

(YPNLHIV_M_17_C1)

During a FGD, the young people in two communities mentioned that bars sold condoms that the clinic or Ministry of Health gave them to distribute freely:

> *"Because everyone should have the ones from the clinic, because even in the bars they sell those ones from the clinic. And, sometimes you do not have any money, so you just have unprotected sex." (FGD_C2)*

From the narratives and interviews, young people's comments about the different HIV prevention methods varied, based on whether or not they were sexually active.

4.5.4 Prevalence of Sexual Activity Among Young People

Out of the 23 study participants, 74% (17) said that they were sexually active. Of the 17, 30% (7) had sex before they had turned 15 years, and of the seven, 9% (2) were young women and 22% (5) were young men. Most young people reported that they did not use condoms the first time they had sex:

R: 13 years.

I: That is when you started having sex?

R: Yes.

I: Were you using condoms?

R: No, we used to have unprotected sex.

I: So, you used to agree to have unprotected sex?

R: Yes, we would agree while working. Sometimes, we would lie that we have gone to buy something at the shop, but in actual fact we have gone to have sex, you know how the village set up is.

(YPLHIV_M_18_C2))

"That time, it just used to happen, and we were just young, I never even knew how to ask him about the condom. Maybe, even him, he didn't know about it."

(YPNLHIV_F_21_C4)

Young people generally felt that sexual activity was quite prevalent in their age-group, and young people sometimes felt that the spread of HIV was also due to engaging in sex too early in young people's relationships**:**

> *"…now this generation, whenever they think about girlfriend and boyfriend, they think about sex to be the symbol of love. No, yes, no wonder a lot of young ones are infected."* (YPLHIV_F_17_C3)

When young people commented about sexuality in their age-group, the common narrative was that there was some form of expectation that, at a given point, relationships had to turn sexual. Young people often felt that the pressure to start having sex in a relationship often came from young men:

> *"The other thing he will ask is why you accepted to be my girlfriend [only] for you to deny me sex. [Do] you think we just supposed to be kissing?" (FGD_C3)*

Some young people mentioned that sex in a relationship sometimes was linked to young women having future expectations of relationships becoming permanent. Some young women were said to succumb to the pressure of having sex in a relationship, because they thought that they might never be able to find another partner, if they lost the one at present, who was demanding sex from them now:

> *"Sometimes, it is found to say [that], if here I will say no, [then] I don't know if I will still find such [a] kind of a person in my life. You know, I don't think if I will still have this one. But, if you [are] going to utilize this [situation], this is the very opportunity. So, I will just need to take it up for me, to preserve my love for him. So, definitely, someone will just say yes for the love and, sometimes, even the body system, the makeup of the ladies, it also forces them to do sex."* (FGD_C4)

Some young people, who were not in support of sex among their peers, mentioned a lot of moral issues that were tied to young people having sex, whilst in a relationship. Young women were often at the centre, and considered to be the key, as to whether or not a relationship became sexual. A young man commented on young women's vulnerability and expectations about sex in relationships, and how this was tied to HIV prevention:

> *"Social issues, such as low self-esteem among young women, cause them to be vulnerable, to accepting sex proposals, thereby increasing their risk of getting HIV. They think they will not be able to find someone else to be in a relationship with… they engage in sex early and increase their risk. With me, what I say, the thing is first, the lady should be mentored in the importance of delaying sex."*
>
> (YPNLHIV_M_21_C3)

4.5.4.1 Multiple Concurrent Sexual Relationships Among Young People

Young people commented that it was pretty common to have more than one sexual partner. Although, it was reported to be more prevalent among young men compared to young women. A young man living with HIV mentioned that he had six girlfriends, and he was sexually involved with all of them, but did not use condoms, because he did not like condoms. Of the six girlfriends, he mentioned that five knew his HIV status, and one did not, because he didn't feel the time was right for her to know:

> *I:* *Okay, so you mentioned that you have six girlfriends and that you have sex with all of them. What methods of HIV prevention do you use?*
>
> R: Okay, to be honest with you, on my part, I hate condoms, I just want it direct, that is the way I want it.
>
> (YPLHIV_M_21_C3)

A 17-year-old young man mentioned that he was in multiple sexual relationships with two young women, one was16 years-old and the other was 19 years-old. He mentioned that he only used protection, when he had sex with the older one, since he believed that because she was older, the risk of contracting HIV from her was higher, as opposed to the 16-year-old who, in his words, was "young" and, possibly, could not have it:

> *I:* *Okay. Have you used a condom with your most recent sexual partner?*
>
> R: No.
>
> *I:* *Okay.*

R: Yes, because I think that she is young, so she can't be sick…of HIV and AIDS.

I: Okay, so do you know your partner's HIV status?

R: No.

I: Okay.

R: But, I think that…on my own, I think that she is not HIV positive, no.

I: In your own thoughts?

R: Yes. In my own opinion.

(YPNLHIV_M_17_C1)

In some cases, multiple concurrent relationships were driven by the availability of money. This was usually from young men to young women. Young men shared that it was easy to get some of their partners to sleep with them, if they (females) were aware that they (males) had money:

I: Ok, so you do not have a girlfriend?

R5: They are a lot.

I: Ok, so you do not do anything with them?

R5: I have sex with them.

I: So, what if she refuses?

R5: She cannot refuse, because she is seeing what I am doing. She even sees the fish I am selling, [so] how can she refuse?

I: Ok.

R5: She knows that when I am done selling fish, [I] will have money, so she cannot refuse.

(YPLHIV_M_18_C2)

4.5.5 Moral Discourse About Young People's Sexuality and Condom Use

Some young people mentioned that they faced a lot of prejudice from the community and their peers, when they tried to access condoms and other SRH services. This was evident, as some participants were not comfortable with the idea that young people should be using condoms or having sex:

> *"Again, what I think is about, my thought, my personal thought, yes, condoms must be banned in Zambia. Because, again, they are encouraging people to have sex before marriage."* (YPLHIV_F_17_C3)

The moral discourse around condom use was sometimes punctuated by religious beliefs, which some of the study participants shared:

> *"Okay first I will start with the issue of condoms, what I know. Condoms, all I know [is] that condoms need a lot of care. And they are things that are not supposed to be exposed anyhow. Yes, they are supposed to use them, because not all are Christians. Yes, not all are Christians."* (YPNLHIV_F_18_C2)

Some of the participants also mentioned that if word got out that a young person was getting condoms, then they would be viewed as 'promiscuous' by their peers and the adult members of the community. Some participants reiterated, in their own words, how the adults would stigmatize those who accessed condoms. There was a strong emphasis on 'staying away from such young people, to avoid being corrupted morally'. A young woman mentioned that it was difficult to even talk about condoms with a partner, because 'they would think that automatically you have been unfaithful or you don't trust them'.

4.5.5.1 Birth Control Versus HIV Prevention

Oftentimes, the issue of birth control or family planning came up in discussions on HIV prevention. Young people were aware of some of the SRH services that were available to them in their respective communities, but the service providers were often judgemental. Sometimes young people were discouraged by their peers. Some participants, who discouraged young people's use of family planning services, felt that their peers were more afraid of falling pregnant than getting HIV:

> *"Um, what I can say about family planning is family planning is a nice thing, but still there are certain risks there ... You are infected with some certain infections through your sexual intercourse there. You will find one will say I have been infected with HIV that is how the relationship can end and other things can happen…. Because risks are still there with family planning. You can be taking family planning, but still [get] HIV/AIDS. Sometimes you can use a condom wrongly, and one ends up pregnant or disease passes through [it] and you get infected. So, indeed, if you are not in marriages, with me I can say [that] I discourage taking family planning, because of the risks which are there, which somebody cannot cope with."* (FGD_C3)

Similarly, a young woman in community four had this to say:

> *"The same family planning is making people become silly, because they know that they will not conceive, so they will be sleeping around and, as a result, they will contract HIV and start taking ARVs. Again, when they take the ARVs for two-to-three weeks, they will stop taking them after they have gained weight. They stop, and that is why they are dying in number[s]."* (FGD_C4)

Young people mentioned that they used condoms, but the underlying reasons were sometimes linked to birth control. For example, a young man living with HIV mentioned that he used condoms consistently. His response positioned condoms as a form of birth control, as opposed to HIV prevention:

> *I:* *Ok, so since you discovered that you are sick, have you ever had unprotected sex, since you have four girlfriends plus your wife? Is there anyone who does not want to use condoms?*
>
> R: I refuse to have unprotected sex, because she might become pregnant, so that she comes back to the house.
>
> *I:* *Ok, so you refuse that you do not want unprotected sex?*
>
> *R:* *Yes, I refuse.*
>
> *(*YPLHIV_M_18_C2)

4.5.6 Young People's Experiences of Sexual Violence and Implications for HIV Prevention

Forceful non-consensual sexual attempts or acts of sexual violence were said to be prevalent among young people in the study communities, and sometimes these were often fuelled by alcohol.

A young man mentioned that his friend claimed to have been ‘used’ sexually by a young woman who got him drunk and high on a substance he could not recognise. The young man mentioned that he had not intended to have sex, but could not remember what happened after he started drinking. The young man shared with his friend how disappointed and bad he felt to wake up the next morning only to find that he had had sex. Other young people in the FGD agreed that that sort of behaviour was common in the community:

> *“The guy started saying no, I need to be off, it’s really late [and] I need to be going home because it’s far. The ladies, they tried to make him stay [a] little [longer]. Then, after convincing him, they were like, we will book a taxi for you to go… that female just gave him a condition that come in the bedroom you will be going [home] right now. You will be going very soon, [but there’s] something I want to show you. ‘How what do you want to show me?’ ‘No just come’. So that guy without insisting, you know, he went there. So, reaching inside there, the lady started undressing. After undressing, due even to the things that was in him, controlling him, he couldn’t control his emotions as well. When he saw whatever was happening... He actually finished the pot of eggs [he had sex]... It was in the morning, when he realised to say [that] this is what he has done. So, it could be clear that the beer made him to do what he was not expecting to do.”* (FGD_C3)

Another young man mentioned that his friends had formed a ‘clique’ of about four young men who often went to drinking places solely to get young women drunk in order to sleep with them. The participant mentioned that oftentimes these young men would all sleep with the same young woman, after getting her drunk and leaving her at the club or wherever it was that their activities took place:

> *I:* *… unwanted sex or defilement, rape all that is sexual violence.*
>
> R: Yes, this happens to those who drink alcohol.
>
> *I:* *Ok, when was the last time you heard of such a thing happening?*
>
> R: Like, there are groups, which come here in the night. So, one of the guys in the group is close to me
>
> *I:* *Ok.*
>
> R: So, there was a day he came rushing to me [saying] that 'we went to drink with a certain girl and she got drunk, and some of my friends started forcing her that they have sex with her. So, they took her somewhere, where people saw them'. So, he left early, coming to tell me [what had happened].
>
> (YPNLHIV_M_21_C2)

4.6 Stigma and HIV Prevention

Participants shared how stigma affected the community and themselves. During the P-ART-Y intervention, young people mentioned that they preferred being accessed at home by the community HIV health care providers, and offered HIV services there. Some participants expressed how they avoided going to the clinic for fear of 'being seen' accessing HIV and SRH services by other members of the community, especially by the adults. YPLHIV shared that the clinic staff often advised them to disclose their HIV status to people they could trust in order to get support from them, as well as to manage or avoid transmission. However, YPLHIV mentioned that it was difficult to disclose to family members, sometimes, because of the stigma that family members exhibited in what they said about PLHIV. As a result, YPLHIV had to be extra careful around others, without explaining why they were protective, for example, in the way that they handled sharps with people around them, especially with siblings in the home, as well as other members of their household and their extended family.

CHAPTER 5: DISCUSSION, CONCLUSION AND RECOMMENDATIONS

5.1 Introduction

This chapter is a discussion of the study results in the context of related literature. It will begin by giving a brief summary of the study results. This will be followed by an interpretation of study results using the social ecological model while making comparisons with existing HIV prevention literature. The chapter concludes with recommendations.

The study revealed that what young people experienced and perceived about HIV prevention provided a lens for understanding what young people knew about HIV prevention. This was often influenced by age, gender and their HIV serostatus. Other factors including socioeconomic status, population-density context, access to SRH services, violence, and alcohol and substance use were also evident as influencing factors that impacted their experiences of HIV prevention.

With regard to age in particular, participants reported that they had a basic and sometimes vague understanding about HIV and its prevention during their pre- and early-teen years. This was similar across gender and HIV serostatus. Participants were able to relate how their experiences and perspectives on HIV prevention became more complex as they grew older. Compared to their younger years, there was a difference in participants' experiences and perspectives as they approached their mid-teens and older. Particularly for YPLHIV, this was the time when they were informed or made aware of their HIV positive serostatus by either their parents or guardians. For these young people, this revelation or experience oftentimes affected how they perceived the future and their reality of leading a 'normal' life, especially an intimate relationship with a serodiscordant

(HIV negative) partner who was not living with HIV. For YPLHIV, the need to prevent HIV transmission to others sometimes created anxiety and fear in view of their relationships with their family, friends and intimate partners. Across the different categories, young people often mentioned that transitioning into adulthood became more complex as they reached puberty, because they had to make choices about how to handle their sexuality in the face of HIV prevention, and the pressure they encountered from their social networks.

The aspect of gender also came into play, when young people highlighted the gender differences that existed at the individual and communal level. Young women compared to young men often fell prey to sterotypes that implied that young women were responsible for the spread of HIV in their communities.

Young people experienced challenges in accessing SRH and HIV prevention services, mainly because some health care workers in their local facilities placed personal restrictions on access to some SRH services. For example, some young people mentioned that they did not want to access free condoms from the clinic, because when they tried to do so, some health care workers demanded that they get an HIV test, before they could access the condoms and other SRH services. The condition of having to test for HIV in order to access SRH services made some young people shun the SRH and HIV prevention services from the clinic.

The present study also found that community level influences, such as religious beliefs and the prevailing views of the adults in the community, had an influence on how young people experienced or perceived HIV prevention methods. Young people were aware of what was considered acceptable or unacceptable behaviour. Young people often started talking about the future, when they talked about HIV prevention, regardless of their HIV status, and oftentimes their perspectives of the future and HIV prevention were filled with anxiety and conflicting expectations, because of the uncertainty they held about being equipped to manage their future.

Just as other studies focused on young people in SSA (McCarraher et al., 2018; Ssewanyana et al., 2018; Toska et al.,2017), the present study revealed that in the context of HIV prevention, young people often found themselves at a crossroads, when transitioning into adulthood, and having to manage their HIV serostatus in life situations that were often punctuated by gender disparities. This is similar to previous findings which indicated that young people sometimes faced challenges in African communities where the culture left little room for them to get acceptable answers and the necessary guidance, as they were transitioning into adulthood. As a result, young people were left with the undesirable option of experimenting in their personal lives, often to their detriment, in order to derive answers to the challenges that confronted them (Motsomi et al., 2016)

The study results indicated that HIV prevention was not a novel concept for young people, and throughout their lives, they were able to relate with issues of HIV prevention at both an individual and communal level. This finding was no different to previous research results, where young people had some basic knowledge about HIV and its prevention (Busza et al., 2012; Carnevale et al., 2011; McCarraher et al., 2018; McLean et al., 2017; Santos, Coelho, Macário, & Oliveira, 2017). The study findings underlined how participants' knowledge about their HIV status or the lack thereof was sometimes evident in their experiences and perspectives on HIV prevention. YPLHIV were more informed about HIV prevention methods compared to the young people in the other two HIV categories (YPNLHIV and YPNTHIV). This was also evident in the exiting literature of YPLHIV. In Zambia, Ghana and Burkina Faso, PLHIV had relatively more information about HIV, and in communities where the adults had more tolerant attitudes towards PLHIV, there was also a higher chance of transference of knowledge to young people in order to help them understand and better navigate their health choices (Stephenson, 2009).

Although TasP was not a known concept to all the study participants, some YPLHIV seemed to have an idea of how developing an undetectable viral load, due to ART adherence, could be a form of prevention. A global study conducted in Zambia, Thailand and Brazil reiterated this finding, and highlighted that PLHIV had suitable knowledge of how ART adherence, as a form of TasP, that was critical in reducing transmission (Rogers et al., 2019).

As indicated in other studies, condoms were the most commonly known method of HIV prevention in the study communities (Denno et al., 2015; MacPhail & Campbell, 2001; McCarraher et al., 2018; Pinchoff et al., 2017). However, gender-based power relationships were often involved in some of the experiences and perspectives on condom use. For example a previous study showed that young women argued that in situations were the male partner in the relationship was not agreeable to the idea of using consoms, insistence on condom use implied a lack of respect and could break one's intimate relationship and destroy one's reputation with peer groups (MacPhail & Campbell, 2001).

Young people's choices about engaging in sex were linked to different factors. For example, in some situations, young people who lived in small houses in high population-density areas, were sometimes granted permission by their parents or guardians to sleep over at their friend's homes, due to sleeping space shortages in their homes. Some young people used such opportunities to go out and engage in sexual activity. This finding resonates with previous research in SSA which highlighted that in the community certain societal influences that were of a materialistic nature had a significant catalytic effect on high-risk sexual behaviour, especially for young people who were materially placed in vulnerable positions (Stephenson, 2009)

Young people's choices about engaging in sex were also linked to their expectations that relationships with their partners 'had' to eventually become sexual. For young women, this expectation was often tied to issues of low self-esteem. It was understood that if young women denied their partner sex, they would lose a potential future spouse and, possibly, be unable to find a suitable replacement. This finding is very similar to that in previous literature that showed that young women, in some instances, felt obliged to offer their partners sex, because they were afraid of the relationship breaking up (Bhana & Pattman, 2011; Maticka-Tyndale et al., 2005; Maughan-Brown et al., 2018; Ssewanyana et al., 2018; Viljoen et al., 2017; Yllequist, 2018).

Additionally, when and how young people had sex was also linked to coercion from partners. Forced sex and gang rape were prevalent in the communities in the current study, and this sometimes was as a result of the perpetrators 'deliberately' intoxicating their victims with alcohol and other drugs in order to take advantage of them sexually. The present study revealed that both young men and young women were victims of sexual violence, though young women were more vulnerable and abused compared to their male counterparts. In this regard, issues of sexual violence, as well as alcohol and substance abuse, were often brought up when young people talked about HIV prevention. The participants often made a conection between gender disparities, alcohol or substance use, and gender-based sexual violence. This outcome was no different to that of previous studies that highlighted a strong association between alcohol and substance abuse, gender-based violence, and HIV transmission (Dick & Ferguson, 2015; Pedersen & Hegna, 2003; Rogers et al., 2019; Ssewanyana et al., 2018). In most cases, young women were more at risk compared to young men.

5.2 Understanding Young People's Experiences and Perspectives of HIV Prevention Using the Social Ecological Model

Health behaviour, and decisions and attitudes about one's health are shaped throughout the course of one's life, and sometimes the environment can be an advantage or disadvantage in influencing one's decision-making about health and health-risk behaviour (Glanz, 2005). According to the social ecological model (SEM), what young people experienced and perceived was not only associated with who they were as a person (individual or intrapersonal factors), but also with whom they related to personally (interpersonal factors), and how they interacted within their community environment (community level) (Banks, Hensel, & Zapolski, 2020; Bekker & Hosek, 2015; Dyson, Mobley, Harris, & Randolph, 2018; Glanz, 2005).

5.2.1 Individual level

An individual's personal characteristics have a very important role to play in building an understanding of health behaviour (Banks et al., 2020; Dyson et al., 2018; Glanz, 2005). Personal characteristics can be a whole range of attributes that are at an internal or personal level. These characteristics are not limited to sex and age, but also extend to include knowledge level, level of education, personal traits, beliefs and attitudes (Banks et al., 2020). The key focus at this level is what shapes one's cognitive process when making health decisions (Glanz, 2005).

In this study, at the personal level, knowledge of one's HIV status was critical in how young people experienced and perceived HIV prevention. The present study affirms the results in previous research, which highlighted that HIV testing and knowing one's HIV status were key to successfully managing HIV risk and infection, especially HIV prevention (Shanaube et al., 2017). Similar to other studies, the present study findings supported the premise that knowledge of one's HIV status, sometimes meant that young people were able to make positive health decisions about HIV prevention, but in other cases it meant that young people engaged in high-risk sexual behaviour (Shanaube et al., 2017; Ssewanyana et al., 2018). The present study also found that the participants' personal beliefs played a key role in their experiences and perspectives regarding HIV prevention. For instance, some beliefs held by young people hindered them from getting an HIV test, including access to essential SRH services. A previous study in Zambia showed that the beliefs inculcated in young people by their parents or guardians and the broader community (such as, HIV testing was only seen as necessary and advocated if one was sexually active), had a significant influence on the way that they made choices about HIV testing, and that healthy family involvement and encouragement had a positive impact on their choices to get tested for HIV specifically (Denison et al., 2014).

Additionally, the present study found that religious beliefs sometimes shaped young people's health decisions and opinions about some of the HIV prevention methods, and this was similar to previous research findings (Eriksson, Lindmark, Haddad, & Axemo, 2014; Motsomi et al., 2016).

For example, some young people who did not believe in condom use for religious and other reasons, chose not to use them, because they believed that such prophylactic methods were not one-hundred percent protective, and that they were not a viable option. Other studies also highlighted that religious and cultural beliefs shaped young people's preferences regarding condom use. For example, some young people who held religious beliefs considered condom use sin against God. Consequently, they engaged in condomless sex and exposed themselves to increased risk (Eriksson, Lindmark, Haddad, & Axemo, 2014; Motsomi et al., 2016; Yllequist, 2018). This anomaly of young people shunning condoms because of religious beliefs, yet engaging in sex that was not sanctioned at the community level, reflected the tensions that existed between the various messaging strategies that sometimes adversely impacted HIV prevention. An example of how culture influenced the choice of condom use, a study among Xhosa-speaking youth in Cape Town, South Africa, showed that young men were raised to believe that 'African sex' should be natural, and that using condoms took away the 'natural African sex' experience (Yllequist, 2018). The present study found similar reasoning for engaging in condomless sex among some young participants, especially the males, regardless of their HIV status.

The present study also highlighted that in the case of abstinence, for most participants, the choice to abstain was also influenced by their cultural and religious beliefs. This was no different to the previous literature (Davis et al., 2015; Edin et al., 2016; Eriksson, Lindmark, Haddad, & Axemo, 2014; Maticka-Tyndale et al., 2018; McCarraher et al., 2018).

5.2.2 Interpersonal level

The interpersonal level focuses on one’s social network, i.e., the relationships with family, friends and peers (Banks et al., 2020; Dyson et al., 2018; Frew et al., 2016; Michielsen et al., 2012). It takes into account the social identity of an individual and how this related to their health choices and behaviour (Banks et al., 2020; Dyson et al., 2018).

The present study highlighted the different relationship dynamics that influenced HIV prevention and the decision-making and health-risk behaviours of young people. Glanz (2005) explained that it was at this level that various intrepersonal roles are executed, beyond the personal confines, depending on how these roles are defined. Similar to previous research, the present study showed that the interpersonal relationships which existed among young people were sometimes punctuated with power dynamics that disadvantaged young people and left very little room for dialogue on issues of HIV prevention (Price et al., 2018; Stephenson, 2009; Yllequist, 2018). Silence about conversations on HIV played a definitive role in compounding what dialogues were sanctioned or unsanctioned (Haffejee et al., 2018; Ssewanyana et al., 2018; Yllequist, 2018). The previous literature showed that because talking about HIV was not a common practice at the household-level, it was equally not easy for peers to talk about HIV amongst themselves (Yllequist, 2018).

In the current study, at the interpersonal level, a complex mix of personal characteristics, such as age, gender and level of education were taken into account in order to build an understanding of the role that power dynamics played in how young people were defined within their social network (Dyson et al., 2018; Glanz, 2005). The way that young people were defined either empowered or disempowered them in deciding what was best for their health in terms of HIV prevention (Maughan-Brown et al., 2018; Viljoen et al., 2017; Yllequist, 2018). For example, the definition of a young woman's role in a given relationship was one of being passive, for instance, when it came to issues of sex. Her opinion did not matter in the relationship, and this disempowerment influenced the health decisions she made for her personal wellbeing and others within her social network (Maticka-Tyndale et al., 2005; Maughan-Brown et al., 2018; Viljoen et al., 2017; Yllequist, 2018). Similarly, the present study found that young women sometimes seemed to find themselves in relationships where they were obliged to be receptive to their male partners demands, regardless of how this impacted the couple's health.

5.2.3 Community level

The community level is a blend of different formal and informal structures that influence society, and how its members behave as individuals or groups (Glanz, 2005). It is at the community level that regulatory efforts are made, and these can either constrain or promote health action and behaviour (Dyson et al., 2018; Glanz, 2005).

The present study indicated that young people's awareness of the written and unwritten rules of sanctioned behaviour within their community, influenced their health choices and behaviour. For example, previous research in SSA showed that the community's expectations were that young people 'should not have sex'. As such, norms and rules often passed through different social channels, including religion and certain forms of cultural practices, in order to ensure that young people were aware of what was and was not expected of them (McCarraher et al., 2018; Motsomi et al., 2016; Svanemyr et al., 2015). However, with their transition into adulthood and the emotional changes that are experienced at that stage, the results in the present study supported that of previous literature which reported that young people often found creative ways of navigating through what was considered unsanctioned behaviour in order to fulfil their personal desires (McCarraher et al., 2018; McCarthy et al., 2016). This sometimes meant that young people engaged in high-risk substance abuse and sexual behaviour that did not take into consideration any form of sanctioned HIV prevention methods (Banks et al., 2020; Ssewanyana et al., 2018; Stephenson, 2009).

In the present study, high population-density environments were perceived to have had an influence on young people's sexual behaviour and choices. Because of this, high population-density environments could be considered enablers of high-risk sexual behaviour among young people. For instance, sleeping space shortages in homes within high population-density areas were said to create opportunties for young people to access alcohol and drugs, as well as engage in high-risk sexual activities, when they were granted permission to sleep at a friend's home.

Similarly, some studies have highlighted how communities affected and shaped young people's sexual choices. A systematic review compared young people's risky sexual behaviour in Zambia, Ghana and Burkina Faso (Stephenson, 2009). Like the current study, the study found that economic conditions had an influence on young people's risky sexual behaviour. Across the three countries, the study showed that residing in a wealthy household reduced young people's chances of engaging in risky sexual behaviour (Stephenson, 2009).

5.3. Understanding the Relationships Between the Various Social Ecological Levels

Young people's experiences and perspectives were not influenced exclusively by a single level at any one point in time, but by the interplay of factors at the various levels. Glanz (2005) indicated that in order to create an understanding of how the social ecological model explained health behaviour and the health decisions made by people, there was need to establish how the personal, interpersonal and community levels interconnected and influenced the health decisions and actions of individuals.

5.3.1 Understanding Health-Risk Behaviours Among Young People

Previous research that used the social ecological framework to understand HIV prevention behaviour among young people indicated that young people's perceptions, knowledge or awareness of risk positively affected the health choices or decisions they made pertaining to HIV prevention (Banks et al., 2020; Dyson et al., 2018). Alternatively, a lack or absence of awareness of risk meant that it would not be easy to make protective health decisions (Banks et al., 2020; Dyson et al., 2018; Govender et al., 2018; Price et al., 2018). The findings in the present study showed that young people's awareness of risk was not enough for them to make good choices about HIV prevention. Based on some of their experiences, it was possible that young people were aware of the risk at a personal level, but because of their interpersonal relationships and the structure of the community environment, it was difficult for them to make protective choices. For instance, the present study found that young women had very little say about sex in an intimate relationship, especially in terms of how and when it happened (i.e., the use of protection or not, and whether the intimacy was consensual or not) that was also reported in other studies (Govender et al., 2018; Maughan-Brown et al., 2018; Nakazwe et al., 2019; Santelli et al., 2015; Stephenson, 2009b; Viljoen et al., 2017; Yllequist, 2018). The current findings resonated with previous studies which highlighted that Zambian young women, like their peers in SSA, were cornered by an African culture that disempowered them from vocalizing their preferences, such as condom use in sexual relationships (Maughan-Brown et al., 2018; Viljoen et al., 2017; Yllequist, 2018).

Similar to other studies, the present study found that young women were victims of sexual violence and, in some cases, the perpetrators (men, both young and old) used alcohol to take advantage of their female partners (Dick & Ferguson, 2015). Previous studies in SSA showed that young women were expected to allow relationships to turn sexual in order to keep their men (Maticka-Tyndale et al., 2005; Maughan-Brown et al., 2018; K Michielsen et al., 2013; Ssewanyana et al., 2018). The present study found that young women's risk of getting HIV was higher, because they could not question their partner's actions. Apart from that, they could not easily leave abusive relationships. Similar to other literature, this was linked to the females' feelings self-worth and 'value' that was considered to have depreciated, when she was no longer considered a virgin. Consequently, this resulted in not being able to find another man and being blamed for relationships when they failed (Dick & Ferguson, 2015; Lundgren & Amin, 2015; Nakazwe et al., 2019; Ssewanyana et al., 2018; Viljoen et al., 2017; Yllequist, 2018).

Avert (2020) indicated that the leading cause of HIV transmission among young people in SSA was through sexual behaviour. Young people in SSA were reported to engage in high-risk sexual activities as early as 15 years on average (Avert, 2020). The situation was no different in Zambia, where the majority of first-time sexual encounters was premature and often condomless (Pinchoff et al., 2017). In Zambia, condom use at the first-time sexual encounter, when disaggregated by age, showed that 30.7% of young women aged 15 to 19 years used condoms at their first sexual encounter compared to 27.1% of young men of the same age range. In contrast, however, 25.6% of young women aged 20 to 24 years used condoms at their first sexual encounter compared to 34.6% of young men of the same age range (Mwale, 2019). Consequently, with increasing age, females because more vulnerable to risk and infection.

