SEX IN THE SHADOW OF HIV

FACTORS ASSOCIATED WITH SEXUAL RISK AMONG ADOLESCENTS IN A COMMUNITY-TRACED SAMPLE IN SOUTH AFRICA

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Hilary Term 2017

Thesis submitted in partial fulfilment of the degree of Doctor of Philosophy in Social Intervention by stand-alone papers at the University of Oxford.

Word count: approximately 57,804

'These teenagers struggle, even in the clinics. I really do give them counselling. To us, they come when they are already having a baby. They don't use contraceptives. They don't use a condom. Some of them want to give their partners HIV. Some of their partners want to give it to them'.

(ART nurse, Bhisho Hospital, 25 October 2014, Hodes et al. 2015)[1]

'There was lots of excitement about getting them [adolescents living with HIV] on treatment but no look at broader support required to keep them on treatment. We can have big drives to get them tested and into care, but then how do we support them to stay in care and understand what it means to be HIV-positive? […] How do we address sexual and reproductive health needs, because adherence is critical to this?'

(Expert Consultation, Female, NGO Executive Director. Zimbabwe, Gittings et al. 2016)

[1] Quotes are provided at the start of each paper to provide background on the content of the paper. They were collected by the study's qualitative team (Dr. Rebecca Hodes and Ms. Lesley Gittings), and have been reproduced with their permission.

PUBLICATIONS AND PRESENTATIONS ARISING FROM THIS THESIS

Accepted:

The candidate has first-authored the following publications from this study:

Toska, E. Cluver L. Boyes, M. Isaacsohn, M. Hodes, R. Sherr, L. (2016) School, supervision and adolescent-sensitive clinic services: combination social protection and reduced unprotected sex among HIV-positive adolescents in South Africa. *AIDS and Behavior.* DOI: 10.1007/s10461-016-1539-y

Toska, E., Gittings, L., Hodes, R., Cluver, L. D., Govender, K., Chademana, K. E., & Gutiérrez, V. E. (2016). Resourcing resilience: social protection for HIV prevention amongst children and adolescents in Eastern and Southern Africa. *African Journal of AIDS Research*, 15(2), 123-140. DOI: 10.2989/16085906.2016.1194299

Toska, E., Cluver, L. D., Hodes, R., & Kidia, K. K. (2015). Sex and secrecy: How HIV-status disclosure affects safe sex among HIV-positive adolescents. *AIDS Care*, 27(sup1), 47-58. DOI:10.1080/09540121.2015.1071775

In submission/ Preparation for submission:

Toska, E. Cluver, L. D. Pantelic, M. Hodes, R. (in preparation) Is knowledge power? HIV-status disclosure and protective sexual practices among adolescent girls and boys in South Africa. (target journal: BMC Public Health)

Toska, E. Pantelic, M. Meinck, F. Keck, K. Cluver, L. D. (in preparation) Sex in the Shadow of HIV: A systematic review of prevalence, predictors, and programmes of sexual practices of HIV-positive adolescents and youth in sub-Saharan Africa. (target journal: PLoS ONE)

Accepted conference abstracts as oral presentations:

Preliminary analyses has also been presented at the following workshops, meetings and conferences. The most recent events are listed first:

Toska, E. Cluver L. D. Hodes, R. and the Mzantsi Wakho study team. *Supervision, School & Adolescent-Sensitive Clinic Care: Reducing unprotected sex among HIV-positive adolescents through combination social protection.* International AIDS Conference – AIDS 2016. Durban, South Africa. 21 July 2016.

Toska, E. Cluver L. Hodes, R. Gittings, L. *The triple-care effect: associations between safe sex and relationships in the home, school and clinics among HIV-positive adolescents.* Children and HIV: Equity Now! Symposium. Durban, South Africa. 15 July 2016.

Toska, E., Cluver L., Hodes R. *When today's children become parents – Child-bearing ideation and access to contraception of HIV-positive adolescents in South Africa: findings and implications for reproductive rights.* 3rd Association for the Social Sciences and Humanities in HIV Conference. Stellenbosch, South Africa. Abstract No: 180. Oral presentation. 6 July 2015.

Toska, E., Hodes, R., Cluver L. *Today's children, tomorrow's parents: Childbearing intention and access to sexual and reproductive health for HIV-positive adolescent girls.* 7th Southern African AIDS Conference, Durban, South Africa. Oral presentation at roundtable on Women and Sexual and Reproductive Health Rights. 9 June 2015.

Toska, E., Cluver, L. Hodes, R., Khidia, K. *Sex and Secrecy: Disclosure and condom use in a community-based sample of HIV-positive teens in South Africa.* 7th Southern African AIDS Conference, Durban, South Africa. Abstract No: 490. Oral presentation. 10 June 2015.

Presentations:

The preliminary analyses for this theses was presented and received feedback at the following academic seminars (most recent first):

Toska, E. and the Mzantsi Wakho team. *Evidence-based social interventions for adolescents and youth in sub-Saharan Africa.* Workshop on The Developmental Origins of Health and Disease (DOHaD) & Sustainable Development Goals (SDGs): Moving Towards Early Implementation in Africa. Stellenbosch Institute for Advanced Studies. 22 September 2016.

Gittings, L. Toska E. and the Mzantsi Wakho team. *Resourcing resilience: The case for social protection for adherence and HIV-related outcomes in children and adolescents in Eastern and Southern Africa.* Webinar hosted by the Eastern and Southern Africa Regional Inter-Agency Task Team on Children Affected by AIDS (RIATT-ESA). 13 September 2016.

Toska, E. Gittings, L. and the Mzantsi Wakho team. *Improving health outcomes among HIV-positive adolescents in South Africa.* Alan J. Flisher Centre for Public Mental Health (CPMH). Stellenbosch University. 25 July 2016.

Gittings, L. Toska, E. and the Mzantsi Wakho team. *Resourcing resilience: The case for social protection for adherence and HIV-related outcomes in children and adolescents in Eastern and Southern Africa.* School of Public Health. University of Cape Town. 7 July 2016.

Cluver, L. Toska, E. and the Mzantsi Wakho team. *Social protection for HIV-positive adolescents: New Data from South Africa, Initial Analyses*. HIV and Social Protection Interagency Task Team. Geneva, 3 March 2016.

Cluver, L. Toska, E. and the Mzantsi Wakho team. *HIV impacts of cash transfers and other social protection interventions.* World Bank, Action on Extreme Poverty and Inequality to End AIDS: Addressing HIV, Poverty, and Inequality in Urban Settings. Washington D.C., 22 February 2016.

Cluver, L. Toska, E. Skracic, Izidora and the Mzantsi Wakho team*. Fighting Gender Injustice in HIV: Cash plus Care for Adolescent Girls.* UN Women Strategic Discussion on gender equality and HIV/AIDS: Putting Gender Justice at the Center of the Fast Track to End AIDS. New York, 18 February 2016.

Toska, E. Hodes, R. *Sex and Secrecy: Associations between knowledge of HIV status, disclosure and sexual practices of HIV-positive adolescents in South Africa.* CSSR Seminar, Centre for Social Science Research, University of Cape Town. 24 March 2015.

Toska, E. *A missing link in HIV prevention? Correlates of high-risk sexual behaviours among HIV-positive adolescents in the Eastern Cape, South Africa.* GRS lunchtime seminar, Department of Social Policy and Intervention. University of Oxford. 10 March 2015.

Toska, E., *Sex and Secrecy: Associations between knowledge of HIV status, disclosure and sexual practices of HIV-positive adolescents in South Africa.* CEBI seminar, Department of Social Policy and Intervention. University of Oxford. 25 February 2015.

TABLE OF CONTENTS

PUBLICATIONS AND PRESENTATIONS ARISING FROM THIS THESIS 2
TABLE OF CONTENTS 4
LIST OF FIGURES 7
LIST OF TABLES 8
ABSTRACT 10
ACKNOWLEDGEMENTS 15
NOTE ON THE CANDIDATE'S RESEARCH ROLE 19
THE CANDIDATE'S ROLE 19
MZANTSI WAKHO – A MIXED-METHODS COHORT STUDY 21
KEY TERMS 25
1. INTRODUCTION 27
2. BACKGROUND AND THEORETICAL FRAMEWORK 32
2.1. HIV-POSITIVE ADOLESCENTS: GLOBAL POPULATION AND LOCAL IMPACT IN SUB-SAHARAN AFRICA 32
2.2. SEXUAL HEALTH OF HIV-POSITIVE ADOLESCENTS 34
2.3. POLICY CONTEXT 35
2.4. SECONDARY 'POSITIVE' PREVENTION FOR HIV-POSITIVE ADOLESCENTS 38
2.5. SEXUAL RISK-TAKING AMONG HIV-POSITIVE ADOLESCENTS 42
2.6. CONCEPTUAL FRAMEWORK 42
2.7. THEORETICAL FRAMEWORK 43
2.8. IMPLICATIONS FOR THIS STUDY 52
2.9. RESEARCH AIMS AND RESEARCH QUESTIONS 54
3. METHODOLOGY 56
3.1. INTRODUCTION 56
3.2. SYSTEMATIC REVIEW METHODS (PAPER 1) 56
3.3. STUDY METHODOLOGY (PAPERS 2 AND 3) 57
3.4. ETHICAL ENTANGLEMENTS: FRAMEWORK, CHALLENGES, AND SOLUTIONS 73
3.5. RESEARCH TEAM 87
3.6. FIELDWORK PROCEDURES, QUESTIONNAIRES, AND MEASURES 92
3.7. RESEARCH CONSTRAINTS 106
4. PAPER 1 – SEXUAL RISK-TAKING AMONG HIV-POSITIVE ADOLESCENTS AND YOUTH IN SUB-SAHARAN AFRICA: A SYSTEMATIC REVIEW OF PREVALENCE RATES, RISK FACTORS, AND INTERVENTIONS 114
ABSTRACT 116

4.1. INTRODUCTION 117
4.2. METHODS 119
4.3. RESULTS 126
4.4. DISCUSSION 154
4.5. CONCLUSION 166
4.6. SUPPLEMENTARY TABLES 167
4.7. REFERENCES 175
5. PAPER 2 – IS KNOWLEDGE POWER? HIV-STATUS DISCLOSURE AND PROTECTIVE SEXUAL PRACTICES AMONG ADOLESCENT GIRLS AND BOYS IN SOUTH AFRICA 185
ABSTRACT 187
5.1. INTRODUCTION 188
5.2. METHODS 190
5.3. RESULTS 196
5.4. DISCUSSION 206
5.5. CONCLUSION 211
5.6. REFERENCES 212
6. PAPER 3 – SCHOOL, SUPERVISION, AND ADOLESCENT-SENSITIVE CLINIC CARE: COMBINATION SOCIAL PROTECTION AND REDUCTED UNPROTECTED SEX AMONG HIV-POSITIVE ADOLESCENTS IN SOUTH AFRICA 216
ABSTRACT 218
6.1. INTRODUCTION 219
6.2. METHODS 222
6.3. RESULTS 227
6.4. DISCUSSION 239
6.5. CONCLUSION 242
6.6. REFERENCES 244
7. DISCUSSION 248
7.1. OVERVIEW 248
7.2. PAPER 1 – SEXUAL RISK-TAKING AMONG HIV-POSITIVE ADOLESCENTS AND YOUTH IN SUB-SAHARAN AFRICA: A SYSTEMATIC REVIEW OF PREVALENCE RATES, RISK FACTORS, AND INTERVENTIONS 251
7.3. PAPER 2 – IS KNOWLEDGE POWER? HIV-STATUS DISCLOSURE AND PROTECTIVE SEXUAL PRACTICES AMONG ADOLESCENT GIRLS AND BOYS IN SOUTH AFRICA 256
7.4. PAPER 3 – SCHOOL, SUPERVISION, AND ADOLESCENT-SENSITIVE CLINIC CARE: COMBINATION SOCIAL PROTECTION AND REDUCTED UNPROTECTED SEX AMONG HIV-POSITIVE ADOLESCENTS IN SOUTH AFRICA 259
7.5. STUDY LIMITATIONS AND STRENGTHS 262

7.6. POLICY IMPLICATIONS 267
7.7. DIRECTIONS FOR FUTURE RESEARCH 270
7.8. DISSEMINATION 272
7.9. CONCLUSION 274
8. BIBLIOGRAPHY 276

LIST OF FIGURES

Figure 2-1. An integrative model developed by Fishbein and Cappella (2006) 47
Figure 2-2. Theoretical model for sexual risk-taking among HIV-positive adolescents 52
Figure 3-1. Map of South African provinces 58
Figure 3-2. Map of Buffalo City Municipality, Eastern Cape province, South Africa 59
Figure 3-3. Estimating total population in the study's sampling frame 62
Figure 3-4. Sampling strategy for HIV-positive sample 63
Figure 3-5. Sample Size Calculator Output for prevalence of condom use 64
Figure 3-6. Study locations: a rural community in the Peddie area (top), Mdantsane, South Africa's second largest township (bottom left), and a rural road in Keiskammahoek (bottom right). 70
Figure 3-7. Sample geotagging of an address 70
Figure 3-8. Mzantsi Wakho progress thermometer – Graphics used to capture progress in the field 72
Figure 3-9. Organizational chart of the Mzantsi Wakho research team in 2014-2015 86
Figure 3-10. Study advisory panels 91
Figure 3-11. Screenshots from the tablet version of the Mzantsi Wakho baseline questionnaire 97
Figure 3-12. Cover and sample page from Mzantsi Wakho Baseline Questionnaire Paper-based Version 103
Figure 3-13. Local newspaper article promoting the Mzantsi Wakho study 107
Figure 3-14. One of the project vehicles painted in 2015 in response to attempted hijacking 110
Figure 4-1. PRISMA flow diagram for identifying the included studies 126
Figure 4-2. Hypothesised factors associated with sexual risk-taking among HIV-positive adolescents and youth in Sub-Saharan Africa 140
Figure 5-1. Levels of Disclosure from adolescents to their partners (boyfriend or girlfriend) 193
Figure 5-2. Predicted probabilities of protective sexual practices by combinations of disclosure types among adolescents girls and boys 200
Figure 6-1. Effects of adolescent-sensitive clinic care by gender 234
Figure 6-2. Marginal effects model testing for additive effects of combination social protections on unprotected sex among HIV-positive adolescents 238

LIST OF TABLES

Table 2-1. Summary of outcomes of interventions among HIV-positive adolescents outside sub-Saharan Africa 41
Table 3-1. Scope of review 56
Table 3-2. Comparison of included and excluded HIV-positive samples 68
Table 3-3. Comparison of included and excluded community control samples 71
Table 3-4. Summary of consultations with academic experts, practitioners and community organizations 94
Table 4-1. Scope of systematic review 119
Table 4-2. Summary of included studies 123
Table 4-3. Prevalence rates of sexual risk-taking among HIV-positive adolescents and youth 129
Table 4-4. Individual-level factors reported in included studies 141
Table 4-5. Relationship-level factors reported in included studies 143
Table 4-6. Family and community-level factors reported in included studies 144
Table 4-7. Structural-level factors reported in included studies 146
Table 4-8. HIV-related factors reported in included studies 147
Table 4-9. Associations between high-risk sexual practices 149
Table 4-10. Summary of included intervention studies 152
Table 4-11. Results of the risk of bias assessments for all included studies 167
Table 4-12. Results of correlates of sexual risk-taking among HIV-positive adolescents and youth by study 169
Table 4-13. Prevalence rates of sexual risk-exposure outcomes reported by included studies 174
Table 5-1. Sample socio-demographic and relationship characteristics by knowledge of HIV-positive status 198
Table 5-2. Rates of protective sexual practices by disclosure type and gender among sexually-active adolescents 199
Table 5-3. Regression models of associations between types of disclosure and protective sexual practices amongst all adolescents (n=1,527) 202
Table 5-4. Regression models testing for gender moderation of associations of disclosure types and protective sexual practices (n=1,527) 202
Table 5-5. Regression models of associations between types of disclosure and protective sexual practices among adolescent girls (n=868) 203
Table 5-6. Regression models of associations between types of disclosure and protective sexual practices among adolescent boys (n=659) 203
Table 5-7. Regression models of associations between all three types of disclosure and protective sexual practices 205
Table 6-1. Socio-Demographic characteristics of the sample by gender 229
Table 6-2. Outcome measures and access to social protection provisions by gender 230
Table 6-3. Associations of unprotected sex with pregnancy and STI symptomology among HIV-positive adolescent 231
Table 6-4. Logistic regression of all social protection provisions and covariates 231
Table 6-5. Gender moderation effects for HIV-positive adolescents (n=1,060) 233
Table 6-6. Gender-disaggregated logistic regressions of social protection provisions and covariates 233

Table 6-7. Logistic regression models of all significant potential social protection factors, interaction terms, and covariates 236
Table 6-8. Logistic regression models of all significant potential social protection factors, interaction terms, and covariates 237

ABSTRACT

Background: Sub-Saharan Africa is home to 85% of the world's HIV-positive adolescents: an estimated 1.3-2.2 million 10-19 year olds. Adolescents living with HIV face multiple sexual and reproductive health risks: unwanted pregnancies and the risk of mother-to-child-transmission, risk of infecting partners, co-infection with other STIs, and the rising but undocumented risk of re-infection by potentially resistant HI-virus strains. Using contraception, especially condoms, is particularly challenging for all adolescents. It is even more difficult for HIV-positive adolescents due to HIV-related factors such as learning their HIV-positive status, withholding or disclosing their HIV-status to sexual partners, and accessing services in the home, clinics, and schools. This thesis aims to understand which factors shape sexual risk-taking among HIV-positive adolescents to inform the development of interventions that promote safe sexual practices in this population.

Methodology: This thesis applies a socio-ecological model to investigate factors associated with sexual risk-taking among HIV-positive adolescents. It consists of three stand-alone papers: a systematic review and two quantitative papers based on a cross-sectional epidemiological and aetiological study of unprotected sex among HIV-positive adolescents and community controls in South Africa. Paper 1 is a systematic review of rates, correlates, and interventions to reduce sexual risk-taking among HIV-positive adolescents and youth in sub-Saharan Africa. Paper 2 looks at associations between HIV-status knowledge and disclosure and protective sexual practices in the cross-sectional study sample. Paper 3 explores the relationship between various social protection provisions and unprotected sex among HIV-positive adolescents.

The candidate co-developed and conducted a community-traced study of adolescents in the Eastern Cape, in South Africa: 1,060 HIV-positive adolescents and 467 community controls. HIV-positive 10-19 year old adolescents were recruited from 53 government facilities in a health sub-district with antenatal HIV prevalence of over 30%. 90.1% of the eligible sample was traced, with only 4.1% refusing to take part. Community controls were neighbouring or co-habiting 10-19 year old adolescents, 92% of whom agreed to take part. Voluntary informed consent was obtained from adolescents and caregivers in the language of their choice: English or Xhosa. Questionnaires were administered by trained research assistants using mobile devices (tablets) with adolescent-friendly graphic content to ensure participant interest and reduce participant burden through skip-patterns.

The systematic review (Paper 1) included studies located through electronic databases and grey literature. The Preferred Reporting Items for Systematic Reviews and

Meta-Analyses guidelines were followed. Quantitative studies reporting on HIV-positive participants (10-24 year old) included data on at least one of eight outcomes (early sexual debut, inconsistent condom use, older sexual partner, transactional sex, multiple sexual partners, sex while intoxicated, sexually transmitted infections, and pregnancy). Only studies conducted in sub-Saharan Africa were included. The candidate and a second author independently piloted all processes, screened studies, extracted data independently, and resolved any discrepancies. Due to variance in reported rates and correlates, no meta-analyses was conducted. The systematic review informed the analyses conducted for the two quantitative papers.

Analyses for Papers 2 and 3 used *condom use at last sexual encounter* (dichotomised either as safe sex/ abstinence or unprotected sex) as the outcome, controlling for a series of covariates. Analyses used SPSS 22 and STATA 11. For each paper, the hypothesised factors were entered as independent variables in multivariate logistic regressions controlling for potential confounders. Based on the findings of the systematic review, gender moderation analyses was run entering a 2-way interaction term of gender*correlate in multivariate logistic regressions, controlling for covariates. Marginal effect models explored the effect of combinations of risk/ protective factors. Predicted probabilities for safe sex/ unprotected sex were computed for different two- and three-way combinations of the independent variables, controlling for covariates significantly associated with the outcome.

Paper 2 tested the effect of three types of disclosure on protective sexual practices: (i) knowledge of one's own HIV-positive status, (ii) disclosing one's HIV-status to a partner, and (iii) knowing a partner's HIV-status. It compared HIV-positive status aware adolescents (n=794) with the rest of the sample (n=733). Paper 3 investigated associations between nine types of social protection provisions and unprotected sex. In line with UNICEF's definition, social protection was defined as any provision aimed at preventing, reducing and eliminating economic and social vulnerabilities to poverty and deprivation among HIV-positive adolescents. The nine social protection provisions tested by the analyses included 'cash' and 'care' factors accessed in the home, school, and community.

Results: Paper 1 – 'Sexual Risk-Taking among HIV-Positive Adolescents and Youth in Sub-Saharan Africa: A systematic review of prevalence rates, risk factors, and interventions.' The systematic review (Chapter 4) found that, despite their heightened vulnerabilities and high rates of sexual risk-taking, there is a dearth of evidence on interventions which may help HIV-positive adolescents engage in safe sexual practices. The review included 35 studies, four of which were interventions aiming to reduce sexual risk-

taking. The quality of the included studies was low with most studies (k=31) reporting findings from cross-sectional data. HIV-positive adolescents and youth reported high rates of sexual risk-taking, however findings were inconsistent about potential factors associated with sexual risk-taking. Factors consistently associated with sexual risk-taking in multivariate analyses included: food insecurity, living alone, living with a partner, and gender-based violence. No significant associations were reported for: rural residence, informal housing, anxiety, religious guidance, STI prevention knowledge, poor birth outcomes, orphanhood, parental monitoring, having a supportive family, social support, maternal education level, poverty, disclosing one's HIV-status to a partner, time on ART, ART adherence, receiving care at a hospital, opportunistic infections. However, most of the above associations were reported by only one study, therefore further analyses is needed to build the evidence base on potential determinants of sexual risk-taking among HIV-positive adolescents and youth. The included interventions consist of three individual- and group-based psychosocial interventions evaluated in three small-scale trials (n<150) and one large trial of combination interventions for HIV-positive orphaned adolescent girls (n=710). Three of these interventions had positive effects in reducing sexual risk-taking: an individual based 18-session counselling intervention in Uganda, a support group intervention in South Africa, and a combination intervention in Zimbabwe.

Quantitative data analyses of cross-sectional study data: Overall, adolescents in the full sample (n=1,527) reported high rates of sexual activity (34.9%) and high rates of unprotected sex (22%), with adolescent girls reporting higher rates of unprotected sex than boys (33% vs. 7%). In univariate ANOVA, rates of unprotected sex among those sexually-active were lower amongst ART-eligible HIV-positive adolescents (p≤.001) compared to community controls, adolescent boys compared to girls (p≤.001), and HIV-positive adolescents who knew their status compared to the rest of the sample (p≤.001). Among sexually-active HIV-positive adolescents who knew their status, horizontally-infected adolescents reported more unprotected sex (64% vs. 44%, p≤.001).

Paper 2 'Is Knowledge Power? HIV-status disclosure and protective sexual practices among adolescent girls and boys in South Africa.' In Paper 2 (Chapter 6), analyses of the full sample of adolescents (n=1,527) found that knowing one's own HIV-positive status was associated with more safe sex (OR1.88, CI1.35-2.63, *p*≤0.001), knowledge of a sexual/ romantic partner's HIV-status (positive or negative) was associated with less safe sex (OR0.45 CI0.29-0.69, *p*≤0.001), while disclosing one's HIV-status to a partner was not associated with safe sex. Gender did not moderate the relationship between HIV-status knowledge and disclosure, and protective sexual practices. Among female adolescents (N=843), the patterns of association between disclosure (*to* and *from*) and safe

sex were the same: HIV-positive status-aware adolescent girls were more likely to report safe sex than the rest of adolescent girls (OR1.86 CI1.26-2.74, p=0.002). When combinations of disclosure were considered, knowing one's own HIV-positive status was associated with higher rates of protective sexual practices, but it was not sufficiently protective when HIV-positive adolescents also disclosed to their partners or knew their partner's HIV-status.

Paper 3 'School, Supervision, and Adolescent-Sensitive Clinic Care: Combination social protection and reduced unprotected sex among HIV-positive adolescents in South Africa.' Analyses in Paper 3 (Chapter 7) tested associations between social protection provisions accessed by HIV-positive adolescents in the home, school and clinics (n=1,060). Participants reported lower rates of unprotected sex if they received strong parental supervision (OR0.54, CI0.33-0.90, p=0.019), had free access to school (OR0.52, CI0.33-0.82, p=0.005), and received adolescent-sensitive care when accessing sexual health services (OR0.43, CI0.25-0.73, p=0.002). Gender acted as a moderator for the positive effect of adolescent-sensitive clinic care: the association between reduced reports of unprotected sex and better clinic care was stronger for girls than boys. Gender-disaggregated regression models confirmed these findings. Analyses then checked for multiplicative or additive effects: whether receiving more than one social protection provision had a greater effect on rates of unprotected sex. No multiplicative effects were found. In marginal effect models, receiving more than one social protection intervention had an additive effect on predicted probabilities of unprotected sex rates, controlling for covariates. This effect was even stronger among adolescent girls: without any social protection, 49% were likely to report unprotected sex; with 1-2 of the interventions 13-38%; and with all interventions only 9%.

Conclusion: This thesis provides new evidence on what may support HIV-positive adolescents engage in safe sexual practices. The findings suggest that some factors may strongly support safe sex: knowledge of own HIV-positive status, good caregiver supervision, access to schools, and adolescent-sensitive sexual healthcare at clinics. These factors are located in various levels of the socio-ecological model, supporting the application of this theoretical model to understand the sexual health of HIV-positive adolescents in South Africa. These findings also highlight the greater vulnerability of adolescent girls, even when they are already HIV-positive, and propose potential interventions that may have positive effects in reducing these vulnerabilities: supported disclosure of their HIV-positive status, access to schools, good parental supervision, and adolescent-sensitive clinic care. By identifying key HIV-specific and HIV-inclusive programmes that may support safe sex,

this thesis contributes to the problem theory for the sexual and reproductive health of HIV-positive adolescents.

ACKNOWLEDGEMENTS

I am incredibly indebted to the 1,527 adolescents who agreed to take part in this study, their families and teachers who facilitated the research process, and staff at the 53 health facilities that partnered with our team to ensure this study was successful. This research would not be possible if you had not opened your homes, schools, offices, and lives to our team. Your stories of resilience in the face of vulnerability were a true inspiration.

My deepest gratitude goes to members of the research team who invested hour after hour in meeting and bonding with, and ensuring our young respondents felt comfortable sharing their life stories. Your generosity of heart and mind kept me going. I hope that the work we have done together will be impactful in ways that befit the trust of our respondents, and time and energy invested in it by all of you.

Thank you to all who were involved in the Mzantsi Wakho baseline study: Amanda Mbiko, Amol Naik, Andre Robb, Aviwe Mboyiya, Bulelani Kinana, Babalwa Makwenkwe, Becca Jopling, Blessing Madondo, Bongiwe Saliwe, Christin Gilmer, Carly Hudelson, Chunyiswa Kama, Dumile Mhlauli, Izidora Skracic, Janina Steinert, Jessica Sandelson, Julia Rosenfeld, Khameer Kidia, Marija Pantelic, Lauren Parmley, Louis Pilard, Mavis Mpumlwana, Maya Isaacsohn, Moses Neel, Nomampondo Sotsonga, Nolusindiso Gwebecimele, Nonkumbuzo Galela, Beauty Kamile, N Nduvana, Niklas Bobrowitz, Philiswa Nokubonga Mjo, Phumla Nobatye, Rachel Smith, Siyavuya Mqalo, Sally Medley, Sindiswa Mona, Siphesihle Tshaka, Thembani Mampangashe, Thembeka Tsiba, Tom Walker, Unathi Mgweba, Unathi Ngesi, Vuyiseka Luke, Yasmin Dunkley, and Zoliswa Marikeni. To members of the current team who are following up on participants with such dedication and passion – thank you for your perseverance and resourcefulness.

While I was preparing to submit this thesis in October 2016, South African universities, including the University of Cape Town from where I wrote these acknowledgements, were embroiled in student protests. The students were demanding many things, but the most important is free decolonised education for all. These are demands that are unlikely to be met overnight. And yet, the daily struggles faced by tens of thousands of predominantly Black students – from finding the money to pay their fees, to finding money to buy their next meal – cannot be ignored. Their passion for justice and equality amidst some of the world's greatest inequality, makes me painfully aware of what an incredible privilege it is to be enrolled something as luxurious as a doctoral degree. For me, this degree is the culmination of a journey that has taken me from a loving but under-resourced family home in small-town post-communist Albania, into a decade-long whirlwind of unbelievable experiences, people and places, to where I find myself today: living a big city life in Cape Town two decades after apartheid. This journey has been the result of a fair bit of work, but a significant amount of luck. A world in which accident of birth and a throw of dice shape more than hard work and love, is not a just world. It is my hope that through some of my current and future work, I can change, however little, the structural inequalities of the elitist and exclusionary global educational system, from which I have benefitted so immensely. A decolonised academic project must be located in the post-colony, not the global North. The irony of this sentence, written in this text, in this context, is not lost to me. But epistemic violence – the valuing of people and knowledge based on the location in which it is generated, and the people who generate or communicate it, rather in the merits of its contribution – must someday stop.

This study has benefitted from the wisdom, patience and expert knowledge of leading medical and public health professionals in the Eastern Cape, South Africa. I would like to thank Dr. Gerry Boon, Dr. Luntu Galo, Dr. Justus Hofmeyr, Dr. Carol Hofmeyr, Dr. Cheree Goldswain, Dr. Verena Linder, Mrs. Bukelwa Mkosi, Mrs. Nato, Ms. Kimberly Crunkleton, Dr. Leanne Brady, Ms. Magda Greyling, and Dr. Sisanda Gaga. Prof. Nicoli Nattrass, Rajen Govender, and Dr. Nompumelelo Zungu have all provided extremely helpful feedback on the overall study. Prof Mark Orkin has been a beacon of statistical insights and learning – through cryptic-yet-genius emails and inspiring cat photos. Finally, none of this would have been possible if I had not had the far-fetched luck of connecting with Ms. Lulama Sidloyi, and through her Mr. Craig Carty. I feel honoured to call both of you my colleagues. Sis Lu – thank you for keeping me grounded during fieldwork with Thursday night all-you-can-eat sushi buffets at the mall, thoughtful feedback, and for being there at the most critical junctures of this study. Craig, you are the king of instant email replies, the wizard of incredible connections, and a soulful person who never ceases to surprise me with your big heart and dedication to collaboration and meaningful impact.

While setting up the study, I reached out to many academics and researchers who have dedicated their lives to improving the health of HIV-positive adolescents in South Africa and beyond. In particular, Prof. Donna Futterman, Dr. Mitch Besser, Dr. G Anita Heeren, Prof. Cynthia Fair, and Dr. Frances Obare, welcomed my queries with warmth and provided crucial insights into the sexual and reproductive health component of this study.

My journey with this remarkable study began one fateful day when I was introduced to Dr. Beth (Bethless) Vale. Thank you for jumping straight into designing this study together, for the long car rides discussing the disputed terrain of (re-)negotiating consent, thinking through the immense complexities of conducting research with HIV-positive adolescents, designing and running amazing workshops, and making Hamburg feel like home, including the late night bat-saving opportunity. Thank you for being… well… you!

Since 2011, when I returned to the UK for my Masters degree, I have been grateful for having Marija Pantelic in my life. Silent J – thank you for the walks on the sandy dunes of Hamburg, the Serbian-Albanian peace project (making baklava while studying for exams!), babysitting Kori, for the beautiful drawings, for the immense contribution to the study, hard months of fieldwork, and for your crucial help with the systematic review.

Returning to the UK more than a decade after finishing high school in Wales, was like returning home in many ways. To the wonderful Angie and Ray Silkstone, Rasnara Begum, Kari Lipschutz, Vanela Bushi, Armela Veliaj, Annabel Smith, Hannah Caruana, and Aly Visram – connecting with you all in Oxford and surrounds made my life feel full of love and laughter – thank you! Nahal Zebarjadi and Tomas Martinak – you were incredibly generous to travel to see me repeatedly – I really loved having you back in my life!

Throughout this doctorate, I have received the support and care of so many colleagues. Thank you Drs. Fran and Jamie for being the trailblazers of thesis-by-publication at DSPI. It is scary to have such big shoes to fill, but amazing to have your positive examples to follow. Dr. Rebecca Hodes – the best combination of a friend and colleague one could ask for – thank you for the beautiful inputs, pastel coloured nail polish/ special tea collection, and complex reminders of the knowledge and resource inequalities that underlie our research. Thank you, too, for providing me with the space to negotiate motherhood and academic life in a nurturing and supporting environment. Thank you Dr. Franziska Meinck, Dr. Jenny Doubt, Sarah Hoeksma, Colleen Kelly, Susan Sentence, Lesley Gittings, Nontuthuzelo Bungane, Marius Coqui, Nondumiso Hlwele, Sarah Walters, and Thobani Ncapani for holding the fort, so that I could finish this doctorate.

There were many times during this doctorate when I needed last-minute help. I am really indebted to Franziska Meinck, Roxanna Haghighat, and Yulia Shenderovich for stepping in to provide feedback and assistance with the systematic review; Lina Taing and Lizzy Button for checking that I got the methodological details right, Andrew Faull and Jenny Doubt for last minute copy-editing and flow-checking, and Esthie Hugo for formatting the appendices. All remaining typos and errors are solely my own.

Coffee has been an important part of my life, but coffee hand-roasted by Garvy in Hamburg holds a special place in my heart. Setting up this study would not have been possible if there were not a little coffee rondavel in which to recharge my batteries through long hours discussing life, the universe and everything else! Thank you for being there before you became a capitalist sell-out.

During my time in the field, there were times when the impossible happened. Thank you Maya Isaacsohn for being a part of those moments with your unbelievable organising skills, fabulous sense of humour, copy-editing, and overall awesomeness. You may not have become a wood-sculptor yet, but you will make a great human mechanic!

At the beginning of this doctorate, I was lucky enough to share an office with the gregarious, Dr. Mark Boyes, whose wit, calmness, and productivity proved that one can live a well-balanced life. Thank you for the Aussie jokes, playing music in the office, and for your brilliant contributions to this study.

This manuscript would not have been completed without the calm and patient feedback from Dr. Marisa Casale, who stepped in as my supervisor while Prof. Lucie Cluver was on maternity leave (something that I tried to provide her some uninvited reverse mentoring on). Thank you for reading and commenting on many drafts while on break, even when such drafts should have never really seen the light of someone else's computer screen.

Finally, last but not least, this doctorate has allowed me to bring together my passion for evidence-building (asking the forever-burning question – so what?) with my drive to improve young women's sexual and reproductive health. None of this would have been possible without the outstanding, academic, professional and personal support of my supervisor, Prof. Lucie Cluver. There are few words to express my gratitude for your mentoring me through this process, beginning with my masters in September 2011, and for providing me with the opportunity to do such meaningful research. Thank you for leading by example, with humility, and extreme pragmatism, while putting all your heart into the cause of vulnerable children and adolescents. Thank you for this inimitable experience. I look forward to our continued collaboration.

This thesis is dedicated to my immediate family (Andrew – the better half of FATE – and Kori Kai, the light of my eyes), my parents, brother, and in-laws, friends near and far (Snafuzoid, Sui, P, Normalita), my yoga and running communities, and the wider UWC family who (try to) keep me humble and grounded every day. Ama, Arber, Dea, Albi, Lori, - Jeni ju, pa jemi ne. Chad, Tefo, Janey, and Ntokozo – umntu ngumntu nabantu. You are such inspiring human beings – thank you for sharing your lives with me and for passionately giving up your free time so that young people can benefit from the incredible UWC education that shaped all of our lives so powerfully. The wonderful Jo Hunter (and Eugene, Eli, Noah and Hana) made writing a doctorate while taking care of two children seem like a piece of cake – I blame you for my optimism in thinking I could do this painlessly. Thank you for welcoming us into your life in Cape Town. I am immensely appreciative that you are my

friend, 17 years and multiple continents after we first met, in a castle on the coast of a kingdom.

It is not easy to be a woman in academia – or perhaps anywhere in this patriarchal world. Which is why Three Ladies Having Whiskey Before Breakfast was a life-saver – thank you Nahal and Deepa for the tri-continental Skypes. They warm my heart and fill me with joy.

Setting up and running a research study of this size is a mammoth task. I was only able to remain (relatively) sane during this doctorate, because of my partner (definitely *not* my 'husband'), Andrew. Thank you for your unwavering faith in my ability to get this done, for moving to East London with me, and for being a formidable partner, particularly when E-Terror struck!

As I immerse myself in parenting, I become increasingly appreciative of my parents, Luljeta and Berti Toska. Thank you for the immense love you continue to give to me, the work ethic you inspired in me, and for encouraging me by never saying NO to my crazy ideas, be they moving half-way around the globe, to being a student until the age of 34 (and hopefully a student of life forever!). Your love of learning and teaching has been infectious. I look forward to passing it on to Kori and his peers.

My brother Bleri and his family (Eriona, Ema, and Alvin), cousin Valbona, and our extended family have been incredibly generous with their long-distance love and care, through Skypes and our vibrant Whatsapp group! Falemnderit te gjitheve. To my new family in South Africa – thank you for making my transition so smooth and for being my home away from home.

Finally, Kori – my Guardian of the Multiverse – you were as much a part of this process as I was – during fieldwork growing inside me, later (once you had actually *been* born) feeding while I talked analysis on Skype, and more recently reminding me that I can function (and nearly finish a doctorate!) on very little sleep. Thank you for making me appreciate the power of unconditional love, bringing balance to my life, and making me want to work even harder for improved health, justice and well-being for all: young people or (young people who look) old.

NOTE ON THE CANDIDATE'S RESEARCH ROLE

THE CANDIDATE'S ROLE

This thesis is based on the baseline data from the largest-known community-traced study among HIV-positive and community-control adolescents – Mzantsi Wakho, introduced in the next section. The candidate was involved in the conceptualisation of the study from its inception in April 2012. Alongside the study Principal Investigator, Prof. Lucie Cluver, the candidate designed, planned, and coordinated the study protocol, data collection tools, and analyses. The candidate led the study's quantitative sexual and reproductive health component, upon which this thesis is based. Starting in October 2012, the candidate led the team in drafting the quantitative study protocol including the development of sexual health scales and measures. The study protocol was finalised with feedback from the University of Oxford Research Ethics Committee and research partner organisations. The candidate was a lead member of the sampling strategy design team with Prof. Cluver, Drs. Orkin and Boyes. Once the study protocol was finalised and submitted for approval to the University of Cape Town, the candidate set up and held a series of consultations in January-May 2013, in South Africa: Cape Town and Buffalo City Municipality (study site) to establish relationships and partnerships necessary for the study. See Chapter 3 for a list of these consultations.

From August – December 2013, as part of the first stage of sampling for this study, the candidate led a team of three researchers (Yasmin Dunkley, Lulama Sidloyi, Christin Gilmer) who mapped the health care facilities providing antiretroviral treatment to HIV-positive adolescents in the study area: Buffalo City Municipality sub-district. This team mapped facilities (n=81) covering an area of about 2,500 km^2, collecting key facility-profile information and information on the number of HIV-positive adolescents in care.

In parallel with the clinic mapping, the candidate led the drafting of the baseline questionnaire, its translation into Xhosa (dominant language of the study site), and piloting with n=25 HIV-positive adolescents in rural and urban sites, the village of Hamburg and city

of Grahamstown, respectively. She also set up and ran multiple workshops with HIV-positive and HIV-affected adolescents in South Africa, who are part of the Teen Advisory Group (TAG) in the Western Cape and Eastern Cape provinces. Once finalised, the baseline questionnaire was programmed to be delivered through mobile devices (tablets); the candidate led the conversion from the questionnaire to the tablet version using an open-source platform: OpenDataKit (www.opendatakit.org).

Starting in January 2014, the candidate set up and co-managed a research team of ten research assistants and five fieldwork coordinators. The candidate interviewed fieldwork staff candidates, developed training materials and provided overall fieldwork management for the team. This included recruitment and administrative processes, ethical compliance, data quality, and financial management. The candidate's colleague, Julia Rosenfeld, managed the referrals process and co-supervised fieldwork operations. The study traced eligible adolescents from n=53 facilities to over 150 communities (neighbourhoods, wards, villages, traditional home-steads, townships, and informal settlements). The candidate managed the fieldwork team to conduct baseline interviews for the initial 750 interviews of this study until October 2014. While the candidate returned to Oxford and started preparing for data cleaning in October 2014, another doctoral student, Ms. Marija Pantelic, managed the fieldwork team to the completion of the baseline survey of 1,527 adolescents in September 2015.

In late 2014 to early 2015, upon completion of fieldwork, the candidate led the data cleaning process for the interviews conducted until December 2014. This data was analysed and presented in high-level USAID and UNICEF meetings in February 2015. The candidate presented preliminary findings in two conferences: the Southern African AIDS Conference (June 2015) and the Association of Social Science and Humanities for HIV (July 2015). The candidate took a term of maternity leave (April – September 2015), during which time the fieldwork team completed the baseline data collection for N=1,060 HIV-positive adolescents and N=467 community controls, reaching 90% and 92% of the eligible samples, respectively.

Following the completion of the baseline interviews in September 2015, the candidate managed the data cleaning process, conducted by the candidate and two colleagues: Alexa Yakubovich and Louis Pilard. The final dataset became available in December 2015. Since then, the candidate has drafted five first-authored papers (three accepted, two in preparation) and six first-authored abstracts to conferences (five accepted as oral presentations and one as a poster). Since mid-2015, the candidate has presented preliminary findings to high-level meetings hosted by UN Women, World Bank, UNAIDS, and The Regional Inter-agency Task Team on Children and AIDS in Eastern and Southern Africa (RIATT-ESA). A lists of these abstracts, publications and presentations is included at the start of this thesis.

The candidate led the systematic review process supported by three co-authors for verifying and extracting data (paper 1) and conducted all the analyses included in this thesis (paper 2 and 3). All the papers submitted in this thesis were conceptualised, analysed and written by the candidate.

MZANTSI WAKHO – A MIXED-METHODS COHORT STUDY

The Mzantsi Wakho (Your South Africa) study (www.mzantsiwakho.org.za) is a mixed-methods longitudinal cohort study of HIV-positive adolescents (n=1,060) and community controls (n=467) set in the Eastern Cape province, South Africa. It was designed and is run by a collaborative team at the Universities of Oxford (UK) and Cape Town (South Africa). The quantitative study's main outcomes are: sexual and reproductive health (lead Investigator: Elona Toska) and adherence to antiretroviral medication (lead Investigator: Prof. Lucie Cluver). The qualitative team is led by Dr. Rebecca Hodes (University of Cape Town), whose main research interests are sexual and reproductive health.

The UK and South Africa-based teams have established strong working relationships between academics, government and civil society, including working partnerships among

University of Oxford, University of Cape Town, UNICEF, USAID, South African national departments of Health, Basic Education and Social Development, an international NGO supporting 250 clinics in 23 sub-Saharan African countries: Paediatric AIDS Treatment for Africa (PATA), a local non-governmental organisation supporting the provision of antiretroviral medication to adolescents and youth in rural Eastern Cape, South Africa: the Keiskamma Trust in Hamburg, Kheth'impilo's Eastern Cape programme based in King Williams Town, Small Projects Foundation in East London, and the Raphael Centre in Grahamstown.

The Mzantsi Wakho research team includes the candidate's supervisor: Prof. Lucie Cluver, and a team of co-investigators: Dr Rebecca Hodes (UCT), Dr. Mark Boyes (U. of Curtin), Prof. Mark Orkin (U. of Witswatersrand), Prof. Lorraine Sherr (UCL), Dr. Daniella Mark (former UCT and PATA), Dr. Franziska Meinck (U. of Oxford), Dr. Beth Vale (U. of Witswatersrand), Mr. Craig Carty (U. of Oxford), and Ms. Marija Pantelic (U. of Oxford). The study's co-Principal Investigator, Dr. Hodes, and a doctoral student, Dr. Beth Vale, conducted a concurrent qualitative study consisting of an ethnography, group-based workshops, and in-depth interviews with youth, caregivers, and healthcare providers. The quantitative and qualitative arms of the study were designed and implemented in parallel, aiming to complement each-other, based on successful mixed methods studies among youth and hard-to-reach populations (Bray, Gooskens, Kahn, Moses, & Seekings, 2010).

From October 2012 to April 2013, the team (led by the candidate) prepared a study protocol (Appendix 1.2). In addition to university approvals, ethics approval was also obtained from the Eastern Cape Department of Health, the Buffalo City sub-district Department of Health, and the Eastern Cape Department of Basic Education. Following approval from these academic and governmental institutions, all necessary ethical approvals were obtained from participating facilities (hospitals, community health centres, and primary clinics) and local organisations (children's homes, community health worker groups, etc.).

Ethical approvals from universities have been obtained for amendments and on-going research (Appendix 2).

Declaration of authorship

I, Elona Toska, hereby declare that this thesis is my own work, except where otherwise stated.

Signed: …….

Date: …….

Place: ……..

KEY TERMS

Key terms and concepts used throughout the thesis are explained in more detail in this section (alphabetically):

Adolescents or adolescence, according to the WHO, include young people 10-19 years old.

Adolescent sexual health – The definition of sexual health has evolved greatly since its first use in the public health agenda in 1975, shaped by a multitude of complex factors including the gay rights movement, the HIV epidemic and the effect of AIDS on communities (Edwards & Coleman, 2004). The World Health Organization has led most efforts to shape our emergent understanding of components of sexual health, with this definition being their most recent:

> Sexual health is a state of physical, emotional, mental and social well-being related to sexuality; it is not merely the absence of disease, dysfunction or infirmity. Sexual health requires a positive and respectful approach to sexuality and sexual relationships, as well as the possibility of having pleasurable and safe sexual experiences, free of coercion, discrimination and violence. For sexual health to be attained and maintained, the sexual rights of all persons must be respected, protected and fulfilled.
>
> WHO 2002 definition [emphasis added]

Antiretroviral treatment (ART) – A single or combination of different antiretroviral drugs which needs to be taken to keep the HIV virus under control (undetectable viral load). The South African national guidelines for antiretroviral treatment at the time this study was conducted, state that adolescents could access antiretroviral treatment through one of three tracks: (1) lifelong treatment, (2) fast track treatment within 7 days of diagnosis for severe AIDS, and (3) monitoring for those with a strong immune system – CD4>350 (Department of Health, 2013).

HIV – The human immunodeficiency virus is a virus transmitted through bodily fluids. In the case of adolescents in South Africa, the two main modes of infection are through parent-to-child transmission and unprotected sexual intercourse.

Horizontally-infected adolescents living with HIV – Though some of the literature refers to these youth as 'behaviourally-infected youth', this phrasing can be stigmatizing. As a result, this thesis will refer to the sub-group of horizontally-infected youth. In the case of South Africa, these youth are primarily infected through heterosexual transmission.

Primary HIV Prevention refers to stopping new HIV infections among HIV-negative people. These prevention programmes and strategies focus on those who are still HIV-negative, and can be targeted to the general population or those most at-risk.

Protective Sexual Practices defined as adolescents engaging in consistent protected sex or never having had sex.

Secondary HIV Prevention efforts focus on stopping HIV-infection from HIV-infected people to their un-infected contacts, such as sexual partners, children, etc. These programmes and strategies focus on those who are already HIV-positive.

Sexual risk-taking refers to any of the following practices: unprotected sex, early sexual debut, older sexual partner, transactional sex, multiple sexual partners, or sex while intoxicated.

Social protection is a widely contested concept in the social sciences. One of the most common definitions states that social protection encompasses 'all public and private measures to provide income or consumption transfers to the poor, protect the vulnerable and enhance the social status of the marginalized, as well as to prevent, reduce and eliminate economic and social vulnerabilities to poverty and deprivation' (Devereux & Sabates-Wheeler, 2004). In practice, these measures can take the shape of cash/ in-kind material benefits (social grants, free meals, or school fees) or psychosocial care (parenting, support groups, home-based care, or disclosure support). Two enhanced definitions are relevant to this study:

> Child-sensitive social protection considers different dimensions of children's well-being and addresses 'the inherent social disadvantages, risks and vulnerabilities children may be born into, as well as those acquired later in childhood' (UNICEF, 2014) while aiming to maximize opportunities and developmental outcomes for children (DFID et al., 2009).
>
> HIV-inclusive social protection is sensitive to HIV, reaching people who are either at risk of HIV infection or vulnerable to HIV consequences (Miller & Samson, 2012). HIV-inclusive social protection advocates a comprehensive approach to addressing the socio-structural drivers of HIV, while avoiding identifying or stigmatizing people on the basis of their HIV-status.

Throughout this study, social protection is used to refer 'a set of public and private policies and programmes aimed at preventing, reducing and eliminating economic and social vulnerabilities to poverty and deprivation' (UNICEF, 2012).

Unprotected sex at last intercourse refers to adolescent's self-report of not using condoms for any part of the sexual encounter *and* not being on contraception the last time they had sex.

Vertically-infected adolescents living with HIV – Adolescents infected in utero, during birth or due to exposure through breastfeeding soon after birth. Some studies refer to these adolescents as perinatally-infected adolescents, but that is technically incorrect.

Xhosa – IsiXhosa is one of the 11 official languages of South Africa, and the main language spoken in the Eastern Cape Province, where this study was conducted.

Youth refers to all people between the ages of 15-24 as defined by the United Nations. This study uses youth interchangeably when referring to adolescents and young people, when considering this crucial developmental stages preceding adulthood.

1. INTRODUCTION

This research responds to a critical evidence gap on the sexual health of HIV-positive adolescents in South Africa, home to the largest population of HIV-positive adolescents in the world (Kassede, 2015). The thesis investigates risk and protective factors associated with sexual risk-taking among HIV-positive adolescents. It aims to extend our understanding of factors that exacerbate adolescent sexual risk-taking or support adolescents to engage in safe sexual practices, in the context of living with HIV. The findings contribute to the limited research on reducing onwards HIV transmission by HIV-positive adolescents as they enter adulthood. The thesis is organised in 7 chapters, with the main empirical work comprising three stand-alone papers prepared for submission to peer-reviewed publications (Chapters 4 through 6).

Chapter 2 – Background and Theoretical Framework provides a context to the study by introducing global and regional data on HIV-positive adolescents, reviewing the policy context in which the study took place, summarising the extant literature on adolescent sexual risk-taking, and introducing the study's conceptual and theoretical frameworks. This research is guided by an adapted socio-ecological model of sexual risk-taking and resilience-building (Bronfenbrenner, 1979; Mburu, Ram, et al., 2014; Skovdal & Daniel, 2012). This theoretical framework proposes potential factors associated with sexual risk-taking, which operate at three main levels: individual (micro-system), family and community (meso-system), and structural-level (exo-system). To fit the unique profile of HIV-positive adolescents, this theoretical framework has been adapted for this thesis to reflect two additional clustering of factors: relationship-level and HIV-specific factors, which are key to adolescence as a developmental stage (Gevers, Jewkes, Mathews, & Flisher, 2012; Vreeman et al., 2014). The framework also takes into account interactions between these levels (macro-system).

Chapter 3 – Methodology describes the methodological approach for this thesis. It starts with a summary of the systematic review protocol. This is followed by a detailed account of the cross-sectional study methods: research setting, sampling strategy, recruitment processes, ethical considerations, data collection tools and measures, and research constraints.

Chapter 4 – Systematic Review (Paper 1) is a systematic review which synthesizes a) existing evidence on the sexual risk-taking rates, b) correlates of sexual risk-taking, and c) evidence on programmes that aim to reduce sexual risk-taking among HIV-positive adolescents and youth in sub-Saharan Africa. In light of the limited research on unprotected sex among HIV-positive adolescents in the region, the review's scope was expanded to include studies reporting on a range of sexual risk practices among HIV-positive adolescents and youth. The systematic review answers the following research questions:

1. What is the evidence base for reducing sexual risk-taking among HIV-positive adolescents and youth in sub-Saharan Africa?
    a. What is the prevalence of sexual risk-taking among HIV-positive adolescents and youth in Sub- Saharan Africa?
    b. What factors (correlates, risk factors, or predictors) are associated with sexual risk-taking among HIV-positive adolescents and youth in sub-Saharan Africa?
    c. Which interventions, aimed at reducing sexual risk-taking among HIV-positive adolescents and youth in sub-Saharan Africa, have been tested, and how effective were they?

Thirty-five studies (43 published and unpublished reports) were included in the systematic review. Thirty-one of these reported on cross-sectional data of prevalence rates and correlates of sexual-risk taking. Four reported results of intervention studies aimed at reducing single or composite sexual risk-taking behaviours among HIV-positive adolescents and youth in sub-Saharan Africa. Results showed wide variation in rates of sexual risk-taking among HIV-positive adolescents and youth. Hypothesised correlates reported by sixteen

studies included factors at the individual, relationship, family, and structural levels, with a group of HIV-specific factors cutting across these levels. Multivariate analyses findings were inconsistent for most potential predictors. Three of the four interventions found significant effects in reducing sexual risk-taking among HIV-positive adolescents and youth. These findings are discussed in more detail in Chapter 4.

Chapter 5 – Is knowledge power? (Paper 2) investigates the role of HIV-status disclosure on adolescent sexual risk-taking in South Africa. The paper uses multivariate regression analyses, controlling for potential confounders, to answer the following research questions:

2. How is knowledge and disclosure of HIV-status associated with protective sexual practices among adolescents in South Africa?
    a. Is knowledge of one's own HIV-positive status associated with protective sexual practices among adolescents in South Africa?
    b. Is disclosure of adolescent HIV-positive status to a sexual partner associated with protective sexual practices among adolescents in South Africa?
    c. Is knowledge of a sexual partner's HIV-status associated with protective sexual practices among adolescents in South Africa?
    d. Does gender moderate the relationship between different types of HIV-status disclosure and protective sexual practices?

The analyses test whether (1) knowledge of own HIV-positive status, (2) disclosure of HIV-positive status to partners, and (3) knowledge of partner HIV-status are associated with protective sexual practices. They also test whether gender moderates these associations and how they differ for adolescent girls and boys. The analyses use a sample of n=1,527 South African adolescents; they compare those who are HIV-positive status-aware (n=794) to the rest of the sample (HIV-positive status unaware and community controls status unaware, n=733). Results show that knowing one's own HIV-positive status is significantly associated with increased protective sexual practices, while knowing one's partner's HIV-

status is associated with reduced protective sexual practices. Disclosing one's HIV-status to a partner is not significantly associated with protective sexual practices. These results are presented and discussed in more detail in Chapter 5.

Chapter 6 – Does social protection reduce unprotected sex? (Paper 3) documents associations between sexual practices and social protection provisions (cash/in-kind and care) among HIV-positive adolescents (n=1,060). In its expanded definition used in this thesis, social protection provisions include factors from several levels of the socio-ecological model of adolescent sexual risk-taking. Social protection has gained significant traction recently as a potential set of measures to reduce HIV-related risk-taking in the general adolescent population. However, little is known about the role of social protection in reducing sexual risk-taking in HIV-positive adolescents. The analyses in this paper seek to answer the following key questions:

3. What are the associations between unprotected sex and social protection provisions in the home, school, and clinic, for HIV-positive adolescents (n=1,060)?

   a. Which social protection provisions, accessed by HIV-positive adolescents, are associated with lower rates of unprotected sex?
   b. Does gender moderate the effect of social protection on unprotected sex among HIV-positive adolescents?
   c. Are there cumulative effects (multiplicative or additive) of combinations of social protection provisions associated with unprotected sex among HIV-positive adolescents in South Africa?

Potential social protection provisions tested include nine 'cash/cash-in-kind' and 'care' provisions: social cash transfers, past-week food security, free school access (no fees and school materials), school feeding, and clothing, and psychosocial 'care' provisions: positive parenting, strong parental supervision, support groups, and adolescent-sensitive care at clinics (respectful treatment by sexual health service providers). Multivariate regression analyses investigates which social protection provisions were associated with reduced

unprotected sex. Next, analyses tests whether gender moderated the effect of social protection on unprotected sex. It then investigates whether there are interactive/ additive effects of receiving multiple social protection provisions using logistic regressions and marginal effects models. Results showed that three social protection provisions are associated with reduced unprotected sex: good parental supervision, access to school, and adolescent-sensitive clinic care. The effect of adolescent-sensitive clinic care is moderated by gender: adolescent girls who received adolescent-sensitive clinic care reported greater reductions in unprotected sex. Combinations of the three provisions have additive effects on reducing the probability of reporting unprotected sex in the full sample and for adolescent girls. These results are detailed in Chapter 6.

Finally, **Chapter 7 – Discussion** summarises the key findings from each paper, pulls together common themes, and highlights key policy and programmatic messages from this thesis. It explains the overall limitations and strengths of the study. The chapter concludes by discussing implications for programming and policy, as well as areas of future research to improve the sexual health of HIV-positive adolescents in sub-Saharan Africa.

A full list of appendices follows the discussion chapter, including the full study protocol, ethics approvals, the systematic review protocol, and quantitative data collection tools.

2. BACKGROUND AND THEORETICAL FRAMEWORK

2.1. HIV-POSITIVE ADOLESCENTS: GLOBAL POPULATION AND LOCAL IMPACT IN SUB-SAHARAN AFRICA

Approximately 2.1 million 10-19 year old adolescents live with HIV globally. Nearly 80% of these adolescents, an estimated 1.7 million, is estimated to live in sub-Saharan Africa (Idele et al., 2014; Kassede, 2015). South Africa is home to the largest HIV-positive adolescent population, with nearly 300,000 HIV-positive adolescents (Kassede, 2015). Though they represent only a small proportion of HIV-positive people in South Africa, the number of HIV-positive adolescents in South Africa is growing. This is due to the simultaneous effect of two trends. First, vertically-infected children are surviving through adolescence due to improved access to ARVs (Patel et al., 2008; Rehle et al., 2010). Among these children, a sub-group of 'slow progressors'[2] are surviving to adolescence even without access to ARVs: a recent study in Southern Africa estimates that 36% of vertically-infected children have a median survival of 16.0 years (Ferrand et al., 2009). Second, high rates of new infections after birth persist among youth, primarily due to heterosexual transmission (UNAIDS & AU, 2015).

The first trend resulting in more HIV-positive adolescents is the significant number of mother-to-child infections in 1994-2000 in South Africa. Significant gains have been made in reducing mother-to-child transmission in South Africa in the last 8 years. However, the vertically-infected adolescents living with HIV are a delayed snap-shot of the high mother-to-child transmission rates when they were born, at a time when treatment for prevention of mother-to-child-transmission was not widely available in South Africa. While the number of children infected through mother-to-child transmission has tapered off due to improved prevention, the number of children who have accessed treatment and survived through adolescence has continued to increase (Nglazi et al., 2012). Unfortunately, more recent or

[2] **Slow progressors** – a sub-group of perinatally-infected HIV-positive children who have survived to adolescence without access to antiretroviral treatment (Ferrand et al., 2009).

exact data on the proportion of vertically-infected adolescents among HIV-positive adolescents in South Africa is not available.

The second trend impacting numbers of adolescents living with HIV in sub-Saharan Africa is the rate of new infections during adolescence, particularly among adolescent girls. HIV infection poses a serious risk to adolescents in the region, with 160,000 new infections among 10-19 year olds annually (UNICEF-ESARO, 2015). Three-quarters of these new infections are among adolescent girls and young women 15-24 years old (UNAIDS & AU, 2015). In South Africa, prevalence rates among 15-19 year old girls were 9 times that of HIV prevalence among their male peers (5.6% vs. 0.7%), at the time of the most recent community-based HIV prevalence study (Shisana et al., 2014). As most youth become sexually active in this age group, these prevalence rates are treated as proxies for the incidence of heterosexual transmission by the national Department of Health (Department of Health, 2012). Recent data estimates 2,000 new infections among adolescents in South Africa every week (UNAIDS & AU, 2015), though exact data on the proportion of horizontally-infected adolescents are also lacking.

Access to ART has resulted in significant reductions in AIDS-related mortality and morbidity in South Africa. A study from rural South Africa estimated that for every 10% increase in ART access, a 17% reduction in HIV prevalence was documented (WHO, UNICEF, & UNAIDS, 2013; Wouters et al., 2010). A 2008 community-based household HIV prevalence survey estimated that survival due to ARVs contributed to 0.8% and 0.2% of the prevalence among male and female 15-19 year olds living with HIV in South Africa, respectively (Shisana et al., 2009). However, AIDS-related illness is the leading cause of death amongst adolescents in sub-Saharan Africa: since 2000, the number of AIDS-related adolescent deaths in the region has tripled (WHO, 2015). Many of these deaths are due to poor ART adherence and poor engagement in care, particularly for HIV-positive young women (Adeniyi, 2016; G Fatti, Shaikh, Eley, Jackson, & Grimwood, 2014). Understanding

the sexual health of HIV-positive adolescents is key to ensuring their long-term well-being, as they enter adulthood and their reproductive years.

2.2. SEXUAL HEALTH OF HIV-POSITIVE ADOLESCENTS

A longitudinal study among vertically-infected HIV-positive adolescents conducted in the United States, suggested initial delays in puberty and sexual activity due to living with HIV (Wiener, Battles, & Wood, 2007). However, additional research shows that HIV-positive youth on antiretroviral treatment attain similar levels of sexual activity to HIV-negatives youth by late adolescence (Bakeera-Kitaka, Nabukeera-Barungi, Nöstlinger, Addy, & Colebunders, 2008; Mergui & Giami, 2011).

The onset of sexual activity and development of intimate relationships is a complex set of experiences for both HIV-positive and HIV-negative adolescents (Gevers et al., 2012; Mburu et al., 2013). However, these new experiences are particularly challenging in the context of adolescent HIV, as sociocultural norms about sexuality and parenthood combine with HIV-related disclosure and stigma. In sub-Saharan Africa, these factors are exacerbated by limited accessibility of local health services, which in turn influences sexual and reproductive decision-making, especially sexual debut, access to and use of contraception (Bakeera-Kitaka, McKellar, et al., 2008; Hodgson, Ross, Haamujompa, & Gitau-Mburu, 2012; Maccarthy, Rasanathan, Ferguson, & Gruskin, 2012).

HIV-positive adolescents face the same sexual and reproductive health risks and challenges as all adolescents, and several HIV-specific ones, such as: the need for prevention of mother-to-child transmission during pregnancy, the risk of re-infection with HIV (particularly with medication-resistant viral strains), and the risk of infecting partners (Bakeera-Kitaka, McKellar, et al., 2008; Jaspan, Li, Johnson, & Bekker, 2009). Research among adolescents living with HIV to date has mostly focused on adolescents in the United States. These studies suggest that their unique needs are affected by several factors,

including age, gender (Mergui & Giami, 2011), mode of transmission (Sharer & Fullem, 2012), access and adherence to antiretroviral treatment (Marhefka, Elkington, Dolezal, & Mellins, 2010), relationship-related factors (Dempsey, Macdonell, Naar-king, & Lau, 2012; Fernet et al., 2011; Mergui & Giami, 2011), family structure and caregiving arrangements, social support and access to health services (Sharer & Fullem, 2012). Most of the literature from sub-Saharan Africa is qualitative, providing a rich narrative of potential factors and their dynamics, but stopping short of developing a problem theory[3] about sexual risk-taking among HIV-positive adolescents in South Africa. It is important to understand current levels of sexual risk-taking and the factors associated with this risk-taking. This will allow us to effectively address the complex vulnerabilities faced by HIV-positive adolescents, and the risk of passing on the virus to sexual partners and children.

2.3. POLICY CONTEXT

This study was designed and developed in a complex policy environment. Policies and guidelines shape available interventions and programming and direct their delivery through the healthcare, education, or social support infrastructures. Policy and programmatic interest in the sexual health of HIV-positive adolescents has grown during the course of this research. Initial dissemination and policy implications are discussed in the final chapter of this thesis in more detail (Chapter 7). This section summarises the key policies and guidelines which shaped the study.

HIV-positive adolescents are an important policy concern in South Africa and the sub-Saharan African region, but often fall into the gap between primary HIV-prevention policies and general health policies, which rarely acknowledge their unique needs and risk profile. National South African adolescent and youth health policies preceding this study

[3] In intervention research, problem theory is the body of evidence detailing risk and protective factors for the outcome of interest, identifies malleable factors which interventions can address and informs the program theory/ theory of change by hypothesising mediating pathways (Fraser at al 2009).

focused on the general adolescent population and on reducing HIV incidence among uninfected adolescents (Delany-Moretlwe et al., 2015). However, as numbers of HIV-positive adolescents and youth increase in sub-Saharan Africa, efforts to provide guidelines and support for secondary HIV prevention are growing. There are no official policies or guidelines for the provision of sexual health services and interventions aimed at reducing sexual risk-taking among HIV-positive adolescents. However, several documents have shaped the policy environment on the sexual health of HIV-positive adolescents; namely: (1) World Health Organization (WHO) and UNAIDS strategies, (2) global sexual and reproductive health strategies, and (3) the global development targets: millennium development goals (2000-2015) and sustainable development goals (2016-2030).

In 2011-2013, WHO issued two policies related to disclosure among HIV-positive children and adolescents: one summarising the evidence and recommendations on children and adolescents learning about their own HIV-positive status (World Health Organization, 2011), and a second document including guidance on how adolescents can be supported to disclose their HIV-positive status to others (World Health Organization, 2013a). These guidelines were informed by the best evidence to date, but the quality of the evidence on both types of disclosure for children and adolescents was relatively weak, with the effect of disclosure on improved outcomes documented mainly through qualitative studies (World Health Organization, 2011). The guidelines recommended that knowing and sharing one's HIV-positive status had positive effects on health outcomes based on studies among HIV-positive adults, but called for stronger evidence on this topic among children and adolescents. In parallel with these two sets of guidelines, UNAIDS and partners developed the Fast Track agenda towards the elimination of HIV/AIDS. The 2014 Fast Track targets to HIV elimination – '90-90-90' by 2020 – recommended that 90% of all people living with HIV, particularly special populations such as adolescents, should know their HIV-status by 2020 (UNAIDS, 2014a). However, at the time that these targets were developed, the evidence on

effects of HIV-positive status disclosure on health outcomes among HIV-positive adolescents remained of low quality.

Strategies on the sexual and reproductive health rights of women and adolescents have long recognised that HIV-positive women and girls face additional barriers to attaining good reproductive health outcomes. A recent survey of women living with HIV concluded that guidelines and recommendations on sexual and reproductive health among HIV-positive adolescent girls and young women, whether vertically or horizontally-infected, is urgently needed (Salamander Trust, 2014). The recent Global Strategy for Women's, Children's and Adolescents' Health (2016-2030) recognises that to meet the complex needs of adolescents, social, behavioural, and biomedical research must be conducted to identify effective interventions (Every Woman Every Child, 2015).

At the time this thesis was being finalised, interest in potential combinations of interventions to reduce sexual risk-taking for HIV-positive adolescents was growing (UNAIDS, 2016), with a particular focus on social protection. This focus on social protection has happened due to two trends. First, a growing literature investigates the potential of social protection to promote protective behaviours and reduce risk behaviours of children and adolescents affected by HIV (Cluver, Orkin, Yakubovich, & Sherr, 2016; E. Miller & Samson, 2012; UNICEF-ESARO, 2015), including secondary prevention for HIV-positive adolescents (Toska et al., 2016).

Second, the potential of social protection has taken on a new imperative following the reduced focus on HIV in the new UN Sustainable Development Goals. While Millennium Development Goal (MDG) 6 focused specifically on HIV-related targets, HIV is only one of multiple health issues covered by Sustainable Development Goal (SDG) 3, rather than a goal in itself. As a result, many governmental and non-governmental actors in sub-Saharan Africa are working to identify interventions that can have HIV-related impact within the SDG framework (Gittings et al., 2016). One such area is SDG 1 which focuses specifically on building social protection systems that can reach large proportions of the most vulnerable by

2030. While social protection definitions vary, this study applied UNICEF's definition which conceptualises social protection as 'a set of public and private policies and programmes aimed at preventing, reducing and eliminating economic and social vulnerabilities to poverty and deprivation' (UNICEF, 2012). This study has responded to this policy environment by including research questions that can contribute to these pressing policy gaps and emerging topics.