This study indicated that young people's sexual behaviour and choices were sometimes driven by the availability of resources within their community. For example, a young person living with HIV mentioned that he started having sex when he was only 13-years-old, and that he did not use condoms at the first encounter, as well as in subsequent encounters, because he neither had access nor knowledge about how to use condoms. In reflecting on his past, he stated that he did not see the possibility of accessing condoms in the village, where he was at that time. In this case, the decision to have sex was made under circumstances that involved a lack of knowledge at a personal level and a lack of access to material resources through the relevant structures at a community level.

Still focusing on the issues of young people's sexuality, the present study found that the participants often made reference to the 'right and wrong age or phase in life' to have sex, when they shared their perspectives on HIV prevention. This was indicative of the common narratives about sexuality and HIV prevention in their communities. Like other studies, the present study found that young people's sexuality was often used as a target for blaming young people for 'spreading' HIV in their communities (Bhana & Pattman, 2011; Haffejee et al., 2018; Mburu et al., 2013). The present study also found that stereotypical accusations of 'young women as spreaders of HIV' were common, even among the participants themselves. Participants were aware of how they were viewed by the broader community as 'sexual beings', and their experiences and perspectives of their sexuality left them at a point where access to appropriate HIV prevention or SRH services could not be guaranteed or sanctioned without prejudice and shame. Similarly, another study highlighted that young people found it difficult to openly talk about their sexuality, let alone think of healthy ways of indulging in sex, because their community or society did not consider their sexuality as a 'right', in a manner of speaking (Motsomi, Kegaugetswe, Chandra Makanjee, 2016).

Some study participants were of the opinion that their communities made it easy for them or their peers to engage in high-risk behaviours, including sex, violence, alcohol and substance abuse, which was no different from previous research in SSA (Santelli et al., 2015; Stephenson, 2009).

Participants sometimes felt that the young people had the opportunity to engage in these activities, because of a lack of proper parental supervision, such as in instances where parents were either absent from the home or when they were not aware of what their children did when they (young people) were away from the home. Young people often seized the opportunity when they could in order to indulge themselves in unsanctioned behaviour, regardless of the health-risk implications. This finding was no different from previous studies, whch showed that some parents denied that their children were engaging in high-risk behaviours (Motsomi et al., 2016). In the current study, participants also mentioned that some young people took advantage of the limited space in their home to leave the house, under the pretence of sleeping over at a friend's house, in order to engage in clandestine or otherwise unsanctioned risky activities.

In addition, economic hardship played a role in HIV transmission in the four study communities. Similar to other studies, the present study found that young people also engaged in high-risk sex for money and, usually, young women were said to engage in sex with older men in order to get the kind of life that they could not afford by any other means (Bhana & Pattman, 2011; Dellar et al., 2015; Ssewanyana et al., 2018).

The present study found that while young people engaged in risky behaviours, they were very concerned about the future and HIV prevention. The levels of uncertainty regarding their safety and the safety of others is in contrast to previous research, which showed that young people were more focused on their experiences in the present (MacPhail & Campbell, 2001; Ssewanyana et al., 2018). The present study indicated that oftentimes, young people had limited options when they were faced with risky situations. Thoughts about the future made it difficult for them to make positive health decisions about their current lives. For example, some young women engaged in high-risk sexual activities in order to secure long-term partners (a possible spouse) for the future. This finding is no different from previous studies which showed that young women sometimes engaged in high-risk sex with their partners, because they believed that they were securing the relationship for the future (Lundgren & Amin, 2015; Maticka-Tyndale et al., 2005; Viljoen et al., 2017; Yllequist, 2018).

5.4. Young People and HIV Testing

HIV testing is key in HIV prevention efforts (Denno et al., 2015; Dyson et al., 2018; Haffejee et al., 2018; Hayes et al., 2019; Shanaube et al., 2017; UNAIDS, 2016a; Yllequist, 2018). Like previous studies, the present study found that gaining an understanding of the experiences and perspectives of YPNTHIV was important. Using the lens of SEM, some studies provided evidence about young people's decision to not get tested for HIV, and these provided evidence on how the various levels were interconnected (Kurth et al, 2015; Yllequist, 2018). From the results of the present study, YPNTHIV highlighted some of the underlying reasons why they chose not to test for HIV, and how vulnerable they felt for doing so. For instance, they sometimes experienced difficulties in accessing HIV prevention and SRH services, because they did not want to get an HIV test. Rejecting an HIV test meant that they could not get access to condoms. Although this may have been a strategy on the part of the health service providers to get YPNTHIV to test and access additional HIV and SRH services, the requirement had a push-effect on the participants, causing many of them to distance themselves from the health services provided. The present study found that young people often kept in mind the myths and misconceptions that they had about HIV and HIV testing (for example getting an HIV positive result, because the nurse used non-sterile instruments to conduct the test), and, because of this, young people chose not to test for HIV.

Like previous research (Haffejee et al., 2018; UNAIDS, 2016a; Yllequist, 2018), the findings in the present study revealed that for some young people the perspectives at the community-level mattered to them more, for example, 'they will think I am sexually active if I get a test'. Participants wanted to avoid any visible association with actions or activities that were considered as 'unsanctioned' by the community. For them, protecting their 'good name' or image was more important than finding out about their HIV status or obtaining condoms and other SRH services. The fact that young people wanted to project an image that was acceptable at community-level, shaped their thinking and health decision-making at a personal level. Similar research findings indicated that young people were aware of what was expected of them at a community level

(Motsomi et al., 2016; Yllequist, 2018). Going against what was morally acceptable in the community, especially if it was connected to young perople's sexuality, sometimes meant that young people would get a 'bad' name, either individually or as a family if they were publically seen to be sexually active (Motsomi et al., 2016; Yllequist, 2018).

In Zambia, the legal position of HIV testing for young people below the age of 18 years is that it had to be done with the consent of the parent or guardian, which made it difficult for young people to get tested (Kalibala & Mulenga, 2011). Similarly, in the present study, some young people opted not to test, because they did not know how to explain sexual behaviour to their parents. Previous studies that focused on families in tackling issues of HIV showed some positive outcomes as a result of family-level involvement. Programmes like 'Families Matter', which created an opportunity for families to be able to hold dialogues about HIV, made it easy for young people to make protective SRH and HIV prevention decisions for their own benefit and those within their network (Denison et al., 2014)

Still on the issue of social networks, like other studies, the present study found that young people's social networks also influenced their choices to test for HIV (Denison et al., 2012; Denison et al., 2014). Some of the study participants shared their experiences about how they convinced their friends to test for HIV, when door-to-door testing was available in the community. This finding not only amplified the significance of social connections in HIV testing, but also highlighted the importance of convenience in service delivery in the community, particularly at a household-level. In this case, a young person had the interpersonal support they needed, and the door-to-door HIV testing service delivery was conveniently instituted through policies that supported community-level HIV service delivery.

5.5 How Young People Perceived Their Role in HIV Prevention

HIV prevention programmes and interventions for young people in SSA often focused on YPNLHIV (Mavedzenge et al., 2011; K Michielsen et al., 2013; Sani et al., 2016; Ssewanyana et al., 2018; Tolli, 2012). Consequently, YPLHIV were occasionally included in these programmes and interventions (Mavedzenge et al., 2011; K Michielsen et al., 2013; Sani et al., 2016; Ssewanyana et al., 2018; Tolli, 2012). As much as YPNLHIV are an important cohort in the HIV prevention efforts (Shanaube et al., 2017; UNAIDS, 2016a, 2019), the strategy had an indirect and somewhat adverse influence on the perspectives of YPLHIV. The present study showed that YPLHIV were aware of this biasness and, sometimes, felt rather misplaced and less important. Young people living with HIV sometimes insinuated that they felt like they were a health threat to others, because the only place where their status was not a very big problem was at the health clinics. The division in HIV prevention efforts for young people with respect to their serostatus had the potential to reduce the opportunities for dialogue that needed to take place between PLHIV and those who were not. Previous research in SSA highlighted that the silence about the experiences of PLHIV made it hard to get rid of the stigma, myths and misconceptions about HIV (Haffejee et al., 2018; Mburu et al., 2013; Yllequist, 2018).

The present study found that YPNLHIV and YPNTHIV rarely had any idea that YPLHIV could play a role in HIV prevention, except by using condoms. Condoms and abstinence were the common forms of HIV prevention young people mentioned or practiced. Collectively, the study participants were aware of the traditional forms of HIV prevention and seldom knew about other relatively new HIV prevention efforts, such TasP. Also, YPLHIV did not fully understand the concept of TasP. In addition, the majority of YPNLHIV and YPNTHIV did not understand or believe that TasP existed and how it worked. Similarly, a systematic review of studies that investigated the acceptability of TasP, such as PrEP, showed that young people expressed uncertainty in the effectiveness of TasP compared to condoms (Eakle, Weatherburn, & Bourne, 2019).

5.6 Limitations of the Study

The study did not conduct interviews with the health service providers and, therefore the reports on health service delivery are dependent on young people's interpretations and the researchers' observations. The study findings may also be limited, because participants were recruited during the PopART trial, which was providing HIV interventions for young people in the community. There could be differences in the young people's experiences in the absence of the PopART intervention.

5.7 Strengths of the Study

In Zambia, not many qualitative studies have been conducted across different communities to explore young people's experiences and perspectives, while being cognizant of their different HIV serostatuses, which is a valuable contribution made by this study. Furthermore, this study was conducted in four geographically spread communities in Zambia that typifies the prevailing socioeconomic circumstances in most communities in Zambia. The study was ethnographic in nature, which meant that it was able to provide an understanding of young people's experiences and perspectives of HIV prevention in-situ, based on researcher observations and interactions over a period of time (4 interviews and observations, 22 drop-in visits conducted over a period of 11 months with each participant). A such, the study used robust methods and techniques to understand young people in the context of HIV, and researchers were able to cross-validate data collected through the different qualitative research techniques employed.

5.8 CONCLUSION

Young people's choices were largely motivated by the need to maintain their innocence and 'good name' and save face in their community, regardless of their HIV serostatus. That is to say, they were caught between conflicting societal images of sexuality that was sanctioned and not sanctioned, and adversely affected by a population-dense environment. Age, gender, level of education and HIV serostatus were key drivers in understanding young people's experiences and perspectives regarding HIV prevention. These often adversely affected young people's choices about HIV prevention. For instance, it was harder for a young woman to leave a risky relationship than to demand that her partner use a condom. Health-risk behaviour remains a threat to HIV prevention efforts for young people. The pervasive silence about YPLHIV outside clinic walls and households made it difficult for them to be understood by other people. The lack of an informed medical and social perspective about YPLHIV and their role in HIV prevention made it easy for the community to stigmatise and overshadow their choices on HIV prevention. In addition, understanding of stigma, treatment and perception of the future for YPLHIV were emphasised in their experiences and perspectives. Evidently, YPLHIV were not very well informed about TasP. The fear that they would be blamed for having an HIV positive status, regardless of how they contracted it, made it difficult for them to openly discuss the issues of HIV prevention with their sexual partners.

HIV prevention efforts ought to understand young people with respect to their HIV serostatus, and include joint input and inclusive efforts from all young people, regardless of their serostatus. Furthermore, interventions need to be inclusive in the way that they incorporate the voices of YPLHIV, to value their efforts as partners in HIV prevention and not stigmatise them as threats to the health of others in society.

5.9 RECOMMENDATIONS

The following recommendations are made in order to improve HIV prevention service delivery for young people:

1. HIV prevention strategies should take into account young people's experiences and perspectives on existing services through participatory methods involving young people in order to improve the uptake of SRH services.
2. Young people of different HIV serostatuses need to be reached on the premise that they are all equally important stakeholders in the HIV prevention strategy. Health service providers working with young people also need to work together to create and improve dialogue among young people.
3. HIV prevention strategies must incorporate multilevel approaches that take into account the personal, interpersonal and community level influences on young people's HIV prevention

behaviours in order to reduce stigma and misconceptions that adversely affect and hamper HIV prevention strategies.

4. HIV prevention programmes must incorporate future perspectives that are inclusive of coaching young people in order to help them manage their anxieties of the future regarding HIV prevention for themselves and others.

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Appendix A: Information sheet for participants under 18 years

Zambart

PARTICIPANT INFORMATION SHEET – QUALITATIVE COHORT OF ADOLESCENTS UNDER 18 YEARS

<u>TITLE OF RESEARCH</u>: Qualitative Cohort – a social science component of the "Population Effects of Antiretroviral Therapy to Reduce HIV Transmission (PopART)" in 12 Zambian communities and 9 South African communities.

<u>PURPOSE OF THE STUDY</u>:

The purpose of the study is to document how health and HIV fit into the everyday lives of adolescent community members (aged 15 to 24 years). We are also documenting the same experiences in a small number of adult members in your community.

<u>DESCRIPTION OF THE STUDY</u>

This research is being carried out in your community because it is a community participating in the PopART study. The ZAMBART project social science team will conduct some participatory data collection activities. Some members of the community will be interviewed. This includes four adolescents in your community. Please note that being a participant in a 'qualitative cohort' study involves being interviewed more than once. Your parent/guardian has given permission for you to participate in this study if you would like to participate. We would like to interview you at least four times between now and November 2017. Three of these interviews will be with you on your own and one will involve meeting with the other three adolescents from the community in a small half-day workshop.

<u>YOUR INVOLVEMENT:</u>

With the permission of your parent/guardian, you have been selected to participate in a series of interviews because of living in a community where the PopART study is being carried out. You are being asked to participate in three interviews with a study staff member who will ask you questions about your life and your own experience of HIV in this community. Each interview is expected to last about 90 minutes. The staff member will take notes, and, with your permission, the interview will be recorded. We may also ask if we can spend a bit longer with you outside the interview, understanding more about your life in this place. In addition, we will ask you to attend a half-day workshop with three other adolescents from this community. We really value the information and time you share with us.

CONFIDENTIALITY:

Your name and any other information that may identify you or your household will be kept confidential. Although we will record the discussion with your permission and with the permission of your parent/guardian. The information will not be linked or traced back to you. When the discussion is fully transcribed (written up), the transcription will not bear actual names of informants. The results of this research may be published and full quotes from individuals may be used, but your identity and confidentiality will be protected, because the quotes will not be linked to named individuals. However, if we identify any serious health or welfare problems during the course of this research, we are obligated to refer to others who can help.

VOLUNTARY PARTICIPATION AND WITHDRAWAL:

Your participation in the research is voluntary. If you feel uncomfortable about any questions we ask, you are free not to answer them. If you or your parent/guardian no longer wish to participate in this research, you may do so with no penalty.

ALTERNATIVES TO PARTICIPATION

The alternative to participating in the interview is not to participate, which, as noted, will not result in any penalty or loss of benefits you or your parent/guardian normally receive.

RISKS AND BENEFITS:

There is a chance that some of our questions may cause discomfort or emotional stress. If so, you are not obligated to answer them. There are no direct benefits associated with participation in these individual interviews or the half-day workshop, but there may be indirect benefits for your community in the future. The information gained in this study may help organizations design future HIV prevention interventions.

COMPENSATION:

You will be interviewed at a time and location convenient to you because we know your time is valuable. This could be at your home or another location of your choice. The workshop will be held at a safe space in the community. All individual interviews will last about one-hour-and-thirty-minutes. The workshop will be half a day. There is no compensation for participating in the interviews or workshop, but refreshments will be provided at the workshop.

REASONS FOR STOPPING PARTICIPATION

You may be withdrawn from the study, if the research study, or this part of the study, is stopped or cancelled. You may also be withdrawn, if the study staff feels that completing the study or this part of the study would be harmful to you or others.

CONTACTS FOR QUESTIONS:

If you have any questions about your participation in this research study, your rights as a research subject, or if you feel that you have experienced a research-related injury, contact:

1. **Principal Investigator & Co-Investigator:** Virginia Bond, ZAMBART Project PO Box 50697, Ridgeway Campus, School of Medicine Lusaka. Telephone: +260 211 254710
2. **The Chairperson**, Biomedical Research Ethics Committee, University of Zambia. Telephone: +260 211 256067

3. **The Director,** Directorate of Research and Graduate Studies, University of Zambia.

   Telephone: +260 211 290258

Appendix B: Assent form for participants under 18 years

Zambart

TITLE OF RESEARCH: Qualitative Cohort – a social science component of the "Population Effects of Antiretroviral Therapy to Reduce HIV Transmission (PopART)".

Qualitative Cohort Consent Form (adolescent under 18 years)

Statement	Please initial or thumbprint* each box
1. I confirm that I am the parent or legal guardian of this young adult	
2. I have received and read/had read to me the information sheet provided by the researchers that explains in detail the reasons for the study. I have read, discussed and understood the purpose of the research. I have asked all the questions that I have about the purpose of the research and feel happy that I have enough information about it.	
3. I understand the reasons for this qualitative cohort research and am willing and happy for the adolescent in my care to participate for it.	
4. I know that the adolescent in my care has the right to leave the discussion at any time or to refuse to answer any questions.	
5. I agree ☐ disagree ☐ for the adolescent in my care to be quoted anonymously in this study	
6. If I do not agree for the adolescent in my care to take part in this discussion I understand that I will not be penalised for doing so by the researchers nor by any medical service personnel in the future.	

I permit his/her participation in the study.

Young adult's Name: ____

Parent/Guardian's name: ______________________________ **(please print)**
(Delete whichever is not applicable)

Parent/Guardian's signature/fingerprint: ____________________ **Date** ________________

Signature of witness (if parent/guardian unable to write)

Signature of witness: ___________________________________Date___________________

Witnessed by (print name): ____

Qualitative Cohort Consent Form Signature of Adolescent Under 18

Statement	**Initial or thumbprint**
1. I have received and read/had read to me the information sheet provided by the Researcher that explains the study in detail.	
2. I have discussed and understood the purpose of the study	
3. I have asked all the questions that I have about the study and feel happy that I have enough information about it.	
4. I agree ☐ disagree ☐ to be quoted anonymously in this study	

I agree to take part in this study.

Young adult's Signature or thumbprint:

____

Young adult's age (years): __________

The person who obtains the informed consent discussion must also sign and date this form.

Signature: ____ Date ________

Name: ____ (please print)

Appendix C: Parent information sheet for participants under 18 years

Zambart

PARTICIPANT INFORMATION SHEET – FOR PARENTS/GUARDIANS CONSENTING FOR ADOLESCENTS UNDER 18 YEARS - QUALITATIVE COHORT PARTICIPANTS

TITLE OF RESEARCH: Qualitative Cohort of Adolescents – a social science component of the "Population Effects of Antiretroviral Therapy to Reduce HIV Transmission (PopART)" in 12 Zambian communities and 9 South African communities.

PURPOSE OF THE STUDY:

The purpose of the study is to document how health and HIV fit into the everyday lives of adolescent community members (aged 15 to 24 years). We are also documenting the same experiences in a small number of adult members in your community.

DESCRIPTION OF THE STUDY

This research is being carried out in your community because it is a community participating in the PopART study. The ZAMBART project social science team will conduct some participatory data collection activities. Some members of the community will be interviewed. This includes four adolescents in your community. Please note that being participant in a 'qualitative cohort' involves being interviewed more than once. We would like to interview the adolescent in your care at least four times between now and November 2017. Three of these interviews will be with the adolescent on their own and one will involve meeting with the other three adolescents from the community in a small half day workshop.

YOUR INVOLVEMENT:

An adolescent in your care has been selected to participate in a series of interviews because of living in a community where the PopART study is being carried out. She/he is being asked to participate in three interviews with a study staff member who will ask she/he questions about her/his life and their own experience of HIV in this community. Each interview is expected to last about 90 minutes. The staff member will take notes, and, with your permission, the interview will be recorded. We may also ask if we can spend a bit longer with her/him outside the interview, understanding more about their life in this place. In addition, we will ask the adolescent in your care to attend a half day workshop with three other adolescents from this community. We really value the information and time they share with us.

CONFIDENTIALITY:

Your name and the name of the adolescent in in your care and any other information that may identify you or your household will be kept confidential. Although we will record with your permission and with the permission of the adolescent in your care the discussion, information will not be linked or traced back to you or to the adolescent in your care. When the discussion is fully transcribed (written up), the transcription will not bear actual names of informants. The results of this research may be published and full quotes from individuals may be used, but your identity and confidentiality will be protected because the quotes will not be linked to named individuals. However, if we identify any serious health or welfare problems during the course of this research, we are obligated to refer to others who can help.

VOLUNTARY PARTICIPATION AND WITHDRAWAL:

The participation of the adolescent in your care in the research is voluntary. If she/he feel uncomfortable about any questions we ask, they are free not to answer them. If you or the adolescent in your care no longer wish to participate in this research, you and she/he may do so with no penalty.

ALTERNATIVES TO PARTICIPATION

The alternative to participating in the interview is not to participate, which, as noted, will not result in any penalty or loss of benefits you or the adolescent in your care normally receive.

RISKS AND BENEFITS:

There is a chance that some of our questions may cause discomfort or emotional stress. If so, the adolescent in your care is not obligated to answer them. There are no direct benefits associated with participation in these individual interviews, but there may be indirect benefits for your community in the future. The information gained in this study may help organizations design future HIV prevention interventions.

COMPENSATION:

The adolescent in your care will be interviewed at a time and location convenient to you and to her/him because we know your and her/his time is valuable. This could be at your home or another location of your choice. All qualitative cohort individual interviews will last about one hour and thirty minutes. There is no compensation for participating in the interview.

REASONS FOR STOPPING PARTICIPATION

The adolescent in your care may be withdrawn from the study if the research study, or this part of the study, is stopped or cancelled. The adolescent in your care may also be withdrawn if the study staff feels that completing the study or this part of the study would be harmful to you, to the adolescent in your care or others.

CONTACTS FOR QUESTIONS:

If you have any questions about the participation of the adolescent in your care in this research study, your and her/his rights as a research subject, or if you or the adolescent in your care feel that you have experienced a research-related injury, contact:

1. **Principal Investigator & Co-Investigator:** Virginia Bond, ZAMBART Project PO Box 50697, Ridgeway Campus, School of Medicine Lusaka. Telephone: +260 211 254710
2. **The Chairperson**, Biomedical Research Ethics Committee, University of Zambia. Telephone: +260 211 256067
3. **The Director,** Directorate of Research and Graduate Studies, University of Zambia. Telephone: +260 211 290258

Appendix D: Information sheet for participants under 18 years (Tonga Language)

Zambart

IZYINA LYA BUVWUNTAUZYI: Milimo ya mibandi iijatikizya bantu ibaiminina munzi ibacilililwa mu buvwuntauzyi – cibeela cilanga bukale bwabantu akuyanzana ica ciiyo ca "Population Effects of Antiretroviral Therapy to Reduce HIV Transmission (PopART)" muzyooko zili 12 mu cisi ca Zambia alimwi azili 9 izya mu cisi ca South Africa.

IPEPA LYA CIZUMINANO ILYA BASIKUTOLA LUBAZU – ILYA BAKUBUSYI IBATANAKWANYA MYAKA 18 IBAIMININA MUNZI MUKUTOLA LUBAZU MUCIIYO

MULIMO WA CIIYO:

Mulimo wa ciiyo ngwakubweza twaambo tujatikizya inseba alimwi a sikalileke mbozyiyaama ibukale ibwamazuba oonse ibwabakubusyi bamumunzi (ibamyaka 15 kusika ku 24). Tulabwezya alimwi twaambo mbobuli tootu mu mweelwe musyoonto iwabamanene ibamumunzi wenu.

IBUPANDULUZI BWA CIIYO

Eeci ciiyo cibelekwa mumunzi wenu akaambo kakuti munzi umwi mwalo imuli ciiyo ca PoPART. Ibacibeela cilanganya maumi abantu abukale mumbunga ya ZAMBART baya kubeleka milimo iitamba bantu ikutola lubazu banoobwezya twaambo. Bamwi ibakala mumunzi bayakuba amubandi. Ooku nkubikilizya abakubusyi bone ibamumunzi wenu. Twamulomba muzyibe ikuti ikuba basikutola lubazu mu mumbunga iyabantu ibaiminina munzi iitegwa 'qualitative cohort' kuyakuba amibandi iyinda nyendo yomwe. Ibazyali/ibamalela bazumizya ikuti mutole lubazu mu ciiyo eeci ikuti na kamuyanda. Tuyanda ikuti tube amubandi andinwe ikuti kwaceya inyendo zyone akati ka lino a mweezi wa November imwaka wa 2017. Imibandi yotatwe iyakuba andinwe ilwenu alimwi umwi uyakuba iwakuswaangana abakubusyi botatwe ibazwa mumunzi mumuswaangano wamilimo imusyoonto uutola musela wa buzuba.

IKUTOLE LUBAZU IKWENU:

Ikucilizya ikuzumizya ikwa bazyali/ibamulela, mwasalwa ikuti mutole lubazu mumibandi icilidene akaambo kakuti mukala mumunzi oomuno mwalo imilimo ya ciiyo ca PoPART mwibelekwa. Mulombwa ikuti mutole lubazu mumibandi yotatwe aba belesyi ba ciiyo balo ibayakumabuzya mibuzyo iijatikizya buumi bwenu anzyomubona mumunzi oomuno ikujatikizya sikalileke. Imubandi umwi a umwi ulangilwa ikutola maminiti aasika ku 90. Ibabelesyi ba ciiyo bayakulemba makani mubufwiifwi, alimwi, mwazumizya, ijwi lyenu ciindi camubandi wenu liyakutolwa mumuncini. Tulalangilwa ikuti inga twalomba ikuti tube andinwe ikwaciindi wamana mubandi, ikuyanda ikuzyiba buumi bwenu mubusena oomuno. Ikuyungizya, tuyakumalomba kuti mukajanike kumuswaangano wamilimo uutola musela wabuzuba abakubusyi ibamwi botatwe ibazwa mumunzi oomuno. Tulalemeka ikapati imakani aciindi ncomuyakwabana andiswe.

MASESEKE:

Izyina lyenu alimwi amakani aamwi aaakonzya ikuti muzyibwe alimwi amukwasyi wenu ayakuyobolwa mumaseseke. Anokuba kuti tuyakubwezya jwi lyenu, mwazumizya alimwi aba bazyali/ibamulela imbubandi, imakani taakatondeki, taakabi nayakujolwa kuli ndinwe. Imubandi waakumana ikulembwa (ikulembwa mupepa), izyiyakulembwa tazyikabi amazyina aabwini aabasikutola lubazu. Izyitikajanwe mu ciiyo eeci zyilalangilwa ikuyolembwa mumabbuku alimwi atwaambo ituzwa kubantu tulakonzya ikuyobelesyegwa mbotubede, pele izyina lyenu alimwi amaseseke ayakukwabililwa nkaambo kakuti itwaambo tatukagami imazyina abantu. Anokuba boobu, ikuti na twajana imakani mapati anseba alimwi amapenzi abukale muciindi ca ciyo, tulipedwe ikuti tumatondezye kuli bamwi ibanga bamugwasya.

IKUTOLA LUBAZU IKWAKULIPA AKUZWA:

Ikutola lubazu mu ciiyo nkwakulyaaba kwenu. Ikuti na mwalimvwa bubi kumakani amibuzyo kufwumbwa, mulaangulukidwe ikutaivwiila. Ikuti na ilwenu na ibazyali/ibamulela tabaciyandi ikutola lubazu muciiyo, inga mwacita oobo kakutakwe impanisi.

INZILA ZYIMBI ZIINDENE AKUTOLA LUBAZU

Inzila iindene akutola lubazu mumubandi nkutatola lubazu, kwalo, mbobuli bwaambwa, takukaleti impanisi na kusweekelwa ikwabubotu bwalo ilwenu na ibazyali/ibamulela mbobatambula lyoonse.

INTENDA A BUBOTU:

Kulalangilwa ikuti imibuzyo yesu imwi inga yapa ikutalimvwa kabotu na kulibilika. Ikuti na kwaba boobu, tamwaangidwe ikuivwiila. Kunyina ibubotu ibumagama akaambo kakutola lubazu mumubandi iwa muntu a muntu na muswaangano iwamimilimo iwa musela wabuzuba, pele inga kwaba ibubotu ibwaambali kumunzi muzya mazuba. Imakani ayakujanwa mu ciiyo inga agwasya imbunga ikubamba milimo yabukwabilizyi ibwa sikalileke.

KULUNGWA:

Imubandi uyakuba a ciindi abusena mbomuyanda akaambo kakuti tulizyi ikuti ciindi cenu cilaabulemu. Ooku inga kwaba kung’anda yenu na busena bumbi ibusalwa andinwe. Imuswaangano uyakuba mubusena busetekene ibwa mumunzi. Yoonse mibandi abantu ibatola lubazu mumubandi iwa mbunga iyabantu ibaiminina munzi iyakutola iwoola lyomwe amusela. Imuswaangano uyakutola musela wabuzuba. Kunyina kubbadelwa akaambo kakuti mwatola lubazu mumibandi na mumuswaangano pele izyakunwa zyiyakupegwa ciindi camuswaangano.

ITWAAMBO TUPA KULEKA KUTOLA LUBAZU

Mulakonzya ikugwisyigwa muciiyo, na cibeela ca ciiyo eeci, caimikwa na kumwaigwa. Alimwi mulakonzya ikugusigwa mu ciiyo ikuti na ibabelesi ba ciiyo bacibona ikuti kuyaambele ikumana ciiyo na eeci cibeela ca ciiyo inga kwaleta penzi kulindinwe nape kulibamwi.

IKEALA ILYA MIBUZYO:

Ikuti na mujisi mibuzyo ijatikizya ndinwe ikutola lubazu muciiyo eeci, inguzu zyenu mbobuli sikutola lubazu mu ciiyo, nape ikuti na mulimvwa ikuti mwalijana muntenda na ikulicisa akaambo kakutola lubazu muciiyo amukwabe:

1. **Beendelezyi bapati abayanzene mubuvwuntauzyi:** Ba Virginia Bond, iba keala lya ZAMBART Project PO Box 50697, Ridgeway Campus, School of Medicine Lusaka. Luwaile: +260 211 254710
2. **Basicuuno**, Iba mbunga ya Biomedical Research Ethics Committee, iba kucikolo cipati Ica University of Zambia. Luwaile: +260 211 256067
3. **Beendelezyi ba milimo ba Director,** iba mbunga ya Directorate of Research and Graduate Studies, ku cikolo cipati ica University of Zambia. Luwaile: +260 211 290258

Appendix D: Assent form for participants under 18years (Tonga Language)

Zambart

IZYINA LYA BUVWUNTAUZYI: Milimo ya mibandi iijatikizya bantu ibaiminina munzi ibacilililwa mu buvwuntauzyi – cibeela cilanga bukale bwabantu akuyanzana ica ciiyo ca "Population Effects of Antiretroviral Therapy to Reduce HIV Transmission (PopART)".

Ipepa lyacizuminano ilya bantu baiminina munzi (Ibamyaka 18 kuzyoka aansi)

Twaambo	Twamulomba mulembe amabbala aakusanguna azyina na pe kuganta cinwe* muma bokesi oonse
1. Ndazumina kuti ndendime muzyali na mupati uzyibilwe ulela mwana oyu.	
2. Nadatambula alimwi akubala/bandibalila ipepa lya twaambo ilya pegwa abavwuntauztyi lipa bupanduluzyi boonse bwa ciiyo ncocicitilwa. Ndabala, kubandika alimwi akuteelela mulimo ya ciiyo. Ndabuzya mibuzyo yoonse njindajesi kujatikizya mulimo wa ciiyo a ku kutila kuti ndijisi luzyibo ali ncico.	
3. Ndateelela mulimo wa ciiyo eeci alimwi ndayanda alimwi ndakondwa ikuti mukubusyi ngwelela ikuti atole lubazu.	
4. Ndilizyi ikuti mukubusyi ngwelela ulaangusu izyakuzwa amubandi kufwumbwa ciindi na ikukaka kuvwiila kufwumbwa mibuzyo.	
5. Ndazumina ☐ Ndakaka ☐ ikuti majwi aamba mukubusyi ngwelela akabandwe ikutakwe zyina lyakwe mu ciiyo eeci.	
6. Ikuti na ndakaka ikuti mukubusyi ngwelela atole lubazu mu mumubandi ooyu ndilizyi ikuti nsekasubulwi abasikuvwuntauzya nape babelesyi banseba kumbele amazuba.	

Ndazumizya ikuti atole lubazu.

Izyina lya mukubusyi:

____

Izyina lya Bazyali/Ibalela :**_____________________________________(Amusinizya kulemba)**
(Amuzimekufwumbwa citeelede)

Kusaina/Kuganta munwe kwa Bazyali/Ibalela: ___________________
Buzuba________________

Kusaina kwabakamboni (Ikuti na bazyali/ibalela tabacikonzya ikulemba)

Kusaina kwaba kamboni:
___________________________________Date___________________

Ibabeleka bukamboni (Amusinizya kulemba zyina):
____

Kusaina kwa mukubusyi uulamya itasiki ku 18 Ipepa lya cizuminano ca bantu ibaiminina munzi

Statement	**Initial or thumbprint**
1. Nadatambula alimwi akubala/bandibalila ipepa lya twaambo ilya pegwa abavwuntauztyi lipa bupanduluzyi boonse bwa ciiyo.	
2. ndabandika alimwi akuteelela mulimo wa ciiyo	
3. Ndabuzya mibuzyo yoonse njindajesi kujatikizya ciiyo alimwi ndakondwa ikuti ndijesi luzyibo lukwene ali ncico.	
4. Ndazumina ☐ Ndakaka ☐ ikuti majwi angu kutakwe zyina lyangu akabandwe mu ciiyo eeci.	

Ndazumina kutola lubazu.

Kusaina/Kuganta munwe kwa mukubusyi:
____

Myaka yakyzyalwa iya mukubusyi (Myaka): __________

Imuntu uubwezya mubandi wakuzumizya weelede awalo asaine alimwi akulemba buzuba apepa eeli.

Kusaina: ____Buzuba ________

Izyina: ____ (Amusinizye kulemba)

Appendix E: Parent information sheet for participants under 18 years (Tonga Language)

Zambart

IZYINA LYA BUVWUNTAUZYI: Milimo ya mibandi iijatikizya bantu ibaiminina munzi ibacilililwa mu buvwuntauzyi – cibeela cilanga bukale bwabantu akuyanzana ica ciiyo ca "Population Effects of Antiretroviral Therapy to Reduce HIV Transmission (PopART)" muzyooko zili 12 mu cisi ca Zambia alimwi azili 9 izya mu cisi ca South Africa.

PEPA LYA CIZUMINANO ILYA BASIKUTOLA LUBAZU – ILYA BAZYALI/IBALELA IBAPA NGUZU KWIIMININA IBAKUBUSYI IBTANA KWANA MYAKA 18 IBAIMININA MUNZI MUKUTOLA LUBAZU MUCIIYO

<u>MULIMO WA CIIYO</u>:

Mulimo wa ciiyo ngwakubweza twaambo tujatikizya inseba alimwi a sikalileke mbozyiyaama ibukale ibwamazuba oonse ibwabakubusyi bamumunzi (ibamyaka 15 kusika ku 24). Tulabwezya alimwi twaambo mbobuli tootu mu mweelwe musyoonto iwabamanene ibamumunzi wenu.

<u>IBUPANDULUZI BWA CIIYO</u>

Eeci ciiyo cibelekwa mumunzi wenu akaambo kakuti munzi umwi mwalo imuli ciiyo ca PoPART. Ibacibeela cilanganya maumi abantu abukale mumbunga ya ZAMBART baya kubeleka milimo iitamba bantu ikutola lubazu banoobwezya twaambo. Bamwi ibakala mumunzi bayakuba amubandi. Ooku nkubikilizya abakubusyi bone ibamumunzi wenu. Twamulomba muzyibe ikuti ikuba basikutola lubazu mu mumbunga iyabantu ibaiminina munzi iitegwa 'qualitative cohort' kuyakuba amibandi iyinda nyendo yomwe. Tuyanda ikuti tube amubandi amukubusyi ngomulela ikuti kwaceya inyendo zyone akati ka lino a mweezi wa November imwaka wa 2017. Imibandi yotatwe iyakuba abakubusyi balike ilwenu alimwi umwi uyakuba iwakuswaangana abakubusyi botatwe ibazwa mumunzi mumuswaangano wamilimo imusyoonto uutola musela wa buzuba.

<u>IKUTOLE LUBAZU IKWENU:</u>

Umukubusyi ngomulela wasalwa ikuti atole lubazu mumibandi icilidene akaambo kakkala mumunzi oomuno mwalo imilimo ya ciiyo ca PoPART mwibelekwa. Walombwa ikuti atole lubazu mumibandi yotatwe aba belesyi ba ciiyo balo ibayakumbuzya mibuzyo iijatikizya buumi bwakwe anzyabona mumunzi oomuno ikujatikizya sikalileke. Imubandi umwi a umwi ulangilwa ikutola maminiti aasika ku 90. Ibabelesyi ba ciiyo bayakulemba makani mubufwiifwi, alimwi, mwazumizya, ijwi ciindi camubandi liyakutolwa mumuncini. Tulalangilwa ikuti inga twalomba ikuti tube anguwe ikwaciindi wamana mubandi, ikuyanda ikuzyiba buumi bwakwe mubusena oomuno. Ikuyungizya, tuyakulomba imukubusyi ngomulela ikuti akajanike kumuswaangano wamilimo uutola musela wabuzuba abakubusyi ibamwi botatwe ibazwa mumunzi oomuno. Tulalemeka ikapati imakani aciindi ncayakwabana andiswe.

MASESEKE:

Izyina lyenu alimwi amakani aamwi aaakonzya ikuti muzyibwe alimwi amukwasyi wenu ayakuyobolwa mumaseseke. Anokuba kuti tuyakubwezya jwi, mwazumizya alimwi amukubusyi ngomulela azumina imbubandi, imakani taakatondeki, taakabi nayakujolwa kuli ndinwe alimwi amukubusyi ngomulela. Imubandi waakumana ikulembwa (ikulembwa mupepa), izyiyakulembwa tazyikabi amazyina aabwini aabasikutola lubazu. Izyitikajanwe mu ciiyo eeci zyilalangilwa ikuyolembwa mumabbuku alimwi atwaambo ituzwa kubantu tulakonzya ikuyobelesyegwa mbotubede, pele izyina lyenu alimwi amaseseke ayakukwabililwa nkaambo kakuti itwaambo tatukagami imazyina abantu. Anokuba boobu, ikuti na twajana imakani mapati anseba alimwi amapenzi abukale muciindi ca ciyo, tulipedwe ikuti tuleezye kuli bamwi ibanga bamugwasya.

IKUTOLA LUBAZU IKWAKULIPA AKUZWA:

Ikutola lubazu mu ciiyo nkwakulyaaba kwamukubusyi ngomulela. Ikuti na walimvwa bubi kumakani amibuzyo kufwumbwa, ulaangulukidwe ikutaivwiila. Ikuti na ilwenu na imukubusyi ngomulela taciyandi ikutola lubazu muciiyo, inga mwacita oobo kakutakwe impanisi.

INZILA ZYIMBI ZIINDENE AKUTOLA LUBAZU

Inzila iindene akutola lubazu mumubandi nkutatola lubazu, kwalo, mbobuli bwaambwa, takukaleti impanisi na kusweekelwa ikwabubotu bwalo ilwenu na imukubusyi ngomulela ngwatambula lyoonse.

INTENDA A BUBOTU:

Kulalangilwa ikuti imibuzyo yesu imwi inga yapa ikutalimvwa kabotu na kulibilika. Ikuti na kwaba boobu, imukubusyi ngomulela taangidwe ikuivwiila. Kunyina ibubotu ibumagama akaambo kakutola lubazu mumubandi iwa muntu a muntu, pele inga kwaba ibubotu ibwaambali kumunzi muzya mazuba. Imakani ayakujanwa mu ciiyo inga agwasya imbunga ikubamba milimo yabukwabilizyi ibwa sikalileke.

KULUNGWA:

Imukubusyi ngomulela uyakuba amubandi a ciindi abusena mbomuyanda alimwi awalo akaambo kakuti tulizyi ikuti ciindi cakwe cilaabulemu. Ooku inga kwaba kung'anda yenu na busena bumbi ibusalwa andinwe. Yoonse mibandi abantu ibatola lubazu mumubandi iwa mbunga iyabantu ibaiminina munzi iyakutola iwoola lyomwe amusela. Kunyina kubbadelwa akaambo kakutolaa lubazu mumibandi

ITWAAMBO TUPA KULEKA KUTOLA LUBAZU

Imukubusyi ngomulela ulakonzya ikugwisyigwa muciiyo, na cibeela ca ciiyo eeci, caimikwa na kumwaigwa. Imukubusyi ngomulela ulakonzya ikugusigwa mu ciiyo ikuti na ibabelesi ba ciiyo bacibona ikuti kuyaambele ikumana ciiyo na eeci cibeela ca ciiyo inga kwaleta penzi kulindinwe kumukubusyi ngomulela nape kulibamwi.

IKEALA ILYA MIBUZYO:

Ikuti na mujisi mibuzyo ijatikizya ikutola lubazu ikwa mukubusyi ngomulela muciiyo eeci, inguzu zyenu azyakwe mbobuli sikutola lubazu mu ciiyo, nape ikuti na ilwenu na imukubusyi ngomulela walimvwa ikuti mwalijana muntenda na ikulicisa akaambo kakutola lubazu muciiyo amukwabe:

1. **Beendelezyi bapati abayanzene mubuvwuntauzyi:** Ba Virginia Bond, iba keala lya ZAMBART Project PO Box 50697, Ridgeway Campus, School of Medicine Lusaka. Luwaile: +260 211 254710
2. **Basicuuno**, Iba mbunga ya Biomedical Research Ethics Committee, iba kucikolo cipati ica University of Zambia. Luwaile: +260 211 256067
3. **Beendelezyi ba milimo ba Director,** iba mbunga ya Directorate of Research and Graduate Studies, ku cikolo cipati ica University of Zambia. Luwaile: +260 211 290258

Appendix F: Information sheet for participants under 18 years (Lozi Language)

Zambart

<u>MUTOMO WA PATISISO</u>: ‘Maikuto ni ze mufita mwa teni mina niba bangwi’ - Sibaka sa social science ‘Patisisi ya pukelezo ya ka kokwani ka hiv, ni kalafo, hamoho cwalo ni pabalelo mwa hala batu (PopART)’mwa licaba ze zinzi 12 mwa Zambia hape nize hinzi 9 kwa South Africa

PARTICIPANT INFORMATION SHEET – QUALITATIVE COHORT ADOLESCENTS UNDER 18 YEARS PARTICIPANTS

TUSO YA PATISISO YE:

Tuso ya tuto kiku n’gola za makete ni za HIV mwa bupilo wa ba nana ba ba hulu (ba ba na ni lilimo 15 kufita fa 24) ka za zi ni za zi mwa sicaba se.Hape lwa n’gola maikuto ni ze ba fita mwa teni ba nana ba ba hulu mwa tu kwata to tu hinyani mwa sibaka sa mina.

TOLOKO YA PATISISO:

Patisiso ye ya hezahala mwa sicaba samina ka kuli sicaba samina sa inga kolo mwa tuto ya PopART. Ka kwata ka social science mwa Zambart kaka heza tupapali nyana kuonga onga litaba. Batu baba ‘ngwi mwa sicaba ba ka bu zi wa li puzo. Amo ho ni ba nana ba ba hulu ba ba ne mwa sicaba sa mina. Lwa mi kupa kuli mu bone kuli kunga kolo kwa ku ambolisana ‘maikuto ni ze mufita mwa teni mina niba bangwi’ ki ku ambolisana isike angwi kono angata. Ba shemi ba mina ba lu lumelisize kuli mina munga kolo mwa tuto ye haiba mwa lata. Lu bata ku ambolisana ni mina ka li nako ze ine ku zwa fa cwalo ni kweli ya mwa November silimo sa 2017. Lu ka ambolisana ka li nako zei lalu amu inzi ba linosi, ku ambolisana ko ku mwi mu yo kopana niba bangwi ba ba lalu ba nana baba hulu ba mwa sicaba sa mina, workshop iyo kalisa ku zwa ku zwa ka ku sa sani kufita musihali kappa ku zwa musihaliku fita manzibwana.

KABELO YA MINA:

Ku lumelisa kw aba shemi ba mina, mu ketilwe kunga kolo mwa mukoloko wa ku ambolisana ka kuli mu pila mwa sicaba mo, se si na ni tuto ya PopART. Lwa mi kupa kuli munga kolo kwa ku ambolisana ko ku lalu ni mu beleki wa tuto yo aka mibuza lipuzo ka za bupilo ni, maikuto amina ni ze mu fitila mwa teni ka za HIV mwa sibaka se. Ku ambolisana ku no inganga nako ye fita 90 minutes. Mu beleki ano ngola ze ambolwa, ni, a mu ka mulumelisa, ku ambolisana ku yo rekodiwa. Lu ka mi kupa hape kuli lu be ni mina kwa nako ye telele a lu feza kuambolisana, ku utwisisa a hulu ka za bupilo bwa mina mwa sibaka se. Ku ekeza, lu ka mi kupa kuli mu yo fumaneha kwa mukopano wa ba nana baba hulu ba bangwi ba ba lalu b aba zwala mwa sicaba se. Lwa intumela ahulu kwa litaba ze mu ikabela ni luna.

KUNUTU

Mabizo a mina ni patahazo ye kona ku ema mina kappa lubasi lwa mina li ka bulukiwa ka kunutu. Kono amu ka lu lumeleze mina ni kulumelisa kwa ba shemi ba mina kubeya ngambolo ye, akuna taba yekasupeza kuli ki ngambolo yamina. Hayiba kukatokwaha kuhatisa ngambolo ye, mampili ana kungolwa mabizo amina. Zeka fumanwa mwa patisiso mwendi likaba lihatisizwe mi litaba ze zwa kw abatu li ka ng’olwa ka mo li bulelezwi kono mabizo abantu bao akabulukiwa ka kunutu. Mwahali a patisiso ye, haiba lu fumana bu tata bwa ku kula ko kutuna, lulukuluhile ku milumela kwa batu baba kona kutusa.

KUNGA KOLO HAPE NI KUZWA MWATENI:

Kuunga kolo mwa patisiso ye, ki kumina kutabela, mi nihe muka tuhelela fahali ha kuna koto yemutafiwa. Haiba mina kappa ba shemi ba mina mwi kutwa kusalukuluha kalipuzo zemwi, mulukuluhile kusa lyaba. Haiba musalati kuzweli pili ni ngambolo ye, mulukuluhile kutehala fahili musafiwi koto.

KUNGA KOLO HAPE NI KUZWA MWATENI:

Kunga kolo kwa mwaana mina yo mu huta mwa patisiso ye, ki ku itombola. Haiba mina kappa mwana min o mu huta a utwa ku sa lukuluhilwa ku taba mi buzo, mu lukuluhilwa ku tuhelela fahali ha kuna koto ye mu ta fiwa. Haiba mina kappa mwana mina mwi kutwa ku sa lukuluha ka li puzo zemwi, mu lukuluhile kusa lyaba. Haiba musalati kuzweli pili ni ngambolo ye, mu lukuluhile kutehala fahili musafiwi koto.

KANA KUNA NI LINZILA ZE NG’WI ZA KUNGA KOLO:

Linzila ze ng’wi za kunga kolo kwa ku ambolisana ki ku sanga kolo, se, si talusa kuli, a kuna koto kappa ku latehelwa miselo yo mu hamuhela ka mita mina kappa ba shemi ba mina sina mo mu hamuhela kamita.

KOZI NI MISELO

Mwendi lipuzozemwi zakona kumitwisa kusa utwa hande kappa kusa lukuluha. Haiba kuba cwalo, amuswaneli kulyalaba. Ha kuna miselo ye mu kafuna mina ka sibili ka kunga kolo kwa ku ambolisana kappa mwa workshop, kono kwa kona kuba miselo mwasi la landa samina kwa pili. Li taba ze kaongwa ongwa li katusa tutengo kufuna mikwa yakusileleza kokwani ka HIV kwapili.

Teko:

Mu ka buziwa lipuzo kanako ni mwasi baka se batabela bona Ku sabisa li tifo ka ku ba sinyeza nako, ze li kona kuba kwa ma ndu kapa kwa kwa sibaka so mu lata mina bengi. Workshop iyo ba mwa sibaka sesi ketila mwa sicaba. Workshop iyo kalisa ku zwa ku zwa ka ku sa sani kufita musihali kappa ku zwa musihaliku fita manzibwana. Kaufela ku ambolisana maikuto ni ze mufita mwa teni mina niba bangwi ku ka inga nako ye fita hola ilimwi ni mizuzu ye mashumi amalalu. Workshop iyo kalisa ku zwa ku zwa ka ku sa sani kufita musihali kappa ku zwa musihaliku fita manzibwana. Akuna teko ku mina fa ku unga kebelo kappa kolo kwa ku ambolisana kappa mwa workshop kono mu yo fiwa za kunwa kwa workshop.

KI LI BAKA ZE CWANI ZE KONA KUNI TUHELISWA KUSINA KUNIBUZA PILI KAPPA KU LUMELISANA NI NA?:

Mwa kona ku tu heliswa mwa patisiso ya tuto ku sina ku mi buza pili kappa ku lumelisana, kappa mwa sibaka sa tuto a sika tu helisiwa kappa patisiso ye ha i tu helisiwi fa hali.Mi hape mwa kona ku heliswa mwa tuto haiba ba beleki ba tuto ba bona kuli ku fiteleza kunga kolo mwa tuto kappa mwa kabelo ya tuto kwa kono kuba ni kozi ku mina kappa ba ba ‘ngwi.

MA BIZO NI LI NOMBOLO ZA MA PHONE A BATU BOMUKONA KUBUZA FA PATISISO YE:

Haiba mu na ni lipuzo ka kunga kabelo kwa mina mwa patisiso ye, kapa mane haiba mu ba ni kolofalo mwa hali ya tuto ye, mu lu kuluhile ku biha taba ku bo:

1. Bo Virginia Bond, bona bo **mweteleli ba lipatisiso zebakwa** ZAMBART Project PO Box 50697, Ridgeway Campus, School of Medicine Lusaka. Telephone : +260 211 254 710
2. **Mwina Sipula**, Bio-medical Research Ethics Committee, University of Zambia. Telephone: + 260 211 256067

3. **Bazamaisi bakatengo** ka Directorate of Research and Graduate Studies, fasikolo sesipahami sa University of Zambia. Telephone: + 260 211 290 258

Appendix G: Assent form for participants under 18 years (Lozi Language)

Zambart

MUTOMO WA PATISISO: Maikuto ni ze mufita mwa teni mina niba bangwi - Sibaka sa social science ‘Patisisi ya pukelezo ya ka kokwani ka hiv, ni kalafo, hamoho cwalo ni pabalelo mwa hala batu (PopART)

Qualitative Cohort Consent Form (adolescent under 18 years)

Londokela/Linolo	Kunyetela
1. Na lumela kuli na ki na mu shemi kappa anula wa mwana o mu hulu yo	
2. Ni hamuhezi ni ku bala/ba ni balezi patahazo imwa pampili ye ba ni file ba batisisi ye tololoka kaufela ka za li baka ni tuso ya tuto ye. Ni balile, ka ndekile ni ku utwa tuso ya patisiso. Ni bu zize li puzo kaufela ka za tuso ya patisiso mi ni tabezi kuli ni na ni patahazo ka za tuto ye.	
3. Ni utwisisize li baka ka za patisiso ye yak u utwa maikuto ni ze ba fita mwa teni tu kwata twa batu mi na bata hape ni tabezi kuli mwana ka o mu hulu ye ni huta anga kolo mwa teni.	
4. Na ziba kuli mwana o mu hulu ye ni hutaa na ni bulukuluhi bwa ku tuhela kunga kolo ku ambolisana nako ye mu latela kappa ku sa alaba li puzo.	
5. Na lumela ☐ na hana ☐ kuli mwanana o mu hulu ye ni huta kuli linolo za ha ye zi yo ng’oliwa ki bitihele/mukunda/kunutu mwa tuto ye.	
6. Haiba a ni lumeli kuli mwanana o mu hulu ye ni huta i sike anga ku ambolisana, na ziba kuli a kuna koto ye ka zwala ku ba batisisi a ni ka eza cwalo kappa ye zwala ku ba beleki ba makete kwa ma za zi a kwa pata.	

I lumelisa kuli anga kolo mwa tuto.

Libizo la mwanana o mu hulu: ____

Mu shemi/aula :_______________________________________**(please print)**
(Delete whichever is not applicable)

Kunyntela kwa mushemi/aula: ____________________ Lizazi _________________

Kunyetala kwa mupaki (haiba mushemi/aula a koni ku ng'ola)

Kunyetala kwa mupaki:
___________________________________Lizazi___________________

Mupaki wene aliteni (print name):
____

Qualitative Cohort Consent Form Signature of Adolescent Under 18

Londokela/Linolo	**Kunyetela (Initial or thumbprint)**
1. Ni hamuhezi ni ku bala/ba ni balezi patahazo ye putezi mwa pampili ye ba ni file ba batisisi ye tololoka kaufela ka za tuto ye.	
2. Ni kandekila ni utwisisa tuso ya tuto	
3. Ni buzize li puzo ka za tuto mi ni tabezi kuli ni na ni patahazo kappa litaba ka za yona tuto ye.	
4. Na lumela ☐ ani lumeli ☐ kuli linolo za ha ye zi yo ng'oliwa ki bitihele/mukunda/kunutu mwa tuto ye.	

Na lumela kunga kolo mwa tuto ye.

Kunyetela kwa mwanana o mu hulu:

____

Lilimo za mwanana o mu hulu (lilimo): _______________

Mutu a eteleza ku tololoka patahazo ni kulumelisana kwa ku ambolisana ni ye na a swanela ku kunyetela ni ku ng'loa lizazi fa pampili ye.

Kunyetela: ____Lizazi ________

Libizo: ____ (please print)

Appendix H: Parent information sheet for participants under 18years (Lozi Laguage)

Zambart

<u>MUTOMO WA PATISISO</u>: 'Maikuto ni ze mufita mwa teni mina banana ba ba hulu' - Sibaka sa social science 'Patisisi ya pukelezo ya ka kokwani ka HIV, ni kalafo, hamoho cwalo ni pabalelo mwa hala batu (PopART)'mwa licaba ze zinzi 12 mwa Zambia hape nize hinzi 9 kwa South Africa

PARTICIPANT INFORMATION SHEET – FOR PARENTS/GUARDIANS CONSENTING FOR ADOLESCENTS UNDER 18 YEARS QUALITATIVE COHORT PARTICIPANTS

TUSO YA PATISISO YE:

Tuso ya tuto kiku n'gola za makete ni za HIV mwa bupilo wa ba nana ba ba hulu (ba ba na ni lilimo 15 kufita fa 24) ka za zi ni za zi mwa sicaba se. Hape lwa n'gola maikuto ni ze ba fita mwa teni ba nana ba ba hulu mwa tu kwata to tu hinyani mwa sibaka sa mina.

TOLOKO YA PATISISO:

Patisiso ye ya hezahala mwa sicaba samina ka kuli sicaba samina sa inga kolo mwa tuto ya PopART. Ka kwata ka social science mwa Zambart kaka heza tupapali nyana kuonga onga litaba. Batu baba 'ngwi mwa sicaba ba ka bu zi wa li puzo. Amo ho ni ba nana ba ba hulu ba ba ne mwa sicaba sa mina. Lwa mi kupa kuli mu bone kuli kunga kolo kwa ku ambolisana 'maikuto ni ze mufita mwa teni mina niba bangwi' ki ku ambolisana isike angwi kono angata. Ba shemi ba mina ba lu lumelisize kuli mina munga kolo mwa tuto ye haiba mwa lata. Lu bata ku ambolisana ni mwanana o mu hulu o mu huta mina ka li nako ze ine ku zwa fa cwalo ni kweli ya mwa November silimo sa 2017. Lu ka ambolisana ka li nako zei lalu amu inzi ba linosi, ku ambolisana ko ku mwi mu yo kopana niba bangwi ba ba lalu ba nana baba hulu ba mwa sicaba sa mina. Workshop iyo kalisa ku zwa ku zwa ka ku sa sani kufita musihali kappa ku zwa musihaliku fita manzibwana.

KABELO YA MINA:

Mwana mina o mu hulu o mu huta u ketilwe kunga kolo mwa mukoloko wa ku ambolisana ka kuli mu pila mwa sicaba mo, se si na ni tuto ya PopART. Lu ka mu kupa kuli munga kolo kwa ku ambolisana ko ku lalu ni mu beleki wa tuto yo a ka mu buza lipuzo ka za bupilo ni, maikuto a ha ye ni ze mu fitila mwa teni ka za HIV mwa sibaka se. Ku ambolisana ku no inganga nako ye fita 90 minutes. Mu beleki ano ngola ze ambolwa, ni, a mu ka mulumelisa, ku ambolisana ku yo rekodiwa. Lu ka mu kupa hape kuli lu be ni ye na kwa nako ye telele a lu feza ku ambolisana ni ye na, ku utwisisa a hulu ka za bupilo bwa mina mwa sibaka se. Ku ekeza, lu ka mu kupa kuli a yo fumaneha kwa mu kopano wa ba nana baba hulu ba bangwi inge ye na ba ba lalu ba ba zwala mwa sicaba se. Lwa intumela ahulu kwa litaba ze mu ikabela ni luna.

KUNUTU

Li bizo la mina ni li bizo la wana o mu hulu wa mina o mu huta ni patahazo ye kona ku ema mina kappa lubasi lwa mina li ka bulukiwa ka kunutu. Kono amu ka lu lumeleze mina ni kulumelisa mina ni k ulu melisa kwa mwana mina kubeya ngambolo ye, akuna taba yekasupeza kuli ki ngambolo yamina. Hayiba kukatokwaha kuhatisa ngambolo ye, mampili ana kungolwa mabizo amina. Zeka fumanwa mwa patisiso mwendi li kaba lihatisizwe mi litaba ze zwa kwa batu li ka ng'olwa ka mo li bulelezwi kono ma bizo abantu bao akabulukiwa ka kunutu. Mwa hali a patisiso ye, haiba lu fumana bu tata bwa ku kula ko kutuna, lulukuluhile ku milumela kwa batu baba kona kutusa.

KUNGA KOLO HAPE NI KUZWA MWATENI:

Kunga kolo kwa mwaana mina yo mu huta mwa patisiso ye, ki ku itombola. Haiba mina kappa mwana min o mu huta a utwa ku sa lukuluhilwa ku taba mi buzo, mu lukuluhilwa ku tuhelela fahali ha kuna koto ye mu ta fiwa. Haiba mina kappa mwana mina mwi kutwa ku sa lukuluha ka li puzo zemwi, mu lukuluhile kusa lyaba. Haiba musalati kuzweli pili ni ngambolo ye, mu lukuluhile kutehala fahili musafiwi koto.

KANA KUNA NI LINZILA ZE NG'WI ZA KUNGA KOLO:

Linzila ze ng'wi za kunga kolo kwa ku ambolisana ki ku sanga kolo, se, si talusa kuli, a kuna koto kappa ku latehelwa miselo yo mu hamuhela ka mita mina kappa mwana mina sina mo mu hamuhela kamita.

KOZI NI MISELO

Ku na ni sibaka kuli mwendi li puzo zemwi za kona ku mi utwisa kusa utwa hande kappa kusa lukuluha. Haiba kuba cwalo, amuswaneli kulyalaba. Ha kuna miselo ye mu kafuna mina ka sibili ka kunga kolo kwa ku ambolisana kappa mwa workshop, kono kwa kona kuba miselo mwasi la landa sa mina kwa pili. Li taba ze kaongwa ongwa li katusa tutengo kufuna mikwa ya ku sileleza kokwani ka HIV kwapili.