2.4. SECONDARY 'POSITIVE' PREVENTION FOR HIV-POSITIVE ADOLESCENTS

From a public health perspective, people living with HIV represent the population where HIV prevention efforts are most likely to have greater impact on onwards HIV transmission. A change in the risk behaviour of a person with HIV has a greater impact on the transmission of HIV than the same behavioural change in a person who is not HIV-infected, particularly among high-risk populations (Kennedy, Medley, Sweat, & O'Reilly, 2010). Multiple interventions – referred to as *positive prevention* – have been proposed, developed and tested to address the risks faced and presented by HIV-positive people: becoming resistant to medication, further re-infection with HIV and STIs, and passing on the virus to sexual partners and children (Kennedy et al., 2010). These interventions include: (i) individually focused health promotion, (ii) scaling up, targeting and improving service and commodity delivery, (iii) community mobilization, and (iv) advocacy, policy change and community awareness (International HIV/AIDS Alliance, 2003). Recent trials have demonstrated that if the HIV-positive partner takes antiretroviral therapy, secondary sexual HIV transmission can be virtually eliminated (Eshleman et al., 2015).

Adolescents living with HIV are a strategic population among whom positive prevention efforts must be focused (Chen, Murphy, Naar-king, Parsons, & and the Adolescent Medicine Trials Network for HIV/AIDS Interventions, 2011). Though some

interventions have been conducted among HIV-positive adolescents in the United States, there is a dearth of research and interventions to meet the needs of HIV-positive adolescents in the developing world. A 2010 WHO review of behavioural interventions for HIV Positive Prevention in middle and lower-income countries found 19 studies, none of which focused on young people (Kennedy et al., 2010). The literature review which informed this study's design, conducted in 2012-2013, located a handful of interventions that addressed sexual practices among adolescents living with HIV, all based in the United States: (1) Adolescent Hemophilia Behavioral Intervention Evaluation Project (Butler et al., 2003), (2) Teens Linked to Care (Lee, Leibowitz, & Rotheram-Borus, 2005), (3) Healthy Choices (Chen et al., 2011), (4) +Click among vertically and horizontally-infected adolescents (Markham, Shegog, Leonard, Bui, & Paul, 2009) and (5) Adolescent Impact (Chandwani, Abramowitz, Koenig, Barnes, & D'Angelo, 2011). Some of these studies showed small effects on a series of outcomes summarised in *Table 2-1*. Only Healthy Choices resulted in increased reported condom use. It was also the only intervention that was adapted to Kenyan and Ugandan contexts as 'Brighter Future I and II' (Njika et al., 2010; Nöstlinger, Loos, et al., 2015). Although the adapted intervention has not been quantitatively evaluated, process evaluation findings indicated that the intervention was feasible and acceptable among 13-17 year old HIV-positive adolescents (Nöstlinger, Loos, et al., 2015).

A 2012 consultation on sexual and reproductive decision-making of HIV-positive adolescents concluded that further research was needed to understand their needs and to hypothesize models of sexual and reproductive decision-making among HIV-positive youth (Fair et al., 2012). In particular, it is important to understand how HIV-positive youth initiate sexual relationships and how they protect themselves and others in these relationships from the outset. In the context of multiple risk profiles, secondary HIV prevention efforts must aim to protect HIV-positive adolescents from unintended pregnancies, potential HIV re-infection, and infecting sexual partners, an extension of existing primary HIV prevention initiatives. To

develop the problem theory of sexual and reproductive practices of adolescents living with HIV in South Africa, additional research is needed. This research should start by documenting the prevalence of sexual risk-taking, followed by research on potential causal factors associated with increased sexual risk-taking.

Table 2-1. Summary of outcomes of interventions among HIV-positive adolescents outside sub-Saharan Africa

Programme	*Population*	*Sample*	*Intervention*	*Control*	*Outcome*	*Results*
Adolescent Hemophilia Behavioral Intervention Evaluation Project (Butler et al. 2003)	Adolescent and young adult males, 12-25 years old	N=104	4 sessions: 2 in a group, 2 in an individual	N/A	Consistent safer sex (consistent condom use, outercourse or abstinence)	Self-efficacy for outercourse improved. No change on other outcomes.
Teens Linked to Care (Lee, Leibowitz, Rotheram-Borus 2005)	Young people living with HIV, most of whom were male, gay or bisexual male (69%)	N=175	three modules in 36 two-hour group sessions	N/A	Health-related outcomes HIV risk outcomes: substance use, sexual risk acts	82% fewer unprotected sexual acts, 45% fewer sexual partners, and a 31% reduction in substance use
Healthy Choices (Chen et al. 2011)	HIV-positive adolescents with high-risk behaviours: HIV medication non-adherence, sexual risk behaviour and substance use	N=186	a four-session motivational enhancement intervention	N=94 randomly selected	Proximal – Motivation, Self-Efficacy and Depression	Lower depression. Higher likelihood to report condom use.
+Click (Markham et al. 2009)	Vertically- and horizontally-infected adolescents	N=32	Web-based, sexual risk reduction	None	Secondary transmission by changing behaviours	High usability rating. Short-term psychosocial outcomes indicate a significant increase in condom use self-efficacy (p=0.008).
Adolescent Impact (Chandwani et al. 2011)	HIV-infected adolescents: 94% African American or Hispanic; 53% female and 59.6% were vertically-infected	N=166	12-session behavioural intervention of individual and group components	Standard of care (n=83)	sexual behaviour and substance use	Only youth attendance published.

2.5. SEXUAL RISK-TAKING AMONG HIV-POSITIVE ADOLESCENTS

Consistent condom use is the only contraception method that confers *full protection* when used correctly, therefore rates and determinants of consistent condom use are the main focus of this thesis. At the time this study was designed, two qualitative studies among adolescents living with HIV in sub-Saharan Africa explored the types of contraception used and adolescents' preferences (Bakeera-Kitaka, Nabukeera-Barungi, et al., 2008; Wanyenze et al., 2013). These studies noted that, while adolescents do not like condoms, they were the preferred contraception in several countries. However, acceptability and actual use of condoms varied among different sub-populations of adolescents, particularly those living with HIV. At the time this study was conceptualised, only a few studies from sub-Saharan Africa had conducted quantitative analysis to explore factors which were associated with condom use among adolescents living with HIV (Beyeza-Kashesya et al., 2011; Birungi, Obare, Mugisha, Evelia, & Nyombi, 2009; Cataldo et al., 2012; Morris et al., 2012). Therefore a systematic review of the literature was necessary to locate both studies that focused on HIV-positive adolescents and studies that recruited HIV-positive adolescents as part of larger samples of adolescents and youth. This review is included in **Paper 1 – Systematic Review (Chapter 4**).

2.6. CONCEPTUAL FRAMEWORK

This study built on this candidate's MSc on Evidence Based Social Interventions, which highlighted the importance of building a problem theory for the outcome of interest: unprotected sex among HIV-positive adolescents in resource-limited settings, such as the Eastern Cape province in South Africa. Although interventions that address the sexual and reproductive health needs of HIV-positive adolescents are urgently needed (Maccarthy et al., 2012; Pretorius, Gibbs, Crankshaw, & Willan, 2015), the evidence base to guide the design of these interventions is weak (Fair et al., 2012). The UK Medical Research Council

Framework on the development and evaluation of complex social interventions recommends that the development phase of any intervention be grounded in existing literature (Craig et al., 2009). Building a solid theory of change requires a strong foundation of problem theory (Fraser, Richman, Galinsky, & Day, 2009). Strong elements of a problem theory include: prevalence rates and risk and protective factors, particularly those that can be modified through interventions. Epidemiological research is needed to establish prevalence of outcomes studied (Bowling, 2009) and to hypothesize modifiable pathways of risk and protective factors (Fraser et al., 2009). This study aims to contribute to building the problem theory for the sexual health of HIV-positive adolescents in South Africa, by providing initial evidence on sexual risk-taking among HIV-positive South African adolescents.

2.7. THEORETICAL FRAMEWORK

This section provides an overview of the theoretical framework for this study. It starts with a brief summary of the main theories applied to adolescent sexual health, noting specifically studies on adolescents living with HIV. The chapter ends with the description of the expanded theoretical model that guided this study. The adaptation process to develop this model drew from existing models for adolescent sexual health, and extended them to take into account the specific characteristics and needs of HIV-positive adolescents.

Many theoretical models have been developed and applied to understand adolescent sexual health. A 2011 Cochrane systematic review of randomised control trials (RCTs) to increase contraception use concluded that theory-based interventions were more likely to have positive effects on the treatment group compared to controls, though successful interventions may combine more than one theoretical model (Lopez, Stockton, Chen, Steiner, & Gallo, 2014). This section will review existing theories and the available empirical evidence on them. It begins with theories for general adolescent sexual health, followed by theories applied only to HIV-positive adolescents' sexual health. Three different categories of

theories are considered: 1) individual-level theories, (2) structural-level theories, and (3) integrative models.

2.7.1. Theoretical Models for General Adolescent Sexual Health

Individual-centred theoretical models: The majority of theories developed to understand and explain adolescent sexual health outcomes are cognitive-behavioural theories (Cook, 2009), including but not limited to theories such as Social Cognitive Theory (Bandura, 1991), Theory of Reasoned Action (Ajzen et al., 1980; M Fishbein, 1963) and Theory of Planned Behaviour (Ajzen, 1991). These theoretical models suggest that behaviour change occurs primarily at the individual-level, shaped by factors such as knowledge, attitudes, and beliefs. The combination of these theories has been shown to explain 20-45% of variance in predicting adolescent pregnancy in the United States (Koniak-Griffin, Lesser, Uman, & Nyamathi, 2003), though such similar evidence for adolescent sexual behaviour in sub-Saharan Africa is not available.

Individual-centred theories that have been applied to adolescent sexual health in South Africa and neighbouring countries include: the Health Belief Model (Agha, 2002; Hendriksen, Pettifor, Lee, Coates, & Rees, 2007; Meekers, 2000), Social Cognitive Theory (Bandura, 1991), the Theory of Planned Behaviour (Jemmott III et al., 2015; Mathews et al., 2009; Protogerou, Flisher, Aarø, & Mathews, 2012), and the Information-Motivation-Behavioural Model (IMB) (Fisher & Fisher, 1992). Each theory looks at a combination of behavioural, psychosocial and demographic factors as determinants of sexual behaviour, with some including inter-personal factors such as peer, family, and community influences.

The Health Belief Model is based on an individual-level cognitive approach that uses a cost-benefit perspective to understand preventive health behaviour (Agha, 2002; Meekers, 2000). It has been applied broadly to help inform social marketing interventions among adolescents in sub-Saharan Africa. A study of four such interventions in Cameroon, Botswana, Ghana,

and South Africa found improvements in perceptions and beliefs but no effect on behaviours (Agha, 2002). The Theory of Planned Behaviour (Ajzen, 1991) is an adaptation of the Theory of Reasoned Action (Ajzen et al., 1980; M Fishbein, 1963). It posits that attitudes about, subjective norms on, and perceived control over a behaviour shape an individual's actual behaviour. Social Cognitive Theory posits that information, support in social settings, self-efficacy – the belief in one's ability to change, combined with negotiation skills, shape individual-level healthy behaviours (Bandura, 1991). An intervention combining the Theory of Planned Behaviour and Social Cognitive Theory to reduce HIV/ STI risk among 9-18 year olds in the Eastern Cape, South Africa found reductions in unprotected vaginal sex, but not in measures of condom use (Jemmott III et al., 2015). The Information-Motivation-Behavioural model suggests that an actual practice, i.e. condom use during sex, depends on a combination of information on the risks and prevention needs, individual motivation to prevent poor outcomes, and actual prevention skills (i.e. putting on a condom accurately (Fisher & Fisher, 1992; Kalichman et al., 2002). The model predicts that information and knowledge affect prevention skills/ behaviours which in turn result in the desired practice. The model has been applied to adolescent health: ART adherence among HIV-positive adolescents in Thailand (Rongkavilit et al., 2010) and adolescent substance users in the United States (Kalichman et al., 2002).

Structural level theories: Though some studies and interventions on adolescent sexual health recognise the complex nature of adolescent risk pathways, most address adolescent sexual practices primarily through individually-centred models. Yet qualitative research on gender norms, and the cultural practices of adolescent sex and teen parenthood, has highlighted the complex influence of structural level factors on individual behaviours (Morrell, 2003; Preston-Whyte, 1994; Varga, 2003). Additional research among South African adolescents suggests that structural level factors also affect access to sexual and reproductive health services (Wood & Jewkes, 2006).

Structural-level theoretical models, such as the Life History Theory and feminist/ 'revisionist'/ gender studies approaches, can enrich the above individual-based and inter-personal-focused behavioural theories. The Life History Theory takes a complex biosocial approach that combines biological influences and the social setting of the individual as co-determinants of reproductive behaviour (Lancaster & Hamburg, 1986). Specifically applied to adolescent sexual health, Life History Theory purports that – controlling for all other factors – individuals experiencing food insecurity, violence, low expected life expectancy, or living in other unstable environments, will exhibit higher rates of sexual activity and reproduction (Figueredo et al., 2006; Hubbeling, 2011). Based on this theory, structural level factors would strongly predict risk-taking, overcoming individual-level factors.

A linked approach is the 'revisionist' feminist perspective, which argues that adolescent sexual health, and outcomes such as pregnancy, must be understood in the context of racism, social discrimination, sexism, extremely compromised health and reduced life expectancy of girls in the developing world (Amaro & Raj, 2000; Macleod, 2002; Tolman, Striepe, & Harmon, 2003). The social structural theory of gender contends that individuals do not have total control on their behaviour (Wingood & Diclemente, 2000), while Tolman's model of adolescent sexual health purports that gender must be seen as a social and political institution variable, rather than an individual-level one (Tolman et al., 2003).

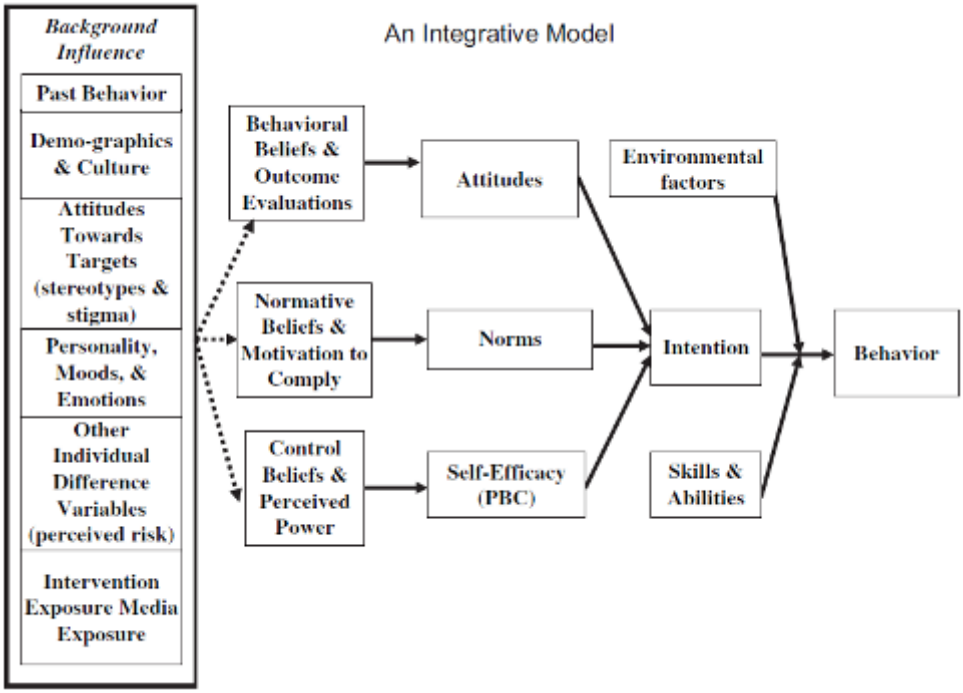
These two theories provide substantial guidance on the conceptual framework and factors that must be considered, but their developers have not necessarily provided guidance on the type of analysis that would be required to provide empirical evidence on their validity. As such they were better positioned to inform this study's conceptualisation, rather than propose modifiable pathways for intervention design.

Integrated theoretical models: Two theoretical models that take into account individual, inter-personal (peer, family and community interactions) and structural level factors have been applied to adolescent sexual health in sub-Saharan Africa: the Integrative Behavioural

Model (*Figure 2-1*) (Martin Fishbein & Cappella, 2006) and Bronfenbrenner's ecological model of human development (Bronfenbrenner, 1979).

The integrative model combines intentions with behavioural beliefs, norms, and agency (Martin Fishbein & Cappella, 2006). The integrative model is more comprehensive than others and enables researchers to hypothesize multiple potential pathways for empirical testing. However, one of its short-comings with regards to this study is its focus on the individual-level measures: environmental factors are a category but no suggested typology or interaction with other types of factors is proposed. Nonetheless, the model provides useful guidance on the types of individual-level variables that a study must measure and has informed the selection of data collection tools presented in the methodology chapter.

Figure 2-1. An integrative model developed by Fishbein and Cappella (2006)



Bronfenbrenner's ecological model of human development (1979), on the other hand, conceptualises determinants of human development in four levels:

- Micro-system, composed of factors interacting at the individual and family level.

- Meso-system, consisting of factors at the community-level, which might not have direct interactions at the family level.
- Exo-system, which interacts with the family or community, without directly affecting the individual, for example legal, socio-political, economic and structural elements.
- Macro-system that encompasses interactions of the micro-, meso- and exo-system, as well as cultural norms and values.

The model conceptualised by Bronfenbrenner has been applied to many aspects of development psychology and sexual health, including adolescent sexual health. An analytical model derived from Bronfenbrenner's theory explained a large proportion of the variance (32%) in adolescent pregnancy in South Africa, in previous analyses conducted as part of this candidate's masters thesis (Toska, 2012). An ecological model to understand adolescent sexual behaviour is highly relevant, given the importance of adolescence as a key transition period in human development (Fayola, 2004; Jacqueline Hoare, 2016). This is the period during which fundamental behavioural patterns take shape, including risk-taking and resilience-building. Moreover, in the context of the South African communities studied, where adolescents and young people are exposed to multiple and complex vulnerabilities, the resulting adolescent sexual risk-taking may be best explained through interacting factors at individual, family and community level. Bronfenbrenner's socio-ecological model – although not originally designed to explain sexual risk-taking – is a relevant theoretical framework to understand complex multi-level risk and resilience factors, and their interactions.

2.7.2. Theoretical Models of the Sexual Health of HIV-positive Adolescents

Individual-centred theories: Several studies have applied individual-centred theories among HIV-positive adolescents outside sub-Saharan Africa. One of the most cited studies among HIV-positive adolescents in the United States (n=104) showed that neither of the two individual-centred theories that guided the intervention (Transtheoretical Model

(Prochaska & DiClemente, 1984) nor Theory of Reasoned Action) explained the observed intervention effects (Butler et al., 2003). The Transtheoretical Model proposes that behavioural change is marked by a progression through five incremental stages of change: pre-contemplation, contemplation, preparation, action, and maintenance (Prochaska & DiClemente, 1984). Theory of Reasoned Action is very closely related to the Theory of Planned Behaviour, explained in the previous section. It posits that an individual's decision to engage in a behaviour is based on the expected outcomes of that behaviour (Ajzen et al., 1980; Gillmore et al., 2002). A second study among Thai youth living with HIV (n=71) also tested the power of the Transtheoretical Model in predicting unprotected sexual acts, concluding that the model fit was excellent, X2(1.663)/df(4)=0.416, p=0.797, RMSEA=0.058, CFI=0.992 (Naar-king et al., 2008). Third, one of the largest studies among HIV-positive adolescents in the United States (n=336) applied a combination of theories to predict prevalence of sexual behaviours: Bronfenbrenner's conceptualisation of peer norms, Theory of Planned Behaviour, and the Health Belief Model (Bauermeister, Elkington, Brackis-Cott, Dolezal, & Mellins, 2009). Three published studies of HIV-positive adolescent sexual health in sub-Saharan Africa were guided by an individual-based theory: (1) a qualitative study in Uganda applied the Information-Motivation-Behavioural Skills Model to HIV-positive adolescents in sub-Saharan Africa is a qualitative study among 13-17 year olds living with HIV in Uganda (Bakeera-Kitaka, Nabukeera-Barungi, et al., 2008), (2) a pilot intervention study among adolescents living with HIV in South Africa used a revised version of the Social Action Theory (Bhana et al., 2013; Mellins et al., 2012), and (3) *Hlanangani!*, an intervention for youth in South Africa, used Bandura's Social Cognitive Theory of self-efficacy (Snyder et al., 2014). Social Action Theory emphasizes the context in which the self-regulation of health behaviours occur, including the role of family, society, and environmental factors (Ewart, 1991).

No known studies have applied **structural-level theories** to the sexual health of HIV-positive adolescents.

Integrated behaviour models: A study from the United States assessed the validity of the integrated model to predict sexual health status among 20 HIV-positive girls who knew their HIV-status (Marhefka et al., 2011). The study found that the model was more complex among HIV-positive adolescent girls than among HIV-negative ones and it recommended the extension of the model to the dyadic model which included partners, as was done for HIV risk among n=75 couples in another US-based study (Harman & Amico, 2009).

Another qualitative study of HIV-positive adolescent needs in Zambia applied a socio-ecological approach to identifying determinants of adolescent well-being (Hodgson et al., 2012; Mburu, Ram, et al., 2014). It concluded that potential factors associated with good health outcomes among HIV-positive adolescents span the social ecology of their context, including individual, family/ community, and structural-levels.

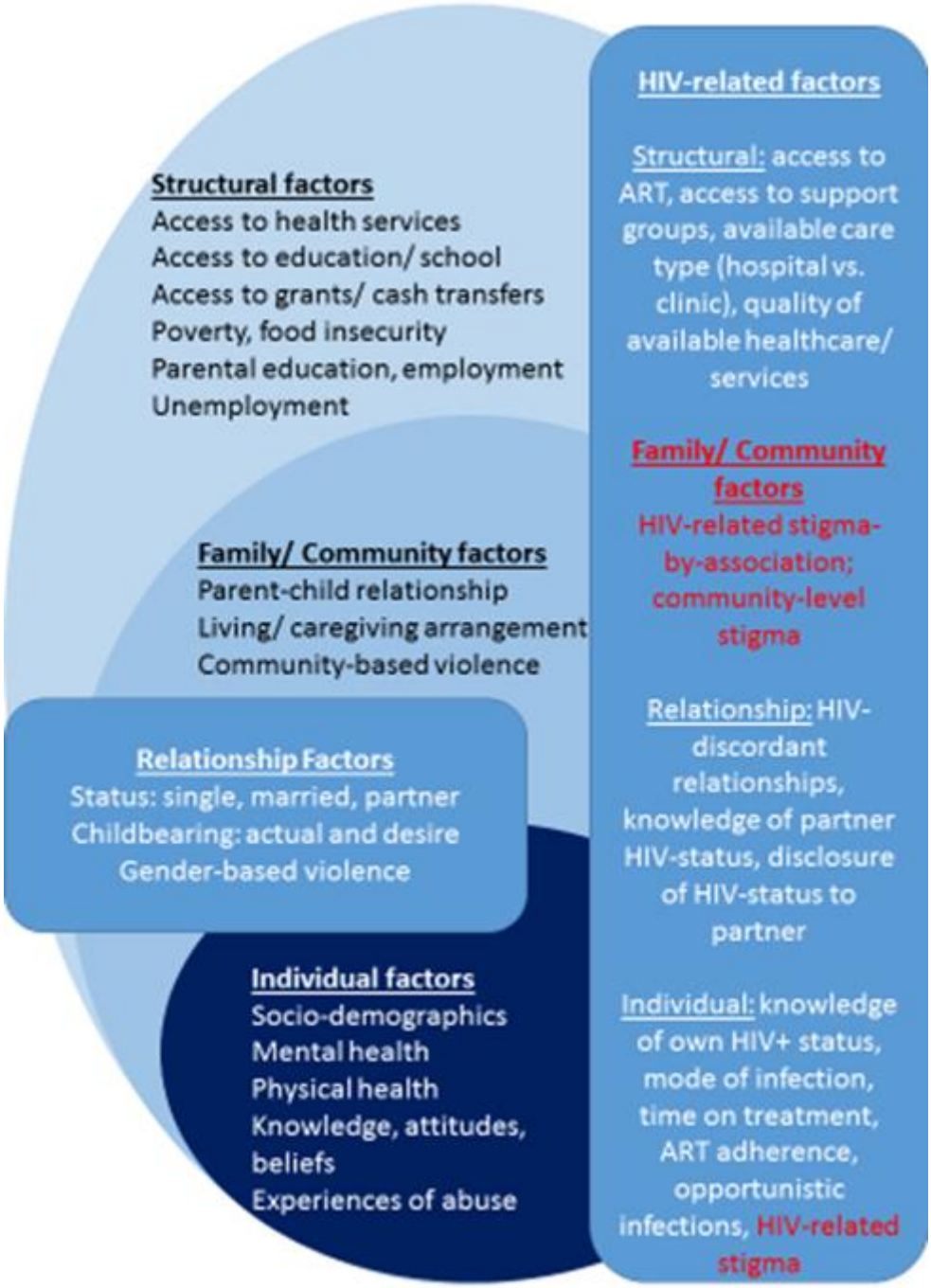
2.7.3. Proposed Model for the Sexual Practices of HIV-positive Adolescents

This study's theoretical framework adapts the socio-ecological model of human development to the sexual practices of HIV-positive adolescents, taking into account the unique needs of HIV-positive adolescents as contextualised by the different theories outlined in the previous sections. Recently, scholars have called for a greater focus on understanding resilience as well as risk patterns that predict an outcome (Skovdal & Daniel, 2012). In the context of South Africa, given cultural and gender norms on sexual and reproductive health that have a strong relational/ community focus, models that give greater weight to relationship-level, community-level, and structural-level factors may be essential.

Taking this into account, this thesis proposes a multi-level theoretical framework guided by Bronfenbrenner's work and the socio-ecological approach to health promotion (Stokols, 1996), including two sets of additional factors: HIV-specific factors and relationship-specific factors. Factors specific to HIV-positive adolescents include (for example):

knowledge of own HIV-positive status, mode of infection, and time on ART treatment. Relationship factors include knowledge of a partner's HIV-status, disclosing to partners, and relationship dynamics. HIV-specific factors were added to take into account the unique set of vulnerabilities of HIV-positive adolescents and youth, such as knowledge of their HIV-status, disclosing it to others, and access to HIV-specific services. Relationship-specific factors were added to take into account the potential factors that shape condom use and unprotected sex among HIV-positive adolescents. Based on the growing empirical evidence on the role of social protection – access to material (cash) and support (care) provisions – the hypothesised model includes multiple family, community and structural-level factors that may be associated with sexual risk-taking. These include family-level factors such as parenting styles and experiences, home-based visits, community-level factors such as engagement in sports, arts, and structural-level factors such as food security, access to education, and healthcare services. A final theoretical model that guided the design of this study's data collection tools and analyses is presented in *Figure 2-2*.

Figure 2-2. Theoretical model for sexual risk-taking among HIV-positive adolescents



2.8. IMPLICATIONS FOR THIS STUDY

The background literature, policy context and theoretical framework summarised in this chapter have multiple implications for this study. First, a better understanding of the existing research on potential predictors of sexual risk-taking among HIV-positive adolescents is

needed. Second, as studies among HIV-positive adolescents in the United States and Canada suggest, HIV-status disclosure may be a key factor shaping their sexual practices (Fernet et al., 2011; Marhefka et al., 2011). In light of existing guidelines to encourage HIV-positive adolescents and youth to learn about their status, additional research on this topic is needed. It is crucial to understand how learning and sharing one's HIV-positive status affects sexual risk-taking among HIV-positive adolescents in sub-Saharan Africa. Third, because of the complex needs of HIV-positive adolescents, interventions should consider components that support reduced sexual risk-taking and reach adolescents in multiple settings: in the home, school, community, and clinics. Identifying which factors support safe sexual practices in these different settings where HIV-positive adolescents live, spend their leisure time, and learn, is an important prequel to evidence-based intervention development. Fourth, gender-focused theories presented in the preceding sections suggest that pathways through which different factors interact result in different sexual health outcomes for boys and girls. This thesis tested these theories by conducting moderator (or sub-group) analysis by gender when possible and justifiable. Last, exposure to complex and multiple adversities may be shaped by multiple risk and protective factors, which interact with each other. Recent conceptualisations of adolescent risk-taking and resilience acknowledge that vulnerable adolescents, who are exposed to multiple adverse outcomes, may need access to combinations of interventions for maximum positive impact on health outcomes (Lucie D Cluver, Orkin, Yakubovich, & Sherr, 2016a). Analyses which takes these potential cumulative effects into account was conducted using a marginal effects model when appropriate.

2.9. RESEARCH AIMS AND RESEARCH QUESTIONS

This thesis aims to contribute to the nascent evidence base on the sexual practices of HIV-positive adolescents in South Africa. It seeks to identify a set of potentially modifiable factors that are associated with unprotected sex and other HIV risk behaviours in this highly vulnerable population, and determine whether these factors vary for adolescent girls and boys. Specifically, it aims to address the following research questions:

1. **Paper 1 – Systematic review:** What is the evidence base for reducing sexual risk-taking among HIV-positive adolescents and youth in sub-Saharan Africa?
    a. What is the prevalence of sexual risk-taking among HIV-positive adolescents and youth in Sub- Saharan Africa?
    b. What factors (correlates, risk factors, or predictors) are associated with sexual risk-taking among HIV-positive adolescents and youth in sub-Saharan Africa?
    c. Which interventions, aimed at reducing sexual risk-taking among HIV-positive adolescents and youth in sub-Saharan Africa, have been tested, and how effective were they?
2. **Paper 2 – Quantitative analyses (n=1,527):** How is knowledge and disclosure of HIV-status associated with protective sexual practices among adolescents in South Africa?
    a. Is knowledge of one's own HIV-positive status associated with protective sexual practices among adolescents in South Africa?
    b. Is disclosure of adolescent HIV-positive status to a sexual partner associated with protective sexual practices among adolescents in South Africa?
    c. Is knowledge of a sexual partner's HIV-status associated with protective sexual practices among adolescents in South Africa?
    d. Does gender moderate the relationship between different types of HIV-status disclosure and protective sexual practices?

3. **Paper 3 – Quantitative analyses (n=1,060):** What are the associations between unprotected sex and social protection provisions in the home, school, and clinic, for HIV-positive adolescents (n=1,060)?

    a. Which social protection provisions, accessed by HIV-positive adolescents, are associated with lower rates of unprotected sex?
    b. Does gender moderate the effect of social protection on unprotected sex among HIV-positive adolescents?
    c. Are there cumulative effects (multiplicative or additive) of combinations of social protection provisions associated with unprotected sex among HIV-positive adolescents in South Africa?

The papers follow a format appropriate for submission to peer-reviewed journals. One paper has already been accepted for publication (Paper 3 in AIDS and Behavior), and two are in preparation for submission at BMC Health (Paper 2) and PLoS ONE (Paper 1). Each paper starts with a title page and abstract, followed by an introduction, methods, results and a discussion section. References are presented at the end of each paper and formatted to meet the requirements of the University of Oxford, rather than journal-specific requirements. Tables and figures are embedded in the text where possible for ease of access.

3. METHODOLOGY

3.1. INTRODUCTION

This chapter starts by summarising the systematic review methodology, then details the methodology for the cross-sectional study, including: research setting, sampling strategy, data collection and analysis – with special attention to ethical considerations, and quantitative measures.

3.2. SYSTEMATIC REVIEW METHODS (PAPER 1)

The protocol detailing the methodology for the systematic review (Prospero database registration: CRD42015025871) is included in Appendix 8. The systematic review methodology followed the Cochrane Collaboration Handbook guidelines (Green et al., 2011), and complied with the Preferred Reported Items for Systematic Reviews and Meta-Analyses (PRISMA) checklist (Moher, Liberati, Tetzlaff, & Altman, 2009). Peer-reviewed articles, unpublished reports, and other grey literature were included, if they met the eligibility criteria. The scope of the review is included in *Table 3-1*.

Table 3-1. Scope of review

Population	Adolescents and Youth living with HIV Age range: 10-24 years old
Outcome	Individual risk behaviours: early sexual debut, inconsistent condom use, having an older partner, transactional sex, having multiple sexual partners, sex drunk or on drugs, sexually transmitted infections, and unintended adolescent pregnancies. OR Composite risk behaviours consisting of any of the above behaviours combined.
Geographic location	Sub-Saharan Africa
Study Design	Randomised controlled trials (individual or cluster), Quasi-experimental studies including quasi-randomized trials, controlled before-after studies, pre- and post-test studies, longitudinal cohort studies, cross-sectional studies

Findings from the systematic review resulted in a hypothesised model of potential risk and protective factors for sexual risk-taking among HIV-positive adolescents and

youth. Although the review was only formalised in 2015, the candidate conducted a preliminary version in 2013, submitted as part of her transfer of status application (October 2013), which informed the study design. Building on this review, a cross-sectional study on the prevalence and key factors associated with unprotected sex among HIV-positive adolescents in South Africa was designed and conducted.

3.3. STUDY METHODOLOGY (PAPERS 2 AND 3)

The remainder of this chapter reviews the methodology of the cross-sectional study on which the two papers (*Disclosure* in Chapter 5 and *Social Protection* in Chapter 6) were based.

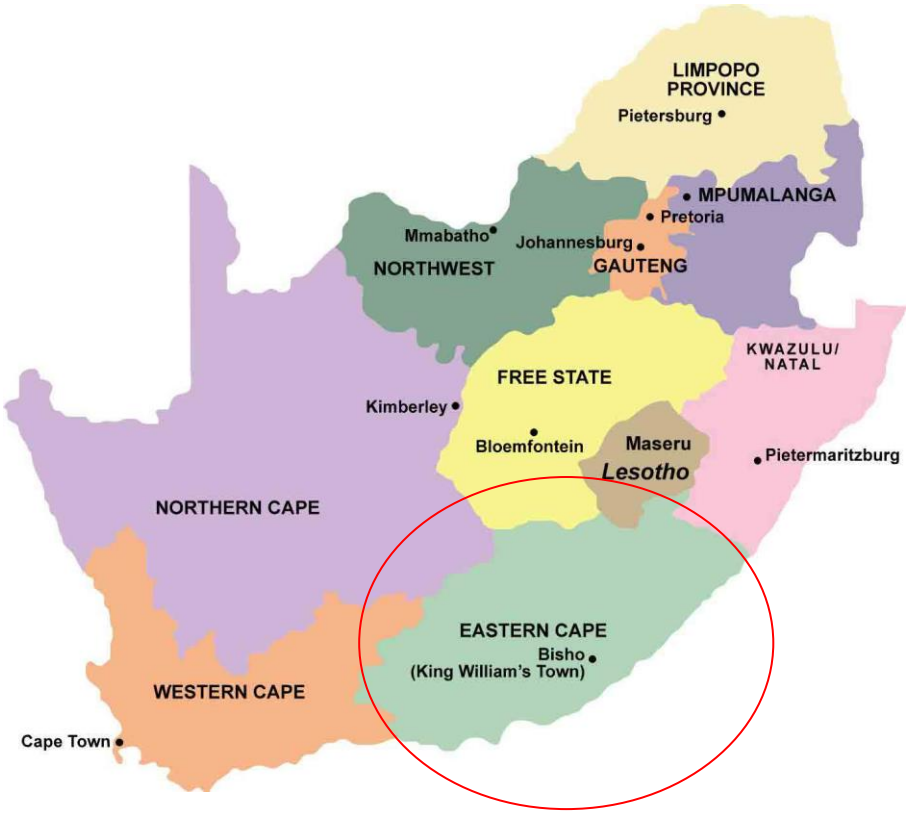
3.3.1. Research Setting

This cross-sectional study was conducted in urban, peri-urban, and rural locations of the Buffalo City Municipality Health District in the Eastern Cape province (Figure 3-1 and Figure 3-2). The Eastern Cape is South Africa's third most populous province: it is home to 6,562,053 people or 12.7% of the total population (SSA, 2012). It, however, is also one of the least-resourced of South Africa's nine provinces, ranking last in many key indicators on access to basic amenities such as water (Statistics South Africa (SSA), 2011). According to the most recent South African Antenatal Sentinel HIV & Syphilis Prevalence Survey conducted in 2012, HIV prevalence among women attending public antenatal services in the Eastern Cape province was 29.1% (95%CI 27.3-30.9) (South African National Department of Health, 2013). Buffalo City Municipality, where the study area is located, has the province's highest antenatal attendance HIV prevalence at 33.4%, which is also higher than the estimated national prevalence of 29.5% (South African National Department of Health, 2013). The municipality is home to 801,238 people, 70% of whom live in urban communities (ECDOH, 2013), which include townships and informal

settlements.[4] The study area included two cities where the research teams were based: East London and King Williams Town.

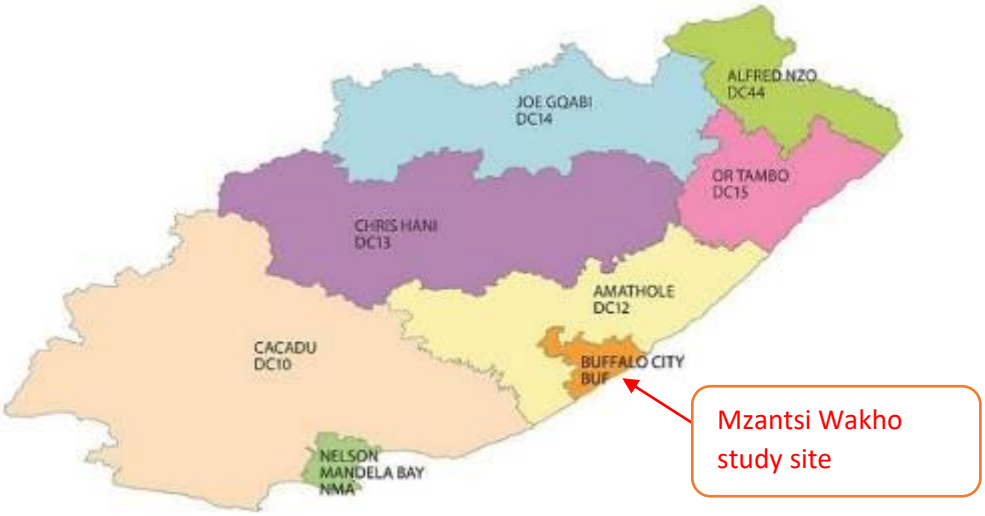
Over the last few years, the proportion of HIV-positive ART-eligible patients who access treatment has increased significantly: the 2012/2013 Provincial Department Annual Report of the Eastern Cape indicated that 237,830 HIV-positive patients could access treatment, and, in 2013, 709 of 748 clinics were providing antiretroviral treatment (ECDOH, 2013). Two-hundred and eighteen of these ART-providing facilities are in the Amathole district, in which the Buffalo City Municipality is located (DHIS data, obtained through personal communication).

Figure 3-1. Map of South African provinces



[4] Townships are unique to South Africa. They were living areas created during the Apartheid regime as spaces reserved for non-White people (Blacks, Coloured, and Indian). Usually built at the periphery of towns and cities, townships are under-developed peri-urban areas that can include formal housing or informal settlements.

Figure 3-2. Map of Buffalo City Municipality, Eastern Cape province, South Africa



Source: South Africa Yearbook 2011/12, published by the Government Communication and Information System; http://www.ecdc.co.za

Under the current healthcare system, paediatric patients from birth until 15 years old are recorded in one of three age groups: birth-1 year, 1-5 years and 6-15 years old.[5] Numbers of adolescents in each clinic are not yet reported in official statistics or in the National Paediatric and Adolescent Working Group's clinic register, which records those under 15 years. Specific data for adolescents 10-19 years old, is not available. In 2012, a national-level register of HIV-positive patients on ART – called Tier.Net - started with support from the Clinton Health Access Initiative and other donors. However, the roll-out process has experienced some delays in the Eastern Cape due to low levels of reporting from clinics with severe infrastructural challenges. Many clinics do not have working computerized systems of clinic registers, due to theft of computers, unrepaired breakages and low reliability of electricity supplies in rural clinic settings, and lack of clinic staff time and training (Eastern Cape Department of Health, 2011).

[5] Based on discussions at the quarterly meeting of the National Technical Working Group in Pretoria on March 14, 2013 attended by this candidate on behalf of the research team.

3.3.2. Sampling Frame

The study's sampling frame included all ART-eligible HIV-positive adolescents, aged 10-19 years in Buffalo City Municipality,[6] Eastern Cape province, South Africa. This sampling frame was chosen for several reasons. First, as discussed in this thesis' background section (Chapter 2), *positive prevention*[7] is likely to have greater impact and effectiveness, when focused on HIV-positive adolescents who have engaged with health services either by testing HIV-positive or starting antiretroviral treatment (Kennedy et al., 2010). Second, with increased access to antiretroviral treatment, a greater number of HIV-positive children and adolescents are surviving into youth and adulthood (Ferrand et al., 2009; Shisana et al., 2014). Adolescence is a time of immense biological, hormonal and cognitive change. HIV-positive adolescents must navigate these changes while facing additional challenges such as low adherence rates and greater vulnerability to HIV-related morbidity and mortality (WHO, 2015). It is imperative to understand the unique needs of HIV-positive adolescents who are eligible for ART, so that we can develop programmes or adapt existing services to best support them to grow into healthy adults. Sampling ART-eligible adolescents enabled this study to assess how global and national strategies (see Policy Context in Chapter 2) are associated with sexual health and well-being when rolled out in South Africa.

HIV-positive adolescents who are not eligible for antiretroviral treatment are an important sub-group that was not included in this study for methodological, ethical, and practical reasons. These adolescents are virtually all horizontally-infected through heterosexual transmission. Only a quarter of them are likely to know their status (Idele et al., 2014; Shisana et al., 2014), which means that only a

[6] The administrative unit is the Buffalo City Municipality, however the Eastern Cape Provincial Department of Health categorises the same geographical area as the Buffalo City Health Sub-District. These terms are used inter-changeably in this thesis.

[7] Efforts to prevent the secondary infection and re-infection of HIV-positive people.

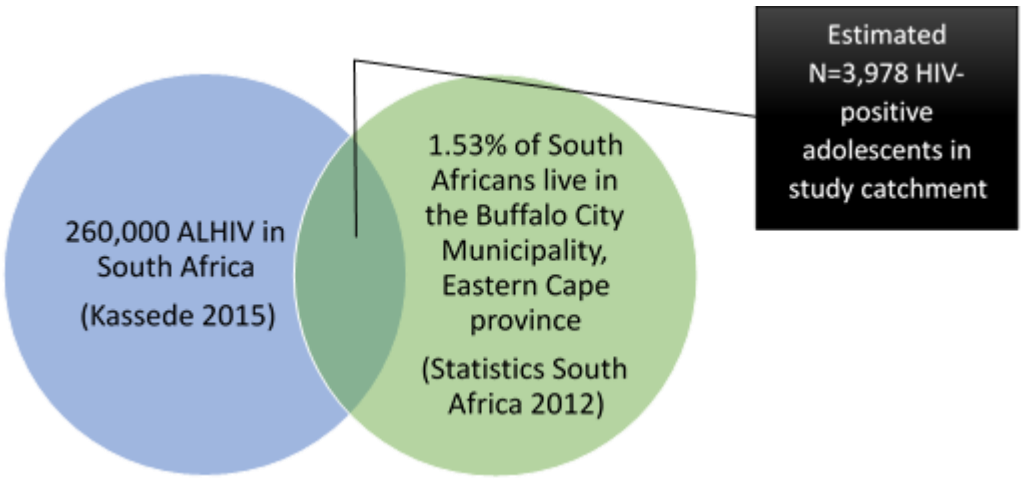
community-based survey with HIV-testing could include those who are HIV positive, but do not know their status. Based on estimated HIV prevalence rates of 13.3% among 10-19 year olds in South Africa (South African National Department of Health, 2013), a community-based surveillance survey would have to interview nearly eight times the desired sample of HIV-positive adolescents, which was not possible or practical given this study's budget and timeline. If the study had included only HIV-positive adolescents who had tested HIV-positive at clinics but were ART-ineligible, the resulting sample would have been biased towards those most likely to test for HIV.

Furthermore, among adolescents who have tested for HIV, most are unlikely to return for their test results and more likely to give false names, addresses and contact details (Shisana et al., 2014). They are also less likely to have accepted their HIV-positive status, and thus are more likely to act similarly to HIV-negative or HIV-status-unknown adolescents in the general population. Therefore, the study's sampling frame is ART-eligible HIV-positive adolescents (10-19 years old), because they are the adolescents most likely to experience and choose sexual behaviours that are unique to their HIV-status.

Sampling frame size estimates: Unfortunately, there is no data on the exact number of HIV-positive ART-eligible adolescents in South Africa. New ART treatment guidelines were issued by the South African government in April 2013, but the degree and timing of their implementation varied by province and district. Since data on the size and characteristics of the study's population and sampling frame were not available, the study design was based on estimates obtained through a literature review and consultations with experts. This candidate calculated the population size of HIV-positive adolescents in the Eastern Cape using the national estimated number

of adolescents living with HIV in South Africa in 2014 (n=260,000) (Kassede, 2015) and the proportion of population living in Buffalo City Municipality based on most recent census (1.53%). As illustrated in *Figure 3-3*, nearly 4,000 HIV-positive adolescents are estimated to live in the study area, though not all of them are ART-eligible.

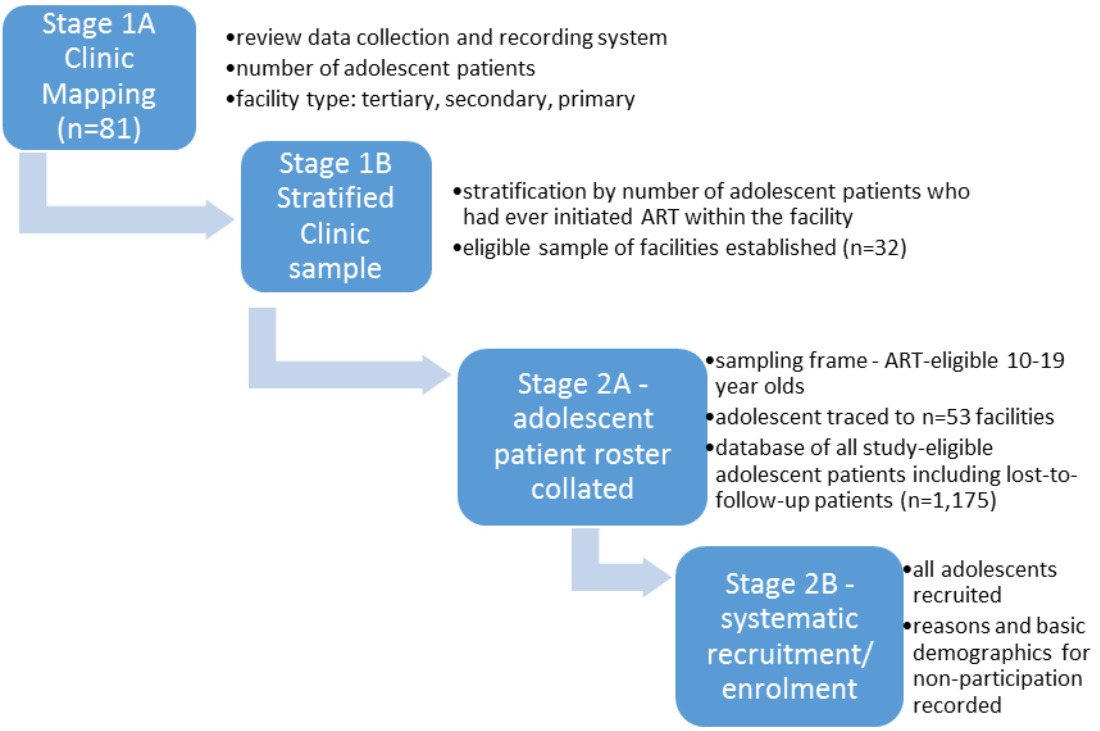
Figure 3-3. Estimating total population in the study's sampling frame



3.3.3. Sampling Strategy

Stratified randomised sampling was used to ensure that the sample recruited was as representative of ART-eligible HIV-positive adolescents living in the Eastern Cape as possible. This sampling strategy is applicable to public health research aiming to determine prevalence and determinants of specific outcomes (Bowling, 2009). The sampling strategy consisted of two stages: 1a) Mapping of health facilities using the Department of Health register to identify eligible facilities; 1b) Stratified Health Facilities Sampling; 2a) Roster of eligible adolescent participants developed based on participating sites; and 2b) Community tracing of all ART-eligible adolescents on health facilities' registers including adolescents on treatment and in care, and adolescents who had defaulted or been lost to follow-up (*Figure 3-4*).

Figure 3-4. Sampling strategy for HIV-positive sample



3.3.4. Sample Size Calculations

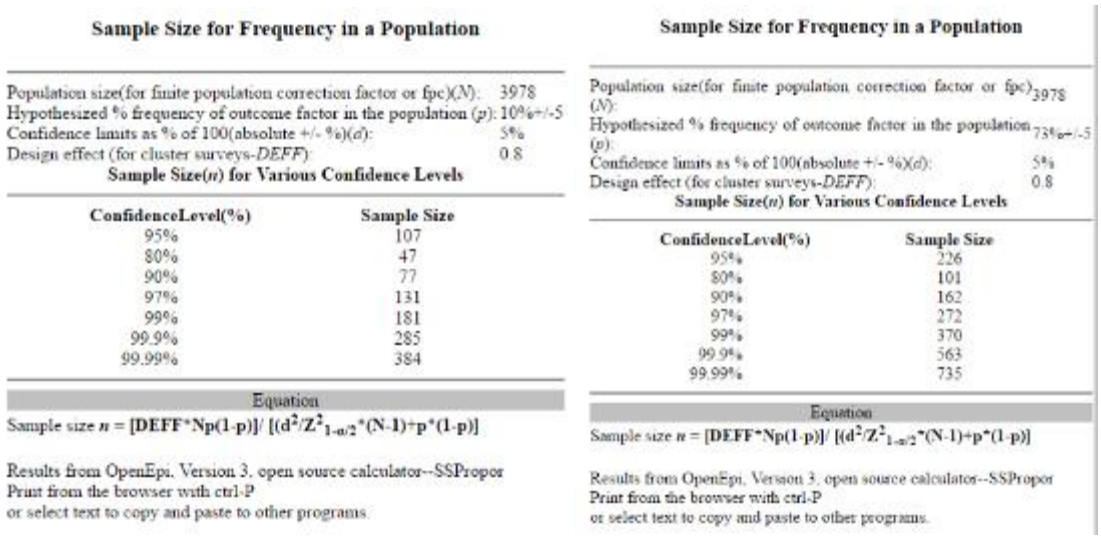
The sample size for the study was calculated using an open-source online tool – www.OpenEpi.com – which computes sample size for a cross-sectional study of the prevalence of an outcome. The computation required the following information:

- total population size (if known),
- hypothesized frequency, and
- confidence limits.

In order for the study to be adequately powered to answer the research questions, sample size calculations were based on unprotected sex rates among HIV-positive adolescents in sub-Saharan Africa. Given the lack of available data on expected prevalence of sexual activity and condom use in the study's population, the highest and lowest values from the literature review were used to compute the maximum and minimum values of sample sizes for the study. The following data was entered into the online tool for the proportions of HIV-positive adolescents that used condoms

consistently: *lowest* – 10% among 10-14 year olds in Zimbabwe and *highest* – 73% among 15-19 year olds in Mozambique (Cataldo et al., 2012). At 80% power and 95% confidence level, this study would need a sample size between 107 and 226 sexually-active participants (*Figure 3-5*), in order for the study to be powered to correctly estimate the rate of condom use among sexually-active HIV-positive ART-eligible adolescents. Therefore, the study aimed to recruit n=230 HIV-positive sexually active adolescents, which is the most conservative choice, given the wide range of frequencies of sexually active adolescents living with HIV, as suggested by research to date.

Figure 3-5. Sample Size Calculator Output for prevalence of condom use



Sample Size for Frequency in a Population

Population size(for finite population correction factor or fpc)(*N*): 3978
Hypothesized % frequency of outcome factor in the population (*p*): 10%+/-5
Confidence limits as % of 100(absolute +/- %)(*d*): 5%
Design effect (for cluster surveys-*DEFF*): 0.8

Sample Size(*n*) for Various Confidence Levels

ConfidenceLevel(%)	Sample Size
95%	107
80%	47
90%	77
97%	131
99%	181
99.9%	285
99.99%	384

Equation

Sample size $n = [DEFF*Np(1-p)]/ [(d^2/Z^2_{1-\alpha/2}*(N-1)+p*(1-p)]$

Results from OpenEpi, Version 3, open source calculator--SSPropor
Print from the browser with ctrl-P
or select text to copy and paste to other programs.

Sample Size for Frequency in a Population

Population size(for finite population correction factor or fpc)(*N*): 3978
Hypothesized % frequency of outcome factor in the population (*p*): 73%+/-5
Confidence limits as % of 100(absolute +/- %)(*d*): 5%
Design effect (for cluster surveys-*DEFF*): 0.8

Sample Size(*n*) for Various Confidence Levels

ConfidenceLevel(%)	Sample Size
95%	226
80%	101
90%	162
97%	272
99%	370
99.9%	563
99.99%	735

Equation

Sample size $n = [DEFF*Np(1-p)]/ [(d^2/Z^2_{1-\alpha/2}*(N-1)+p*(1-p)]$

Results from OpenEpi, Version 3, open source calculator--SSPropor
Print from the browser with ctrl-P
or select text to copy and paste to other programs.

In light of estimated sexual-activity rates of 33% in a multi-country study of 10-19 year old HIV-positive adolescents (Cataldo et al., 2012), a target sample of n=700 10-19 year old HIV-positive adolescents was needed for the study to be adequately powered to detect rates of unprotected sex.

3.3.5. Participants

This study aimed to interview at least 700 HIV-positive ART-eligible adolescents, aged 10-19, from the study area. To reach this target sample size, the study

recruited all HIV-positive ART-eligible adolescents, both vertically and horizontally infected, in the study area. Adolescents were interviewed directly, since discussing sexual and reproductive issues with their parents and healthcare providers can be difficult or inaccurate, as studies among HIV-positive adolescents in Sub-Saharan Africa have confirmed (Busza, Besana, Mapunda, & Oliveras, 2013; Hodgson et al., 2012; Obare et al., 2010). The study started recruitment at clinics where adolescents had received or were receiving treatment and care, followed by tracing eligible participants in the communities where they lived. Ethical considerations for participant recruitment are included in section 3.4.

There are multiple types of clinics where adolescents living with HIV access healthcare services in South Africa, including ART and reproductive health products. Their entry point to the healthcare system depends on their age, gender and mode of infection/ detection of HIV status. Vertically-infected adolescents, likely to have been identified *in utero*, during birth or childhood, would have initiated treatment and received health care services from 1) *paediatric clinics*. Based on national guidelines, at the age of 15, they would be transferred to 2) *general healthcare clinics*. HIV-positive adolescents who initiate treatment aged 15 and older can also access services in *general healthcare clinics*. Adolescent girls who are diagnosed HIV-positive during pregnancy or child-birth would initially access healthcare services from 3) *antenatal clinics*, but then continue to access their care at a *general healthcare clinic*. Some clinics are within a hospital, others are linked to a hospital but can be several hours drive away.

In addition, the South African Department of Health has started rolling out a strategy of primary health re-engineering, which requires hospitals to down-refer patients, who are stable, to local clinics. As a result, all HIV-positive patients are expected to obtain their medication and other necessary healthcare services in a primary general healthcare clinic, which also acts as a '*down-referral ART clinic*'. Given extremely low capacity in many of these smaller and rural clinics (Department

of Health, 2013), this down-referral system is usually only an option for patients who are considered stable and adherent to ART and whose health condition is good. Some of the smaller clinics only provide ART to over-15 year olds, whilst others cover all age groups.

Stage 1a – Eligibility Criteria for Clinic Participation

The Tier.net data system was used to select ART-providing paediatric, adult and antenatal clinics with available records that include records of adolescents on treatment and those who are lost-to-follow-up. In September-November 2013, this candidate led a three-person research team to conduct an initial mapping of all the clinics in Buffalo City Municipality Health Sub-District, estimated at n=81 based on the Demographic Health Information System national database. The candidate developed a clinic mapping tool, which was then piloted and tested in 5 facilities (Appendix 6.1). The following information was collected using a standardised tool in all 81 facilities:

- Type of clinic (paediatric, general, antenatal care or ARV unit);
- Number of adolescent patients, including number of adolescents on treatment and number of adolescents lost-to-follow-up;
- Data available: viral load, CD4 count, pharmacy refill records, pill counts, reasons for being lost-to-follow-up;
- Mode of data recording: paper, computer, none;
- Services offered at each clinic: paediatric, antenatal care, voluntary counselling and testing for HIV and STIs, family planning, or general primary care; and
- Willingness to participate in study.[8]

[8] While consent to become a study partner facility was negotiated over time, this mapping process gauged an initial interest in engaging in the research project was assessed.

The above information was entered into a database by the candidate and a research assistant.

Stage 1b – Stratified Clinic Sample

Based on the initial list of clinics mapped, clinics were selected on the following eligibility criteria by the core investigator team (this candidate, Prof. Cluver, Prof. Orkin, Dr. Boyes, and sampling expert Dr. Ariane Neethling):

- Care for at least n=5 adolescents living with HIV;[9]
- Have a register with records of lost-to-follow-up adolescent patients; and
- Are government-run.

The selected clinics and the estimated number of eligible adolescents in each facility is included in Appendix 6.2, though the list was later expanded due to down-referrals, as explained in the next section.

Stage 2a – Study-eligible adolescent roster

A study roster of all adolescents who had tested positive and were ART-eligible in the selected facilities was developed on a roll-in basis, as the research team built relationships with clinic management and healthcare provider staff. Based on data available from two recent studies among general clinics (Evans et al., 2013) and paediatric clinics (Nglazi et al., 2012), the following criteria were applied to determine participant eligibility:

- Patient was between the ages of 10-19 years old, i.e. born between 1 January 1999 and 31 December 2004;
- Patient had tested positive and was deemed eligible for ART in one of the participating facilities;

[9] The main reason for a size limit is that partnering with clinics that have at least 5 HIV-positive adolescent patients allowed for maximizing the use of research assistant time. Focusing on such clinics resulted in only 32 eligible facilities in the study's original facility sample.

- Both the patient and the legal guardian gave written, informed and voluntary consent.

In the process of building the study roster and recruiting study-eligible adolescents, the research team realised that many of the adolescents who were deemed ART-eligible in hospitals were down-referred to smaller facilities, once their treatment had been initiated. This was the case for all HIV-positive adolescents but particularly during pregnancy/ child-birth for HIV-positive girls. The team traced the down-referrals, which were documented in patient files. Additional clinics were then added to the facility sample if they met the same clinic inclusion criteria. An additional 21 clinics were added to the final list (Appendix 6.2).

The final study-eligible sample of HIV-positive adolescents was n=1,176. Of these, 90.1% (1,060 HIV-positive adolescents) were interviewed. The remaining 9.9% were excluded because: the caregiver or adolescent refused to participate (4.1%); the adolescents could not be traced (3.7%) or had severe cognitive delays (0.9%); or the research team could not reach them because it was unsafe to trace the adolescents, the adolescents had moved out of the study area, or had received an emergency referral (1.2%). A comparison of the included and excluded eligible HIV-positive adolescents based on known information: age, gender and rural/ urban residential location identified no statistically significant differences between the interviewed and excluded samples (Table 3-2):

Table 3-2. Comparison of included and excluded HIV-positive samples

	HIV+ (n=1060)	Excluded (n=116)	Comparison tests
Age (mean, SD)	13.8, 2.834	14.8, 2.91	z=1.96, p=.671
Female (n, %)	587, 55.2%	66, 56.9%	Chi2(df)=.098(1), p=.769
Rural (n, %)	228, 21.4%	26, 22.4%	Chi2(df)=.050(1), p=.813

Stage 2b – Recruitment

Following the pooling of adolescent patients across all clinics that chose to participate in the study (Stage 2A), all adolescents were approached in one of

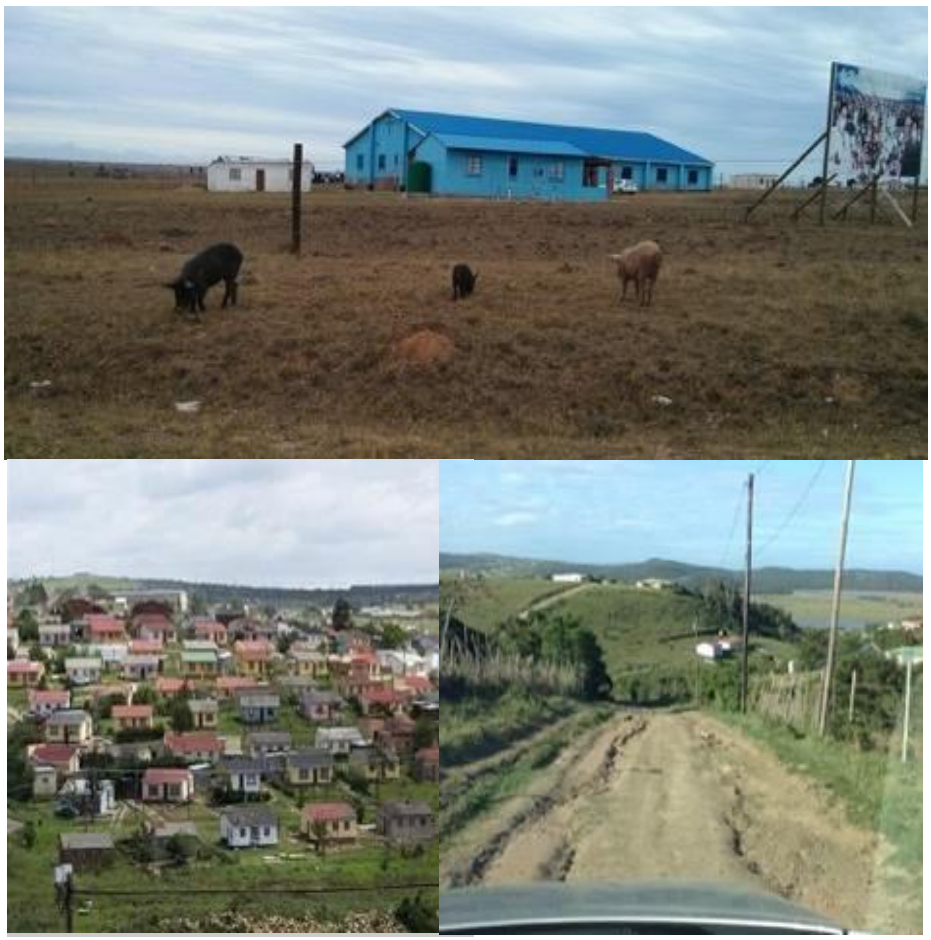
multiple settings (Stage 2B). The study was introduced to prospective participants through a summary information sheet by either: (a) a research assistant in the community or clinic, (b) a community health worker during outreach, and more rarely (c) the healthcare provider in the clinic setting. If they assented to participate, the study information package was reviewed prior to obtaining parental/ caregiver consent for those <18 and a consent form being signed for participants 18-19 years old as explained in more detail in section 3.4.

In order to reach hard-to-get subgroups of the target sample, such as defaulters or lost-to-follow-up adolescents, the research team devised a community-tracing strategy together with the administrator of Cecilia Makiwane Hospital, Dr. Luntu Galo. The research assistants recruited participants through any of the following scenarios:

1. Caregiver met at clinic while they were collecting adolescent treatment;
2. Adolescent met at clinic while they were collecting antiretroviral treatment;
3. Adolescent and caregiver met at clinic together while collecting treatment;
4. Caregiver met at household during community tracing;
5. Adolescent met at household during community tracing; or
6. Caregiver and adolescent met at household during community tracing.

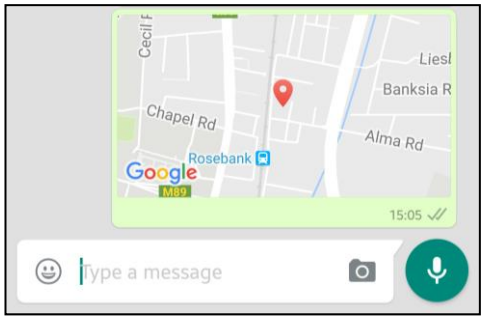
Community tracing: Using data from the patient files at each clinic, the research team identified clusters of addresses in the communities around the participating health facilities. In light of high levels of stigma towards people living with HIV/AIDS in South Africa (Deacon & Stephney, 2007; Skinner & Mfecane, 2004), and low levels of disclosure among HIV-positive adolescents (Ferrand et al., 2009; Petersen et al., 2010), community-based recruitment did not mention HIV or AIDS. The study was presented as investigating overall health and social service access for adolescents (see blank consent form in Appendix 3.1). The research team conducted interviews in over 150 villages, neighbourhoods, wards, and townships (Figure 3-6).

Figure 3-6. Study locations: a rural community in the Peddie area (top), Mdantsane, South Africa's second largest township (bottom left), and a rural road in Keiskammahoek (bottom right).



Participants chose to do interviews in their homes, post offices, ward counsellor offices, community centres, libraries, city centre (to which they travelled from the communities where they lived), school yards and churches. Research assistants geo-tagged participant homes using Google Maps and Whatsapp location utilities to facilitate emergency referrals and follow-up interviews (Figure 3-7).[10]

Figure 3-7. Sample geotagging of an address



[10] Geo-tagging entails recording the coordinates of a participant's home. This was done using the research assistants' tablets or phones, which were password-protected. The research study stored

Community Controls: To avoid unintended disclosure, additional 10-19 year old adolescents from the neighbouring or same home of the participant were invited to take part in the study, a sub-sample that acted as 'community controls'. The same consent processes were followed. An additional n=507 adolescents, whose HIV status was unknown or negative and who were not on antiretroviral treatment, were reached through this methodology and N=467 (92.1%) were interviewed. The n=40 not interviewed were excluded for the following reasons: n=4 (0.8%) refused, n=4 (0.8%) moved away during recruitment, n=1 (0.2%) had severe cognitive issues, n=1 (0.2%) lived in an unsafe area, n=23 (4.5%) did not meet age criteria, and n=7 (1.4%) could not be found to interview. There were no differences in age, gender and rural/ urban location between the included and the excluded community controls (Table 3-3).

Table 3-3. Comparison of included and excluded community control samples

	Community controls (n=467)		Excluded (n=40)		Comparison tests
Age (mean, SD)	N=467	14.6, 3.0	N=10	16.9, 2.5	z=1.96, p=.29
Female (n, %)	N=467	284, 60.8%	N=28	22, 78.6%	Chi2(df)=3.529(1), p=.06
Rural (n, %)	N=467	110, 23.6%	N=40	9, 22.5%	Chi2(df)=.023(1), p=.88

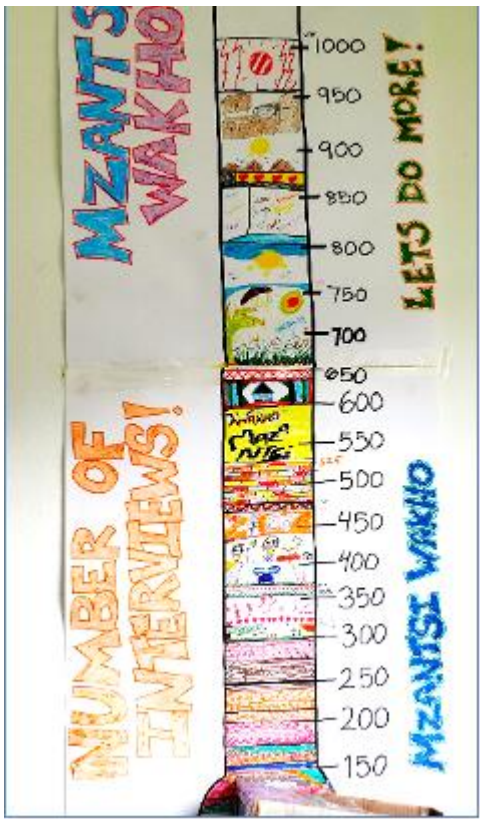
HIV-positive status determination: All potential participants (whether HIV-positive or not) were screened by research assistants prior to interviews using a health history approach (i.e. whether adolescents had ever been sick or on long-term medication for two-weeks or longer) using pre-agreed questions (Appendix 5.1). *HIV-positive status* was verified through a combination of ways: adolescent self-report of HIV-status or during a short health screening, caregiver or healthcare provider confirmation. *Adolescent HIV-positive status-awareness* was verified through two questions: (1) Does the adolescent report being HIV-positive? AND (2) Does the adolescent report taking ARVs for HIV? The two questions were necessary to

these in an anonymised map. The example provided here is of the candidate's home in South Africa to protect participant anonymity.

eliminate participants who would report being HIV-positive, but did not fully comprehend the meaning of their HIV-positive status, based on feedback from qualitative research with the same sample (Vale & Thabeng, 2015). Over two-thirds of the HIV-positive sample disclosed their HIV-status to the research assistant in confidence during the screening process (n=678, 64%). An additional n=115 who shared more information during their interviews which amounted to HIV-positive status disclosure, for a total of (n=794, 75%) of the HIV-positive sample disclosing their HIV-positive status.