Teko:

Mwana mina o mu hulu yo mu huta u ka bu ziwa lipuzo kanako ni mwasi baka se batabela bona Ku sabisa li tifo ka ku ba sinyeza nako, ze li kona kuba kwa ma ndu kapa kwa kwa sibaka so mu lata mina bengi. Workshop iyo ba mwa sibaka sesi ketila mwa sicaba. Kaufela ku ambolisana maikuto ni ze mufita mwa teni mina niba bangwi ku ka inga nako ye fita hola ilimwi ni mizuzu ye mashumi amalalu. Akuna teko ku mina fa ku unga kebelo kappa kolo kwa ku ambolisana.

KI LI BAKA ZE CWANI ZE KONA KUNI TUHELISWA KUSINA KUNIBUZA PILI KAPPA KU LUMELISANA NI NA?:

Mwana mina o mu hulu yo mu huta wa kona ku tu heliswa mwa patisiso ya tuto ku sina ku mi buza pili kappa ku lumelisana, kappa mwa sibaka sa tuto a sika tu helisiwa kappa patisiso ye ha i tu helisiwi fa hali. Mi hape wa kona ku heliswa mwa tuto haiba ba beleki ba tuto ba bona kuli ku fiteleza kunga kolo mwa tuto kappa mwa kabelo ya tuto kwa kono kuba ni kozi ku ye na kappa ba ba 'ngwi.

MA BIZO NI LI NOMBOLO ZA MA PHONE A BATU BOMUKONA KUBUZA FA PATISISO YE:

Haiba mu na ni lipuzo ka kunga kabelo kwa mwana mina o mu hulu yo mu huta mwa patisiso ye, kapa mane haiba a ba ni kolofalo mwa hali ya tuto ye, u lu kuluhile ku biha taba ku bo:

1. Bo Virginia Bond, bona bo **mweteleli ba lipatisiso zebakwa** ZAMBART Project PO Box 50697, Ridgeway Campus, School of Medicine Lusaka. Telephone : +260 211 254 710
2. **Mwina Sipula**, Bio-medical Research Ethics Committee, University of Zambia. Telephone: + 260 211 256067

3. **Bazamaisi bakatengo** ka Directorate of Research and Graduate Studies, fasikolo sesipahami sa University of Zambia. Telephone: + 260 211 290 258

Appendix I: Information sheet for participants under 18 years (Cinyanja Language)

Zambart

MUTU WA KAFUFUZO: Cohort Yoyenera - gawo lazasayansi yokhudza chikhalidwe cha anthu pa "Zotsatira za Kuchuluka kwa Mankhwala Opatsirana Kuchepetsa Kufala kwa HIV (PopART)". Mu malo khumi ni'ziwiri mu Zambia ndi zisani n'zinayi ku South Africa

PEPAPALA YA ZAMBIRI ZA OTHENGAKO MBALI – COHORT YOYENERA- PEPELA YO TENGAKO MBALI WACHINYAMATA WOSAKWANA ZAKA KHUMI N'ZISANU NZITATU

LINGO YA PHUNZILO:

Lingo ya phunzilo ndi kusunga momwe umoyo wa HIV ulili mu umoyo wathu wamasiku onse wa anyamata ndi atsikana mu mzinda (azaka khumi limodzi ndi zisanu mpaka zaka makumi awiri ndi zinai). Tisunganso zolingana ndi izi mukagulu kang"ono ka akulu mumamembala a muzinda wanu.

KUFOTOKOZA ZA PHUNZILO

Kufufuza uku kucitikila mu muzinda wanu cifukwa ndi muzinda omwe utengako mbali phunzilo ya PopART. A ZAMBART gulu ya sayansi yamakhalidwe azacita kutengako mbali pa zinthu zotengela uthenga. Ena mwa mamembala mu muzinda aza kambilana nao. Izi zizakhuza acicepele anai mumuzinda wanu. Chonde ziwani kuti kutengako mbali mu 'qualitative cohort' kukhuza kukambilana kopitilila kamodzi. Makolo/omusunga apasa cilolezo kuti mutengeko mbali kuphunzilo iyi ngati mufuna kutelo. Tizafuna kukambisana kanai kwatsopano mpaka mu November 2017. Katatu mwakukambisana uku kuzakhala kwa inu chabe ndipo kamodzi mwakukambisana uku azakumana acicepele ndi acicepele azawo akumuzinda wina kukamusokhano kang"ono kwatheka la tsiku.

KUKHUZIDWA KWA INU:

Ndi cilolezo kucokela kumakolo/omusungani, mwasankhidwa kutengako mbali mukukambisana cifukwa cokhala muzinda momwe mucitika phunzilo ya PopART. Ndipo mufunsidwa kutengako mbali mukukambisana katatu ndi mamembala aphunzilo omwe azakufusani mafunso ya za umoyo wanu ndi momwe mubvelela ndi HIV muzinda wanu. Kukambisana kuli konse kufunika kutenga 90 minutes. Membala azalemba ndi cilolezo canu kukambisana uku kuzajambulidwa. Tingafunse ngati tinga tengeko kathawi ka tali kunja kwa kukambisana kuziwa zambili za umoyo wanu mu malo anu. Mo onjezela tizamufunsani ngati mungatengeko mbali mukukambisana kwateka la tsiku ndi acicepele atatu ocokela mumzinda uno. Uthenga ndi nthawi yomwe mwagawana nafe tiika pamutengo wapatali.

CHISINSI:

Dzina yanu ndi uthenga uli wonse unga ziwise inu ndi banja lanu uzasungedwa mwa chisinsi. Ngakhale tezajambula mwacilolezo canu ndi cilolezo ca makolo anu kukambisana, uthenga siuzaziwika kapena kuziwisa inu. Pamene kukambisana kuzalembedwa sikuzakhala ndi maina yeni yeni ya ouzidwa. Zotulukamo mukufufuza uku zinga ulusidwa ndi kutenga uthenga wonse wa munthu umodzi wonse unga sewenzesedwa koma coziwesa imwe ndi cisinsi canu cizatetezedwa cifukwa zo ulusa sizizakuza dzina la munthu. Koma ngati taona ciliconse ca umoyo kapena makhaledwa pamene kufufuza kucitika, ndife ololedwa kutuma kwa ena amene anga nthandize.

KUTENGAKO MBALI KOZIPELEKA NDI KULEKA:

Kutengako mbali kwanu mukufufuza ndi kozipeleka. Ngati sinabvele bwino pamafunso ena yomwe tikufunsani ndimwe omasuka kusayankha. Ngati imwe kapena makolo/womusunga siafuna kuti mutengeko mbali mukufufuza uku, munga telo kopanda cilango.

NJILA INAYOTENGAKO MBALI

Njila inayotengako mbali mukukambilana ndi kusatengako mbali yamene yaziwika ndipo siiza kupasani cilango kapena kutaya zopatamo kwa inu kapena makolo/womusungani zomwe alandila nthawi zonse.

ZOIPA NDI ZABWINO ZOPEZEKAMO:

Kuli mpata kuti ena mwamafunso anga kubveseni kuipa kapena osakhala bwino. Muli ololedwa kusayakha mafunso amenewa. Kulibe zabwino zo onekela pakutengako mbali pakukambisana kwa inu kapena kukambisana kwa theka latsiku, koma kungakhale zotulukamo zo onekelatu zabwino kumuzinda musogolo.

Uthenga wapezeka muphunzilo iyi uzathandiza ‘organisations’ kupanga zoteteza matenda ya HIV musogolo.

MALIPILO:

Tizakambisana pa nthawi ndi malo yomwe mubvela bwino cifukwa tiziwa kuti nthawi yanu ndi ya mutengo wapatali. Izi zinkhale kunyumba kwanu kapena kumalo ena yomwe mwasakha. Musokhano wokambisana uzakhala potetezedwa muzinda wanu. Kukambisana konse kwa ‘qualitative cohort kwa munthu yense pa yekha payekha kuzatenga ola imodzi ndi mphindi makumi atatu (1 hour 30 minutes). Musokhano uzakhala watheka la tsiku). Kulibe malipilo pakutengako mbali mukukambilana kapena musokhano koma muzapasidwa madilingi musokhano.

CIFUKWA COLEKELA KUTENGAKO MBALI

Mungacosedwa muphunzilo ngati phunzilo yofufuza, kapena mbali iyi ya phunzilo yalekedwa kapena yalesedwa. Muzacosedwa muphunzilo ngati membala wa kufufuza a ona kuti kupitiliza phunzilo kapena mbali ya phunzilo izabwelesa mabvuto kwa inu kapena ena.

NAMBALA YA MAFUFUNSO:

Ngati muli ndi mafunso pakutengako mbali wacicepele womwe musunga mukufufuza kwaphunzilo iyi, ufulu wanu ndi ufulu wa wamene musunga mukufufuza uku kapena imwe olo wamene musunga mubvela kuti mwakhumudwa ndi kufufuza mungakambe ndi:

1. **Principal Investigator & Co-Investigator:** Virginia Bond, ZAMBART Project PO Box 50697, Ridgeway Campus, School of Medicine Lusaka. Telephone: +260 211 254710
2. **The Chairperson**, Biomedical Research Ethics Committee, University of Zambia. Telephone: +260 211 256067

3. **The Director,** Directorate of Research and Graduate Studies, University of Zambia. Telephone: +260 211 290258

Appendix J: Assent form for participants under 18 years (Cinyanja Language)

Zambart

MUTU WA KAFUFUZO: Cohort Yoyenera - gawo lazasayansi yokhudza chikhalidwe cha anthu pa "Zotsatira za Kuchuluka kwa Mankhwala Opatsirana Kuchepetsa Kufala kwa HIV (PopART)".

Pepela yo tengako mbali wachinyamata wosakwana zaka khumi n'zisanu nzitatu

	Mawu	Conde coyambila cadzina kapena kudinda ndi cala mubokusi ili yonse
1.	Ndibvomeleza kuti ndine kholo kapena kuti ndi wobvomelezewa kusunga wacicepele uyu	
2.	Ndalandila ndi kuwerenga/ a ndiwerengela pepala ya uthenga yomwe yapasidwa ndi wofufuza ndi kufotokoza kweni kweni zalingo yaphunzilo. Ndawerenga, takambilana ndipo nabvesa lingo ya kufufuza uku. Ndafunsa mafunso onse omwe ndinali nayo ya kufufuza ndipo ndibvela bwino kuti ndili ndi uthenga wokwanila.	
3.	Ndabvela malingo a kufufuza kwa 'qualitative cohort ndipo ndi wobvomeleza kuti wacicepele womwe ndisunga anga tengeko mbali.	
4.	Ndiziwa kuti wacicepele womwe ndisunga ali ndi ufulu woleka kukambilana nthawi ili yonse kapena kukana kuyankha mafunso.	
5.	Ndibvomela ☐ Sindibvomela ☐ kuti wacicepele womwe ndisunga anga funsidwa mosaziwa muphunzilo iyi.	
6.	Ngati sindibvomela kuti wacicepele womwe ndi ndisunga kuti a tengeko mbali mukukambisana uku ndi ziwa kuti sindizalandila cilango pocita zimenezi kucokela ku wofufuza kapena kuwocita nchito za umoyo musogolo.	

Ndipasa cilolezo kuwacicepele ku tengako mbali kuphunzilo.

Dzina ya wacicepele: ____

Dzina ya makolo/ Wosunga :______________________________________**(Conde lembani)**
(Cosani zonse zomwe sizifunika)

Kusaina makolo/Wosunga/Kudinda: ____________________ **Tsiku** _________________

Kusaina kwa mboni (Ngati makolo/Wosunga sanga lembe)

Kusaina kwa mboni: ___________________________________Tsiku___________________

Ndakhalila omboni (Lembani dzina):

____

Qualitative Cohort Consent Form Signature of Adolescent Under 18

Mawu	**Coyambila cadzina kapena kudinda**
1. Ndalandila ndi kuwerenga/ a ndiwerengela pepala ya uthenga yomwe yapasidwa ndi wofufuza ndi kufotokoza kweni kweni zalingo yaphunzilo	
2. Takambilana ndipo ndabvesa zalingo ya phunzilo	
3. Ndafunsa mafunso onse omwe ndinali nayo ya kufufuza ndipo ndibvela bwino kuti ndili ndi uthenga wokwanila.	
4. Ndibvomela ☐ sindibvomela ☐ ufunsidwa mosaziwa muphunzilo iyi	

Ndabvomela kutengako mbali kuphunzilo iyi.

Kusaina kwa wacicepele kapena kudinda:

____

Musinkhu wa wacicepele (dzaka): __________

Muthu omwe azatenga cilolezo ca kukambisana asaine ndi kulemba tsiku ya cilolezo.

Kusaina: ____Tsiku ________

Dzina: ____ (**Conde lembani**)

Appendix K: Parent information sheet for participants under 18 years (Cinyanja Language)

Zambart

MUTU WA KAFUFUZO: Cohort Yoyenera - gawo lazasayansi yokhudza chikhalidwe cha anthu pa "Zotsatira za Kuchuluka kwa Mankhwala Opatsirana Kuchepetsa Kufala kwa HIV (PopART)". Mu malo khumi ni'ziwiri mu Zambia ndi zisani n'zinayi ku South Africa

PEPAPALA YA ZAMBIRI ZA OTHENGAKO MBALI – COHORT YOYENERA- PEPELA YO TENGAKO MBALI YA MOKOLO AKU VOMEKEZA

WACHINYAMATA WOSAKWANA ZAKA KHUMI N'ZISANU NZITATU

LINGO YA PHUNZILO:

Lingo ya phunzilo ndi kusunga momwe umoyo wa HIV ulili mu umoyo wathu wamasiku onse wa anyamata ndi atsikana mu mzinda (azaka khumi limodzi ndi zisanu mpaka zaka makumi awiri ndi zinai). Tisunganso zolingana ndi izi mukagulu kang"ono ka akulu mumamembala a muzinda wanu.

KUFOTOKOZA ZA PHUNZILO

Kufufuza uku kucitikila mu muzinda wanu cifukwa ndi muzinda omwe utengako mbali phunzilo ya PopART. A ZAMBART gulu ya sayansi yamakhalidwe azacita kutengako mbali pa zinthu zotengela uthenga. Ena mwa mamembala mu muzinda aza kambilana nao. Izi zizakhuza acicepele anai mumuzinda wanu. Chonde ziwani kuti kutengako mbali mu 'qualitative cohort' kukhuza kukambilana kopitilila kamodzi. Tizafuna kukambitsana kanai ndi omwe musunga kwa tsopano ndi November 2017. Kukambisana kwathu katatu kuzakhala kukambisana ndi omwe musunga okha ndiponso kukumana kwa kamodzi kuzakhuza kukumana acicepele akumuzinda wina kukamusonkhano kang"ono ka theka la tsiku.

KUKHUZIDWA KWA INU:

Wacicepele womwe musunga asankhidwa kutengako mbali mukukambisana kosiyana-siyana cifukwa akhala muzinda momwe phunzilo ya PopART icitidwa. Afunsidwa kutengako mbali mukukambisana kutatu ndi membala waphunzilo wamene azafunsa mafunso ya umoyo wake ndi momwe akhalila ndi HIV muzinda uyu. . Kukambisana kuli konse kufunika kutenga 90 minutes. Membala azalemba ndi cilolezo canu kukambisana uku kuzajambulidwa. Tingafunse ngati tinga tengeko kathawi ka tali kunja kwa kukambisana kuziwa zambili za umoyo wanu mu malo anu. Mo onjezela tizafunsa wacicepele womwe musunga kuti atengeko mbali kumusokhano wa teka la tsiku pamodzi ndi acicepele amuzinda uno. Tiika pamutengo wapatali uthenga ndi nthawi agawana ndi ife.

CHISINSI:

Dzina ya omwe musunga ndi uthenga uli wonse unga ziwise inu kapena banja lanu uzasungedwa mwa chisinsi. Ngakhale tezajambula mwacilolezo canu ndi cilolezo cawamene musunga kukambisana, uthenga siuzaziwika kapena kuziwisa inu kapena kuziwisa wamene musunga. Pamene kukambisana kuzalembedwa sikuzakhala ndi maina yeni yeni ya ouzidwa. Zotulukamo mukufufuza uku zinga ulusidwa ndi kutenga uthenga wonse wa munthu umodzi wonse unga sewenzesedwa koma coziwesa imwe ndi cisinsi canu cizatetezedwa cifukwa zo ulusa sizizakuza dzina la munthu. Koma ngati taona ciliconse ca umoyo kapena makhaledwa pamene kufufuza kucitika, ndife ololedwa kutuma kwa ena amene anga nthandize.

KUTENGAKO MBALI KOZIPELEKA NDI KULEKA:

Kutengako mbali kuwacicepele womwe musunga mukufufuza uku ndi kozipeleka. Ngati iye sabvela bwino ena mwamafunso omwe tifunsa ndi omasuka kusayakha. Ngati imwe kapena wacicepele omwe musunga safuna kutengako mbali mukufufuza uku, imwe kapena iye mungatelo kopanda cilango.

NJILA INAYOTENGAKO MBALI

Njila ina yotengako mbali mukukambilana ndi kusatengako mbali yamene yaziwika ndipo siiza kupasani cilango kapena kutaya zopatamo kwa inu kapena makolo/womusungani zomwe alandila nthawi zonse.

ZOIPA NDI ZABWINO ZOPEZEKAMO:

Kuli mpata kuti ena mwamafunso anga kubveseni kuipa kapena osakhala bwino. Muli ololedwa kusayakha mafunso amenewa. Kulibe zabwino zo onekela pakutengako mbali pakukambisana kwa inu kapena kukambisana kwa theka latsiku, koma kungakhale zotulukamo zo onekelatu zabwino kumuzinda musogolo. Uthenga wapezeka muphunzilo iyi uzathandiza 'organisations' kupanga zoteteza matenda ya HIV musogolo.

MALIPILO:

Wacicepele womwe musunga azakambisidwa pa nthawi ndi pa malo yabwino kwa iye cifukwa tiziwa kuti nthawi ndi yofunikila kwa iye. Ici cingakhala pa nyumba panu kapena pa malo omwe mwa sankha.Kukambisana konse kwa 'qualitative cohort' kwa munthu yense pa yekha payekha kuzatenga ola imodzi ndi mphindi makumi atatu (1 hour 30 minutes).Kulibe malipilo pakutengako mbali mukukambilana uku.

CIFUKWA COLEKELA KUTENGAKO MBALI

Wacicepele womwe musunga anga azacosedwa muphunzilo ngati phunzilo yofufuza, kapena mbali iyi ya phunzilo yalekedwa kapena yalesedwa. Wacicepele womwe musunga naye anga lesedwa ngati membala wa kufufuza a ona kuti kupitiliza kuzabwelesa mabvuto kwa inu, wacicepele womwe musunga kapena kwa ena.

NAMBALA YA MAFUFUNSO:

Ngati muli ndi mafunso pakutengako mbali wacicepele womwe musunga mukufufuza kwaphunzilo iyi, ufulu wanu ndi ufulu wa wamene musunga mukufufuza uku kapena imwe olo wamene musunga mubvela kuti mwakhumudwa ndi kufufuza mungakambe ndi:

1. **Principal Investigator & Co-Investigator:** Virginia Bond, ZAMBART Project PO Box 50697, Ridgeway Campus, School of Medicine Lusaka. Telephone: +260 211 254710
2. **The Chairperson**, Biomedical Research Ethics Committee, University of Zambia. Telephone: +260 211 256067

3. **The Director,** Directorate of Research and Graduate Studies, University of Zambia. Telephone: +260 211 290258

Appendix L: Information sheet for participants under 18 years (Cibemba Language)

Zambart

UMUTWE WA MULIMO: ILYASHI LYA BUSAMBILILO - IMBALI YA SOCIAL SCIENCE MUKUCHEFYANYAKO UKUSANDANA KWA TUSHISHI TWA HIV (POPART) MUNCENDE ISHILI IKUMI LIMO NA SHIBILI (12) MU ZAMBIA NENCENDE ISHILI PABULA (9) MU SOUTH AFRICA

IBULA LYA BALESANDEMO ULUBALI – ILYA BUSAMBILILO LYA BANTU ABASHICILILE IMYAKA IKUMI LIMO NA CINE KONSE KONSE (UNDER 18 YEARS) ABALESENDAMO ULUBALI

IFYO UYU MULIMO UBELELEKO:

Ifyo uyu mulimo wa masambillo ubeleleko kufwaya ukutila babikile pamo ifishinka pama lyashi ya bumi na kashihi ka HIV mubwikalo bantu abali ne myaka yakufyalwa ikumi limo na isano nokushinta pa amakumi yabili na cine lubali (aged 15 to 24) muncende yenu. Elyo tulebika pamo efyo tulepitamo mubantu abanono mu ncende sha bantu abakalamba muncende yenu.

UBULONDOLOSHI BWA MASAMBILILO AYA:

Uku kufwailisha kuletungululwa mu ncende yenu pantu nincende yenu ile tumpamo mumasambililo ya PopART. Ba Zambart project imbali ya social science bakasendako amalyashi mukupitila uku kucita ifyangalo. Bamo aba muncende yenu abali nga imwe bakepushiwa amepusho. Elyo ibukisheni ukuti ukusendamo ulubali muli ilyashi lya busambililo nakukwata ukumwipusha amepusho imiku ukupitilila umukumo. Abafyashi benu atemwa abamisunga nabatupela insambu ukuti musangwemo muli ubu busambililo nga cakuti mulefwaya. Kuti twatemwa ukumwipusha amepusho ukulingana imiku ine ukwambilapo ino nshita ukufika mu mwenshi wa November 2017. Ya tatu pali aya amepusho yakacitwa naimwe mweka elyo na imo ikaba yakukumana bantu bamuncende yenu mwibumba ilinono mushiku bumo pakati mu workshop.

UKUSENDAKO ULUBALI KWENU:

Nomulandu wabafyashi benu nangula abamisunga nabasumishisha namusalwa ukuibimba mukulashanya uko pamulandu wakwikala munchende umo busambililo bwaba POPART buletungulwa. Mulelombwa ukusendamo ulubali mu mepusho no bonfi wa busambililo uwakulamipusha amepusho pafya bumi bwenu nefyo mupitamo palwa HIV muncdnde yenu. Uku kulanshyana ukulikonse kulecetekela ukusenda inshita insa imo na hafu (at least 90 minutes). Umubofi wa Popart akulalemba ifyo ulelanda elyo mukusuminisha kwenu ukulanshyana kulika pali nokukopa pa kalimba. Elyo kuti twmilomba ukuti tulundeko inshita panono naimwe panse pamemupusho mukufyalisha ifingi pa bwikalo bwenu muno munchende. Mukulundapo, twa milomba ukuti musangwemo mukusambilishanya kwa bushiku bumo na bantu ba tatu muncende yenu. Tule pela bukankala sana amalyashi nenshita mwakwata naifwe.

INKAMA YA PALWA KULANDISHANYA:

Ishina lyenu pamofye ne fintu fyonse ifingalenga ukutila imwe no lupwa lwenu mwamonekela/mwaishibikwa filesungwa mu nkama. Nelyo twala tepin'ga fyonse ifyo twalalandishanya mu kalimba (waileshi) nga abafyashi benu nagula abamisunga batupela insambu, tapabe amashiwi ayali yonse aya kalenga mwaishibikwa. Ishina lyenu talyakabikwe mu malyashi tukalemba ukufuma mukulandishanya uku. Fimo fine fikakonkwa palwa kwishibikwa kwenu ne nkama ya palwa imwe ngacakutila twalemba ifiletumbuka mu mulimo uyu mu mapepala. Ifikatumbukamo muli ubu busambililo kuti fyalembwa mumapepala no kulemba ifishinka ukufuma kufyo abantu balelanda, lelo inkama yenu ikasungwa umulandu wakuti tafyakakume ku mashina yenu. Nomba ngacakutila twasanga ubwafya ubukulu ubwa pa mikalile ya muntu pa nshita ya busambililo ubu, twaliba abakwipushiwa ukutuma umuntu ku bantu bambi abengamwafwilisha bwino.

UKUSENDAKO NO KUFUMA MU MULIMO UYU:

Ukusendako ulubali mu mulimo uyu kuli kwa kuipelesha ukufuma ku mutima wenu. Ngachakutila tamumfwile bwino na mepusho ayali yonse ayo twaipusha, muli abakakulwa no kukana ukuyaasuka.

Ngacakutila imwe nangu abafyashi benu nangu abamisunga tamusekelemo ukuba mu kulandishanya uku, kuti mwakana ukwabula umulandu uli onse.

INSHILA SHIMBI UKUKSAMDEMO ULUBALI:

Inshila imbi iyo mwinga sendelamo ulubali mukulanshaynya uku kukana sangwako, nga kulingana ifhyo mwishibe kale tacakalenge ukumipela umulandu uli onse nangula ukulusa amalipilo ayo imwe nangu abafyashi benu nangu abamisunga bengapokelela.

UBUKANKALA NA MASAKAMIKO:

Kuti kwaba inshita shimo elyo amepusho yesu yamo yengalenga abantu ukukana umfwa bwino nangu ukubaletela amatontonkanyo. Ngacacitika ici kuti mwasalapo ukukana yasuka. Takuli ubwafwilishiwo ubukapelwa kuli imwe mweka pa kusendako ulubali mu kulandishanya uku, nomba limbi kuti mwafuma ifintu fimo ifikafwilisha incende yenu kuntanshi. Ilyashi ililesangwa mu mulimo uyu kuti lyaba ilyakwafwilisha utubungwe/amakampani ukupekanya bwino imibombelo yabo iya palwa kucimfya akashishi ka HIV.

AMALIPILO:

Tukalandishanya nenu panshita ne ncende iyo mulefyaya pantu natwishaba ukuti inshita yenu ikankala. Ifi kuti fyacitikwa ku N'ganda yenu nangula ku ncende iyo mwasala mwebene. Ukulandishanya kwa mwibumba kukacitikila ku ncende iyafisama muncende yenu. Bonse abakaibimba busambililo ubu, bukalasenda inshita ilingene ne nsa imo na half. Ukulandishanya kwa mwibumba kukasenda inshita ukufika pakati pakasuba. Takuli ubwafwilishiwo ubukapelwa kuli imwe pa kusendako ulubali mu kulandishanya uku nangu mukulanshanya kwamwibumba, lelo ifyakulya mukapelwa pa ncende ya kulanshanya kwamwibuma.

IFINTU IFINGALENGA UKUTI UKUSENDAMO ULUBALI KULESHEWE :

Kuti bamifumya muku sendamo lubali mubusambililo ubu nga cakuti abale tungulila ubusambililo ubu, nagnula fimo mubusambililo ubu baleshya nangula bafiminika. Elyo kuti bamifumyamo busambililo ubu abaletungilila nga bamona ukuti ukupwisha ubusambililo ubu nangu incende imo iya busambililo ubu taiyene kuimwe nangula kubantu bambi.

ABO MWINGEPUSHA AMEPUSHO (AMASHINA, AMAKEYALA NA MALAMYA):

Nga namukwata amepusho ali yonse palwa ikuibimbamo kenu muli ubu busambililo, insambu shenu nge cibombelo cesambililo, nangu mwamona ukuti ifyo mwapitamo panshita ya ubu busambililo nafimi chena, landeni na:

Intungushi ya mulimo nenkonkani yabo mufya kufwalisha: Ba Virginia Bond, ukufuma ku ZAMBART Project, P.O. Box 50897, Ridgeway Campus, school of Medicine, Lusaka.

Lamya: +260 211 254710.

1. **Abakumupando**, Biomedical Research Ethics Committee, University of Zambia. Telephone: +260 211 256067
2. **Ba Kangalila,** Directorate of Research and Graduate Studies, University of Zambia. Telephone: +260 211 290258

Appendix M: Assent form for participants under 18 years (Cibemba Language)

Zambart

UMUTWE WA MULIMO: Ilyashi lya busambililo- imbali ya social science mukuchefyanyako ukusandana kwa tushishi twa HIV (PopART)

Ichipepala ca Kusuminishanya – Abalesendamo ulubali Mwilyashi Lya Mubusambililo abali nemyaka yakufyalwa panshi pa ikumi limo na cine konse konse (adolescent under 18 years)

Icipope	Lembeni ifibalilepo kuma shina yenu nangula fwatikeni mu kabokoshi* Konse
1. Ndesuminisha ukutila ndi mufyashi nangula uyasumishiwa ukusunga uyu muntu.	
2. Ni pokelela no kubelenga nangula nabambelengela ibula ili ku baletungulila ubusambililo ubyu ilelondolola mukufikapo ifinshika pafya busambililo ubu. Ni mbelenga, elyo natu lanshanya nokumfwa ningumfwa echo ubusambililo ubu buleleko. Nijipusha amepusho yonse ayapa busambililo ubu elyo namona ukuti nikwata ifishika fyonse pa busambililo ubu.	
3. Ningumfwikisha ifyo balefwaya muli ubu busambililo elyo ndesumisha ukuti nintemwa umuntu nsunga engasandemo ulubali muli ubu busambililo.	
4. Nijishaba ukuti umuntu nsunga nakwata insambu ukufuma mukulanshanya uku inshita iliyonse nangula ukuna yasuka amepusho ayali yonse.	
5. Na sumina ☐ Na kana ☐ ukutila umuntu uyo ine nsunga ba mulumbule mubusambililo ubu.	
6. Ngacakuti nshilesuminisha ukutila umuntu nsunga asendemo ulubali muli ubu busambililo ubu tabampele umulandu uli onse kuli abo abaletungililila ubu busambililo nangula ababomfi ba medical service kuntanshi.	

Ndesuminisha ukuti asendemo ulubali muli ubusambililo ubu.

Ishina lya musungwa:

____

Ishina lya bafyashi nangu abamusunga
:**____ (Lembeni mufilembo ifikulu)**

(Futeni ifyo tamwabofye)
Ukusaina/Ukfwatika kwa mufyashi/abamusunga: ____________________
Ubushiku___________

Ukusaina kwa baleimininako (nga cakuti abafyashi/abamusunga teti bakwanishe ukulemba)

Ukusaina kwa baleimininako:
______________________________Ubushiku___________________

Ishina lya baleimininako
:**____ (Lembeni mufilembo ifikulu)**

Ichipepala ca Kusuminishanya ukusaina kwa balesendamo ulubali abali nemyaka yakufyalwa panshi pa ikumi limo na cine konse konse (adolescent under 18 years)

Icipope	Lembeni ifibalilepo kuma shina yenu nangula fwatikeni
5. Ni pokelela no kubelenga nangula naba mbelengelela ifila mwicipepala ici ica busambililo kuli abatungulila ubu busambililo ukulodolola ukufikapo.	
6. Natulanshanya elyo ningumfwikisha ifyo ubu busambililo bubeleleko.	
7. Elyo nijipusha amepusho yonse ayo nkwete palwa ubu busambililo elyo nokutila ati ndi uwansansa nakwata ifishika ifingi pali ubu busambililo.	
8. Na sumina ☐ Na kana☐ ukuti ba bofye ifyo ndelanda ukwabula ukujishibisha.	

Ndesumina ukusendamo ulubali mubu sambililo ubu.

Ukusaina nangu ukufwatika kwa musungwa: ______________________________________

Imyaka ya muntu musungwa: ____

Umuntu uwasenda icipepala ca kusuminishanya no kulanshanya afwile uku saina nokubikapo ubushiku pa cipepala ici.

Ukusaina: ____Ubushiku _______________

Ishina: ____
(**Lembeni mufilembo** ifikulu)

Appendix N: Parent information sheet for participants under 18 years (Cibemba Language)

Zambart

UMUTWE WA MULIMO: Ilyashi lya busambililo - imbali ya social science mukuchefyanyako ukusandana kwa tushishi twa HIV (PopART) muncende ishili ikumi limo na shibili (12) mu Zambia nencende ishili pabula (9) mu South Africa.

IBULA LYA BALESANDEMO ULUBALI – ILYA BAFWASHI NANGU ABUSUNGA LYA BANTU ABASHICILILE IMYAKA IKUMI LIMO NA CINE KONSE KONSE (UNDER 18 YEARS) ABALESENDAMO ULUBALI MUBUSAMBILILO UBU

IFYO UYU MULIMO UBELELEKO:

Ifyo uyu mulimo wa masambillo ubeleleko kufwaya ukutila babikile pamo ifishinka pama lyashi ya bumi na kashihi ka HIV mubwikalo bantu abali ne myaka yakufyalwa ikumi limo na isano nokushinta pa amakumi yabili na cine lubali (aged 15 to 24) muncende yenu. Elyo tulebika pamo efyo tulepitamo mubantu abanono mu ncende sha bantu abakalamba muncende yenu.

UBULONDOLOSHI BWA MASAMBILILO AYA:

Uku kufwailisha kuletungululwa mu ncende yenu pantu nincende yenu ile tumpamo mumasambililo ya PopART. Ba Zambart project imbali ya social science bakasendako amalyashi mukupitila uku kucita ifyangalo. Bamo aba muncende yenu abali nga imwe bakepushiwa amepusho. Elyo ibukisheni ukuti ukusendamo ulubali muli ilyashi lya busambililo nakukwata ukumwipusha amepusho imiku ukupitilila umukumo. Abafyashi benu atemwa abamisunga nabatupela insambu ukuti musangwemo muli ubu busambililo nga cakuti mulefwaya. Kuti twatemwa ukumwipusha amepusho ukulingana imiku ine ukwambilapo ino nshita ukufika mu mwenshi wa November 2017. Ya tatu pali aya amepusho yakacitwa naimwe mweka elyo na imo ikaba yakukumana bantu bamuncende yenu mwibumba ilinono mushiku bumo pakati mu workshop.

UKUSENDAKO ULUBALI KWENU:

Nomulandu wababafyashi benu nangula abamisunga nabasumishisha namusalwa ukuibimba mukulashanya uko pamulandu wakwikala munchende umo busambililo bwaba PopART buletungulwa. Mulelombwa ukusendamo ulubali mu mepusho no bonfi wa busambililo uwakulamipusha amepusho pafya bumi bwenu nefyo mupitamo palwa HIV muncdnde yenu. Uku kulanshyana ukulikonse kulecetekela ukusenda inshita insa imo na hafu (at least 90 minutes). Umubofi wa Popart akulalemba ifyo ulelanda elyo mukusuminisha kwenu ukulanshyana kulika pali nokukopa pa kalimba. Elyo kuti twmilomba ukuti tulundeko inshita panono naimwe panse pamemupusho mukufyalisha ifingi pa bwikalo bwenu muno munchende. Mukulundapo, twa milomba ukuti musangwemo mukusambilishanya kwa bushiku bumo na bantu ba tatu muncende yenu. Tule pela bukankala sana amalyashi nenshita mwakwata naifwe.

INKAMA YA PALWA KULANDISHANYA:

Ishina lyenu pamofye ne fintu fyonse ifingalenga ukutila imwe no lupwa lwenu mwamonekela/mwaishibikwa filesungwa mu nkama. Nelyo twala tepin'ga fyonse ifyo twalalandishanya mu kalimba (waileshi) nga abafyashi benu nagula abamisunga batupela insambu, tapabe amashiwi ayali yonse aya kalenga mwaishibikwa. Ishina lyenu talyakabikwe mu malyashi tukalemba ukufuma mukulandishanya uku. Fimo fine fikakonkwa palwa kwishibikwa kwenu ne nkama ya palwa imwe ngacakutila twalemba ifiletumbuka mu mulimo uyu mu mapepala. Ifikatumbukamo muli ubu busambililo kuti fyalembwa mumapepala no kulemba ifishinka ukufuma kufyo abantu balelanda, lelo inkama yenu ikasungwa umulandu wakuti tafyakakume ku mashina yenu. Nomba ngacakutila twasanga ubwafya ubukulu ubwa pa mikalile ya muntu pa nshita ya busambililo ubu, twaliba abakwipushiwa ukutuma umuntu ku bantu bambi abengamwafwilisha bwino.

UKUSENDAKO NO KUFUMA MU MULIMO UYU:

Ukusendako ulubali mu mulimo uyu kuli kwa kuipelesha ukufuma ku mutima wenu. Ngachakutila tamumfwile bwino na mepusho ayali yonse ayo twaipusha, muli abakakulwa no kukana ukuyaasuka.

Ngacakutila imwe nangu abafyashi benu nangu abamisunga tamusekelemo ukuba mu kulandishanya uku, kuti mwakana ukwabula umulandu uli onse.

INSHILA SHIMBI UKUKSAMDEMO ULUBALI:

Inshila imbi iyo mwinga sendelamo ulubali mukulanshaynya uku kukana sangwako, nga kulingana ifhyo mwishibe kale tacakalenge ukumipela umulandu uli onse nangula ukulusa amalipilo ayo imwe nangu abafyashi benu nangu abamisunga bengapokelela.

UBUKANKALA NA MASAKAMIKO:

Kuti kwaba inshita shimo elyo amepusho yesu yamo yengalenga abantu ukukana umfwa bwino nangu ukubaletela amatontonkanyo. Ngacacitika ici kuti mwasalapo ukukana yasuka. Takuli ubwafwilishiwo ubukapelwa kuli imwe mweka pa kusendako ulubali mu kulandishanya uku, nomba limbi kuti mwafuma ifintu fimo ifikafwilisha incende yenu kuntanshi. Ilyashi ililesangwa mu mulimo uyu kuti lyaba ilyakwafwilisha utubungwe/amakampani ukupekanya bwino imibombelo yabo iya palwa kucimfya akashishi ka HIV.

AMALIPILO:

Tukalandishanya nenu panshita ne ncende iyo mulefyaya pantu natwishaba ukuti inshita yenu ikankala. Ifi kuti fyacitikwa ku N'ganda yenu nangula ku ncende iyo mwasala mwebene. Ukulandishanya kwa mwibumba kukacitikila ku ncende iyafisama muncende yenu. Bonse abakaibimba busambililo ubu, bukalasenda inshita ilingene ne nsa imo na half. Ukulandishanya kwa mwibumba kukasenda inshita ukufika pakati pakasuba. Takuli ubwafwilishiwo ubukapelwa kuli imwe pa kusendako ulubali mu kulandishanya uku nangu mukulanshanya kwamwibumba, lelo ifyakulya mukapelwa pa ncende ya kulanshanya kwamwibuma.

IFINTU IFINGALENGA UKUTI UKUSENDAMO ULUBALI KULESHEWE :

Kuti bamifumya muku sendamo lubali mubusambililo ubu nga cakuti abale tungulila ubusambililo ubu, nagnula fimo mubusambililo ubu baleshya nangula bafiminika. Elyo kuti bamifumyamo busambililo ubu abaletungilila nga bamona ukuti ukupwisha ubusambililo ubu nangu incende imo iya busambililo ubu taiyene kuimwe nangula kubantu bambi.

ABO MWINGEPUSHA AMEPUSHO (AMASHINA, AMAKEYALA NA MALAMYA):

Nga namukwata amepusho ali yonse palwa ikuibimbamo kenu muli ubu busambililo, insambu shenu nge cibombelo cesambililo, nangu mwamona ukuti ifyo mwapitamo panshita ya ubu busambililo nafimi chena, landeni na:

1. **Intungushi ya mulimo nenkonkani yabo mufya kufwalisha:** Ba Virginia Bond, ukufuma ku ZAMBART Project, P.O. Box 50897, Ridgeway Campus, school of Medicine, Lusaka.
   Lamya: +260 211 254710.

2. **Abakumupando**, Biomedical Research Ethics Committee, University of Zambia. Telephone: +260 211 256067

3. **Ba Kangalila,** Directorate of Research and Graduate Studies, University of Zambia. Telephone: +260 211 290258

Appendix L: Information sheet for participants 18 years and older

ZAMBART PROJECT

Ridgeway Campus
University of Zambia
PO Box 50697
Ridgeway
Lusaka
ZAMBIA

Tel/Fax: 01-25.47.10
Email: info@zambart.org.zm

PARTICIPANT INFORMATION SHEET- for Adolescent Participants

TITLE OF RESEARCH:

Population Effects of Antiretroviral Therapy to Reduce HIV Transmission (PopART): A cluster-randomized trial of the impact of a combination prevention package on population-level HIV incidence in Zambia and South Africa.

PURPOSE OF THE STUDY:

The research you are being asked to participate in is one part of a larger study. The larger study is called HPTN 071 (PopART). It is evaluating whether a program to try to reduce HIV infection in a community like yours works or not. This HPTN 071 (PopART) study is being done in 21 communities in total, including 9 communities in South Africa (all in the Western Cape), and 12 other communities in Zambia. If you would like more information about the HPTN 071 (PopART) evaluation, please ask the researcher who can also supply you with a study fact sheet.

Part of this bigger study called HPTN 071 (PopART) is what we as the researchers call the social science component. This social science component is the part of the study that helps us to understand the experiences of people implementing the research, living in the study communities, or who are important in other ways. The social science component aims to give detailed, real, contextual explanations of how and why things happen as they do to complement the larger evaluation of 'if' the intervention works or not. Typically, most of this social science component involves spending time with people, observing their daily lives, and listening to their stories. Broadly, there are three aims to the social science components of HPTN 071 (PopART); (1) telling the story of the study and the intervention it is evaluating, (2) explaining peoples' choices to take-up offers of HIV counselling and testing and ante-retroviral therapy or not, and (3) describing the social context of life in the study communities (for example, how and why things like unemployment is important to the story of health). More information on why the social science research team would like you to participate is included in the section on "**participant eligibility – why am I being asked to participate**" below.

PARTICIPANT ELIGIBILITY – WHY AM I BEING ASKED TO PARTICIPATE

As part of the social science components of HPTN 071 (PopART), it is of utmost importance that the everyday lives of community members in the study communities are described; especially in relation to the way health issues (including HIV) intersect with wider social issues and contextual experiences. You are being invited to participate because you live in one of these study communities. We believe that you have valuable information to share about your life and the lives of people living in your community and we would be very grateful if you share this with us.

WHAT WILL HAPPEN DURING THIS STUDY?

The social science field team would like to spend time with you as representatives of people living in the HPTN 071 (PopART) study communities. In order to properly understand your lives (it is our assumption that everyone lives complex, complicated, and interesting lives) we would like to spend a significant portion of time with you; at your homes, in the places you go to during the day and evening, and anywhere else you think that would help us to clearly understand your life. For most participants, we will spend at least a week worth of interactions with them at the beginning (not quite living with them, but definitely visiting for a while), then call again to see how things are about three months later. During this time, the research team will ask you questions and may ask you to do some activities (like ranking of alternatives). The research team will make notes of what they see and hear and will also keep records like audio recordings and photographs of relevant parts of their observations. You are being invited to participate in all of these interactions. The research team would also like you to refer us to other people that are your significant others, or otherwise important to understanding your life that we can have discussions with during the time spent with you.

DESCRIPTION OF THE STUDY AND YOUR INVOLVEMENT:

We are interested in talking to you because you are between the ages 12 and 24, live in one of the HPTN 071 (PopART) sites, and your parent/ guardian has given permission for you to participate in this study if you would like to. If you agree, we will ask you to take part in a one day workshop and three individual interviews where you will be invited to take part in discussions about your experiences, your life, health and access to healthcare at an agreed venue. We would like to use a recorder to record the interviews so we don't miss anything, and a research team member will be taking notes. However, we will not record or write any names, and once the recording is transcribed, we will destroy it.

CONFIDENTIALITY:

We will take every precaution to protect your confidentiality. We will not share any personal information with anyone else – even a family member – and notes will only be accessible to our research team. You will not be identifiable in any publications or presentations resulting from this study. We will combine responses from all the participants and write reports without mentioning their names.

LONG TERM STORAGE OF THE DATA AND INCLUSION IN A SOCIAL SCIENCE DATABANK

If you sign the consent document, you are agreeing to allow the researchers to use the information you share with them to answer the questions described above. Hard copies of the data will be stored in secure, lockable cabinets and soft copies on secure, password-protected computer platforms. The data will be stored for a minimum of 7 years and destroyed after 7 years or after study completion.

VOLUNTARY PARTICIPATION AND WITHDRAWAL:

Your participation in the research is voluntary. If you feel uncomfortable about any questions we ask, please feel free not to answer them. If you no longer wish to participate in this research, it will not affect any of your access to or participation in services.

WHAT ARE SOME REASONS WHY THE RESEARCHERS MAY DECIDE TO WITHDRAW YOUR PARTICIPATION IN THE STUDY?

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

- The research study, or this part of the study, is stopped or cancelled

- The study staff feels that completing the study or this part of the study would be harmful to you or others
- The scientific goals for the research have already been met and continuing would be of no further scientific benefit
- If you as participant would not be able to, or would be unwilling to participate in the study in such a way that is in accordance with the needed study procedures

RISKS AND BENEFITS:

There is a chance the adolescent in your care may feel uncomfortable or upset while talking about the various issues that s/he experiences. S/he does not have to answer any question if s/he does not want to and s/he can end the interview at any time. It is possible that the adolescent may want to speak to you about the interview, these issues or her experience related to it. If you want, you can call us. We have also provided you a sheet with the contact information of the research team that can assist you and the adolescent to discuss these issues.

There is also a risk that being seen with us might lead other people to make assumptions about you. As part of the HPTN 071 (PopART) study, we have tried to make it common knowledge about why we are in the community (to learn about HIV prevention). However, some few people might still make wrong assumptions. Please inform us if you ever feel that this is the case and we can make alternate arrangements, for example finding a private or neutral venue to meet.

This is a research study, not a service delivery programme. You will not receive any direct benefit from being part of this study, other than the opportunity to share your experiences with us. The aim of the research is to produce information that will benefit people living in this place, in Africa, and across the world.

<u>CONTACTS FOR QUESTIONS</u> (Names, addresses and phone numbers of the following):

1. **Director:** Virginia Bond, ZAMBART Project PO Box 50697, Ridgeway Campus, School of Medicine Lusaka. Telephone: +260 211 254 710; Cell No: +260 977 846 726
2. **Chairperson,** Bio-medical Research Ethics Committee, University of Zambia. Telephone: 260 211 256067

Appendix M: Consent form for participants 18 years and older

ZAMBART PROJECT

Ridgeway Campus
University of Zambia
PO Box 50697
Ridgeway
Lusaka
ZAMBIA

Tel/Fax: 01-25.47.10
Email: info@zambart.org.zm

CONSENT FORM (Written Consent Form for adolescents participating)

TITLE OF RESEARCH: Population Effects of Antiretroviral Therapy to Reduce HIV Transmission (PopART): A cluster-randomized trial of the impact of a combination prevention package on population-level HIV incidence in Zambia and South Africa.

HPTN 071 (PopART) – Social Science Component

- I have been given sufficient time to consider whether to take part in this study.
- My taking part in this research study is voluntary. I may decide not to take part or to withdraw from the research study at any time without penalty or loss of benefits or treatment to which I am entitled.
- The research study may be stopped at any time without my consent.
- I have had an opportunity to ask the researcher questions about this research study. My questions so far have been answered to my satisfaction.
- I have been told what participation would mean in terms of what may be asked of me and how long this may take; including that the research may take pictures and make audio and recordings.
- I have been informed of the procedures that may be performed during the research study.

- I have been told what the possible risks and benefits are from taking part in this research study. I may not benefit if I take part in this research study.
- I do not give up my legal rights by signing this form.
- I have been told that before any study related procedures are performed, I will be asked to voluntarily sign this Informed Consent Form for Social Science Participants.
- I have been told that unless I indicate otherwise below, the data I contribute to this study will be stored in a databank for future social scientific analysis and research.
- I will receive a signed and dated copy of this Informed Consent Form for Social Science Participants.

VOLUNTARY CONSENT

I have read (or have had explained to me) the information about this research as contained in the Participant Information Sheet. I have had the opportunity to ask questions about it and any questions I have asked have been answered to my satisfaction.

I agree/disagree to be quoted anonymously in this study.

I now consent voluntarily to be a participant in this study and understand that I have the right to withdraw at any time, and to choose not to answer particular questions that are asked in the course of the interview.

Signature below says that I am willing to participate in this research:

Participant's name (Printed):

……………………………………..............………………....................

Participant's signature/thumb print ………………………. Consent Date: ……………...

Witness' name (Printed):………………………………… Date:……………………………

Witness' signature:………………………………………………….

Researcher Conducting Informed Consent (Printed)……………….……….......................

Signature of Researcher: …………………………….................. Date: ....……

PERMISSION FOR USE OF PHOTOS AND AUDIO/VIDEO RECORDINGS

We work at Zambart Project and part of our work is to do research. The photos and recordings we make are part of the research process, which we can analyse to better understand health issues from the perspective of community members. We also give presentations to fundraise for research and want to put up work related pictures in our offices. Photographs and quotations are also very useful to illustrate our reports as it helps to explain our findings to funders and others.

It is our practice when using photos or making recordings during research and training, to obtain your signed permission before including photos or anonymous quotations of you/your business/ your organization/ your home or child. No names or surnames will be used. The photos will not be used for media publications.

Hereby I ________________________________ give permission that the photo/s taken/recordings made today in which I/ my business/ my organization/ my home/ my child appear, may be used for the following purposes:

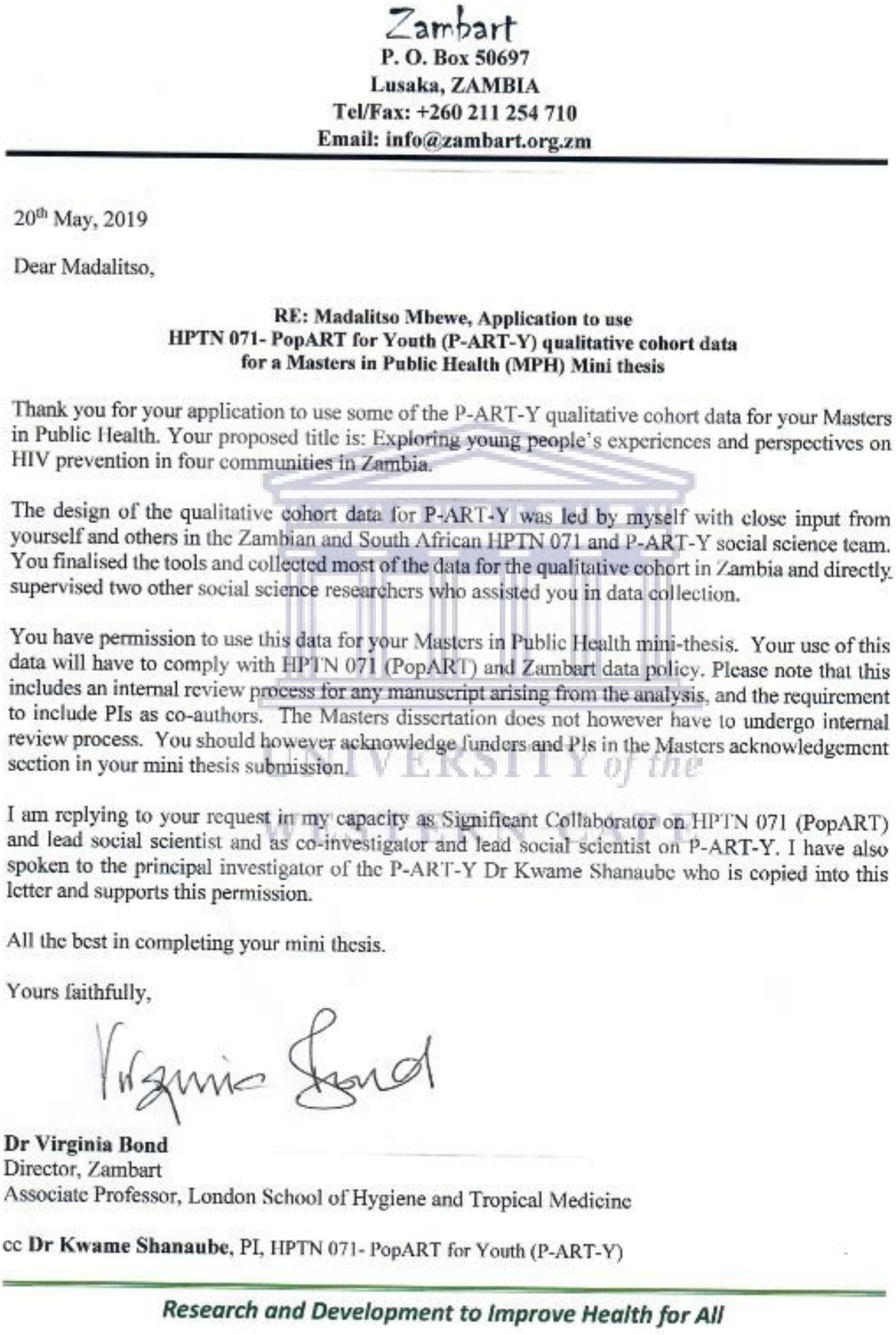
- o Providing contextual detail to qualitative research
- o Training of students and raising awareness
- o Talks and presentations by staff from Zambart and other researchers
- o To put up at Zambart office
- o To illustrate reports written by Zambart
- o To be included as part of a social science database on 'health in context'

Signed at ____ (city/suburb/community)

on ___________________________ (date).

___________________________	___________________________
Signature of representative	Signature of photographer
___________________________	___________________________
Name and surname of representative	Name and surname of photographer

Appendix Q: Permission from Zambart to use PopART Qualitative cohort data



Zambart
P. O. Box 50697
Lusaka, ZAMBIA
Tel/Fax: +260 211 254 710
Email: info@zambart.org.zm

20th May, 2019

Dear Madalitso,

RE: Madalitso Mbewe, Application to use
HPTN 071- PopART for Youth (P-ART-Y) qualitative cohort data
for a Masters in Public Health (MPH) Mini thesis

Thank you for your application to use some of the P-ART-Y qualitative cohort data for your Masters in Public Health. Your proposed title is: Exploring young people's experiences and perspectives on HIV prevention in four communities in Zambia.

The design of the qualitative cohort data for P-ART-Y was led by myself with close input from yourself and others in the Zambian and South African HPTN 071 and P-ART-Y social science team. You finalised the tools and collected most of the data for the qualitative cohort in Zambia and directly supervised two other social science researchers who assisted you in data collection.

You have permission to use this data for your Masters in Public Health mini-thesis. Your use of this data will have to comply with HPTN 071 (PopART) and Zambart data policy. Please note that this includes an internal review process for any manuscript arising from the analysis, and the requirement to include PIs as co-authors. The Masters dissertation does not however have to undergo internal review process. You should however acknowledge funders and PIs in the Masters acknowledgement section in your mini thesis submission.

I am replying to your request in my capacity as Significant Collaborator on HPTN 071 (PopART) and lead social scientist and as co-investigator and lead social scientist on P-ART-Y. I have also spoken to the principal investigator of the P-ART-Y Dr Kwame Shanaube who is copied into this letter and supports this permission.

All the best in completing your mini thesis.

Yours faithfully,

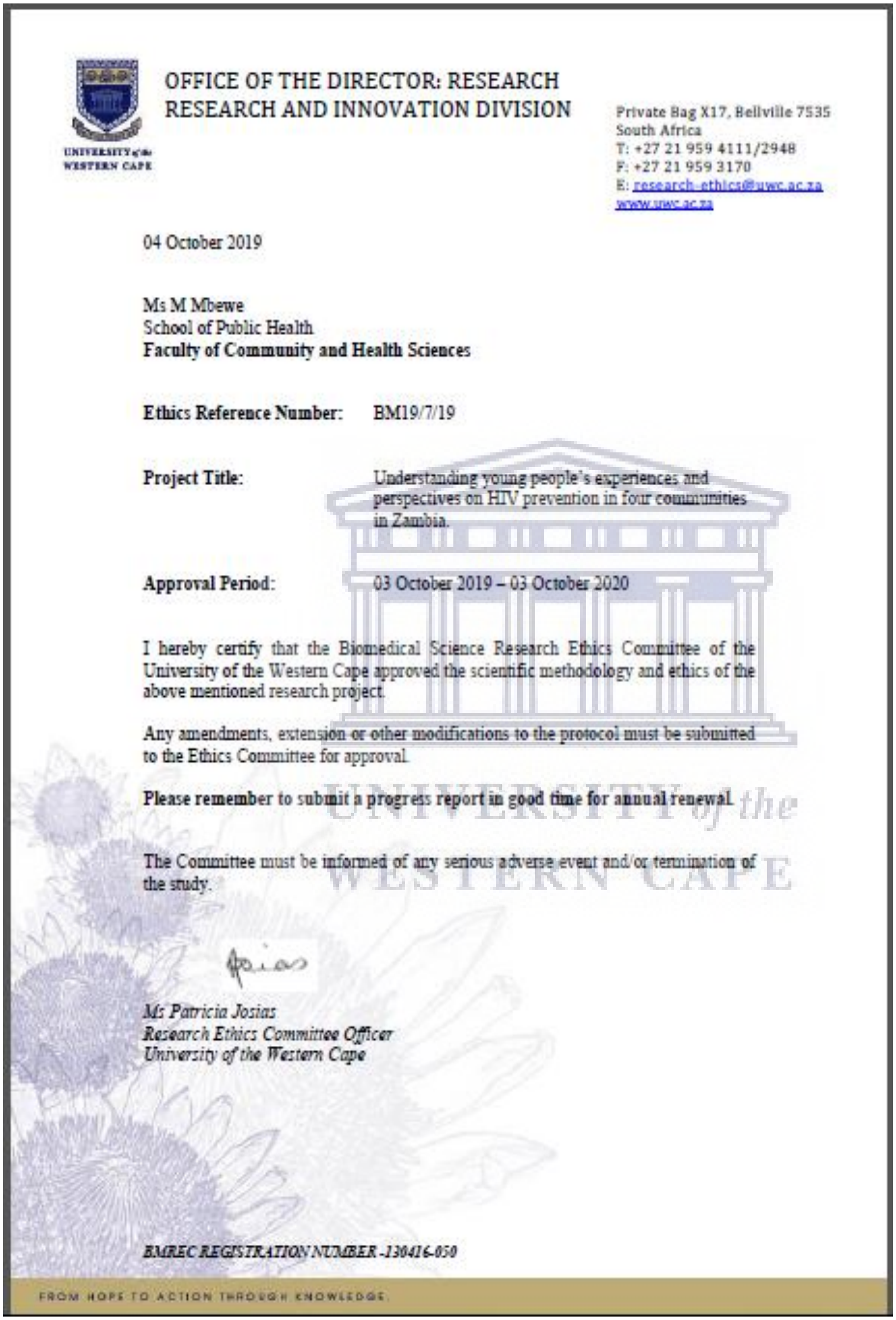
Virginia Bond

Dr Virginia Bond
Director, Zambart
Associate Professor, London School of Hygiene and Tropical Medicine

cc **Dr Kwame Shanaube**, PI, HPTN 071- PopART for Youth (P-ART-Y)

Research and Development to Improve Health for All

Appendix N: Biomedical Research Ethics Committee Approval Letter



UNIVERSITY of the WESTERN CAPE

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04 October 2019

Ms M Mbewe
School of Public Health
Faculty of Community and Health Sciences

Ethics Reference Number: BM19/7/19

Project Title: Understanding young people's experiences and perspectives on HIV prevention in four communities in Zambia.

Approval Period: 03 October 2019 – 03 October 2020

I hereby certify that the Biomedical Science Research Ethics Committee of the University of the Western Cape approved the scientific methodology and ethics of the above mentioned research project.

Any amendments, extension or other modifications to the protocol must be submitted to the Ethics Committee for approval.

Please remember to submit a progress report in good time for annual renewal.

The Committee must be informed of any serious adverse event and/or termination of the study.