If the adolescent disclosed their HIV-positive status during the health history screening, the research assistant used an HIV-specific version of the questionnaire. A non-HIV specific questionnaire was used for: (i) HIV-positive adolescents who did not know their status (n=266, 17.4%), (ii) HIV-positive adolescents who did not disclose their HIV-status to the research assistant during the screening process (n=116, 7.8%), and (iii) 'community control' adolescents (n=467, 30.6%). This questionnaire used terminology such as 'health', 'illness' and 'medication' rather than 'HIV/AIDS' and 'ART' in health-related measures. The non-HIV-specific questionnaire excluded 7 items that could not be adapted into non-HIV-specific questionnaires: HI-viral load, CD4 count measure, number of HIV-positive children, whether participant took ARVs without knowing what they were, how they felt when they learned their HIV-positive status, which HIV support group type they attended, and whether they took ARVs together with their caregiver. The research team

Figure 3-8. Mzantsi Wakho progress thermometer – Graphics used to capture progress in the field



received extensive training on these recruitment strategies and successfully recruited n=1,060 HIV-positive adolescents and n=467 community control adolescents this way (Figure 3-8).

3.4. ETHICAL ENTANGLEMENTS: FRAMEWORK, CHALLENGES, AND SOLUTIONS

Starting in August 2012, this candidate led the process of developing a study protocol that focused primarily on ethical considerations. Since then, the study team has continued to update the protocol on a regular basis as ethical and methodological challenges and solutions are encountered. The most recent version of this protocol is included in Appendix 1.2. The most salient points are summarised in this section.

3.4.1. Ethical and Regulatory Compliance

There is an extensive body of local and international literature on ethical concerns in conducting research with vulnerable children and young people. The ethical guidelines for this study were informed by several key sources. These include the ongoing academic debate on informed consent and confidentiality (Morrow, 2008), the ethical requirements of the universities and research institutions involved in research design (Universities of Oxford and Cape Town), and ethical guidelines from psychological research bodies such as the British Psychological Society (The British Psychological Society, 2009).

Additionally, the study's ethical guidelines were also informed by the following research guidelines and legislation in South Africa: the Department of Health's Ethics in Health Research Guidelines (Department of Health, 2004), the Department of Health, Guidelines for Good Clinical Practice in South Africa (Department of Health, 2006), the Open Society Foundation for South Africa's 'Best Practice Guide to HIV

Disclosure' (Open Society Foundation for South Africa, 2009), 'Selected ethical-legal norms in child and adolescent HIV prevention research: Consent, confidentiality and mandatory reporting' (Strode & Slack, 2012), the National Health Act 61 of 2003 (enforced starting 2012), the Children's Act (38 of 2005), the Children's Amendment Act (41 of 2007) and the Sexual Offences Act (32 of 2007). The use of South Africa-specific documents were further supplemented by international guidelines, such as the WHO's Guidelines on HIV Disclosure and Counselling for Children up to 12 Years of Age (World Health Organization, 2011), and the Helsinki Declaration (World Medical Association, 2001). Research team members consulted with colleagues at the University of Cape Town's Health Sciences Research Ethics Committee, the University of the Witwatersrand, and social workers at Child Welfare, about the study protocol. The ethics processes and procedures proposed in this research project were reviewed and approved by the following ethics committees and institutions:

(1) Inter-Departmental Research Ethics Committee of the Social Sciences and Humanities Division, University of Oxford for the study protocol included in Appendix 1.1 (Ref No: SSD/CUREC2/12-21).
(2) Centre for Social Science Research, University of Cape Town (CSSR2013/04).
(3) Eastern Cape Department of Health ethics approval (29 August 2013).
(4) Buffalo City Municipality Health sub-district approval (23 Jan 2014, 2 Oct 2015).
(5) Eastern Cape Department of Basic Education approval (4 April 2014).

All of these ethical approvals are included in Appendix 2.

3.4.2. Process of Obtaining Informed Consent

Adolescent consent

All information sheets and consent forms were given to potential participants and their legal guardians by the researcher or members of the fieldwork team in English and Xhosa, the latter being most common home language of the majority of the

Eastern Cape population (See Appendix 5.1 for the Baseline Consent Form in English). All information sheets and consent forms were read to participants in their preferred language to prevent poor literacy from hindering a participant's understanding of the methods and purpose of the study. Research assistants explained all aspects of the project to adolescents and answered any questions they had, in the adolescent's preferred language. In order to ensure fully informed, voluntary consent for adolescent participants, the adolescent was asked for their consent to participate only after the purpose of the study and the format of the interview had been explained. Written informed consent from each participant in this study and their caregiver was obtained as relevant. If participants were illiterate, they were able to give verbal consent and indicate with a cross on the signature line of the consent form. All research assistants had prior experience working with vulnerable children affected or infected by HIV/AIDS.

Particular attention was given to issues surrounding statutory requirements to break confidentiality (i.e. if the adolescent or a member of their household asked for help or was at significant risk). Participants were told they had the right to decline to participate, could withdraw at any time, and that all the results would remain confidential. Any avoidance of study participation was understood as a lack or withdrawal of consent. Any adolescent who declined to participate before or after the research assistant had explained the project was not interviewed, even if the legal guardian or nominated adult agreed to, or encouraged participation. Adolescents who refused to participate, or who stopped the interview, still received snacks and certificates. Participants were included if they were capable of giving their own consent, and were excluded if deemed unable to comprehend the consent process.

Vertical (parent-to-child) HIV-infection can cause cognitive delays in children (Sherr, Croome, Parra Castaneda, Bradshaw, & Herrero Romero, 2014). These can be reflected in a wide range of difficulties, for example a lowered reading age or a lowered cognitive age. The effects and impacts of this for adolescents are still under-

researched (Laughton, Cornell, Boivin, & Rie, 2013). As such there are no clear guidelines on how to take these difficulties into account while conducting research with children and adolescents who are vertically-infected with HIV. Many vertically infected children look much younger than their real age, may have developmental and educational delays, but feel and understand themselves to be teenagers (Dago-Akribi & Adjoua, 2004; Lowick, Sawry, & Meyers, 2012). There is also an ethical imperative not to exclude adolescents based on an inappropriate understanding of their delay. This study addressed this by carefully training research assistants to assess cases in which adolescents did not appear to understand the process or meaning of participation. In these cases research assistants obtained guidance from expert study advisors. In total, n=11 adolescents (0.7%) were excluded due to severe cognitive delays. Estimates of the number of adolescents with cognitive challenges, which did not hinder them from participating but affected their overall well-being, are greater, and will be subject of future analyses not included in this thesis. All attempts were made to ensure that the research was a positive and participatory experience for all participants, and that consent was both voluntary and informed.

Legal guardian consent for adolescent participation[11]

For adolescents younger than 18 years old, their legal caregiver also provided consent for participation in this study, and was provided with information describing the study in their chosen language. The most recent draft of the *HIV status disclosure guidelines for children and adolescents in South Africa* defines a caregiver as anyone who is primarily responsible for the care of a child. In the absence of a biological parent, the South Africa Child Health Act recognises the following caregivers:

[11] The following process and procedure was applicable to adolescents who had not yet turned 18. Adolescents who were 18-19 years old were treated as adults with regards to informed consent issues, in compliance with all the of regulations cited in this protocol.

- Grandmothers, aunts and other relatives;
- A foster parent;
- A child (16 years and older) heading a household (child-headed household);
- The head of a Child and Youth Care Centre or shelter where the child is placed or lives in, and
- A Child and Youth Care Worker supporting a child without family care in the community.

Exceptions to legal guardian consent

In some exceptional circumstances related to HIV/AIDS vulnerability, the adolescent wished to participate but the legal guardian was unavailable (due to death, living away and not contactable, or being too sick to give consent). In these cases, adolescents had an option to nominate another adult whom they trusted, such as an aunt or social worker, in the place of a guardian. These cases included adolescents in child-headed households, and adolescents whose primary caregiver was experiencing severe AIDS-related dementia.

The National Child Act, passed in 2003, includes additional guidance on consent procedures. A growing South African literature (Singh et al., 2006; Strode, Slack, Grant, & Mushariwa, 2005; Zuch, Mason-jones, Mathews, & Henley, 2012) argues that Section 71 of South Africa's National Health Act, which requires active written consent from a legal guardian where research subjects are under 18, runs the risk of compromising adolescents' constitutional right to privacy, confidentiality and dignity. This is especially relevant to research on stigmatised topics such as HIV, antiretroviral treatment and sexual and reproductive health (Zuch et al., 2012). It also produces a recruitment bias in favour of respondents who communicate with their guardians about sexual health. Disclosing an HIV-positive status to family members may result in discrimination, violence and social ostracism (Norman, Chopra, &

Kadiyala, 2005). Hence, additional parental or guardian consent may a) be logistically impossible, b) necessitate breaching of confidentiality, and/or c) place the participant at risk of harm (Zuch et al., 2012).

The study followed the South African national ethical guidelines for conducting research among adolescents as outlined in the Child Care Act (2005) and the Department of Health Ethics in Health Research (2004). Where the adolescent stated that their caregiver would not consent to their participation in the study due to the fear that their abuse of the adolescent (as reported by the adolescent) would be revealed, or in exceptional cases where the adolescent was unwilling to disclose their HIV-status to their caregiver (and was concerned that the research – whilst not focused on HIV, would reveal this to the caregiver), researchers asked the adolescent to identify another trusted adult who would be able to consent to their participation. Researchers subsequently made social service referrals for all children and adolescents who reported abuse. The research team, managed by this candidate for sixteen months, ensured that they did *not* take advantage of this concession in order to sidestep caregiver consent where this was inconvenient. This protocol for seeking consent was only used for this specific subset of children and adolescents.

3.4.3. Risks and Benefits to Participants

This study recruited adolescents as young as 10 years old. As the research assistants were either youths (>20 years old) or adults, this presented a significant power inequality, which was sensitively and carefully considered during the project design and research assistant training. Building trust and rapport with participants during data collection, data analysis and reporting of the study was essential in generating high-quality data and research findings. When research assistants were employed and trained for the study, attention was focused on equalising power

relations and attempts made to reduce their impact on adolescents during the interviews. However, it is also important to recognise that in a positive and youth-centred research environment, adolescents may benefit from the opportunity to interact with adult facilitators. The research team did not anticipate that the interviews would cause any additional distress either to adolescent participants or their caregivers. However, in order to reduce any risk of respondents becoming distressed, guidelines were developed and included in the study protocol. The following summarises some of the considerations on risk and benefits to the participants resulting from participation in the study:

- Research assistants were trained to give adolescents the option to use tablets to respond to sections including sensitive questions such as abuse, sexual activity, or adherence to ART, if they chose to. However, in quite a few cases, abuse was reported after the interview was completed (for example, 5 of the n=36 past-year contact sexual abuse cases were recorded after the interview), which is reflective of the time required to build a rapport and trust between participant and research assistants). These cases were coded separately and a dummy variable was included in the dataset to ensure that the referrals and related risk were recorded appropriately.
- The adolescents in this study included HIV-positive and HIV-status unknown 10-19 year olds. Three-quarters of the HIV-positive adolescents shared their HIV-positive status with the researchers during this study. This study recognises the duty of researchers to uphold participants' constitutional right to privacy and dignity, particularly in a context where HIV remains highly stigmatised. Therefore, in line with the National Health Act (2003) and legal guidelines from the Open Society Foundation (2009), researchers did not disclose the status of adolescent participants to others (family members, healthcare providers, etc.) without their explicit consent.

- In cases where HIV-positive participants reported having unprotected sex with their partners, resulting in a tension between the participant's right to confidentiality and the public health impetus to protect at-risk partners, researchers adopted the following procedure as per relevant guidelines:
  a. advised the adolescent about the risks of unprotected sex for both their own health and the health of their partner;
  b. encouraged the participant to seek counselling to identify ways to safely disclose their HIV-status to their partners. The findings of the second paper on disclosure of HIV-status suggest that the recommendation to disclose their HIV-positive status to partners should be made very carefully, given the potential to result in even higher levels of unprotected sex which our analyses highlights (Chapter 5); and
  c. suggested a joint session with a trained HIV/AIDS counsellor who could assist the adolescent in disclosing or negotiating safer sex.
- This study identified a number of adolescents who had defaulted or not yet initiated medication, including ART or TB medication. In cases when participants reported non-adherence, the researchers highlighted the life-saving importance of adherence to medication and encouraged the participant to consult their healthcare workers and treatment buddies. Specific information obtained on the dosage, adherence patterns and other influencing factors for each individual was not shared with their healthcare worker or legal guardian in order to maintain participant confidentiality. However, adolescents experiencing symptoms of TB, pneumonia or any other opportunistic infections were referred to a healthcare professional. Given the risk of significant harm, this constituted a legitimate breach of confidentiality. Participants were told at the informed consent stage and in consent forms that there were limits to confidentiality when someone was deemed to be at risk of significant harm.

- In order to protect the participants' confidentiality, and to protect them from the stigma associated with HIV/AIDS in many South African communities, each interview was conducted with as much privacy as possible in a space chosen by the participant. In addition, the study was presented within communities as investigating youth access to health and social services experiences generally, rather than being an HIV-specific study. This approach allowed the study to maintain the confidentiality of the HIV-positive adolescents who knew their status, avoid unintended disclosure of HIV-status to those who did not know their status, and to recruit community control adolescents.

- In all previous studies that the research team had been involved in, a range of complex cases of children and youth in extreme need were identified. This was partly because the study interview was often the first opportunity a child had to discuss their lives in detail. There were high levels of disclosure regarding rape or abuse, either of participants or other young family members (Lucie D Cluver, Boyes, et al., 2015). The research team planned for the possibility that participants would take the opportunity to disclose difficult living circumstances or abuse before, during or after the interviews. Most research with vulnerable children in South Africa considers it an ethical principle to provide help for children whom the research identifies as in need. For example, research undertaken by the Medical Research Council Unit for Anxiety and Stress Disorders routinely referred children to child psychiatric services or to the University of the Western Cape Child Psychology clinic in cases in which there was need for these services (Seedat, Van Nood, Vythilingum, Stein, & Kaminer, 2000). A University of Cape Town study on child mental health referred children in need to social services, as did research in the Africa Centre on HIV-positive caregivers and infants (Stein et al., 2005). The study protocol recognised that researchers have a responsibility towards children who may disclose information

showing them to be at risk of severe harm. Reflections on prior research on these issues in South Africa was carefully considered by the research team (Lucie D Cluver, Boyes, et al., 2015), and all suggested practical and ethical recommendations were incorporated into the day-to-day management of the study. Guidelines have been set out by the HSRC/ UNICEF study on children's psychological adjustment in South Africa (Dawes et al., 2004) and in the South African Children's Institute/ ACESS Child Participatory Poverty Research (Alliance for Children's Entitlement to Social Security, Soul City, & The Children's Institute, 2002). These promise confidentiality except when the research shows a child to be at risk.

- The team set up a process of responding to and referring these cases to the appropriate local services (see study protocol for more details). Adolescent interviews and conversations with family members before and after the interviews resulted in n=94 (6.2%) referral cases in the full sample of this study, of which n=68 (6.4%) cases were among HIV-positive adolescents. In cases of risk reported or observed, and with the consent of the child, participants or their relatives were either referred to organisations that could provide assistance and/ or their caregivers were told – if the latter were not the source of risk/ potential harm. All cases were discussed in detail with a qualified South African child protection social worker, who was part of the research team, and the option with the best potential outcomes for the child/ adolescent was chosen. Given the very low availability and sometimes poor quality of social services in the study site and surroundings, close supervision by the team's social worker (Prof. Cluver) was provided in all cases of referrals and any supportive action taken by the team. Researchers in this team have been investigators on three previous studies with AIDS-affected children in South Africa. Based on these studies and on protocols devised from research studies with similarly vulnerable groups (Bostock, 2002),

the following protocol was followed:

a. Informing all participants at the consent stage that everything said would be confidential unless it became clear that they were at risk of significant harm.

b. If information was disclosed that suggested that the participant, their sexual partner, or a member of the household was at risk of significant harm, the researcher discussed concerns with the participant at the end of the interview before any further action was taken.

c. If the participant or a member of their close network was at risk of severe harm, the researcher discussed the possibilities for referral with the participant or person at risk. If the participant did not consent to the sharing of information, and the harm was not considered to be significant, the participant was given information about self-referral agencies such as ChildLine SA, Life Line, FAMSA, etc.

d. However, if the harm was considered to be significant the researcher, assisted by fieldwork coordinators, consulted with social services or other organisations. If the decision was made to take action, the participant(s) were informed. If referral required disclosing the child's HIV-status, then the procedures described in 2) above were followed.

- This study had an obligation to plan for the possibility of participants or adult caregivers becoming distressed – which happened in a few isolated incidents. Only two such cases were recorded in the 790 interviews that this candidate co-supervised. To help the fieldwork team manage such cases, the research team included a social worker, a psychologist and HIV counsellors who were available to supervise researchers and help them discuss issues with the families and children following the interviews. As discussed above, if there was a need for a participant to access more extensive support, such as consulting a counsellor or

attending a clinic, referrals were made. The team identified a network of healthcare providers that were providing good quality disclosure support and referred the participants to them rather than the regular services, when their quality was not consistent. Complex cases were assessed and problem-solved by the fieldwork manager (this candidate), research assistants, social worker, psychologist, as well as the participants and relevant family members.

Participants had an opportunity to share their experiences and concerns with trusted adults and access referrals where necessary. Through the network of partners and collaborators, and because of the objectives of this study, participants' responses are being used to inform health policy and programming for youth at local, national and regional levels. Health facilities and organisations participating in the study received specific (though anonymous) feedback about the experiences of their youth patients, the aim of which is to positively impact service provision.

3.4.4. Privacy and Confidentiality

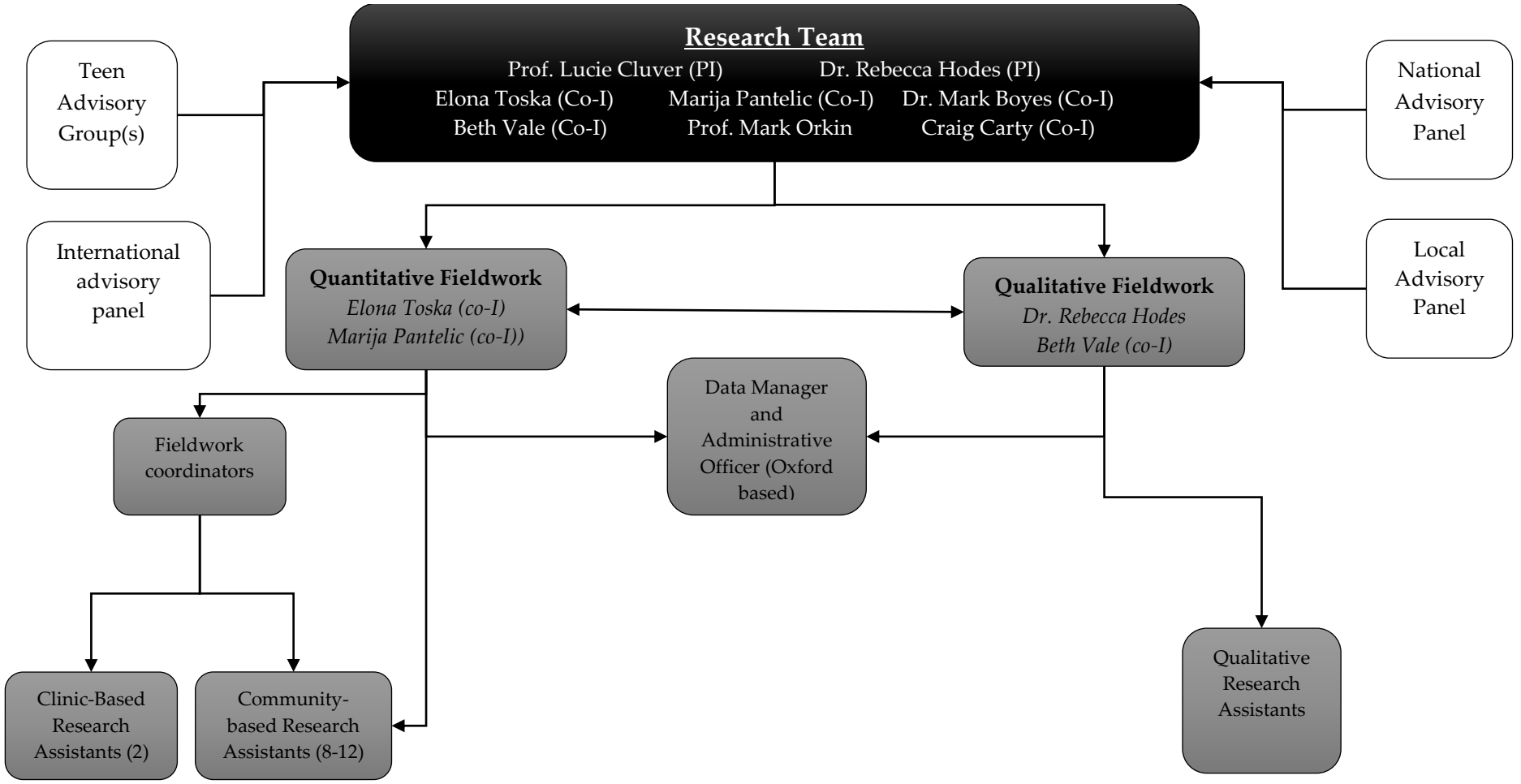
Participants chose the time, location and nature of their engagement with the research assistants. It often meant that the research assistants scheduled interviews multiple times before they actually took place, resulting in significant time investments by the research team for each interview. The researcher assistants used this opportunity to build a rapport with the adolescent and their family members. The use of mobile devices (tablets) helped increase the privacy and confidentiality of the answers given by participants by ensuring that if the participant chose to keep the answers secret, the fieldworkers did not see the given answers. All research materials included a landline and a cell phone number available to all those who were interested in and had already participated. If participants sent a free 'please call me' text message to the cell phone number, a member of the research team

contacted them at no cost to the participant. When participants shared their contact details with researchers, this information was kept confidential.

3.4.5. Reimbursement for Participation

Financial incentives were not provided for participation in this study, for two reasons. First, financial incentives can, in some cases, lead to conflicts within the community or household. Second, in order to prevent adolescents agreeing to participate in the study in order to access money – which would reduce the voluntary nature of consent. Each participant received 'participant packs' that contained toothbrush, toothpaste, biscuits, chips, and fruit juice as a token of appreciation for participating in structured research activities, as well as a Certificate of Participation regardless of whether they completed their interview or not (see Appendix 4.1). Pregnant girls and new mothers also received a 'baby pack' to assist with the material and emotional cost of becoming a parent, which included nappies and baby cream. If the participant chose to travel for the purpose of maintaining privacy, transport costs were reimbursed and, if necessary, another research assistant helped with childcare while the interview took place.

Figure 3-9. Organizational chart of the Mzantsi Wakho research team in 2014-2015



3.5. RESEARCH TEAM

Figure 3-9 presents the research team for the Mzantsi Wakho cohort study (www.mzantsiwakho.org.za). This candidate led the quantitative sexual and reproductive health aspects of the study and also acted as a Quantitative Fieldwork Manager for half of the baseline interviews. She has been involved in project design and development since its inception in August 2012. Since October 2012, under the supervision of Prof. Cluver, and supported by the other co-investigators,[12] this candidate developed ethics approval documents, researched quantitative measures and scales for the study and consulted with experts, practitioners and adolescents living with HIV in South Africa. As the lead investigator for the quantitative sexual and reproductive health aspects of the study, this candidate was in charge of the following tasks: selecting appropriate scales and measures, questionnaire design and piloting, recruitment and training of research assistants, overseeing data collection, data cleaning and analyses.

Between December 2012 and April 2013, this candidate conducted a rigorous literature review and designed sample methodology and scales/ measures for the sexual health component of the study. This included an in-depth literature review of the use of mobile devices (tablets) for data collection among HIV-positive adolescents, which informed the technical and technological choices for the entire study. Ethical approval protocols, grant applications, and consultations presented in this chapter have been designed and conducted by this candidate together with the research team.

[12] The work of this candidate to date has been conducted in parallel and collaboration with two other doctoral candidates at Oxford's Department of Social Policy and Intervention, Dr. Beth Vale, and Ms. Marija Pantelic. Dr. Vale's research involved an in-depth qualitative exploration of the lived experiences of HIV-positive adolescents with a particular focus on their medication-taking practices and sexual and reproductive health. Ms. Pantelic's research focuses on developing and validating a stigma scale for HIV-positive adolescents and investigating factors associated with internalised HIV stigma as an outcome.

From August 2013-October 2014, this candidate managed the project's baseline quantitative data collection and liaised with the qualitative research team in the field.[13] As a Quantitative Fieldwork Manager, this candidate's role included setting up and managing two sets of data collection: interviews with adolescents and clinic-level data collection. Carrying out these tasks involved:

- Setting up the study's office and sourcing furniture and equipment.
- Identifying, hiring and training research assistants.[14] Ten community-based research assistants identified, recruited and interviewed eligible adolescents who consented to participate in data collection in their communities or homes. Moreover, community-based research assistants recruited in the community those who were lost-to-follow-up, using secondary information identified by the staff at the clinics. As described in the Ethical Considerations section, when possible, this was coupled with existing efforts of community-based health workers to track lost-to-follow-up patients.
- Drafting, programming, and finalising the baseline questionnaire using tablets sourced by the candidate;
- Coordinating with the IT specialist at the Department of Social Policy and Intervention, University of Oxford, to set up the data storage and security processes;
- Setting up and managing questionnaire piloting;
- Developing and managing fieldwork processes in terms of participant recruitment, ethical requirements, financial management, referrals and clinic-relationship management; and

[13] Ms. Pantelic became the quantitative fieldwork manager who replaced the candidate in the field and led fieldwork for the second half of the data collection for this cross-sectional study (October 2014-September 2015).

[14] The fieldwork team was based only in East London until September 2014, at which time this candidate set up and trained a second research team in King Williams Town.

- Setting up and maintaining relationships with provincial and district Departments of Health and Basic Education, and partner organisations in the study area.

Clinic-related work conducted by this candidate involved:

- Initiating, negotiating and maintaining the relationship between the project and the clinic management;
- Setting up processes for identifying eligible participants in collaboration with clinic staff;
- Setting up the systems for recording secondary data for enrolled participants together with clinic-based research assistants;
- Liaising with the community-based research assistant team to ensure that the team could track and recruit lost-to-follow-up patients; and
- Training of clinic-based research assistants, who were permanently based at specific clinics.

The main tasks of clinic-based research assistants were to: (1) conduct interviews for those participants that preferred to participate while at the clinic,[15] (2) collect clinic records for consenting participants, while applying data collection protocols which respect confidentiality and anonymity of research participants.

The research team also included several international Fieldwork Coordinators whose work was managed by the candidate and fellow fieldwork managers. Fieldwork coordinators supported the clinic- and community-based research assistants to identify and recruit participants by coordinating small teams, driving project vehicles, and ensuring smooth day-to-day operations. These Fieldwork Coordinators also supported the team with computer-based administrative tasks

[15] This allowed the team to maximise patient interest during recruitment (if their caregiver and participant gave consent) and to engage with the patient while they might be waiting to see a healthcare provider or pick-up their medication.

such as managing the study roster, data backup, and financial reporting. Volunteers not based in South Africa supported the research study by conducting rapid literature reviews as needed and reviewing materials required for fieldwork such as certificates, paper-based questionnaires, and related tasks. A full list of the research team involved in this study and their exact roles is included in Appendix 9.

3.5.1. Advisory Panels

The work of the research team has benefitted immensely from the support of several advisory panels, which have provided feedback on methodological, policy, ethical and strategic issues (Figure 3-10). This candidate also consulted relevant experts from local and national non-governmental organisations during the study protocol development, including: Keiskamma Trust, Small Projects Foundation, Paediatric AIDS Treatment for Africa, Rafael Centre, and The Relevance Network. For details on these partner organisations, please see Appendix 9. The study also benefitted from feedback from the Teen Advisory Group.

The Teen Advisory Group (TAG) is a group of AIDS-affected youth who provided feedback on various matters including the study design, topics to be included in the questionnaire, and methodologies to recruit young people. Set up by Prof. Cluver to support a study among AIDS-affected youth in South Africa – Young Carers – TAG met annually during this study for weekends of participatory research sessions. During this study, adolescents living openly with HIV joined the TAG to ensure that their perspectives were taken into account in the study design and implementation.

Figure 3-10. Study advisory panels

3.5.2. Fieldwork Research Team – Recruitment and Training

The clinic-based and community-based research assistants were locally recruited from the Eastern Cape, when possible in collaboration with community based organisations and NGOs that are part of this research partnership. Initially, a team of ten community-based research assistants was set up in East London, followed by a team of four research assistants in King Williams Town starting September 2014. To ensure that the research tools were delivered in an ethical and rigorous way, research assistants underwent a rigorous two-week training programme, focusing on recruitment, referrals, arising ethical issues and data collection techniques. The

training included confidentiality, referral protocols, safety measures, and training on the ethical-legal research norms surrounding HIV-related research. All processes and procedures followed standards and protocols of the South African national and provincial Departments of Health, as well as specific clinics. To provide regular support to the research assistants and to ensure quality control, monthly refresher training sessions on administering the questionnaire were led by this candidate and other fieldwork managers. The team held regular (weekly) meetings to review challenges of recruitment, interviewing, and data quality that emerged during fieldwork. Individual training and mentoring sessions were held with specific team members as requested and appropriate.

3.6. FIELDWORK PROCEDURES, QUESTIONNAIRES, AND MEASURES

This section focuses on the fieldwork for the cross-sectional study which took place in February 2013 – September 2015. It starts with a summary of consultations to set up the study, followed by steps taken in designing the data collection tool, and actual fieldwork processes which resulted in the 1,527 interviews completed. Finally, data collection and management processes are summarised.

3.6.1. Consultations and Formative Research (February-April 2013)

In February-April 2013, this candidate together with a colleague doctoral student, Dr. Beth Vale, supported by Prof. Lucie Cluver and the research team, organised and conducted three youth camps with AIDS-affected youth in partnership with the Keiskamma Trust (Hamburg) and Raphael Centre (Grahamstown) in the study area. In addition to organising team-building and leadership activities, the camps were a unique opportunity to consult with the study's target population on topics of interest

emerging from the on-going literature review this candidate was conducting. All participants and parents/ caregivers were informed of the aim of the camps. Consent was obtained from all participants and caregivers, for those under 18 years old, prior to participation in the youth camps. Participatory consultations with three youth groups covered three topics: 1) disclosure, 2) stigma and discrimination, and 3) gender, sexuality and relationships.

The disclosure session highlighted the varying levels of disclosure to different people. It confirmed that disclosure is a fluid process on a spectrum between not knowing at all and sharing experiences of someone's HIV status and medication taking. The session on stigma suggested that the study explore internalised stigma, which became the focus of the doctoratal thesis of Ms. Marija Pantelic. Finally, the discussions on relationships and sexual and reproductive health highlighted the need to discuss contraception and the fluidity of relationships among adolescents. All these issues were reflected in the measures used for the baseline quantitative study.

Consultations with Experts

In addition to the three youth camps, this candidate consulted with many other practitioners and academics involved in research on and care for HIV-positive adolescents in South Africa and/ or other countries (Table 3-4). This candidate also established initial contact with multiple facilities in the study area in preparation for the study's launch.

Table 3-4. Summary of consultations with academic experts, practitioners and community organizations

Expert Name	*Organization*	*Date (mode)*	*Consultation topic*	*Contribution to the study*
*Dr. David Harrison[16]	D. G. Murray Trust, former executive director of LoveLife	11 December 2012 (meeting/ email)	Risk behavior models among South African youth	Literature on risk behavior models and theoretical underpinnings
*Dr. Melissa Wallace, Kate Snyder and Thola Bennie	Desmond Tutu Foundation	13 December 2012 (meeting/ email)	Research among HIV-positive adolescents	Advice on sampling and contacts for fellow researchers Visited DTF Youth Centre in Masiphumelela
Amelia Mfiki	Treatment Action Campaign, South Africa	13 December 2012 (meeting)	Adolescents living with HIV – their experiences of the healthcare system	Rates of testing among HIV-positive adolescents, access to ARVs and issues with sexual and reproductive health
*Dr. Mitch Besser	Mother-2-Mother Programme	6 January 2013 (meeting)	Sampling of HIV-positive adolescents	Further contacts in the Eastern Cape
*Dr. Justus Hofmeyr	Cecilia Makiwane Hospital	9 January 2013 (meeting)	Sampling of HIV-positive adolescents	Information on health service access among HIV-positive adolescents
*Dr. Carol Hofmeyr and the Keiskamma Adolescent Health Programme	Keiskamma Trust	Ongoing since 10 January 2013	Adolescents living with HIV in rural Eastern Cape	Topics that would support the programme to design better services included in the survey, such as stigma, discrimination and disclosure
Dr. Paul Cromhout Ms. Rose Ewing	Small Projects Foundation	Ongoing since 9 January 2013	Sampling and access to clinics Topics of relevance to SPF programming	Sexual and reproductive health topics Contacts with Eastern Cape ethics process and committee Introduction to 13 clinics supported by SPF in the Eastern Cape
Dr. Cathy Matthews	University of Cape Town, PI of PREPARE trial among adolescents in the Western Cape	8 February 2013	Sexual activity and condom use measures among South African adolescents	Sample PREPARE questionnaire including questions on condom use intention and sexual debut.
Zak Kauffman	London School of Hygiene and Tropical Medicine	Ongoing	Using mobile devices for data collection	Respondent burden, types of questions and responses obtained, addressing literacy using mobile devices and costs
Prof. Ann Shuttleworth-Edwards	Professor at University of Rhodes, Grahamstown, South Africa	February 2013 (meeting/ email)	Neurocognitive measures among Xhosa adolescents in the Eastern Cape	Proposed reduced battery of tests for adolescents based on the Wechsler Child and Adolescent Intelligence tests normed and standardized by Dr. Edwards.
National Technical Working Group on Pediatric and Adolescent	Multiple organizations represented, coordinated by the National Department of	13 March 2013	Introduced study and discussed potential population wide data available to design sampling frame	Relationship with Clinton Health Access Initiative resulted in access to the Eastern Cape provincial data from the national

[16] All of the consultations marked with an (*) included specific discussions of sexual and reproductive health outcomes, in addition to the overall study.

Expert Name	*Organization*	*Date (mode)*	*Consultation topic*	*Contribution to the study*
Health	Health			DHIS.
*Dr. Curtis Dolezal	Columbia University, United States	April 2013 (email)	Adolescent Sexual Behaviour Assessment used in multiple studies among HIV-positive adolescents of similar age range: 13-19	Using gateway questions to explore sexual activity in an age-sensitive way Sample of the male and female questionnaires
*Dr. Francis Obare	Population Council	October 2012 (email)	Survey methodology and question types to explore SRH needs of HIV-positive adolescents in Uganda	Sample of questionnaire and advice on sampling.
Dr. Costa Gazidis	Former director of Cecilia Makiwane and Frere hospitals in East London, South Africa	19 February 2013	Health care service in the Eastern Cape Sampling of HIV-positive adolescents	Contacts of organisations and doctors working with HIV-positive adolescents
Dr. Caroline Kuo	Brown University	20 Feb 2013	Parenting measures	Potential measures of aspects of parent-child relationship proposed
*Dr. Cynthia Fair	Professor at Elon University, USA	December 2012-January 2013 (skype/ email)	Sampling, study design	Sample survey questions, especially on sexual relationships and parenthood ideation
*Dr. Donna Futterman	PI and researcher of Adolescent AIDS Program (USA) and	February 27, 2013 (meeting)	Sampling, study design	Sampling, study design, sexuality-related questions
Dr. Anita Heeren	University of Fort Hare, South Africa	December 2012 (skype/ email)	Ethics, fieldwork with HIV-positive children in the Eastern cape, measuring disclosure	Support in designing questions exploring the spectrum of disclosure
*Dr. Daniel Westreich	Duke University	March 2013 (email)	Reproductive health outcomes among HIV-positive adolescents	Appropriate outcome selection for target age group of sample
*Dr. Denise Evans	University of Witswatersrand	March – April 2013 (email)	Reproductive health outcomes among HIV-positive adolescents	Information on quality of data on adolescents initiating, dropping out and remaining in care based on study of 7 clinics in Gauteng and Mpumalanga province
*Dr. Alexandre Mergui	INSERM, France	November-December 2012 (email)	Author of literature review located	Available updates on study and leads on studies in Sub-Saharan Africa
Ms. Alice Clarfelt	Gender Advisor, Eastern Cape AIDS Council & GIZ	April 2013 (meeting/ email)	Research among adolescents, key partners in the Eastern Cape	Presentation of the study to the Eastern Cape AIDS Council to be coordinate Local NGO partners identified

3.6.2. Data Collection (March 2014 – September 2015)

The data collected for this baseline cross-sectional study came from 1,527 interviews conducted with 10-19 year old adolescents in the study area. Though not reported in detail in this thesis, the research team also collected secondary data from:

- Adolescent's clinic folders, including time since infection, treatment line (if available), viral load and CD4 count data.
- Clinics they attended, relating to structural-level factors such as staffing or services available.

This section focuses primarily on the *primary data collection source – adolescent interviews*, rather than the two other sources of data collection. Based on recommendations from the consultations, data for this study was collected through tablets. Questionnaires were designed using OpenDataKit (www.opendatakit.org), an open-source software platform that is freely available online used increasingly in large-scale household surveys and trials in South Africa and similar research settings. This candidate converted the paper-based questionnaire into the tablet-based version with support from the OpenDataKit online community. Research assistants helped the adolescents to use the tablets, reading and explaining the questions and entering the answers correctly. However, older adolescents and those who could read were able to use the tablets directly if they chose to, in either English or Xhosa: n=77 (5%) chose to use the tablet independently, while n=101 (6.6%) chose to input the answers directly, after the research assistant had read and explained the questions.

By using low-cost mobile devices (tablets), the study benefitted from the advantage of computerised data collection. These benefits included improved mobility as handsets were easily transported by research assistants to the participants, and confidentiality through password-protected access, which ensured that completed questionnaires were not accessible to non-team members, even if the tablets were lost or stolen. A key advantage to tablet-assisted data collection was the reduced participant burden, which was achieved

through built-in skip-patterns and careful question selection and phrasing. This allowed the study to administer two versions of the questionnaire: one for HIV-positive adolescents who knew their status and one for the rest of the sample. Studies have reported that participants responding through mobile or tablet-assisted data collection can answer around 160 items in 19-36 minutes (Kurth et al., 2004; Mcclamroch, 2011). This was consistent with the experience of a local NGO running three RCTs in South Africa, Zimbabwe, etc. which reported that participants needed 25-30 minutes for a 146-item questionnaire using mobile-assisted data collection (Kauffman, personal communication, February 2013). The final questionnaire for this study consisted of nearly 450 items. Most interviews took around 90 minutes to complete, based on this team's research experience with similar age groups in South Africa (Lucie D Cluver, Operario, Lane, & Kganakga, 2011).

In addition to the scales and measures listed in section 3.6.6, the questionnaires included graphic content and vignettes to help participants feel relaxed and not judged (Figure 3-11).

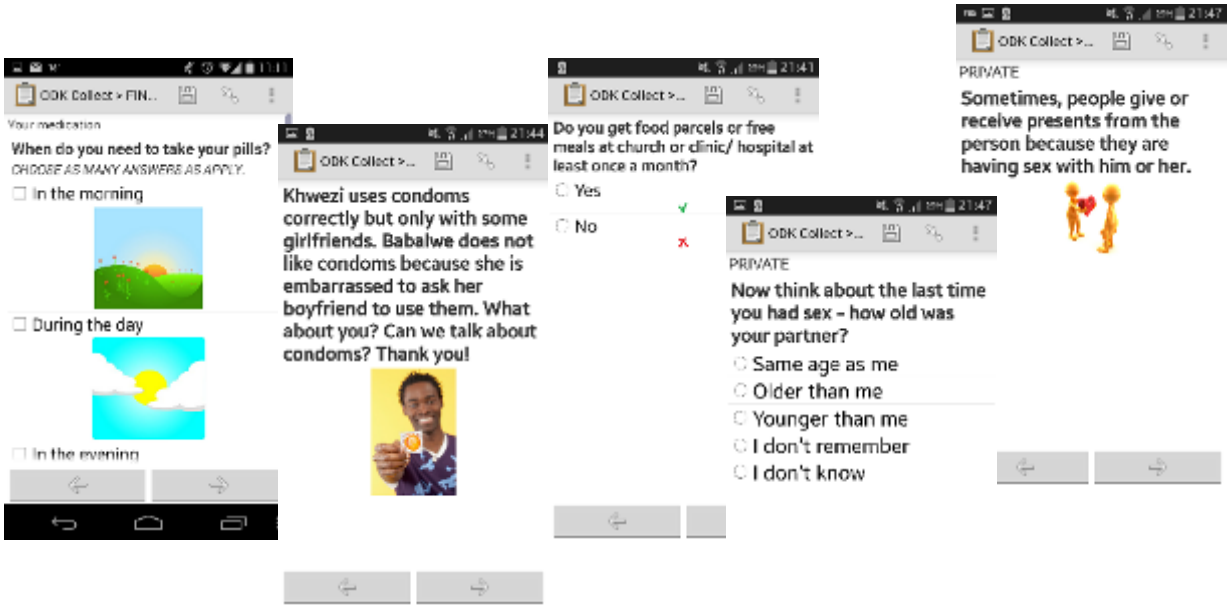


Figure 3-11. Screenshots from the tablet version of the Mzantsi Wakho baseline questionnaire

Following each interview, the research assistant recorded process-related information in a reflection form (Appendix 5.4). This allowed for the candidate and other fieldwork managers

to have additional information on necessary referrals, data quality issues, and details that allowed addressing ambiguous or inconsistent answers. Reflection form data was added to the interview dataset and was particularly crucial in appropriately recording two types of data:

- Disclosure level of the HIV-positive participant – research assistants noted whether the adolescent was HIV-positive status-aware, knew that they were taking ARVs, or both. Only participants that knew both were coded as aware of their own HIV-positive status; and
- Cases of abuse, extreme hunger, or learning disabilities, which were only disclosed to the team members after the interview was completed.

This additional information has been used to triangulate self-reported interview data and to update the study roster.

Data collection started on March 4th, 2014 and continued until September 25th, 2015. This candidate co-managed data collection in the first fieldwork team – East London – and then moved to set up and train a second fieldwork team – King William's Town - in September 2014. The second study team was necessary because the East London-based study team was travelling extensively to interview the participants living around the King Williams Town area, which cost a lot and required considerable amounts of time spent travelling to and from the office. In each new facility and community, the research team followed a flexible yet consistent process:

- Introduce the study at each included facility, obtain the necessary facility-level approvals, and identify all the ART-eligible adolescents who had ever received care in the facility.
- Add the information of all study-eligible adolescents to the study roster and double-check whether the participants were already interviewed or located in other facilities.[17]

[17] Over 300 adolescents had received care in more than one facility.

- Discuss with facility data capturers, ART or general care nurses the best way to meet and recruit participants from the facility.
- Conduct interviews with adolescents during their appointment days to capitalize on the fact that adolescents and/ or caregivers would spend a long time in clinics waiting to see healthcare providers and receive medication refills.
- Trace participants to homes and communities in collaboration with ward counsellors, community health workers, and community guards.[18] A series of meetings with ward counsellors and local government leaders were held to prepare for the community canvassing and recruitment. Community guards were recruited from local councils, churches or tribal leader homesteads. In facilities that had community-based health workers, the research assistants shadowed them in their home visits and were introduced to study-eligible participants.
- Introduce the study to the community in non HIV-specific way and invited all 10-19 year old adolescents to participate.
- Follow up on referral cases by providing immediate access to food parcels or medication, or facilitating access to services such as social workers, medical treatment.

3.6.3. Data Management

The study roster – a document including contact details of all study-eligible participants, whether they were interviewed or not, and their contact details – was set up and managed by the candidate with support from two fieldwork coordinators. No responses from the questionnaires were included in the study roster, to avoid breaches of confidentiality. Coded language was used to support planning and review of data collection to date and to protect participants in cases of possible security breaches. Participants were coded as Giraffes if they were HIV-positive and knew their status, Elephants if they were HIV-positive and did not

[18] Community guards were community members identified by ward counsellors who helped the research team navigate areas that they had never been in before, both in terms of finding the right address and in terms of security.

know their status, and Bears if they were community controls (HIV-status-unknown/ HIV-negative).

One of the key advantages of mobile device-assisted data collection is that it integrates data collection, entry, editing, coding and cleaning into a single process (Gravlee, 2002; Gravlee, Zenk, Woods, Rowe, & Schulz, 2006). Mobile-assisted interviewing (MASI) instantly transmits participant responses to a server where the data is automatically captured, thus minimising data entry errors. Data collected on research handsets could not be accessed unless key coded when uploaded to a central network server. Data was validated regularly and merged as the study progressed to allow for constant data quality monitoring – the candidate cleaned and reviewed the data at three points during the study: June 2014 (3 months into baseline data collection), December 2014 (9 months into baseline data collection), and May 2015 (14 months into data collection, with Ms. Janina Steinert). Full data cleaning was conducted at the end of data collection (October-November 2015). A database was set up using unique identifiers for all baseline participants. Data was stored in an online server based at the Department of Social Policy and Intervention, and backed up at the University. Each tablet with anonymised data was also backed up at each field site. In this way, data was protected from both server failure and confidentiality breaches. All study documentation including paper-based questionnaires, informed consents forms, and reflection forms were kept in locked cupboards. Consent documents were kept separate from reflection forms. Any hard-copy data (rosters, transcripts, field notes and questionnaires) were coded – removing identifiers when interview data was included so that only the researchers are able to link it to individuals using a study master list/ roster of participants. The data collected will be kept in an anonymized version of the dataset for a period of up to five years after collection. Every effort was made to maintain participants' confidentiality. All data was identified by a unique participant number. No individual identifying information was collected or disclosed in reports, publications, or presentations.

In December 2014, six data collection tablets were stolen. Though the interview data was recovered from back-ups, the backups of the media files: photos, audio messages and

video messages set up at the Department of Social Policy and Intervention had failed. These data sources were not used for the analysis in this thesis, as the majority of the questions were qualitative explorations of quantitative measures and fun/ engaging activities. Following this data loss, back-up systems were improved and tested by several team members in response to the identified technology and communication failure.

Final baseline data cleaning: Following exports from the mobile-submitted dataset, the quantitative data was converted and entered into SPSS 22.0 and cleaned by this candidate and two team members (Alexa Yakubovich and Louis Pilard). MASI produces better data quality than paper-based questionnaires as the design software allows for logical rules and controls to be established. This feature of MASI minimizes missing data and inconsistent replies. Where missing or inconsistent data was identified, analyses used mean imputation – recoding missing data with the sample mean for that variable – a conservative approach to managing missing data (Tabachnick & Fidell, 2007). However, due to the skip patterns and use of tablets for data collection, missing data was minimal from n=0 (0%) in socio-demographics and n=3 (0.1%) in the disclosure variables. This candidate crosschecked variables with research assistants to establish consistency and discuss discrepancies with the principal investigators. This procedure is consistent with the finding of an experimental trial that found that (i) the least accurate editors were the researchers with no field experience in the survey sites, and (2) when provided with only partial information on which to make editing decisions, fieldworkers edited more accurately than both data managers and data users (Sana & Weinreb, 2008).

3.6.4. Data Collection Tools

The development of the data collection tools and procedures for this thesis was informed by a rigorous review of existing studies from the region, consultations with authors of published studies and with practitioners. Two data collection tools were developed for use during this thesis:

1. Questionnaire for adolescent participants, administered through face-to-face research assistants or self-completed by participants (Appendix 5.2), and
2. Biomarker data (viral load test results) from participant's patient files collected at participating clinics (section 3.6.7).

3.6.5. Adolescent Questionnaire Development and Piloting

Three data collection tools were obtained from researchers and practitioners, all of which had been used among adolescents living with HIV in the United States or sub-Saharan Africa:

1. Adolescent Sexual Behaviour Assessment: Male and Female versions © 2006 Dolezal, Mellins, Brackis-Cott and Meyer-Bahlburg. Though the questionnaire was developed in 2006, it was recently applied in a sample of HIV-positive adolescents in the US (Dolezal et al., 2012);
2. Survey Tool developed by Population Council, used among ALHIV in Kenya and Uganda (Obare et al., 2010); and
3. CHIVA Adolescent Sexual Risk Assessment tool used among HIV-positive adolescents in South Africa.

These three data collection tools were complemented by items and measures from the English/ Xhosa/ Afrikaans data collection tool developed, piloted and rolled out among 13-18 year old school-goers in the Western Cape by the team of Dr. Cathy Mathews, Department of Child Psychiatry at University of Cape Town (Mathews et al., 2013). The content of the questionnaire used by HIV-positive adolescents who knew their status is included in Appendix 5.2. Sample pages from the paper-based questionnaire are included in *Figure 3-12*, while screen-shots of the tablet-administered version were shown in *Figure 3-11*.

The final draft questionnaire was translated and back-translated into Xhosa by four research assistants in September-November 2013, to ensure cultural equivalence of items used (Brislin, 1970). At the end of 2013, this candidate worked with the research team to translate and pre-pilot the baseline questionnaire with participants in the qualitative arm of the study in rural parts of the study area. Changes from pre-piloting were included in the final questionnaire draft piloted in early 2014 with HIV-positive adolescents in rural and urban residential areas of the study area. Piloting took place with n=25 adolescents from the Teen Advisory Group, Keiskamma youth group and others who were not included in the final quantitative sample. In addition to pre-testing of the items in terms of comprehension, respondent interest, fatigue and acceptability, the questionnaire piloting also collected process data which allowed the research team to assess which sections took longer and were harder to comprehend. At the end of piloting, information on comprehension of questions, respondent burden, and ease of use of mobile devices were used to adapt and finalise the questionnaire.

Figure 3-12. Cover and sample page from Mzantsi Wakho Baseline Questionnaire Paper-based Version

3.6.6. Measures and Scales

Literature reviews were conducted for specific measures proposed by experts and studies assessing whether they had ever been used among adolescents living with HIV, specifically focusing on measures used in Sub-Saharan Africa. Authors of specific scales were contacted as appropriate and asked for permission to use the scales for research purposes.

This section starts with the outcome measures followed by an introduction to the various measures included in the final conceptual model for this thesis.

Primary Outcome Measures

The primary outcome measure for this thesis is protective sexual practices/ unprotected sex. This outcome is computed using two questions regarding condom use at most recent intercourse (male or female) as follows: *unprotected sex* (if adolescents reported having sex but using no male or female condoms), and *protective sexual practices* (if adolescents reported having sex using a male or female condom or being abstinent). All adolescents who were sexually active are coded as not engaging in *protective sexual practices*.

Condom and Contraception Use was assessed through a series of measures adapted based on the findings of the literature review and preparation of the systematic review protocol (Toska, Pantelic, Cluver, Meinck, & Keck, 2015). Similar to other studies among HIV-positive adolescents in Sub-Saharan Africa, two measures of condom use and other contraception methods were used:

- Use at most recent sexual experience. Though asking about the most recent sexual intercourse is only a snapshot, studies in South Africa have shown that given recall issues, *most recent sexual experience* is the best proxy for consistent condom use (Morroni, Smit, McFadyen, Mqhayi, & Beksinska, 2003). This was the most commonly included measure of condom and contraception use documented by the systematic review (Ankunda, Atuyambe, & Kiwanuka, 2016; Holub, 2010; Kembo, 2012; Mbalinda, Kiwanuka, Eriksson, Wanyenze, & Kaye, 2015; Mhalu, Leyna, & Mmbaga, 2013; Morris et al., 2012; Snyder et al., 2014)
- Use during sexual intercourse in the last year. Whilst more prone to recall bias, it is a common measure used in studies of adolescent sexual health in South Africa and the region (Beyeza-Kashesya et al., 2011; Santelli et al., 2013; Toska, Cluver, Boyes,

Pantelic, & Kuo, 2015).

Adolescents were coded as *sexually transmitted infection (STI) symptomatic* if they reported having one of four STI symptoms: genital sores/ warts, burning whilst urinating, genital itching/ redness, anal itching/ soreness/ bleeding, in the last 6 months, following WHO guidelines for syndromatic diagnosis of STIs (World Health Organization (WHO), 2004).

Adolescent pregnancy among girls, dichotomised as 1= ever having been pregnant before or during data collection, was measured using an item from the National Survey of HIV and Risk Behaviour Amongst Young South Africans (A. E. Pettifor et al., 2004).

Potential correlates of protective sexual practices/ unprotected sex

Measures and scales that were used to record the correlates included are described in more detail in the methods section of each paper (Chapters 5 and 6). A summary of scales and measures used in the full study questionnaire is included in Appendix 5.3. The summary includes sources of scales and measures, existing validation studies, and when possible reliability scores for the study sample reported in this thesis.

3.6.7. Biomarkers for HIV-positive Adolescents

At the time paper 3 was finalised, the research team had collected viral load data for a subset of adolescents from randomly-selected clinics: n=266 (25% of the HIV-positive adolescents). These data were extracted from patient files of HIV-positive participants – following informed consent – by two clinic-based research assistants using a paper-based tool (Appendix 6.3). Data were linked through an anonymised unique participant ID and entered into a dataset using the same tablet-based platform as the adolescent questionnaires. Participants with viral load counts >1,000 copies/ml were coded as reporting *virological failure* using WHO standards (World Health Organization (WHO), 2014). This data was used in the last paper of this thesis (Chapter 6).

3.7. RESEARCH CONSTRAINTS

This section details the various research challenges that were encountered during the study and the solutions that the research team designed and implemented in response.

3.7.1. HIV/AIDS-related Stigma and HIV-status Confidentiality

Despite the extensive roll-out of antiretroviral medication in South Africa since 2004, HIV-related stigma persists (Maughan-Brown, 2010). The research team was acutely aware that a research project which aimed to recruit HIV-positive adolescents would be ethically and methodologically challenging. Matters taken into consideration included unintended disclosure to adolescents who did not know their status, increased refusal to participate because of self-stigma by adolescents or caregivers, and actual marking of homes as HIV-affected by association with the study.

To facilitate tracing, the research team used participant lists that grouped participants by location of residence. Though these participant rosters did not include HIV-status markers, the team was wary of this information being accessible to non-research team members. However, in June 2014 one of these rosters was lost outside one of the health facilities. To protect the identity of the names on the lost roster, additional rosters with study participants, classmates and neighbours were created as part of the planning for a Youth Day held in the health facility where the participants were accessing information. No further incidents were reported in this area.

To address these challenges of stigma and confidentiality, the team applied several strategic and methodological solutions. First, when tracing adolescents in the community, the study was presented as a study on adolescent health and access to services. This message was reinforced through meetings with community leaders, communities and through media articles, written by the team in collaboration with local journalists (Figure 3-13).

Figure 3-13. Local newspaper article promoting the Mzantsi Wakho study

6 THE BUGLE FRIDA

Click on Tools to PDF.

Mzantsi Wakho interview 1000 teens

THE friendly faces of Mzantsi Wakho research assistants are commonly seen in communities around East London and King William's Town. Who are they? They are central to a world-leading research project that aims to discover more about the lives of teens (ages 10 -19).

This research helps the South African government and organizations such as UNICEF to provide better services for young people.

Mzantsi Wakho was designed in collaboration with the Departments of Education, Social Development and Health as well as Oxford University and the University of Cape Town with the valued help of young South Africans.

The research assistants have become known for their warm kindness in communities in the Eastern Cape. Their work involves visiting communities and interviewing young people in the safety of their homes with the consent of their parents or guardians.

"I believe the work we do is important because children cannot vote and we are making their voices heard," says Nokubonga Mjo, Research Assistant at Mzantsi Wakho.

MEETING THE TEENS: Mzantsi Wakho Research Assistants Sindiswa Mona, Amanda Mbiko, Nokubonga Mjo, Nomambondo Sontsonga, and Zoliswa Markeir delivering training to new incoming team members in Quigney, East London.

Amanda Mbiko is also a Research Assistant from Mzantsi Wakho, she says: "The Mzantsi Wakho study is important because it aims to bring change to the lives of the teens who face daily challenges".

Research participants are rewarded for their participation with packs containing tasty snacks, a toothbrush, toothpaste, and a pencil box with pens and a pencil. Young mums receive a special hamper for their baby. The information shared by teens is kept anonymous and confidential. One participant said: "It made me happy to talk about my life with someone who was really listening."

The most important finding from the study so far is that it is often not the fault of young people if they struggle to realize their full potential. For example, it is often because of poverty that children are unable to do well in school. Hunger is also a problem: children who have enough food to eat tend to perform better in school.

The research team also found that children who have lost their parents struggle to do well in school because they are burdened with too much household work and adult responsibilities while most other children are able to learn and play. Chores, such as taking care of the younger brothers and sisters, domestic labor, and work outside of the home, often keep these kids from attending school.

These research findings are already helping to inform how services can be better provided for teens in South Africa, but there is still much work and many interviews to complete. If Mzantsi Wakho talk to more teens, it is more likely that better quality services will be delivered. If you are a young person or have a young person in your family you may be lucky enough to have a visit from Mzantsi Wakho!

Second, in collaboration with the administrator of the largest facility in the study – Dr. Luntu Galo, administrator of the Cecilia Makiwane Hospital in Mdantsane – the research study determined that the recruitment of a cohort of adolescents from the community was necessary to avoid study participants being labelled as HIV-positive. The research team recruited 467 community control adolescents during the baseline study. They were either neighbouring or cohabiting adolescents who met the age criteria for the study. The health history of these adolescents was screened and if they disclosed being HIV-positive, they were included in the main study sample. If they were HIV-negative or their HIV status was unknown, they were interviewed using a version of the questionnaire that was not HIV-specific.

Third, when tracing an HIV-positive participant referred from a health facility, the research team ran the risk of exposing HIV-positive participants by using their names. Sometimes HIV-positive adolescents wanted to refer their HIV-positive peers to the study, effectively disclosing their status to the study team without the peer's consent. To avoid various forms of unintended disclosure, a rigorous research assistant training programme

was developed, coupled with recruitment of neighbours, siblings, and co-habiting adolescents. A three-tier process of identifying and training research assistants was developed. It consisted of official interviews and reference-checking, followed by a probationary training period, and a probationary time conducting interviews in the field. To protect participant confidentiality, research assistants signed Confidentiality Agreements and recused themselves from interviewing participants whom they knew from the researchers' home communities.

3.7.2. Tracing a complex sample from clinics to communities

The eligible sample for this study was very complex, including sub-groups of adolescents that did not know their status, had not disclosed their status at home, or were defaulting from treatment. Tracing this sample in the communities required careful planning and execution of recruitment strategies. Unfortunately, n=42 adolescents had died before the team traced them, though they were still listed in the clinic rosters. The team paid their respects to the families when these cases of death were recent and updated clinic records to avoid causing additional trauma to family members of potential participants.

To address the potential stigma-by-study-association, the team recruited neighbouring and cohabiting adolescents as described in detail in section 3.3.5. Among young women who were pregnant or new mothers, research assistants encountered high levels of reticence to disclose HIV-positive status, despite adolescents being interested in participating in the study. In response to this reticence, this candidate collaborated with the qualitative lead investigator and the field research team to develop an additional recruitment protocol (called Mzanti Wakho Plus Baby Protocol – Appendix 1.3). The recruitment protocol included prolonged introductory meetings and a relaxed conversation, which helped the young women to become comfortable with the research assistants, preceding the interviews. Through these efforts, the rate of disclosure among HIV-positive pregnant adolescents or new moms increased substantially.

3.7.3. Crime

The study took place in communities where adolescents, their families and the local research team members experience high levels of crime and violence. For example, 45% of this study's participants reported being attacked or robbed in the last year, and 75% of them reported more than one type of physical victimization (physical abuse, domestic abuse, theft or robbery). Based on experience from previous studies and fieldwork preparation requirements, this candidate conducted a risk assessment (form included in Appendix 11.1), led the drafting of a detailed safety protocol (Appendix 11.2), and attended two fieldwork safety courses. The research team underwent several training sessions focusing on minimizing the risk of anyone (researchers, adolescents, and their families) becoming exposed to crime while the research was conducted. Fieldwork only took place during daylight hours, with research assistants excluding from interviews areas that were deemed too unsafe to visit, and arranging for alternative locations to meet adolescents when possible. As a result, only 0.3% of the eligible sample (n=4) was excluded as a result of safety concerns.

Despite these efforts, a group of young men attempted to rob two team members in June 2014, multiple adolescents reported regular physical abuse, the team transported severely injured women to and from hospital, attempted hijackings were reported twice, and six of the ten tablets in use by the team were stolen from the back of a car at the end of a fieldwork day, resulting in partial loss of data.[19] In response, the team developed the following safety measures:

1. Hired local community guides who knew the communities better and could help the team to avoid unsafe areas and find addresses and homes of eligible participants;

[19] Due to a technological glitch at the back-up site at the Department of Social Policy and Intervention, the data was saved, except for recordings, photos, and videos submitted as part of the questionnaire. This data was not used for the analyses presented in this thesis.

2. Painted cars so that they were less desirable for hijacking, as the painting lowered their resell value and made them easily and uniquely identifiable (*Figure 3-14*). Team drivers were also trained in defensive driving techniques by principal investigator, Prof. Lucie Cluver.
3. Data collection tablets were insured, and the team strengthened the data backup systems.

In addition to the safety protocol, the research team set up a referrals team which responded to the violence reported by participants, led by a dedicated fieldwork manager (Ms. Julia Rosenfeld).

Figure 3-14. One of the project vehicles painted in 2015 in response to attempted hijacking

3.7.4. Violence

In addition to crime-related violence, the Eastern Cape province and the study area experienced significant election, politically- and labour-related violence during the baseline study. The majority of these protests have been due to frustrated service beneficiaries, national elections, and in one occasion, a suspicious community that thought the study team planned to kidnap children.

When such reports of violence were received, fieldwork was immediately stopped. This candidate and fieldwork managers ensured all team members were safe and engaged with local leaders/ ward counsellors in order to access up-to-date information on the protests. Monitoring via community contacts and local team members helped the team ascertain when it was safe to resume fieldwork. In the case of the community that believed the team wanted to kidnap children, the team members initiated a community meeting where the study was explained to local leaders and interested community members. It introduced

the study as one of research on adolescent health and access to services. This helped ensure the safety of team members and participants.

3.7.5. Road Safety

South Africa has very high rates of road vehicle accidents. In 2010-11 (most recent data) over 13,802 road fatalities were reported, a rate of 25.1 per 100,000 residents. This ranks the country 23rd out of the 50 African countries included in the World Health Organization's annual report for 2015 (World Health Organization (WHO), 2015). The research team experienced only one accident during the baseline study, which resulted in no fatalities. However, due to injuries and potential worry over HIV exposure through open wounds, the research team members involved received extensive medical care and, when relevant, post-exposure prophylaxis treatment. All fieldwork vehicles are insured, including medical insurance for occupants.

3.7.6. Infrastructure

The research area includes a primarily urban and peri-urban site (East London), and one primarily rural site (King Williams Town). Though the primary and secondary road network in South Africa is good, a number of participants lived in areas that are very difficult to access, either due to informal construction or to poor rural roads access. The team addressed these issues first by purchasing and using big vehicles that could handle off-road travel. Team members also drove in groups to ensure that if a vehicle was stuck or stranded, no one was isolated and unable to get assistance.

In 2015, South Africa experienced prolonged load-shedding, a phrase used to describe interruptions to electricity supply. This occurred at planned and random times of day and night in both study sites. In instances when load shedding made work impossible, the research team had to take time off or adapt by working from the homes of team members who had access to electricity depending on which areas were affected by

electricity cuts at any time. Paper-based questionnaires were designed as a back-up in event of tablets not charging due to load-shedding, but their use was minimised to ensure data collection consistency.

3.7.7. Trauma

In addition to the high levels of trauma reported and experienced by the study's participants, some members of the research team experienced significant levels of vicarious trauma during fieldwork. In response, the Oxford and South Africa-based research teams received counselling (on site and via Skype), an 8-week training in mindfulness meditation, and structured time off was given to team members most in need. Training offered to doctoral students in Oxford prior to embarking on such projects is being explored.

'These children will tell you, I cannot have one boyfriend, because I need to have another man for my hair, I must get another man because I have to have food… you find that they are engaging in a number of relationships. Multiple partners to have different needs met.'

(Mzantsi Wakho Research assistant, Female, Age 20-30 King Williams Town, Gittings et al. 2016)

'When it comes to risk of transmission, if that child is having food to eat there will be no need for that child to go out there, but if that child has no food to eat they are forced to go out and do whatever.'

(Learner Support Agent, Female, Age 20-30, Eastern Cape, South Africa, Gittings et al. 2016)

'I did not tell my boyfriend (that I am HIV positive) because I'm scared he may run away, and he is very supportive towards my child and if I do tell him, he might leave… I may even suffer when it comes to my child… he does not want to use a condom sometimes.'

(20-year old young mother, Mdantsane, Hodes 2015)

4. PAPER 1 – SEXUAL RISK-TAKING AMONG HIV-POSITIVE ADOLESCENTS AND YOUTH IN SUB-SAHARAN AFRICA: A SYSTEMATIC REVIEW OF PREVALENCE RATES, RISK FACTORS, AND INTERVENTIONS

(In preparation for submission to PLoS ONE)

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This paper is a systematic review addressing the first three research questions of this thesis – what is the evidence base on sexual risk-taking among HIV-positive adolescents and youth in sub-Saharan Africa. Due to the dearth of research on unprotected sex among HIV-positive adolescents in sub-Saharan Africa, this review was extended in two ways: (1) additional sexual risk-taking outcomes were included, (2) the target age was extended to include youth (10-24 year old). The review documents the evidence to date on the rates and correlates of sexual risk-taking, and effective interventions to reduce sexual risk-taking among HIV-positive adolescents and youth in sub-Saharan Africa. The introduction summarises why this topic is important and introduces existing research on the topic. The methods section includes search terms and strategies, inclusion and exclusion criteria, as well as data extraction and synthesis processes. Sexual risk-taking outcomes included: early sexual debut, inconsistent condom use, having an older partner, transactional sex, multiple sexual partners, sex while intoxicated, STIs, and unintended pregnancy. Results are presented in nine sub-sections. First, prevalence rates of the eight outcomes are discussed. Then the correlates tested by the included studies are summarised in five groups: individual,

relationship, family/community, structural, and HIV-related. This is followed by a section discussing associations between different sexual risk outcomes, and another on interventions to reduce sexual risk-taking in the region. The discussion section summarises key findings, discusses strengths and limitations, and deliberates on the implications for policy, practice, and future research. Specifically, the systematic review answers the following research questions:

1. *What is the evidence base for reducing sexual risk-taking among HIV-positive adolescents and youth in sub-Saharan Africa?*
    a. *What is the prevalence of sexual risk-taking among HIV-positive adolescents and youth in Sub- Saharan Africa?*
    b. *What factors (correlates, risk factors, or predictors) are associated with sexual risk-taking among HIV-positive adolescents and youth in sub-Saharan Africa?*
    c. *Which interventions, aimed at reducing sexual risk-taking among HIV-positive adolescents and youth in sub-Saharan Africa, have been tested, and how effective were they?*

Author statement: ET conducted the majority of the work involved in this review. She conceptualised the study, developed the protocol, and led the systematic review process (search strategy development, title, abstract and full-text review, data extraction and quality assessment) and drafted the manuscript. MP contributed to the search strategy development, data extraction and quality assessment processes, and piloted the tools used for these processes. KK tested the search strategy developed by ET, and contributed to title, abstract, and full-text review. ET extracted data from all included studies, and MP, FM, and RH conducted independent secondary data extraction. MP and FM contributed to the write-up and interpretation of findings. LC contributed to the design and conceptualisation of the review, write-up and interpretation of findings. All co-authors have reviewed and approved this author statement.