Josias

Ms Patricia Josias
Research Ethics Committee Officer
University of the Western Cape

BMREC REGISTRATION NUMBER -130416-050

FROM HOPE TO ACTION THROUGH KNOWLEDGE.

Appendix O: Discussion Guide for Young People Not Living with HIV

Adolescent community member

Discussion Guide

<u>Purpose:</u> This document is to be used by the HPTN 071 (PopART) SocSci field team to guide their discussion for Aim 3 of the qualitative component of the study. This guide is for a discussion with an adolescent member of the community to describe contextual factors in communities in relation to their experiences in the elements of the HPTN 071 (PopART) intervention roll-out. This interview guide has to be used in conjunction with an ARF.

<u>Form of data recording:</u> (1) Audio-recording of all talk from "Preamble" to "Closing" depending on the tool used. (2) Notes of key points per topic area handwritten by the facilitator into a printed copy of this document. (3) Photographs of each of the activities, including individual photographs of each individual response. (4) Handwritten notes by participants during the course of the discussion.

<u>Note:</u> The activities and questions in this manual need not be done uninterruptedly and may be done over the course of one or several days. If the activities are done at different times, each recording should start as follow: Today is the (insert date [day xxth Xxx xxxx]) and it is (insert time XX: XX). This is a discussion with a (community member). This is activity (number).

<u>Expected time needed per use:</u> About a week's worth of interactions (while hanging-out)

Date activity conducted: ___________________________

Place conducted: _____________________________

Time period: ______________________________

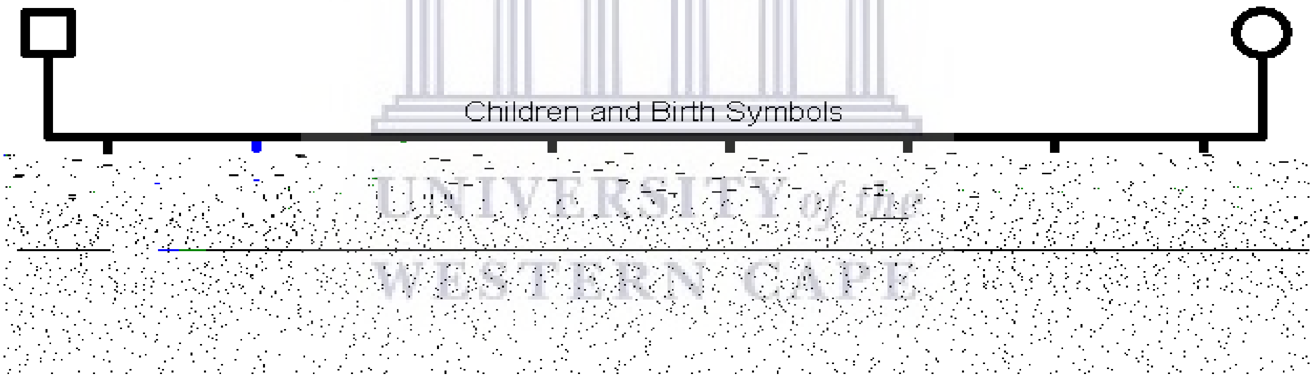
Preamble (to be read by facilitator): Today is the (insert date [day xxth Xxx xxxx]) and it is (insert time XX: XX). This is a discussion with an (adolescent community member). Thank you for your time. As we have explained, we are conducting this interview as part of the qualitative component of the HPTN 071 (PopART) study. These interviews are part of one of the aims of the qualitative component of the HPTN 071 (PopART) study which is to describe contextual factors in communities in relation to their experiences of HIV, ART, UTT roll-out, and other elements. For this interaction we would like to find out more about your life. All information collected here will be reported anonymously. I remind you that we are audio recording this discussion and ask that you speak loudly and clearly. As the facilitator I will also be taking some notes. As I mentioned when I explained the consent form, today's discussion is the second of at least four interactions that I would like to have with you. Do you have any questions before we begin?

Interview one:

Topic area 1 – Family composition (facilitator to read bolded text below and elaborate with prompts at their discretion): **By way of starting, we would like to know a bit about you, please introduce yourself.**

12. **Were you born in this community?** If no, where are you from? When did you move to this community? Why did you move to this community? Do any of your family members also live in this community?
13. **Can you tell us more about your household?** Who is the household head? What is your relationship with the head of the house? Do you live with both parents? If not why? Who lives with you? Do you have any children? How old?
14. **In your household, is there a person living with HIV?** Or do you suspect that you have a household member living with HIV? How old is he/she? (If yes, build on this with questions from the extended guide or PLWH guide or adolescent interview guide)
15. **Would you mind doing a kinship diagram/genogram?** This is also known as a family tree, where we map out members of your family. (Use the guide below. This can always be drawn up later).

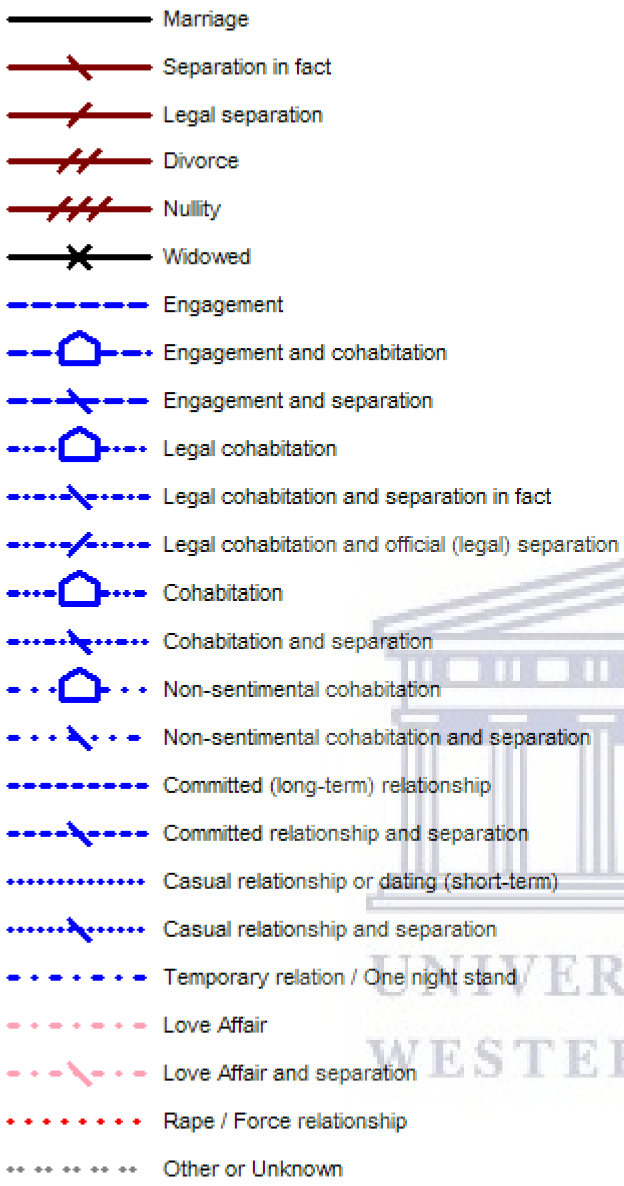
Standard Gender Symbols for a Genogram



Genogram Symbols for Children's Links and Pregnancy Terminations

Child links are joined for multiple births such as twins and triplets

(Source: http://www.genopro.com/genogram/symbols/)



Family Relationships Key
(Source: http://www.genopro.com/genogram/family-relationships/)

Topic area 1: Facilitators notes

Topic area 2 – how they get by (facilitator to read bolded text and elaborate with prompts at their discretion): **Next we would like to talk about the way you get by.**

1. **Can you tell us more about a 'normal' day in your life?** What activities do you usually do on a daily basis? Do you go to work? If you work, where do you work? Have you been working there ever since? Are you in school? If so, what are you studying? How do you contribute to household living? Are there other means you earn a living i.e. gifts, social cash transfer, support from social welfare or non-governmental organization? Do you have a garden/make-shift-stall or have you ever thought of having one? Is there a family member or relative outside your home who assist you with finances or some other support? Who makes financial decisions i.e. what to buy, when and why? What kind of meals do you usually have on a daily basis i.e. such as for breakfast, lunch and supper, and in-between meals? How often do you have them in a day? Who owns most of the assets that you have?(As a researcher spends a day with the participant, should also observe the kind of meals that are prepared, also observe kinds of assets they own)

2.2. What else keeps you occupied apart from work/school? Do you perform any household chores? If yes, what kind? How often do you do these chores? Do you get any help when carrying out these chores? If yes, who from? What things do you do that others cannot help with? Could it be churches/religious activities? What recreation activities are you involved in? Which of these social activities do you find most fulfilling?

Topic area 2: Facilitators notes

Topic area 3 – Use of spaces in community (Facilitator to read bolded text and elaborate with prompts at their discretion): **Next we would like to know more about you and your community. To do this I have an old map which was drawn by some community members in 2013. It is not a perfect map representing the community but I would like you tell me the places that are of significant to you, if there are not on the map we can include them using a pencil.**

3.1. **Can you tell us about your community and what it is like living here?** How many schools are there? Is there a library? How is the quality of schools like? What social activities happen in this community? Describe the people who live here?

3.2. **What places do you like going to in this community?** Ask what places mean to them? On what days and time do you go to these places? Is this typical of your age – of being an adolescent? What places are linked to being a young man or a young woman living with HIV?

3.3. **Do you ever attend school, health facility, church, go to market?** How often? When is the last time you were there? What challenges are found in these places? What kind of places are you uncomfortable to go to? What options are there for treatment when ill?

[**May draw a timeline of their movements/life –this may be represented over time**]. Has the place been like that all the time? Read the text in bold (**If you do not mind I would like to accompany you whenever you take a walk to any of the places around the community even visiting your friends or neighbourhood)**

Topic area 3: Facilitators notes

Topic area 4 – Meta-structural (facilitator to read bolded text and elaborate with prompts at their discretion): **Next we would like talk about how you related to some situations.**

4.1. Do **you listen to news?** What concerns or interests you when you hear or watch news?

4.2. **What social protection services are available in this community?** Ask for if there are institutions which offer assistance such as food stuff, school support, health support, clothing etc.

4.3**. How are sanitation, roads?** How do each of these affect your daily life routine? Ask concerning water supply and sanitation i.e. toilets, garbage disposal, flooding

4.4. **How does social status influence relations in this community?** Do some social position such as politicians, wealthy residents, educated residents or persons in authority have power over certain resources in the community? How does that affect you?

Topic area 4: Facilitators notes

Topic area 5– Social networks (Materials needed: pens, colour pens, last page of this document - remember to reattach after activity). (Facilitator to read bolded text and elaborate with prompts at their discretion): **We are also interested in how people interact in your community. To do this we would like you to draw your social network. A network is similar to a tree with different branches. All of the branches are connected to the same tree.**

5.1. We would like you to draw your own network. For your network, you will be in the middle and all the people you interact with will be placed around you. Some of these people or groups you see or talk to more often and you can place these people closer to you. Other people/groups/organisations that you interact with less often can be placed further away from you. (*Take a picture of the completed network.)*

5.2. Please explain your network and your relationship with each person/organisation/group. Where would you put your spouse/boyfriend /girlfriend? What kind of relationship do you have with your spouse/boyfriend/ girlfriend?

5.3. Who in this network do you spend the most time with? What would you do together?

5.4. Do you know if any of the people in this network is affected by HIV? Who is affected and how?

Topic area 5: Facilitators notes

Interview Two:

Topic Area 6 – HIV timeline. (Materials needed: pens, colour pens, second last page of this document - remember to reattach after activity). (Facilitator to read bolded text below and elaborate with prompts at their discretion): **To understand how the progression of HIV and ART in the community and your life, we would like you to complete a timeline on the page provided**

- **6.1 Please make use of the timeline** (on the last page of this document) **to show us the history of HIV in this community. Also, indicate when and where the events took place (more or less). If you cannot remember the exact date, you can just indicate broadly.** Think of things like when you first heard of HIV in this community, when you first met someone that you knew was HIV positive, when testing started in the community, when you became aware of ARVs, when ARVs became available in the community. Do you know when PMTCT was first provided? (*Take a picture of the completed timeline.)*
- **6.2 Is there anything else you would like to add to the timeline?** You can also add any relevant events to the timeline, any stories that you think relate to HIV.

Topic area 7: Facilitators notes

Topic area 7 – HPTN 071 (PopART) knowledge (facilitator to read bolded text and elaborate with prompts at their discretion): **Next we would like to talk about your knowledge of the PopART study.**

- **7.1 What do you know about the HPTN 071 (PopART) study?** Where did you hear about HPTN 071 (PopART)? When did you hear about HPTN 071 (PopART)? What do you know about the P-ART-Y study? When did you hear about the P-ART-Y study?
- **7.2 What was your first impression when you heard about the study?** Has this perception changed since? What has change? What has changed since the CHiPs started going around the community testing people door to door?
- **7.3 I have given you a stack of cards and a pen. Please write down all the methods of HIV prevention that you are aware of. Please write down one idea per card. Remember, there are no wrong answers.** What about alternative forms of prevention? What about MMC? PMTCT? ART?

7.4 **Which of these do you think works the best for this community?** Why? Which ones are not as effective?

7.5 **Which of these do you think are most commonly used?** Why don't they use this (PMTCT, MMC, condoms, etc.) prevention method? Do you think that people in this community should use this prevention method? What do you think will encourage more people to use this prevention method? What kind of condoms are common? Have you ever heard of mood / scented condoms? Where do people find them?

7.6 **Do you know any other HIV testing and treatment programs in this community? What do you think is the difference between the way that HPTN 071 (PopART) works and the way that other HIV testing and treatment programmes work?**

7.7 **Do you think HPTN 071 (PopART) will work on a large scale?** Why or why not? Do you think HPTN 071 (PopART) should eventually be implemented everywhere? Have you heard about ART as prevention? Do you think that this will affect the use of condoms?
Who do you think is responsible for preventing HIV transmission? Do you think HIV is ever transmitted on purpose?

Topic area 8: Facilitators notes

Topic area 8 – Disclosure, ART and stigma discussion. **As part of our study we are also interested in people's understanding and experiences of Antiretroviral treatment, or ART.**

8.1 **How did you feel when you found out about your status?** How has it changed your life? Has it affected your relationships with family and friends? Did you disclose your HIV status to anyone? Why did you disclose to that person/why did you not disclose?
Please elaborate on your experiences with HIV service providers.

8.2 **What is your understanding of ART?** What do you think the drugs do? Do you know how they work? Why do you think people have to take the treatment? Do you think it is effective? Are there any other forms of treatment besides ART? Have you or do you know anyone who has tried any alternative treatments? What are the beliefs in the community around ART?

8.3 **What do you understand about the process of ART initiation?** Do you know anyone on ART? What do you expect the process to be like? What do you think happens when people are put on the medication? When is the best time to start ART? What do you understand by early ART, CD4 count and viral load?

8.4 **What do you think is important for adherence?** What are the challenges? When and how does one have to take ART? Is there specific diet one has to follow while on ART? Do you think alcohol plays a role in adherence? If yes what role does it play? What about drugs? How do alcohol and drug use affect sexual behaviour and HIV prevention? Had a relative or a friend or a doctor or another health personnel being concerned about someone on ART drinking alcohol or using drugs, or suggested that they cut down? If yes, why? If no, why not? Have you ever heard of anyone forgetting to take their after drinking alcohol? If yes, how did it happen?

8.5 Why do you think people sometimes stop taking the medication? Do you know any people who stopped taking their medication?

8.6 How would you define stigma? Do PLWH ever experience stigma in this community? How? Can you give an example? Have you stigmatised any PLWH? Is there name-calling for PLWH on ART? Do some people avoid being seen at the clinic?

8.7 Do you think ART has had an impact on stigma? How? Why? Do you think ART has had an impact on stigma? How? Why?

8.8 What do you think are the experiences of young people accessing HIV and ART? Are there challenges in accessing HIV and ART services? Shortage of medication? Long lines at the clinic? Waiting periods at clinic? What support systems exist in the community for PLWH to access ART? Where do most PLWH collect their ART? Who decides that they must be collecting from there? Do you think the confidentiality of one's status is upheld? If not why?

Topic area 9: Facilitators notes

Topic area 9 – Sex, Love and SRH (facilitator to read bolded text and elaborate with prompts at their discretion): **Next we would like to talk about sex, love and Sexual Reproductive Health.**

9.1 Are you in a relationship? What characteristics do you look for in a potential partner? Are you in a relationship? Is this your first relationship? How did you get married? Who do you trust? **When in a relationship do you trust your partner? Why or why not?**

9.2 Do you think it is important to have a partner? Why? Do you think men and women need different things from relationships? What do women need? What do men need? Can you tell me about a healthy relationship?

9.3 How old were you when you had your first relationship? Can you tell me about this person? How old were you when you first had sex? Did you consent to this?

9.4 How did you meet your current/recent partner? Tell me about your partner's background How long have you been together? How would you describe your partner? What do you like most about them? Does your partner work? How does your partner help you financially? How does your partner help you with your children? How does your partner help you with your home?

9.5 Do you have another partner(s)? Can you tell me about them?

9.6 As part of the HPTN 071 (PopART) study one of the things that is important is to understand condom use. Have you ever used a condom? Have you used a condom with your most recent sexual partner(s)? Tell us about your relationship. How did you meet him/her? How long after your meeting did your relationship become sexual? How did you decide that it was the right time? Can you please tell us about condom negotiations in your relationship? Who decides to use the condom? Where do you get your condoms? Do you know your partner's HIV status? At what point in your relationship did you decide to stop using condoms? Describe the process.

9.7 What sexual reproductive health (SRH) services and information do you or have you ever access(ed)/receive (d)? Probe about; condoms and condom use, contraceptives, safer sex, unwanted pregnancy, and STIs. Who did you get this information from; organisation within or outside community, older fiends-in a group/individually, friends of the same age- in a group or individually, boy/girlfriend, media, mom, dad, aunt, uncle, grandmother/father, school- club, in class by teacher or outreach visits to the school, clinic- nurse, doctor, counsellor, youth friendly corner? How often do you receive these services? What are your reasons for accessing these services? What challenges do face in accessing these services or information? Have you received SRH information and services that you didn't want? Can you tell me more about what happened?

9.8 How would you prefer to receive SRH information? Where-clinic or other specify? Would you rather be talked or read? Would you rather receive SRH information in a group or as an individual? Why?

9.9 **What SRH information and services would you prefer to receive?** Have you ever received/ accessed this kind of SRH information and services? If not are there any challenges in accessing that particular SRH service and information? Why do you think this is so?

9.9.1Who would you prefer to discuss sex and sexual reproductive health issues with? organisation within or outside community, older fiends-in a group/individually, friends of the same age- in a group or individually, boy/girlfriend, media, mom, dad, aunt, uncle, grandmother/father, school- club, in class by teacher or outreach visits to the school, clinic- nurse, doctor, counsellor, youth friendly corner? Who do you prefer the least of the above sources? Why?

Topic area 10: Facilitators notes

Interview Three:

Topic area 10 – Relationships (Gender based violence) (facilitator to read bolded text and elaborate with prompts at their discretion): **Now, we would like to talk about relationships.**

10.1 **What do you understand by 'gender-based violence'?**

10.2 **What different types of gender-based violence are prevalent in your community?** (Probe: for different forms of violence): Have you ever heard of Physical aggression (slapping, hitting, kicking, beating etc.), Psychological abuse (Intimidation, constant belittling , humiliation etc.), Sexual violence (attempt to obtain sexual act, unwanted sexual comments or advances, forced vaginal or anal sex), Controlling behaviours (Isolating a person from a family or friends, monitoring her movement, restricting access to information, denying decision making authority Economic abuse (withholding funds, control survivors access to health care, denying employment/business, denying access to property) happening to anyone in your community?

10.3 **What groups of people more likely to experience gender based violence?** Are there specific reasons for violence among different people?

10.4 **What characteristics make a woman more likely to experience violence?** How does your community react to a woman who experienced gender-based violence? Do you agree to this? Why/Why not?

10.5 **What characteristics make a man more likely to experience violence?** How does your community react to a man who experienced gender-based violence? Do you agree to this? Why/why not?

10.6 **What situations in life is gender based violence accepted?**

10.7 **What are the causes of gender-based violence?** How do you think alcohol, Gender inequalities, men's attitudes to women, culture, poverty and religion relate to gender-based violence, and HIV status?

10.8 **In case someone faces intimate partner violence in your community due to being HIV positive or accessing ART care, what do they do?** Are there available support and resilience mechanisms for violence survivors? Are there non-governmental or social services available for individuals who experienced gender-based violence? Are you familiar with the services offered in this community? What are the health services offered to individuals whom experienced violence in this community?

10.9 **Have you ever experienced any form of violence that you have just described?** If yes, were you the perpetuator or victim? If no ask has anyone close to you experienced any forms of violence you just described? Was this form of violence related to your HIV status or accessing ART care?

10.10 **What type of violence was this?** Why did it happen? How did it happen? When did it happen? How often did it happen? What did you/they do when it happened? (Why?) Are there times this improved or got worse? (Why?)

10.11 **If experienced violence: Have people living in your household seen or heard you experience violence from your partner because of your HIV status?** How often was this? What was their reaction to this? Have children in your household been hurt physically by your partner during a violent incident?

10.12 **Did you as a child experience or witnessed or involved in violence?** Have you heard of a minor experience violence? If yes, kindly tell me what happened?

Topic area 12: Facilitators notes

Topic area 11– Body mapping (Materials needed: pens, colour pens, flipchart pages pasted together – big enough to draw the outline of a person [3x2]/ roll of paper). (Facilitator to read bolded text and elaborate with prompts at their discretion): **Another way in which we are able to understand people and the community they live in is through an activity that we call 'body mapping'. A body map starts with the outline of a person's body. This empty outline is then filled in with different things that this person finds important or relevant. This will also give you the opportunity to be creative and to use more than just words to explain how different things are experienced in your life. We would like you to create your own body map.**

11.1. **To draw a body map, we are going to draw the outline of your body. The first bit is just a little uncomfortable. We need you to please lie down on the paper; we are going to trace your outline. We would like you to lie in a position that best represents who you are (e.g. working posture, sleeping, dancing etc.)** (Trace a few centimetres away from the participant so that you do not have to come in direct contact with his/her body. If the participant is unwilling to lie down, ask the Research Assistant to act as the model. The participant can instruct the research assistant to move their bodies into the preferred position).

11.2. **To fill in the body, we are not just adding the normal things that we usually draw in pictures, but we are adding different things to tell the story of our different experiences. We are going to ask you to illustrate different things on your outline. The first thing that we would like you to illustrate is how your circumstances have affected your body in any way [Assuming it has]? Remember, there is no wrong answer, and you can draw anything or anywhere to illustrate this.** Illustrate on the parts of the body which you feel are affected by poverty. How are they affected by poverty?

11.3. **In the same way, can you illustrate any specific marks on your body that relate to health issues?** Can you draw parts of your body which have been inflicted with pain? Indicate whether the pain was physical or emotional. You can also draw healing or medication. **[For 11.3 colour 'blue' for parts inflicted with pain]**

11.4. **Think about people's reaction to your health issues? How would you draw that?** Now please draw this on your body map. **[For 11.4 colour 'green' for parts of the body reacted to]Is there anything else you would like to add to your body map?** Facilitator to take a picture of the completed body map. **[For 11.5 colour 'yellow' for any add to the body map]**

Topic area 11: Facilitators notes

Topic area 12 – Horizon and ambitions/fears (facilitator to read bolded text and elaborate with prompts at their discretion): **Next we would like talk about your horizon and ambitions.**

11.1 **Where <u>do</u> you see yourself or where <u>did</u> you see yourself?** What do you want to be in future? What could change? What do others want/ed you to be? How would you define success? What is possible for people in this community? What do they expect or would want? What do other people want for others i.e. hopes for community over time?

11.2 **What are your fears/regrets and, opportunities?** Have you ever had to take time off work/school/studies to address your health needs? How often? Has this impacted on your ability to do your work/studying? How? Are there any people who are dependent on you? Do you have any children? Do you plan to have children in the future? What is your opinion of women living with HIV having children?

Topic area 12 – Open discussion (Facilitator to read bolded text and elaborate with prompts at their discretion): **We really appreciate that we have been able to spend some time with you. I know we have discussed many issues and I have learned so much. We just have a few more open questions so that we can make sure that we didn't miss anything.**

12.1 **Is there anything related to HIV and health in this community that you feel we need to know? How do you think it has affected** your life?

12.2 **What have you heard of the HPTN 071 (PopART) intervention?** Do you know what the study entails? Do you know what it means at community level? Do people talk about the study? What do people say about the study?

12.3 **Has the study impacted your life in any way?** Have there been any changes in your life due to the study? Has your community changed in any way?

12.4 **Do you think the study will succeed?** What do you think will help the study to succeed?

12.5 **What do you think will prevent the study from succeeding?**

12.6 **Is there anything else you would like to add?**

Topic area 12: Facilitators notes

Closing (to be read by facilitator): Thank-you again for your time. Do you have any final thoughts before I turn off the audio recorder and call this discussion to a close?

Appendix P: Discussion Guide for Young People Who Have Never Tested for HIV

Adolescent community member

Never tested

Discussion Guide

<u>Purpose:</u> This document is to be used by the HPTN 071 (PopART) SocSci field team to guide their discussion for Aim 3 of the qualitative component of the study. This guide is for a discussion with an adolescent member of the community to describe contextual factors in communities in relation to their experiences in the elements of the HPTN 071 (PopART) intervention roll-out. This interview guide has to be used in conjunction with an ARF.

<u>Form of data recording:</u> (1) Audio-recording of all talk from "Preamble" to "Closing" depending on the tool used. (2) Notes of key points per topic area handwritten by the facilitator into a printed copy of this document. (3) Photographs of each of the activities, including individual photographs of each individual response. (4) Handwritten notes by participants during the course of the discussion.

<u>Note:</u> The activities and questions in this manual need not be done uninterruptedly and may be done over the course of one or several days. If the activities are done at different times, each recording should start as follow: Today is the (insert date [day xxth Xxx xxxx]) and it is (insert time XX: XX). This is a discussion with a (community member). This is activity (number).

<u>Expected time needed per use:</u> About a week's worth of interactions (while hanging-out)

Date activity conducted: ______________________________

Place conducted: ______________________________

Time period: ______________________________

Preamble (to be read by facilitator): Today is the (insert date [day xxth Xxx xxxx]) and it is (insert time XX: XX). This is a discussion with an (adolescent community member). Thank you for your time. As we have explained, we are conducting this interview as part of the qualitative component of the HPTN 071 (PopART) study. These interviews are part of one of the aims of the qualitative component of the HPTN 071 (PopART) study which is to describe contextual factors in communities in relation to their experiences of HIV, ART, UTT roll-out, and other elements. For this interaction we would like to find out more about your life. All information collected here will be reported anonymously. I remind you that we are audio recording this discussion and ask that you speak loudly and clearly. As the facilitator I will also be taking some notes. As I mentioned when I explained the consent form, today's discussion is the second of at least four interactions that I would like to have with you. Do you have any questions before we begin?

Interview one:

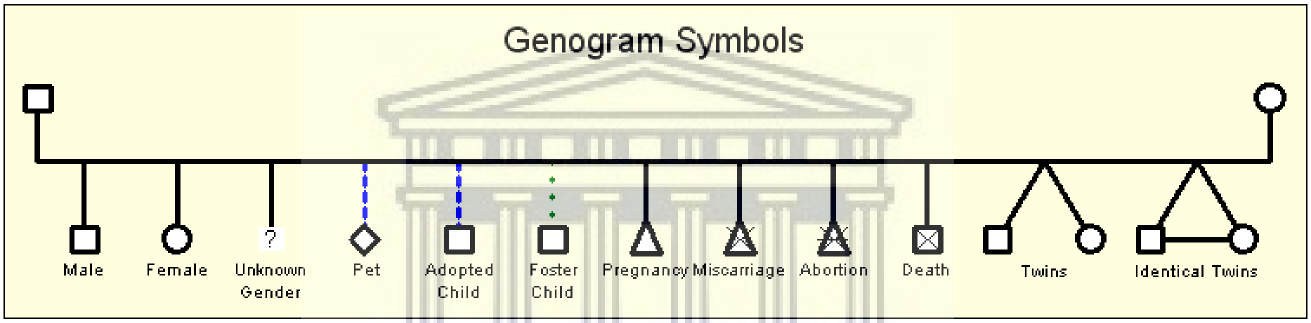
Topic area 1 – Family composition (facilitator to read bolded text below and elaborate with prompts at their discretion): **By way of starting, we would like to know a bit about you, please introduce yourself.**

1.1. **Were you born in this community?** If no, where are you from? When did you move to this community? Why did you move to this community? Do any of your family members also live in this community?

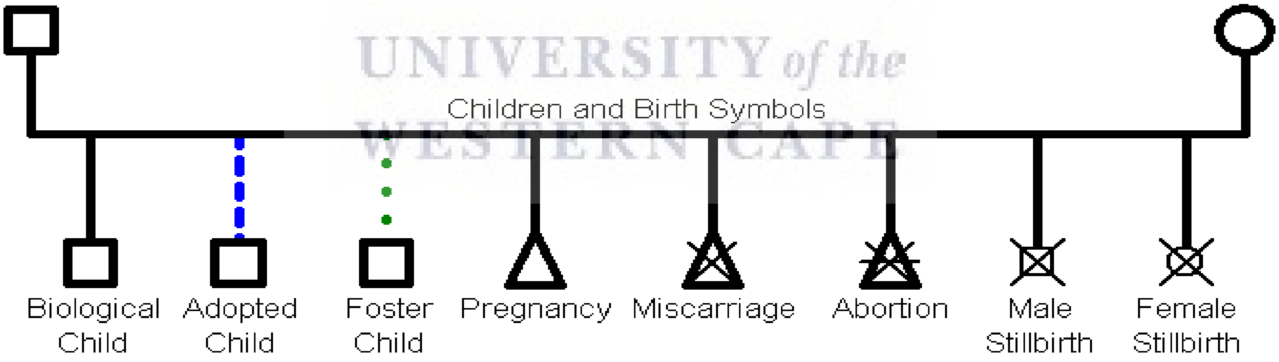
1.2. **Can you tell us more about your household?** Who is the household head? What is your relationship with the head of the house? Do you live with both parents? If not why? Who lives with you? Do you have any children? How old?

1.3. **In your household, is there a person living with HIV?** Or do you suspect that you have a household member living with HIV? How old is he/she? (If yes, build on this with questions from the extended guide or PLWH guide or adolescent interview guide)

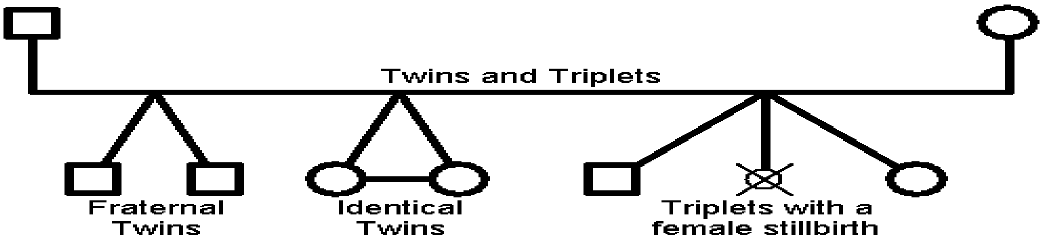
1.4. **Would you mind doing a kinship diagram/genogram?** This is also known as a family tree, where we map out members of your family. (Use the guide below. This can always be drawn up later).



Standard Gender Symbols for a Genogram

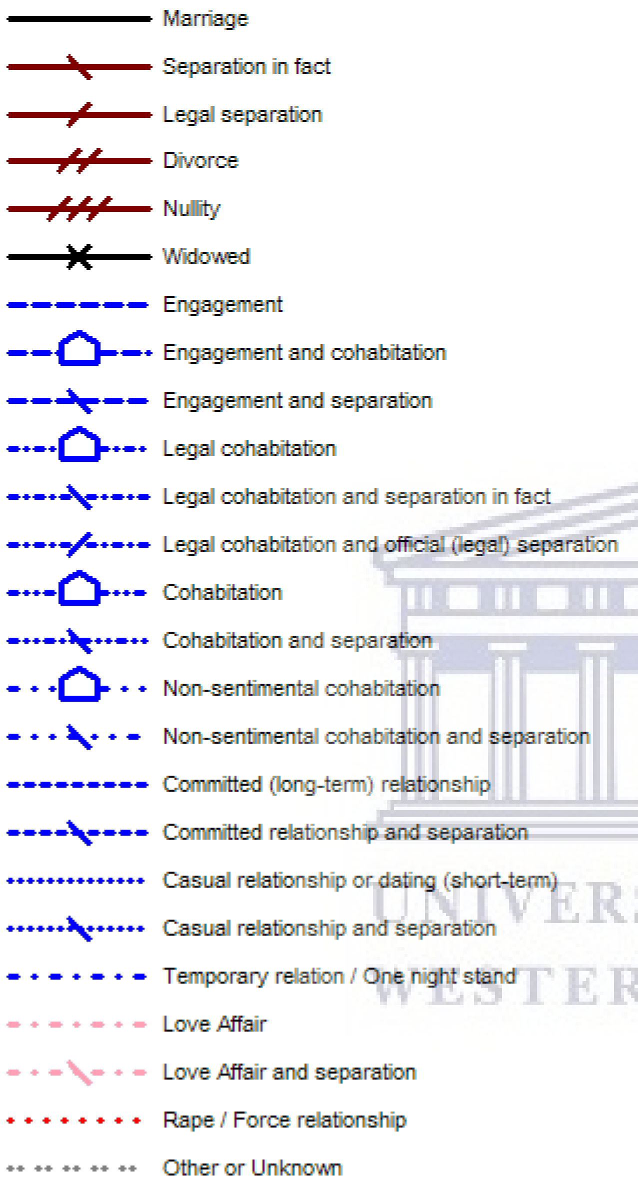


Genogram Symbols for Children's Links and Pregnancy Terminations



Child links are joined for multiple births such as twins and triplets

(Source: http://www.genopro.com/genogram/symbols/)



Family Relationships Key
(Source: http://www.genopro.com/genogram/family-relationships/)

Topic area 1: Facilitators notes

Topic area 2 – how they get by (facilitator to read bolded text and elaborate with prompts at their discretion): **Next we would like to talk about the way you get by.**

2.1. **Can you tell us more about a 'normal' day in your life?** What activities do you usually do on a daily basis? Do you go to work? If you work, where do you work? Have you been working there ever since? Are you in school? If so, what are you studying? How do you contribute to household living? Are there other means you earn a living i.e. gifts, social cash transfer, support from social welfare or non-governmental organization? Do you have a garden/make-shift-stall or have you ever thought of having one? Is there a family member or relative outside your home who assist you with finances or some other support? Who makes financial decisions i.e. what to buy, when and why? What kind of meals do you usually have on a daily basis i.e. such as for breakfast, lunch and supper, and in-between meals? How often do you have them in a day? Who owns most of the assets that you have?(As a researcher spends a day with the participant, should also observe the kind of meals that are prepared, also observe kinds of assets they own)

2.2. **What else keeps you occupied apart from work/school?** Do you perform any household chores? If yes, what kind? How often do you do these chores? Do you get any help when carrying out these chores? If yes, who from? What things do you do that others cannot help with? Could it be churches/religious activities? What recreation activities are you involved in? Which of these social activities do you find most fulfilling?

Topic area 2: Facilitators notes

Topic area 3 – Use of spaces in community (Facilitator to read bolded text and elaborate with prompts at their discretion): **Next we would like to know more about you and your community. To do this I have an old map which was drawn by some community members in 2013. It is not a perfect map representing the community but I would like you tell me the places that are of significant to you, if there are not on the map we can include them using a pencil.**

3.1. **Can you tell us about your community and what it is like living here?** How many schools are there? Is there a library? How is the quality of schools like? What social activities happen in this community? Describe the people who live here?

3.2. **What places do you like going to in this community?** Ask what places mean to them? On what days and time do you go to these places? Is this typical of your age – of being an adolescent? What places are linked to being a young man or a young woman living with HIV?

3.3. **Do you ever attend school, health facility, church, go to market?** How often? When is the last time you were there? What challenges are found in these places? What kind of places are you uncomfortable to go to? What options are there for treatment when ill?

[**May draw a timeline of their movements/life –this may be represented over time**]. Has the place been like that all the time? Read the text in bold (**If you do not mind I would like to accompany you whenever you take a walk to any of the places around the community even visiting your friends or neighbourhood)**

Topic area 3: Facilitators notes

Topic area 4 – Meta-structural (facilitator to read bolded text and elaborate with prompts at their discretion): **Next we would like talk about how you related to some situations.**

4.1. Do **you listen to news?** What concerns or interests you when you hear or watch news?

4.2. **What social protection services are available in this community?** Ask for if there are institutions which offer assistance such as food stuff, school support, health support, clothing etc.

4.3**. How are sanitation, roads?** How do each of these affect your daily life routine? Ask concerning water supply and sanitation i.e. toilets, garbage disposal, flooding

4.4. **How does social status influence relations in this community?** Do some social position such as politicians, wealthy residents, educated residents or persons in authority have power over certain resources in the community? How does that affect you?

Topic area 4: Facilitators notes

Topic area 5– Social networks (Materials needed: pens, colour pens, last page of this document - remember to reattach after activity). (Facilitator to read bolded text and elaborate with prompts at their discretion): **We are also interested in how people interact in your community. To do this we would like you to draw your social network. A network is similar to a tree with different branches. All of the branches are connected to the same tree.**

- **5.1. We would like you to draw your own network. For your network, you will be in the middle and all the people you interact with will be placed around you. Some of these people or groups you see or talk to more often and you can place these people closer to you. Other people/groups/organisations that you interact with less often can be placed further away from you.** (*Take a picture of the completed network.)*
- **5.2. Please explain your network and your relationship with each person/organisation/group.** Where would you put your spouse/boyfriend /girlfriend? What kind of relationship do you have with your spouse/boyfriend/ girlfriend?
- **5.3. Who in this network do you spend the most time with?** What would you do together?
- **5.4. Do you know if any of the people in this network is affected by HIV? Who is affected and how?**

Topic area 5: Facilitators notes

Interview Two:

Topic Area 6 – HIV timeline. (Materials needed: pens, colour pens, second last page of this document - remember to reattach after activity). (Facilitator to read bolded text below and elaborate with prompts at their discretion): **To understand how the progression of HIV and ART in the community and your life, we would like you to complete a timeline on the page provided**

- **6.1 Please make use of the timeline** (on the last page of this document) **to show us the history of HIV in this community. Also, indicate when and where the events took place (more or less). If you cannot remember the exact date, you can just indicate broadly.** Think of things like when you first heard of HIV in this community, when you first met someone that you knew was HIV positive, when testing started in the community, when you became aware of ARVs, when ARVs became available in the community. Do you know when PMTCT was first provided? (*Take a picture of the completed timeline.)*
- **6.2 Is there anything else you would like to add to the timeline?** You can also add any relevant events to the timeline, any stories that you think relate to HIV.

Topic area 7: Facilitators notes

Topic area 7 – HPTN 071 (PopART) knowledge (facilitator to read bolded text and elaborate with prompts at their discretion): **Next we would like to talk about your knowledge of the PopART study.**

7.1 What do you know about the HPTN 071 (PopART) study? Where did you hear about HPTN 071 (PopART)? When did you hear about HPTN 071 (PopART)? What do you know about the P-ART-Y study? When did you hear about the P-ART-Y study?

7.2 What was your first impression when you heard about the study? Has this perception changed since? What has change? What has changed since the CHiPs started going around the community testing people door to door?

7.3 I have given you a stack of cards and a pen. Please write down all the methods of HIV prevention that you are aware of. Please write down one idea per card. Remember, there are no wrong answers. What about alternative forms of prevention? What about MMC? PMTCT? ART?

7.4 Which of these do you think works the best for this community? Why? Which ones are not as effective?

7.5 Which of these do you think are most commonly used? Why don't they use this (PMTCT, MMC, condoms, etc.) prevention method? Do you think that people in this community should use this prevention method? What do you think will encourage more people to use this prevention method? What kind of condoms are common? Have you ever heard of mood / scented condoms? Where do people find them?

7.6 Do you know any other HIV testing and treatment programs in this community? What do you think is the difference between the way that HPTN 071 (PopART) works and the way that other HIV testing and treatment programmes work?

7.7 Do you think HPTN 071 (PopART) will work on a large scale? Why or why not? Do you think HPTN 071 (PopART) should eventually be implemented everywhere? Have you heard about ART as prevention? Do you think that this will affect the use of condoms?

Who do you think is responsible for preventing HIV transmission? Do you think HIV is ever transmitted on purpose?

Topic area 8: Facilitators notes

Topic area 8 – Disclosure, ART and stigma discussion. **As part of our study we are also interested in people's understanding and experiences of Antiretroviral treatment, or ART.**

8.1 How did you feel when you found out about your status? How has it changed your life? Has it affected your relationships with family and friends? Did you disclose your HIV status to anyone? Why did you disclose to that person/why did you not disclose?
Please elaborate on your experiences with HIV service providers.

8.2 What is your understanding of ART? What do you think the drugs do? Do you know how they work? Why do you think you/people have to take the treatment? Do you think it is effective? Are there any other forms of treatment besides ART? Have you or do you know anyone who has tried any alternative treatments? What are the beliefs in the community around ART?

8.3 What do you understand about the process of ART initiation? Do you know anyone on ART? What do you expect the process to be like? What do you think happens when people are put on the medication? When is the best time to start ART? What do you understand by early ART, CD4 count and viral load?

8.4 What do you think is important for adherence? What are the challenges? When and how does one have to take ART? Is there specific diet one has to follow while on ART? Do you think alcohol plays a role in adherence? If yes what role does it play? What about drugs? How do alcohol and drug use affect sexual behaviour and HIV prevention? Had a relative or a friend or a doctor or another health personnel being concerned about someone on ART drinking alcohol or using drugs, or suggested that they cut down? If yes, why? If no, why not? Have you ever heard of anyone forgetting to take their after drinking alcohol? If yes, how did it happen?

8.5 Why do you think people sometimes stop taking the medication? Do you know any people who stopped taking their medication?

8.6 How would you define stigma? Do PLWH ever experience stigma in this community? How? Can you give an example? Have you stigmatised any PLWH? Is there name-calling for PLWH on ART? Do some people avoid being seen at the clinic?

8.7 Do you think ART has had an impact on stigma? How? Why? Do you think ART has had an impact on stigma? How? Why?

8.8 What do you think are the experiences of young people accessing HIV and ART? Are there challenges in accessing HIV and ART services? Shortage of medication? Long lines at the clinic? Waiting periods at clinic? What support systems exist in the community for PLWH to access ART? Where do most PLWH collect their ART? Who decides that they must be collecting from there? Do you think the confidentiality of one's status is upheld? If not why?

Topic area 9: Facilitators notes

Topic area 9 – Sex, Love and SRH (facilitator to read bolded text and elaborate with prompts at their discretion): **Next we would like to talk about sex, love and Sexual Reproductive Health.**

9.1 Are you in a relationship? What characteristics do you look for in a potential partner? Are you in a relationship? Is this your first relationship? How did you get married? Who do you trust? **When in a relationship do you trust your partner? Why or why not?**

9.2 Do you think it is important to have a partner? Why? Do you think men and women need different things from relationships? What do women need? What do men need? Can you tell me about a healthy relationship?

9.3 How old were you when you had your first relationship? Can you tell me about this person? How old were you when you first had sex? Did you consent to this?

9.4 How did you meet your current/recent partner? Tell me about your partner's background How long have you been together? How would you describe your partner? What do you like most about them? Does your partner work? How does your partner help you financially? How does your partner help you with your children? How does your partner help you with your home?

9.5 Do you have another partner(s)? Can you tell me about them?

9.6 As part of the HPTN 071 (PopART) study one of the things that is important is to understand condom use. Have you ever used a condom? Have you used a condom with your most recent sexual partner(s)? Tell us about your relationship. How did you meet him/her? How long after your meeting did your relationship become sexual? How did you decide that it was the right time? Can you please tell us about condom negotiations in your relationship? Who decides to use the condom? Where do you get your condoms? Do you know your partner's HIV status? At what point in your relationship did you decide to stop using condoms? Describe the process.

9.7 What sexual reproductive health (SRH) services and information do you or have you ever access(ed)/ receive (d)? Probe about; condoms and condom use, contraceptives, safer sex, unwanted pregnancy, and STIs. Who did you get this information from; organisation within or outside community, older fiends-in a group/individually, friends of the same age- in a group or individually, boy/girlfriend, media, mom, dad, aunt, uncle, grandmother/father, school- club, in class by teacher or outreach visits to the school, clinic- nurse, doctor, counsellor, youth friendly corner? How often do you receive these services? What are your reasons for accessing these services? What challenges do face in accessing these services or information? Have you received SRH information and services that you didn't want? Can you tell me more about what happened?

9.8 How would you prefer to receive SRH information? Where-clinic or other specify? Would you rather be talked or read? Would you rather receive SRH information in a group or as an individual? Why?

9.9 **What SRH information and services would you prefer to receive?** Have you ever received/ accessed this kind of SRH information and services? If not are there any challenges in accessing that particular SRH service and information? Why do you think this is so?

9.9.1Who would you prefer to discuss sex and sexual reproductive health issues with? organisation within or outside community, older fiends-in a group/individually, friends of the same age- in a group or individually, boy/girlfriend, media, mom, dad, aunt, uncle, grandmother/father, school- club, in class by teacher or outreach visits to the school, clinic- nurse, doctor, counsellor, youth friendly corner? Who do you prefer the least of the above sources? Why?

Topic area 10: Facilitators notes

Interview Three:

Topic area 10 – Relationships (Gender based violence) (facilitator to read bolded text and elaborate with prompts at their discretion): **Now, we would like to talk about relationships.**

10.1 **What do you understand by 'gender-based violence'?**

10.2 **What different types of gender-based violence are prevalent in your community?** (Probe: for different forms of violence): Have you ever heard of Physical aggression (slapping, hitting, kicking, beating etc.), Psychological abuse (Intimidation, constant belittling , humiliation etc.), Sexual violence (attempt to obtain sexual act, unwanted sexual comments or advances, forced vaginal or anal sex), Controlling behaviours (Isolating a person from a family or friends, monitoring her movement, restricting access to information, denying decision making authority Economic abuse (withholding funds, control survivors access to health care, denying employment/business, denying access to property) happening to anyone in your community?

10.3 **What groups of people more likely to experience gender based violence?** Are there specific reasons for violence among different people?

10.4 **What characteristics make a woman more likely to experience violence?** How does your community react to a woman who experienced gender-based violence? Do you agree to this? Why/Why not?

10.5 **What characteristics make a man more likely to experience violence?** How does your community react to a man who experienced gender-based violence? Do you agree to this? Why/why not?

10.6 **What situations in life is gender based violence accepted?**

10.7 **What are the causes of gender-based violence?** How do you think alcohol, Gender inequalities, men's attitudes to women, culture, poverty and religion relate to gender-based violence, and HIV status?

10.8 **In case someone faces intimate partner violence in your community due to being HIV positive or accessing ART care, what do they do?** Are there available support and resilience mechanisms for violence survivors? Are there non-governmental or social services available for individuals who experienced gender-based violence? Are you familiar with the services offered in this community? What are the health services offered to individuals whom experienced violence in this community?

10.9 **Have you ever experienced any form of violence that you have just described?** If yes, were you the perpetuator or victim? If no ask has anyone close to you experienced any forms of violence you just described? Was this form of violence related to your HIV status or accessing ART care?

10.10 **What type of violence was this?** Why did it happen? How did it happen? When did it happen? How often did it happen? What did you/they do when it happened? (Why?) Are there times this improved or got worse? (Why?)

10.11 **If experienced violence: Have people living in your household seen or heard you experience violence from your partner because of your HIV status?** How often was this? What was their reaction to this? Have children in your household been hurt physically by your partner during a violent incident?

10.12 **Did you as a child experience or witnessed or involved in violence?** Have you heard of a minor experience violence? If yes, kindly tell me what happened?

Topic area 12: Facilitators notes

Topic area 11– Body mapping (Materials needed: pens, colour pens, flipchart pages pasted together – big enough to draw the outline of a person [3x2]/ roll of paper). (Facilitator to read bolded text and elaborate with prompts at their discretion): **Another way in which we are able to understand people and the community they live in is through an activity that we call 'body mapping'. A body map starts with the outline of a person's body. This empty outline is then filled in with different things that this person finds important or relevant. This will also give you the opportunity to be creative and to use more than just words to explain how different things are experienced in your life. We would like you to create your own body map.**

- **11.1. To draw a body map, we are going to draw the outline of your body. The first bit is just a little uncomfortable. We need you to please lie down on the paper; we are going to trace your outline. We would like you to lie in a position that best represents who you are (e.g. working posture, sleeping, dancing etc.)** (Trace a few centimetres away from the participant so that you do not have to come in direct contact with his/her body. If the participant is unwilling to lie down, ask the Research Assistant to act as the model. The participant can instruct the research assistant to move their bodies into the preferred position).
- **11.2. To fill in the body, we are not just adding the normal things that we usually draw in pictures, but we are adding different things to tell the story of our different experiences. We are going to ask you to illustrate different things on your outline. The first thing that we would like you to illustrate is how your circumstances have affected your body in any way [Assuming it has]? Remember, there is no wrong answer, and you can draw anything or anywhere to illustrate this.** Illustrate on the parts of the body which you feel are affected by poverty. How are they affected by poverty?
- **11.3. In the same way, can you illustrate any specific marks on your body that relate to health issues?** Can you draw parts of your body which have been inflicted with pain? Indicate whether the pain was physical or emotional. You can also draw healing or medication. **[For 11.3 colour 'blue' for parts inflicted with pain]**
- **11.4. Think about people's reaction to your health issues? How would you draw that?** Now please draw this on your body map. **[For 11.4 colour 'green' for parts of the body reacted to]Is there anything else you would like to add to your body map?** Facilitator to take a picture of the completed body map. **[For 11.5 colour 'yellow' for any add to the body map]**

Topic area 11: Facilitators notes

Topic area 11 – Horizon and ambitions/fears (facilitator to read bolded text and elaborate with prompts at their discretion): **Next we would like talk about your horizon and ambitions.**

- **11.3** **Where <u>do</u> you see yourself or where <u>did</u> you see yourself?** What do you want to be in future? What could change? What do others want/ed you to be? How would you define success? What is possible for people in this community? What do they expect or would want? What do other people want for others i.e. hopes for community over time?
- **11.4** **What are your fears/regrets and, opportunities?** Have you ever had to take time off work/school/studies to address your health needs? How often? Has this impacted on your ability to do your work/studying? How? Are there any people who are dependent on you? Do you have any children? Do you plan to have children in the future? What is your opinion of women living with HIV having children?

Topic area 12 – Open discussion (Facilitator to read bolded text and elaborate with prompts at their discretion): **We really appreciate that we have been able to spend some time with you. I know we have discussed many issues and I have learned so much. We just have a few more open questions so that we can make sure that we didn't miss anything.**

- **12.1** **Is there anything related to HIV and health in this community that you feel we need to know? How do you think it has affected** your life?
- **12.2** **What have you heard of the HPTN 071 (PopART) intervention?** Do you know what the study entails? Do you know what it means at community level? Do people talk about the study? What do people say about the study?
- **12.3** **Has the study impacted your life in any way?** Have there been any changes in your life due to the study? Has your community changed in any way?
- **12.4** **Do you think the study will succeed?** What do you think will help the study to succeed?
- **12.5** **What do you think will prevent the study from succeeding?**
- **12.6** **Is there anything else you would like to add?**

Topic area 12: Facilitators notes

Closing (to be read by facilitator): Thank-you again for your time. Do you have any final thoughts before I turn off the audio recorder and call this discussion to a close?

Appendix Q: Discussion Guide for Young People Living with HIV

'A day in the life of an Adolescent' LWHIV

Discussion guide

Purpose: This document is to be used by the HPTN 071 (PopART) SocSci field team to guide their introduction of aim 3 of the HPTN 071 (PopART) qualitative component with ADLWH participants. This guide is for discussing the lived realities of ADLWH to describe contextual factors in communities in relation to their experiences in the elements of the HPTN 071 (P-ART-Y) intervention roll-out. This discussion guide has to be used in conjunction with the "A day in the life of an Adolescent"ARF (3.8.32.73.) and RIDD (3.8.32.74.).

Form of data recording: (1) Audio-recording of all talk from "Preamble" to "Closing" depending on the tool used. (2) Notes of key points per topic area handwritten by the facilitator into a printed copy of this document. (3) Photographs of each of the activities as needed, including individual photographs of each individual response. (4) Handwritten notes by participants during the course of the discussion.

Note: The activities and questions in this manual need not be done uninterruptedly, but rather over the course about a week's worth of interactions with each participant (see "A day in the life of" ARF (3.8.32.73.) for further details).

Expected time needed per use: About a week's worth of interactions (while hanging-out)

Date activity conducted: ___________________________

Place conducted: _____________________________

Time period: _____________________________

Preamble (to be read by facilitator): Today is the (insert date [day xxth Xxx xxxx]) and it is (insert time XX: XX). This is a discussion with a person from (insert name of site). Thank you for your time. As we have explained, we are conducting this discussion as part of a variety of interactions with you. This discussion is part of describing contextual factors for adolescents living with HIV in relation to their experiences of HIV, ART, UTT roll-out, and other elements. All information collected here will be reported anonymously; that is, we will say that '*someone*' said the things that you will tell us, *NOT* that '*you*' said them. I remind you that we are audio recording this discussion at some point and ask that you speak loudly and clearly. As the facilitator I will also be taking some notes. As I mentioned when I explained the consent form, today's discussion is the first of a series of interactions that I would like to have with you, so it is by way of introduction. Do you have any questions before we begin?

Interview one:

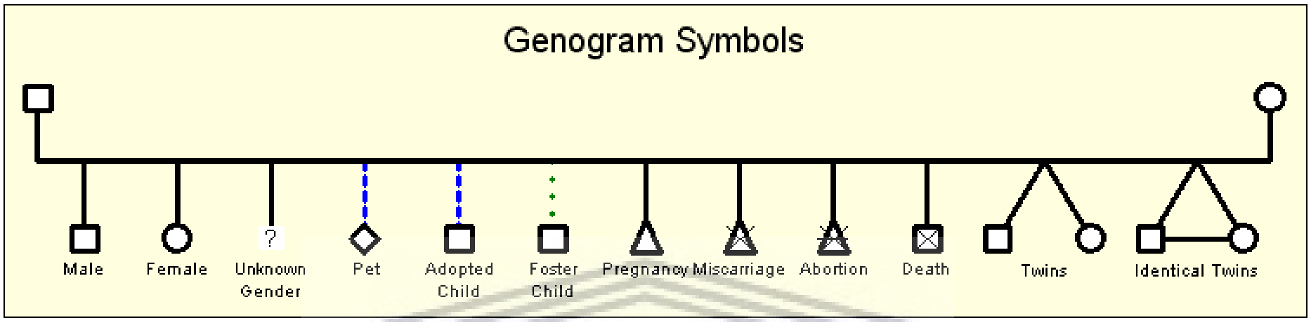
Topic area 1 – Family composition (facilitator to read bolded text below and elaborate with prompts at their discretion): **By way of starting, we would like to know a bit about you, please introduce yourself.**

1.5. **Were you born in this community?** If no, where are you from? When did you move to this community? Why did you move to this community? Do any of your family members also live in this community?

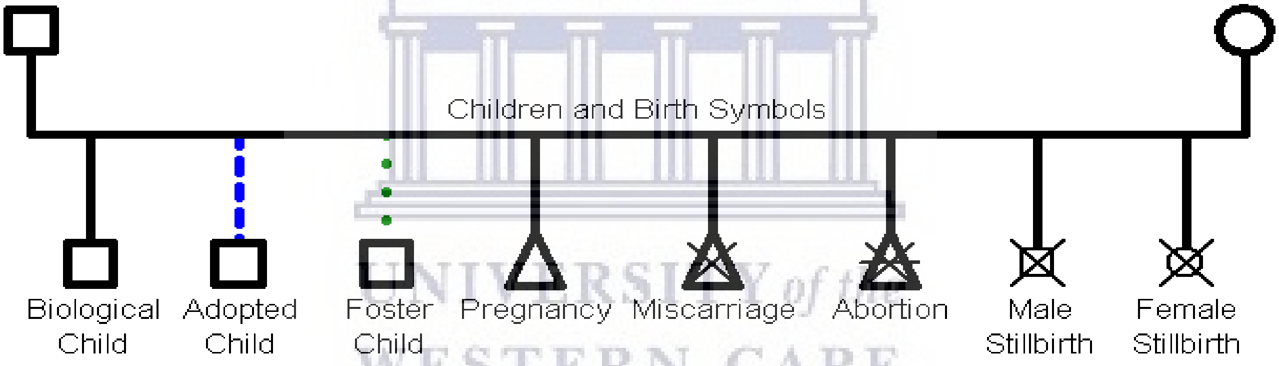
1.6. **Can you tell us more about your household?** Who is the household head? What is your relationship with the head of the house? Do you live with both parents? If not why? Who lives with you? Do you have any children? How old?

1.7. **In your household, is there a person living with HIV?** Or do you suspect that you have a household member living with HIV? How old is he/she? (If yes, build on this with questions from the extended guide or PLWH guide or adolescent interview guide)

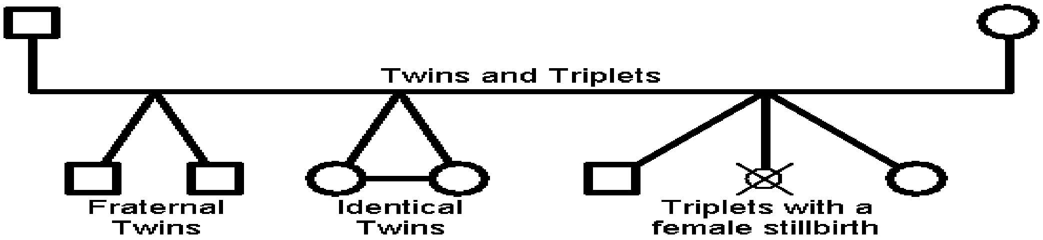
1.8. **Would you mind doing a kinship diagram/genogram?** This is also known as a family tree, where we map out members of your family. (Use the guide below. This can always be drawn up later).