Acknowledgments: The authors would like to thank the authors of the primary research studies from sub-Saharan Africa for their dedication to the sexual health and well-being of HIV-positive adolescents and youth in the region. We especially thank the researchers who sent additional data and information to complete this review: Prof. Renee Heffron, Dr. Irving Hoffman, Dr. Kimberly Powers, Dr. Edna Viegas, Dr. Christiana Nöstlinger, Dr. Olive Shisana, Dr. Kangelani Zuma, and Goitseono Mafoko, Dr. Karine Dube, Dr. Vicky Jespers, Prof. Anna-Lise Williamson, Dr. Leigh Johnson, Dr. Gabriela Paz-Bailey, Nicola Willis, Dr. Webster Mahvu, Edward Pettitt II.

ABSTRACT

Background: Evidence on sexual risk-taking among HIV-positive adolescents and youth in sub-Saharan Africa is urgently needed. This systematic review synthesizes the extant research on rates, correlates, and interventions to reduce sexual risk-taking among HIV-positive adolescents and youth in sub-Saharan Africa.

Methods: Studies were located through electronic databases, grey literature, reference harvesting, and contact with researchers. Preferred Reporting Items for Systematic Reviews and Meta-Analyses guidelines were followed. Quantitative studies that reported on HIV-positive participants (10-24 year olds), included data on at least one of eight outcomes (early sexual debut, inconsistent condom use, older partner, transactional sex, multiple sexual partners, sex while intoxicated, sexually transmitted infections, and pregnancy), and were conducted in sub-Saharan Africa were included. Two authors piloted all processes, screened studies, extracted data independently, and resolved any discrepancies. Due to variance in reported rates and correlates, meta-analyses were not conducted.

Results: 610 potentially relevant titles and abstracts were identified. Full text was reviewed for 251 records. Forty-two records reporting on 35 studies were included. Data on one or multiple sexual practices were reported for 13,536 HIV-positive adolescents/ youth from 13 sub-Saharan African countries. Participants in the included studies were mostly female, vertically-infected, and on antiretroviral treatment. No prospective cohort data was found. Sixteen studies reported on individual, relationship, family, structural, and HIV-related correlates of sexual risk-taking, but findings were inconsistent. Of the four intervention studies (three RCTs), three reported group-based interventions and one reported an individual-focused combination intervention. Three of the interventions were effective at reducing sexual risk-taking, with one reporting no difference between the intervention and control groups.

Conclusion: Sexual risk-taking among HIV-positive adolescents and youth is high, with inconclusive evidence on potential determinants. Few known studies test secondary HIV-prevention interventions for HIV-positive youth. Effective and feasible low-cost interventions to reduce risk are urgently needed for this group.

Keywords: sexual risk behaviours, HIV-positive, adolescents, youth, sub-Saharan Africa, systematic review, prevalence, risk factors, interventions

Wordcount: 299 words

4.1. INTRODUCTION

With increased access to antiretroviral treatment in sub-Saharan Africa, the number of children vertically-infected with HIV who survive to adolescence has risen (Ferrand et al., 2009; UNAIDS, 2015). Coupled with sustained high HIV-incidence among youth in the region, this has resulted in nearly 1.7 million HIV-positive 10-19 year old adolescents in sub-Saharan Africa, with girls representing nearly two-thirds of this total (Africa's Health Project, 2012; Kassede, 2015; UNAIDS, 2014b). Despite global reductions in HIV prevalence, rates of new HIV infections remain the highest among 15-24 year old youth in sub-Saharan Africa (UNAIDS & AU, 2015). As their numbers continue to grow globally, adolescents and youth living with HIV are an essential group for secondary HIV prevention efforts (UNAIDS, 2014a).

HIV-positive adolescents and youth are at risk of passing on the virus to their sexual partners and children (Ajose, Mookerjee, Mills, Boulle, & Ford, 2012; WHO, 2012). They are additionally vulnerable to potential re-infection by HIV and more vulnerable to other sexually transmitted infections (STIs) compared to their HIV-negative peers (Sharer & Fullem, 2012). Adolescents are more likely than adults or younger children to adhere poorly to their medication (Evans et al., 2013; Hudelson & Cluver, 2015; Nachega et al., 2009) and in particular to treatment regimens to prevent mother-to-child-transmission (G Fatti et al., 2014). Low adherence and retention in care rates are strongly associated with resistance to available antiretroviral therapies, including second-line treatment when available (Chawana et al., 2016; Schramm et al., 2016). With limited access to second and third-line antiretroviral treatment, HIV-positive adolescents risk running out of treatment options or infecting others with resistant strains of the virus. In addition, HIV-positive adolescents experience a range of vulnerabilities that reduce the efficacy of generalised prevention programmes, including cognitive and mental health issues (Lowenthal et al., 2014; Sherr et al., 2014), family-related challenges (Amzel et al., 2013; Wiener & Battles, 2006), and material deprivation (Busza et al., 2013; Mellins et al., 2012). Adolescents living with HIV in sub-Saharan Africa are

particularly vulnerable to these risks due to poor access to healthcare services such as family planning, HIV testing, and treatment (Busza, 2011; Jaspan et al., 2009; Mburu et al., 2013; Shisana et al., 2009; Wood & Jewkes, 2006).

A small number of studies on adolescents living with HIV in sub-Saharan Africa report high rates of unprotected sex (Cataldo et al., 2012; Mergui & Giami, 2011; Shisana et al., 2014), however little is known about rates of other high-risk practices, such as transactional sex, sex with older partners, and multiple concurrent sexual partners (Morris et al., 2012). In the general adolescent population, these high-risk sexual practices have been associated with higher odds of becoming infected with HIV (Santelli et al., 2013). Though the evidence on different high-risk sexual practices among HIV-positive adolescents is nascent, understanding factors associated with sexual risk-taking is crucial for intervention development.

Although some interventions to reduce sexual risk behaviours have been conducted among HIV-positive adolescents in the United States (Butler et al., 2003; Chandwani et al., 2011; Chen et al., 2011; Lee et al., 2005; Markham et al., 2009), there is a dearth of research and interventions on secondary prevention among HIV-positive adolescents in the developing world (Pretorius et al., 2015). A 2010 WHO review of behavioural interventions for HIV positive prevention in middle and lower-income countries found 19 studies, none of which focused on young people (Kennedy et al., 2010). A recent review of sexual and reproductive health and rights interventions for youth living with HIV in sub-Saharan Africa located six small-scale interventions (Pretorius et al., 2015), only three of which quantitatively measured change in a sexual risk behaviour (Lightfoot, Kasirye, Comulada, & Rotheram-Borus, 2007; Senyonyi, Underwood, Suarez, Musisi, & Grande, 2012; Snyder et al., 2014).

To fill the evidence gap in effective interventions for this vulnerable population, further research is needed to elucidate HIV-positive adolescent sexual and reproductive health needs. This includes a better understanding of the epidemiology of sexual risk-taking

as well as hypothesized models of sexual health decision-making among HIV-positive adolescents and youth (Fair et al., 2012). This systematic review synthesizes existing evidence of sexual risk-taking among HIV-positive adolescents and youth in sub-Saharan Africa (10-24 years old): 1) prevalence 2) risk-factors, and 3) interventions.

4.2. METHODS

This review follows the Preferred Reporting Items for Systematic Reviews and Meta-Analyses (PRISMA) guidelines (Moher et al., 2009). The scope of this review (*Table 4-1*) is to assess the state of the evidence for three research questions:

a. What is the prevalence of sexual risk-taking among HIV-positive adolescents and youth in Sub- Saharan Africa?
b. What factors (correlates, risk factors, or predictors) are associated with sexual risk-taking among HIV-positive adolescents and youth in sub-Saharan Africa?
c. Which interventions, aimed at reducing sexual risk-taking among HIV-positive adolescents and youth in sub-Saharan Africa, have been tested, and how effective were they?

Table 4-1. Scope of systematic review

Population	Adolescents and Youth living with HIV Age range: 10-24 years old
Outcome	Individual risk behaviours: early sexual debut, inconsistent condom use, having an older partner, transactional sex, having multiple sexual partners, sex drunk or on drugs, sexually transmitted infections, and unintended adolescent pregnancies. OR Composite risk behaviours consisting of any of the above behaviours combined.
Geographic location	sub-Saharan Africa
Study Design	Randomised controlled trials (individual or cluster), Quasi-experimental studies including quasi-randomized trials, controlled before-after studies, pre- and post-test studies, longitudinal cohort studies, cross-sectional studies

Inclusion criteria applied consisted of: study population, design, sampling strategy, outcome measures, population type and language (Appendix 8.1.1). To document outcome

prevalence rates and factors associated with the outcomes, cross-sectional surveys and longitudinal prospective cohort studies were included. Though RCTs provide the strongest form of evidence about intervention impact, due to the small number of RCTs identified in preliminary searches, this review also included studies with less rigorous designs: pre–post intervention comparisons and post-intervention comparisons with 'control' populations. Studies measuring at least one of eight high-risk sexual practices either as a primary or secondary outcome were included. High-risk sexual practices included: early sexual debut, inconsistent condom use, having an older partner, transactional sex, having multiple sexual partners, sex whilst intoxicated, sexually transmitted infections, and unwanted adolescent pregnancies, or a composite measure of two of these outcomes. Reports in English and French were reviewed to allow for publications from Western and Central Africa.

Exclusion criteria: Studies of special populations such as sex workers, men who have sex with men, truck drivers, male factory workers, were excluded.

Search Strategy*:* In September-November 2015, the first author searched the online databases of PsycARTICLES, Embase, Global Health, MEDLINE, and PsycINFO, PubMed, CINAHL, ProQuest, and WHO Afro Library, the Cochrane and Campbell databases and the PROSPERO register of systematic reviews. The first author also searched International AIDS Society conference abstracts and presentations, as well as websites of major international and regional organisations, such as the World Health Organization (WHO), Joint UN Program for HIV/AIDS (UNAIDS), the UN Children's Fund (UNICEF), United States Agency for International Development (USAID), UN Family Planning Agency (UNFPA), International Planned Parenthood Federation (IPPF), and Population Council. Key search terms for sample population (children, adolescents, teenagers and youth), all high-risk sexual practices, location (sub-Saharan Africa) and timeline were included (Tables 1-4, Appendix 8.4). All searches were conducted within the publication date limits of 1983 or the closest date limit available, reflecting the time since HIV has been diagnosed in adolescents and youth. Search terms were adapted to include the requirements of different databases

and were included in the systematic review protocol: (PROSPERO registration number CRD42015025871).

Screening: The screening process followed the Cochrane Collaboration Handbook guidelines (Green et al., 2011). Following merging and de-duplication, two authors reviewed titles and abstracts for relevance. When available, full-text documents were retrieved and checked for eligibility against inclusion and exclusion criteria (Table 1, Appendix 8.4), and a set of pre-agreed screening questions (Appendix 8.2.1). Email requests for clarifications, unpublished data, and data from published studies were sent to researchers working on sexual risk-taking of HIV-positive adolescents and youth. Recent guidance on systematic reviews suggests that there is a potential bias from including studies with very small samples in systematic reviews (Roberts & Ker, 2016). To minimise this bias, when studies reported ≥50 HIV-positive adolescents and youth, but age-disaggregated data was not available in the included reports, authors were contacted for age-disaggregated data for 10-24 year old HIV-positive participants. If additional data were provided, the studies were included in the review. Reference lists of the included studies and of other relevant reviews were screened for further eligible titles.

Data extraction: Data was extracted from full-text records by the first author (ET) using a pre-piloted data extraction form (Appendix 8.2.3). A second independent reviewer checked the data extraction for each included study (MP/FM/RH) and any discrepancies were resolved through discussion. Records reporting analyses from the same dataset were checked for data duplication, with the largest sample taken if multiple reports were available for the same outcome measure. For longitudinal studies reporting a change in an outcome of interest, baseline values of the reported outcome were extracted as prevalence rates. If data was not reported for HIV-positive adolescents or youth specifically but authors provided the raw data, prevalence rates for sexual risk-taking were calculated for HIV-positive adolescent or youth, via frequencies in SPSS. In such instances, the same definition of the sexual risk outcome as the primary study was used. For example, Viegas and colleagues reported rates

of early sexual debut defined as ‘before the age of 18’ for a sero-assorted sample (Viegas et al., 2015). Using a dataset shared by the research team, this review’s first author computed the prevalence of ‘sexual debut before 18 years old’ for HIV-positive youth. Where relevant, the prevalence of risky sexual practice was computed based on the prevalence of related safe sexual practices reported. For example, if a study reported condom use at last intercourse as 40%, the rate of unprotected sex at last intercourse included in Table 2 was computed as 60%. Both reported and computed rates of inconsistent condom use/ unprotected sex are reported in *Table 4-2*.

Risk of bias across studies was assessed using a Study Quality Checklist and risk assessment form (Appendix 8.2.2). The form drew from guidance on assessing systematic bias from the Cochrane Handbook for experimental designs (randomised controlled trials (RCTs), non-randomised controlled trials and pre- and post-test experimental design) (Green et al., 2011), and the Cambridge Quality Checklist for systematic reviews of risk factors (Murray, Farrington, & Eisner, 2009). The checklist was adapted in line with a systematic review of internalised stigma among people living with HIV (Pantelic, Shenderovich, Cluver, & Boyes, 2015). Adaptation included assessing sampling strategies at two levels: facility/ community and individual level, and assessing each individual associations between potential factors and the outcome of interest. For each potential determinant, each outcome-determinant relationship was scored as a percentage of the total score possible from the Study Quality Checklist (SQC). SQC scores for each outcome-predictor relationship are reported in *Table 4-12*.

Data synthesis: Given the diversity of primary studies and outcomes measured, and the cross-sectional nature of the majority of the included studies, a meta-analyses was not conducted, in order to avoid potentially misleading conclusions (Murray et al., 2009). To reflect the diversity of reported prevalence rates, data was reported as the range of reported values for studies using the same definitions for each outcome.

Table 4-2. Summary of included studies

First author, year	*Location*	*Study design*[1]	*Sampling strategy*[2]	*Target population*	*HIV+ adolescents/ youth*	*Early sexual debut*[3]	*Inconsistent condom use*	*Contraception*	*Older partner*	*Transactional sex*	*Multiple sexual partners*	*Sex intoxicated*	*Sexually Transmitted*	*Unwanted pregnancies*	*Other outcomes*
Ankunda 2011; Ankunda 2016	Uganda	CS	FP; TR	15-24 year old HIV+ (n=425 (2011) n=335 (2016))	n=425 (2011) n=335 (2016)	1	1, 2				1				1
Bakeera-Kitaka 2008	Uganda	CS	FP; PS	15-24 year old HIV+ (n=75)	n=75	1					1				
Banura 2008	Uganda	CS	FP; CS	12-24 year old (n=1,275)	n=82								1		
Baryamutuma 2010	Uganda	CS	FP; CS	13-19 year old HIV+: n=386	n=386	1, 2	1, 2		2				1, 2	1, 2	
Beyeza-Kasheysa 2011	Uganda	CS (PCS)	FP; CS	15-24 year old HIV+ & HIV-: n=624 (2011), n=777 (2009)	n=276 (2009) n=206 (2011)		1	1			1			1	
Birungi 2009a; Birungi 2009b; Obare 2010a	Uganda	CS	FP-CP; CS	15-19 year old (n=2,945, n=2,213 HIV-status unknown)	n=732	1	1, 2	1, 2						1, 2	
Birungi 2011; Obare 2012	Kenya	CS	FP; PS	15-19 year old HIV + females (n=757)	n=757			1, 2						1, 2	
Cataldo 2012	Malawi, Mozambique, Zambia, Zimbabwe	CS	NR; CS	10-19 year old HIV+ (n=1,703)	n=1,703	1	1, 2								
Gavin 2006	Zimbabwe	CS	CRS; TR	15-19 year old (n=1,807)	n=192	1	1			1	1		1	1	
Gray 1998	Uganda	CS (RCT)	CRS; TR	15-49 year old women (n=4,813)	n=361									1	

First author, year	*Location*	*Study design[1]*	*Sampling strategy[2]*	*Target population*	*HIV+ adolescents/ youth*	*Early sexual debut[3]*	*Inconsistent condom use*	*Contraception*	*Older partner*	*Transactional sex*	*Multiple sexual partners*	*Sex intoxicated*	*Sexually Transmitted*	*Unwanted pregnancies*	*Other outcomes*
Heffron 2010	Eastern Africa: Kenya, Rwanda, Tanzania, Uganda Southern Africa: Botswana, South Africa, Zambia	CS	CRS; TR	18-45 year old women (n=3,407)	n=523		1	1							
Hendriksen 2007; Steffenson 2011	South Africa	CS	CRS; TR	15-24 year old (n=7,686 2007; n=7,692 2011)	n=1,235 (2007); n=1,091 (2011)		1				1				
Hoffman 2008	Malawi	CS (PCS)	FP; PS	18+ year old HIV+ women (n=227)	n=90			1							
Holub 2010	Democratic Republic of Congo	CS	FP; PS	14-24 year old HIV+ (n=103)	n=103	1	1, 2			1	1				
Kaggwa 2012	Uganda	CS	FP; NR	16-24 year old HIV + (n=453))	n=453		1, 2				1, 2				1
Katusiime 2012	Uganda	CS	FP; PS	15-24 year old HIV+ (n=148)	n=148								1, 2		
Kembo 2012	Zimbabwe	CS	CRS; NR	15-24 year old (n=6,139)	n=477	1	1				1		1		
Lightfoot 2007	Uganda	RCT	CNR; CS	14-21 year old HIV+ (n=100)	n=100	1	1, 3								1, 3
Malaju 2013	Ethiopia	CS	FP; NR	15-24 year old (n=405)	n=104	1									
Mbalinda 2015a; Mbalinda 2015b	Uganda	CS	FP-FRS; PS	10-19 year old HIV+ (n=624)	n=624	1	1				1		1	1	1, 2
Mhalu 2013	Tanzania	CS	FRS; TR	15-24 year old HIV+ (n=232)	n=232	1, 2	1, 2				1, 2				
Morris 2012	Cameroon	CS	FRS-CP; TR	12-26 year old (n=534, n=210 HIV-, n=210 unknown)	n=114	1	1		1		1				

First author, year	*Location*	*Study design*[1]	*Sampling strategy*[2]	*Target population*	*HIV+ adolescents/ youth*	*Early sexual debut*[3]	*Inconsistent condom use*	*Contraception*	*Older partner*	*Transactional sex*	*Multiple sexual partners*	*Sex intoxicated*	*Sexually Transmitted*	*Unwanted pregnancies*	*Other outcomes*
Muyindike 2012	Uganda	CS	FP; NR	18-49 year old women (n=826)	n=211			1							
Nhamo 2013; Nhamo 2014	Zimbabwe	RCT	NR; NR	16-19 year old HIV+ (n=710)	n=710		3			1, 3	1, 3			1, 2	1, 2
Noestlinger 2015	Uganda	CS (PCS)	FC-CC; PS	13-17 year old HIV+ (n=532)	N=532	1	1								
Obare 2010b	Kenya	CS	FP; PS	15-19 year old HIV+ (n=606)	n=606		1, 2	1, 2	1, 2					1, 2	1, 2
Pascoe 2015	Zimbabwe	CS	CRS; TR	18-22 year old (n=2,593)	n=199	1	1		1	1	1		1		
Santelli 2013	Uganda	CS (PCS)	CRS; TR	15-24 year old (n=6,741)	n=204		1				1		1		
Senyonyi 2012	Uganda	RCT	FP; CS	12-18 year old HIV+ (n=115)	n=115										1, 3
Shisana 2014	South African	CS	CRS; TR	All ages (n=28,997)	n=443	1	1		1		1	1			1
Snyder 2016	South Africa	PPT	FC-CC; CS	16-24 year old HIV+ (n=65)	n=65		1, 3								
Test 2012	Rwanda	CS	FC-CC; CS	16-24 year old HIV+ (n=107)	n=107	1	1, 2		1, 2	1, 2	1, 2	1			
Toska 2015	South Africa	CS	FRS-CP; TR	10-19 year old HIV+ (n=858)	n=858	1	1, 2								
Viegas 2015	Mozambique	CS	FC; PS	18-24 year old (n=1,380)	n=85	1	1				1		1		
Wanyenze 2011	Uganda	CS	FP; CS	15-49 year old HIV+ (n=1,142)	n=159			1							

Notes:

[1] CS cross-sectional study, PCS prospective cohort survey, PPT pre and post-test; RCT randomised controlled trial.

[2] Sampling strategy documented at two levels: (1) cluster: facility random and/ or stratified (FRS); facility purposeful (FP), community random and/or stratified (CRS), community purposeful (CP), mixed – see symbols (2) individual: total/ random (TR), purposeful (PS), convenience (CS); NR – not reported.

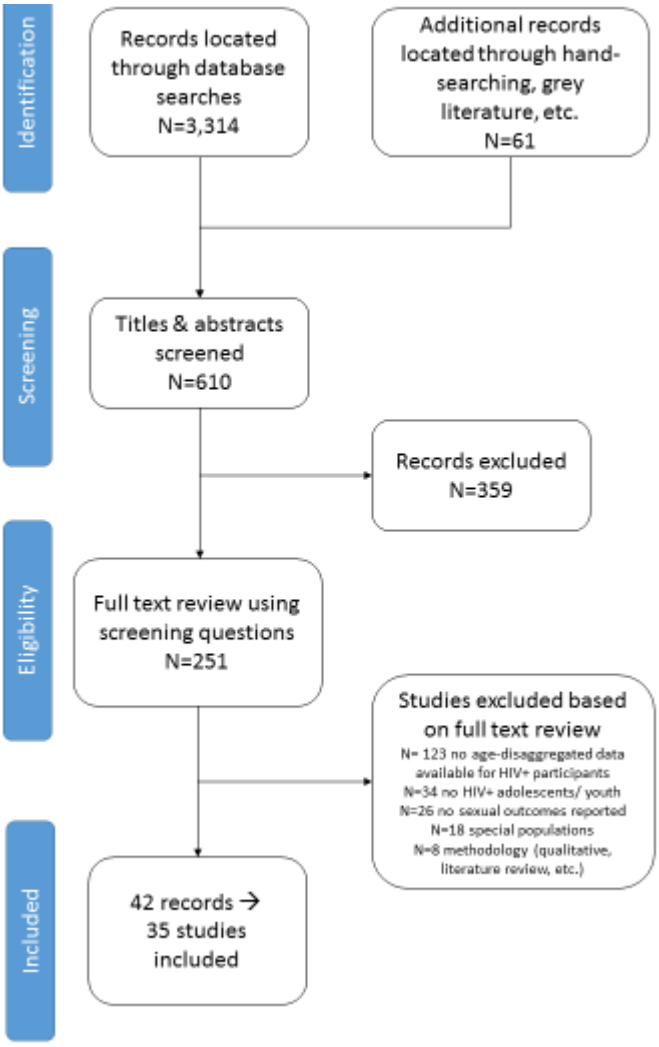
[3] 1 – prevalence; 2 – correlates/ predictors; 3 – intervention/ programme

4.3. RESULTS

4.3.1. Characteristics of included studies

Figure 4-1 shows the PRISMA flow diagram for included studies. Results from different database searches were merged, resulting in 3,314 records. Grey literature searches and hand-searches of references of included studies resulted in an additional 61 records. After de-duplication, two authors (ET/KK) reviewed 610 titles and abstracts to remove search results that did not meet the inclusion criteria. Full text documents for 251 results were reviewed by two authors (ET/KK). A total of 42 records were included in this systematic review, which reported data from k=35 studies.

Figure 4-1. PRISMA flow diagram for identifying the included studies



Study design: The 35 included studies reported data from N=13,536 HIV-positive adolescents and youth living in 13 countries. Four studies described interventions evaluated through RCTs (k=3), pre- and post-test experimental design (k=1), and the remaining 31 reported on cross-sectional data (Table 4-2).

Participant characteristics: Participants were mostly female (k=35 studies: 47%-100%), vertically-infected (k=9 studies: 43%-100%), and on ART (k=9 studies: 0%-88%).[20] Of the 17 studies that reported whether HIV-positive adolescents and youth knew their status, most recruited only adolescents who knew their status (k=13). In the six studies which recorded disclosure of HIV status to others, just under half of HIV-positive adolescents had shared their HIV-positive status with their partners (31%-74%) (Ankunda et al., 2016; Birungi, Mugisha, Obare, & Nyombi, 2009; Mbalinda, Kiwanuka, Eriksson, et al., 2015; Nöstlinger, Bakeera-Kitaka, Buyze, Loos, & Buvé, 2015; Obare et al., 2010; Toska, Cluver, Hodes, & Kidia, 2015).

Sampling: Twenty studies only included HIV-positive adolescents and youth (Ankunda, Atuyambe, & Kiwanuka, 2011; Ankunda et al., 2016; Bakeera-Kitaka, Nabukeera-Barungi, et al., 2008; Baryamutuma, Nabaggala, Muhairwe, & Baingana, 2010; Birungi, Obare, Kwaak, & Namwebya, 2011; Cataldo et al., 2012; Holub, 2010; Kaggwa & Hindin, 2012; Katusiime & Kambugu, 2012; Lightfoot, Kasirye, et al., 2007; Mbalinda, Kiwanuka, Eriksson, et al., 2015; Mbalinda, Kiwanuka, Kaye, & Eriksson, 2015; Mhalu et al., 2013; Nhamo et al., 2013; Nöstlinger, Bakeera-Kitaka, et al., 2015; Obare et al., 2010; Obare, Kwaak, & Birungi, 2012; Senyonyi et al., 2012; Snyder et al., 2014; Test et al., 2012; Toska, Cluver, Hodes, et al., 2015), nine studies included HIV-positive adolescents/ youth alongside peers who were HIV-negative or HIV-status unknown (Banura et al., 2008; Gavin et al., 2006; Hendriksen et al., 2007; Kembo, 2012; Malaju & Asale, 2013; Morris et al., 2012; Pascoe et al., 2015; Santelli et al., 2013; Viegas et al., 2015), and the remaining six included HIV-positive adolescents and youth alongside other participants. Of these six studies, two included HIV-positive adolescents and youth alongside HIV-positive individuals from other age groups (Hoffman et al., 2008; Wanyenze et al., 2011), and four studies HIV-positive adolescents and youth alongside HIV-negative participants from other age groups (Gray et

[20] An additional k=5 studies reported that some of the participants were on ART but did not report the proportion of ART-experienced partipants.

al., 1998; Heffron et al., 2010; Muyindike et al., 2012; Shisana et al., 2014). Thirty-three studies assessed sexual practices of HIV-positive adolescents as the primary outcome, two reported them as secondary outcomes.

Outcome measures: The outcomes measured varied in terms of the recall periods of measurement and exact definitions (Table 4-3). Nine studies reported on only one sexual practice, while the rest reported on two or more sexual practices (Table 4-2). The most common definitions for each reported outcome were: (1) sex before 15 years old (k=3), (2) sex before 18 years old (k=3), (3) inconsistent/ no condom use at last sexual encounter (k=14), (4) current use of modern contraception (k=6), (5) having an older partner at first sexual intercourse (k=4), (6) having ever had transactional sex (k=3), (7) multiple sexual partners in the past 12 months (k=5), (8) sex while intoxicated (k=2), (9) ever having had an STI or STI symptoms (k=5), and (10) ever been pregnant (k=7). All outcomes were based on self-reports, except for two studies reporting results of STI tests for Hepatitis B (HBV) (Katusiime & Kambugu, 2012) and Human Papillomavirus (HPV) (Banura et al., 2008). One study reported on a composite sexual risk-taking score (Senyonyi et al., 2012). Three of the included studies reported on outcomes related to one of the main outcomes: gender-based violence, forced sex, and sexual abuse. These outcomes were not included in this review as outcomes, but as potential risk-exposure factors where appropriate data was available.

Table 4-3. Prevalence rates of sexual risk-taking among HIV-positive adolescents and youth

Outcome	*Definition*	*Studies*	*Rates (% or M)*	*Gender or age disaggregation*	*Actual reported outcome (actual value reported in the study)*
Early sexual debut	Not defined	Ankunda 2011	35.1%	NR	Abstinence/ never having had sex (64.9%
		Baryamutuma 2010	39.9%	NR	Early sexual initiation
			33%	31% F; 37% M	Ever had sex (all under 19 years old)
		Birungi 2009a	Mal 10%; 38%	NR	Ever had sex (all under 19 years old)
		Cataldo 2012	Moz: 11%; 65% Zam: 5%; 29% Zim 3%; 16%	Moz 10-14 y.o. (4% F; 17% M) 15-19 y.o. (69% F vs. 49% M)	
		Lightfoot 2007	40%	NR	Ever had sex (all under 19 years old)
		Obare 2010b	84%	88% F; 73% M	Ever had sex (all under 19 years old)
		Toska 2015	15.1%	19.2% F; 10.7% M	Ever had sex (all under 19 years old)
	Age of sexual debut	Ankunda 2016	16.9 (2.62)	17.1 (2.41) F; 15.4 (3.85) M	Mean age (SD) of sexual debut
		Gavin 2006	16.4 (0.14)	NR	Mean age (SD) of sexual debut
		Morris 2012	17.2 (2.3)	NR	Mean age (SD) of sexual debut
		Nöstlinger 2015	13 (11-14)	NR	Median age (IQR) of sexual debut
		Test 2012	17 (15-18)	17 (15-18) F; 16 (15-17.5) M	Median age (IQR) at consensual sexual debut
	<15 years old	Kembo 2012	28.1%	NR	
		Mhalu 2013	51.5%	68% F; 84.8% M	
		Shisana 2014	7.4%	4.4% F; 19.1% M	
	≤15 years old	Bakeera-Kitaka 2008	42.1%	NR	
		Holub 2010	48.5%	45% F; 65% M	
	<18 years old	Malaju 2013	63.6%	NR	
		Pascoe 2015	36.2%	NR	
		Viegas 2011	77.6%	78.6% F; 70% M	
	≤19 years old	Kembo 2012	87.0%	NR	Sex between 15-19 58.9% & sex before 15 28.1%
Inconsistent condom use/ Unprotected sex	Not clearly defined	Ankunda 2011	61.7%	NR	Condom use (38.3%)
		Baryamutuma 2010	56.3%	NR	Consistent condom use (43.7%)
		Beyeza-	28.2%	NR	No contraception at all (28.2%)

Outcome	*Definition*	*Studies*	*Rates (% or M)*	*Gender or age disaggregation*	*Actual reported outcome (actual value reported in the study)*
		Kashesya 2011	76%	NR	Consistent condom use (24%)
		Heffron 2010	32.3%	NR	Unprotected sex
		Mhalu 2013	58.6%	NR	Used condoms at every sexual act (41.4%) – timeline not defined
		Pascoe 2015	82.4%	NR	Sometimes/ never used condoms with any partners (82.4%)
	Never	Beyeza-Kashesya 2011	39%	NR	Never used condoms (39%)
		Morris 2012	11.9%	NR	Ever used condoms (88.12%)
		Nöstlinger 2015	43.5%	NR	Ever used a condom (56.5%)
	First sex	Kembo 2012	77.4%	NR	Condom use (22.6%)
		Nöstlinger 2015	75%	NR	Condom use at first sex (25%)
		Toska 2015	23.6%	21.1% F; 16.2% M	Unprotected sex (25.8%, 23.6% F, 16.2% M)
	Last sex	Ankunda 2016	46.7%	NR	Consistent condom use (53.3%)
		Gavin 2006	80.3%	All female	Condom use at last sex (19.7%)
		Hendriksen 2007	37.9%	51.3% F; 55% M	Unprotected sex
		Holub 2010	18.5%	NR	Unprotected sex
		Kaggwa 2012	49.5%	NR	No condom use at last sex (49.5%)
		Kembo 2012	82.7%	NR	Condom use (17.3%)
		Mbalinda 2015b	43.7%	NR	Unprotected sex (43.7%)
		Mhalu 2013	55.3%	NR	Condom use (44.7%)
		Morris 2012	45%	NR	Condom use (55%)
		Pascoe 2015	58.8%	NR	Unprotected sex
		Shisana 2014	39.1%	37.8% F; 44.5% M	Condom use at last sex (60.9%, 62.2% F, 55.5% M)
				NR	Condom use at baseline (pre-intervention 71%)
		Snyder 2014	29%	31.9% F; 13.5% M	Unprotected sex at last sex (28.9%, 31.9% F, 13.5% M)
		Toska 2015	28.9%	38.7% F; 30% M	Condom use (62.4%, 61.3% F, 70% M)
		Viegas 2015	37.6%		
	Last 3 months	Lightfoot 2007	87.5%	NR	Always use condoms at baseline for full intervention sample (12.5%)
	Last 6 months	Ankunda 2016	53.6%	NR	Consistent condom use (46.4%)
		Mbalinda 2015a	77.5%	NR	Use at every sexual act (22.5%)
		Test 2012	56%	57% F; 50% M	Inconsistent condom use (56%, 57% F, 50% M)

Outcome	*Definition*	*Studies*	*Rates (% or M)*	*Gender or age disaggregation*	*Actual reported outcome (actual value reported in the study)*
	Last 12 months	Santelli 2013	88.7%	92.6% F; 78.6% M	Never or inconsistent condom use (88.7%, 92.6% F, 78.6% M)
	Current	Birungi 2009a	48%	41% F; 52% M	Condom use: sometimes or rarely
		Obare 2010a	60.7%	61.8% F; 59.2% M	Current using condoms (39.3%, 38.2% F, 40.8% M)
				NR	Condom use: sometimes or never (69.3%) vs. always (30.7%)
		Morris 2012	69.3%		
				16% F; 4% M	Condom use (86%, 84% F, 96% M)
		Obare 2010b	14%		
Contraception	Ever any method	Beyeza-Kasheysa 2009	33%	33%	Ever used any contraception (n=345)
		Birungi 2009b	49.6%	43.8% F; 58.2% M	Any contraception in past/ current relationships
				72% F; 70% M	
		Obare 2010b	72%	NR	Ever used contraception
		Wanyenze 2011	78.7%		Any family planning method (including traditional)
	Ever pill/ injectable	Obare 2010a	12.5%	All female	Pill OR injectable among sexually active females
	First sex	Birungi 2009a	36.4%	37.5% F; 34.7% M	Used a method to prevent HIV infection/ reinfection at first sex
		Obare 2010	14%	15% F; 12% M	
		KEN			Any method
	Current modern	Beyeza-Kashesya 2011	33.9%	NR	Contraception use at baseline
		Obare 2010a	42.6%	41% F; 44.9% M	Current modern contraception
		Hoffman 2008	36.7%	All female	At baseline
		Muyindike 2012	29.9%	All female	Current use at enrolment in study
		Obare 2010b	66%	65% F; 68% M	Any method
		Wanyenze 2011	63.8%	NR	Any modern method of family planning
		Wanyenze 2011	25.5%	NR	Any effective method of family planning (excluding condoms)
	Current pill/ injectable	Beyeza-Kashesya 2011	21%	All female	Hormonal contraception
	Oral contraceptives	Heffron 2010	4.0%	All female	At baseline
		Obare 2010b	6%	6% F; 3%M	
	Injectable	Heffron 2010	14.7%	All female	At baseline
		Obare 2010b	23%	28% F; 2% M	
	Implants	Heffron 2010	0.6%	All female	At baseline
		Obare 2010b	2%	2% F; 2% M	

Outcome	*Definition*	*Studies*	*Rates (% or M)*	*Gender or age disaggregation*	*Actual reported outcome (actual value reported in the study)*
	Hysterectomy	Heffron 2010	0.6%	All female	At baseline
	Post-partum contraception	Birungi 2011	61%	All female	After pregnancies had ended
	Contraception uptake	Beyeza-Kashesya 2011	28.4%	NR	Started using any methods of contraception in past 12 months
	Long-term contraception use	Beyeza-Kashesya 2011	17.8%	NR	At baseline, 6 and 12 months follow up
		Heffron 2010	26.3%	All female	% quarterly visits reporting contraception use during 24-month follow-up
	Discontinued contraception	Beyeza-Kashesya 2011	23.6%	NR	Stopped using contraception during 12 month follow-up period
	Dual method use	Beyeza-Kashesya 2009	5%	NR	Unclear definition
Older sexual partner	First sexual partner	Gavin 2006	6.6 (0.87)	All female	Age difference between participant and partner – mean (SD)
		Morris 2012	65.7%	NR	6+ years older
		Obare 2010b	52%	61% F; 20% M	Older
		Obare 2010b	4%	4% F; 3% M	Much older
		Test 2012	66%	75% F; 17% M	>5 years older
		Test 2012	37%	41% F; 17% M	>10 years older
	Any	Pascoe 2015	28.1%	NR	6-10 years old
		Pascoe 2015	18.1%	NR	11+ years older
	Last sexual partner	Gavin 2006	5.0 (0.67)	All female	Age difference between participant and partner – mean (SD)
	Current sexual partner	Obare 2010b	56%	68% f; 10% M	Older partner
		Obare 2010b	9%	11% F; 1% M	Much older
		Shisana 2014	35.4%	40.6% F; 12.7% M	Other options: 5+ years younger, less than 5 years difference
Transactional sex	Ever	Holub 2010	22.3%	23.3% F; 17.6% M	Ever received money for sex
		Pascoe 2015	22.6%	NR	Had sex with partner for material/other support
		Test 2012	20.6%	66% F; 17% M	Ever had sex for money
	Last partner	Gavin 2006	37.9%	NR	Received goods or money for sex with the last partner
	Not clearly defined	Nhamo 2014	60%	All female	Not clear, at baseline of RCT
Multiple sexual partners	Number of lifetime partners	Beyeza-Kashesya 2011	3 2.5 (1-5)	NR 3 (1-6) F; 3 (2-4.8)	Unclear if mean or median, IQR (1-4) Median (IQR)

Outcome	*Definition*	*Studies*	*Rates (% or M)*	*Gender or age disaggregation*	*Actual reported outcome (actual value reported in the study)*
		Test 2012		M	
	Lifetime	Gavin 2006	15.7%	All female	Multiple lifetime sexual partners
		Morris 2012	81.2%	NR	2 or more lifetime sexual partners
		Pascoe 2015	26.1%	NR	2 or more lifetime sexual partners
		Viegas 2015	88.2%	86.7% F; 100% M	More than 1 lifetime sexual partner
	Last 6 months	Mbalinda 2015b	16%	NR	More than 1 partner
		Nhamo 2014	6%	All female	Multiple sexual partners at baseline of RCT
	Last 12 months	Steffenson 2011	11.5%	7.1% F; 30% M	Concurrent partnerships
		Holub 2010	7.7%	9% F; 0% M	2 or more partners
		Kembo 2012	4.6%	NR	2 or more sexual partners
		Santelli 2013	18.1%	12.2% F; 33.9%	2 sexual partners
		Santelli 2013	10.8%	2.0% F; 33.9% M	3 or more sexual partners
		Santelli 2013	9.8%	2.0% F; 30.4% M	2 or more sexual partners from outside the community
		Shisana 2014	15.4%	11.8% F; 29.5% M	2 or more sexual partners
	Current	Ankunda 2016	30.4%	NR	At time of interview
		Beyeza-Kashesya 2011	18%	NR	Current polygamous relationships
		Mhalu 2013	14.5%	15.9% F; 10.6% M 4.7% F; 35.7% M	Compared to those with 0-1 sexual partners
		Santelli 2013	13.2%		Concurrent partnerships at interview
	Not clearly defined	Bakeera-Kitaka 2008	36.8%	NR	2 or more sexual partners
Sex intoxicated	Sex after alcohol	Shisana 2014	5.5%	5.8% F, 4.2% M	Drank alcohol before sex with most recent partner
		Shisana 2014	3.7%	4.9% F, 1.7% M	Drank alcohol before sex with the second most recent partner
		Test 2012	29%	NR	Drank alcohol up to 6 hours before sex
STIs	Ever had STIs	Baryamutuma 2010	17.6%	NR	Self-reported
		Gavin 2006	21.9%	All female	Self-reported symptoms
		Mbalinda 2015a	13.1%	NR	Ever had STI treatment (self-reported)
		Mbalinda 2015a	14.8%	NR	Ever had STI symptoms: genital sores
		Mbalinda 2015a	27.7%	NR	Ever had STI symptoms: genital itching
		Mbalinda 2015a	10.9%	NR	Ever had STI symptoms: genital discharge
		Mbalinda 2015a	16.8%	NR	Ever had STI symptoms: lower abdominal pain

Outcome	*Definition*	*Studies*	*Rates (% or M)*	*Gender or age disaggregation*	*Actual reported outcome (actual value reported in the study)*
		Pascoe 2015	46.2%	NR	Ever had STI symptoms
		Viegas 2015	36.5%	34.7% F; 50% M	Self-reported
	Last 6 months	Toska 2015	13.8%	NR	2+ STI symptoms
	Last 12 months	Kembo 2012	5.4%	NR	Self-reported occurrence
		Santelli 2013	25.5%	20.9% F; 37.5% M	STI symptoms: genital ulcers
		Santelli 2013	35.8%	42.6% F; 17.9% M	STI symptoms: genital discharge
		Santelli 2013	39.2%	All female	STI symptoms: vaginal discharge
		Santelli 2013	64.2%	All female	STI symptoms: vaginal itching
		Santelli 2013	16.2%	All female	STI symptoms: unpleasant vaginal odour
		Santelli 2013	14.7%	16.9% F; 8.9% M	STI symptoms: frequent urination
		Santelli 2013	23.0%	22.3%nF: 25% M	STI symptoms: painful urination
		Santelli 2013	11.3%	12.8% F; 7.1% M	STI symptoms: pain during intercourse
		Santelli 2013	1.5%	2.0% F; 0% M	STI symptoms: bleeding during intercourse
		Santelli 2013	29.4%	35.8% F; 12.5% M	STI symptoms: lower abdominal pain
		Santelli 2013	6.9%	8.1% F; 3.6% M	STI symptoms: genital warts
	Current STI	Banura 2008	87.8%	NR	HPV – any infection (single or multiple strain – biomarker)
		Banura 2008	64.6%	NR	
		Banura 2008	23.2%	NR	HPV – single strain (biomarker)
		Katusiime 2012	6.1%	NR	HPV – multiple strains (biomarker)
		Pascoe 2015	49.7%	NR	HBV – positive for HBsAg (biomarker) HSV-2 infection (biomarker)
Pregnancy	Ever	Baryamutuma 2010	13.2%	NR	Ever pregnant/ impregnated someone
		Obare 2010a	41.%	All female	Ever pregnant among sexually active females
		Birungi 2011	52%	All female	Ever pregnant
		Gavin 2006	15%	All female	Ever pregnant: 13.7% among 10-14 y.o.; 20.6% among 15-19 y.o.
		Mbalinda 2015	49%	56.9% F; 33.3% M	Ever been or made someone pregnant
		Nhamo 2014	40%	All female	At baseline of RCT
		Obare 2010b	60%	68% F; 27% M	Ever been or made someone pregnant
	Current	Beyeza-Kashesya 2011	5%	NR	Pregnant at the time of the study
		Gray 1998	15%	All female	20.6% in 15-10 year olds; 13.7% in 20-24 year olds
	Multiple pregnancies	Birungi 2011	24.1%	All female	

Outcome	*Definition*	*Studies*	*Rates (% or M)*	*Gender or age disaggregation*	*Actual reported outcome (actual value reported in the study)*
	Unintended pregnancy	Birungi 2011 Nhamo 2014 Obare 2010b	73.9% 75% 75%	All female All female NR	Among those reporting at least one pregnancy Baseline of RCT, among all pregnancies
Safe sex	Not reported	Cataldo 2012	Malawi: 29%; 53% Mozambique: 20%; 73% Zambia: 33%; 70% Zimbabwe: 10%-37%	NR	Among sexually active participants only (rate among 10-14 year olds; rate among 15-19 year olds)
	Highly protected sex	Lightfoot 2007	69.5%	NR	Abstinent or consistent condom use at RCT baseline
Composite sexual risk-taking	HIV transmission risk behaviour	Senyonyi 2012	2.11 (SD 2.75) intervention group 1.83 (SD 2.57) control group	NR	Score of several behaviours: number of sexual encounters (intercourse or penetrative sex) + number of sexual partners + unprotected penile penetrative vaginal sexual acts

4.3.2. Quality Assessment of Included Studies

Of the seventeen studies that reported on potential correlates or intervention effects, most scored below 50% in the Study Quality Checklist (k=14, range 10%-75%, *Table 4-12*). The reasons for the low scores included: study design and analyses, sampling strategies, response/ retention rates, and sample size.

Study design: Included studies consisted of sixteen cross-sectional studies, three prospective cohort studies, one pre and post-test experimental study, and seven RCTs. The three prospective cohort studies did not report analyses of change, nor did they assess longitudinal predictors of sexual risk-taking, hence only relevant baseline data was extracted on prevalence rates and potential correlates. Data from four RCTs reported only on prevalence or correlates of the outcomes of interest using cross-sectional data from the baseline of the study. The included data on prevalence rates and potential correlates were cross-sectional (k=31), while intervention data was based on a pre and post-test experimental study (k=1) and three RCTs (k=3).

Sampling: Sampling strategies were assessed at two levels: community/ clinics and individual level. Of the 31 observational studies, seventeen recruited only from healthcare facilities, primarily through purposefully selected facilities (k=14) (Ankunda et al., 2016; Bakeera-Kitaka, Nabukeera-Barungi, et al., 2008; Banura et al., 2008; Baryamutuma et al., 2010; Beyeza-Kashesya et al., 2011; Birungi et al., 2011; Hoffman et al., 2008; Holub, 2010; Kaggwa & Hindin, 2012; Katusiime & Kambugu, 2012; Malaju & Asale, 2013; Muyindike et al., 2012; Obare et al., 2010; Wanyenze et al., 2011). Most of these studies recruited only HIV-positive participants (k=11). Seven other studies recruited only from communities through random or stratified sampling (Gavin et al., 2006; Gray et al., 1998; Heffron et al., 2010; Hendriksen et al., 2007; Kembo, 2012; Pascoe et al., 2015; Shisana et al., 2014). Most of these studies recruited HIV-positive participants as part of larger community-based samples. Five studies recruited participants through combined facility/ community sampling (Birungi, Obare, et al., 2009; Morris et al., 2012; Nöstlinger, Bakeera-Kitaka, et al., 2015;

Test et al., 2012; Toska, Cluver, Hodes, et al., 2015). The remaining two studies did not report clear recruitment strategies at the community of clinic level.

At the individual-level sampling, 11 studies recruited through total or random sampling at each study site (Ankunda et al., 2016; Gavin et al., 2006; Gray et al., 1998; Heffron et al., 2010; Hendriksen et al., 2007; Mhalu et al., 2013; Morris et al., 2012; Pascoe et al., 2015; Santelli et al., 2013; Shisana et al., 2014; Toska, Cluver, Hodes, et al., 2015), eight recruited through purposeful sampling (Bakeera-Kitaka, Nabukeera-Barungi, et al., 2008; Birungi et al., 2011; Hoffman et al., 2008; Holub, 2010; Katusiime & Kambugu, 2012; Mbalinda, Kiwanuka, Eriksson, et al., 2015; Nöstlinger, Bakeera-Kitaka, et al., 2015; Viegas et al., 2015), and another eight through convenience sampling (Banura et al., 2008; Baryamutuma et al., 2010; Beyeza-Kashesya et al., 2011; Birungi, Obare, et al., 2009; Cataldo et al., 2012; Obare et al., 2010; Test et al., 2012; Wanyenze et al., 2011). Data on the type of individual-level sampling strategy was not available for the remaining three studies. The three intervention studies which reported sampling data recruited through a combination of purposeful and convenience sampling at both the facility/ community and individual levels (Lightfoot, Kasirye, et al., 2007; Senyonyi et al., 2012; Snyder et al., 2014). Results of the risk of bias assessment are included in *Table 4-11*.

Sample sizes: The included studies reported on N=13,536 HIV-positive adolescents and youth (10-24 years old), with sample sizes ranging between n=65 and n=1,703. Fourteen of thirty-five studies had a sample size smaller than n<400 participants, which was chosen as the cut-off for a study powered to detect predictors and intervention effects. This sample size was chosen based on a recent systematic review which assessed studies of predictors of internalised HIV-stigma (Pantelic et al., 2015).

Response and retention rates: Most studies (k=26) did not report response or retention rates or did not have response rates for the HIV-positive sub-population, making it difficult to assess the extent of selection bias. Of studies which reported response or retention rates (k=9), most (8 studies) reported rates of retention ≥90% (Ankunda et al.,

2011; Beyeza-Kashesya et al., 2011; Birungi, Obare, et al., 2009; Lightfoot, Kasirye, et al., 2007; Obare et al., 2010; Senyonyi et al., 2012; Test et al., 2012; Toska, Cluver, Hodes, et al., 2015), with only one reporting a retention rate of 89.6% (Cataldo et al., 2012). Two of the three small-scale intervention studies analysed only data from completers, who accounted for 67.3% (Senyonyi et al., 2012) and 59.6% (Snyder et al., 2014) of those who enrolled in the studies.

Strength of associations between correlates/ interventions and outcomes: In the cross-sectional data analyses, 13 studies conducted univariate analyses (such as Chi square tests, univariate logistic regressions, or Student's t-tests) and eleven reported on multivariate analyses (such as logistic regressions, multivariate log binomial regression, random effects logit model estimations) of associations between potential factors and the outcomes, controlling for potential confounders (*Table 4-12*). Of the three prospective cohort studies, none assessed change in the outcome over time while taking into consideration potential confounding variables. Only two non-intervention studies recorded within-group change in rates but did not conduct any univariate or multivariate analyses (Beyeza-Kashesya et al., 2011; Hoffman et al., 2008). All four experimental design studies reported within-group change for at least one sexual behaviour over time, with three randomising participants to a control and an intervention group (Lightfoot, Kasirye, et al., 2007; Nhamo, 2014; Senyonyi et al., 2012).

4.3.3. Prevalence of sexual risk-taking behaviours

All 35 studies reported the prevalence of at least one high-risk sexual practice: prevalence rates reported by each study and the exact definitions are included in Table 4-3. Prevalence rates for the most commonly reported definition of each outcome varied: (1) sexual debut before 15 years old (k=3 studies, 7%-52%), (2) sexual debut before 18 years old (k=3 studies, 36%-78%), (3) inconsistent/no condom use at last sexual encounter (k=14, 19%-83%), (4) current use of modern contraception (k=6, 26%-66%), (5) having an older partner

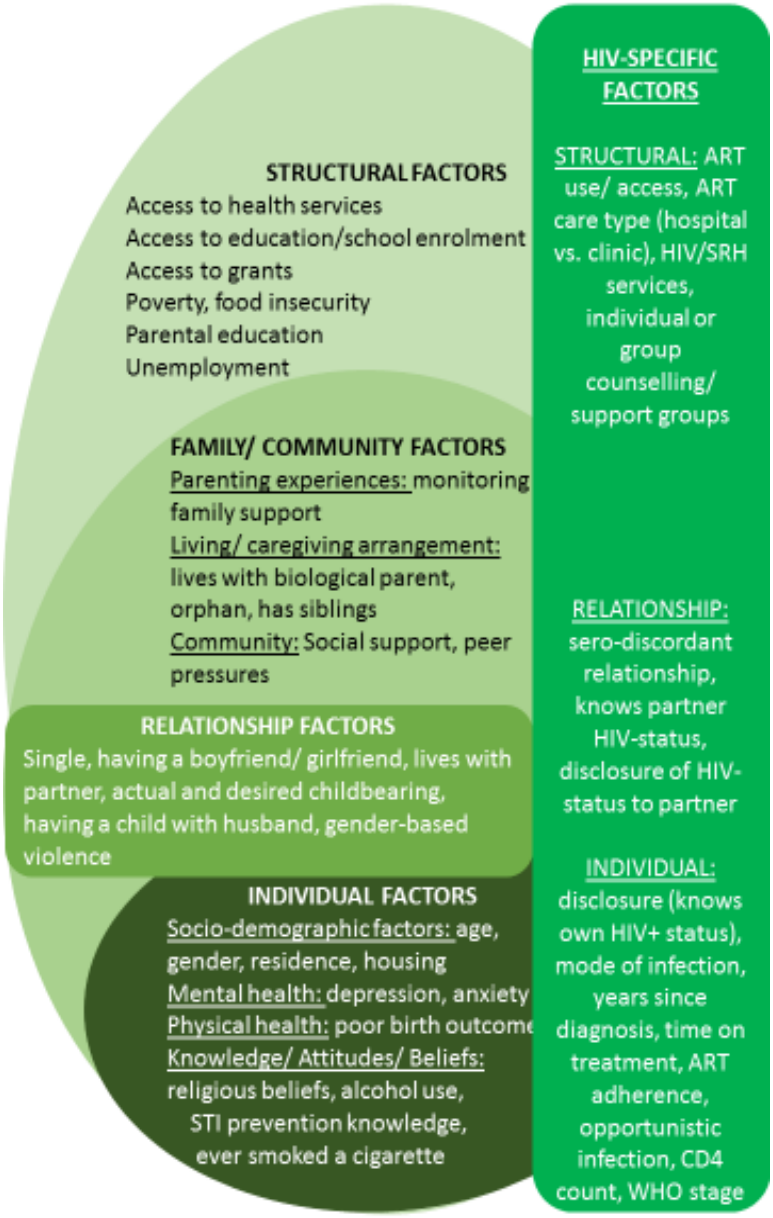
at first sexual intercourse (k=4, 4%-66%), (6) having ever had transactional sex (k=3, 21%-23%), (7) multiple sexual partners in the past 12 months (k=5, 5%-18%), (8) sex while intoxicated (k=2, 6%-29%), (9) ever had an STI or STI symptoms (k=5, 11%-46%), and (10) ever been pregnant among female participants (k=6, 15%-68%). Fourteen studies included gender-disaggregated data (Beyeza-Kashesya et al., 2011; Birungi, Mugisha, et al., 2009; Hendriksen et al., 2007; Holub, 2010; Mbalinda, Kiwanuka, Eriksson, et al., 2015; Mhalu et al., 2013; Muyindike et al., 2012; Obare et al., 2012; Santelli et al., 2013; Shisana et al., 2014; Test et al., 2012; Toska, Cluver, Hodes, et al., 2015; Viegas et al., 2015; Wanyenze et al., 2011) with seven others reporting on all-female samples (Birungi et al., 2011; Gavin et al., 2006; Gray et al., 1998; Heffron et al., 2010; Hoffman et al., 2008; Nhamo et al., 2013; Obare et al., 2010). Gender-disaggregated prevalence rates (Table 4-3) suggest that HIV-positive adolescent girls/ young women engage in higher levels of risk-taking compared to HIV-positive adolescent boys/ young men. However, when gender was included in multivariate analyses, no significant differences were observed. Three studies reported age-disaggregated data for at least one of the outcomes (Cataldo et al., 2012; Gavin et al., 2006; Gray et al., 1998) (Table 4-3). Prevalence rates disaggregated by other socio-demographic factors, such as residential community (rural, urban), HIV mode of infection, and other HIV-related factors, were not available.

In addition to the above high-risk sexual practices, three studies reported on risk-exposure sexual outcomes such as forced sex, non-consensual first sex, gender-based violence, as their main outcomes. These outcomes were beyond the scope of the initial study protocol, information on sexual risk-exposure outcomes is provided in *Table 4-13*.

4.3.4. Factors associated with sexual risk-taking behaviours among HIV-positive adolescents and youth

Seventeen of the included studies (23 publications) reported associations between one or more correlates and sexual outcomes, with univariate and multivariate analyses testing the strength of these relationships. Potential predictors and correlates of sexual risk-taking among HIV-positive adolescents and youth are presented in five groups following the theoretical framework of this thesis: (1) individual-level factors, (2) relationship-related factors, (3) family and community factors, (4) structural factors, and (5) HIV-specific factors (*Figure 4-2*). Nine studies included associations between the review's outcomes, which are summarised in last sub-section. Only multivariate results are described in detail in this section with all associations and actual statistical test results – where available – included in *Table 4-12*.

Figure 4-2. Hypothesised factors associated with sexual risk-taking among HIV-positive adolescents and youth in Sub-Saharan Africa



Individual-level factors (Table 4-4)

Table 4-4. Individual-level factors reported in included studies

Factor	*Outcomes*	*Results*		
Socio-demographic factors				
Age (older)	Ever had sex	Mbalinda 2015a	MV[1]	+[2]
	Unprotected sex	Holub 2010	CSQ	0
		Mhalu 2013	MV	-
		Toska 2015	MV	0
	Condom use	Ankunda 2011	UV	+
		Kaggwa 2012	MV	+[3]
		Kaggwa 2012	MV	0[4]
	Contraception use[5]	Birungi 2009b	CSQ	+
	Multiple sexual partners	Mhalu 2013	MV	0
		Kaggwa 2012	MV	0
	Transactional sex	Test 2012	CSQ	0
Gender (female)	Ever had sex	Mbalinda 2015a	CSQ	+
	Early sexual debut	Mhalu 2013	CSQ	+
		Viegas 2015	CSQ	0
	Unprotected sex	Holub 2010	CSQ	0
		Mhalu 2013	MV	0
		Toska 2015	MV	0
	Condom use	Birungi 2009a	CSQ	0
		Obare 2010a	CSQ	-
		Test 2012	CSQ	0
		Viegas 2015	CSQ	0
	Contraception use	Birungi 2009b	MV	0
		Obare 2010b[6]	CSQ	+
		Obare 2010b[7]	CSQ	0
	Older partner	Baryamutuma 2010	CSQ	+
		Obare 2010b	CSQ	+
		Test 2012	CSQ	+
	Transactional sex	Test 2012	CSQ	+
	Multiple sexual partners	Mhalu 2013	MV	0
		Test 2012	CSQ	+
		Viegas 2015	CSQ	0
	STIs	Viegas 2015	CSQ	0
	Ever (been/made someone) pregnant	Obare 2010b	CSQ	+
Rural residence	Unprotected sex	Toska 2015	MV	0
Informal housing	Unprotected sex	Toska 2015	MV	0
Study site	Contraception use	Birungi 2011	MV	-
	Unintended pregnancy	Birungi 2011	MV	0
	Ever had sex	Mbalinda 2015a	CSQ	+
		Nöstlinger 2015	CSQ	+
	Unprotected sex	Mhalu 2013	MV	0
	Multiple sexual partners	Mhalu 2013	MV	0
Mental and physical health				
Depression (clinical)	Condom use	Kaggwa 2012	MV	-
	Multiple sexual partners	Kaggwa 2012	MV	0
Anxiety	Condom use	Kaggwa 2012	MV	0
	Multiple sexual partners	Kaggwa 2012	MV	0
Poor birth outcomes	Contraception use[iv]	Birungi 2011	MV	0†
Knowledge, attitude, beliefs and practices				
Does not drink alcohol	Ever had sex	Mbalinda 2015a	MV	-
	Unprotected sex	Mhalu 2013	MV	-

Factor	*Outcomes*	*Results*		
	Multiple sexual partners	Mhalu 2013	MV	0
Religious guidance	Unprotected sex	Holub 2010	CSQ	0
	Ever had sex	Mbalinda 2015a	CSQ	0
Ever smoked a cigarette	Ever had sex	Mbalinda 2015a	CSQ	+
STI prevention knowledge	Unprotected sex	Mhalu 2013	MV	0
	Multiple sexual partners	Mhalu 2013	MV	0

Notes:
[1] Analyses type: NR – not reported, CSQ – chi square, UV – univariate modelling, MV – multivariate modelling. When more than one analyses was available, the most rigorous results are reported in the table.
[2] Direction of association:
0 – a non-significant association between factor and outcome;
+ indicates a positive association between the reported factor and the outcome: an increase in the factor is associated with higher rates of the reported outcome;
- indicates a negative association between the reported factor and the outcome: an increase in this factor is associated with lower rates of the reported outcome.
[3] 19-21 year olds compared to 16-18 year olds.
[4] 22-24 year olds compared to 16-18 year olds.
[5] All contraception-related outcomes are included: at first sex, ever used any modern method, and current use of any method. † indicates factors associated with post-partum contraception.
[6] Rates of injectable contraception reported
[7] Rates of contraception at first sex, lifetime, and currently using reported.

Individual-level factors were assessed by ten studies. They are summarised in three groups: (i) socio-demographic factors, (ii) mental and physical health factors, and (iii) knowledge, attitudes, and behaviours. *Socio-demographic* factors included: age (Ankunda et al., 2016; Birungi, Obare, et al., 2009; Holub, 2010; Mbalinda, Kiwanuka, Eriksson, et al., 2015; Mhalu et al., 2013; Test et al., 2012; Toska, Cluver, Hodes, et al., 2015), gender (Ankunda et al., 2016; Baryamutuma et al., 2010; Birungi, Mugisha, et al., 2009; Holub, 2010; Mhalu et al., 2013; Obare & Birungi, 2010; Test et al., 2012; Toska, Cluver, Hodes, et al., 2015), rural residence (Toska, Cluver, Hodes, et al., 2015), and informal housing (Toska, Cluver, Hodes, et al., 2015). *Mental and physical health factors* included: clinical depression (Kaggwa & Hindin, 2012), anxiety (Kaggwa & Hindin, 2012), and having poor birth outcomes[21] (Birungi et al., 2011). *Knowledge, attitude, and behaviours* included: drinking alcohol (Ankunda et al., 2016; Mhalu et al., 2013), religious guidance (Holub, 2010), and STI prevention knowledge (Mhalu et al., 2013). Findings from four studies were inconsistent on whether age is associated with greater sexual risk-taking: three reported that older age is associated with both higher and lower with some high-risk sexual practices (Birungi, Obare, et al., 2009;

[21] Poor birth outcomes include pre-mature birth, small birth weight, and child being small for gestational age.

Kaggwa & Hindin, 2012; Mhalu et al., 2013), but no significant associations with others (Birungi, Obare, et al., 2009; Kaggwa & Hindin, 2012; Mhalu et al., 2013; Toska, Cluver, Hodes, et al., 2015). Three studies reported non-significant multivariate analyses on the relationship between gender and sexual risk-taking (Birungi, Obare, et al., 2009; Mhalu et al., 2013; Toska, Cluver, Hodes, et al., 2015). Rural residence and informal housing were not significantly associated with any sexual practices.

Two studies reported mental and physical health factors associated with sexual risk-taking: depression, anxiety, and poor birth outcomes. Clinical depression was associated with lower condom use in multivariate analysis, but not significantly associated with having multiple sexual partners (Kaggwa & Hindin, 2012). Anxiety and poor birth outcomes were not significantly associated with any of the outcomes (Birungi et al., 2011; Kaggwa & Hindin, 2012).

Three studies tested associations between knowledge, attitudes, and behaviours potentially associated with sexual risk-taking. Of these, two found that adolescents who reported alcohol-drinking were more likely to be sexually active and less likely to use condoms in cross-sectional multivariate analyses (Mbalinda, Kiwanuka, Eriksson, et al., 2015; Mhalu et al., 2013), but no statistically significant association between drinking alcohol and reporting multiple sexual partners (Mhalu et al., 2013). Religious guidance and STI prevention knowledge were not significantly associated with unprotected sex (Holub, 2010; Mhalu et al., 2013).

Relationship factors (Table 4-5)

Table 4-5. Relationship-level factors reported in included studies

Factor	*Outcome*	*Results*[1]		
Has children with husband	Contraception use	Birungi 2011†	MV[2]	0[3]
	Unintended pregnancy	Birungi 2011	MV	+
Status: single	Condom use	Baryamutuma 2010	CSQ	+
Living arrangement: lives with partner	Contraception use	Birungi 2009b	MV	-
	Unintended pregnancy	Nhamo 2013	MV	+
Desires children	Condom use	Ankunda 2011	UV	-
Gender-based violence	Unintended pregnancy	Birungi 2011†	MV	+
		Nhamo 2013	MV	+
	Multiple sexual partners	Nhamo 2013	MV	+

Notes:
[1] † indicates factors associated with post-partum contraception.
[2] Analyses type: NR – not reported, CSQ – chi square, UV – univariate modelling, MV – multivariate modelling.
[3] Direction of association:
0 – a non-significant association between factor and outcome;
+ indicates a positive association between the reported factor and the outcome: an increase in the factor is associated with higher rates of the reported outcome;
- indicates a negative association between the reported factor and the outcome: an increase in this factor is associated with lower rates of the reported outcome.

Relationship-level factors were tested by five studies included relationship status (single, living with partner), having a child with one's husband, desiring children, and gender-based violence. In multivariate analyses, HIV-positive adolescents and youth were more likely to report unintended pregnancy if they had biological children (Birungi et al., 2011). They were more likely to report multiple sexual partners and unintended pregnancies if they lived with their partner (Nhamo et al., 2013), and experienced gender-based violence (Birungi et al., 2011; Nhamo et al., 2013).

Family and community factors (Table 4-6)

Table 4-6. Family and community-level factors reported in included studies

Factor	*Outcome*	*Results*		
Lives with biological parent	Unprotected sex	Toska 2015	MV	0
	Contraception use	Birungi 2009b	CSQ	0
	Unintended pregnancy	Baryamutuma 2010[4]	CSQ	-
Lives alone	Ever had sex	Mbalinda 2015a	MV	+
Orphanhood	Unprotected sex	Holub 2010	CSQ	0
		Toska 2015	MV	0
Has no siblings	Contraception use	Birungi 2009b	CSQ	+
Parental monitoring	Unprotected sex	Holub 2010	CSQ	0
Supportive family	Unprotected sex	Mhalu 2013	CSQ	0
	Multiple sexual partners	Mhalu 2013	CSQ	0
Parental monitoring*social support	Unprotected sex	Holub 2010[5]	MV	-
Social support	Unprotected sex	Holub 2010	CSQ	0
	Condom use	Kaggwa 2012	MV	0
	Multiple sexual partners	Kaggwa 2012	MV	0
Peer: Friend who smoked	Ever had sex	Mbalinda 2015a	CSQ	+
Peer: friend who drunk	Ever had sex	Mbalinda 2015a	CSQ	+
Peer pressure: influenced to drink or smoke	Ever had sex	Mbalinda 2015a	CSQ	+

Notes:
[1] Potential factors for all the different contraception-related outcomes are included: contraception at first sex, ever used any modern method of contraception, and current use of any contraception.
† indicates factors associated with post-partum contraception.
[2] Analyses type: NR – not reported, CSQ – chi square, UV – univariate modelling, MV – multivariate modelling.
[3] Direction of association:
0 – a non-significant association between factor and outcome;
+ indicates a positive association between the reported factor and the outcome: an increase in the factor is associated with higher rates of the reported outcome;
- indicates a negative association between the reported factor and the outcome: an increase in this factor is associated with lower rates of the reported outcome.
[4] Factor reported only for ever been pregnant.
[5] Study reported that social support moderated the effect of parental monitoring on unprotected sex but the p-value was p=0.11.

Seven studies tested associations between eight family and community factors associated with one or more sexual risk practices (Baryamutuma et al., 2010; Birungi, Obare, et al., 2009; Holub, 2010; Kaggwa & Hindin, 2012; Mbalinda, Kiwanuka, Eriksson, et al., 2015; Mhalu et al., 2013; Toska, Cluver, Hodes, et al., 2015). Family factors included: living with at least one biological parent, orphanhood, having siblings, parenting relationship (monitoring), and having a supportive family. Ugandan adolescents living alone were more likely to be sexually active in one study (Mbalinda, Kiwanuka, Eriksson, et al., 2015). Orphanhood, living with at least one biological caregiver, social support, parental monitoring, and having a supportive family were not significantly associated with any of the outcomes. One study reported on whether social support moderated the effect of parental monitoring on reduced unprotected sex (Holub, 2010). Though the authors reported a protective moderated effect, the relationship was not significant when controlling for confounders (p=0.11).

Structural factors (Table 4-7)

Eleven studies: eight cross-sectional and three interventions tested the effect of eight structural factors or provisions on sexual risk-taking: poverty, food insecurity, participant employment, educational attainment, accessing grants, receiving livelihood training, and accessing health services (group or one-on-one counselling).

Table 4-7. Structural-level factors reported in included studies

Factor	*Outcome*	*Results*		
Education	Early Sexual debut	Baryamutuma 2010	CSQ[1]	-[2]
	Ever had sex	Mbalinda 2015a	MV	-
	Unprotected sex	Holub 2010	CSQ	0
		Mhalu 2013	MV	0
	Contraception use	Birungi 2009b	CSQ	0
	Multiple sexual partners	Mhalu 2013	MV	0
	Transactional sex	Test 2012	CSQ	0
Maternal education	Contraception use	Birungi 2011†	MV	0
	Unintended pregnancy	Birungi 2011	MV	0
Poverty	Unprotected sex	Toska 2015	MV	0
Food insecurity	Unintended pregnancy	Nhamo 2013	MV	+
Employment	Transactional sex	Test 2012	CSQ	0
	Ever had sex	Mbalinda 2015a	MV	+
Intervention – access to health services: one-on-one counselling	Highly protected sex	Lightfoot 2007	UV	+
	Consistent condom use	Lightfoot 2007	UV	+
	Multiple sexual partner	Lightfoot 2007	UV	-
Intervention – access to health services: group counselling	Sexual transmission score	Senyonyi 2012	UV	0
Intervention – combination social protection: grants + livelihood training + SRH services	Condom use	Nhamo 2014	MV	+
	Multiple sexual partners	Nhamo 2014	MV	0
	Transactional sex	Nhamo 2014	MV	-

Notes:
[1] Analyses type: NR – not reported, CSQ – chi square, UV – univariate modelling, MV – multivariate modelling.
[2] Direction of association: 0 – a non-significant association between factor and outcome;
+ indicates a positive association between the reported factor and the outcome: an increase in the factor is associated with higher rates of the reported outcome;
- indicates a negative association between the reported factor and the outcome: an increase in this factor is associated with lower rates of the reported outcome.

Access to education was not associated with sexual risk-taking in one study (Mhalu et al., 2013), but adolescents enrolled in school were less likely to have ever had sex in another study (Mbalinda, Kiwanuka, Eriksson, et al., 2015). Employment was not significantly associated with reduced transactional sex (Test et al., 2012), but employed adolescents were more likely to have ever had sex even when taking age into account (Mbalinda, Kiwanuka, Eriksson, et al., 2015). Food insecurity was strongly associated with unintended pregnancies in the baseline sample of an RCT for HIV-positive orphaned and out of school

adolescent girls in Zimbabwe (Nhamo et al., 2013). Accessing health services as part of an intervention was associated with reduced sexual risk-taking in a small-scale study of one-on-one counselling sessions (Lightfoot, Kasirye, et al., 2007), but not in a study testing the effect of group counselling (Senyonyi et al., 2012). Accessing grants in a combination with health services and vocational training was associated with increased condom use and reduced transactional sex in a large-scale RCT among highly-vulnerable HIV-positive adolescent girls in Zimbabwe, but no reduction in multiple sexual partners was documented (Nhamo, 2014).

HIV-related factors (Table 4-8)

Table 4-8. HIV-related factors reported in included studies

Factor	*Outcome*	*Results*		
Individual-level factors				
Knows own HIV+ status	Unprotected sex	Holub 2010 Toska 2015	CSQ[1] MV	0[2] -
Mode of infection (vertical)	Unprotected sex	Toska 2015	MV	-
	Condom use	Kaggwa 2012	MV	0
	Multiple sexual partners	Kaggwa 2012	MV	0
	Transactional sex	Test 2012	CSQ	0
Time since diagnosis (years)	Unprotected sex	Holub 2010	CSQ	-
Time on ART	Unprotected sex	Toska 2015	MV	0
ART adherence	Unprotected sex	Toska 2015	MV	0
Opportunistic infections	Unprotected sex	Toska 2015	MV	0
CD4 count >250 cells/mm^3	STIs	Katusiime 2012	CSQ	+
WHO stage I or II	STIs	Katusiime 2012	CSQ	+
Relationship-level factors				
Partner status – HIV-discordant	Contraception use	Birungi 2009a	CSQ	0
Partner HIV-status not known	Unprotected sex	Mhalu 2013 Toska 2015	MV MV	0 0
	Multiple sexual partners	Mhalu 2013	MV	+
Disclosed HIV-status to partner	Unprotected sex	Toska 2015	MV	0
Structural factors				
ART use/ access	Unprotected sex	Mhalu 2013	MV	0
	Condom use	Kaggwa 2012	MV	0
	Multiple sexual partners	Kaggwa 2012	MV	0
		Mhalu 2013	MV	-
ART care (hospital vs. primary)	Unprotected sex	Toska 2015	MV	0
Intervention – access to health services: HIV support groups	Condom use	Snyder 2014	UV	+

Notes:
[1] Analyses type: NR – not reported, CSQ – chi square, UV – univariate modelling, MV – multivariate modelling.
[2] Direction of association: 0 – a non-significant association between factor and outcome;
+ indicates a positive association between the reported factor and the outcome: an increase in the factor is associated with higher rates of the reported outcome;
- indicates a negative association between the reported factor and the outcome: an increase in this factor is associated with lower rates of the reported outcome.

Eight studies tested associations between fourteen HIV-related factors and sexual risk-taking practices. At the individual level, knowing your own HIV-positive status was associated with reduced unprotected sex, while being horizontally-infected with higher rates of reported unprotected sex (Toska, Cluver, Hodes, et al., 2015). Time since HIV diagnosis, time on ART, ART adherence, and reporting opportunistic infections were not significantly associated with unprotected sex, nor with contraception use (Ankunda et al., 2016; Birungi et al., 2011; Holub, 2010; Katusiime & Kambugu, 2012; Toska, Cluver, Hodes, et al., 2015). At the relationship/ inter-personal level, knowing one's partner's HIV-status was associated with having multiple sexual partners (Mhalu et al., 2013), but not with unprotected sex (Mhalu et al., 2013; Toska, Cluver, Hodes, et al., 2015). Having disclosed one's HIV-status to a partner was not significantly associated with unprotected sex (Toska, Cluver, Hodes, et al., 2015). At the structural level, accessing antiretroviral therapy was strongly associated with lower rates of multiple sexual partners in one study (Mhalu et al., 2013), but not in a second study (Kaggwa & Hindin, 2012). There was no association between ART use and unprotected sex or condom use in two studies (Kaggwa & Hindin, 2012; Mhalu et al., 2013). Receiving hospital care (compared to primary-level care) was not associated with sexual risk-taking (Toska, Cluver, Hodes, et al., 2015), while attending an HIV support group as part of an intervention study was associated with increased condom use at post-test (Snyder et al., 2014).

Relationships between high-risk sexual practices (Table 4-9)

Table 4-9. Associations between high-risk sexual practices

Factor	Outcomes	Results		
Current contraceptive use	Condom use	Ankunda 2011	NR[1]	+[2]
Inconsistent condom use/	Transactional sex	Test 2012	CSQ	0
Unprotected sex	Unintended pregnancy	Nhamo 2013	MV	+
Early sexual debut	Unprotected sex	Mhalu 2013	MV	0
	Multiple sexual partners	Mhalu 2013	MV	0
	Transactional sex	Test 2012	CSQ	0
Pregnancy order	Contraception use[3]	Birungi 2011†	MV	0
	Unintended pregnancy	Birungi 2011†	MV	0
Age at first pregnancy	Contraception use	Birungi 2011†	MV	0
	Unintended pregnancy	Birungi 2011†	MV	0
Unintended pregnancy	Contraception use	Birungi 2011†	MV	0
Multiple sexual partners	Transactional sex	Test 2012	CSQ	0
	Unintended pregnancy	Nhamo 2013	MV	+
Older sexual partner[4]	Transactional sex	Test 2012	CSQ	0
	STI risk	Baryamutuma 2010	CSQ	+
Transactional sex	Unprotected sex	Holub 2010	CSQ	0
STI symptoms	Unprotected sex	Toska 2015	MV	0
Ever had STI treatment	Ever had sex	Mbalinda 2015a	MV	+

Notes:
[1] Analyses type: NR – not reported, CSQ – chi square, UV – univariate modelling, MV – multivariate modelling.
[2] Direction of association: 0 – a non-significant association between factor and outcome;
+ indicates a positive association between the reported factor and the outcome: an increase in the factor is associated with higher rates of the reported outcome;
- indicates a negative association between the reported factor and the outcome: an increase in this factor is associated with lower rates of the reported outcome.
[3] Potential factors for all the different contraception-related outcomes are included: contraception at first sex, ever used any modern method of contraception, and current use of any contraception. † indicates factors associated with post-partum contraception.
[4] Factors associated with both older sexual partners at first and most recent sexual encounters are included.

Nine studies tested associations between sexual risk outcomes (Ankunda et al., 2011; Baryamutuma et al., 2010; Birungi et al., 2011; Holub, 2010; Mbalinda, Kiwanuka, Eriksson, et al., 2015; Mhalu et al., 2013; Nhamo et al., 2013; Test et al., 2012; Toska, Cluver, Hodes, et al., 2015). Most associations were not statistically significant. Only two studies reported significant multivariate associations using cross-sectional data: inconsistent condom use and having multiple sexual partners were associated with unintended pregnancy (Birungi et al., 2011; Nhamo et al., 2013). Early sexual debut was not associated with unprotected sex and

multiple sexual partners in one study (Mhalu et al., 2013). Neither pregnancy order[22], nor age at first pregnancy were associated with unintended pregnancy nor post-partum contraception in a study among HIV-positive adolescent girls in Kenya (Birungi et al., 2011).

4.3.5. Interventions addressing sexual risk-taking behaviours among HIV-positive adolescents and youth

This review located eight studies of interventions aiming to address one or more sexual risk practices among HIV-positive adolescents or youth (Bhana et al., 2013; Mellins et al., 2014; Mupambireyi, Bernays, Bwakura-Dangarembizi, & Cowan, 2014; Njika et al., 2010; Nöstlinger, Loos, et al., 2015; Parker et al., 2013), but data on intervention effects were only available for four interventions, which are included in this review (Lightfoot, Kasirye, et al., 2007; Nhamo, 2014; Senyonyi et al., 2012; Snyder et al., 2014). Three of the included intervention studies were individual-level randomised controlled trials (Lightfoot, Kasirye, et al., 2007; Nhamo, 2014; Senyonyi et al., 2012) (Table 4-10), with one pre and post-test experimental design study (Snyder et al., 2014). Three studies included HIV-positive adolescents (Lightfoot, Kasirye, et al., 2007; Senyonyi et al., 2012; Snyder et al., 2014), with the fourth recruiting only HIV-positive adolescent girls who were orphaned, out of school, and not pregnant at enrolment (Nhamo, 2014). Three of the interventions were designed on principles of cognitive-based therapy (Lightfoot, Kasirye, et al., 2007; Senyonyi et al., 2012; Snyder et al., 2014), one of them guided by Bandura's Social Cognitive Theory (Snyder et al., 2014), and the last was an intervention combining sexual health/ HIV services with two livelihood components: vocational training and a small grant (Nhamo, 2014). Two interventions were group-based, delivered by trained counsellors (Senyonyi et al., 2012; Snyder et al., 2014). The other two were delivered to individual participants (Lightfoot, Kasirye, et al., 2007; Nhamo, 2014), one of which by trained nurses (Lightfoot, Kasirye, et

[22] Whether a pregnancy was the first, second or third for the participating woman.

al., 2007). Three of the intervention studies had small sample sizes (<120) (Lightfoot, Kasirye, et al., 2007; Senyonyi et al., 2012; Snyder et al., 2014), while the fourth recruited n=710 adolescent girls, randomised to one of two arms (Nhamo, 2014). All interventions measured at least one high-risk sexual practice, with all measuring condom use or unprotected sex, three measuring number of sexual partners, and one measuring transactional sex. One of the studies reported effects on a composite sexual behaviour transmission score (Senyonyi et al., 2012). All four studies reported increases in condom use following the intervention, however, in one study the increase was not significant when intervention and control groups were compared post-intervention (Senyonyi et al., 2012). Findings from the combination intervention suggested that the results were due to the combination intervention rather than the life skills component alone (Nhamo, 2014).

Table 4-10. Summary of included intervention studies

Author Year, Country	*Intervention name, content, delivery mode*	*Study design*	*Follow-up time*	*Sample*[23]	*SQC score*[24]	*Outcomes*	*Results*
Lightfoot 2007, Uganda	Cognitive Based Therapy (CBT) One-on-one with nurses 18 sessions	RCT Intervention: 50 Control: 50 Retention rate: 90%	Assessed at baseline and 3 months	14-21 year olds 72% female Not reported	75%	Number of sexual partners Consistent condom use Highly protected sex (abstinence or consistent condom use)	**Number of sexual partners:** Log number of sexual partners decreased (F 1,19=4.68, p=0.04) **Consistent condom use:** Consistent condom use increased from 10% to 93% in intervention (p<0.01), control did not significantly change, from 15 to 12%. **Highly protected (abstinent or consistent condom use):** in intervention arm significantly increased from 74% to 98% (p<0.01), no change in control from 65% to 62%, NS.
Nhamo 2014, Zimbabwe	Shaping the Health of Adolescents in Zimbabwe (SHAZ)-Plus! <u>0-6 months:</u> both arms receive HIV/ SRH services + Life Skills education <u>7-12 months:</u> *intervention* receives HIV/ SRH	RCT pre- and post-test N=710 Retention rate not reported	Baseline and follow-up at 6, 12, and 18 months; sexual outcomes reported for pre-test (baseline) to post-test (18 months)	16-19 years old 100% female Mode of infection not reported; orphaned and out of school, not pregnant at enrolment	66%	Multiple sexual partners Transactional sex Condom use	**Multiple sexual partners:** changed from 6% to 7%, OR=1.05, .90-1.23, p=0.504 **Transactional sex:** changed from 60% to 49%, OR=0.87, 0.75-1.01, p=0.067 **Condom use:** RR=1.43 95%CI1.16-1.76, p<0.001

[23] When available, age, gender, mode of infection, and other inclusion criteria are included.

[24] Study Quality Checklist score.

Author Year, Country	*Intervention name, content, delivery mode*	*Study design*	*Follow-up time*	*Sample*[23]	*SQC score*[24]	*Outcomes*	*Results*
	services + livelihood intervention (vocational training & grant); *control* receives only HIV/SRH services <u>13-18 months:</u> both groups receive only HIV/ SRH services including testing						
Senyonyi 2012, Uganda	CBT Group counselling delivered by trained counsellors Recurring weekly sessions 80 min per session	RCT 328 contacted; 171 selected to participate in intervention N=115 completed 3+ sessions: n=80 intervention, n=35 control	No information	12-18 years 53% female Vertically acquired HIV	55%	Sexual transmission score=number of sexual encounters (intercourse or penetrative sex), number of sexual partners, and unprotected penile penetrative vaginal sexual acts (intercourse; i.e., use of condoms, and continued abstinence)	**Sexual transmission behaviour score:** decrease in total score for both the intervention and control groups, Wilk's λ=0.951, $F_{1,113}$ =5.866, p=0.017, partial η2=0.049. Repeated measures ANOVA showed no significant group differences at post-test, Wilk's λ = 1.00, F(1,113) = 0.024, **p = 0.876**, partial η2 ≤ 0.001.
Snyder 2014, South Africa	Hlanangani CBT Social Cognitive Theory Support groups delivered by lay counsellors 3 (2 hour) sessions over 11 months	Pilot study n=109, 74 (68%) returning for all three sessions, analyses of	Start of session 1 (baseline) to end of session 3 (follow-up). Analyses n=65 completers	16-24 years 95% female Unknown mode of infection Past-year diagnosis	41%	Condom use in previous 3 weeks (during intervention)	**Condom use:** increased by 12% (p=0.049).

4.4. DISCUSSION

This review includes 35 studies documenting prevalence and correlates of high-risk sexual practices, or interventions for reducing sexual risk-taking in HIV-positive adolescents and youth from 13 sub-Saharan African countries. All studies reported on rates of high-risk sexual practices, sixteen reported on at least one potential correlate. No predictors or causal risk factors were identified in the included studies. Four studies reported on interventions to reduce sexual risk-taking among HIV-positive adolescents.

4.4.1. Key findings

Key findings of this systematic review are discussed in four parts: (1) quality of the included studies, (2) prevalence of sexual risk-taking, (3) determinants of sexual risk-taking, and (4) interventions to reduce sexual risk-taking.

Quality of the studies included: Most studies scored <50% in the Study Quality Checklist due to low scores on whether studies could establish causality. Notably, this was due to more than half the studies recruiting HIV-positive adolescents and youth as part of larger community-based samples, and not conducting analyses on the HIV-positive sub-sample, as this was not part of the original study aims. Secondary data analyses of the HIV-positive sub-samples in these studies may provide additional – more generalizable – insights from community-based samples. Most of the included studies focused on HIV-positive adolescents and youth recruited from facility-based samples. This limits the generalisability of some of the studies' findings to adolescents and youth who are not engaged in care. By engaging mostly adolescents who are already receiving care and support, the included studies are likely to under-estimate rates of sexual risk-taking, as adolescents who are not engaged in care are more likely to experience poor sexual health outcomes (Hodgson et al., 2012). A further limitation of the quality of included studies is that the majority of studies

reported on cross-sectional analyses which limited our ability to reach any conclusions about the causality and strength of the reported relationships between hypothesised factors and high-risk sexual practices. Rigorous longitudinal research is needed to better understand and test pathways of increased sexual risk-taking among HIV-positive adolescents and youth in sub-Saharan Africa.

Further, nearly half of the studies that tested hypothesised determinants reported only on univariate analyses, mostly chi-square tests. Univariate analyses test relationships without taking into account other factors, such as age, gender, rural or urban location which could explain the observed associations, and thus might represent biased results. A systematic review of condom use studies among adolescents in the United States, also found that the majority of reviewed studies utilised univariate rather than multivariate analyses (Buhi & Goodson, 2007). Theory- and policy-driven multivariate analyses are needed to gain a clearer picture of factors associated with sexual risk taking in HIV-positive adolescents and youth. Quasi-experimental analyses can then be applied to assess which modifiable factors can be changed to reduce sexual risk-taking in this highly vulnerable population (Agha, 2002; Shadish, Cook, & Campbell, 2002). The poor quality of the studies and limited analyses techniques utilised may also explain why most of the reported findings were inconsistent.

Last, sample sizes of HIV-positive adolescents and youth in the included studies varied between n=65 and n=1703, with only 13 studies reporting on more than 400 HIV-positive adolescents and youth. While several studies were powered to identify significant findings, most did not conduct multivariate analyses or did not report odds ratios and *p*-values. Moreover, for most of the 50 hypothesised correlates only one study tested associations to multiple high-risk sexual practices.

Prevalence of high-risk sexual practices varied widely by outcome and should be interpreted with caution alongside data on study methodology, sampling strategy and size, response rates, and definition of outcome measures (Table 4-2 and Table 4-3). Nonetheless several trends were notable. First, most studies reported high rates of sexual risk-taking in relatively young populations (<19 years old). Rates of inconsistent condom use varied considerably, though most of the studies found that between a third and half of participants reported unprotected sex at last intercourse. These rates are comparable to unprotected sex rates reported by studies in the general adolescent population in South Africa (Hendriksen et al., 2007), Uganda (Santelli et al., 2013), and other sub-Saharan African countries (Asante & Doku, 2010; Davidoff-Gore, Luke, & Wawire, 2011). Of the studies reporting current contraception use, a third of the sample were on a form of contraception at the time of the study, but only one study documented extremely low rates of dual protection – 5% of combined contraception and condom use – in Uganda (Beyeza-Kashesya et al., 2011). These results suggest that a high proportion of sexual acts by HIV-positive adolescents and youth in sub-Saharan Africa are unprotected. Given the potentially unique needs and experiences of HIV-positive adolescents, it is difficult to compare these rates to the general adolescent populations without a comparison group in each specific study site. However, in light of the high rates of sexual risk-taking reported in the included studies, immediate attention to supporting safer sexual practices among HIV-positive adolescents and youth is needed (Fairlie, Sipambo, Fick, & Moultrie, 2014).

Second, where studies reported sexual debut, nearly half of the adolescents had had sex. This is an important finding since most of the included participants were HIV-positive adolescents under 19 years old, which suggests early sexual debut for a large part of the HIV-positive adolescent population. Early sexual debut has been linked to reduced protected sex in the general adolescent population in South Africa (A. Pettifor, O'Brien, Macphail, Miller, & Rees, 2009). Third, between half and two thirds of adolescents reported having an older sexual partner during first sex, which is linked to reduced condom use in the general

adolescent population (Gavin et al., 2006). Fourth, one in five participants reported engaging in transactional sex or having sex for money or goods, a result that was consistent across multiple studies (Holub, 2010; Pascoe et al., 2015; Test et al., 2012).

HIV-positive adolescent girls reported higher rates of transactional sex, having older sexual partners, and unprotected sex, though adolescent boys were more likely to report early sexual activity and multiple sexual partners. Rates of engaging in transactional sex were higher among HIV-positive adolescent girls though when gender was included in multivariate analyses it was not significantly associated with sexual risk-taking. Adolescent girls in age-disparate relationships are less able to negotiate condom use (Toska, Cluver, Boyes, et al., 2015). Even though gender is not a determinant of these rates, programming and services should take into account the higher absolute rates of such behaviours reported by adolescent girls, particularly HIV-positive ones. Additional gender-moderated analyses should be conducted to explore the different causal mechanisms that lead to these differential rates.

Fifth, rates of multiple sexual partners varied widely, though most studies reported that at least one in ten participants had had at least two sexual partners in the last 12 months and one in three male participants reported multiple sexual partners (Santelli et al., 2013; Shisana et al., 2014; Steffenson, Pettifor, Seage, Rees, & Cleary, 2011). Sixth, studies testing for biomarkers of HSV-2 and HPV found 50% and 88% infection rates in HIV-positive adolescents, respectively (Banura et al., 2008; Pascoe et al., 2015). This suggests high levels of unprotected sex and higher risk for co-infection with other sexually transmitted infections. Finally, nearly three-quarters of all pregnancies among HIV-positive adolescent women were reported to be unintended (Birungi, Obare, et al., 2009; Nhamo, 2014; Obare et al., 2010), higher than reported rates of unintended pregnancies among adolescent girls in South Africa (Macleod & Tracey, 2010). While unintended pregnancy is not a risk practice in itself, being pregnant during adolescence for HIV-positive adolescents presents a two-fold risk. First, adolescent pregnancy and motherhood has been linked to poorer health,

educational, and socio-economic outcomes for both mother and child (Grant & Hallman, 2008; Macleod & Tracey, 2010; Makiwane, Desmond, Richter, & Udjo, 2006; Panday, Makiwane, Ranchod, & Letsoalo, n.d.). Second, children of HIV-positive adolescent mothers are at increased risk of mother-to-child-transmission, due to poor adherence to ART and retention in care (G Fatti et al., 2014). Reducing unintended pregnancies can have great positive effects in improving maternal and child health outcomes, particularly among HIV-positive adolescents (Every Woman Every Child, 2015). The rates of unintended pregnancies among HIV-positive adolescents and youth suggest that the unmet contraceptive need among this population is even higher. Potential barriers to accessing contraception include quality of sexual and reproductive health services received at health facilities (Wood & Jewkes, 2006), stigma and discrimination (Hodgson et al., 2012; Mburu et al., 2013), and lack of integration of family planning and HIV care services (Maynard-tucker, 2011).

Determinants of sexual risk-taking: No studies reported on determinants of sexual risk-taking. Correlates of high-risk sexual practices reported by the included studies were grouped in five categories: (1) individual and socio-demographic, (2) other sexual practices, (3) family and relationship, (4) HIV and health-related and (5) structural level factors. The definitions of the outcome measures and potential predictors varied between studies. It is difficult to reach conclusions about which factors were consistently associated with sexual risk-taking among HIV-positive adolescents and youth because of the quality of the evidence. However, a few correlates were documented by the included in three cross-sectional studies. This review found that living alone (compared to living with family at home), living with a partner (compared to living with family at home), experiencing gender-based violence, and reporting greater food insecurity were associated with greater risk-taking in one study each. Knowing one's own HIV-positive status associated with less sexual risk-taking in another study. These findings suggest that HIV-positive adolescents and youth

from poorer communities and those in relationships are more likely to engage in unprotected sex. Additional research is needed to explore factors consistently associated with risk-taking among HIV-positive adolescents.

Non-significant multivariate associations were reported for: rural residence, informal housing, anxiety, religious guidance, STI prevention knowledge, poor birth outcomes, orphanhood, parental monitoring, having a supportive family, social support, maternal education level, poverty, disclosing one's HIV-status to a partner, time on ART, ART adherence, receiving care at a hospital, and opportunistic infections.

Inconsistent associations were reported between being older, gender, study site, depression, drinking alcohol, living with a biological parent, having children with one's husband, access to ART, education, knowing one's HIV-positive status, mode of HIV infection, and knowing one's partner's HIV-status. Large-sample studies with longitudinal design reporting on multivariate analyses should test whether these discrepancies are due to country-level differences, sample size, varying methodologies or different measurement tools.

The implications of these findings are multiple fold. First, they suggest that similarly to general adolescent populations, knowledge and beliefs on their own are necessary but not sufficient to cause behaviour change (Paul-Ebhohimhen, Poobalan, & van Teijlingen, 2008). Second, although HIV-positive adolescents are regularly engaging with the healthcare system to receive their treatment and care, a considerable gap remains in ensuring they access contraception or counselling and support for safer sex. Third, in nine studies, sexual health outcomes were associated with other sexual risk-taking practices, for example unintended pregnancy was associated with having multiple sexual partners. Only one intervention aimed to reduce multiple risk-taking, with no significant results between intervention and control groups (Senyonyi et al., 2012). Better understanding of factors shaping syndemic of risk-taking among HIV-positive adolescents and youth will be important to help healthcare providers screen for and support those adolescents most at risk.

Secondary HIV Prevention Interventions: Among the three interventions that had significant effects on reducing sexual risk-taking, one was an individual-based 18-session intervention delivered by nurses (n=50 intervention and n=50 control) (Lightfoot, Kasirye, et al., 2007), the second a group-based intervention focused on improving self-efficacy (n=65) (Snyder et al., 2014), and a third focused on addressing both individual and structural drivers of risk-taking through group-based life-skills training and livelihood support through grants and vocational training (n=710) (Nhamo, 2014). Though the first two studies are promising, the studies testing them reported on small sample sizes (n<120). To test their generalisability and scalability, these interventions need to be replicated with larger samples in real-life settings. The only large-scale intervention included in the review reported positive results from an intervention combining HIV/STI health services, life skills training, and livelihood components, such as small grants (Nhamo, 2014). This intervention focused on highly vulnerable HIV-positive adolescent girls, so additional research on whether these interventions may works among HIV-positive adolescents and youth in general would be beneficial.

4.4.2. Implications for Future Research and Practice

None of the included studies assessed longitudinal predictors, making it difficult to inform the design of large-scale policies and programming for HIV-positive adolescents and youth. However, the findings of this review have several implications for policy and practice.

First, HIV-positive adolescents and youth are reporting high levels of sexual risk-taking, which could lead to passing the virus to uninfected partners and children. These rates are high even though most of the included HIV-positive adolescents and youth were already in treatment and care. This suggest that improved sexual and reproductive health services for HIV-positive adolescents should be provided as part of regular HIV treatment and care. Successful models of integrating sexual and reproductive health services with HIV treatment and care should be designed, tested and rolled out. Some adolescent- and youth-friendly

models documented from this study's research partner, the Paediatric AIDS Treatment for Africa, should be further explored (Soeters, Hatane, Gittings, & Mark, 2015).

Second, HIV-positive adolescents who are most vulnerable may also be those at highest risk for onwards HIV transmission. Although most associations reported in the included studies were inconsistent, both HIV-specific and general factors are associated with sexual risk-taking. These findings suggest that policies and programming must take into consideration the unique needs and profile of HIV-positive adolescents. Practitioners should be sensitised and trained to deal with the specific needs of HIV-positive adolescents and youth, as they initiate sexual and romantic relationships, and enter their reproductive years.

Third, the evidence on potential interventions, although based primarily on small-scale trials, suggests that improved non-medical care, psychosocial care and support, may reduce sexual risk-taking among HIV-positive adolescents. Testing the scalability of low-cost interventions delivered by lay counsellors such as support groups will be key to evidence-based programming for HIV-positive adolescents. HIV-specific support groups have had encouraging results in improving HIV treatment outcomes among adolescents and youth in other parts of South Africa (Snyder et al., 2014; Wilkinson et al., 2016), in neighbouring countries (Kossow et al., 2015; Pettitt, Greifinger, Phelps, & Bowsky, 2012), as well as in this sample (Lucie D. Cluver et al., 2016).

Finally, the results of the largest randomised controlled trial included in the review (n=710) suggest that combinations of interventions may have a stronger impact on reducing sexual risk-taking among HIV-positive adolescents and youth (Nhamo, 2014). Similarly to primary HIV prevention efforts, potential combinations of behavioural, biomedical and structural interventions should be tested (Coates, Richter, & Caceres, 2008; Toska et al., 2016). Complex multi-level interventions require comprehensive financial, capital, and human resources to be designed and conducted. Therefore, testing where combinations of existing low-resource real-life interventions, potentially using pragmatic research

methodologies such as quasi-experimental designs, should precede setting up and testing potential combinations of interventions through randomised controlled trials.

Based on the quality of the evidence base, additional foundational and intervention research is needed to inform interventions for HIV positive teens. Evidence-based policy and programming could benefit from additional research with representative samples of HIV-positive adolescents and youth. The following research gaps were identified through this systematic review:

High-risk sexual practices: This review has highlighted several gaps in research. First, better understanding of adolescents who are at risk of engaging in multiple high-risk sexual practices is pivotal to improved care and support programming. Second, although this systematic review did not focus on adolescent experiences of violence such as forced sex, gender-based violence, and domestic violence, multiple of the included studies found high rates of forced sexual initiation and gender-based violence amongst HIV-positive adolescents (Birungi, Obare, et al., 2009; Nhamo et al., 2013; Test et al., 2012). In light of the growing evidence linking exposure to violence and abuse among adolescents with poor health outcomes (Jewkes, Dunkle, Nduna, & Shai, 2010; Y. Li et al., 2014), it is important to understand whether and how violence exposure is associated with high-risk sexual practices in HIV-positive adolescents.

Under-studied potential determinants of sexual risk-taking A recently updated systematic review reports that vertically-infected HIV-positive adolescents experience significant neurocognitive delays (Sherr et al., 2014). These findings are confirmed from research in South Africa, which has document significant brain damage due to vertical HIV infection (J Hoare et al., 2012). However, none of the included studies recorded whether the HIV-positive participants had neurocognitive problems, which may shape how they engage in sexual relationships. Only one study reported on mental health outcomes, controlling for sexual health outcomes (Mbalinda, Kiwanuka, Kaye, et al., 2015), with data from a second study testing whether depression or anxiety were associated with sexual risk-taking. Further

research is needed to elucidate how HIV-specific mental health issues affect sexual practices among HIV-positive adolescents and youth.

Mode of infection may be an important determinant of risk taking, with horizontally-infected adolescents continuing to engage in higher risk-taking following HIV infection. Most of the studies in this review which reported mode of infection recruited primarily vertically-infected adolescents. Though mode of infection is often difficult to ascertain and record (Vale & Thabeng, 2016) future studies should attempt to document factors that could ascertain the participants' mode of infection, such as: time on treatment, age at HIV diagnosis, maternal orphanhood (Sharer & Fullem, 2012). Additional research is needed on longitudinal predictors and interventions for sexually-infected adolescents and youth. Few studies reported age-disaggregated data, which would help providers to better understand how to tailor services and programmes to different age groups, and to adapt to the changing needs of growing HIV-positive adolescent populations.

Studies of older adolescents and youth recorded several key relationship factors, such as whether the HIV-positive participant lived with their partners, had children with their husband vs. boyfriend, wanted additional children, or had disclosed their status in the relationship. However, most of the findings on these relationship topics were inconsistent. As HIV-positive adolescents get older and navigate sexual and romantic relationships, additional research is needed to understand how HIV-positive status, its disclosure and other relationship-related factors interact to shape sexual and reproductive outcomes (Fair et al., 2012; Fairlie et al., 2014; Maccarthy et al., 2012).

The included studies reported data on several structural factors, however findings were inconsistent. Evidence from a general adolescent population in South Africa links structural drivers to increased sexual risk-taking (Lucie Dale Cluver, Orkin, Meinck, Boyes, & Sherr, 2016). Further research is needed on the structural factors associated with sexual risk-taking among HIV-positive adolescents and youth. Such research is key to informing

debates on what are the most appropriate interventions to support this at-risk population, particularly with regards to social protection (Toska et al., 2016).

Four studies (Beyeza-Kashesya et al., 2011; Malaju & Asale, 2013; Morris et al., 2012; Obare & Birungi, 2010) recruited a comparison sample of HIV-negative or HIV-status unknown adolescents or youth, with three documenting how HIV-status knowledge was associated with sexual health outcomes (Beyeza-Kashesya et al., 2011; Morris et al., 2012; Obare & Birungi, 2010). Though this comparison was beyond the scope of this review, HIV-positive status was associated with increased protective sexual practices in one study, and increased risk-taking in two other studies. These findings confirm those of a similar review which included studies from North America and Europe (Mergui & Giami, 2011), but did not report consistent associations between *knowledge* of HIV-positive status and sexual practices. Findings from a nationally-representative community-based study in South Africa suggest that knowledge of HIV-status, whether positive or negative, is strongly associated with reduced sexual risk-taking (Shisana et al., 2014). Further analyses on the effect of knowing one's HIV-positive status on sexual risk-taking is needed, particularly in light of the UNAIDS Fast Track target of 90% of HIV-positive adolescents learning their status by 2020 (UNAIDS, 2014a).

Intervention research gaps: First, although results from three cognitive-based therapy trials were encouraging, they need to be tested in larger-scale trials. Second, the majority of the studies in this review (17 of 35) took place in Uganda including three of the four interventions. Additional quantitative and intervention research is needed on secondary HIV prevention in other sub-Saharan countries, particularly South Africa, Nigeria, and Kenya, home to the largest populations of HIV-positive adolescents in the region (Kassede, 2015). Third, several family-level factors were associated with reduced risk-taking in cross-sectional univariate analyses (Baryamutuma et al., 2010; Birungi, Obare, et al., 2009; Holub, 2010; Mbalinda, Kiwanuka, Eriksson, et al., 2015). Although adolescence is a time for exploring and testing boundaries (Fayola, 2004), family-based interventions may be key to support

with difficult HIV-related issues such as disclosure, transition in care, and accessing prevention-of-mother-to-child treatment. Fourth, in-depth analyses are needed of linkages between healthcare experiences (quality of services, access to services such as family planning, counselling and support groups) of HIV-positive adolescents and youth and their sexual and reproductive practices. Evidence to date is limited and inconsistent on the role of group-based care and support, though promising evidence from several programmes has been documented in recent conferences and workshops (Kossow et al., 2015; Pettitt et al., 2012; Rosebush et al., 2015; Wilkinson et al., 2016).

4.4.3. Review limitations

In addition to the research gaps identified above, this review had several limitations. First, it included multiple outcomes to measure sexual risk-taking. Although evidence on linkages between sexually transmitted infections and high risk practices in adolescents are established (Doyle, Mavedzenge, Plummer, & Ross, 2012; Magadi & Uchudi, 2015; Santelli et al., 2013), evidence that this review's outcomes are associated with secondary HIV transmission is limited. Second, studies varied widely in terms of sample size, sampling strategies, and exact definition of outcome measures, and the majority of studies were cross-sectional. Therefore, a meta-analyses was not possible, and our ability to reach conclusion on the rates and determinants of sexual risk-taking among HIV-positive adolescents and youth was limited. Third, the analyses reported by the included studies was mostly univariate with actual statistics often not reported and confidence intervals missing, which resulted in a low quality of included evidence. Finally, the majority of studies were conducted in Uganda, including mostly HIV-positive adolescents and youth in care, therefore the results are not generalizable across the whole HIV-positive adolescent and youth population in sub-Saharan Africa. The evidence presented here must be interpreted with these methodological limitations in mind.

4.5. CONCLUSION

HIV-positive adolescents have been neglected in HIV-prevention efforts in the region, with few studies testing interventions aimed at supporting HIV-positive adolescents to reduce sexual and onwards vertical transmission (secondary prevention). Very few studies have rigorously documented potential risk and protective factors associated with increased secondary HIV-transmission risk. Longitudinal research is needed to establish and test emerging patterns between HIV-transmission risk and socio-demographic, HIV-specific, relationship, family, and structural-level factors. To address the potential for onwards HIV transmission, evidence on the effectiveness and feasibility of low-cost interventions to reduce HIV transmission from adolescents, both vertically and horizontally-infected, is urgently needed.

4.6. SUPPLEMENTARY TABLES

4.6.1. Results of risk of bias assessment

Table 4-11. Results of the risk of bias assessments for all included studies

Study	*Selection bias*	*Performance bias*	*Outcome bias*	*Attrition bias*	*Reporting bias*	*Other bias*
Ankunda 2011, 2016	low-high	not clear	high	not clear	high	not clear
Bakeera-Kitaka 2008	high	high	high	low	not clear	not clear
Banura 2008	high	low	low	low	low	not clear
Baryamutuma 2012	not clear	not clear	not clear	not clear	not clear	not clear
Beyeza-Kasheysa 2011	low	low	high	low	low	not clear
Birungi 2009a, 2009b, Obare 2010a	low	low	high	low	low	not clear
Birungi 2011, Obare 2012	high	high	high	low	low	not clear
Cataldo 2012	high	high	high	high	high	not clear
Gavin 2006	low	not clear	high	low	low	not clear
Gray 1998	low	low	low	low	low	low
Heffron 2010	low	not clear	not clear	high	low	low
Hendriksen 2007; Steffenson 2011	low	low	high	low	high	not clear
Hoffman 2008	low-high	low	low	not clear	low	not clear
Holub 2010	high	low	high	not clear	low	not clear
Kaggwa 2012	high	high	high	high	high	not clear
Katusiime 2012	high	low	low	not clear	high	not clear
Kembo 2012	low	low	low	low	low	not clear
Lightfoot 2007	low-high	high	low	low	low	not clear
Malaju 2013	low-high	high	high	low	low	not clear
Mbalinda 2015a, 2015b	high	high	high	not clear	low	not clear
Mhalu 2013	low	not clear	high	not clear	low	not clear
Morris 2012	low	low	high	not clear	high	not clear

Study	*Selection bias*	*Performance bias*	*Outcome bias*	*Attrition bias*	*Reporting bias*	*Other bias*
Muyindike 2012	low-high	high	high	low	low	not clear
Nhamo 2012, 2014	low	low-high	low-high	not clear	high	not clear
Noestlinger 2015	high	high	high	not clear	high	not clear
Obare 2010b	high	high	high	low	low	not clear
Pascoe 2015	low	low	low	low-high	low	not clear
Santelli 2013	low	high	high	high	low	not clear
Senyonyi 2013	high	high	high	high	low	not clear
Shisana 2014	low	low	high	high	low	not clear
Snyder 2014	high	high	high	high	low	not clear
Test 2012	high	high	high	low	low	not clear
Toska 2015	low	high	high	low	low	not clear
Viegas 2015	high	high	low	not clear	low	not clear
Wanyenze 2011	high	high	high	high	low	not clear

4.6.2. Summary of findings by study

Table 4-12. Results of correlates of sexual risk-taking among HIV-positive adolescents and youth by study

First author, year	*Outcome*	*SCQ score*[25]	*Factors: correlates or predictors (test results and significance, NR – not reported, NS – not significant)*[26]
Ankunda 2011	Condom use	38%	**Individual:** current contraceptive use (PRR=4.07, 95%CI 1.62-85.78)
Ankunda 2016		38%	**Family:** desiring a child (PRR=0.44, 95%CI 0.21-0.90)
Baryamutuma 2012	Early sexual debut	10%	**Structural:** out of school (chi sq NR, p<0.001)
	Condom use	10%	**Relationship:** single (chi sq NR, p<0.05)
	Older sexual partner	10%	**Individual:** females (chi sq NR, p=0.008)
	STI risk	10%	**Sexual practices:** older sexual partner (chi sq NR, p<0.001)
	Pregnancy	10%	**Family:** not living with parents (chi sq NR, p<0.001)
Birungi 2009a; Birungi 2009b; Obare 2010a	Contraception use at first sex	41%	**Individual:** older age more use (chi sq, p<0.05 among HIV+ only)
		41%	**Individual:** sex (NS)
		41%	**Family:** lives with at least one biological parent (NS)
		41%	**Family:** no siblings (compared to any siblings) (chi sq NR, p<0.05)
		41%	**Structural:** attend school (NS)
		41%	**HIV:** knows HIV+ status (NS in mixed sample)
		41%	**HIV:** discordant relationship (CQC 41%) (45% vs. 65% in concordant, NS)
	Contraception use in current/ past relationship	41%	**Individual:** Older age (chi sq, p<0.05)
		41%	**Individual:** Male gender (chi sq, p<0.05)
		41%	**Individual:** Attends school (NS)
		41%	**Family:** lives with at least one biological parent (NS)
		41%	**Family:** lives with siblings (NS)
		41%	**Relationship:** married/ lives with partner (-0.55 (0.19), p<0.001)
Birungi 2011; Obare 2012	Post-partum contraception	34%	**Individual:** study site (OR=0.5, 95%CI 0.2-0.9, p<0.05)
		34%	**Individual:** poor birth outcomes (NS)
		34%	**Relationship:** paternity husband vs. boyfriend/ fiancé (NS)
		34%	**Structural:** maternal education (NS**)**
		34%	**Sexual practices:** pregnancy order (NS)
		34%	**Sexual practices:** age at 1st pregnancy (NS)
		34%	**Sexual practices:** unintended pregnancy (NS)

[25] Percentage score of the quality of the association between the outcome and the correlate based on the Study Quality Checklist (SQC).

[26] When multiple results were available from several studies, results of the most rigorous methodology or the largest sample size are reported here.

First author, year	*Outcome*	*SCQ score*[25]	*Factors: correlates or predictors (test results and significance, NR – not reported, NS – not significant)*[26]
	unintended pregnancy	34%	**Individual:** study site (NS)
		34%	**Relationship:** paternity husband vs. boyfriend/ fiance (OR=0.1, 95%CI 0.1-0.2), p<0.001)
		34%	**Structural:** maternal education (NS)
		34%	**Sexual practices:** pregnancy order (NS)
		34%	**Sexual practices:** age at 1st pregnancy (NS)
Holub 2010	unprotected sex/ protected sex/ no sex	24%	**Individual:** age (NS)
		24%	**Individual:** Gender(NS)
		24%	**Individual:** religious guidance (NS)
		28%	**Family:** # parents lost (NS)
		31%	**Family:** parental monitoring (NS)
		24%	**Family:** social support (NS)
		24%	**Family:** monitoring*support (OR=1.65, 95%CI 0.98-2.79, p=0.06); aOR=1.57, 95%CI 0.91-2.75, p=0.11
		24%	
		24%	**Structural:** currently in school (NS)
		24%	**HIV:** knows HIV status (NS)
		24%	**HIV:** Time since diagnosis less than one year, more unprotected sex (chi sq, p=0.03)
			Sexual practices: ever had transactional sex (NS)
Kaggwa 2012	Condom use at last sex	24%	**Individual:** Age 19-21 year olds vs. 16-18 year olds (OR=0.27, p<0.01)
		24%	**Individual:** Age 22-24 year old vs. 16-18 year olds (NS)
		24%	**Individual:** Clinically depressed (OR=0.68, p<0.05)
		24%	**Individual:** Anxiety – low compared to moderate (NS) or high (NS)
		24%	**Family/ Community:** Social support (NS)
		24%	**HIV:** Mode of infection (NS)
		24%	**HIV:** ARV use (NS)
	>1 partner in past 12 months	24%	**Individual:** Age 19-21 year olds vs. 16-18 year olds (NS)
		24%	**Individual:** Age 22-24 year old vs. 16-18 year olds (NS)
		24%	**Individual:** Clinically depressed (NS)
		24%	**Individual:** Anxiety – low compared to moderate (NS) or high (NS)
		24%	**Family/ Community:** Social support (NS)
		24%	**HIV:** Mode of infection (NS)
		24%	**HIV:** ARV use (NS)
Katusiime 2012	HBV infection	41%	**HIV:** CD4+ count >250 (chi sq, p<0.001)
		28%	**HIV:** WHO stage I or II (chi sq, p<0.001)
Lightfoot 2007	Consistent condom use	75%	**Intervention:** access to healthcare services → one-on-one nurse-led counselling (NR, p<0.01)
	Number of sexual partners	75%	**Intervention:** access to healthcare services → one-on-one nurse-led counselling (F 1,19=4.68, p=0.04)

First author, year	*Outcome*	*SCQ score*[25]	*Factors: correlates or predictors (test results and significance, NR – not reported, NS – not significant)*[26]
	Highly protected sex	75%	**Intervention:** access to healthcare services → one-on-one nurse-led counselling (NR, p<0.01)
Mbalinda 2015a; Mbalinda 2015b	ever had sex	38%	**Individual:** age 15-19 (CQC 38%) OR=6.28, 2.63-14.99, p<0.001;
		35%	**Individual:** female gender (chi sq, p<0.05)
		35%	**Individual:** being a volunteer/ at home vs. student (chi sq, p<0.05)
		35%	**Individual:** education level (NS)
		35%	**Individual:** region (chi sq, p<0.05)
		38%	**Individual:** never drunk alcohol (OR=0.49, 95%CI 0.28-0.87, p=0.02)
		35%	**Individual:** ever smoked a cigarette (chi sq, p<0.05)
		35%	**Individual:** religion (NS)
		38%	**Family/ Community:** living alone (OR=4.33, 95%CI 1.13-16.62, p=0.03;
		35%	**Family/ Community:** had a friend who smoked (chi sq, p<0.05)
		35%	**Family/ Community:** friend who drunk (chi sq, p<0.05)
		38%	**Family/ Community:** influenced to drink/ smoke (chi sq, p<0.05)
		35%	**Structural:** in school (CQC 38%) OR=.20, 0.13-0.30, p<0.001
		35%	**Structural:** education level (NS)
		35%	**Structural:** occupation → being a volunteer vs. student (OR7.28, 3.85-13.75, p<0.001)
		41%	**Structural:** occupation → at home vs. student (OR8.61, 5.15-14.41, p<0.001)
			HIV: never STI treatment (OR=0.19, 95%CI 0.11-0.32, p<0.001)
Mhalu 2013	sexual debut <=15	38%	**Individual:** female gender (chi sq=3.865, p=0.048)
	multiple sexual partners	41%	**Individual:** older age (NS)
		41%	**Individual:** gender (NS)
		41%	**Individual:** not using alcohol (NS)
		41%	**Individual:** district of residence (NS)
		41%	**Individual:** STI prevention knowledge (NS)
		41%	**Family/ Community:** supportive family (NS)
		41%	**Structural:** education status (NS)
		41%	**HIV:** not knowing partner's HIV status (OR=2.62, 95%CI 1.14-5.10, p=0.023)
		41%	**HIV:** ART use (OR=.38, 95%CI 0.17-0.85, p=0.018)
		41%	**Sexual practices:** sexual debut before 15 (NS)
	unprotected sex	41%	**Individual:** younger age 15-19 (OR=2.76, 95%CI 1.05-7.27, p=0.040)
		41%	**Individual:** gender (NS)
		41%	**Individual:** not using alcohol (OR=0.40, 95%CI 0.17-0.84, p=0.017)
		41%	**Individual:** district of residence (NS)
		41%	**Individual:** STI prevention knowledge (NS)
		41%	**Family/ Community:** supportive family (NS)
		41%	**Structural:** education status (NS)

First author, year	*Outcome*	*SCQ score*[25]	*Factors: correlates or predictors (test results and significance, NR – not reported, NS – not significant)*[26]
		41%	**HIV:** not knowing partner's HIV status (NS)
		41%	**HIV:** ART use (NS)
		41%	**Sexual practices:** sexual debut before 15 (NS)
Nhamo 2013	Unintended pregnancy	52%	**Relationship:** GBV (aRR=1.28, 95%CI 1.05-1.57)
		52%	**Sexual practices:** multiple sex partners (aRR=2.94, 95%CI 2.38-3.63)
		52%	**Sexual practices:** sex without a condom (aRR=1.83, 95%CI 1.48-2.26)
		52%	**Relationship:** being married/living with a partner (aRR=3.00, 95%CI 2.45-3.68)
		52%	**Structural:** food insecurity (aRR=1.68, 95%CI 1.51-2.30)
Nhamo 2014	Condom use	66%	**Intervention - Structural:** grants + livelihood training + SRH services (RR=1.43, 95%CI 1.16-1.76, p<0.001)
	Transactional sex	66%	**Intervention - Structural:** grants + livelihood training + SRH services (OR=0.87, 95% CI 0.75-1.01, p0.067)
	Multiple sexual partners	66%	**Intervention - Structural:** grants + livelihood training + SRH services (NS)
Nöstlinger 2015	Ever had sex	31%	**Individual:** Study site: NS
Obare 2010b	Condom use	34%	**Individual:** Male gender (chi sq. p<0.05)
	Injectable contraception	34%	**Individual:** Female gender (chi sq, p<0.01)
	Pregnant	34%	**Individual:** Female gender (chi sq, p<0.01)
	Older partner currently	34%	**Individual:** Female gender (chi sq, p<0.01)
	Older partner at first sex	34%	**Individual:** Female gender (chi sq, p<0.01)
	Used contraception at first sex	34%	**Individual:** gender (NS)
	Ever used contraception	34%	**Individual:** gender (NS)
	Currently using contraception	34%	**Individual:** gender (NS)
Senyonyi 2012	Sexual transmission behaviour score	55%	**Intervention – Structural:** group counselling (Wilk's λ = 0.951, F(1,113) = 5.866, p = 0.017, partial η2 = 0.049 for pre and post-test comparisons, but NS comparing intervention to control group).
Snyder 2014	Condom use at last sex	41%	**Intervention – HIV:** support groups (+12%, p<0.01)
Test 2012	partner 5+ years older	31%	**Individual:** Female gender (chi sq, p<0.01)
	partner 10+ years old	31%	**Individual:** Gender (NS)
	Transactional sex	31%	**Individual:** Female gender (chi sq, p=0.03)
	condom use past 6 months	31%	**Individual:** Gender (NS)
	lifetime number of partners	31%	**Individual:** Gender (NS)
	Transactional sex (among females only n=32)	31%	**Individual:** Age (NS)
		31%	**Individual:** median number of school years (NS)
		31%	**Individual:** works for wage (NS)

First author, year	*Outcome*	*SCQ score*[25]	*Factors: correlates or predictors (test results and significance, NR – not reported, NS – not significant)*[26]
		31%	**Sexual practices:** median lifetime partners (chi sq, p=0.03)
		31%	**Sexual practices:** condom use inconsistent (NS)
		31%	**Sexual practices:** median age at sexual debut (NS)
		31%	**Sexual practices:** age asymmetry at first sex (NS)
		31%	**HIV:** sexual HIV acquisition (NS)
Toska 2015	Unprotected sex at last intercourse	45%	**Individual:** Age (NS)
		45%	**Individual:** Female gender (NS)
		45%	**Family/ Community:** Lives with biological caregiver (NS)
		45%	**Family/ Community:** Orphanhood (NS)
		45%	**HIV:** knowledge of own HIV+ status (OR=4.36, 95%CI 1.08-17.5, p<0.05)
		45%	**HIV:** mode of infection (NR, p<0.05)
		45%	**HIV:** Time on ART (NS)
		45%	**HIV:** ART adherence (NS)
		45%	**HIV:** knows partner HIV status (NS)
		45%	**HIV:** disclosed to partner (NS)
		45%	**HIV:** Opportunistic Infections (NS)
		45%	**HIV:** Hospital care (NS)
		45%	**Sexual practices/ outcomes:** STI symptoms (NS)
Viegas 2015	Sex before 18	25%	**Individual:** Gender (NS)
	Condom use at last sex	25%	**Individual:** Gender (NS)
	Multiple sexual partners	25%	**Individual:** Gender (NS)
	STIs	25%	**Individual:** Gender (NS)

4.6.3. Sexual risk-exposure outcomes

Table 4-13. Prevalence rates of sexual risk-exposure outcomes reported by included studies

Outcome	*Definition*	*Studies*	*Rates)*	*Gender disaggregation*	*Notes*
Gender-based violence	any self-reported experience of physical, sexual abuse or forced sex	Nhamo 2013	34%	All female	28% physical; 13% sexual; 7% forced sex
Forced sex	Had consensual first sex	Birungi 2009a, 2009b	73%	63% F, 89% M	
	Ever forced sex	Nhamo 2013	7%	All female	
	Not clear	Test 2012	22%	29% F, 7% M	

4.7. REFERENCES

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'We use a condom sometimes. At times my boyfriend would complain that the condom tightens his penis. He would forget to get them before I come to visit him and when I get there he would not have condoms. And sometimes I would insist on having sex with a condom and if he does not have one, we will not have sex.'

(17 year old adolescent girl, Mdantsane – Hodes 2015)

'They are more committed to a secret than survival.'
(Nurse, Gompo clinic, 20 June 2014 – Hodes 2015)

'When I had the test, they counselled me, and the sister told me that I must disclose to my sexual partners. But no-one is going to do that, no one can. Maybe some can, but they are scared that their partners will blame them. Because if the boy didn't go to test, he is going to say to you, "You are the one who has brought this to me," even though he doesn't know his status.'

(18-year old adolescent girl, Gompo clinic, 23 June 2014 – Hodes 2015)

5. PAPER 2 – IS KNOWLEDGE POWER? HIV-STATUS DISCLOSURE AND PROTECTIVE SEXUAL PRACTICES AMONG ADOLESCENT GIRLS AND BOYS IN SOUTH AFRICA

(In preparation for submission to BMC Public Health)

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This paper builds on the findings of the systematic review, as well as current global policies and guidelines on disclosure of HIV-status to and from HIV-positive adolescents. It explores how adolescents' knowledge and disclosure of their HIV-positive status is associated with protective sexual practices. The introduction presents the evidence base to date, followed by a detailed section on the methodology used: study design, participant recruitment, measures, and analyses. Results are presented in four sections: characteristics of the 1,527 adolescents who took part in the study, comparing HIV-positive status-aware adolescents (n=794) to the rest of the sample (n=793). Then associations between three types of disclosure and protective sexual practices are investigated: (i) knowledge of own HIV-positive status, (ii) disclosing one's HIV-positive status to a partner, and (iii) knowing one's

partner's status. Next, results on gender moderation analyses are shown, followed by gender-disaggregated analyses. The discussion interprets these findings, drawing implications for future research. Specifically, this paper answers the following research questions:

2. How is knowledge and disclosure of HIV-status associated with protective sexual practices among adolescents in South Africa?

a. *Is knowledge of one's own HIV-positive status associated with protective sexual practices among adolescents in South Africa?*
b. *Is disclosure of adolescent HIV-positive status to a sexual partner associated with protective sexual practices among adolescents in South Africa?*
c. *Is knowledge of a sexual partner's HIV-status associated with protective sexual practices among adolescents in South Africa?*
d. *Does gender moderate the relationship between different types of HIV-status disclosure and protective sexual practices?*

Author statement: ET conducted the majority of the work for this paper. ET led the quantitative study design, data analysis and writing. LC and ET conceptualized the quantitative study, and contributed to data analysis and writing. ET and MP led the data collection and cleaning. MP supported with data analyses and writing. RH contributed to conceptualising analyses and writing. All authors have read and approved the final text. All co-authors have reviewed and approved this author statement.

ABSTRACT

Background: To stem AIDS-morbidity and stop HIV transmission, UNAIDS recommends that 90% of HIV-positive people know their status by 2020, including adolescents. HIV-positive adolescents who engage in unsafe sex are at risk of transmitting HIV to partners and children. Little is known about linkages between knowing and disclosing one's HIV-positive status and practicing safe sex among adolescents.

Methods: This study tests whether (1) knowledge of one's own HIV-positive status, (2) disclosure of HIV-positive status to partners, and (3) knowledge of partner HIV-status are associated with protective sexual practices. The study interviewed n=1,527 HIV-positive and negative adolescents (10-19 years old, 57% female) in a health district in South Africa's poorest province: of whom n=794 knew their own HIV-positive status. Interviews used standardised questionnaires and validated scales. Analyses used multivariate logistic regressions and marginal effects models, controlling for socio-demographic covariates.

Results: n=532 (34.9%) of the sample were sexually-active, with n=451 (29.6%) reporting a boy/girlfriend. HIV-positive status-aware adolescents were more likely to report protective sexual practices (44%) compared to the rest of the sample (29.3%), $p<0.02$. In individual multivariate regression analyses, knowing own HIV-positive status was associated with protective sexual practices (OR1.88, CI1.35-2.63, $p<0.001$), disclosing one's HIV-status to a partner was not associated with protective sexual practices, while knowledge of partner HIV-status was associated with less protective sexual practices (OR0.45, CI0.29-0.69, $p<0.001$). Gender did not moderate the effect of disclosure on protective sexual practices, and patterns of association were the same among female and male adolescents: those who knew their HIV-positive status reported more protective sexual practices ($p<0.05$), while those who knew their partner status reported less protective sexual practices ($p<0.05$).

Conclusion: Knowing one's HIV-positive status has a positive effect on adolescent safer sex practices. However, these findings suggest that HIV-status disclosure in sexual relationships may not be protective for adolescents, whose ability to practice safer sex is premised on factors beyond the mere disclosure of HIV-status. Better understanding of the mechanisms through which different types of disclosure are associated with protective sexual practices is necessary to inform healthcare practices that support HIV-positive adolescents engage in safe sex.

Keywords: HIV status; disclosure; safe sex; HIV-positive adolescents; South Africa

Wordcount: 344 words

5.1. INTRODUCTION

In 2014, UNAIDS issued the 90-90-90 targets to reduce AIDS-related morbidity and end the HIV/AIDS epidemic by 2030 (UNAIDS, 2014a). Target 1 recommends that 90% of HIV-positive people know their HIV-status, as an important precursor to initiating antiretroviral treatment and preventing HIV transmission vertically to children or horizontally to sexual partners. This target is particularly relevant in in sub-Saharan Africa, the region most-disproportionately affected by the epidemic. Sub-Saharan Africa is home to 90% of the world's HIV-positive adolescents: an estimated 1.3-2.2 million vertically and horizontally-infected 10-19 year olds (UNICEF, 2013). Less than 50% of HIV-positive people in the region know their status, particularly among key populations such as adolescents. However, the evidence on the effect of knowing one's HIV-positive status and safe sex among adolescents is scarce.

Research to date shows high rates of unprotected sex with other adolescents (Cataldo et al., 2012), low rates of knowing one's own status (Lowenthal & Marukutira, 2013), and low rates of disclosure of HIV-status to sexual partners (Ankunda et al., 2016; Birungi, Mugisha, et al., 2009; Dempsey et al., 2012; Mbalinda, Kiwanuka, Eriksson, et al., 2015; Nöstlinger, Bakeera-Kitaka, et al., 2015). Negotiating safe sexual practices is particularly challenging for HIV-positive adolescents, many of whom experience difficulties in learning and accepting their status (Lam, Naar-king, & Wright, 2007), and withhold their HIV-status to sexual partners (Dempsey et al., 2012; Hardon & Posel, 2012; Mburu, Hodgson, et al., 2014; Nöstlinger, Bakeera-Kitaka, et al., 2015). World Health Organisation guidelines recommend disclosure to adolescents of their own status (WHO, 2011), but recommend prior counselling on potential benefits and risks of disclosure to others (WHO, 2013).

The paucity of research of associations between HIV-status disclosure and safe sex was highlighted in a recent systematic review (Maccarthy et al., 2012). A community-based study among 15-49 year old South Africans indicates that knowing one's HIV-status positively affects safe sexual behaviour: those who had ever tested were more likely to

report condom use at last sex in a recent national community-based prevalence study in South Africa (Shisana et al., 2009). However, studies among HIV-positive adolescents from Uganda report inconsistent associations between knowing own HIV-positive status and protected sex (Beyeza-Kashesya et al., 2011; Obare & Birungi, 2010). A study comparing HIV-positive adolescents who knew their status (n=732) to adolescents who did not know their status (n=2,213), found that HIV-positive adolescents who knew their status were significantly more likely to report using contraception and current condom use (Obare & Birungi, 2010). A second study comparing HIV-positive (n=276) to HIV-negative (n=501) youth (15-24 years old) reported lower rates of condom use among HIV-positive adolescents, 38% vs. 24% respectively (Beyeza-Kashesya et al., 2011).

Only two known studies worldwide test associations of disclosure of status from HIV-positive adolescents to their sexual partners using samples recruited from adolescents attending healthcare facilities only, in Uganda and the United States. The Ugandan study found lower, but not statistically significant, rates of condom use among HIV-positive adolescents who had disclosed to their partners in Uganda compared to those who had not disclosed to their partners (Birungi, Mugisha, et al., 2009). The second study – using a U.S.-based sample – reported that disclosure of status to partners was not associated with safe sex (Dempsey et al., 2012). A single study among n=282 HIV-positive 15-24 year olds in Tanzania tested whether knowing partner's HIV-status was associated with sexual risk-taking (Mhalu et al., 2013). In multivariate analyses, it concluded that knowing partner's HIV-status was associated with lower odds of having multiple sexual partners, but found no significant association with unprotected sex (Mhalu et al., 2013).

Qualitative research from sub-Saharan Africa suggests that disclosure in sexual and romantic relationships is shaped by complex factors. Knowing one's partner's status (Alemayehu, Aregay, Kalayu, & Yebyo, 2014), stigma (R. J. Li et al., 2010), medication-taking (Marhefka et al., 2010), desire for love and acceptance (Busza et al., 2013; Zamudio-

Haas, Mudekunye-Mahaka, Lambdin, & Dunbar, 2012), and progression of HIV disease (Cooper et al., 2007) are associated with reduced HIV-status disclosure in sexual relationships. In particular, HIV-positive adolescent girls are at greater risk of unwanted pregnancy and vertical HIV transmission due to complex factors associated with limited ability to negotiate condom use, age-disparate sexual partnerships and stigma due to their HIV-positive status (Maccarthy et al., 2012; Toska, Cluver, Hodes, et al., 2015). Quantitative research to date does not report any gender-disaggregated analyses of how disclosure of HIV-status in sexual relationships is associated with safe sex among HIV-positive adolescents.

This study adds to the limited existing evidence on how disclosure *to* and *by* HIV-positive adolescents is associated with protective sexual practices, using a community-traced sample of adolescents eligible for antiretroviral treatment and community controls from South Africa. Analyses compares HIV-positive adolescents who know their status (HIV-positive status-aware) to adolescents who do not know their status (status-unaware, whether HIV-positive or negative). To test potential associations between disclosure types and protective sexual practices amongst adolescent girls suggested by qualitative research, analyses were first run on the full sample (n=1,527), followed by moderator and gender-disaggregated analyses. The effect of combinations of types of disclosure on protective sexual practices was also estimated for both adolescent boys and girls.

5.2. METHODS

This study was designed using integrated quantitative and qualitative methods: preliminary qualitative research findings guided quantitative measures, particularly items on disclosure, a preferred practice in studies of adolescent health (Pluye & Hong, 2014). A mixed-methods

approach also guided analyses, with emerging quantitative findings framing the thematic focus of qualitative research, and additional topics followed up through in-depth interviews (Creswell, 2013). The study protocol was reviewed and approved by Research Ethics Committees at the Universities of Cape Town (CSSR 2013/4), Oxford (SSD/CUREC2/12-21), and Eastern Cape Departments of Health and Basic Education, and ethical review boards of facilities.

5.2.1. Participants and procedures

The study recruited 1,527 adolescents, 1,060 of whom were HIV-positive adolescents, residing in the Eastern Cape province of South Africa. To recruit HIV-positive adolescents, every public health facility in the study area, a mixed rural-urban health sub-district, was mapped in 2013. All clinics providing antiretroviral treatment (ART) to >4 adolescents were included in the sample (n=53). Clinical registers were used to identify all patients aged 10-19 who were ART-eligible, regardless of clinic attendance (N=1,202): 1,060 HIV-positive adolescents were interviewed (90.1% of eligible sample, 4.1% refused, 0.9% were excluded due to severe cognitive delays, 1.2% excluded due to other reasons and 3.7% could not be traced). To ensure that adolescents not engaged in care during recruitment were included in the sample, eligible participants identified in health facilities were traced in their home, communities or schools ('community-tracing'). To prevent the possibility of stigma from participation in HIV-related research, the study centred on adolescent use of health and social services, rather than narrowly on HIV-specific research questions. The study sampled sero-assorted adolescents: HIV-positive status-aware and status-unaware adolescents (whether positive or negative). Status-unaware adolescents from neighbouring homes and some co-resident siblings/ cousins were also interviewed (N=467). Voluntary informed consent was obtained from adolescents and caregivers. No incentives were provided, but all participants received a small gift pack and a certificate of participation.

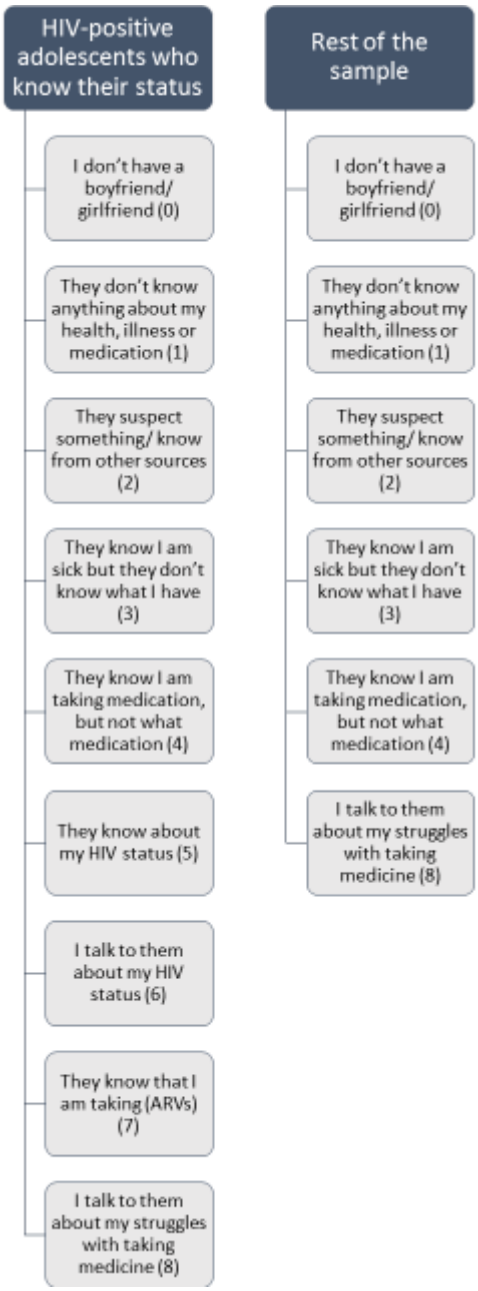
5.2.2. Data Collection Tools

Data collection utilised tablet-based questionnaires, a method documented to improve data quality and reduce missing data (Gorbach et al., 2013; Jaspan et al., 2007). Questionnaires and consent forms were translated and back-translated in consultation with research assistants fluent in the rural and urban vernacular spoken by young people (Harkness & Schoua-Glusberg, 1998). All materials were piloted with a 'teen advisory group' of HIV-positive and HIV-affected adolescents. Interviews lasted approximately 90 minutes and were conducted in the adolescent's language of choice: English or Xhosa using mobile-assisted self-interviews on tablets. In cases of low literacy, researchers trained in ethics and interviewing vulnerable adolescents read out the questions and inputted answers. During the consent process, participants were assured that confidentiality and anonymity would be maintained, except in cases of significant harm or requested assistance. Where participants reported serious risk of harm (such as on-going abuse, recent rape or suicidal attempts), referrals were made to relevant child protection and health services. The study's principal investigator, who is a social worker, oversaw referrals and follow up support.