Standard Gender Symbols for a Genogram

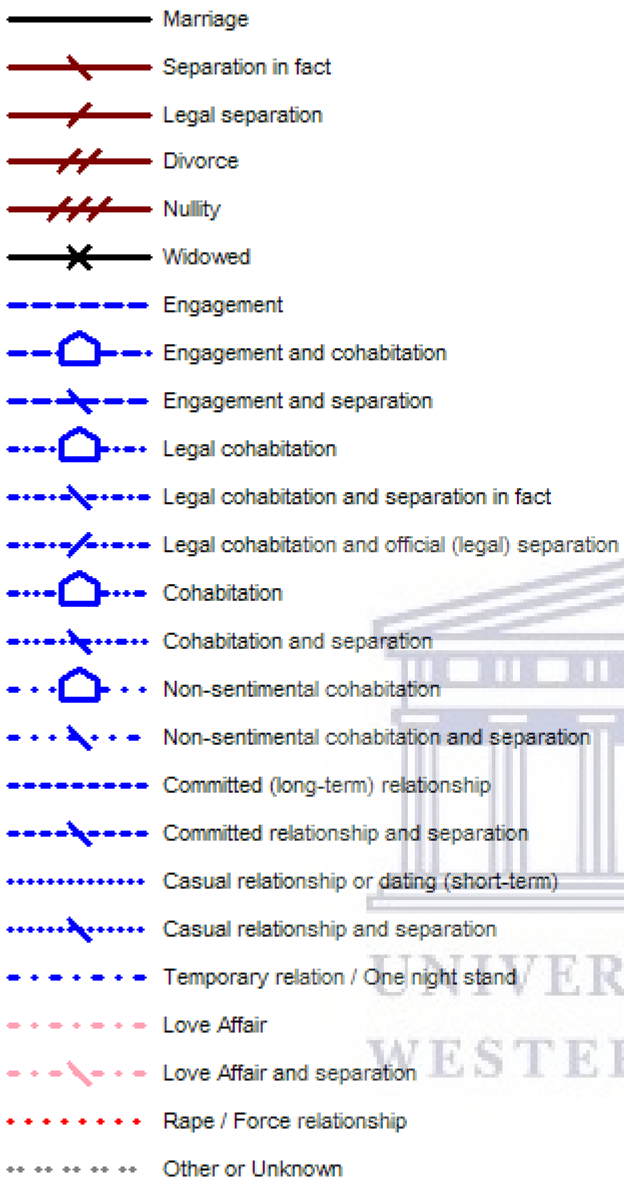


Genogram Symbols for Children's Links and Pregnancy Terminations



Child links are joined for multiple births such as twins and triplets

(Source: http://www.genopro.com/genogram/symbols/)



Family Relationships Key
(Source: http://www.genopro.com/genogram/family-relationships/)

Topic area 1: Facilitators notes

Topic area 2 – how they get by (facilitator to read bolded text and elaborate with prompts at their discretion): **Next we would like to talk about the way you get by.**

2.2. **Can you tell us more about a 'normal' day in your life?** What activities do you usually do on a daily basis? Do you go to work? If you work, where do you work? Have you been working there ever since? Are you in school? If so, what are you studying? How do you contribute to household living? Are there other means you earn a living i.e. gifts, social cash transfer, support from social welfare or non-governmental organization? Do you have a garden/make-shift-stall or have you ever thought of having one? Is there a family member or relative outside your home who assist you with finances or some other support? Who makes financial decisions i.e. what to buy, when and why? What kind of meals do you usually have on a daily basis i.e. such as for breakfast, lunch and supper, and in-between meals? How often do you have them in a day? Who owns most of the assets that you have?(As a researcher spends a day with the participant, should also observe the kind of meals that are prepared, also observe kinds of assets they own)

2.2. **What else keeps you occupied apart from work/school?** Do you perform any household chores? If yes, what kind? How often do you do these chores? Do you get any help when carrying out these chores? If yes, who from? What things do you do that others cannot help with? Could it be churches/religious activities? What recreation activities are you involved in? Which of these social activities do you find most fulfilling?

Topic area 2: Facilitators notes

Topic area 3 – Use of spaces in community (Facilitator to read bolded text and elaborate with prompts at their discretion): **Next we would like to know more about you and your community. To do this I have an old map which was drawn by some community members in 2013. It is not a perfect map representing the community but I would like you tell me the places that are of significant to you, if there are not on the map we can include them using a pencil.**

3.1. **Can you tell us about your community and what it is like living here?** How many schools are there? Is there a library? How is the quality of schools like? What social activities happen in this community? Describe the people who live here?

3.2. **What places do you like going to in this community?** Ask what places mean to them? On what days and time do you go to these places? Is this typical of your age – of being an adolescent? What places are linked to being a young man or a young woman living with HIV?

3.3. **Do you ever attend school, health facility, church, go to market?** How often? When is the last time you were there? What challenges are found in these places? What kind of places are you uncomfortable to go to? What options are there for treatment when ill?
[**May draw a timeline of their movements/life –this may be represented over time**]. Has the place been like that all the time? Read the text in bold (**If you do not mind I would like to accompany you whenever you take a walk to any of the places around the community even visiting your friends or neighbourhood)**

Topic area 3: Facilitators notes

Topic area 4 – Meta-structural (facilitator to read bolded text and elaborate with prompts at their discretion): **Next we would like talk about how you related to some situations.**

4.1. Do **you listen to news?** What concerns or interests you when you hear or watch news?

4.2. **What social protection services are available in this community?** Ask for if there are institutions which offer assistance such as food stuff, school support, health support, clothing etc.

4.3**. How are sanitation, roads?** How do each of these affect your daily life routine? Ask concerning water supply and sanitation i.e. toilets, garbage disposal, flooding

4.4. **How does social status influence relations in this community?** Do some social position such as politicians, wealthy residents, educated residents or persons in authority have power over certain resources in the community? How does that affect you?

Topic area 4: Facilitators notes

Topic area 5– Social networks (Materials needed: pens, colour pens, last page of this document - remember to reattach after activity). (Facilitator to read bolded text and elaborate with prompts at their discretion): **We are also interested in how people interact in your community. To do this we would like you to draw your social network. A network is similar to a tree with different branches. All of the branches are connected to the same tree.**

5.1. We would like you to draw your own network. For your network, you will be in the middle and all the people you interact with will be placed around you. Some of these people or groups you see or talk to more often and you can place these people closer to you. Other people/groups/organisations that you interact with less often can be placed further away from you. (*Take a picture of the completed network.)*

5.2. Please explain your network and your relationship with each person/organisation/group. Where would you put your spouse/boyfriend /girlfriend? What kind of relationship do you have with your spouse/boyfriend/ girlfriend?

5.3. Who in this network do you spend the most time with? What would you do together?

5.4. Do you know if any of the people in this network is affected by HIV? Who is affected and how?

Topic area 5: Facilitators notes

Topic area 2: Network activity

Remember to indicate all relevant network points. The closer you work with a person/team, the closer their 'nodes' should appear to yours.

Interview two:

Topic area 6 – HPTN 071 (PopART) knowledge (facilitator to read bolded text and elaborate with prompts at their discretion): **Next we would like talk about your knowledge of the PopART study.**

6.1. What do you know about the HPTN 071 (PopART) study? Where did you hear about HPTN 071 **(**PopART)? When did you hear about HPTN 071 (PopART)?

6.2. What was you first impression when you heard about the study? Has this perception changed since? What has change? What would be/are the effects of changes in intervention?

6.3. **I have given you a stack of cards and a pen. Please write down all the methods of HIV prevention that you are aware of. Please write down one idea per card. Remember, there are no wrong answers.** What about alternative forms of prevention? What about MMC? PMTCT? ART?

6.4 **Which of these do you think works the best for this community?** Why? Which ones are not as effective?

6.5 **Which of these do you think are most commonly used?** Why don't they use this (PMTCT, MMC, condoms, etc.) prevention method? Do you think that people in this community should use this prevention method? What do you think will encourage more people to use this prevention method? What kind of condoms are common? Have you ever heard of mood / scented condoms? Where do people find them?

6.6 **What do you think is the difference between the way that HPTN 071 (PopART) works and the way that other HIV testing and treatment programmes work?**

6.7 **Do you think HPTN 071 (PopART) will work on a large scale?** Why or why not? Do you think HPTN 071 (PopART) should eventually be implemented everywhere? Have you heard about ART as prevention? Do you think that this will affect the use of condoms?
Who do you think is responsible for preventing HIV transmission? Do you think HIV is ever transmitted on purpose?

Topic area 7: Facilitators notes

Topic area 7 – ART/HIV timeline

(Materials needed: pens, colour pens, second last page of this document - remember to reattach after activity). (Facilitator to read bolded text below and elaborate with prompts at their discretion): **To understand how the progression of HIV and ART in the community and your life, we would like you to complete a timeline on the page provided**

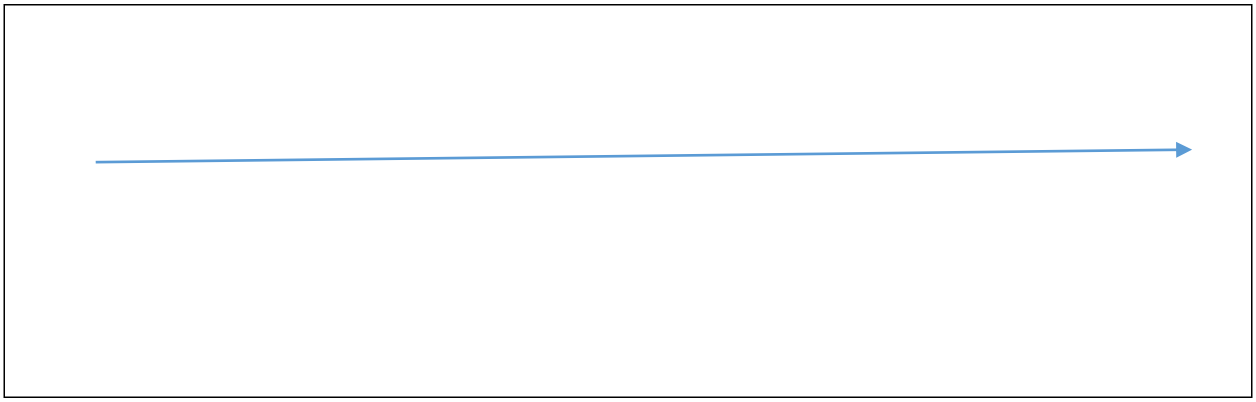
7.1 **What is your understanding of ART?** Why do you think you have to take the treatment? Are there any other forms of treatment besides ART? Have you tried any alternative treatments? What are your beliefs around ART? What do community members say about ART?

7.2 **Who informed you about ART? When did you receive this information? Are you aware of others who initiated ART? If yes, when did they initiate ART? Why did they initiate ART?**

7.3 **If you have already been initiated on ART what was your experience of the process/counselling?** If you have not, then what do you expect the process will be like? If you have been initiated on ART was it easy to understand the information given? When is the best time to start ART? Do you remember what the CD4 cell count was?

7.4 **What do you think is important for adherence?**

Topic area 7: Facilitators notes



Topic area 8 – Disclosure, ART and stigma discussion. **As part of our study we are also interested in people's understanding and experiences of Antiretroviral treatment, or ART.**

8.1 How did you find out about your status? How did you feel when you found out about your status? How has it changed your life? Has it affected your relationships with family and friends? Did you disclose your HIV status to anyone? Why did you disclose to that person/why did you not disclose? **Refer to disclosure network below.**

8.2 What is your understanding of ART? What are the challenges? When and how do you have to take ART? How often would you take ART? Is there specific diet you have to follow while on ART? What do you think the drugs do? Do you know how they work? Why do you think you/people have to take the treatment? Do you think it is effective? Are there any other forms of treatment besides ART? Have you or do you know anyone who has tried any alternative treatments? What are the beliefs in the community around ART?

8.3 What do you understand about the process of ART initiation? Do you know anyone on ART? What do you expect the process to be like? What do you think happens when people are put on the medication? When is the best time to start ART? What do you understand by early ART, CD4 count and viral load?

8.4 What do you think is important for adherence? What are the challenges? When and how do you have to take ART? Is there specific diet you have to follow while on ART? Do you think alcohol plays a role in adherence? If yes, what role does it play? What about drugs? How do alcohol and drug use affect sexual behaviour and HIV prevention? Did a relative or a friend or a doctor or another health personnel been concerned about someone on ART drinking alcohol or using drugs, or suggested that they cut down? If yes, why? If no, why not? Have you ever heard of anyone forgetting to take their after drinking alcohol? If yes, how did it happen?

8.5 Why do you think people sometimes stop taking the medication? Do you know any people who stopped taking their medication?

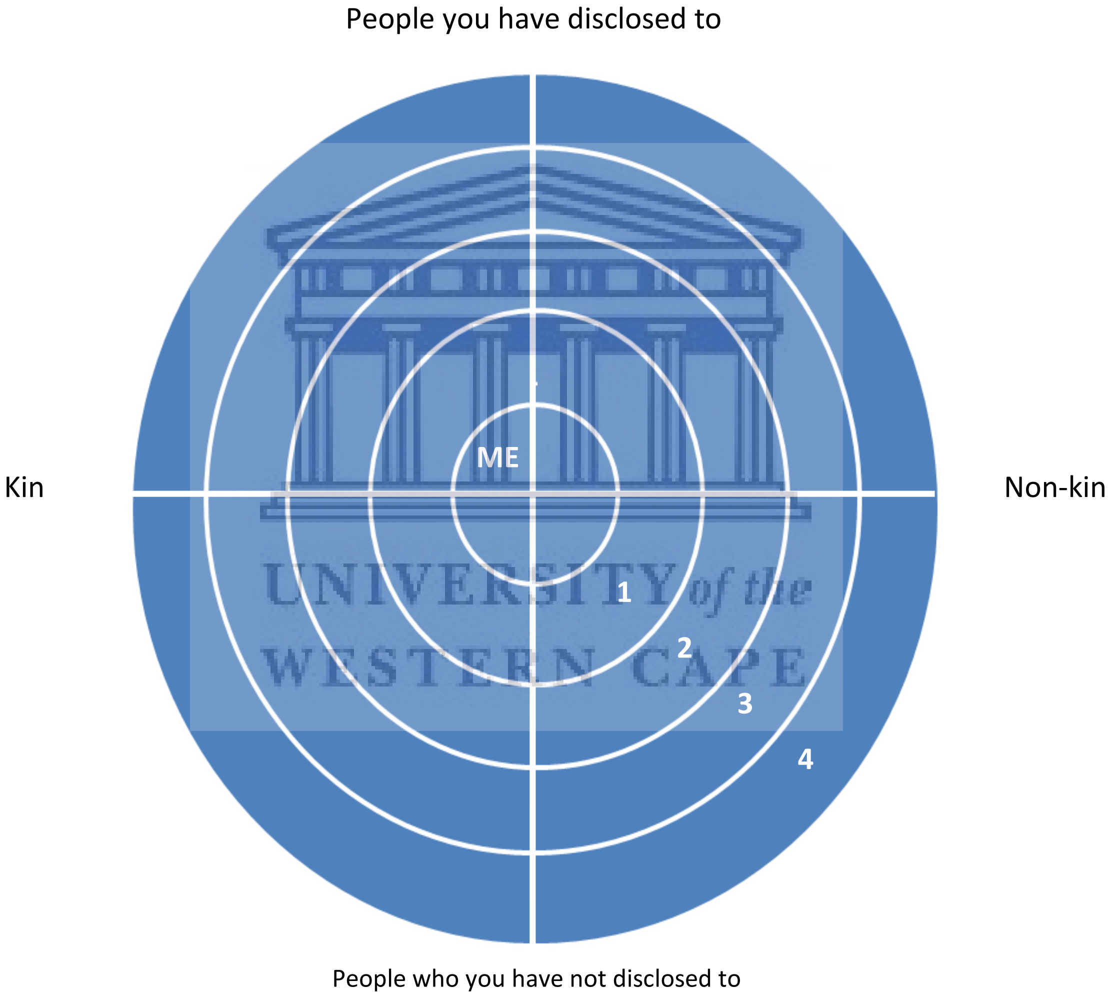
8.6 How would you define stigma? Do PLWH ever experience stigma in this community? How? Can you give an example? Have you stigmatised any PLWH? Is there name-calling for PLWH on ART?? Why would people avoid being seen at the clinic?

8.7 Do you think ART has had an impact on stigma? How? Why?

8.8 Describe your experiences of accessing HIV and ART services? Please elaborate on your experiences with HIV service providers. Are there challenges in accessing HIV and ART services? Shortage of medication? Long lines at the clinic? Waiting periods at clinic? What support system do you have to access ART? Where do you collect your ART? Who decides that you must be collecting from there? Do you think the confidentiality of your status is upheld? If not, why? Are you comfortable taking ART in the presence of your partner/family? Who helps you when you are busy or cannot go to get the drugs?

Topic area 8 – HIV disclosure Network

We would like to draw a diagram to capture if and how you have disclosed to different people. Here we have different circles that represent how close you feel to different people. If we put you in the centre, the smallest circle around you are people who you feel closest too (important family and friends you feel very close to). The next circle represents people who you feel close to, but not as close as the smallest circle (family and friends who you have fairly regular contact with). The third circle represents relatives with whom you usually have outside contact and people you see outside the home, while the forth represents distant relatives and people you hardly ever see. As you go out to the bigger circles, they represent people who you feel less close to. The circle is divided into kin and non-kin (family and non-family) – and we will populate this with people you have disclosed to. The bottom section represents people you have not disclosed to



Key – Family
1 = Family you feel most close to
2 = Close relatives who you have fairly regular contact with
3 = Relatives with whom you usually have outside contact (eg. Visiting)
4 = Distant relatives

Key – Non-Family
1 = Friends you feel close to
2 = Friends who you have regular contact with
3 = People you see outside the home (eg. In school, or health facilities)
4 = People you know but hardly ever see

Topic area 9 – Sex, Love and SRH (facilitator to read bolded text and elaborate with prompts at their discretion): **Next we would like to talk about sex, love and Sexual Reproductive Health.**

9.1 Are you in a relationship? What characteristics do you look for in a potential partner? Are you in a relationship? Is this your first relationship? How did you get married? Who do you trust? **When in a relationship do you trust your partner? Why or why not?**

9.2 Do you think it is important to have a partner? Why? Do you think men and women need different things from relationships? What do women need? What do men need? Can you tell me about a healthy relationship?

9.3 How old were you when you had your first relationship? Can you tell me about this person? How old were you when you first had sex? Did you consent to this?

9.4 How did you meet your current/recent partner? Tell me about your partner's background How long have you been together? How would you describe your partner? What do you like most about them? Does your partner work? How does your partner help you financially? How does your partner help you with your children? How does your partner help you with your home?

9.5 Do you have another partner(s)? Can you tell me about them?

9.6 As part of the HPTN 071 (PopART) study one of the things that is important is to understand condom use. Have you ever used a condom? Have you used a condom with your most recent sexual partner(s)? Tell us about your relationship. How did you meet him/her? How long after your meeting did your relationship become sexual? How did you decide that it was the right time? Can you please tell us about condom negotiations in your relationship? Who decides to use the condom? Where do you get your condoms? Do you know your partner's HIV status? At what point in your relationship did you decide to stop using condoms? Describe the process.

9.7 What sexual reproductive health (SRH) services and information do you or have you ever access(ed)/receive (d)? Probe about; condoms and condom use, contraceptives, safer sex, unwanted pregnancy, and STIs. Who did you get this information from; organisation within or outside community, older fiends-in a group/individually, friends of the same age- in a group or individually, boy/girlfriend, media, mom, dad, aunt, uncle, grandmother/father, school- club, in class by teacher or outreach visits to the school, clinic- nurse, doctor, counsellor, youth friendly corner? How often do you receive these services? What are your reasons for accessing these services? What challenges do face in accessing these services or information? Have you received SRH information and services that you didn't want? Can you tell me more about what happened?

9.8 How would you prefer to receive SRH information? Where-clinic or other specify? Would you rather be talked or read? Would you rather receive SRH information in a group or as an individual? Why?

9.9 **What SRH information and services would you prefer to receive?** Have you ever received/ accessed this kind of SRH information and services? If not are there any challenges in accessing that particular SRH service and information? Why do you think this is so?

9.9.1Who would you prefer to discuss sex and sexual reproductive health issues with? organisation within or outside community, older fiends-in a group/individually, friends of the same age- in a group or individually, boy/girlfriend, media, mom, dad, aunt, uncle, grandmother/father, school- club, in class by teacher or outreach visits to the school, clinic- nurse, doctor, counsellor, youth friendly corner? Who do you prefer the least of the above sources? Why?

Topic area 10: Facilitators notes

Interview Three:

Topic area 10 – Relationships (Gender based violence) (facilitator to read bolded text and elaborate with prompts at their discretion): **Now, we would like to talk about relationships.**

10.13 What do you understand by 'gender-based violence'?

10.14 What different types of gender-based violence are prevalent in your community? (Probe: for different forms of violence): Have you ever heard of Physical aggression (slapping, hitting, kicking, beating etc.), Psychological abuse (Intimidation, constant belittling , humiliation etc.), Sexual violence (attempt to obtain sexual act, unwanted sexual comments or advances, forced vaginal or anal sex), Controlling behaviours (Isolating a person from a family or friends, monitoring her movement, restricting access to information, denying decision making authority Economic abuse (withholding funds, control survivors access to health care, denying employment/business, denying access to property) happening to anyone in your community?

10.15 What groups of people more likely to experience gender based violence? Are there specific reasons for violence among different people?

10.16 What characteristics make a woman more likely to experience violence? How does your community react to a woman who experienced gender-based violence? Do you agree to this? Why/Why not?

10.17 What characteristics make a man more likely to experience violence? How does your community react to a man who experienced gender-based violence? Do you agree to this? Why/why not?

10.18 What situations in life is gender based violence accepted?

10.19 What are the causes of gender-based violence? How do you think alcohol, Gender inequalities, men's attitudes to women, culture, poverty and religion relate to gender-based violence, and HIV status?

10.20 In case someone faces intimate partner violence in your community due to being HIV positive or accessing ART care, what do they do? Are there available support and resilience mechanisms for violence survivors? Are there non-governmental or social services available for individuals who experienced gender-based violence? Are you familiar with the services offered in this community? What are the health services offered to individuals whom experienced violence in this community?

10.21 Have you ever experienced any form of violence that you have just described? If yes, were you the perpetuator or victim? If no ask has anyone close to you experienced any forms of violence you just described? Was this form of violence related to your HIV status or accessing ART care?

10.22 What type of violence was this? Why did it happen? How did it happen? When did it happen? How often did it happen? What did you/they do when it happened? (Why?) Are there times this improved or got worse? (Why?)

10.23 If experienced violence: Have people living in your household seen or heard you experience violence from your partner because of your HIV status? How often was this? What was their reaction to this? Have children in your household been hurt physically by your partner during a violent incident?

10.24 Did you as a child experience or witnessed or involved in violence? Have you heard of a minor experience violence? If yes, kindly tell me what happened?

Topic area 12: Facilitators notes

Topic area 11– Body mapping (Materials needed: pens, colour pens, flipchart pages pasted together – big enough to draw the outline of a person [3x2]/ roll of paper). (Facilitator to read bolded text and elaborate with prompts at their discretion): **Another way in which we are able to understand people and the community they live in is through an activity that we call 'body mapping'. A body map starts with the outline of a person's body. This empty outline is then filled in with different things that this person finds important or relevant. This will also give you the opportunity to be creative and to use more than just words to explain how different things are experienced in your life. We would like you to create your own body map.**

11.1. **To draw a body map, we are going to draw the outline of your body. The first bit is just a little uncomfortable. We need you to please lie down on the paper; we are going to trace your outline. We would like you to lie in a position that best represents who you are (e.g. working posture, sleeping, dancing etc.)** (Trace a few centimetres away from the participant so that you do not have to come in direct contact with his/her body. If the participant is unwilling to lie down, ask the Research Assistant to act as the model. The participant can instruct the research assistant to move their bodies into the preferred position).

11.2. **To fill in the body, we are not just adding the normal things that we usually draw in pictures, but we are adding different things to tell the story of our different experiences. We are going to ask you to illustrate different things on your outline. The first thing that we would like you to illustrate is how your circumstances have affected your body in any way [Assuming it has]? Remember, there is no wrong answer, and you can draw anything or anywhere to illustrate this.** Illustrate on the parts of the body which you feel are affected by poverty. How are they affected by poverty?

11.3. **In the same way, can you illustrate any specific marks on your body that relate to health issues?** Can you draw parts of your body which have been inflicted with pain? Indicate whether the pain was physical or emotional. You can also draw healing or medication. **[For 11.3 colour 'blue' for parts inflicted with pain]**

11.4. **Think about people's reaction to your health issues? How would you draw that?** Now please draw this on your body map. **[For 11.4 colour 'green' for parts of the body reacted to]Is there anything**

else you would like to add to your body map? Facilitator to take a picture of the completed body map. **[For 11.5 colour 'yellow' for any add to the body map]**

Topic area 11: Facilitators notes

Topic area 12 – Horizon and ambitions/fears (facilitator to read bolded text and elaborate with prompts at their discretion): **Next we would like talk about your horizon and ambitions.**

12.1 Where <u>do</u> you see yourself or where <u>did</u> you see yourself? What do you want to be in future? What could change? What do others want/ed you to be? How would you define success? What is possible for people in this community? What do they expect or would want? What do other people want for others i.e. hopes for community over time?

12.2 What are your fears/regrets and, opportunities? Have you ever had to take time off work/school/studies to address your health needs? How often? Has this impacted on your ability to do your work/studying? How? Are there any people who are dependent on you? Do you have any children? Do you plan to have children in the future? What is your opinion of women living with HIV having children?

Topic area 13 – Open discussion (Facilitator to read bolded text and elaborate with prompts at their discretion): **We really appreciate that we have been able to spend some time with you. I know we have discussed many issues and I have learned so much. We just have a few more open questions so that we can make sure that we didn't miss anything.**

13.1 Is there anything related to HIV and health in this community that you feel we need to know? How do you think it has affected your life?

13.2 What have you heard of the HPTN 071 (PopART) intervention? Do you know what the study entails? Do you know what it means at community level? Do people talk about the study? What do people say about the study?

13.3 Has the study impacted your life in any way? Have there been any changes in your life due to the study? Has your community changed in any way?

13.4 Do you think the study will succeed? What do you think will help the study to succeed?

13.5 What do you think will prevent the study from succeeding?
13.6 Is there anything else you would like to add?

Topic area 12: Facilitators notes

Closing (to be read by facilitator): Thank-you again for your time. Do you have any final thoughts before I turn off the audio recorder and call this discussion to a close?

APPENDIX R: Materials Checklist (to be completed before heading into the field)

Materials	
1. Two copies of the guide	
2. Colour pens/pencils	
3. Pens	
4. Colour paper	
5. Flipchart/roll of paper	
6. Markers	
Forms	
7. Information sheets	
8. Consent forms	
Supplies	
9. Camera	
10. Batteries (charged)	
11. Digital Recorder (charged)	
12. A4 Envelopes	
13. Refreshments	

____
Name

____
Signature

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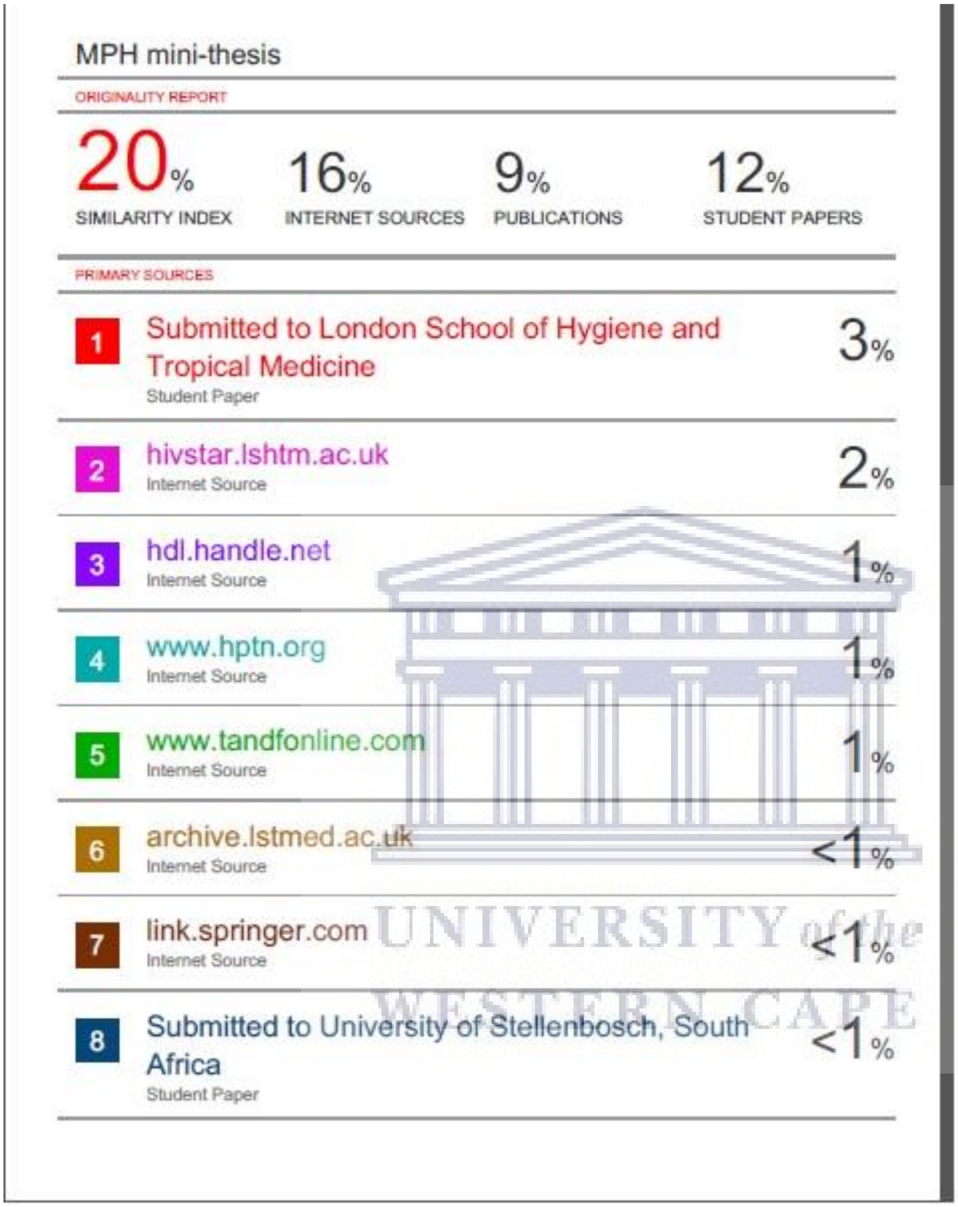
Date

Appendix S: Turnitin Originality Report



MPH mini-thesis

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