5.2.3. Quantitative measures

Sex and relationship-related factors: Questions on *sexual experiences*: age of sexual debut, type of contraception and condom use at most recent sexual encounter, were adapted from other studies with HIV-positive youth (Bauermeister, Elkington, Robbins, Kang, & Mellins, 2012). A dichotomous variable was created for *'protective sexual practices'* (1=abstinence or condom use, 0=unprotected sex at most recent sexual encounter).

Figure 5-1. Levels of Disclosure from adolescents to their partners (boyfriend or girlfriend)



Disclosure to and from adolescents: *Adolescent knowledge of HIV-positive status* was assessed triangulating data from their healthcare workers, their primary caregivers and the adolescent themselves during the consent process. To prevent unintentional disclosure of HIV-status to participants, interviewers followed a screening protocol to confirm the adolescents' understanding of their HIV-positive status. The screening tool involved a set of questions about recent history of health, illness, use of healthcare services and medication-taking without specific mention of HIV or ART unless the adolescents disclosed this themselves. Those who did not know their HIV-positive status responded to a questionnaire with questions about 'illness' and 'medication' instead of 'HIV' and 'ART', respectively.

Disclosure to partners was measured by adolescent report using an 8-point gradient of disclosure levels (Figure 5-1). Levels of disclosure were conceptualised as incremental, based on qualitative literature and piloting with HIV-positive youth (Lam et al., 2007; Michaud et al., 2009; Peele, D'Angelo, Chandwani, Abramowitz, & Koenig, 2012). Adolescents who did not know their status were asked if they had told their boyfriend/ girlfriend that they were taking medication. The variable was coded into a binary variable: 1=partner knows adolescent is HIV-positive and/ or taking ARVs, 0=partner does not know.

Participants were asked whether they were in a relationship and whether they knew their *partner's HIV-status*, with response options: HIV-positive, HIV-negative, or HIV-status unknown. This variable was coded as 1=knows HIV-status of partner is either HIV-positive or HIV-negative, 0=does not know partner HIV-status.

Socio-demographic characteristics: Items adapted from the South African census (Statistics South Africa (SSA), 2011) measured key socio-demographic factors such as adolescent age, gender, language, urban/ rural location, and formal/ informal housing, and relationship to primary caregiver. Household poverty was measured through an index measuring lack of eight highest socially-perceived necessities for children, corroborated by >80% of the population in the nationally-representative Social Attitudes Survey (Pillay, Roberts, & Rule, 2006). The index included necessities such as shoes and three meals a day. It was dichotomised as 1=lacking at least one basic household necessity and 0=access to all basic household necessities.

5.2.4. Data analyses

Analyses were conducted using SPSS22.0. Missing data was minimal (<1%), due to careful in-field data checking and the use of mobile-assisted technology. All analyses compared outcomes between two sub-groups: HIV-positive adolescents who knew their status ('HIV-positive status-aware', n=794) and the rest of sample who were unaware of their status ('status-unaware', n=733). Additional gender-disaggregated analyses compared two sets of subgroups: (a) HIV-positive status-aware girls (n=441) to status-unaware adolescent girls (n=426), and (b) HIV-positive status-aware boys (n=352) to status-unaware adolescent boys (n=307).

Quantitative analysis followed a five-stage process. First, socio-demographic frequencies were calculated for the full sample, comparing HIV-positive status-aware adolescents to status-unaware adolescents.

Second, chi-square tests compared rates of the different types of disclosure among adolescent girls and boys: HIV-positive status-aware compared to status-unaware. Gender-disaggregated marginal effect analysis tested potential additive effects of multiple types of HIV-status disclosure. Using STATA 11.2, predicted probabilities of protective sexual practices under each potential combination of types of disclosure, with all covariates held at mean values, were computed.

Third, multivariate regressions explored associations between safe sex and the three types of HIV-status disclosure, using a sequential approach. Each type of disclosure (knowledge of own HIV-positive status, sharing HIV-positive status with sexual partners, and knowledge of partner status) was added as an independent variable in a multivariate regression model, controlling for age, gender, poverty, rural/ urban residence, formal/ informal housing type, language, and caregiving arrangement. All types of disclosure were added in one final multivariate regression model.

Fourth, moderation analyses for gender and each type of disclosure was tested using multivariate regression models. Each type of disclosure and an interaction term with gender were added as independent variables, controlling for age, gender, poverty, rural/ urban residence, formal/ informal housing type, language, and caregiving arrangement.

Fifth, gender-disaggregated multivariate regressions to explore associations between the three types of HIV-status disclosure and safe sex were run. Analyses compared HIV-positive status-aware adolescents (boys or girls) to the rest of the adolescents in the sample (boys or girls, respectively), controlling for: age, poverty, rural/ urban residence, formal/ informal housing type, language and caregiving arrangement.

5.3. RESULTS

5.3.1. Socio-demographic characteristics (Table 5-1)

Adolescent age ranged from 10-19 years old (mean=14.06, SD=2.91). The sample was 56.8% female, 96.1% spoke Xhosa at home. Just over one-fifth lived in rural areas, with 17.7% living in informal housing (shack in a separate plot or someone's yard). More than two thirds (66.3%) could not afford basic household necessities, including warm clothes, 3 meals a day or medical expenses. About half of the adolescents lived with at least one of their biological caregivers.

5.3.2. Sexual practices of adolescents by knowledge of HIV-positive status (Table 5-2)

About a third (n=452, 29.6%) of the full sample reported having a boy/ girlfriend, with over a third n=533 (34.9%) ever having had sex. Of those who had a boy/ girlfriend, two thirds (n=338, 22.1%) had ever had sex. Among sexually-active adolescents in a relationship (n=338), 19.5% (n=66) had disclosed HIV-positive status or medication-taking to their partner, and nearly half 45.3% (n=183) knew their partner's HIV-status (positive or negative). There were no significant differences between HIV-positive status-aware adolescents and the rest of the sample in terms of sexual activity, being in a relationship or knowing their partners status. One in ten of HIV-positive status-aware adolescents were in sero-discordant relationships (9.6%, n=22).

5.3.3. Protective sexual practices of adolescents by disclosure type (Table 5-2)

37.3% (n=199) of all sexually-active adolescents reported protective sexual practices, defined as abstinent or reporting condom use at the last sexual intercourse. Amongst sexually-active adolescents, girls were less likely to report protective sexual practices than adolescent boys (17.4% vs. 75.8%, X^2 (df)=174.987 (1), p<.001). HIV-positive status-aware

participants, those who had not disclosed to their partner and those who did not know their partner's HIV-status, were more likely to report protective sexual practices ($p \leq .001$).

Marginal effects models tested the cumulative effect of combinations of types of disclosure, controlling for significant covariates held at mean values (Figure 2). For both adolescent boys and girls, combinations of disclosing of HIV-positive status to partner and knowledge of partner status is worse than knowledge of adolescent own HIV-positive status alone. Among adolescent girls, those who had disclosed their HIV-positive partner to their status *and* knew their partner's HIV status were the least likely to report protective practices (55%), while knowledge of adolescent girls' own HIV-positive status increased the likelihood of protective sexual practices when combined with other disclosures to 69-80%. The highest likelihood of protective sexual practices was reported by HIV-positive adolescent girls who knew their HIV-positive status but had not disclosed to their partners, nor knew their partners status (82%). A similar pattern was observed for HIV-positive adolescent boys.

Table 5-1. Sample socio-demographic and relationship characteristics by knowledge of HIV-positive status

Category	*Factor*	*Knows HIV-positive status (n=794)*[1]	*Rest of the sample (n=733)*[a]	*Total sample (n=1,527)*[a]	*p-value*
Gender	Female	442 (55.7)	426 (58.1)	868 (56.8)	0.334
	Male	352 (44.3)	307 (41.9)	659 (43.2)	
Age	Age in years	14.46 (2.77)	13.62 (3.00)	14.06 (2.91)	**0.002**
	10-14 years old	426 (53.7)	451 (61.5)	877 (57.4)	
	15-19 years old	368 (46.3)	282 (38.5)	650 (42.5)	
Residence	Urban	644 (81.4)	537 (73.8)	1181 (77.7)	**≤.001**
	Rural	147 (18.6)	191 (26.2)	338 (22.3)	
Ethnicity	Xhosa	771 (97.1)	696 (95.0)	1467 (96.1)	**0.031**
	Other	23 (2.9)	37 (5.0)	60 (3.9)	
Housing Type	Informal	150 (18.9)	121 (16.5)	271 (17.8)	0.228
	Formal	644 (81.1)	611 (83.5)	1255 (82.2)	
Poverty	Missing any of the basic 8 necessities	547 (68.9)	466 (63.6)	1013 (66.3)	**0.028**
Caregiving arrangement	Living with biological parent	338 (42.6)	404 (55.8)	742 (48.6)	**≤.001**
Sexual and romantic relationships	Has a boyfriend or girlfriend	228 (28.8)	224 (30.6)	452 (29.6)	0.440
	Ever had intercourse (vaginal or anal)	294 (37.0)	239 (32.6)	533 (34.9)	0.070
	Sexually active and in a relationship	178 (22.4)	160 (21.8)	338 (22.1)	0.781
Among sexually-active adolescents in relationships		*Knows HIV-positive status (n=178)* [a]	*Rest of sample (n=160)* [a]	*Total sample (n=338)* [a]	*p-value*
Disclosure	Disclosure of HIV-positive status or ARV/ medication-taking to partner	55 (30.9)	11 (6.9)	66 (19.5)	**≤.001**
	Knowledge of partner status	72 (40.0)	81 (50.6)	183 (45.3)	0.061

Notes:

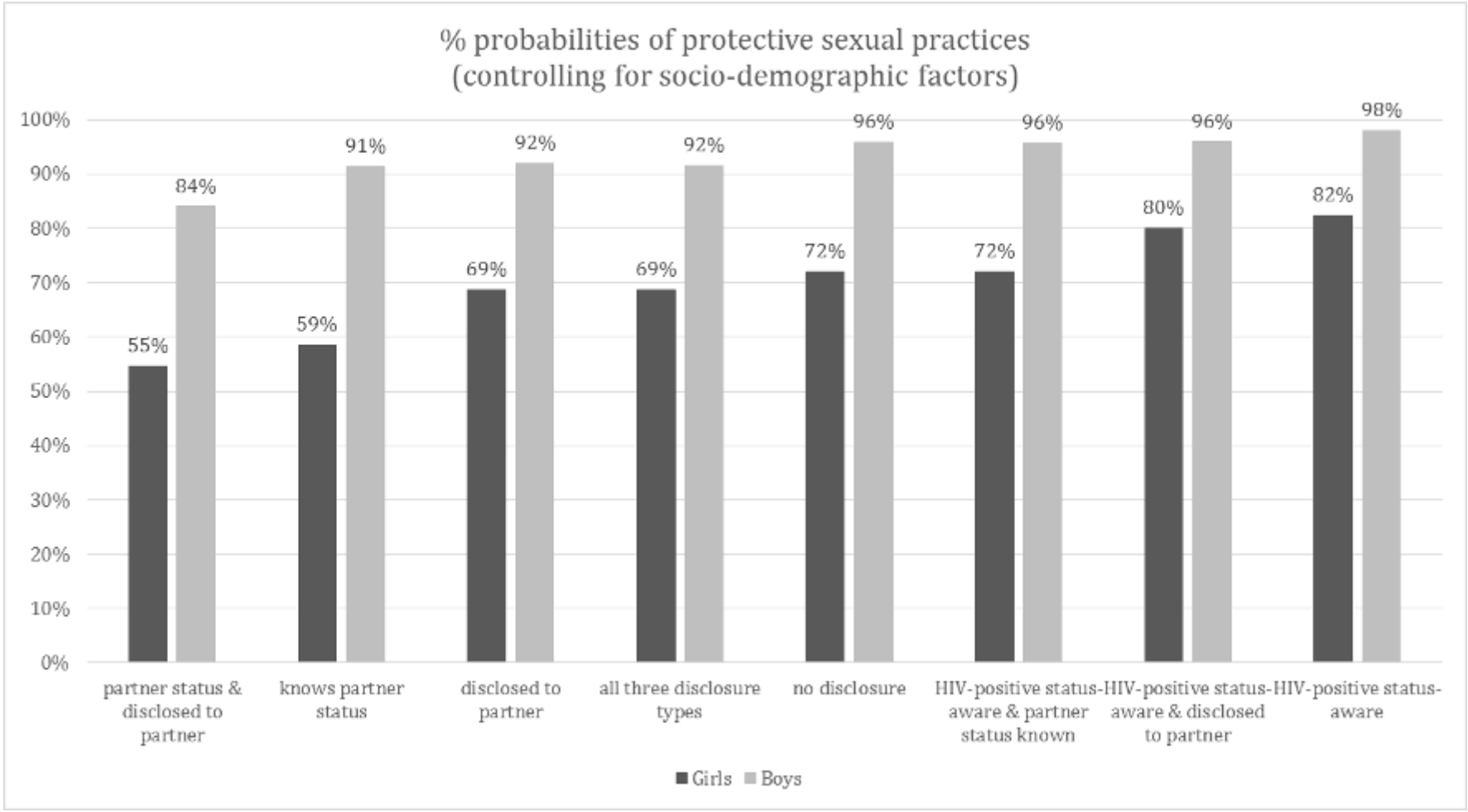
This table includes the results of a series of chi-square tests with knowing one's HIV-positive status as an outcome. The first two columns display numbers and proportional percentages within groups, the third column displays numbers and shares between groups.

[1] All values displayed are numbers (%) except for age in years, and years on treatment. These display mean (SD).

Table 5-2. Rates of protective sexual practices by disclosure type and gender among sexually-active adolescents

		Rates of protective sexual practices			
Disclosure type	*Category*	*Girls (n=351)*	*Boys (n=182)*	*Total (n=533)*	*p-value*
Total rates of protective sexual practices		61 (17.4)	138 (75.8)	199 (37.3)	≤0.001
Knowledge of HIV-positive status	Yes No	41 (67.2) 20 (32.8)	88 (63.8) 50 (36.2)	129 (64.8) 70 (35.2)	≤0.001
Disclosure of HIV-positive status or ARV/ medication-taking to partner	Yes No	17 (27.9) 44 (72.1)	6 (4.3) 132 (95.7)	23 (11.6) 176 (88.4)	0.268
Knows partner HIV status (positive or negative)	Yes No	22 (36.1) 39 (63.9)	17 (12.3) 121 (87.7)	39 (19.6) 160 (80.4)	≤0.001

Figure 5-2. Predicted probabilities of protective sexual practices by combinations of disclosure types among adolescents girls and boys



5.3.4. Associations between type of HIV-status disclosure and safe sex

There were three principal findings regarding associations between type of HIV-status disclosure and protective sexual practices (Table 3). First, knowing one's HIV-positive status was associated with higher likelihood of protective sexual practices (OR1.880 CI1.345-2.629, *p*<.001). Second, disclosing one's HIV-positive status or medication-taking to one's partner was not associated with protective sexual practices (OR.775 CI.424-1.416, *p*=.407). Third, knowledge of a partner's HIV status was associated with a lower likelihood of protective sexual practices (OR.449 CI.293-.688, *p*<.001). Of potential covariates: age, gender, poverty, rural/ urban residence, formal/ informal housing type, and caregiving arrangements, only age, gender, and poverty remained significantly associated with protective sexual practices. In all regression analyses, older and female adolescents, and those who could not access all eight basic necessities were more likely to report lower rates of protective sexual practices (*p*<.001, *p*<.001, and *p*<.02 respectively).

None of the moderation effects between gender and disclosure types were significant (Table 4). Gender-disaggregated multivariate logistic regressions examined associations of the three types of HIV-status disclosure controlling for socio-demographics. These regressions showed similar patterns for the three types of disclosure among adolescent girls (n=868, Table 5) and boys (n=659, Table 6). Knowing one's own HIV-positive status was associated with greater reports of protective sexual practices among girls (OR1.855 CI1.258-2.735, p=.002) and boys (OR2.083 CI1.041-4.170, p=.038). Disclosing one's status to a partner was not significantly associated with protective sexual practices for either adolescent girls or boys. Knowing one's partner HIV-status was associated with lower reported rates of protective sexual practices among girls (OR.476 CI.291-.779, p=.003) and boys (OR.379 CI.163-.879 p=.024). Among adolescent girls, with increased reporting of protective sexual practices was associated younger age (p≤.001) and having access to all eight necessities (p≤.005). Among adolescent boys, younger age was the only covariate factor significantly associated with higher rates of reported protective sex (≤.001).

Table 5-3. Regression models of associations between types of disclosure and protective sexual practices amongst all adolescents (n=1,527)

Variables	*Knowledge of adolescent's own HIV-positive status*[1]			*Disclosure of own status to partner*[1]			*Knowledge of partner's status*[1]		
	OR	*95%CI*	*p-value*	*OR*	*95%CI*	*p-value*	*OR*	*95%CI*	*p-value*
Age	**.561**	**.524-.602**	**≤0.001**	**.574**	**.535-.616**	**≤0.001**	**.595**	**.554-.639**	**≤0.001**
Gender	**.154**	**.104-.228**	**≤0.001**	**.163**	**.110-.240**	**≤0.001**	**.165**	**.112-244**	**≤0.001**
Rural residence	.711	.484-1.044	.081	.671	**.458-.983**	**.040**	.683	.465-1.003	.052
Informal housing	.977	.638-1.497	.915	1.013	.664-1.546	.950	1.001	.654-1.533	.997
Xhosa language	.521	.220-1.238	.140	.672	.292-1.545	.349	.635	.272-1.485	.295
Living with biological caregiver	.804	.580-1.113	.188	.740	.537-1.020	.066	.751	.543-1.039	.083
Poverty	**.621**	**.432-.892**	**.010**	**.647**	**.452-.926**	**.017**	**.635**	**.442-.912**	**0.014**
Disclosure type[1]	**1.880**	**1.345-2.629**	**≤0.001**	.775	.424-1.416	.407	**.449**	**.293-.688**	**≤0.001**

Notes:
[1] Each model included one type of disclosure as the independent variable, controlling for the factors listed.

Table 5-4. Regression models testing for gender moderation of associations of disclosure types and protective sexual practices (n=1,527)

Variables	*Knowledge of adolescent's own HIV-positive status*[1]			*Disclosure of own status to partner*[1]			*Knowledge of partner's status*[1]		
	OR	*95%CI*	*p-value*	*OR*	*95%CI*	*p-value*	*OR*	*95%CI*	*p-value*
Age	**.562**	**.524-.603**	**≤0.001**	**.572**	**.533-.614**	**≤0.001**	**.595**	**.554-.639**	**≤0.001**
Gender	**.176**	**.103-.301**	**≤0.001**	**.155**	**.104-.232**	**≤0.001**	**.160**	**.103-.249**	**≤0.001**
Rural residence	.708	.483-1.040	.078	**.666**	**.454-.975**	**.037**	.682	.464-1.002	.051
Informal housing	.981	.641-1.502	.929	1.013	.664-1.546	.952	1.000	.653-1.532	.999
Xhosa language	.535	.225-1.273	.158	.671	.292-1.540	.346	.636	.273-1.484	.295
Living with biological caregiver	.808	.583-1.120	.200	.738	.535-1.017	.063	.750	.542-1.037	.082
Poverty	**.620**	**.432-.891**	**.010**	**.641**	**.448-.918**	**.015**	**.634**	**.442-.911**	**.014**
Disclosure type[1]	3.022	.729-12.529	.128	.184	.011-3.099	.240	.347	.063-1.919	.225
Interaction: Gender*Disclosure type[2]	.765	.351-1.668	.501	2.184	.479-9.962	.313	1.158	.450-2.981	.761

Notes:
[1] Each model included one type of disclosure as the independent variable, controlling for the factors listed.
[2] Each model included an interaction term of gender and the respective disclosure type entered as an independent variable.

Table 5-5. Regression models of associations between types of disclosure and protective sexual practices among adolescent girls (n=868)

Variables	*Knowledge of adolescent's own HIV-positive status1*			*Disclosure of own status to partner[1]*			*Knowledge of partner's status[1]*		
	OR	*95%CI*	*p-value*	*OR*	*95%CI*	*p-value*	*OR*	*95%CI*	*p-value*
Age	**.551**	**.509-.597**	**≤0.001**	**.562**	**.517-.610**	**≤0.001**	**.585**	**.538-.635**	**≤0.001**
Rural residence	.727	.472-1.118	.146	.679	.444-1.040	.075	.693	.451-1.064	.094
Informal housing	1.022	.635-1.644	.929	1.065	.667-1.699	.793	1.049	.654-1.683	.843
Xhosa language	.459	.182-1.157	.099	.615	.253-1.495	.283	.584	.236-1.448	.246
Living with biological caregiver	.877	.604-1.273	.490	.817	.565-1.179	.280	.842	.581-1.219	.362
Poverty	**.526**	**.346-.800**	**.003**	**.551**	**.364-.833**	**.005**	**.547**	**.360-.829**	**.005**
Disclosure type[1]	**1.855**	**1.258-2.735**	**.002**	.919	.480-1.758	.798	**.476**	**.291-.779**	**.003**

Notes:
[1] Each model included one type of disclosure as the independent variable, controlling for the factors listed.

Table 5-6. Regression models of associations between types of disclosure and protective sexual practices among adolescent boys (n=659)

Variables	*Knowledge of adolescent's own HIV-positive status[1]*			*Disclosure of own status to partner[1]*			*Knowledge of partner's status[1]*		
	OR	*95%CI*	*p-value*	*OR*	*95%CI*	*p-value*	*OR*	*95%CI*	*p-value*
Age	**.592**	**.509-.688**	**≤.001**	**.598**	**.514-.969**	**≤.001**	**.624**	**.535-.729**	**≤.001**
Rural residence	.688	.285-.1.662	.406	.640	.263-1.556	.325	.670	.275-1.635	.379
Informal housing	.888	.329-2.400	.815	.902	.332-2.445	.839	.907	.334-2.460	.848
Xhosa language	1.040	.121-8.693	.971	.940	.112-7.883	.955	.839	.095-7.381	.874
Living with biological caregiver	.672	.333-1.356	.267	.565	.286-1.116	.100	.547	.274-1.093	.088
Poverty	.949	.457-1.969	.889	.940	.456-1.937	.867	.908	.437-1.890	.797
Disclosure type[1]	**2.083**	**1.041-4.170**	**.038**	.423	.108-1.663	.218	**.379**	**.163-.879**	**.024**

Notes:
[1] Each model included one type of disclosure as the independent variable, controlling for the factors listed.

In final models with all three types of disclosure entered together alongside covariates (Table 5-7), knowledge of adolescent's own HIV-positive status remained associated with protective sex in the full sample (OR1.819 CI1.286-2.572, p≤.001), for girls (OR 1.764 CI 1.179-2.638, p=.006) and for boys (OR 2.054 CI1.005-4.196, p=.048). Disclosure of one's HIV-status to partners was not statistically associated with protective sexual practices, while knowledge of a partner's status was associated with reduced likelihood of protective sexual practices in the full sample (OR.506 CI1.286-2.572 p=.003) and among adolescent girls (OR.528 CI.316-.882, p=.015). Poverty remained significantly associated with reduced protective sexual practices in the full sample and among adolescent girls.

Table 5-7. Regression models of associations between all three types of disclosure and protective sexual practices

Variables	*Total sample (n=1,527)*			*Girls (n=868)[1]*			*Boys (n=659)[1]*		
	OR	*95%CI*	*p-value*	*OR*	*95%CI*	*p-value*	*OR*	*95%CI*	*p-value*
Age	**.587**	**.545-.631**	**≤.001**	**.574**	**.527-.625**	**≤.001**	**.614**	**.524-.719**	**≤.001**
Gender	**.162**	**.109-.241**	**≤.001**						
Rural residence	.725	.491-1.069	.104	.736	.476-1.137	.168	.688	.281-1.683	.413
Informal housing	.960	.624-1.478	.854	1.009	.624-1.632	.969	.867	.318-2.365	.781
Xhosa language	.503	.209-1.210	.125	.450	.176-1.150	.095	.869	.095-7.933	.901
Living with biological caregiver	.820	.590-1.141	.239	.898	.616-1.309	.577	.654	.320-1.337	.244
Poverty	**.619**	**.430-.893**	**.010**	**.528**	**.346-.806**	**.003**	.896	.428-1.875	.771
Knowledge of adolescent's own HIV-positive status	**1.819**	**1.286-2.572**	**.001**	**1.764**	**1.179-2.638**	**.006**	**2.054**	**1.005-4.196**	**.048**
Disclosure of own status to partner	.786	.418-1.478	.455	.910	.457-1.812	.788	.493	.116-2.094	.338
Knowledge of partner's status	**.506**	**.325-.789**	**.003**	**.528**	**.316-.882**	**.015**	.459	.189-1.103	.082

Notes:
[1] Gender was not entered as a covariate in gender-disaggregated regression models.

5.4. DISCUSSION

This study documents rates of disclosing one's HIV-positive status to partners and knowing partner's HIV-status. Forty percent of HIV-positive status-aware adolescents knew their partner's status, which is comparable to studies among HIV-positive adolescents in Uganda and Tanzania (Ankunda et al., 2016; Mbalinda, Kiwanuka, Eriksson, et al., 2015; Mhalu et al., 2013), but lower than that among HIV-positive adolescents in Kenya (Obare et al., 2010). In all but one study, less than half of the adolescents knew their partner's status. Further analyses on HIV-positive adolescents who are in relationships where both partners are aware of each-other's status would provide key insights into sero-sorting practices and the potential risk for passing on HIV to sexual partners.

Just under a third of HIV-positive status-aware adolescents in this study had told their partner about their HIV-positive status or ART-taking. This rate was similar to that reported by two studies among HIV-positive Ugandan and Kenyan adolescents (Ankunda et al., 2016; Nöstlinger, Bakeera-Kitaka, et al., 2015), but lower than the rate reported by two other studies in the same countries (Mbalinda, Kiwanuka, Eriksson, et al., 2015; Obare et al., 2010). All but one of these studies however report that less than 50% of HIV-positive adolescents in relationships had disclosed their HIV-positive status to their partners suggesting high levels of reluctance among this young population.

The study then quantitatively explored how different types of HIV-status disclosure are associated with safer sexual practices among HIV-positive adolescents. These findings indicate that knowing one's own HIV-positive status was associated with protective sexual practices, but knowing your partner's status was associated with higher likelihood of unprotected sex among this community-traced adolescent cohort in South Africa. No significant associations were found between disclosing your status to your partner and protective sexual practices. These effects did not differ between girls and boys, though rates of disclosure to partners and knowledge of partner HIV-status were higher among adolescent girls.

Adolescents who knew their HIV-positive status were nearly twice as likely to report protective sexual practices as those who did not know their status, whether HIV-positive or HIV-negative. This was true in both the full sample and gender-disaggregated analyses. The findings on patterns of safe sex by disclosure type among adolescent girls quantitatively confirm qualitative evidence from South Africa and Zimbabwe. This qualitative research has found that while knowledge of HIV-positive status has an empowering effect, knowledge of male sexual partner's HIV-status may trump this positive gain (Toska, Cluver, Hodes, et al., 2015; Zamudio-Haas et al., 2012). To safeguard their sexual and romantic relationships, adolescents are willing to give up condom use compensating for their self-perceived loss of desirability by being HIV-positive (Hodes & Morrell, 2016).

This paper's findings provide support for UNAIDS' Fast Track targets: knowledge of own HIV-positive status remained strongly associated with protective sexual practices, even when adolescents knew their partner status or disclosed their HIV-positive status to their partners. However, research on *how* knowledge of HIV-positive status supports safe sex, whether through HIV-positive adolescents becoming more cautious in engaging in sex, more convincing in negotiating safe sex, or through self-stigma, avoiding sexual and romantic relationships altogether, remains sparse. This is partly due to the complexity of unbundling pathways between protective mechanisms – both social and clinical – and risk behaviours. Further research is needed to test potential mechanisms to support protective behaviours, to inform interventions among HIV-positive adolescents and at-risk populations.

Among HIV-positive status-aware adolescents, protective sexual practices were not associated with disclosure of their HIV-positive status or medication-taking to a partner. These findings support WHO disclosure guidelines, which recommend that HIV-positive adolescents are counselled on the risks and benefits of disclosure to their partners. This study's findings suggest that guidelines on counselling HIV-positive adolescents should focus on knowledge of own HIV-positive status and promoting safe sex with all sexual

partners as the first priority, which may be more valuable than focusing on promoting disclosure to sexual partners or knowledge of partner's HIV status.

Adolescents who knew their partner's status were twice less likely to report protective sexual practices, when controlling for potential covariates. These associations may be explained by qualitative research which reports that fear of rejection, exposure and stigma discouraged HIV-positive adolescents from disclosing to their partners (Toska, Cluver, Hodes, et al., 2015; Zamudio-Haas et al., 2012). These factors could operate through several mechanisms. For example, HIV-positive status-aware adolescents who knew their partners were HIV-negative may have not felt confident to disclose their HIV-positive status to their partner. In turn, their HIV-negative partner may use their HIV-negative status to justify not needing to use condoms during sex, as suggested by qualitative research within the same study (Toska, Cluver, Hodes, et al., 2015). Among the adolescents who knew their partner's status, 12.5% (n=22) had HIV-positive partners and 33% (n=59) were in sero-discordant relationships. Given the small sub-sample of adolescents in relationships with HIV-positive partners, more complex analyses were not possible using this dataset. Additional analysis is needed to understand how sero-concordance (both adolescent and partner having the same HIV-status) and two-way disclosure (an adolescent who knows their partner's status and has disclosed to their partner) affect safe sexual practices.

Both adolescent boys and girls reported fewer protective sexual practices when they knew their male partner's status. However, qualitative research to date suggests that the dynamics of negotiating protected sex via disclosure are gendered. HIV-status disclosure to sexual partners may not be a viable strategy for negotiating safer sex among female adolescents as male sexual partners are likely to have greater power in using the disclosure of their own HIV-status (whether positive or negative) to negotiate unprotected sex (Toska, Cluver, Hodes, et al., 2015). Additional research is needed to understand the factors that may determine and shift the locus of power that underlie sexual practices for adolescent boys and girls.

The associations between disclosure and protective sexual practices reported in this article raise concerns about the quality of disclosure *from* HIV-positive adolescents to their sexual partners. If disclosure is encouraged, adolescents may require more support in ensuring that this then leads to safer sex. HIV-positive adolescents in two studies from Uganda and South African study reported stronger motivation for contraception use to prevent pregnancy than any other sexually-transmitted infections, including HIV (Birungi, Mugisha, et al., 2009; Toska, Cluver, Hodes, et al., 2015). Focusing on adolescents' motivation to prevent pregnancy and STIs may enable healthcare providers to support adolescent efforts to negotiate safe sex with all partners. These findings suggest that disclosure counselling for HIV-positive adolescents could be enhanced by improving patient confidentiality, by addressing adolescent fears on the dangers of disclosure, and by empowering HIV-positive adolescents to negotiate safer sex.

Sexually-active adolescent girls were more likely to report unprotected sex compared to adolescent boys. Given the high rates of defaulting from antiretroviral treatment for prevention of mother-to-child-transmission during pregnancy among HIV-positive adolescent girls (Geoffrey Fatti, Sheikh, Mothibi, & Eley, 2014), this is an urgent and alarming finding. However, this paper's results highlight the protective effect of knowing one's HIV-positive status in the full sample and among adolescent girls, even among those who knew their partners HIV-status. Policy and programming must prioritise knowledge of adolescents' own HIV-positive status to ensure that HIV-positive adolescents benefit from the protective effect of HIV-positive status awareness.

The analyses presented here also confirms that poverty – lack of access to basic necessities – is strongly associated with risky sexual practices. Research on potential factors that mitigate poverty and its negative outcomes: reduced school enrolment, hunger, non-adherence, should be conducted. Further analyses should explore the causal pathways between poverty and unprotected sex among HIV-positive adolescents, particularly girls, in

light of their increased vulnerability to onwards HIV transmission and poor sexual and reproductive health outcomes.

This study has several limitations and strengths. First, similar to other studies among adolescents in the region (Birungi, Mugisha, et al., 2009; Toska, Cluver, Hodes, et al., 2015; Zamudio-Haas et al., 2012), rates of self-reported disclosure to sexual partners were very low. These low rates and sub-sample sizes may have limited the statistical power of the analyses included here. Second, the analyses presented here is based on cross-sectional data which limits our ability to draw conclusions about causal relationships and directionality. Third, knowledge of adolescent's own HIV-positive status was dependent on whether the participants felt comfortable disclosing to their interviewers. Though the research team triangulated information from participant, caregivers and healthcare providers, it is likely that some HIV-positive adolescents who knew their status concealed this from interviewers. Fourth, small sub-sample sizes may have affected these findings. For example, it was not possible to conduct separate analyses for whether adolescents reported their sexual partner's HIV-status to be positive or negative due to small sample size. Adolescent boys also reported very low rates of disclosure to partners (4%) and knowledge of partner status (12%). Fifth, some of the study measures, for example disclosure of HIV-status or medication-taking to a sexual partner, were based on adolescent self-reports and could not be verified. However, the study documented no reasons to expect greater desirability bias for disclosure compared to other self-reported constructs. Sixth, the study was not able to reach 9.1% of the eligible sample, which may exclude particularly vulnerable adolescents from the sample. However, the community-tracing methodology did ensure that adolescents were sampled outside of clinical facilities, and accompanying qualitative research with especially vulnerable adolescents – including severely physically and mentally disabled – helped to include the perspectives of these marginalised groups. It is the only study to include both vertically and horizontally-infected adolescents amongst the HIV-positive sample. Finally, the study was conducted in a health sub-district in South Africa, which limits

the generalizability of its findings. However, by choosing a high HIV-prevalent region in the poorest province, it is possible to draw some parallels with other resource-limited settings in the region.

5.5. CONCLUSION

Understanding the challenges that adolescents face in learning about their status, disclosing it to sexual partners, and learning about their partner's status are critical to successfully stemming the HIV/AIDS epidemic by 2030. Moreover, understanding sexual risk-taking within sexual partnerships, as behaviours negotiated or imposed not solely by individuals, must be the focus of future research. A greater elucidation of the mechanisms through which different types of disclosure are associated with greater or lower rates of protective sexual practices is necessary to inform practices that support HIV-positive adolescents engage in safe sex.

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'This can exacerbate risks because they disengage with the clinic and care that they need because they feel like they have fallen short of what is expected of them. Social protection services that have a specific moral position or are infantilizing can exacerbate children's risk. Instead of responding to young people, young people disconnect at the point when they are most in need of these mechanisms.'

(Expert Consultation, Academic, Female, 30-40 years old, Gittings et al. 2016)

'They are adolescents like everyone else. Look at them as any other adolescent – have social protection programmes that cater to their needs like education, nutrition and health.'
(Expert Consultation, Male, NGO worker, Zimbabwe, Gittings et al. 2016)

'The critical outcome of psychosocial support is resilience. Resilience is the ability to get up when life has knocked, you down and still stand up and keep going. Very often however it is someone who reaches you and helps you to stand up… If you can imagine a child with enough people around them, enough hands reaching them, that in fact they never fall all the way to the ground.

As life is knocking them, there are hands there to help them keep moving. And not just keep moving, but look up and see the stars and have hope that there is a better tomorrow and that I will reach that better tomorrow…'

(Lynette Mudekunye, REPSSI, 2015)

6. PAPER 3 – SCHOOL, SUPERVISION, AND ADOLESCENT-SENSITIVE CLINIC CARE: COMBINATION SOCIAL PROTECTION AND REDUCTED UNPROTECTED SEX AMONG HIV-POSITIVE ADOLESCENTS IN SOUTH AFRICA

(Published in AIDS and Behaviour, 2016, doi:10.1007/s10461-016-1539-y)

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Dream Consultation acted out by the Teen Advisory Group in Grahamstown, South Africa

The last paper in this thesis investigates which social protection provisions are associated with unprotected sex in a sample of HIV-positive adolescents (n=1,060). The findings of the HIV-status disclosure paper confirmed that adolescents who reported greater deprivation (poverty) are at greater risk of engaging in unprotected sex. A growing evidence base has documented the potential of social protection to address structural vulnerabilities such as

poverty and inequality. This paper defines social protection as any programme, service or intervention which is available through governmental, community, or individual-level mechanisms. Nine social protection provisions: five cash and four care were hypothesised to be associated with unprotected sex based on the systematic review and previous research on social protection and sexual risk-taking. The introduction summarises the evidence on social protection and reduced risk-taking, highlighting the lack of research among HIV-positive adolescents. The methods section introduces the study sample, measures, and data analyses. Results are presented in five sections: first sample socio-demographics are reported, followed by rates of access to social protection. Next, associations between social protection provisions and unprotected sex are tested. The results of gender moderation and gender-disaggregated analyses are then reported. Finally, the effect of combination social protection is documented in the last sub-section of results. The discussion section reviews the implications of these findings and proposes areas for future research. Specifically, this paper answers the following research questions:

3. *What are the associations between unprotected sex and social protection provisions in the home, school, and clinic, for HIV-positive adolescents (n=1,060)?*

    a. *Which social protection provisions, accessed by HIV-positive adolescents, are associated with lower rates of unprotected sex?*
    b. *Does gender moderate the effect of social protection on unprotected sex among HIV-positive adolescents?*
    c. *Are there cumulative effects (multiplicative or additive) of combinations of social protection provisions associated with unprotected sex among HIV-positive adolescents in South Africa?*

Author Statement: ET conducted the majority of the work for this paper. ET conceptualised this analyses and led the writing of this paper. LC, ET and MB conceptualised, designed and set up the quantitative study. ET and MI managed the data collection, cleaning and analyses. RH and LS provided feedback on the study design, analyses, and contributed to writing. All authors have read and approved this manuscript. All co-authors have reviewed and approved this author statement.

ABSTRACT[27]

Social protection can reduce HIV-risk behaviour in general adolescent populations, but evidence among HIV-positive adolescents is limited. This study quantitatively tests whether social protection is associated with reduced unprotected sex among 1,060 ART-eligible adolescents from 53 government facilities in South Africa. Potential social protection included nine 'cash/cash-in-kind' and 'care' provisions. Analyses tested interactive/ additive effects using logistic regressions and marginal effects models, controlling for covariates. 18% of all HIV-positive adolescents and 28% of girls reported unprotected sex. Lower rates of unprotected sex were associated with access to school (OR0.52, CI0.33-0.82, *p*=0.005), parental supervision (OR0.54, CI0.33-0.90, *p*=0.019), and adolescent-sensitive clinic care (OR0.43, CI0.25-0.73, *p*=0.002). Gender moderated the effect of adolescent-sensitive clinic care. Combination social protection had additive effects amongst girls: without any provisions 49% reported unprotected sex; with 1-2 provisions 13-38%; and with all provisions 9%. Combination social protection has the potential to promote safer sex among HIV-positive adolescents, particularly girls.

Keywords: HIV-positive adolescents, social protection, unprotected sex, positive prevention, South Africa

Wordcount: 150 words

[2727] This abstract follows the AIDS and Behavior journal guidelines. As per journal requirements, a Spanish version of the abstract was also submitted, but it is not included in this thesis.

6.1. INTRODUCTION

There are an estimated 1.3–2.2 million HIV-positive adolescents in Sub-Saharan Africa, both vertically and horizontally infected (UNICEF, 2013). Studies included in the systematic review (Chapter 4) documented high rates of unprotected sex reported by HIV-positive adolescents even after HIV infection (19%-83%) (Beyeza-Kashesya et al., 2011; Birungi, Obare, et al., 2009; Cataldo et al., 2012; Mergui & Giami, 2011). While rates of unprotected sex among HIV-positive adolescents are comparable to those among the general adolescent population (Mergui & Giami, 2011), HIV-positive adolescents are a key population for reducing onwards HIV transmission to sexual partners and children. In addition, HIV-positive adolescents experience a range of vulnerabilities that are likely to reduce the efficacy of HIV prevention programmes aimed at general populations, including cognitive and mental health issues (Lowenthal et al., 2014; Sherr et al., 2014), family-related challenges (Amzel et al., 2013; Wiener & Battles, 2006) and material deprivation (Busza et al., 2013; Mellins et al., 2012).

Adolescent girls and young women bear a disproprotionate burden of the epidemic: three-quarters of all new HIV infections in Africa are among adolescent girls, and 80% of all HIV-positive adolescent girls live in Sub-Saharan Africa (UNAIDS & AU, 2015; UNICEF-ESARO, 2015). While notable research and resources are focused on supporting adolescent girls and young women to remain HIV-negative, there is a dearth of research and programming for HIV-positive girls. HIV-positive adolescent girls face multiple potential risks: low rates of condom and contraceptive use, greater rates of unwanted pregnancies and related health complications, as well as lower enrollment, adherence to, and retention in prevention–of-mother-to-child transmission programmes, and, consequently, increased risk of transmitting HIV to their partners and children (Lucie D Cluver, Hodes, Toska, et al., 2015; G Fatti et al., 2014; Obare et al., 2012; Test et al., 2012; Toska, Cluver, Hodes, et al., 2015).

Increasingly, social protection provisions are showing potential to reduce the negative impacts of structural deprivations faced by adolescents in high-prevalence

contexts, and to improve their long-term health outcomes (Lucie D Cluver, Hodes, Sherr, et al., 2015). Although traditionally defined as a set of economic measures such as welfare payments or social cash transfers, recent conceptualisations of social protection recognise that it may take one of multiple forms (Lucie D Cluver, Hodes, Sherr, et al., 2015; Devereux & Sabates-Wheeler, 2007; Toska et al., 2016): 'cash/cash-in-kind' provisions to address economic barriers to food security, school access and health services, or psychosocial 'care' interventions such as support groups, supportive parenting or community services (The African Child Policy Forum (ACPF), 2014). This definition of social protection is broader than the traditional understanding of social welfare systems. It encompasses any provisions received by the adolescent at home, at school, in the community or at health facilities. The expanded definition had two added benefits: first, it provided a theoretical framework to organise the various provisions which may support reduced risk behaviour among HIV-positive adolescents. Second, it allowed for this study's analyses to identify modifiable factors that can be targeted through interventions in various settings where adolescents engaged with adults, institutions and authorities to receive support and access services.

Most evidence to date has focused on impacts of social cash transfers in addressing structural vulnerabilities to HIV-infection among adolescents in Sub-Saharan Africa (UNICEF-ESARO, 2015). But recent studies suggest that combinations of 'cash/cash-in-kind' and 'care' social protection provisions may have greater potential for reducing HIV risk-behaviour than single interventions (Lucie D Cluver, Orkin, Boyes, & Sherr, 2014; Lucie D Cluver, Orkin, et al., 2016a). Two studies from South Africa and Kenya suggest that social protection may function differently for boys and girls (Lucie D Cluver, Orkin, et al., 2016a; Handa, Halpern, Pettifor, & Thirumurthy, 2014). A longitudinal study of n=2,668 South African adolescents found that different combinations of 'cash' and 'care' social protection were associated with reductions in sexual risk-taking among adolescent girls compared to adolescent boys (Lucie D Cluver, Orkin, et al., 2016a). The evaluation of the Kenya cash transfer programme for orphans and vulnerable children showed overall reductions in sexual debut with greater impact among girls compared to boys (Handa et al., 2014). A recent

review in Eastern and Southern Africa reported an increasing evidence base on how social protection can reduce HIV infection among HIV-negative adolescents, but found no studies that investigate the role of social protection in preventing onwards HIV-transmission among HIV-positive adolescents (Toska et al., 2016). There is a need for evidence on whether social protection provisions alone or in combination can reduce HIV-risk behavior for HIV-positive adolescents, and to understand potential gender differences.

To date, only a few programmes have tested any interventions to improve sexual and reproductive health among HIV-positive adolescents in Sub-Saharan Africa. A small-scale randomised trial of a behavioural intervention among 14-21 year old HIV-positive youth in Uganda reported that intervention youth (n=50) increased consistent condom use and reduced number of sexual partners significantly compared to controls (n=50) (Lightfoot, Kasirye, et al., 2007). Three studies suggest that 'care' interventions of support groups may be helpful in reducing risk behaviors amongst HIV-positive adolescents (Parker et al., 2013; Senyonyi et al., 2012; Snyder et al., 2014). A pre-post test pilot study of structured support group sessions for HIV-positive adolescents (n=65) in South Africa found improvements in self-reported condom use (Snyder et al., 2014). A qualitative study (n=13) in the Democratic Republic of Congo, consisting of a 6-session group-based healthy living intervention reported better communication with sexual partners (Parker et al., 2013). However, no large-scale or quantitative research has examined impacts of either 'cash/cash-in-kind' or 'care' social protection provisions, alone or in combination, on the sexual practices of HIV-positive adolescents. Combination social protection may have cumulative effects, that is beneficiaries of two or more provisions may do better than those receiving each provision alone. These effects may be multiplicative or additive (Lucie D Cluver, Orkin, et al., 2016a).

This study aims to address this essential research gap. It uses the world's largest community-traced sample of HIV-positive adolescents to investigate whether different types of social protection provisions: 'cash/cash-in-kind' or 'care', are associated with lower rates of unprotected sex. Based on the systematic review in Chapter 4 and a review of the literature on social protection for HIV prevention (Toska et al., 2016), the following nine

social protection provisions were tested: 'cash/cash-in-kind': social cash transfers, past-week food security, free school access (no fees and school materials), school feeding, and clothing, and psychosocial 'care' provisions: positive parenting,[28] strong parental supervision, support groups, adolescent-sensitive care at clinics (respectful treatment by sexual health service providers). It tests 1) associations of each social protection provisions with unprotected sex, 2) the effects of gender on social protection provisions significantly associated with unprotected sex, 3) potential interactive effects of significant social protection provisions, and 4) potential additive effects of combination social protection provisions.

6.2. METHODS

6.2.1. Participants and Procedures

1,060 HIV-positive adolescents (10-19 year olds) were recruited from a health district in the Eastern Cape province, South Africa. This was selected as the country's poorest province with high HIV-prevalence rates (Department of Health, 2012). The study was designed in collaboration with South African Departments of Health and Basic Education, UNICEF, PEPFAR-USAID, Paediatric AIDS Treatment for Africa (PATA) and local NGOs. Ethical approval for this study was provided by Research Ethics Committees at the Universities of Oxford (SSD/CUREC2/12-21) and Cape Town (CSSR 2013/4), Eastern Cape Departments of Health and Basic Education, and ethical review boards of participating hospitals.

The study aimed to include all 10-19 year old adolescents within the health district who were eligible to initiate ART. First, all healthcare facilities providing ART were visited (n=83): all facilities who reported more than five ART-eligible adolescents were included in the study (n=39). As the study progressed, the South African Department of Health

[28] Positive parenting is one of the two dimensions of parenting and caregiving practices linked to reduced disruptive behaviour (Elgar et al., 2007) and HIV-related risky practices (Lucie D Cluver et al., 2014). It focuses on measuring positive engagements between a child/ adolescent and their parent/ caregiver, such as praise, physical warmth, and talk about friends.

implemented a primary healthcare reengineering programme, as a result of which the adolescents receiving care in the initial facilities were transferred to a total of 53 healthcare facilities including hospitals, community healthcare centres, and primary healthcare clinics. All 53 facilities were then included in the study.

Adolescents were recruited at clinics where they were receiving antiretroviral treatment and care, or traced into their home communities for those not reachable at the clinics. All caregivers and adolescents participating in the study gave written informed consent prior to interviews, which took place in the language of their choice and lasted an average of 90 minutes. Of all study-eligible adolescents, n=1,060 (90.1%) were interviewed, 4.1% refused participation (either adolescent or caregiver), 0.9% were excluded due to severe cognitive disability, 1.2% were excluded due to living in very unsafe areas, and 3.7% were untraceable. Participants who asked for help or disclosed abuse, neglect, defaulting from antiretroviral treatment or clinic care, severe hunger, or risk of significant harm were immediately assisted and linked to existing services (n=66, 6.2%). Due to high HIV-stigma rates, the study was presented in participating communities as a general study on adolescent access to health and social services. In order not to draw attention to HIV-affected families, when participants were traced and interviewed in communities, an additional n=467 cohabitating or neighbouring age-peers were interviewed using a non HIV-specific version of the questionnaire (not included in this analysis).

Quantitative and qualitative research were combined iteratively during the study: qualitative research guided the design and content of the quantitative data collection tools and processes, preliminary quantitative analysis provided themes to be futher explored by qualitative research, and these in-depth explorations shaped quantitative analyses. Quantitative questionnaires used standardised scales and validated measures when available. Tools were translated into Xhosa and back-translated for improved conceptual validity (Brislin, 1970), then piloted with 25 HIV-positive adolescents from rural and urban sites in the health district. Questionnaires included graphics, interactive games and vignettes to introduce questions around sensitive topics. Interviews were administered by trained

research assistants or via tablet-assisted self-interviewing, based on the participants' literacy levels.

6.2.2. Measures

Sexual outcome: *Unprotected sex at last sexual intercourse* was measured as no condom use at most recent sexual encounter. It was dichotomised as: '1=unprotected sex' and '0=abstinence or protected sex'. Adolescents were coded as *STI symptomatic* if they reported having at least one of the following four STI symptoms: genital sores/ warts, burning whilst urinating, genital itching/ redness, or anal itching/ soreness/ bleeding, in the last 6 months, following WHO guidelines for syndromatic diagnosis of STIs (World Health Organization (WHO), 2004). *Adolescent pregnancy among girls* was defined as ever having been pregnant before or during data collection, measured using an item from the National Survey of HIV and Risk Behaviour Amongst Young South Africans (A. E. Pettifor et al., 2004).

Socio-demographic characteristics (age, gender, home language, housing situation, urban/ rural location) were measured using items from South Africa's Census (Statistics South Africa (SSA), 2011). *Housing* was coded as 1=informal if the adolescent lived in a hut, rondavel (traditional home), or a shack, and 0=formal if they lived in a brick/concrete house or apartment. *Orphanhood* status was coded as death of either mother or father or both (Joint United Nations Programme on HIV/AIDS (UNAIDS), (UNICEF), & (USAID), 2004).

HIV-related factors: *Mode of infection* was asssesed following similar studies and modelling from Southern Africa (Evans et al., 2013; Ferrand et al., 2009): adolescents were coded as vertically-infected if they had started ART prior to age 12 or if they had been on treatment for more than 5 years, based on the year of widely available ART access in the study area. Adolescent's *knowledge of their own HIV-positive status* was determined through a stepwise process: initally healthcare providers' report, followed by confirmation by

caregiver during the consent process. Additional checks on adolescent knowledge of own HIV-status were conducted using a screening on recent health and medication-taking histories to avoid unintentional disclosure. Adolescents who did not know their own HIV-positive status responded to a questionnaire on 'illness' and 'medication' instead of 'HIV' and 'antiretrovirals', respectively. Most recent viral loads were extracted from patient records for a random sub-sample (n=266, 25%). Participants with viral load counts >1,000 copies/ml were coded as reporting *virological failure* using WHO standards (World Health Organization (WHO), 2014).

Social protection provisions: 'Cash/cash-in-kind' provisions of social protection included the following: *Social cash transfers* referred to participants' household receiving at least one of South Africa's five social welfare grants: child support grant, foster child grant, pension, disability or care dependency. *Past-week food security*, defined as at least two meals daily for the past week, was measured through items from the National Food Consumption Survey (Labadarios et al., 2005). *Access to school* was defined as access to free schooling or ability to afford school fees, uniform and equipment. *School feeding* referred to receiving at least one free meal at school daily. *Sufficient clothing* was measured using an item from the South African Social Attitudes Survey (Pillay et al., 2006). Psychosocial 'care' provisions included: *Positive parenting* – including items on praise and positive reinforcement from caregiver – and *good parental supervision* – including monitoring of adolescent social activities and home rule-setting – were measured using two sub-scales of the Alabama Parenting Questionnaire (Elgar, Waschbusch, Dadds, & Sigvaldason, 2007). Attending an *HIV-support group* was measured as past-month attendance at either a youth-focused or general HIV-support group. *Adolescent-sensitive care at clinics* was measured through two items asking adolescents about their experience obtaining contraception at the clinic: whether they felt disrespected or were scolded. These items were developed based on extensive qualitative research and consultations with HIV-positive adolescents in the study's teen advisory group (Toska, Cluver, Hodes, et al., 2015).

6.2.3. Data Analysis

Data analysis consisted of five steps: first, the included sample (90.1%) was compared to the rest of the eligible sample across available key demographics (age, gender and residential location) to check for any differences. Descriptive statistics of socio-demographic characteristics, access to each social protection provision, and rates of unprotected sex were calculated for the full included sample and by gender. Covariates and social protection provisions were excluded from further analysis if sub-group sizes were too small for reliable analysis (cut-off n<100 in the full sample, n<50 per gender). To check the extent of risk for onwards HIV-transmission, analyses tested whether unprotected sex was associated with virological failure, a marker of high transmission risk through unprotected sex (Eshleman et al., 2015).

Second, validation checks for self-reported unprotected sex were conducted by testing associations between a) unprotected sex and STI symptomology (full sample) and b) unprotected sex and pregnancy (females only). These used multivariate logistic regression models controlling for all potential covariates.

Third, analyses tested potential associations of unprotected sex and seven social protection provisions: three ‘cash-in-kind’ and four ‘care’, using a multivariate logistic regression model, controlling for covariates. Covariates entered included: adolescent age, gender, language, housing type, residential location, maternal and paternal orphanhood, living with biological caregiver, mode of infection, and knowledge of own HIV-positive status.

Fourth, analyses tested whether gender acted as a moderator for each social protection provision. Moderator analyses were conducted using logistic regression models with two-way interaction terms of gender and each social protection provisions entered in separate models, controlling for covariates found significant in the above step. Subsequently, based on existing literature suggesting different social protection provisions may work for adolescent boys and girls, and because a moderator effect was found, multivariate logistic regressions were run separately for HIV-positive girls and boys.

Fifth, effects of combinations of social protection provisions on unprotected sex were tested for the full and then gender-disaggregated samples. To check for potential interaction effects, all significant social protection variables, covariates and interaction terms from stage 3 above ($p<.05$) were added in a stepwise multivariate logistic regression model, following processes applied by similar studies (Lucie D Cluver, Orkin, et al., 2016a). *Step 1* – all covariates significant from the model in stage 3, *Step 2* – all significant social protection variables, *Step 3* – all two-way interaction terms of significant social protection variables, *Step 4* – all three-way and higher order interaction terms of significant social protection variables. Subsequently, marginal effect analysis in STATA tested potential additive effects of significant social protection provisions by computing predicted probabilities of unprotected sex under each potential combination of significant social protection provisions, with all significant covariates held at mean values.

6.3. RESULTS

6.3.1. Socio-demographic and HIV-related factors (Table 6-1):

Over half the sample was female (55%) with average age 13.8 (SD=2.8). 19% lived in informal housing. 22% lived in rural areas. Almost all participants spoke Xhosa at home (97%) and just under half lived with a biological caregiver (45%). 44% were maternal orphans, 30% paternal orphans, and 15.4% had lost both parents. 67% were vertically-infected and 75% knew their own HIV-positive status. Due to small sub-sample sizes of non-Xhosa speakers (<50 for each gender), home languge was excluded from further analyses. There were no significant differences between the included (n=1,060) and excluded eligible participants (n=116), when compared across age, gender and residential location.

6.3.2. Sexual outcomes and access to social protection (Table 6-2)

Sexual outcomes: 18% of HIV-positive adolescents reported having unprotected sex at last intercourse, with girls reporting significantly higher rates than boys (28% vs. 4%, $p\leq0.001$).

32% of HIV-positive girls were STI symptomatic compared to 27% of boys (p=.059), with 13% of all HIV-positive girls reporting past or current pregnancy.

Access to social protection provisions. 'Cash/cash-in-kind': 95% of adolescents reported that their household received at least one cash grant and 77% had enough food to eat in the past week. 66% had no economic barriers to access school, 93% had regular school feeding, and 67% had enough clothes to stay warm and dry. 'Care': 13% attended any HIV support group, 41% reported high parental supervision and 50% reported high positive parenting. HIV-positive adolescent boys reported higher rates of food security (X^2 (df)=9.395 (1), p=.002), greater access to school (X^2 (df)=15.393 (1), p≤0.001), and more adolescent-sensitive SRH care at clinics (X^2 (df)=16.610 (1), p≤0.001) than girls. Due to the very small groups of adolescents not receiving social cash transfers and school feeding schemes (<100 in the full sample, <50 by gender), these provisions were excluded from further analyses.

Table 6-1. Socio-Demographic characteristics of the sample by gender

Factor grouping	*Factor*	*Excluded eligible sample N=166[1] N (%)[2]*	*Included eligible sample N=1,060[a] N (%)*	*Total sample N=1,060*	
				Female N=584 (55.1%)	*Male N=476 (44.9%)*
Age	Years (Mean (SD))	14.8 (2.91)	13.8 (2.8)	14.3 (3.0)	13.3 (2.5)
	10-14		659 (62.2)	324 (55.5)	335 (70.4)
	15-19		401 (37.8)	260 (44.5)	141 (29.6)
Gender	Female	66 (56.9)	584 (55.1)	584 (100)	n/a
Language	Xhosa		1,028 (97.0)	572 (97.9)	456 (95.8)
Housing	Formal		861 (81.3)	469 (80.3)	392 (82.5)
	Informal		198 (18.7)	115 (19.7)	83 (17.5)
Residence	Urban	140 (77.6)	828 (78.4)	451 (77.5)	377 (79.5)
	Rural	26 (22.4)	228 (21.6)	131 (22.5)	97 (20.5)
Family and caregiver characteristics	Maternal orphan		464 (43.8)	250 (42.8)	214 (45.0)
	Paternal orphan		320 (30.2)	183 (31.3)	137 (28.8)
	Living with biological caregiver		476 (44.9)	275 (47.1)	201 (42.2)
HIV-related factors	Vertical infection		708 (66.8)	348 (59.6)	360 (75.6)
	Horizontal infection		352 (33.2)	236 (40.4)	116 (24.4)
	Knows HIV-positive status		794 (74.9)	442 (75.7)	352 (73.9)

Notes:
[1] Statistical tests comparing the excluded and included eligible participants were non significant.
[2] N (%) reported unless noted otherwise.

Table 6-2. Outcome measures and access to social protection provisions by gender

Factor grouping	*Factor*	*Female N=584 (55.1%)*	*Male N=476 (44.9%)*	*Total N=1,060 (100%)*
Outcome	Unprotected sex at last intercourse	164 (28.1)	21 (4.4)	185 (17.5)
	STI symptomatic	187 (32.0)	127 (26.7)	314 (29.6)
	Pregnant (current or ever)	78 (13.4)	n/a	n/a
	Virological failure[1]	33 (24.8)	35 (26.3)	68 (25.6)
Economic 'cash/ cash-in-kind' social protection provisions	Social cash transfers	553 (94.7)	450 (94.7)	1,003 (94.7)
	Food security	431 (73.8)	389 (81.7)	820 (77.4)
	Access to school	355 (60.8)	344 (72.3)	699 (65.9)
	School feeding	538 (92.1)	448 (94.1)	986 (93.0)
	Clothing	393 (67.3)	318 (66.8)	711 (67.1)
Psychosocial 'care' social protection provisions	Positive parenting	298 (51.0)	233 (49.1)	531 (50.1)
	Good parental supervision	227 (38.9)	206 (43.4)	433 (40.9)
	HIV support group	76 (13.0)	65 (13.7)	141 (13.3)
	Adolescent-sensitive clinic care	487 (83.4)	437 (91.8)	924 (87.2)

Notes:
[1] Sample size for viral load data n=266, n=133 girls (50%) and n=133 boys (50%). Virological failure defined as >1,000 copies/ml.

6.3.3. Transmission risk and validating self-reported unprotected sex

Unprotected sex was strongly associated with virological failure in the sub-sample for whom viral load data was available (n=266, OR2.57, CI1.01-6.53, p=0.048), suggesting that a sub-group of HIV-positive adolescents who are not virally suppressed and engage in unprotected sex are at high risk for HIV-transmission to uninfected sexual partners and children. Gender-disaggregated analyses were not possible due to small sub-sample sizes. In multivariate logistic regression analyses (Table 6-3), self-reported unprotected sex was strongly associated with STI symptomology in the full sample (OR1.54, CI1.00-2.38, p=0.05) and with adolescent pregnancy among girls only (OR5.72, CI2.51-13.03, p≤0.001).

Table 6-3. Associations of unprotected sex with pregnancy and STI symptomology among HIV-positive adolescent

Outcome: unprotected sex at last intercourse				
Factors	*Model 1: HIV-positive adolescents girls (N=584)*		*Model 2: HIV-positive adolescents (N=1,060)*	
	OR (95% CI)	*p*	*OR (95% CI)*	*p*
Age	1.607 (1.419-1.819)	**≤.001**	**1.723 (1.554-1.910)**	**≤.001**
Gender	Not entered in model		**6.591 (3.884-11.155)**	**≤.001**
Informal housing	.832 (.455-1.522)	.551	.869 (.510-1.481)	.607
Rural residence	1.499 (.858-2.622)	.155	1.384 (.848-2.260)	.194
Maternal Orphan	.524 (.266-1.030)	.061	.619 (.349-1.095)	.100
Paternal Orphan	.773 (.461-1.296)	.329	.722 (.464-1.122)	.147
Lives with biological caregiver	.726 (.370-1.426)	.353	.803 (.454-1.422)	.452
Knows own HIV-positive status	1.396 (.640-3.049)	.402	1.236 (.772-1.979)	.377
Mode of infection – horizontal	1.076 (.618-1.872)	.796	0.958 (.501-1.830)	.896
Pregnancy	**5.717 (2.507-13.033)**	**≤.001**	Not entered in model	
STI symptomology	Not entered in model		**1.708 (1.000-2.380)**	**.050**

6.3.4. Associations of individual social protection provisions with unprotected sex (Table 6-4)

Table 4 shows the results of the multivariate regression model of the included social protection provisions. In the full sample, 'cash-in-kind' provision of school access (OR0.52, CI0.33-0.82, p=0.005), 'care' good parental supervision (OR0.54, CI0.33-0.90, p=0.019), and adolescent-sensitive 'care' at the clinic (OR0.43, CI0.25-0.73, p=0.002) were associated with less unprotected sex.

Table 6-4. Logistic regression of all social protection provisions and covariates

Outcome: Unprotected sex (full sample of HIV-positive adolescents N=1,060)		
Factors	*OR (95% CI)*	*p*
Age	**1.644 (1.476-1.830)**	**≤.001**
Gender	**5.727 (3.339-9.824)**	**≤.001**
Informal housing	.927 (.532-1.614)	.788
Rural residence	1.447 (.865-2.422)	.159
Maternal Orphan	.596 (.331-1.074)	.085
Paternal Orphan	.711 (.451-1.121)	.142
Lives with biological caregiver	.737 (.408-1.332)	.312
Knows own HIV-positive status	.956 (.476-1.921)	.900
Mode of infection – horizontal	1.272 (.778-2.079)	.337
Cash-in-kind – past-week food security	.778 (.459-1.318)	.351
Cash-in-kind – access to school	**.523 (.333-.823)**	**.005**
Cash-in-kind – clothing	1.051 (.638-1.733)	.844
Care – positive parenting	1.471 (.936-2.314)	.095
Care – parental supervision	**.544 (.327-.904)**	**.019**
Care – HIV support group	1.472 (.828-2.616)	.188
Care – adolescent-sensitive clinic care	**.429 (.254-.726)**	**.002**

*Gender effects (*Table 6-5 *and* Table 6-6*):* Of all social protection provisions only the interaction between gender and adolescent-sensitive clinic care was significant (OR0.08, CI0.01-0.69, p=0.021), suggesting that the effect of adolescent-sensitive clinic care on reducing unprotected sex was significantly greater among HIV-positive adolescent girls than boys (Figure 6-1): adjusted probabilities of reporting unprotected sex among HIV-positive girls who accessed adolescent-sensitive clinic services was 14% compared to 28% among those who did not. The effect of accessing adolescent-sensitive clinic services was weaker among HIV-positive adolescent boys: with access to services 3% were likely to report unprotected sex compared to 6% among those who did not report adolescent-sensitive clinic services.

In subsequent gender-disaggregated regression analyses (Table 6), lower odds of unprotected sex among HIV-positive girls were significantly associated with three social protection provisions: school access (OR0.49, CI0.29-0.82, p=0.007), good parental supervision (OR0.54, CI0.30-0.98, p=0.043) and adolescent-sensitive clinic care (OR0.32, CI0.17-0.58, p≤.001). No social protection provisions were associated with unprotected sex amongst HIV-positive boys.

Table 6-5. Gender moderation effects for HIV-positive adolescents (n=1,060)

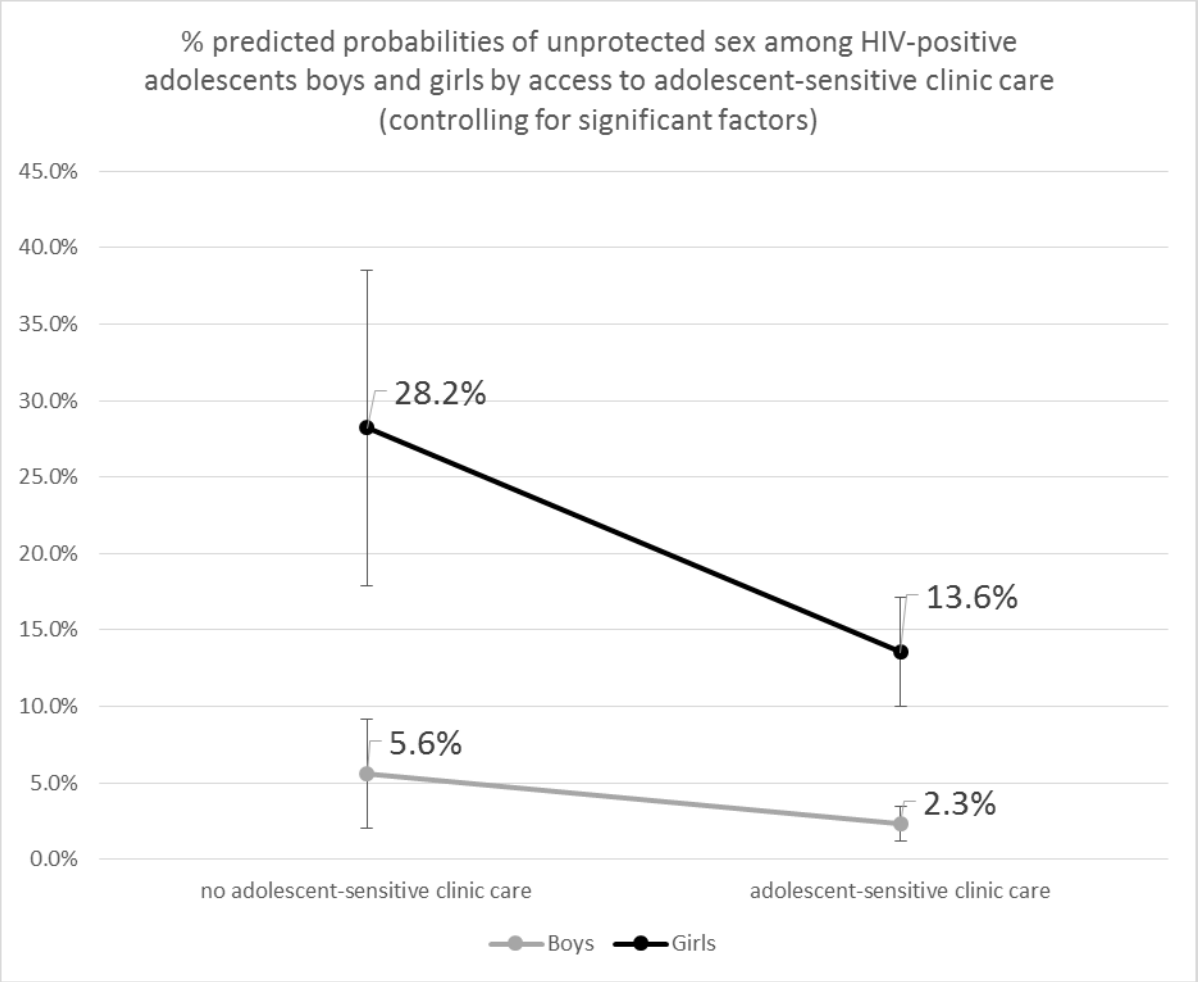
Outcome: Unprotected Sex[1]								
	Age		*Gender*		*Social Protection*		*Gender*Social Protection[a]*	
Social Protection Provisions	*OR (95% CI)*	*p*	*OR (95% CI)*	*p*	*OR (95% CI)*	*p*	*OR (95% CI)*	*p*
Past-week food security	**1.734 (1.591-1.890)**	**≤.001**	**8.045 (2.788-23.213)**	**≤.001**	.907 (.093-8.842)	.933	.832 (.247-2.801)	.766
Access to school	**1.713 (1.571-1.867)**	**≤.001**	**8.031 (3.581-18.010)**	**≤.001**	.852 (.121-6.013)	.872	.771 (.269-2.209)	.628
Clothing	**1.747 (1.602-1.905)**	**≤.001**	**10.012 (4.246-23.608)**	**≤.001**	1.886 (.258-13.793)	.532	.608 (.208-1.781)	.365
Positive parenting	**1.753 (1.607-1.912)**	**≤.001**	**6.492 (3.322-12.688)**	**≤.001**	.701 (.099-4.994)	.723	1.260 (.438-3.622)	.668
Parental supervision	**1.718 (1.574-1.874)**	**≤.001**	**7.390 (4.009-13.622)**	**≤.001**	.783 (.096-6.395)	.820	.809 (.259-2.531)	.716
HIV support group	**1.749 (1.605-1.907)**	**≤.001**	**7.777 (4.326-13.981)**	**≤.001**	2.034 (.210-19.673)	.540	.765 (.220-2.667)	.675
Adolescent-sensitive clinic care	**1.703 (1.562-1.858)**	**≤.001**	**62.987 (7.708-514.724)**	**≤.001**	46.297 (.679-3157.684)	.075	**.078 (.009-.685)**	**.021**

Notes:
[1] Results for logistic regression models including age, gender, social protection provision and the interaction term for gender and each social protection term.

Table 6-6. Gender-disaggregated logistic regressions of social protection provisions and covariates

	Unprotected sex (HIV-positive adolescent GIRLS)		***Unprotected sex (HIV-positive adolescent BOYS)***	
Factors	*OR (95% CI)*	*p*	*OR (95% CI)*	*p*
Age	**1.667 (1.474-1.887)**	**≤.001**	**1.559 (1.228-1.979)**	**≤.001**
Informal housing	.878 (.474-1.626)	.679	1.168 (.287-4.759)	.828
Rural residence	1.537 (.854-2.766)	.152	1.030 (.291-3.646)	.964
Maternal Orphan	**.450 (.221-.917)**	**.028**	1.483 (.446-4.932)	.520
Paternal Orphan	.761 (.451-1.285)	.307	.582 (.204-1.660)	.312
Caregiving arrangement	.654 (.321-1.330)	.241	.958 (.269-3.407)	.947
Mode of infection – horizontal	1.402 (.793-2.479)	.245	1.033 (.360-2.967)	.952
Knows own HIV-positive status	1.152 (.516-2.571)	.729	.627 (.142-2.770)	.538
Cash-in-kind – past-week food security	.868 (.474-1.590)	.648	.629 (.185-2.137)	.458
Cash-in-kind – access to school	**.489 (.290-.823)**	**.007**	.638 (.228-1.789)	.393
Cash-in-kind – clothing	.958 (.535-1.717)	.886	1.195 (.398-3.582)	.751
Care – parental supervision	**.542 (.300-.982)**	**.043**	.606 (.207-1.778)	.362
Care – positive parenting	1.616 (.958-2.725)	.072	1.019 (.370-2.809)	.971
Care – HIV support group	1.512 (.764-2.992)	.236	1.622 (.521-5.049)	.404
Care – adolescent-sensitive care at clinic	**.317 (.174-.579)**	**≤.001**	3.598 (.428-30.229)	.238

Figure 6-1. Effects of adolescent-sensitive clinic care by gender



6.3.5. Potential interactive and additive effects (Table 6-7 and Table 6-8):

No significant interactive/ multiplicative effects of social protection provisions were found in the full sample or for gender-disaggregated sub-samples. However, the independently significant effects of social protection provisions in Table 4 suggested potential additive effects. Strong additive effects were shown in the full sample and among HIV-positive adolescent girls. Among all HIV-positive adolescents, who had no access to school, good parental supervision, nor adolescent-sensitive care, 22% reported unprotected sex at last intercourse. Those receiving one social protection 11-15% reported unprotected sex, and with any two: 6-8% probability of unproteced sex. Adolescents receiving all three social protection provisions were likely to report just under 4% unprotected sex. Amongst HIV-positive girls, rates of unprotected sex dropped from 49% with no social protection provisions, to 23-38% with one, 13-24% with two and just under 9% with all three social protection provisions (Figure 6-2). As no social protection provisions were significantly associated with unprotected sex among HIV-positive boys, marginal effects models were not conducted.

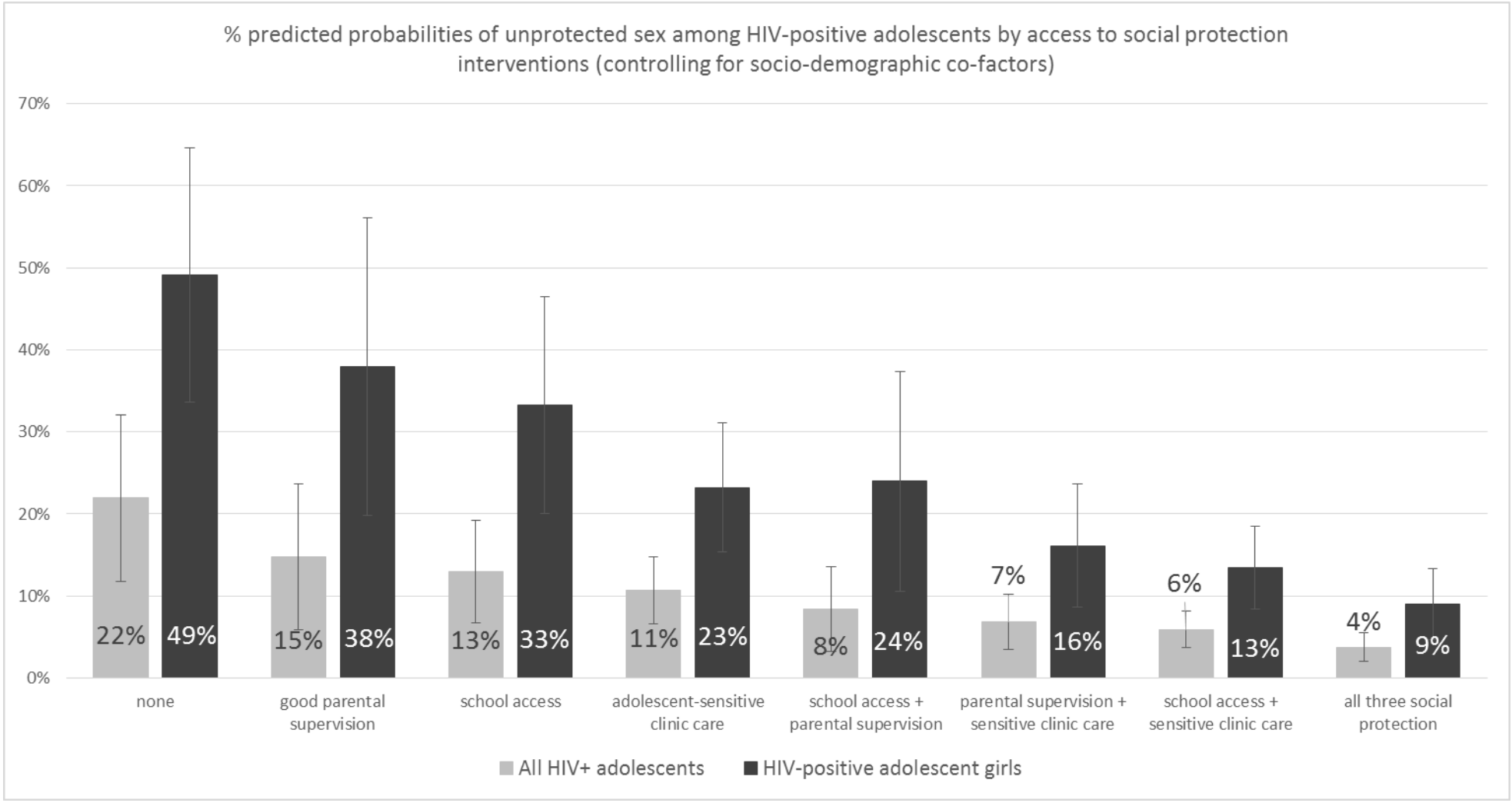
Table 6-7. Logistic regression models of all significant potential social protection factors, interaction terms, and covariates

Outcome: Unprotected sex	*All HIV-positive adolescents (n=1,060)*			
Step 1	*OR (95% CI)*	*p*	*ΔR^2*	*p*
Age	**1.650 (1.512-1.801)**	**≤.001**		
Gender	**6.226 (3.683-10.523)**	**≤.001**		
Maternal Orphan	Not included		**.517*** **	**≤.001**
Cash-in-kind – school access	**.530 (.349-.804)**	**.003**		
Care – good parental supervision	**.616 (.383-.992)**	**.046**		
Care – adolescent-sensitive clinic care	**.424 (.254-.707)**	**.001**		
Step 2	*OR (95% CI)*	*p*	*ΔR^2*	*p*
Age	**1.653 (1.514-1.806)**	**≤.001**		
Gender	**6.329 (3.729-10.741)**	**≤.001**		
Maternal Orphan	Not included			
Cash-in-kind –school access	**.457 (.183-1.142)**	**.094**		
Care – good parental supervision	**1.831 (.477-7.031)**	**.378**	.517	.906
Care – adolescent-sensitive clinic care	**.435 (.195-.970)**	**.042**		
Interaction – school access * parental supervision	.740 (.281-1.951)	.543		
Interaction – school access * adolescent-sensitive clinic care	1.359 (.486-3.798)	.558		
Interaction – parental supervision * adolescent-sensitive clinic care	.336 (.087-1.297)	.114		
Step 3	*OR (95% CI)*	*p*	*ΔR^2*	*p*
Age	**1.653 (1.513-1.806)**	**≤.001**		
Gender	**6.332 (3.731-10.747)**	**≤.001**		
Maternal Orphan	Not included			
Cash-in-kind –school access	.447 (.167-1.195)	.109		
Care – good parental supervision	1.703 (.281-10.327)	.563	.516	.926
Care – adolescent-sensitive clinic care	**.428 (.184-.996)**	**.049**		
Interaction – school access * parental supervision	.850 (.071-10.155)	.898		
Interaction – school access * adolescent-sensitive clinic care	1.398 (.452-4.323)	.561		
Interaction – parental supervision * adolescent-sensitive clinic care	.366 (.052-2.603)	.316		
Interaction – school access * parental supervision * adolescent-sensitive clinic care	.849 (.057-12.578)	.905		

Table 6-8. Logistic regression models of all significant potential social protection factors, interaction terms, and covariates

Outcome: Unprotected sex	*HIV-positive adolescents girls(n=584)*			
Step 1	*OR (95% CI)*	*p*	*ΔR^2*	*p*
Age	**1.699 (1.536-1.880)**	**≤.001**		
Gender	Not included			
Maternal Orphan	**.587 (.361-.955)**	**.032**	**.528*** **	**≤.001**
Cash-in-kind – school access	**.515 (.318-.833)**	**.007**		
Care – good parental supervision	.634 (.364-1.103)	.107		
Care – adolescent-sensitive clinic care	**.313 (.174-.564)**	**≤.001**		
Step 2	*OR (95% CI)*	*p*	*ΔR*	*p*
Age	**1.716 (1.547-1.903)**	**≤.001**		
Gender	Not included			
Maternal Orphan	**.591 (.362-.966)**	**.036**		
Cash-in-kind –school access	.513 (.182-1.443)	.206		
Care – good parental supervision	3.634 (.714-18.490)	.120	.537	.146
Care – adolescent-sensitive clinic care	**.392 (.160-.964)**	**.041**		
Interaction – school access * parental supervision	.738 (.235-2.321)	.604		
Interaction – school access * adolescent-sensitive clinic care	1.147 (.354-3.720)	.819		
Interaction – parental supervision * adolescent-sensitive clinic care	**.158 (.030-.819)**	**.028**		
Step 3	*OR (95% CI)*	*p*	*ΔR^2*	*P*
Age	**1.714 (1.545-1.902)**	**≤.001**		
Gender	Not included			
Maternal Orphan	**.588 (.359-.962)**	**.035**		
Cash-in-kind – school access	.487 (.162-1.464)	.200		
Care – good parental supervision	3.006 (.361-25.029)	.309	.537	.785
Care – adolescent-sensitive clinic care	**.378 (.147-.969)**	**.043**		
Interaction – school access * parental supervision	1.092 (.053-22.650)	.955		
Interaction – school access * adolescent-sensitive clinic care	1.229 (.343-4.407)	.752		
Interaction – parental supervision * adolescent-sensitive clinic care	.197 (.020-1.950)	.165		
Interaction – school access * parental supervision * adolescent-sensitive clinic care	.634 (.024-16.674)	.785		

Figure 6-2. Marginal effects model testing for additive effects of combination social protections on unprotected sex among HIV-positive adolescents



6.4. DISCUSSION

Findings from this study have several important implications. First, this study documented high rates of unprotected sex reported by HIV-positive adolescents, and significantly higher rates of virological failure amongst HIV-positive adolescents engaging in unprotected sex. HIV-positive adolescents experiencing viral failure (i.e. have a high viral load) and who engage in unprotected sex results in a higher transmission risk to uninfected peers and their children. Adolescents who experience sustained HIV viral suppression and who engage in unprotected sex pose very little risk to passing HIV to their sexual partners. Therefore, additional research is needed on which sub-groups of adolescents are both virally active and engage in unprotected sex with sexual partners. It is clear that effective programming to reduce sexual risk behaviour for this vulnerable group is essential.

Second, it identifies three types of social protection provisions that are strongly associated with reduced unprotected sex among HIV-positive adolescents: access to schools, good parental supervision, and adolescent-sensitive sexual health care at clinics. These findings reflect emerging evidence on combinations of social protection for reducing sexual risk-taking among general samples of adolescents (Lucie D Cluver, Orkin, et al., 2016a). They support recent calls for adolescent-sensitive HIV-inclusive social protection, that is social protection that reaches HIV-positive and HIV-affected adolescents without using HIV status as a targeting condition (Toska et al., 2016). This study's results show that HIV-inclusive social protection has the potential to reduce HIV risk-taking without the associated stigma of HIV-specific interventions.

Third, this study extend this existing research by showing that combining two *types* of social protection: 'cash-in-kind' (school access) and 'care' (good parental supervision and adolescent-sensitive sexual health clinic care) has the greatest potential to reduce unprotected sex the most. Compared to those receiving none or one social protection provision, adolescents who receive two types of social protection reported lower rates of unprotected sex, with those receiving three types of social protection reporting the lowest

rates. These findings suggest that 'care' social protection may act as the 'glue' for cash social protection to have positive effects, or vice-versa. Additional research is needed to elucidate these potential mechanisms.

Fourth, these findings highlight the importance of receiving social protection in three key locations for adolescents: school, home and clinic. Adolescents who reported strong parental supervision – i.e. they communicated with their caregiver about their whereabouts, shared information on their friends, and knew where their caregiver was at all times – reported significantly lower rates of unprotected sex. Findings on caregiver supervision support the literature on parental supervision among adolescents in the United States. This body of evidence suggests that good parental supervision is associated with reduced risk-taking (DiClemente et al., 2001; Holub, 2010; Stanton et al., 2004). These studies from the US have hypothesized that through this improved communication, caregivers/ parents exert a positive influence on risk-taking among adolescents. The results of this thesis indicate that this is true among HIV-positive adolescents as well, a highly vulnerable population. Although not yet tested in low-resource settings, a randomised controlled trial of a one-session caregiver/ parental monitoring and communication session in the United States significantly impacted drug and alcohol use (Stanton et al., 2004). Further research is needed to test interventions to help caregiver/ parents provide appropriate monitoring and supervision to their children and adolescents. These results also confirm evidence from the region on adolescents more generally, with access to school serving as a 'social vaccine', bolstering social pathways associated with improved resilience (UNICEF-ESARO, 2015). By attending schools free of financial barriers adolescents are less likely to engage in high-risk sex, which in South Africa often happens in the context of transactional sex and sex with older partners (Lucie D Cluver, Orkin, Boyes, Gardner, & Meinck, 2011b; Toska, Cluver, Boyes, et al., 2015).

Additionally, receiving adolescent-sensitive 'care' services from sexual healthcare providers at clinics was also associated with lower rates of unprotected sex. This finding supports qualitative reports from South Africa on the negative effect of poor clinic care on

adolescent sexual and reproductive health outcomes (Wood & Jewkes, 2006). Further analyses, including in-depth qualitative research, are needed to better understand the mechanisms through which classroom- and clinic-level support is linked to reduced unprotected sex.

Fifth, gender-disaggregated analyses resulted in different significant social protection for boys and girls, though this may also be due to reduced power and the lower rates of sexual activity reported by the HIV-positive adolescent boys in this sample (Toska, Cluver, Hodes, et al., 2015). Three of the social protection provisions that were tested have significant effects on HIV-positive adolescent girls: access to schools, good parental supervision, and adolescent-sensitive sexual health clinic care. Supporting adolescent girls beyond the home setting, at school and clinics, will not only ensure they reach services critical to their long-term well-being, but also support them in engaging in safer sex. Notably, these three provisions are – when available – targeted at all adolescents, whether HIV-positive or not. This suggests that social protection that reaches at-risk populations such as adolescents, even when not targeted to HIV-positive ones, can be effective to reduce their vulnerabilities. These findings resonate with advocacy for generalised social protection in the Sustainable Development Goals (UNICEF-ESARO, 2015). They also underline the importance of ensuring that HIV-positive adolescents are not excluded from accessing social protection.

This study has several methodological limitations. Cross-sectional analyses always limit our ability to reach conclusions on the direction of the observed associations, due to potential reverse causality for significant associations. Future research can valuably test these associations in longitudinal quasi-experimental studies or randomised controlled trials. Second, self-reported sexual health outcomes contain risk of social desirability bias. As a check for validity, the study tested associations of self-reported unprotected sex with two other sexual and reproductive health outcomes. Unprotected sex was significantly associated with pregnancy and STI symptomology. Third, although over 90% of all eligible adolescents in the health district were included in this sample, it is possible that adolescents

at highest risk were those who refused or were untraceable. However, comparison of the sample reached and those not reached showed no significant differences by age, gender and residential location – the only information available to us. Despite this limitation, this study is the first and largest study of HIV-positive adolescents traced into their homes and communities, and thus may allow more representativity of the overall population than clinic-based samples that are thus restricted to those who attend healthcare services. Moreover, by including study sites with high HIV prevalence and relatively poor resources, these findings may be applicable to contexts with similar socio-economic and epidemiological profiles. Finally, access to the social protection provisions was measured only through adolescent self-reports, which is an important limitation. Because the reporting of care provisions experienced by adolescent (e.g. good parental monitoring and interactions with healthcare providers) could be shaped by individual factors such as mental health, it is important for future analyses to explore how the mental health of HIV-positive adolescents shapes their self-reported access to care social protection provisions. Nonetheless, participants in this sample reported very high coverage of certain social protection provisions: social cash transfers and school feeding (>90%). These coverage rates not only limited our ability to conduct sub-group analyses but also precluded us from reaching any conclusions on whether they may be associated with sexual health outcomes among HIV-positive adolescents. However, given prior evidence from South Africa on the effectiveness of social cash transfers in reducing sexual risk-taking among AIDS-affected adolescents (Lucie D Cluver et al., 2013, 2014), these findings suggest that the positive effect of additional social protection may extend gains from the social cash transfer and school feeding schemes documented by prior studies in the region.

6.5. CONCLUSION

Despite the above limitations, the study provides key insights for sexual health programming among HIV-positive adolescents in and out of clinical care. The interventions identified are

available in real-life settings and have statistically and practically significant associations with reduced unprotected sex, particularly when accessed in combination. Increasing access to these social protection provisions among HIV-positive adolescents has the potential to support HIV-positive adolescents to reduce unprotected sex, and its related outcomes of unwanted pregancies and onwards HIV-transmission.

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7. DISCUSSION

7.1. OVERVIEW

The main objective of this thesis was to contribute to the problem theory of sexual risk-taking among HIV-positive adolescents in Sub-Saharan Africa. The thesis had three specific aims: (1) systematically identify and review the literature on sexual risk-taking among HIV-positive adolescents and youth in Sub-Saharan Africa, (2) test the effects of HIV-status disclosure to and from adolescents on protective sexual practices, and (3) investigate associations between social protection and unprotected sex among HIV-positive adolescents. The socio-ecological model was the theoretical backbone of this study. During the study design phase, this model was extended to include two sets of additional relevant factors: HIV-specific and relationship-level factors.

The empirical findings from this thesis suggest that this adapted socio-ecological model of adolescent sexual health is relevant to studying the sexual practices of HIV-positive adolescents. The systematic review confirmed that a multitude of factors at all levels of the socio-ecological model, both general and HIV-specific, may determine sexual risk-taking among HIV-positive adolescents and youth. In multivariate analyses of cross-sectional data from a community-traced study in South Africa, factors associated with reduced risk-taking range from individual-level factors such as HIV-positive status-awareness, family-level factors such as parental supervision, structural level factors such as access to free school and adolescent-sensitive clinic care. As the adapted socio-ecological model suggested, they include both HIV-specific and general factors. An important next step in this analyses should incorporate all factors significantly associated with reduced sexual risk-taking to identify their relative contribution. Future research should apply advanced statistical analyses to identify which of the factors explains the greatest variance in the outcome, for example by reviewing the ΔR^2 for Nagelkerke's R^2 in multivariate logistic regression models. These results should

then inform the development of interventions which aim to change the most important factors.

Given evidence that theory-driven interventions are more likely to be effective (Lopez et al., 2014), this theoretical model and the findings of this thesis could be useful to inform future intervention design and development. This chapter discusses the key findings of each paper, which address the three above-indicated aims of this doctoral research. It deliberates on the relevance of the findings in the context of available research and programming on the sexual and reproductive health of HIV-positive adolescents in South Africa and neighbouring countries. Following the detailed discussion of each paper's findings, the chapter goes on to discuss the study limitations and strengths. It then considers the policy implications of these findings and provides recommendations for future research and practice. The chapters concludes by summarising dissemination efforts to date and future plans for making the study findings available to programmers and policy-makers.

The three papers included in this thesis contribute to a number of critical gaps in the research on HIV-positive adolescents and youth in Sub-Saharan Africa in general, and in South Africa specifically. The first paper, a systematic review (Chapter 4), summarised the evidence on prevalence rates and potential determinants of sexual risk taking, and identified interventions that aim to reduce sexual risk-taking among HIV-positive adolescents and youth in Sub-Saharan Africa. This systematic review complemented and extended a recent literature review (not a systematic review) on sexual and reproductive health and rights of HIV-positive youth in Sub-Saharan Africa (Pretorius et al., 2015), which identified four interventions that were completed or under implementation. The systematic review in this thesis identified additional interventions and broadened our understanding of sexual risk-taking among HIV-positive adolescents. It documented rates of eight different high-risk sexual practices among HIV-positive adolescents and youth. By systematically reviewing the evidence to date, this paper guided the analyses of the other two papers and identified critical gaps for future research.

The second paper (Chapter 5) focused on an individual-level predictor of risk that is a central issue for people living with HIV: the potential gains from HIV-status disclosure. It provides evidence on the benefits of applying guidelines on HIV-status disclosure: WHO's guidelines on disclosure to children and adolescents living with HIV, WHO's guidelines on HIV testing and counselling, and UNAIDS's Fast Track targets (UNAIDS, 2014a; World Health Organization, 2011, 2013a). The second paper investigated how three different forms of HIV-status disclosure were associated with protective sexual practices: (1) knowledge of an adolescent's own HIV-positive status, i.e. being HIV-positive status-aware (2) disclosing one's HIV-positive status to sexual partners, and (3) knowing one's sexual partner's HIV status. It compared HIV-positive status-aware adolescents (n=794) with adolescents who did not know their HIV-positive status (n=733). Associations between each type of HIV-status disclosure and protective sexual practices were analysed using multivariate regressions, controlling for potential confounders. Next, analyses looked at whether gender moderated the effect of these different types of HIV-status disclosure and knowledge on protective sexual practices among adolescent girls and boys. Marginal effect analyses explored how combinations of these different kinds of analyses were associated with protective sexual practices.

The third paper (Chapter 6) responded to the growing interest from providers and policy-makers on whether social protection can address the structural and complex vulnerabilities of adolescents in Sub-Saharan Africa (Lucie D Cluver, Hodes, Sherr, et al., 2015; Miller & Samson, 2012). While social protection has many definitions, increasingly practitioners and policy-makers recognise that different provisions (biomedical, behavioural, or structural) may work better for different vulnerable populations, alone or in combination (Coates et al., 2008; Padian, McCoy, Balkus, & Wasserheit, 2010; Toska et al., 2016). The analyses in this paper aimed to determine which of nine real-life social protection provisions were associated with reduced unprotected sex rates in the world's largest community-traced sample of HIV-positive adolescents (n=1,060). Both cash/ in-kind material provisions ('cash') and

psychosocial support ('care') provisions were included. The choice of which provisions to include was informed by the systematic review findings, evidence from social protection among the general adolescent population, and consultations with international partners such as UNICEF, UNAIDS, and the Eastern and Southern Africa Regional Inter-Agency Task Team on Children Affected by AIDS (RIATT-ESA).

7.2. PAPER 1 – SEXUAL RISK-TAKING AMONG HIV-POSITIVE ADOLESCENTS AND YOUTH IN SUB-SAHARAN AFRICA: A SYSTEMATIC REVIEW OF PREVALENCE RATES, RISK FACTORS, AND INTERVENTIONS

The first study summarised three sets of evidence on sexual risk-taking among HIV-positive adolescents and youth (10-24 year olds) in Sub-Saharan Africa. First, it documented prevalence rates of eight high-risk sexual practices in this population: early sexual debut, inconsistent condom use, sex with older partners, transactional sex, multiple sexual partners, sex while intoxicated, STIs, and unintended adolescent pregnancy. Second, it identified factors associated with sexual risk-taking among HIV-positive adolescents and youth in Sub-Saharan Africa. And third, it assessed the quality of interventions aimed at reducing sexual risk-taking in this population. The review included 35 studies from 13 Sub-Saharan African countries, reporting on 13,536 HIV-positive adolescents and youth. Half of the studies (n=17) were conducted in Uganda, highlighting the need for research from other Sub-Saharan countries home to large populations of HIV-positive adolescents and youth: South Africa, Tanzania, and Zimbabwe (Kassede, 2015). Although four intervention studies were included in the review, most of the remaining studies reported only on univariate cross-sectional data. Multivariate analyses using longitudinal data to advance the problem theory for sexual risk-taking among HIV-positive adolescents is needed.

Rates of reported sexual risk-taking were high, although they varied by country, sample size, and study methodology. Notably, studies reported consistent rates of transactional sex (about one in five), unintended adolescent pregnancies (three quarters of all adolescent pregnancies), and sexual debut before 16 years old (40-50% in most studies). Rates of the remaining self-reported outcomes varied considerably for unprotected sex, older sexual partners, multiple sexual partners, and STIs. These findings resonate with a 2011 global literature review of the sexual practices of HIV-positive adolescents, which located only studies conducted in the United States, Canada, and European countries. It confirmed that, despite initial delays in puberty, HIV-positive adolescents engaged in similar types and rates of sexual practices to their HIV-negative/ HIV-status unknown peers (Mergui & Giami, 2011). The rates of contraception reported by adolescents living with HIV in sub-Saharan Africa were comparable to those reported in studies in the United States, though there was significant variation among the reports from different samples in the US, similar to this review's findings (Belzer et al., 2001; Brogly et al., 2007). Furthermore, rates of condom use were similar to the rates of condom use reported by sexually-active school learners in the Mhlakulo region of the Eastern Cape, South Africa: 54% reported the use of condoms; of these only 62% used them consistently (Bana et al., 2010). However, HIV-positive adolescents and youth are more vulnerable than their HIV-negative peers to poor sexual health outcomes such as unintended pregnancies, poor birth outcomes, or other STIs (Sharer & Fullem, 2012). Therefore, additional research is needed to support healthcare providers appropriately differentiate services offered to HIV-positive adolescents and screen them for potential poor sexual health outcomes.

The hypothesised risk and protective factors reported by studies included in the review belong to all five levels of this thesis' theoretical framework, which applies an adapted socio-ecological model of adolescent development (Bronfenbrenner, 1979; Mburu, Ram, et al., 2014). This adapted socio-ecological model comprises potential risk and protective factors in five groups: individual, relationship, family, structural and HIV-specific. There was

no consistency across results on outcomes nor potential risk and protective factors reported by the included 35 studies. All of the quantitative associations were based on cross-sectional data, which limits our ability to draw conclusions on causality and directionality. Few studies conducted multivariate analyses taking into account potential confounders. Only findings of multivariate analyses are discussed here. The majority of the factors tested by the studies were individual-level and HIV-related factors. Only four factors were significantly associated with increased sexual risk-taking in multivariate regression analyses: living alone (compared to living with their families), living with a partner (compared to living with their families), gender-based violence, and greater food insecurity. Knowledge of one's own HIV-positive status was associated with reduced risk-taking. Non-significant multivariate associations were reported for individual factors (rural residence, informal housing, anxiety, religious guidance, STI prevention knowledge, poor birth outcomes), family factors (orphanhood, parental monitoring, supportive family, social support), structural factors (maternal education, poverty), and HIV-related factors (disclosing HIV-status to partner, time on ART, ART adherence, hospital-based ART care, opportunistic infections). Findings for the remaining potential correlates were inconsistent, therefore additional research is needed to document which factors are consistently associated with sexual risk-taking among HIV-positive adolescents and youth.

It was not possible to reach conclusions on the prevalence of each high-risk sexual practice included in the systematic review. This was due to two reasons: heterogeneity of definitions applied by the included studies and variations in the actual reported sample sizes, methodology, and actual rates of different outcomes. For these reasons, it was not possible to conduct meta-analyses. To allow for cross-setting comparisons and generalisability, it is necessary for practitioners and policy-makers to agree on what sexual risk-taking measures are most appropriate for this important life stage. However, sexual risk-taking may take many different forms in different contexts, even among HIV-positive adolescents. Therefore, potential alternatives to help cross-setting comparison could be to group high-risk sexual

practices by typology of risk-taking. For example, a recent study in South Africa clustered HIV-risk taking behaviours into 'economic sex' (transactional and age-disparate sex), 'incautious sex' (unprotected sex, multiple partners, casual partners, and sex using substances) and 'pregnancy' (females only, current and past pregnancy) (Lucie D Cluver, Orkin, Yakubovich, & Sherr, 2016b). Qualitative research may help to clarify the different dynamics of these 'risk typologies' by taking into account sexual risk exposure in the context of relationships, such as intimate partner violence and forced sex.

A second option would be to look at sub-groups most at risk of engaging in multiple high-risk behaviours. Only one of the 35 included studies used a composite score of sexual risk-taking (Senyonyi et al., 2012). Given the very limited available data on the confluence of sexual risk-taking among HIV-positive adolescents and youth, these findings suggest that additional research is needed on the 'syndemic' of risk-taking among HIV-positive adolescents, i.e. HIV-positive young people who engage in multiple high-risk sexual behaviours.

All of the included studies reported on cross-sectional data analyses, so the causality of all reported associations could not be established, even when controlling for potential confounders. It is important to measure adolescent sexual risk-taking, hypothesised determinants, and potential confounders over time to make sure that causality can be tested. Longitudinal studies, including quasi-experimental analyses of cumulative effects and most vulnerable sub-groups, is needed to strengthen the current evidence base.

While several interventions have been developed and piloted, this thesis located only four that have been quantitatively evaluated and reported. Three of these interventions were tested through small-scale RCTs (n<150), two of which showed promising results: a support group intervention in South Africa (Snyder et al., 2014) and a one-on-one nurse-administered counselling programme in Uganda (Lightfoot, Rotheram-Borus, & Tevendale, 2007). Larger scale trials or large-sample quasi-experimental longitudinal analyses are necessary to test the effectiveness of these interventions in real-life settings and inform

future intervention trials (Shadish et al., 2002). Results from the only large-scale RCT (n=710) were available only as a workshop power-point presentation, so assessing the quality of the study design and results was difficult. However, its findings suggest that non HIV-specific social protection provisions, such as small grants, vocational training, and improved healthcare services, may reduce sexual risk-taking among very vulnerable HIV-positive adolescent women, particularly when delivered in combination (Nhamo, 2014). One of the key innovations of this last intervention is testing 'capability' social protection provisions, which aim to support adolescents to prepare for youth and adulthood by equipping them with skills necessary to enter the job market and have sustainable livelihoods (Gittings et al., 2016). This finding suggests that research should test whether social protection provisions have similar effects among other HIV-positive adolescents and youth, including adolescent boys.

Despite the inconsistent findings, which did not allow for solid conclusions to be drawn, the systematic review contributed meaningfully to the study design. The study's theoretical model was populated with hypothesised correlates and their conceptual groupings (individual, family, relationship, structural, and HIV-specific) were confirmed. Through this contribution, the systematic review shaped the main study and results presented in this thesis. In particular, it highlighted the need to start this thesis analyses by checking the associations between HIV-status knowledge and disclosure and sexual practices, as the key factor distinguishing this study's sample from a general adolescent population. To contribute to the evidence on which future guidelines and policies may be based, the subsequent chapter in this thesis that focused on disclosure (Chapter 5) looked at three types of HIV-status knowledge and disclosure. Moreover, the systematic review suggested potential wider factors from different levels of the socio-ecological model (family and structural-level factors) which may be associated with sexual risk-taking: parenting relationships, food security, poverty, access to school, and access to health services. These factors were analysed in the social protection paper (Chapter 6).

7.3. PAPER 2 – IS KNOWLEDGE POWER? HIV-STATUS DISCLOSURE AND PROTECTIVE SEXUAL PRACTICES AMONG ADOLESCENT GIRLS AND BOYS IN SOUTH AFRICA

Overall, just over a third of the sexually-active adolescents in this sample reported protective sexual practices (37%), with a significantly lower proportion of sexually-active adolescent girls reporting protective sexual practices compared to adolescent boys (17% vs 76%, $p<0.001$). Among adolescents who were sexually active and in relationships, 45% knew their partner's status and 31% of HIV-positive status-aware adolescents had shared their HIV-status with their sexual partners. These rates of disclosure were similar to those of comparable studies in Uganda (Birungi, Obare, et al., 2009; Mbalinda, Kiwanuka, Kaye, et al., 2015; Nöstlinger, Bakeera-Kitaka, et al., 2015). An adolescent's knowledge of his/her own HIV-positive status was associated with higher rates of protective sexual practices, while knowing a partner's HIV-status was associated with reduced protective sexual practices. Disclosure of HIV-positive status to a partner was not significantly associated with protective sexual practices.

The study provided strong evidence on the benefits of knowing one's own HIV-positive status, comparing n=794 HIV-positive status-aware adolescents with n=733 who did not know their HIV-status. It contributes to the growing but mostly inconsistent evidence on how disclosing one's HIV-status to a sexual partner and knowing a sexual partner's HIV-status (whether positive or negative) is associated with sexual practices (Beyeza-Kashesya et al., 2011; Obare & Birungi, 2010). HIV-positive adolescents who knew their status were nearly twice as likely to report protective sexual practices compared to the rest of the sample. These findings are similar to those of a study with n=732 HIV-positive adolescents in Uganda, which found increased safe sex among HIV-positive adolescents who knew their status (Beyeza-Kashesya et al., 2011).

Recent research from the same study has shown that HIV-positive adolescents who knew their HIV-status are more likely to adhere to their ART medication (Lucie D Cluver, Hodes, Toska, et al., 2015). Non-adherent adolescents who engage in unprotected sex are most likely to be virally active, thus exposing their partners and children to HIV (Marhefka et al., 2010). Therefore, these findings suggest that promoting HIV-positive status disclosure among adolescents in South Africa may have a positive impact on their own health outcomes and reduce the risk of infecting children and sexual partners. However disclosure support should include caregivers and healthcare providers when possible and follow an age-appropriate information-sharing process as laid out in the WHO guidelines (Lucie D Cluver, Hodes, Toska, et al., 2015; World Health Organization, 2011).

Disclosing one's HIV-status or medication-taking to sexual partners was not associated with safe sex, which raises significant concerns with regards to current counselling practices. Disclosing one's HIV-positive status to a sexual partner is an event of significant enormity in an adolescent's life (Mbalinda, Kiwanuka, Kaye, et al., 2015; Nöstlinger, Bakeera-Kitaka, et al., 2015). However, HIV-positive adolescents must weigh the benefits and risks of disclosure alongside other individual and structural factors such as fear of rejection, being 'outed', and extreme deprivation (Toska, Cluver, Hodes, et al., 2015). Several reasons could explain this association. Older adolescents in longer-term relationships may view these relationships as protective enough, once they are on stable ART and virally suppressed. Alternatively, HIV-positive adolescents who know their partner's status may not be able to negotiate safe sex for fear of losing their partner's love and support, material or emotional (Toska, Cluver, Hodes, et al., 2015). Additional quantitative research should model how these relationship-specific factors interact to shape disclosure patterns and how disclosure, in turn, shapes sexual practices.

Knowing one's partner's HIV-status was associated with unprotected sex. No other studies have looked at whether knowing your partner's status is associated with unprotected sex among HIV-positive adolescents. The systematic review (chapter 4) included only one

study of n=282 Tanzanian HIV-positive adolescents which found that those who did not know their partner's status were more likely to report multiple sexual partners (Mhalu et al., 2013). As this study was cross-sectional, findings could be explained by reverse directionality, i.e. adolescents may report not knowing their partner's status because they had multiple sexual partners and may not have known the status of all of those sexual partners. This association could be explained by several potential dynamics: HIV-positive adolescents may feel disempowered to negotiate condom use with a sexual partner when that partner has disclosed their status, for fear of being outed. An HIV-negative partner may also feel safe in engaging in unprotected sex with an HIV-positive partner who is taking ART and is potentially non-infectious. It is important for additional qualitative research to shed light on potential explanations for this relationship. Longitudinal quantitative research could then test potential mechanisms and establish causality.

Gender did not moderate the relationship between these different types of disclosure and protective sexual practices. The same patterns of associations were true for both adolescent girls and boys, with older age and poverty significantly associated with reduced safe sex in multivariate analyses. Disclosure is a complex process that includes a spectrum of information-sharing and practices (Fernet et al., 2011; Hardon & Posel, 2012; Nöstlinger, Bakeera-Kitaka, et al., 2015). Additional future research is needed to determine which factors may moderate or mediate the effect of different types of disclosure on safe sex, including poverty and relationship-specific factors. Evidence on effective interventions to address the increased vulnerability of adolescent girls from resource-deprived communities is urgently needed.

This large-scale study, including both adolescent girls and boys recruited from clinics and communities, provides strong evidence on disclosure 'to and from' adolescents. Its findings suggest that, while knowing one's own HIV-positive status may have strong protective effects against sexual risk-taking, it is not sufficiently protective when HIV-positive

adolescents also disclose to their partners or learn their partner's HIV-status. These findings have considerable implications for HIV-status disclosure support guidelines and practice.

7.4. PAPER 3 – SCHOOL, SUPERVISION, AND ADOLESCENT-SENSITIVE CLINIC CARE: COMBINATION SOCIAL PROTECTION AND REDUCTED UNPROTECTED SEX AMONG HIV-POSITIVE ADOLESCENTS IN SOUTH AFRICA

The last paper of this thesis was informed by the findings of the systematic review and current policy context on adolescent sexual health and HIV prevention. It tested which social protection provisions (five 'cash' and four 'care') were associated with reduced unprotected sex among HIV-positive adolescents in the sample. There is growing evidence on the effectiveness of social protection in improving health outcomes for general adolescent populations (Lucie D Cluver, Hodes, Sherr, et al., 2015). While social protection definitions vary, this study applied UNICEF's definition, which conceptualises social protection as 'a set of public and private policies and programmes aimed at preventing, reducing and eliminating economic and social vulnerabilities to poverty and deprivation' (UNICEF, 2012). In the field of HIV prevention – primary or secondary – social protection can be conceptualised as provisions, either cash/ in-kind or care, which address structural risk factors associated with increased sexual risk-taking (Lucie D Cluver, Orkin, et al., 2016b). This paper's analyses probed whether social protection may work in reducing sexual risk-taking for HIV-positive adolescents. It tested nine cash/ in-kind and care social protection provisions available to HIV-positive adolescents in the home, clinic, school, or community. Three provisions were strongly associated with reduced unprotected sex: access to school (cash/ in-kind), good parental supervision (care), and adolescent-sensitive clinic services (care).

HIV-positive adolescents who were able to access no-fee schools, or able to afford school fees, uniforms, books and materials, were more likely to report safe sex. These

findings confirm HIV prevention research, which considers education as a 'social vaccine' (Baker, Leon, & Salinas, 2011). Keeping adolescents, particularly girls, in school is key to enabling them to engage in safe sexual practices (Duflo, Dupas, & Kremer, 2015). Nearly two thirds of the HIV-positive adolescents in this sample were able to access school without financial barriers, though rates of access among HIV-positive boys were much higher than those among adolescent girls (72% vs. 61%, $p<0.001$). Understanding why school access may vary by gender, age, and additional factors such as orphanhood, is needed so that the positive benefits of accessing school can be maximised among different sub-groups of HIV-positive adolescents.

Adolescents who received good parental supervision were nearly twice less likely to report unprotected sex. This finding resonates with a causal relationship hypothesised by a smaller-scale study among HIV-positive adolescents in the Democratic Republic of the Congo (Holub, 2010), and studies among the general adolescent population in the United States (DiClemente et al., 2001, 2008; Stanton et al., 2004) that link good parental monitoring/ supervision with reduced risk-taking. A trial in the United States found that adolescent-parent dyads attending a joint intervention session on parental monitoring were less likely to report non-sexual high-risk behaviours such as smoking and substance use (Stanton et al., 2004). Additional research in the United States has found that higher perceived parental supervision is strongly associated with reduced sexual risk-taking (DiClemente et al., 2008). However, despite these strong findings, only 41% of the HIV-positive adolescents in this sample reported good parental monitoring/ supervision. This suggests that work remains to be done in supporting caregivers and parents to provide adequate supervision to the children and adolescents they care for.

Finally, adolescent-sensitive clinic care was strongly associated with lower odds of unprotected sex. Qualitative research suggests that experiences of sexual and reproductive health services significantly shape adolescent sexual practices in South Africa (Harrison, Xaba, & Kunene, 2001; Wood & Jewkes, 2006): adolescents who receive poor treatment by

nurses and healthcare providers at clinics are less likely to have good sexual health outcomes. The findings of this doctoral work provide quantitative evidence of this relationship. Adolescents who reported more respectful and positive care while accessing sexual and reproductive health services were less likely to report unprotected sex. The mechanism through which improved care results in unprotected sex should be further explored. One potential explanation is that adolescent-sensitive clinic care supports HIV-positive young people feeling respected, thus increasing their feelings of self-efficacy. In turn, improved self-efficacy leads to greater use of health products, such as condoms. Additional research is needed to explore the mechanism through which this care results in higher rates of safe sex.

Gender moderated the effect of adolescent–sensitive clinic care: the effect of receiving positive clinic care was stronger among HIV-positive adolescent girls. However, rates of accessing adolescent-sensitive care suggest that adolescent girls are more likely to be treated more harshly at clinics than adolescent boys: 83% of HIV-positive adolescent girls reported positive care, compared to 92% of HIV-positive adolescent boys. Improving the interaction between healthcare providers and HIV-positive adolescent women in the clinic setting could have significant benefits for HIV-positive adolescent girls.

Combinations of these three ‘cash/in-kind’ and ‘care’ interventions had additive effects on reducing unprotected sex. Without accessing any provisions, 22% of HIV-positive adolescents were likely to report unprotected sex, but this rate went down to 4% among adolescents who accessed all three provisions. These findings are similar to research among a general adolescent sample in South Africa (Lucie D Cluver, Orkin, et al., 2016b). The effect of combination social protection on reducing unprotected sex was stronger among HIV-positive adolescent girls: without access to social protection 49% were likely to report unprotected sex, with all three provisions only 9%. Recent analyses of the same sample also shows that combination social protection is associated with higher rates of reported ART adherence (Lucie D. Cluver et al., 2016). An on-going study in Uganda is testing whether

adolescents who receive combinations of social protection provisions are more likely to report improved adherence and retention in care (Ssewamala, 2015), with preliminary promising findings reported at the recent International AIDS Conference (Bermudez et al., 2016). The findings of this thesis suggest that social protection provisions, alone and in combination, may be effective tools to reduce the risk of secondary HIV transmission by HIV-positive adolescents.

Overall, HIV-positive adolescents in the sample reported high rates of accessing 'cash/ in-kind' social protection: social cash transfers, school access, school feeding, and food security (66%-95%), but rates of access to psychosocial support 'care' provisions were lower (13%-87%). Providers should focus on increasing the reach of such effective social protection provisions among HIV-positive adolescents. Additional research must also document which factors shape access to specific social protection provisions, particularly care social protection.

7.5. STUDY LIMITATIONS AND STRENGTHS

7.5.1. Limitations

This study has several limitations. First, the cross-sectional nature of the data mandates that all results be interpreted with caution, as causality cannot be established. One of the key conditions for causality is that the cause precedes the effect (Field, 2009). Cross-sectional data are insufficient to establish temporality; hence analysis results are primarily hypothesis-generating. The association between long-term school absence and adolescent sexual initiation exemplifies this limitation. Long-term school absence due to individual, family or structural reasons could increase the likelihood that an adolescent girl will engage in high-risk sexual practices. However, becoming sexually active and perhaps falling pregnant during adolescence could also result in long-term school absence. While cross-sectional studies provide opportunities to develop hypotheses, the temporal relationship between

determinants and outcome are best established through longitudinal studies (Fraser et al., 2009). This study's findings were interpreted with this caveat in mind, aiming to eliminate reverse causality in significant associations when relevant. Reverse causality has been noted when likely, but in most of these findings reverse associations was less likely. For example, access to free schooling may be causally associated with more protective sexual practices, but it is unlikely that engaging in protective sexual practices (abstinence or safe sex) increases access to free school as this is a government provision, dictated by location. Bearing in mind this limitation, further exploratory and confirmatory research is needed to improve the generalisability of this study's findings.

Second, self-reported measures always contain risk of social desirability bias, particularly sexual practices among adolescents (Plummer et al., 2004). As recommended by a study comparing 5 different data collection tools, to check the quality of the key outcome of interest for this thesis, *self-reported unprotected sex*, this candidate validated it with two other sexual and reproductive health outcomes in the third paper (Chapter 6) (Plummer et al., 2004). Unprotected sex was significantly associated with pregnancy and STI symptomology. This analysis suggests that, while based on self-reports, the items measuring unprotected sex at last intercourse are strongly related to rates of STIs and pregnancies in the study's sample. Adolescent reports on whether they knew their HIV-positive status were dependent on whether the participants felt comfortable disclosing to their interviewers. Though the team triangulated information from participants, caregivers and healthcare providers, it is likely that some HIV-positive adolescents who knew their status may have still kept that information from the research team. Moreover, some of this study's measures about third parties, namely whether their partners knew the HIV status of the participant, were based on adolescent self-reports and could not be verified.

Third, while the use of mobile devices (tablets) for data collection resulted in improved data quality and minimal missing data, it is not clear whether their use improved reporting of data on stigmatised behaviours such as unprotected sex. This was in part

because the use of mobile-assisted interviewing during this study was not complemented by audio-assisted interviewing. During this study, each participant was given the choice to use the tablets without support, to respond with support from the research assistant, or to be asked the questions from the research assistant who then also proceeded to enter the data using the device. These different modes of responding to the questionnaire varied by age and literacy level of the participants, with some adolescents fluent in their home language (Xhosa) but unable to read it and other unable to understand written English but able to read it. While this flexible data collection methodology ensured that participants were comfortable and able to complete the full questionnaire, there is no data to test how these different data collection methodologies may affect response rates for high-risk sexual practices. Further research is needed to explore how using mobile devices (with or without audio-assisted interviewing) may shape the data collected among adolescents. This component was added during the second wave of data collection which will be completed in March 2018, and can be used to explore how technology affects response rates among adolescents, particularly those living with HIV (openly or not). Despite this challenge, the rate of unprotected sex in our sample were comparable to other studies of similar age groups, however further analyses should explore the effect of using mobile devices and computer-assisted data collections methods on adolescent reporting of complex outcomes such as sexual abuse, non-adherence, and high-risk sexual practices.

Fourth, a limited number of scales validated among adolescents living with HIV in sub-Saharan Africa were available. Where possible, scales previously used among adolescents in South Africa were chosen. However this was not always possible, as shown by the literature review and measures and scales document (Appendix 5.3). In cases when no validated scales in South Africa were available, the candidate chose the most reliable scales that had been applied among HIV-positive adolescents in neighbouring countries, and adapted these through workshops and further piloting with HIV-positive adolescents.

Fifth, although over 90% of all study-eligible HIV-positive adolescents in the included health facilities, and 92% of community controls, were included in this sample, it is possible that some of the adolescents at highest risk were those who refused or were untraceable. The study's community-based sample did not actively include higher-risk populations such as sex workers and street children, and was not able to reach 9.1% of the eligible HIV-positive sample and 8% of the community controls, for reasons explained in more detail in Chapter 3. However, comparison of the sample reached and those not reached showed no significant differences by age, gender and residential location – the only information available to the study team. Despite this limitation, this study is the first and largest study of HIV-positive adolescents traced and interviewed in their homes and communities. It is therefore likely to be more representative of the overall HIV-positive adolescent population than samples restricted to adolescents who attend healthcare services. Moreover, by conducting the study in the high HIV-prevalent Eastern Cape province in South Africa, this research aimed to reflect settings similar to other resource-limited communities in Sub-Saharan Africa.

Sixth, the analyses presented in the two quantitative papers may be underestimating rates of unprotected sex by including adolescents who had never had sex in the comparison group for *protective sexual practices*. To analyse for the outcome of interest *adolescents who engage in unprotected sex* were compared to *the rest of the sample (those who have never had sex or those engaging in protected sex)*. In this way, the analyses in this thesis focused on identifying factors for sexual-risk taking (i.e. unprotected sex) and considered delayed sexual debut as a protective behaviour. Using the full sample for analyses also increased the power of the study and enabled this candidate to conduct more complex analyses for the two empirical papers. To ensure that these underestimates did not bias the full-sample analyses, point estimates using the sexually-active sub-sample were used to illustrate the trends observed through more advanced analyses (see Chapter 5).

Finally, despite the efforts invested in ensuring linguistic equivalence and accessibility, translation may have affected data quality. The questionnaires were translated and back-translated from English into the local language of Xhosa by a team fluent in both languages working in pairs (Brislin, 1970). During this process, many questions on sexual practices required prolonged explanations and deliberations to ensure that the right translation was included. Piloting with n=25 HIV-positive adolescents from rural, peri-urban and urban centres helped the team to finalise the English and Xhosa versions of the questionnaires. For cases when participants used the English questionnaire but required support from research assistants, regular training was provided to the research team to ensure that the correct question was being asked, and relevant explanations were provided by the interviewers to the respondents.

7.5.2. Strengths of the study

Despite the limitations listed above, this study provides key insights for sexual health programming among HIV-positive adolescents. The supportive factors identified – disclosure of HIV-positive status and access to social protection – represent provisions/ services that can be made available in real-life settings. Encouraging HIV-positive adolescents to learn about their HIV-positive status in a supported manner and providing social protection to HIV-positive adolescents may lead to reduced unprotected sex and fewer poor health outcomes such as unintended pregnancies and secondary HIV-transmission.

Second, the study sample included HIV-positive adolescents that were both in and out of clinical care, by tracing adolescents who were not regularly at healthcare facilities into their home communities. The research team conducted interviews in more than 150 neighbourhoods, villages, traditional homesteads, and wards (administrative units). The community-tracing efforts ensured that adolescents who were not actively and regularly engaged in care were invited to be part of the study. This thesis' results are more

generalizable to other HIV-positive adolescents than those of most other studies conducted to date, which recruit only adolescents presenting for care in healthcare facilities.

Third, the study experienced low rates of refusal to participate (4% in the HIV-positive sample and 0.8% in the community controls). This was in part due to the intensive and iterative training sessions held by the research team, led for a year by this candidate, to ensure that ethical protocols were followed and any potential recruitment challenges addressed promptly and sensitively.

Fourth, the study used mobile devices (tablets) to automatise data entry, checking, submission, and storage. The platform used is available in an open source format to anyone who wants to use it. As a result of this data collection tool, the team was able to build complex sets of questions that were only asked to the relevant subsets of the sample using complex skip patterns, while minimising missing data (<1%).

Sixth, HIV-positive adolescents in the cross-sectional quantitative study included both participants who knew their HIV-positive status and those who did not – whilst many studies only include those who are aware of their HIV-positive status. This sample composition allowed us to test the effect of knowing one's HIV-positive status on sexual practices, and provide strong evidence to inform future updates of guidelines on HIV-status disclosure.

Finally, the study recruited the world's largest sample of HIV-positive adolescents – providing more power for statistical analysis. It used a questionnaire that included both health and social factors, thus allowing the candidate to address research questions that have, to date, never been examined.

7.6. POLICY IMPLICATIONS

Our findings have several possible implications for policy. First, the disclosure findings in Paper 2 confirm the potential impact that reaching UNAIDS Fast Track 90-90-90 targets

could have on reducing the burden of HIV/AIDS in Sub-Saharan Africa and globally. In particular, this study supports the first target: 90% of HIV-positive adolescents should know their status. This thesis' findings on HIV-positive status-awareness suggest that HIV-positive adolescents should be supported to learn about and disclose their status, as this disclosure can translate into positive health outcomes: safe sex (chapter 5) and ART adherence (Lucie D Cluver, Hodes, Toska, et al., 2015). Research must explore the most effective ways to provide HIV-positive adolescents with this disclosure support.

Second, these findings suggest that recommendations to counsel HIV-positive adolescents to disclose their status to sexual partners should be implemented with caution. It is imperative that HIV-positive adolescents are not pushed to disclose to their partners, unless this disclosure can lead to positive interactions and safe sex negotiations (WHO, 2013).

Third, learning a sexual partner's status could lead to more unprotected sex and therefore temper the positive effects of adolescent HIV-positive status-awareness on sexual risk taking. One of the key reasons for this association could be the dynamics of sexual and romantic relationships among adolescents (Gevers, Mathews, Cupp, Russell, & Jewkes, 2013). These relationships include fluid shifts between friendships to romantic to sexual relationships, which often come with partial or incomplete acknowledgement of the relationship. In this context, these findings suggest that conventional adult couples-based approaches such as couples testing or couples counselling may not work in the same way for adolescents. Further research is needed to compose guidelines for effectively supporting HIV-adolescents in engaging in safe sex.

Fourth, the findings from the last paper confirm that certain social protection provisions which are already available to some adolescents in Sub-Saharan African settings – namely free access to school and good parental supervision – can lead to less unprotected sex among HIV-positive adolescents. The next step is to support HIV-positive adolescents in

accessing these services at comparable or higher rates to the general adolescent population, to help build the resilience of HIV-positive adolescents.

Fifth, Sustainable Development Goal 1 states that by 2030 countries should have social protection systems in place, and achieve substantial coverage of those most vulnerable (UN, 2015). Therefore, a key point in improving the reach of social protection programmes is to document rates of access to different provisions. Research should also investigate which factors shape adolescents' access to different types of social protection. Measuring the coverage of psychosocial support 'care' interventions is complex. Nonetheless, this study has allowed us to assess the current reach by different social protection provisions in this sample of HIV-positive adolescents. The study documented higher rates of access to cash/ in-kind social protection provisions (66%-95%) compared to 'care' provisions (13%-87%) among HIV-positive adolescents. Care social protection is vital to meet the changing needs of adolescents. Therefore ensuring improved access to care social protection may be an important priority for policy. Adolescent-focused care could be provided through age-appropriate parenting interventions (Lucie Dale Cluver, Lachman, et al., 2016) or psychosocial support programmes delivered individually (Bhana et al., 2013) or in group-settings (Snyder et al., 2014), which have been shown to improve adolescent outcomes.

Last, combinations of interventions may be better at addressing the multiple syndemic vulnerabilities faced by HIV-positive adolescents. HIV-positive adolescents are exposed to multiple vulnerabilities, as research from South Africa has documented. AIDS orphanhood and living with an AIDS-sick caregiver each result in worse physical and mental health outcomes and increased risk-taking among adolescents (Lucie D Cluver, Orkin, Boyes, Gardner, & Meinck, 2011a; Lucie D Cluver, Orkin, Boyes, Gardner, & Nikelo, 2012). Additionally, HIV-positive adolescents have to contend with additional factors such as HIV-status disclosure and the potential ensuing rejection, resource-deprivation, or exposure to violence in sexual and romantic relationships (Nhamo et al., 2013; Nöstlinger, Bakeera-

Kitaka, et al., 2015; Toska, Cluver, Hodes, et al., 2015). These multiple vulnerabilities may only be attenuated through access to multiple interventions rather than through single interventions. There is no silver bullet in ensuring HIV-positive adolescents live long and healthy lives, including having positive sexual and reproductive health outcomes.

7.7. DIRECTIONS FOR FUTURE RESEARCH

This study's analyses and findings have highlighted several areas of future research. Some of them have already been highlighted throughout this chapter, with an additional set of key priorities discussed in more detail below.

7.7.1. Longitudinal analyses

This cross-sectional study is only the first step in developing a rigorous problem theory for HIV-positive adolescent sexual health in South Africa. Longitudinal analysis allows for hypotheses of temporal relationships to be theorised and tested (Mann, 2003), and for potential causal mechanisms to be addressed through intervention research (Fraser et al., 2009). To identify modifiable factors, this candidate has continued to work with the research team to conduct a second wave data collection in 2015-2016, and is planning a third wave of data collection for 2017-2018. This candidate will analyse longitudinal data for sexual risk-taking as part of her planned postdoctoral studies. Longitudinal analyses will enable the candidate and collaborators to hypothesise and test theories of change for sexual risk-taking among HIV-positive adolescents and their community peers, contributing to the design of evidence-based social and health interventions as well as programming. It will allow for the causality of associations observed in this thesis to be tested. By measuring change in potential predictors and outcomes, longitudinal research will allow for investigation of potential causal pathways through mediation analyses. Moreover, longitudinal data will also enable the candidate to identify predictors of risk-taking for sub-groups at higher risk, for example HIV-positive adolescent mothers and pregnant HIV-positive teenagers.

7.7.2. Age Matters – Capabilities Research

Longitudinal research with this cohort will also provide unique insights into the factors that support adolescents during the pivotal period of entering youth and adulthood. Most importantly, it provides an opportunity to research the less-explored field of social protection 'capabilities': interventions and provisions that can support young people to become emotionally, physically, and financially independent adults. Preliminary findings from two interventions among HIV-positive adolescents in Uganda and Zimbabwe suggest that 'capabilities' components may reduce poor outcomes such as unprotected sex, transactional sex and treatment success (Nhamo, 2014; Ssewamala, 2015). Additionally, several qualitative and quantitative studies have demonstrated the potential of 'capabilities' interventions such as life-skills training, to improve health outcomes among adolescents and youth in sub-Saharan African countries (Bandiera, Buehren, Burgess, Goldstein, & Gulesci, 2013; Dunbar et al., 2014; Kaufman et al., 2010; Strasser & Gibbons, 2014). This may be an important area of future research.

7.7.3. Highly vulnerable sub-populations

There are several sub-populations of HIV-positive adolescents that warrant further research and analyses. HIV-positive adolescents who engage in unprotected sex are twice more likely to experience virological failure (Chapter 6). This sub-group of HIV-positive adolescents, who are virally unsuppressed and engaging in high-risk sex, should be the focus of future research. Second, the potential syndemic of HIV-positive status and orphanhood should be explored in further analyses, since orphanhood has been linked to increased sexual risk-taking in HIV-negative/ status unknown adolescent populations (Operario, Underhill, Chuong, & Cluver, 2011). Moreover, it is unclear which factors shape safe sex for key

adolescent populations, such as adolescents with physical and neuro-cognitive disabilities, and adolescents exposed to violence and abuse.

7.7.4. Combinations of interventions

One of the most important contributions that social protection provisions can make is through novel interventions that straddle biomedical and social spheres (Lucie D Cluver, Hodes, Sherr, et al., 2015). An important next step in HIV prevention research and programming is actively combining social protection and biomedical programmes (Coates et al., 2008). The DREAMS initiative is one such example, which includes 'combination prevention' of social protection (for example, cash transfers and parenting programmes) and biomedical and behavioural interventions (i.e. HIV testing, condom provision and PrEP) (PEPFAR, 2014). Questions regarding the scalability and durability of these interventions remain unanswered (Delany-Moretlwe et al., 2015), presenting a powerful potential for further research in this field. The next generation of research and programming must answer the questions of what works best, for whom, under which circumstances, and most cost effectively.

7.8. DISSEMINATION

A central principle of this candidate's research is to ensure that the evidence stemming from this thesis is made available to programmers, policy makers, and stakeholders, to inform decision-making and improved services for HIV-positive adolescents. Dissemination efforts to date have been both proactive and responsive to invitations to present findings at different opportunities. This dissemination has included: publications in peer-reviewed journals, presentations at conferences and high-level closed meetings, and webinars/ talks at universities, advocacy platforms and local/ national organisations.

The candidate has published 3 first-authored articles on topics related to this thesis, including Paper 3 (chapter 6). A full list of publications is included at the beginning of this

thesis. An additional two papers will be submitted for publication following the submission of this thesis. All accepted papers have been turned into policy briefs: one-page summaries, which make findings accessible to non-academic audiences. Parts of this thesis' research have been featured in newsletters such as the monthly UNAIDS HIV Science Now – HIV This Month[29] and AIDSFree Prevention Update[30].

The candidate has presented preliminary findings on the results of this thesis at six international and national conferences: 6th Southern African AIDS Conference (SAAIDS) in June 2015 (two oral presentations), 3rd International Conference of the Association for the Social Sciences and Humanities in HIV in July 2015 (oral presentation), 20th International Workshop on HIV Observational Databases in April 2016 (poster presentation), The Coalition for Children Affected by AIDS symposium in July 2016 (oral presentation), 21st International AIDS Conference – AIDS2016 in July 2016 (oral presentation), and the annual conference of the Public Health Association of South Africa in September 2016 (two oral presentations).[31] Abstracts based on this thesis were accepted for presentation at a best practices meeting hosted by the national South Africa Department of Health at the end of October 2016. Preliminary findings have also been presented by the candidate to the World Bank group and partners (February 2016), a UN Women high-level meeting on HIV (February 2016), UNAIDS Social Protection Working Group (March 2016), and the Eastern and Southern Africa Regional Inter-Agency Task Team on Children Affected by AIDS (RIATT-ESA) advocacy platform (July 2016, September 2016). Academic presentations have included two seminars at the Department of Social Policy and Intervention in Oxford, two presentations at the University of Cape Town (South Africa), and two presentations at Stellenbosch University (South Africa).

[29] https://sciencenow.unaids.org/post/reduce-sexual-transmission-165
[30] https://aidsfree.usaid.gov/sites/default/files/9.16_aidsfree_prev-up_0.pdf
[31] Both presentations were based on Chapters 5 and 6, however as this candidate could not travel, two team members: Ms. Amanda Mbiko and Ms. Lesley Gittings, gave the oral presentations.

One important component of disseminating the findings of this research involves reporting these findings to local health and education providers, provincial government, health facility administrators, and community leaders. The candidate has trained the fieldwork research team on presenting these preliminary findings and supported four local team members to present at the conference of the Public Health Association of South Africa (PHASA) in September 2016. A longer-term local dissemination plan is being developed, involving the capacity building of local team members to share these findings. Future dissemination plans for this research include presenting to all participating health facilities, local NGOs and research partners, which include: Kheth'Impilo, PATA, Small Projects Foundation, and Keiskamma Trust, South African national and provincial departments of Health, Basic Education, and Social Development, as well as international partners such as UNICEF Eastern and Southern Africa Regional Office (UNICEF-ESARO).

7.9. CONCLUSION

This is the world's largest study of sexual practices among HIV-positive adolescents. Large-scale analyses identified key factors associated with sexual risk-taking among adolescents living in a high HIV-prevalence, resource-deprived setting in South Africa. A systematic review was conducted and findings were used to adapt a widely used conceptual framework – Bronfenbrenner's socio-ecological model of human development – to the sexual health needs of HIV-positive adolescents. Associations between several of these key factors included in the model, and protective sexual practices, were tested. Findings show that both HIV-specific and wider factors are associated with reduced sexual risk-taking among HIV-positive adolescents. They suggest that interventions aimed at supporting safe sexual practices among HIV-positive adolescents should encourage age-appropriate HIV-positive status disclosure, refrain from pressurising HIV-positive adolescents to disclose to their sexual partners, and support them to negotiate safe sex when they know their partner's status. Findings also suggest that improving access to combination social protection to HIV-

positive adolescents, particularly adolescent girls, is key to reducing onwards HIV transmission to sexual partners and children. While further research and longitudinal data analyses would be important to reinforce and extend these findings, results have important implications for policy and practice. In the meantime, it is this candidate's hope that these findings can contribute to shaping adolescent services and programming in South Africa and neighbouring countries, where most HIV-positive adolescents live, spend their free time, and love.

8. BIBLIOGRAPHY

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SEX IN THE SHADOW OF HIV

FACTORS ASSOCIATED WITH SEXUAL RISK AMONG ADOLESCENTS IN A COMMUNITY-TRACED SAMPLE IN SOUTH AFRICA

Elona Toska

Department of Social Policy and Intervention

Green Templeton College

Hilary Term 2017

Thesis submitted in partial fulfilment of the degree of Doctor of Philosophy in Social Intervention by stand-alone papers at the University of Oxford.

APPENDICES

LIST OF APPENDICES

1. ETHICS APPLICATION AND STUDY PROTOCOL 3
1.1 UNIVERSITY OF OXFORD CUREC-2 APPLICATION 3
1.2 MZANTSI WAKHO RESEARCH PROTOCOL 32
1.3 MZANTSI WAKHO PLUS BABY PROTOCOL 75
2. ETHICS APPROVAL LETTERS 94
2.1 UNIVERSITY OF OXFORD I-DREC APPROVAL 94
2.2 I-DREC STUDY AMENDMENT UPDATE 95
2.3 I-DREC APPROVAL FOR STUDY PROTOCOL AMMENDMENTS 97
2.4 UNIVERSITY OF CAPE TOWN, CENTRE FOR SOCIAL SCIENCE RESEARCH 98
2.5 EASTERN CAPE DEPARTMENT OF HEALTH APPROVAL 99
2.6 BUFFALO CITY HEALTH SUB-DISTRICT RESEARCH APPROVAL 100
2.7 EASTERN CAPE DEPARTMENT OF BASIC EDUCATION RESEARCH APPROVAL 102
2.8 LETTER OF ENDORSEMENT – UNICEF 104
2.9 LETTER OF SUPPORT – PAEDIATRIC AIDS TREATMENT FOR AFRICA (PATA) 106
3. INFORMATION SHEETS AND CONSENT FORMS 107
3.1 ADOLESCENT INFORMATION SHEET AND CONSENT FORM 107
3.2 FACILITY (CLINIC) INFORMATION SHEET 109
3.3 SCHOOL INFORMATION SHEET 113
4. CERTIFICATES 117
4.1 ADOLESCENT PARTICIPANT CERTIFICATE 117
4.2 FACILITY CERTIFICATE 118
5. ADOLESCENT-FOCUSED DATA COLLECTION TOOLS 119
5.1 SCREENING FORM 119
5.2 ADOLESCENT QUESTIONNAIRE 120
5.3 SCALES AND MEASURES SUMMARY 197
5.4 REFLECTION FORM 212
6. CLINIC-BASED DATA COLLECTION 214

6.1 CLINIC MAPPING TOOL 214
6.2 LIST OF PARTICIPATING FACILITIES 216
6.3 PATIENT FILE DATA EXTRACTION FORM 219
7. REFERRAL LETTERS – EXAMPLES 224
8. SYSTEMATIC REVIEW DOCUMENTS 232
8.1 SYSTEMATIC REVIEW PROTOCOL 232
8.2 SYSTEMATIC REVIEW PROTOCOL APPENDICES 250
8.3 SYSTEMATIC REVIEW REGISTRATION ON PROSPERO 257
8.4 SYSTEMATIC REVIEW APPENDICES 258
9. FULL BASELINE STUDY RESEARCH TEAM 262
10. RESEARCH PARTNER ORGANISATIONS 264
11. HEALTH AND SAFETY FORMS 265
11.1 RISK ASSESSMENT FORM: ELONA TOSKA 265
11.2 MZANTSI WAKHO SAFETY PROTOCOL 269

1. ETHICS APPLICATION AND STUDY PROTOCOL

1.1 UNIVERSITY OF OXFORD CUREC-2 APPLICATION

Not all research project leaders need to fill in this form. **Before starting work on this form**, please fill in CUREC's checklist (CUREC/1), which will show if you need to complete this form. Please also ensure you have consulted the following CUREC guidance documents available on the CUREC website (http://www.admin.ox.ac.uk/curec/resrchapp/index.shtml):

- Guidance on approval process
- Glossary
- FAQs

Definitions of terms marked with an asterisk are to be found in CUREC's glossary and guidance.

Attachments:

1. Information and consent form for adolescent participants (qualitative)
2. Guardian consent form for adolescent participation (qualitative)
3. Information and consent forms for caregiver participation (qualitative)
4. Information and consent forms for health worker participation (qualitative)
5. Information and consent form for Adolescent Questionnaire (quantitative)
6. Adolescent questionnaire (draft)
7. Guardian consent form for adolescent participation (quantitative)
8. Example referral forms for adolescents
9. Adolescent Certificate of Participation
10. 'Measures and Constructs': Summary and provenance of items in Adolescent Questionnaire
11. Researchers Ethics Guidelines (draft).

SECTION 1: PROJECT TITLE, RESEARCHERS, AND CONTACT DETAILS

1. Person to whom IDREC/CUREC should direct correspondence:

***Principal investigator/supervisor/student researcher**

Title and name: Dr Lucie Cluver

Appointment: University Lecturer

Department: Department of Social Policy and Intervention

Institution: University of Oxford

Address: Department of Social Policy and Intervention, Barnett House, 32 Wellington Square, Oxford, OX1 2ER

Phone: +44 1865 270325 Fax: +44 1865 270324

e-mail: lucie.cluver@spi.ox.ac.uk

Will you need training to participate in this project?

☐ Yes ☒ No

2. Full project title and proposed starting date:

Youth Pulse: Identifying risk and protective factors for adherence to long-term medication amongst adolescents in South Africa

Starting Date: March 2013

Office use only: **IDREC Ref. No.**_____ **Date of Approval: / /**

Application date: / /

Approval Period: from / / to / /

Signature of IDREC approver: _____

Name (printed) and position of approver: _____

Date applicant informed of approval: / /

3. Are you submitting this project to another ethics committee or has it been previously submitted to an ethics committee?

☒ Yes - provide details.

☐ No

This application will be submitted to Provincial government committees (in the Eastern Cape, Education Department) and to the University of Cape Town Research Ethics committee. Both require Oxford approval prior to submission.

If other relevant approvals for this research are required (e.g. from other universities' ethics committees) please attach them.

4. Have you made use of professional/CUREC guidelines in framing your research project and preparing documentation?

Note: the CUREC guidelines are available online (http://www.admin.ox.ac.uk/curec/oxonly/protocols/guidelines.shmtl) or by emailing curec@admin.ox.ac.uk

☒ Yes - provide details.

We have made sure to use the CUREC guidelines (particularly SSH/IDREC/2008/P13.1) in framing our research project and preparing documentation with regards to recruitment, training and administration of interviews, responding to participants experiencing acute distress, and recording details and making referrals in case of serious incidents. The consent forms we provide clarify the purposes of this study, in addition to the nature of the research to be conducted and explicit statements regarding participants' rights to opt-out at any point. Given that this study is taking place in South Africa, we have additionally used a number of other sources for guidelines, such as South African legislation: including the Department of Health's Ethics in Health Research Guidelines 2004, the Department of Health, Guidelines for Good Clinical

Practice in South Africa, 2nd Edition 2006, the Open Society Foundation for South Africa's 'Best Practice Guide to HIV Disclosure' (2009), the AIDS Law Projects' 'HIV and the Law: A Resource Manual'(2003), the National Health Act 61 of 2003 (expected to be enforced starting 2012 - 13), the Children's Act 38 of 2005, the Children's Amendment Act 41 of 2007 and the Sexual Offences Act 32 of 2007. These South Africa specific documents were supplemented by international guidelines, such as WHO's Guidelines on HIV disclosure and counselling for children up to 12 years of age (2011).

5. Researchers involved in this project

Please supply one completed copy of this box for each researcher.

*For each researcher who requires training to participate in this project, describe training on a **separate page** and include the name of the trainer(s).*

***Associate researcher/student researcher** Title and name: **Dr Mark Boyes**
Appointment: Postdoctoral Researcher
Department: Department of Social Policy and Intervention
Institution: University of Oxford
Address: Department of Social Policy and Intervention, Barnett House, 32 Wellington Square, OX1 2ER Phone: +44 18652 70336 Fax: +44 1865 270324
e-mail: mark.boyes@spi.ox.ac.uk
Role in this project: Co-Investigator Qualifications and relevant experience for this project: Dr Mark Boyes has worked extensively with Dr Cluver on projects examining the impact of familial HIV/AIDS on child and adolescent wellbeing. He also has a strong research background in individual differences in stress reactivity and coping and has an MPsych in developmental and educational psychology. Will this researcher be approved by the principal researcher as competent to obtain *informed consent from participants? No
Will this researcher need training to participate in this project? ☐ Yes ☒ No

***Associate researcher/student researcher** Title and name: **Prof. Mark Orkin**
Appointment: (retired) Professor, University of Witwatersrand
Department: School of Public and Development Management
Institution: University of the Witwatersrand

Address: School of Public and Development Management, University of the Witwatersrand, 2 St David's Place, Johannesburg, 2050, South Africa Phone: +27 11 717 3506 Fax: n/a
e-mail: morkin@mweb.co.za
Role in this project: Statistical support Qualifications and relevant experience for this project: Professor Orkin, prior to retirement, was Professor of Social Research in the University of Witwatersrand, then Chief Statistician of South Africa after the fall of apartheid. He has particular expertise in large-scale intervention studies, and was both President of the Human Sciences Research Council and a Director-General in the South African national government. Degree course (if relevant): Will this researcher be approved by the principal researcher as competent to obtain *informed consent from participants? No.
Will this researcher need training to participate in this project? ☐ Yes ☒ No

***Associate researcher/student researcher** Title and name: Tintswalo Mercy Hlungwani
Appointment: Senior Lecturer
Department: Wits School of Public Health
Institution: University of Witwatersrand
Address: Wits School of Public Health, Faculty of Social Sciences, University of Witwatersrand, Johannesburg, South Africa Phone: +27 (0)11-717-2734 Fax: +27 (0)11-717-2084
e-mail: Tintswalo.Hlungwani@wits.ac.za
Role in this project: Co-PI Qualifications and relevant experience for this project: Ms. Hlungwani is a Senior Lecturer/Senior Researcher in the School of Public Health, Faculty of Health Sciences: University of the Witwatersrand (Wits). She lectures Health Promotion in Bachelor of Health Sciences; in the Graduate Entry Medical Programme(GEMP); and in the Masters in Public Health programme. She also coordinates and teaches Social and Behavioural Sciences in the Community- Doctor theme of the GEMP. Her research to date has involved developing socially accountable mental health intervention programmes in rural schools in collaboration with Soul City Institute for Health & Development Communication, Oxford University Department of Psychiatry, Mpumalanga Department of Health and Department

of Education, and the Local Non Governmental Organizations affiliated to the Agincourt Health and Population Unit.

Degree course (if relevant): N/A

Will this researcher be approved by the principal researcher as competent to obtain *informed consent from participants? No

Will this researcher need training to participate in this project? ☐ Yes ☒ No

***Associate researcher/student researcher**

Title and name: Rebecca Hodes

Appointment: **Post-doctoral Fellow**, Institute for the Humanities in Africa; **Research Associate**, AIDS and Society Research Unit, Centre for Social Science Research

Department: Institute for the Humanities in South Africa

Institution: University of Cape Town

Address: Institute for the Humanities in South Africa, University of Cape Town, Cape Town, South Africa

Phone: +27 (0)21-650-6591 Fax: +27 (0)11-717-2084

e-mail: rebecca.hodes@gmail.com

Role in this project: Co-PI

Qualifications and relevant experience for this project: Dr. Hodes is a post-doctoral fellow at the Institute for the Humanities in Africa and Research Associate at the AIDS and Society Research Unit, Centre for Social Science Research, University of Cape Town. Her research focuses on HIV and antiretroviral treatment in South Africa, the history of reproductive healthcare in southern Africa, access to medicines, social welfare policies for people living with HIV. In 2010-2012, she was the Deputy Director of the AIDS and Society Research Unit, Centre for Social Science Research, Humanities Faculty. In that capacity, she was engaged in interdisciplinary research on the social aspects of HIV in southern Africa, with a focus on 'faith healing', reproductive healthcare and the challenges and opportunities of the public provision of antiretroviral treatment. Over the last decade, Rebecca has tutored and taught on the politics of the response to the HIV/AIDS epidemic in South Africa at University of Oxford, Rhodes University, and Oxford Brooks University. She is a journal referee for *Culture, Health & Society, Journal of the International AIDS Society, Journal of Southern African Studies, South African Historical Journal*.

Degree course (if relevant): N/A

Will this researcher be approved by the principal researcher as competent to obtain *informed consent from participants? No

Will this researcher need training to participate in this project? ☐ Yes ☒ No

***Associate researcher/student researcher** Title and name: **Beth Vale**
Appointment: DPhil candidate
Department: Social Policy and Intervention
Institution: Oxford University
Address: Department of Social Policy and Intervention, Barnett House, 32 Wellington Square, Oxford, OX1 2ER Phone: Fax:
e-mail: elizabeth.vale@spi.ox.ac.uk
Role in this project: Student researcher Qualifications and relevant experience for this project: MA in Sociology, investigating how South African community health workers, serving as antiretroviral adherence supporters, negotiate between policy and practice. Research methods included piloting a body-mapping project with community health workers as a data collection tool and form of therapeutic debriefing. Work experience includes five years of HIV/AIDS and gender advocacy, including education, training and lobbying with student HIV/AIDS organisations (2007-2009), an institutional position as Rhodes University's HIV/AIDS advocacy officer, and internships with two public health NGOs – namely Kheth'Impilo and the Treatment Action Campaign. Advocacy work has included the development and facilitation of HIV/AIDS peer education programmes for high school learners in the Eastern Cape and assistance with community support programmes for teenagers affected by HIV/AIDS. In addition to MA, relevant qualifications include: emergency first aid and fieldwork planning and supervision training attended. Degree course (if relevant): DPhil Will this researcher be approved by the principal researcher as competent to obtain *informed consent from participants? YES
Will this researcher need training to participate in this project? ☐ Yes ☒ No

***Associate researcher/student researcher** Title and name: **Elona Toska**
Appointment: DPhil candidate
Department: Social Policy and Intervention
Institution: University of Oxford
Address: Department of Social Policy and Intervention, Barnett House, 32 Wellington Square, Oxford, OX1 2ER Phone: +44 7818 462377 Fax:
e-mail: elona.toska@spi.ox.ac.uk
Role in this project: Student Researcher Qualifications and relevant experience for this project: MSc in Evidence-Based Social Interventions studying risk and protective factors for adolescent pregnancy among girls living in high HIV prevalence communities in South Africa. Previous work experience includes prevention of mother to child transmission of HIV in Western Cape, South Africa, prevention of HIV and STIs among highly stigmatised populations of sex workers, transgender men and migrant populations in South East Asia and monitoring and evaluation of donor projects in several countries. In addition to MSc, relevant qualifications include: mental health first aid, emergency first aid, and fieldwork planning and supervision, respondent driven sampling training attended. Degree course (if relevant): DPhil Will this researcher be approved by the principal researcher as competent to obtain *informed consent from participants? YES
Will this researcher need training to participate in this project? ☐ Yes ☒ No

SECTION 2: PROJECT DESCRIPTION

6. Description of project

Please give a description (300-800 words) of your project to supplement the information already provided in Section A of the checklist (CUREC/1), detailing those aspects of the project which involve *human participants, particularly any aspect which is beyond already established and accepted techniques. Please attach all other documents (e.g. questionnaire, recruitment advertisements, participant information, and consent forms) that you plan to use in the study. **Please note that detailed scientific background is not required unless directly relevant to ethical issues.**

This proposed study is a direct collaboration between UNICEF, UNAIDS, the South African government and researchers. It addresses a major gap in research: that of understanding adherence to lifesaving antiretroviral medication amongst adolescents in sub-Saharan Africa. By providing rigorous evidence of risk and protective factors for adherence, it will inform the development of interventions and services for a highly vulnerable group. The

study will aim to identify factors predicting adherence, distinguishing between adherence to ARVs compared to other types of long-term medication.

The UNAIDS Investment Framework for a global HIV response identifies improving antiretroviral adherence as a key priority (UNAIDS 2011). Very limited research is available on adherence to ARVs amongst adolescents, but what is available suggests exceptionally low adherence rates of around 20% (Nachega, Hislop et al. 2009). This low adherence has direct impacts on illness and mortality. In addition, as adolescents become sexually active, there are severe public health risks for transmission of drug-resistant strains of HIV.

This study has been planned in partnership between academics, non-governmental organisations, and the South African government. By taking an approach of active inter-sectoral collaboration, this study aims from the outset to assure the policy impact of its findings. The study will combine quantitative methods (with 1000 adolescents) and qualitative methods (with small samples of 20-40 adolescents and caregivers) with a multidisciplinary team from psychology, social work, health economics and anthropology. The quantitative component will focus on identifying risk and resilience-promoting factors for ARV adherence and compare them to factors that predict adherence to other long-term medication among adolescents in South Africa. The qualitative study will provide a rich and in-depth understanding of the factors driving ARV-specific medication-taking behaviour. It aims to build and empirically test a theoretical model of adolescent antiretroviral adherence in Sub-Saharan Africa. The study hypothesises an interactive model of multiple interlinking influences on adolescent adherence, with potential risk and protective factors including neurocognitive, health service-related, financial, psychological, family, cultural, nutritional and peer relationships. By identifying potentially modifiable intervening factors, this study will inform evidence-based interventions to respond to a major public health challenge of our time**.**

Sampling will use the WHO definition of adolescents: aged 10-19 (WHO 2007, UNICEF 2011), and will aim to include a wide range of HIV+ adolescents, including urban and rural, boys and girls, those infected peri-natally and post-natally, living in various caregiving arrangements and with a range of ages. All of the very few other known studies to date of adherence amongst children and adolescents have used clinic-based samples. This is problematic as, by default, it excludes key groups of non-adherent adolescents who do not attend their clinic appointments (rather like examining truancy by using a sample of school-attending children and adolescents). In order to access both clinic-attending and other at-risk groups within HIV+ adolescents, a range of targeted sampling strategies will be used, with recruitment in a range of locations, including antenatal clinics, HIV treatment clinics, testing centers, schools, prisons, children's homes, home-based care organisations and community-based sampling. A two-stage screening process will allow identification of adolescents accessing health and other services, and then inclusion in the main study. In light of high levels of stigma towards people living with HIV/AIDS in South Africa (Skinner & Mfecane, 2004; Deacon *et al*., 2009), and low levels of disclosure among adolescents (Morrel, 2003; Ferrand *et al*., 2010: 428; Peterson *et al*., 2010: 972), recruitment will not use sampling approaches which may lead to unintentional disclosure or stigmatization (such as Respondent-Driven Sampling). In addition the quantitative study promotion process will not emphasize HIV or AIDS, and will be presented as investigating **health and social service access for adolescents**. In contrast, the qualitative study will recruit HIV-positive adolescents who are taking antiretrovirals and have disclosed their status to the researchers.

This research builds on 5 years of longitudinal studies of mental health, educational and physical outcomes of HIV-affected children in high HIV prevalence communities in South Africa and recent qualitative research on access to treatment of HIV-positive adolescents.

As a generation of HIV-positive children reach adolescence, this research is crucial to elucidate the complex factors that affect the well-being of HIV-positive adolescents, their access to life-saving drugs and overall healthcare services.

The qualitative research will aim to elicit the views of 20-40 HIV+ adolescents regarding risk and resilience-promoting factors for adherence and will use purposive sampling to achieve maximum variation in a small sample of adolescents eligible for antiretroviral treatment. Adolescent participants in the qualitative study will be engaged over a year-long period, using ethnographic methods to explore their retention and attrition in antiretroviral treatment programmes. In order to triangulate methods (Punch, 2002: 24), the ethnography will be complemented by a range minimally invasive, participatory (Morrow & Richards, 1996: 100) and more structured data collection methods: semi-structured in-depth interviews, treatment diaries (Odendaal *et al*., 2011; Richardson, 1994; Verbrugge, 1980; Zimmerman & Wieder, 1977), body mapping[1] (Vasquez 2004; MacGregor, 2009), and semi-structured focus groups. Group activities (body mapping and focus groups) will be limited to openly disclosed adolescents within pre-existing groups, i.e. support groups or programmes for HIV-positive youth. The qualitative study will also conduct semi-structured in-depth interviews with a small sample (20-40) of caregivers and healthcare workers, who may or may not be linked to adolescent participants. Recruitment, data collection and data analysis will occur concurrently, allowing emerging understandings to inform interview guides and following key principles of Grounded Theory (Glaser & Strauss, 1967).

The quantitative survey will include a self-report questionnaire that is completed with an interviewer due to low levels of literacy. This will collect information about sociodemographics, health service access and potential risk and resilience-promoting factors. Interview booklets are structured and presented in the style of a teen magazine quiz. This is the result of a suggestion of a group of teens in our Teen Advisory Group comprised of AIDS-affected teenagers, who helped guide previous qualitative and quantitative research on Young Carers. The 'teen advisory group' of children living with HIV (TAG group) has been established and integrated with our existing advisory group of children living in AIDS-affected families, with whom we have conducted collaborative research since 2008 (approved by Oxford IDREC in 2008 and again in 2012).

7. Literature search

If the research involves significant risk to the human participants please describe what literature searches have been undertaken to obtain information to aid risk reduction/management.

There is an extensive body of work, both in the UK and South Africa, on ethical concerns in research with 'vulnerable' children and young people. The proposed ethical guidelines for this study are informed by a number of sources. These include the ongoing academic debate on issues such as informed consent and confidentiality (Alderson & Morrow, 2004; Strode *et al*., 2005; Singh *et al*., 2006; Flicker & Guta, 2007; Zuch *et al.,* 2012), the ethical requirements of the universities and research institutions involved in designing the research, and ethical guidelines from psychological research bodies such as the British Psychological Society (BPS, 2006).

Furthermore, key research guidelines and legislation in South Africa have been considered, including the Department of Health's Ethics in Health Research Guidelines 2004, the

[1] Body mapping has been used as a therapeutic technique and an educational tool (Wienand, 2006), but more recently, it has served as a participatory qualitative research method used to facilitate interaction and generate visual data. A body map is a life-sized art piece comprised of symbols, pictures and writing, which participants draw in and around a life-sized outline of their own bodies. As a source of qualitative data, body maps can tell us how participants conceive of their bodies - as objects of health interventions, as vehicles through which they experience the world, and as features of self-identity.

Department of Health, Guidelines for Good Clinical Practice in South Africa, 2nd Edition 2006, the Open Society Foundation for South Africa's 'Best Practice Guide to HIV Disclosure' (2009), the AIDS Law Projects' 'HIV and the Law: A Resource Manual'(2003), the National Health Act 61 of 2003 (enforced starting 2012), the Children's Act 38 of 2005, the Children's Amendment Act 41 of 2007 and the Sexual Offences Act 32 of 2007. These South Africa specific documents were supplemented by international guidelines, such as WHO's Guidelines on HIV disclosure and counselling for children up to 12 years of age (2011).

SECTION 3: RESEARCH INVOLVING CONTACT WITH *HUMAN PARTICIPANTS

If the project does NOT involve contact with*human participants, but only use of data about them, do NOT complete this section, but go to Section 4. If you are not completing Section 3 please delete it from your application to save paper.

8. Description of participants

How many participants will be involved in the project?

The proposed qualitative research with approximately 30 adolescent respondents on long-term medication (ARVs, TB treatment or other chronic medication), and approximately 40 key informants including adolescent caregivers, healthcare workers and stakeholders in local health organisations or government departments.

The quantitative research with approximately 1000 adolescents, nearly 600 of these being HIV-positive and eligible for treatment. The research will be located in the Eastern Cape province of South Africa, rural and urban sites. The quantitative study will not include youth involved in the qualitative study, and the qualitative sample will not be recruited from the quantitative sample as this could lead to passive disclosure of the HIV-positive adolescents.

9. Details of participants

(a) What types of people will be recruited e.g. students,* children, people with learning disabilities? [Please see the Glossary on the CUREC website for information on how the meaning of *capacity to consent has been altered by the Mental Capacity Act 2005]

We will be interviewing adolescents between 10 and 19, the majority of whom will be HIV-positive and on antiretrovirals in the Eastern Cape province. However, given the high levels of stigma, low levels of disclosure and access to treatment in these communities, participants recruited for the quantitative component of the study will include any adolescents in the communities that have used health and social services, with an oversampling of those that have experienced a serious illness and/or are (or have been) on long-term medication for an illness (such as diabetes, asthma). By shifting the focus of the quantitative study away from HIV/AIDS and antiretroviral therapy, participants will include both HIV-positive and HIV-negative adolescents. The qualitative component of the proposed research will purposively sample HIV-positive adolescents on antiretroviral therapy, who know their status and are willing to disclose to the researchers and, if they opt for group activities, to other participants.

Additional participants in the qualitative part of the research will include healthcare workers and caregivers of adolescent participants (only where full disclosure has already taken place regarding adolescent HIV-positive status) to participate in focus group discussions.

(b) What will be the age range of participants?

Adolescent participants will be between the ages of 10 and 19 (as per the WHO definition of adolescent).

(c) How will the competence of participants to give *informed consent be determined?

We will obtain written informed consent from each participant in this study.

1) Consent for adolescents to participate

In order to ensure fully informed, voluntary consent for adolescent participants, all adolescents will be provided with information sheets describing the study in their first chosen language, which interviewers will read aloud (due to low literacy levels). All explanations will be easily understandable for adolescents in this study, and the adolescent's right to decline participation and to withdraw at any time will be thoroughly explained. Particular attention will be given to issues surrounding statutory requirements to break confidentiality (see below). Only after the purpose of the study and the format of the interview have been explained will the adolescent be asked for their consent to participate.

*2) Caregiver consent for adolescent participation**

(the following process and procedure is applicable to adolescents who have not yet turned 18. Adolescents who are 18-19 years old, will be treated as adults with regards to informed consent issues, in compliance with all the of regulations cited in this CUREC form).*

Each adolescent's legal caregiver will also provide consent for participation in this study, and will be provided with information describing the study in their first chosen language. In some exceptional circumstances related to HIV/AIDS vulnerability, the adolescent may wish to participate but the primary caregiver is unavailable or too unwell to be able to give consent, and here the adolescent can nominate another adult whom they trust in his or her place (such as an aunt, or social worker). These circumstances include adolescents in child-headed households, and adolescents whose primary caregiver is experiencing AIDS-related dementia. Adolescents may also nominate an alternative adult to give consent in place of their primary caregiver if asking for guardian consent amounts to involuntary disclosure of HIV status. The National Child Act, passed in 2003, includes additional guidance on consent procedures. As the regulations and guidance on its enforcement are in the process of being issued, this ethics proposal will be revised upon their publication.

In our prior work with Young Carers, we identified a very small but worrying group of orphaned children who wanted to participate in the study but who explained to us that they lived with a foster carer who was forcing them to undertake large amounts of domestic work against their will, and that the carer would not want the research to take place in case this was revealed. When consent was requested from the caregiver, they did refuse. Furthermore, in cases when children and adolescents experience abuse from caregivers or guardians, consent for the study would be difficult to obtain, as these caregivers would not want to be reported. In light of research highlighting the high levels of abuse experienced by HIV-affected children in the Young Carers project (Cluver *et al*. 2011), we expect that such a difficulties will also affect our research in this study.

We engaged in extensive discussion regarding this issue with colleagues at the University of Cape Town Health Sciences REC, at the University of Witwatersrand, and with Social Workers at Cape Town Child Welfare. We also consulted South African legislation, particularly the Department of Health Research Ethics Guidelines, 2004. The ethics processes and procedures proposed in this research project were reviewed and approved

by the following ethics committees and institutions:

(1) Inter-Divisional Research Ethics Committee (I-DREC) of the Social Sciences and Humanities Division, University of Oxford for the Preventing Abuse of Children in PACCASA study (Ref. No.: SSD/CUREC2/11-40), Young Carers Round 2 study (Ref. No.: SSD/CUREC2/11-02 and SSD/CUREC2/09-52).

(2) Research Office at the University of KwaZulu-Natal: ethical clearance number HSS/0254/09),

(3) Research Ethics Committee at the Health Sciences Faculty, University of Cape Town (Rec Ref 389/2009),

(4) Department of Social Development, Republic of South Africa (date: 15/12/08),

(5) Department of Health, KwaZulu-Natal province (reference HRKM091/09),

(6) Department of Education, KwaZulu-Natal province (Ref. 0048/2009),

(7) Department of Education, Mpumalanga province (date: 13/05/2010),

(8) Department of Health, Mpumalanga province (date: 25/02/2010), and

(9) Department of Education, Western Cape province (Ref. 20100225-0034).

These allow for unassisted consent for adolescents in the following circumstances: i) that the research contains no more than minimal risk to the adolescent, ii) that the nature of the research is acceptable to the research ethics committee and to the community at large, iii) that the inclusion of adolescents in the study is justified, and iv) that the unassisted consent is justified. This has been used previously for studies where parents or caregivers would be unlikely to consent to adolescent participation, or where children do not want their caregiver to know they are participating, such as studies examining contraception use amongst sexually active adolescents. However, we do not propose unassisted consent in this study.

A growing South African literature (Strode *et al*. 2005, Singh *et al*. 2006, Mason-Jones 2010; Zuch *et al*. 2012) argues that Section 71 of South Africa's National Health Act, which requires active written consent from a legal guardian where research subjects are under 18, while well-intentioned, runs the risk of compromising adolescents' constitutional right to privacy, confidentiality and dignity. This is particularly the case with regards to research on stigmatised topics such as HIV, treatment and sexual and reproductive health (Zuch *et al*. 2012). It also produces a recruitment bias in favour of respondents who communicate about sexual health with their guardians. Disclosing an HIV-positive status to family members can amount to discrimination, violence and social ostracism (Norman *et al*. 2005). Hence additional parental or guardian consent can in several cases cases be a) logistically impossible, b) necessitate breaching of confidentiality, c) and place the participant at risk of harm (Zuch *et al*. 2012).

We thus propose to follow ethics guidance for conducting research among adolescents as laid out in the Child Care Act (2005) and DOH Ethics in Health Research (2004): For adolescent children only (using the WHO definition of adolescence: 10-19 yrs), where the adolescent specifically, and unprompted, states that their caregiver will not consent due to exploitative treatment of the adolescent, or in exceptional cases where the adolescent is unwilling to disclose their HIV-status to their caregiver (and are concerned that the research – whilst not focused on HIV, will reveal this to the caregiver), we will ask the adolescent to identify another trusted adult who would be able to give consent for the adolescent to participate. (We would, of course, subsequently make social services referrals for all children and adolescents in abusive situations – see below). As a research team, it is clear that we would *not* take advantage of this concession in order to sidestep caregiver consent where this is inconvenient – and it would be used only for this specific and small subset of children and adolescents.

Further guidelines consulted on this issue include South Africa's Children's Act 2005, which allows for minors under 18 to participate in research if there is a therapeutic effect for them (DOH, 2004). Given the invaluable biological, sociological, behavioural, and clinical data that the inclusion of adolescents will generate in HIV/AIDS research, the enrolment of this cohort is crucial for future prevention and treatment interventions in this group. It is also widely recognised (WHO 2011, Wrang 2012) that sharing the experience of living with HIV and taking treatment has therapeutic effects.

Any adolescent who declines to participate before or after the interviewer has explained the project will not be interviewed, even if the caregiver or nominated adult agrees to or encourages participation.

3) Informed consent for adult caregivers (qualitative study only)

Where adolescent participants allow it, their caregivers will also serve as interview respondents. This study will obtain informed consent for each adult caregiver. All adults will fill in 'opt-in' consent forms if they agree to participate. All information sheets, consent forms, and interview materials will be translated into participants' first language.

4) Informed consent for professional and community health workers

Healthcare workers will provide crucial information that will allow the research team to triangulate findings on factors affecting access to treatment (Punch, 2002) during the qualitative part of research. This study will obtain informed consent for each healthcare worker included. They will be given information sheets, consent forms, and interview materials in the participants' first language. Professional and lay health workers will be reminded not to mention their adolescent patients by name or to give any details that might make patients identifiable either to the researchers or to other members of the focus group. Focus group respondents will sign a confidentiality agreement. No real names (either of health workers or the patients they may accidentally mention) will be recorded in interview transcripts.

Copies of all information sheets, consent forms and interview materials are attached.

(d) What are the *defining criteria for participation in the study?

A screening process will identify participants between 10 and 19 years old who have accessed social or health services over the last 6-month period. Social services accessed will include welfare grants, support from community-based organisations like food gardens, food parcels, etc. Access to health services will include taking long-term medication for asthma, diabetes, TB, HIV, blood pressure or any other long-term illness experienced by the participating adolescents.

On the basis of these responses, fieldworkers will interview a range of adolescents, with oversampling of those receiving long-term medication, but not restricting the sample to HIV+ adolescents in order to avoid stigmatization.

10. Recruitment of participants

(a) Describe how, where, and by whom participants will be identified, approached, and recruited.

Adolescent participants for the qualitative study will be purposively sampled from health facilities and support groups for HIV-positive youth. During quantitative research, similar to previous studies, participants will be identified through door-to-door canvassing of households in communities (Boyes et al. 2012a, 2012b; Cluver et al. 2008a, 2008b, 2009, 2011). After the study has been introduced through a summary information sheet, a screening sheet will be used to identify eligible participants for the quantitative study. Upon identification of eligible adolescents, information on the study will be reviewed once more

prior to the consent form being signed.

(b) If your research involves any use of *personal data obtained from a *third party, describe the steps you have taken to ensure that the *third party has arrangements in place to permit disclosure.

Clinic-based sampling will involve disclosure of names of adolescents to research staff. This will only take place after following Department of Health procedures to obtain approval for this at provincial, district and clinic level.

(c) Will any *unequal relationships exist between anyone involved in the recruitment and the potential participants?

☒ Yes

If yes:

(i) Describe the nature of the unequal relationship.

We will be interviewing adolescents as young as 10 years old, and as the interviewers are adults there exists an unequal age relationship. In addition, a substantial proportion of the adolescent in this study will be HIV-positive.

It is crucial that while recognising these inequalities, we make all attempts to reduce their impacts on adolescent and adult participants. However, it is also important to recognise that in a positive and youth-centred research environment, adolescent and adults can benefit from the opportunity to interact with adult facilitators.

In light of the history of South Africa (and many other places across the world), the race, language and class of researchers will carry assumed and entrenched inequalities that will need to be honestly addressed and considered. Building trust and rapport with participants will be essential during the qualitative study in addition to explicit self-reflexivity during data collection, data analysis and reporting of the study. All interview questions will be properly translated into a language that the respondent is most comfortable with.

(ii) Explain how ethical problems arising from the unequal relationship will be resolved.

All attempts will be made to ensure that the research is a positive and participatory experience for all participants, and that all consent is both voluntary and informed. All interviewers will have experience in working with vulnerable children affected or infected by HIV/AIDS. If the participants have sensory difficulties, the research team will ensure they can access the questions, for example, a signer will sign the questions to deaf adolescents. Reading the questions out loud will ensure that blind adolescents can participate.

To ensure that children and adolescents do not feel obliged to participate in the research, emphasis will be placed on their ability to refuse to participate, or to cease participation at any point during the research (*See attached Draft Consent and Information Sheets*).

Following British Psychological Society Guidelines (2006), any avoidance by adolescents of the interview situation will be taken as evidence of failure to consent. Adolescents who refuse to participate, or who stop the interview, will still receive snacks and certificates.

All research materials will be provided in English and all widely-spoken local languages in that province (such as Xhosa and Zulu). Interviewers will explain all aspects of the project to adolescents and answer any questions they may have in adolescent's preferred language.

It is important to recognise that the inequalities between researcher and participant can also function as a positive attribute, giving adolescents a trusted adult to confide in and an

opportunity to access information in a confidential setting.

(d) Describe any *financial or other rewards which will be offered to participants.

All adolescents will be given small snacks such as fruit to eat while being interviewed. Following participation all participants will receive a Certificate of Participation (attached) regardless of completion.

As in previous research that we have conducted, we will not use financial rewards as they have a tendency to lead to problems involving jealousy within the community or household. Carrying around money also places interviewers and participants at risk in high-crime areas of South Africa.

We have consistently found an overwhelming level of agreement to participate in these studies, based on an understanding of the policy-focused nature of the project, and its close collaboration with government and NGOs.

11. *Participant information

It is essential that written information is easily understandable by participants. Failure to provide this information in appropriate lay language is the most frequent reason for delays in ethical approval.

(a) Will participants receive **written** information about the project before giving their consent?

☒ Yes - please attach.

Qualitative study:

Adolescent information sheet and consent form (Attachments 1)

Guardian information sheet and consent form for adolescent participation (Attachment 2)

Information sheet and consent form for caregiver participation (Attachment 3)

Information sheet and consent form for health worker participation (Attachment 4)

Quantitative study:

Adolescent questionnaire (with information and consent form on first pages) (Attachments 5 & 6)

Guardian consent form for adolescent participation in quantitative research (Attachment 7)

(b) Who will give the participants the information and how?

All information sheets and consent forms will be given to adolescents and their caregivers or nominated adult by the interviewer. All information sheets and consent forms will be read to participants in their preferred language to prevent illiteracy from hindering a participant's understanding about the methods and purpose of the study. All participants will be told they have the right to decline to participate, drop out at any time, and that all the results will remain confidential.

Once consent has been obtained from both the adolescent and caregiver or nominated adult, the questionnaire booklet will be read to the adolescent, and positioned so that both interviewer and participant can see the pack. Interview materials have been designed in conjunction with a Teen Advisory Group specifically to cater to our target group's tastes.

(c) Does the research involve deliberate *deception of participants?

☒ No

(d) Please describe the basis on which you have decided how long participants will have to think about the information provided before giving consent.

Participants may consent to participate only after having the information sheet been read to them and the there has been an opportunity for questions. This way they are fully informed about the study and have had the chance to ask any questions that might have arisen.

Participants will have the opportunity to consider consent for up to a week, before interviewers return. However, when we have previously offered participants periods of 24 hours to 1 week to consider consent, the vast majority have requested to participate immediately. In light of this, we propose that participants are offered the choice of whether to consent or refuse immediately, or to have 1-7 days to consider whether they choose to consent.

12. *Informed consent

(a) Will you obtain written consent?

☒ Yes - please attach *consent form.

After giving detailed information on the study, participants (adolescents, healthcare workers and caregivers) will be asked for written consent (see attached).

(b) If participants are unable to give valid consent, how and from whom will you obtain consent? [Please see the Glossary on the CUREC website for information on how the meaning of *capacity to consent has been altered by the Mental Capacity Act 2005]

All participants should be capable of giving their own consent, and we will not interview any adolescent or adults deemed incompetent. Special care will be taken to ensure that all participants are fully aware of and understand the research, and in these particular cases, all consent procedures will be supervised by a social worker or facilitator experienced in working with vulnerable children.

It is important to be aware that perinatal HIV-infection can bring with it cognitive delays for children. These can be reflected in a wide range of difficulties – for example including a lowered reading age or a lowered cognitive age – however the effects and impacts of this for adolescents is still under-researched (WHO 2011, Fair *et al.* 2012, Ferguson & Jelsma 2009). Therefore, there is no clear guidance available to determine how this should be considered when determining capacity to consent amongst perinatally-infected children. It is also important to be aware that many perinatally-infected children look much younger than their real age and have developmental delays (Lowick *et al.* 2012, Ferguson & Jelsma 2009), may have educational delay, but feel and understand themselves to be teenagers, so there is an ethical imperative in the other direction not to exclude adolescents based on an inappropriate understanding of their delay. This study hopes to address this area by very careful training of research assistants to assess cases where adolescents do not seem to understand the process or meaning of participation in research, and in these cases will refer to project managers for consultation. We understand that this is a complex issue, and would welcome the advice of ethics committees in addressing this.

(c) List those researchers who will, with the authorisation of the principal researcher (or supervisor in the case of student researchers), secure the consent of participants.

Beth Vale, Elona Toska – two student researchers will act as fieldwork supervisors and researchers. All the research assistants will be experienced and trained in working with

adolescents experiencing long-term illness, including HIV/AIDS. Training will stress confidentiality and a roadmap for addressing ethical concerns will be developed (see draft). Fieldwork safety will be a core component of training for research assistants and fieldwork supervisors.

13. Consequences of participation

(a) What are the potential risks or actual ill effects of participation (if any) e.g. invasive procedures, distress, deception etc, and what will be done to minimise these risks

(i) to the participants?

This study aims to investigate risk and protective factors for antiretroviral adherence among adolescents in South Africa. We do not anticipate that the interviews will cause any additional distress either to adolescent participants or their caregivers. However, in order to reduce any risk of respondents becoming distressed:

1) Quantitative interview materials are designed to look like teen magazine quizzes, so that participants have more fun while completing them.

2) The majority of adolescents in this study will be HIV-positive and will have disclosed their HIV-status to the researcher in confidence. This study recognises the duty of researchers to uphold participants' constitutional right to privacy and dignity, particularly in a context where HIV remains highly stigmatised. Therefore, in line with the National Health Act (2003) and legal guidelines released by the Open Society Foundation (2009) as well as the former AIDS Law Project (2003), researchers will not disclose the status of adolescent participants without their explicit consent. In cases where HIV-positive participants report having unprotected sex with their partners, resulting in a tension between the participant's right to confidentiality and the public health goal of protecting at-risk partners, researchers will adopt the following procedure as per recent guidelines: 1) advise the adolescent about the risks of unprotected sex for both their own health and the health of their partner, 2) encourage voluntary disclosure and safer sex and provide support to the participant, 3) suggest a joint session with a trained HIV/AIDS counsellor who can assist the adolescent in disclosing or negotiating safer sex, 4) if all the above recourses fail, the researcher should inform the participant that they will be passing the information on to their doctor or healthcare worker, explaining the ethical obligation to do so. This is in line with section 14(2) of the National Health Act, which makes provisions for disclosure if non-disclosure amounts to a serious threat to public health. At the point of getting informed consent, participants should be made aware that their confidentiality will only be breached to prevent grave harm and never before consulting or, in the worst-case scenario informing, the participant. Disclosure of a participant's HIV-status without their consent will be avoided at all costs and the ethical and other implications of disclosing for the public good will be deeply considered. If researchers have to resort to informing a healthcare worker of a participant's unsafe sex practices and non-disclosure, it will be recommended that the relevant health worker follow established best practice for HIV disclosure outlined in published legal guidelines (Open Society Foundation, 2009; AIDS Law Project, 2003).

3) Given the complex nature of adhering to long-term medication, this study will identify a number of adolescents who are not taking life-saving medication, including ARVs or TB medication. In cases when participants report non-adherence, the researchers will highlight the importance of adherence and encourage the participant to consult their healthcare workers and adherence buddies. Specific information obtained on the dosage, adherence patterns and other influencing factors for each individual will not be shared with their healthcare worker in order to

respect participant confidentiality.

4) In order to protect confidentiality of the participants from the stigma associated with HIV/AIDS, each interview will be conducted with as much privacy as possible.

5) As in all research with children and adolescents, there is a possibility that participants will take the opportunity to disclose difficult living circumstances or abuse. This study recognises that researchers have a responsibility towards children who may disclose information showing them to be at risk of severe harm. Recent research in South Africa has carefully considered these issues. Guidelines are set out by the ongoing HSRC/UNICEF study on children's psychological adjustment in South Africa (Dawes *et al*., 2007) and in the South African Children's Institute/ACESS Child Participatory Poverty Research (ACESS, 2002). These promise confidentiality except when a child is shown through the research to be at risk, in which case (with the child's consent) they will be referred to organisations that can provide assistance (ACESS study), or caregivers will be told (UNICEF study). It is to be noted that the majority of research with vulnerable children in South Africa considers it an ethical principle to provide help for children whom the research identifies as in need. For example, research undertaken by the Medical Research Council Unit for Anxiety and Stress Disorders routinely refers children to child psychiatric services or to the University of the Western Cape Child Psychology clinic where there is need for these services (Seedat et al., 2004; Seedat *et al*., 2000). A University of Cape Town study on child mental health referred children in need to social services, as does ongoing research in the Africa Centre on HIV+ caregivers and infants (Stein, *et al*., 2005). Following these, and protocols devised from research studies with similarly vulnerable groups (Bostock, 2002) the following protocol is proposed. This protocol has been used in our previous three studies with AIDS-affected children in South Africa, and has been approved by Oxford, University of Witwatersrand, and University of Cape Town Research Ethics Committees.

    1) Informing all participants at the consent stage that everything said will be confidential unless it becomes clear that they are at risk of significant harm.

    2) If information is disclosed that suggests that the participant, their sexual partner, or a member of the household is at risk of significant harm, the researcher will discuss concerns with the child at the end of the interview before any further action is taken. If the participant or a member of their close network is at risk of severe harm, the researcher will discuss the possibilities for referral with the child participant. If the child does not consent to sharing of information, and the harm is not considered to be significant, the child will be given information about self-referral agencies such as ChildLine SA. However, if the harm is considered to be significant the researcher will consult with social services or other organisations. If the decision is made to take action, the participant(s) will be informed (*Please see attached draft referral form in Attachment 8*). If referral requires disclosing the child's HIV-status, then the procedure described in 2) above should be followed.

(ii) to the researchers?

No risks to the research staff as a result of this project are foreseen. There are the general risks of working in urban and rural poor areas, and we ensure that all RAs and fieldwork staff are trained in awareness and safety measures. We provide all staff with panic alarms. Staff do not undertake interviews in any situation in which they feel uncomfortable or unsafe, and are encouraged to travel in pairs in areas which are less safe. Consulting community organisations about the methods and purpose of the research in each area will also ensure that researchers do not face suspicion and mistrust from non-participants in the

community and are thus safer. University counselling services will be made available to researchers should they need psychological support.

All staff cars are equipped with tools, spare tyres, water and oil, and all staff who are driving staff cars are trained in basic car maintenance.

Our research projects have a 'staff safety protocol,' which we are happy to send if helpful.

(iii) to others (e.g. the university, family)?

No risks anticipated.

(b) Is there a need for support or counselling?

☒ Yes - describe the form of support or counselling and how, when, and by whom it will be conducted.

This study has an obligation to plan for the possibility of participants, child or adult caregiver, becoming distressed. All interviews will be trained and experienced in working with affected children and families. The research team will include a qualified social worker who will be available to supervise researchers and help them to discuss issues with the families and children following the interviews. As discussed above, if there is a need for a participant to access more extensive support (such as seeing a counsellor or attending a clinic) referrals will be made (*Please see attached draft referral form*).

(c) Is there a need for debriefing or follow-up discussion?

☒ Yes - describe the form of debriefing or follow-up discussion and how, when, and by whom it will be conducted.

We are obligated to any participant who may feel distressed following the study or reports behaviours that require follow-up counselling. All interviewers are trained and experienced in working with affected children and their families. If a participant is to become distressed, interviewers will be available to discuss any issues he or she may have, and make referrals if required. Interviewers also contact the project manager by cellphone when they have a particular concern, or when a participant requires information or discussion. Furthermore, in cases laid out in question 13.a (i), additional sessions might be needed to ensure that risks identified are addressed by participants.

(d) Are there any potential benefits to the participants?

☒ Yes - describe them below.

Previous participatory studies with children in South Africa have been reported by child participants to be beneficial and stimulating (ACESS, 2002; Clacherty & Budlender, 2003). Participants in this study will have the opportunity to share their experiences with warm and attentive researchers. Aspects of the qualitative study, including body mapping workshops and focus group discussions, will allow adolescents living with HIV to meet and share their experiences. It is now widely recognised (WHO 2011, Wrang 2012) that sharing the experience of living with HIV and taking treatment has therapeutic effects. Additional benefits include the research goals of informing government policy for their benefit, programming, and legislation for adolescents in South Africa.

14. *Adverse events

How will adverse events be monitored and reported?

Please see above for protocols connected to any disclosure by children during research

process. Interviewers will address any minor accidents or injuries that may happen as the research is taking place (with due concern for HIV-infection prevention if there is any risk). Any adverse events will result in immediate contact with supervisors and in depth conversations to discuss appropriate actions. All research assistants will be first aid trained and a protocol for dealing with adverse events will be in place.

15. Monitoring

Explain how and by whom (e.g. supervisor in the case of student research projects) the ethical aspects of the project will be monitored to ensure that they conform to the procedures set out in this application.

The student researchers will have weekly teleconference meetings with the supervisor, and several in person meetings while the supervisor is in the field.

All student researchers and RAs will be trained in responding to child disclosure and in communicating with children, first aid, and on fieldwork project management.

The PI (Dr Lucie Cluver) is a qualified social worker, and will monitor ethical processes on regular field visits.

SECTION 4: RESEARCH INVOLVING COLLECTION, USE, OR *DISCLOSURE OF *PERSONAL DATA

Your project must meet the standards laid down in the Data Protection Act (1998) with respect to the collection, use, and storage of *personal data about *human participants.

Please delete questions or parts of questions that you are not required to answer to save paper*.*

16. Need I complete this section?

Does the project involve the collection, use or disclosure of personal information including sensitive and/or genetic information?

☒ Yes – you must answer questions in this section. **Go to Question 17.**

17. Type of activity proposed

Does the research involve:

(a) disclosure of personal information?

☒ Yes

(b) collection of personal information?

☒ Yes – **go to Question 18.**

18. Collection of information directly from individuals

(a) Does the project involve collection of information directly from individuals about themselves?

☒ Yes – answer the following questions:

(b) Do the *participant information and the *consent form include the following:

the name of the study?	☒ Yes ☐ No

the name and status (e.g. doctoral student) of the researcher collecting the information and how to contact him/her?	☒ Yes ☐ No
the purpose of the study?	☒ Yes ☐ No
declarations that the participant has read the participant information sheet?	☒ Yes ☐ No
has had the opportunity to ask questions about the study and has received satisfactory answers to questions, and any additional details requested?	☒ Yes ☐ No
understands that s/he may withdraw from the study without penalty at any time by advising the researchers of this decision?	☒ Yes ☐ No
understands that this project has been reviewed by, and received ethics clearance through, the University of Oxford Central University Research Ethics Committee?	☒ Yes ☐ No
understands who will have access to personal data provided, how the data will be stored; and what will happen to the data at the end of the project?	☒ Yes ☐ No
agrees to participate in this study?	☒ Yes ☐ No
understands how to raise a concern and make a complaint?	☒ Yes ☐ No

(c) Are the consent form and participant information on headed letter paper which bears the name of the University and the name and address of the department to which the principal researcher is attached?

☒ Yes

(d) Are the participant and the researcher who secures the consent required to sign, print and date their names?

☒ Yes

19. Collection of information from a third party

(a) Does the project involve collection of information about an individual from a source other than the individual?

☒ No – **Go to Question 20.**

20. Form in which data are to be stored

Are the data to be kept

(a) with an open identifier, i.e. in non-anonymised form ☐ Yes ☒ No

(b) as anonymised but potentially identifiable data ☒ Yes ☐ No

(c) as anonymised, non identifiable data ☐ Yes ☒ No

21. Use or disclosure of information about individuals

(a) Does the project involve the use or disclosure of information potentially or actually ascribed to an individual?

☒ No – **go to Question 22.**

22. Data collection, storage, and disposal

(a) How many records will be collected, used or disclosed? Specify the information that will be collected, used, or disclosed e.g. date of birth, medical history, number of convictions.

Number of records: quantitative research with 1000-1200 adolescents, qualitative research with 20-40 adolescents, 30 caregivers, 30 healthcare workers

Type of information: Self-report questionnaire documenting information about sociodemographics, health service access and potential risk and resilience-promoting factors. *Individual and mental health factors* include depression, neurocognitive impairment (Antinori *et al*., 2007), myths and fears surrounding medication (Steinberg, 2009). *Family factors* include family relationships (Hammami *et al*., 2004), changes of primary caregiver due to death and illness (Cluver *et al*., 2009), domestic conflict and violence (Jewkes *et al*., 2010), and abuse (Cluver *et al*., 2011), disclosure of parental and adolescent HIV-status (Vreeman *et al*., 2010, Murphy, 2008). *Social protection and economic factors* include food security (Weiser *et al*., 2012), distance and transport to clinics, and provision of services such as social welfare grants and social work services. *School, peer and community factors* include stigma inside and outside school (Fox *et al*., 2010), drug and alcohol use, crime and incarceration (Swart and Seedat, 2010), and school attendance and support. *Gender and cultural factors* include use of traditional health services (Muhamadi *et al*., 2011) and teen parenthood, as well as sexual health and relationships. *Antiretroviral and Health service factors* include complexity of regimens, side-effects and palatability of medication, attitudes of healthcare staff (Richter and Mfolo, 2006) and availability of support groups or adherence services.

Qualitative information will include interview transcriptions, body-maps, participant diaries and researcher field notes documenting the lived experience of HIV-positive adolescents, including their perceptions of HIV, their bodies and their sexuality; their relationships with peers and family members, their experiences and perceptions of health services and their ARV treatment practices.

Additionally to in-depth research among adolescents living with HIV, qualitative research will include interviews with caregivers of young people on ARVs and other long-term medication, as well as health care workers. These interviews will not include data unique to specific adolescents, but overall perspectives and views on factors affecting adherence. Before interviewing community or professional health care workers in regards to specific adolescent participants, written consent will be sought from the relevant adolescent participant and their guardian.

(b) How, where, and under what security arrangements will electronic and paper data be stored? Who will have and control access to the information?

Electronic data will be stored on a password-protected computer, and paper data will be stored in locked cabinets. Availability of this data will be limited to lead researchers on this team.

(c) When, how and by whom will the information be disposed of?

Information will be stored for five years and then disposed of by lead researchers following completion of this study.

(d) How will the privacy of individuals be respected in any publication arising from this

project?

In reporting the findings of this study, we will omit names and only report provincial locations in which the study took place. Data will be kept for a period of up to five years after collection in an anonymised version.

(e) Have you explained in the *participant information and *consent form that maintenance of confidentiality of information is subject to normal legal requirements?

☒ Yes

23. Adverse and unforeseen events

How will adverse and unforeseen events relating to the collection, use, or disclosure of information be managed, monitored and reported?

Any adverse events will be reported to the principal investigator. All precautions will be taken to ensure confidentiality for all participants. We do not anticipate adverse events of this kind due to the confidentiality of the participants' information.

SECTION 5: MISCELLANEOUS ISSUES

24. *Conflict of interest

(a) Do researchers on this project have a financial or other interest in its conduct or outcomes?

☒ No

(c) Are there any other potential conflicts of interest e.g. research findings that could compromise the researcher's relationship with the university?

None

25. *Peer review

Has this project been peer reviewed?

☒ Yes – explain by whom (e.g. by a, tutor, supervisor, funding body etc) and with what outcome.

☐ No – explain why not.

This project has been developed in collaboration with UNICEF and UNAIDS.

26. Funding

List all bodies and individuals from whom funding has been or will be sought.

Source	**Amount in £**	**Status of Funds** Available	Applied for
John Fell Fund	£30,000	Yes ☒ No ☐	Yes ☐ No ☐
ESRC	£TBD	Yes ☐ No ☒	Yes ☒ No ☐
Nuffield Foundation	£TBD	Yes ☐ No ☒	Yes ☒ No ☐
International AIDS Alliance - CIPHER.	£150,000	Yes ☐ No ☒	Yes ☒ No ☐

27. Reporting of results

(a) Will the project outcomes be made public at the end of the project?

☒ Yes – describe the intended report and how and to whom it will be made available.

Dissemination and outputs will take place throughout the study and will include both peer-reviewed publications and dissemination strategies specifically targeted towards policy-makers and programmers. With the research partners UNICEF, UNAIDS and the South African government, dissemination will include one-page policy briefs (www.youngcarers.org.za/publications), presentations at key policy meetings such as the International AIDS Conference, the International Conference for AIDS and STI's in Africa, as well as smaller, high-level policy forms with government ministers in the Southern African region, major funders such as UNAIDS/PEPFAR and the Global Fund. Dissemination will also take place on a local level, with health services and community meetings, and with local leaders such as chieftains and ward counsellors.

We will make all efforts to provide participant children and adults with 'brief reports,' regarding the progress of the research in a non-stigmatising way.

(b) Will a report(s) of the project outcomes (for example, individual or group data) be made available to participants at the end of the project?

☒ Yes – describe report and how it will be made available.

Feedback to participants is a key part of a child-focus research design (Herth, 1998). At each stage of review and data collection, the study will create 'brief reports': easily understandable summaries of study findings in lay language. These will focus on findings relevant to NGOs, clinics and government in their work with children. The second stage of the qualitative research will ask participants to respond to some of the quantitative findings, which will also serve as a form of feedback. No identifiable details will be given in any dissemination or feedback.

28. Declaration by researchers

Full project title: **Youth Pulse: Identifying risk and protective factors for adherence to long-term medication amongst adolescents in South Africa**

I/We, the researcher(s) agree:

- To start this research project only after obtaining approval from IDREC/CUREC;
- To carry out this research project only if funding is adequate to enable it to be carried out according to good research practice and in an ethical manner;
- To provide additional information as requested by IDREC/CUREC before approval is secured and as research progresses;
- To maintain the confidentiality of all data collected from or about project participants;
- To notify IDREC in writing immediately of any proposed change which would increase the risks that any participant is exposed to and await approval before proceeding with the proposed change;
- To notify IDREC if the principal researcher on the project changes and supply the name of the successor;
- To notify IDREC in writing within seven days if any serious *adverse event occurs in the course of research;
- To use data collected only for the study for which approval has been given;
- To grant access to data only to authorised persons; and

- To maintain security procedures for the protection of personal data, including (but not restricted to): removal of identifying information from data collection forms and computer files, storage of linkage codes in a locked cabinet and password control for access to identified data on computer files.

Signed by principal researcher/supervisor/student researcher:……Lucie Cluver…

Date:…7th October 2012……

Print name (block capitals)……Dr Lucie Cluver ……

29. Certification by *principal researcher/supervisor/student researcher and head of department

Full project title: **Youth Pulse: Identifying risk and protective factors for adherence to long-term medication amongst adolescents in South Africa**

Certification by *principal researcher/supervisor/student researcher

I accept responsibility for the conduct of this research project.

I certify that all researchers and other personnel involved in this project are appropriately qualified and experienced or will undergo appropriate training to fulfil their role in this project.

Signed by principal researcher/supervisor/student researcher: Lucie Cluver……

Date 7th October 2012…… Print name (block capitals)…DR LUCIE CLUVER ……

Acceptance by head of department/other senior member of the department if the principal researcher is the head of department

I have read the research project application named above.

On the basis of the information available to me, I judge the principal researcher/supervisor/student researcher to be award of her/his ethical responsibilities in regard to this research. I am satisfied that the proposed project has been/will be subject to appropriate peer review and is likely to contribute to existing knowledge and/or to the education and training of the researcher(s) and that it is in the public interest.

Name of head of department/other senior member of the department (e.g Chair of DREC, Director of Graduate Studies for student projects):

……

Signature …… Date……..…

FINAL CHECK

To prevent delay please check each of the following before submitting the application.

Have you answered all relevant questions in Sections 1-5? ☒
Have you defined all technical terms and abbreviations used? ☒
Have you included all questionnaires and participant information, consent forms, advertisements, and surveys to be used? ☒
Have you included all relevant approvals and supporting letters? ☒
Have you declared all potential conflicts of interest? ☒
Are all pages (including appendices and attachments) numbered? ☐
Have you completed the declaration by researcher(s)? ☒
Have you completed the certification by principal researcher and head of department? ☐
Revised March 2012

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1.2 MZANTSI WAKHO RESEARCH PROTOCOL

1.2.1 Purpose of the Study

Southern Africa is home to 1.2 million HIV-infected adolescents (1) , whose long-term health outcomes depend on strict adherence to antiretroviral therapy (ART). The limited research conducted with adolescent ART-users in Africa reflects low adherence rates (2) and poor access to sexual and reproductive health (SRH) services (3). As adolescence is a time of increased risk-taking and experimentation, HIV-positive teenagers represent an especially vulnerable and challenging group for HIV service providers. However, their retention in ART programmes and use of SRH services remain under-investigated, and HIV-positive adolescents have rarely been included as partners in the design and operationalization of their own HIV and SRH services.

This research applies innovative investigative strategies to study the health needs of HIV-positive young people growing up in contexts of extreme risk, investigating their potential for resilience, and exploring how to support their adherence to ART and uptake of SRH services. It fills a pressing research gap by investigating areas of intersection between adolescent ART adherence and SRH, while also offering methodological and programmatic innovation through the development of youth-driven tools to support ART adherence and SRH service uptake.

This study uses both qualitative and quantitative methods to achieve two aims:

(1) To identify and investigate risk and resilience-promoting factors for ART adherence and access to SRH services amongst HIV-positive teenagers, through linked qualitative and quantitative studies.

(2) To collaborate with HIV-positive adolescents, healthcare and social service providers to design support tools to improve adolescent ART adherence and SRH service uptake.

In line with these aims, this mixed-methods research project will have four components:

1. In-depth **qualitative** research with 50 adolescents and 70 key informants (caregivers, health and social workers) to explore: 1) how HIV-positive adolescents use, adopt and resist HIV care and treatment, and SRH services, and 2) how those caring for HIV-positive adolescents experience and perceive challenges and facilitators of ART adherence and SRH uptake.

2. Participatory **qualitative** workshops to involve adolescents as key stakeholders in the collaborative design of youth-driven support tools to:

a) Support ART adherence and SRH service uptake,

b) Assist youth in negotiating the barriers and challenges that impede their desired retention in care, and

c) Customize ART and SRH interventions for optimized adolescent outcomes.

3. A linked **3-year longitudinal quantitative** study of 600 HIV-positive adolescents will assess risk and resilience-promoting factors for ART adherence and SRH utilization. This quantitative study will be directly informed by the ongoing qualitative research, and will be conducted in collaboration with a clinical research team coordinated by Dr. Craig Carty.

4. Finally, the linked **quantitative** study will test the acceptability of the support tools developed in participatory workshops with a in the larger-scale quantitative sample.

The aims and methods for this study were developed through collaborative planning between HIV-positive adolescents, researchers from health and social sciences, UNICEF and South African National Departments of Health, Social Development, Basic Education and Women, Children and Disabilities, alongside clinical researchers at the Eastern Cape Department of Health, Frere and Cecilia Makiwane hospitals, NGO Pediatric AIDS Treatment for Africa (PATA), and CBOs (Raphael Centre, Small Projects Foundation and Keiskamma Trust). Ongoing consultations with these and other partners, including the Treatment Action Campaign and Kidzpositive, have underlined the importance of combining three information sources: in-depth qualitative research on the experiences of HIV-positive adolescents, particularly as these relate to ART and SRH; active collaboration with teens to develop relevant support tools; and quantitative survey methods to identify causal mechanisms and test acceptability of tools on a wider scale.

The interdisciplinary and collaborative nature of this study, and its inclusion of a range of partners, aims to inform a broad-based, inclusive approach to HIV policy and programming. Since the study is planned in collaboration with HIV-positive adolescents, as well as state and non-state partners at local, national and global levels, it provides an opportunity to bring the experiences of youth into the policy arena. Policy and programming impact are integral aims of this research, and will be combined with ongoing results dissemination to NGOs, CBOs, government and health sectors, as well as to participating communities.

This study has a direct capacity-building aim, and includes a South African Principal Investigator (RH) who will gain further research skills through mentorship, two South African PhD students and a further two students (one PhD, one Master's) from within the South African government. Additionally, all staff take part in capacity-building programmes within the project (see section 13 for details).

1.2.2 Background

90% of adolescents living with HIV reside in Southern Africa, including those infected perinatally, in childhood, and in youth (4). South Africa has the world's largest population of HIV-positive adolescents: 292,000 in 2011 (1). ART provides an opportunity for long-term survival and wellbeing (5,6), but requires diligent lifetime adherence of 87-95% (7) to attain viral suppression and prevent viral resistance (8,9). Non-adherence is particularly hazardous in most low- and middle-income countries, where there are commonly only two drug regimens available in the public health sector (10). Non-adherence also presents a wider public health threat: transmission of drug-resistant HIV (11).

Adolescence is often a time of initiating sexual relationships, characterized by low levels of communication and openness (12). Many health programs use models of 'therapeutic citizenship' (13,14), proscribing disclosure of sero-status to romantic partners and others, the use of condoms during sex, and adherence to both ART and contraception. However, fear of rejection and internalized stigma result in low rates of disclosure to partners (15). In contrast, research has found low levels of adherence among HIV-positive youth (2), and demonstrated that AIDS-affected youth are more sexually vulnerable than other adolescents, with high levels of unprotected sex (2,3). Adherence and SRH service uptake are closely linked for HIV-positive adolescents,

but their specific needs present challenges to resource-constrained health services (16). In order to develop effective interventions to support HIV-positive adolescents and improve their

health outcomes, this research seeks to understand risk and resilience-promoting factors for adherence and SRH service utilization.

Despite the crucial role played by HIV-positive adolescents in their own retention in care and in preventing HIV transmission, few programming approaches have been led by youth themselves. Advocacy groups of people living with HIV (PLHIV) have repeatedly called for increased community participation in health service delivery and greater involvement of PLHIV in research (17). By leveraging the participation of HIV-positive adolescents in the design of youth-friendly support tools, the study will aim to further programmatic collaboration between service-users and service-providers and to enable adolescent-focused approaches to ART adherence and the uptake of SRH services.

2.1. State of the evidence

Limited research and interventions exist for adolescents living with HIV (ALHIV) outside of the United States (US) (18). The available, largely qualitative, work identifies challenges with romantic relationships, education, gender and family roles (often within homes disrupted by parental death), illness and depression (19,20). Preliminary reviews have identified one published qualitative (21) and two quantitative studies (2,22) on adolescent ART adherence in sub-Saharan Africa. Nachega et al. reported adherence rates, but not risk or protective factors, in 154 adolescents in a private sector clinic programme in nine countries. Adolescent adherence was 21% at 6 months and 7% at two years, lower than that of adults. Evans et al. used clinic records in 7 NGO-supported clinics in Mpumalanga and Gauteng provinces. Older adolescents (15-19 years old) showed greater levels of unsuppressed viral load, virological failure and loss to follow-up. Two further adolescent studies in the region investigate linked outcomes: in a US-run specialist clinic in Botswana, psychological distress was associated with virologic failure amongst 692 adolescents (23); and in Uganda, 575 adolescents on publicly-funded treatment showed 2-year mortality of 8.5% (24).

The limited research on HIV-positive adolescents in sub-Saharan Africa reveals the complex challenges that arise from disclosure of HIV status, ART adherence and the uptake of SRH services. These challenges include individual-level ones (mental health, self-perception), family-level (parental death, parenting), community-level (norms about sexual activity, stigma), and structural ones (transition to care, poverty). ALHIV are confronted by difficulties associated with transition from paediatric to adult HIV care (25), HIV status disclosure to peers (26), the taboos associated with young people's sexuality (27), parental AIDS illness and death (28,29), and the resultant poverty, stigma and bullying victimization (30). Longitudinal evidence also suggests that adolescents who have lost a parent due to AIDS are at heightened risk of psychological distress due to stigma-by-association (31). Teenagers must grapple with these challenges within caregiving arrangements that may include parental death and sickness (19,21). Beliefs regarding pollution and uncleanliness – related to HIV and to medication side-effects – may create ambiguity in adolescents' understandings of their own bodies and medical rituals, and this is complicated further by the experiential overlays of peer interactions, romantic relationships, the negotiation of gender and family roles, and the transition into and out of school.

Although research has been conducted on reproductive intentions and services for HIV-positive adult women in South Africa (32,33) there are significant evidence gaps on access to SRH and retention in HIV care for HIV-positive adolescents, both in relation to ART and SRH programmes. The available studies have found that access to ART has accelerated pubertal and sexual maturation (34), with 88% of HIV-positive 15-19 year old girls reporting sexual activity in Kenya (3). Research has also demonstrated inconsistent condom use, poor uptake

of SRH services and repeated unintended pregnancies and terminations among HIV-positive adolescents (3). While access to prevention of mother to child transmission (PMTCT) services has reduced rates of vertical transmission in South Africa (35), research on whether female HIV-positive adolescent are accessing these services and outcomes is limited (36).

Gender, age, environment (urban/rural) and route of transmission may all play a role in determining ART adherence and SRH service uptake, but further research is needed. HIV-positive adolescents differ in clinical and social markers, such as disease stage, neurological impact of ART, and disclosure to and by families. For example, perinatally-infected adolescents have more resistant virus mutations, while those infected in adolescence are more likely to have been diagnosed through pregnancy, and almost nothing is known about those infected through South Africa's high rates of childhood sexual abuse[2].

This study of HIV-positive adolescents hypothesizes an interactive model of individual, family, school, structural and service-level factors influencing ART adherence and SRH service uptake, potentially mediated by HIV-disclosure, stigma associated with ART and with adolescent sexual activity, and the potential side-effects of both ART and contraception. This model also presents an opportunity for research to inform policy and practice. Even when some risk factors may be unalterable (such as orphanhood), the identification of *modifiable* risk and resilience factors provides valuable evidence to inform interventions. This study will be the first to investigate risk and protective factors for ART adherence and its connections to SRH service uptake amongst HIV-positive adolescents in South Africa. Using both qualitative and quantitative methodologies, it aims to unpack the complex interplay between these health services and to use participatory and youth-driven methods to develop a tool to promote ART adherence and SRH service uptake.

1.2.3 Methodology

This study combines research and programmatic development, and asks the crucial questions: what are the lived experiences of HIV-positive adolescents in relation to ART and SRH, and what obstructs or promotes their ART adherence and uptake of SRH services? It uses participatory methods to ensure that adolescents are active agents in the conceptualization and design of a tool to facilitate ART adherence and SRH service utilisation.

This study uses mixed qualitative and quantitative methods to achieve two aims:

(1) To identify and investigate risk and resilience-promoting factors for ART adherence and access to SRH services amongst HIV-positive teenagers, through linked qualitative and quantitative studies.

(2) To collaborate with HIV-positive adolescents, healthcare and social service providers to design support tools to improve adolescent ART adherence and SRH service uptake.

This study will use:

i) Systematic reviews of risk and protective factors in ART adherence, SRH service uptake and internalised stigma for HIV-positive adolescents (underway); and

[2] Amongst those perinatally-infected, some have been on treatment from an early age, and new research suggests that around a third are 'slow progressors': surviving without diagnosis or care, but becoming ill around puberty (4).

reviews of best practice in support tools and programmes for HIV-positive adolescents (based on the UNICEF Lessons Learned report on strengthening health services and outcomes for adolescents living with HIV, 2013);

ii) Qualitative and participatory methods with 50 adolescents and 70 key informants (caregivers and service providers), followed by

iii) Participatory workshops with five groups of adolescents. These workshops are conducted in collaboration with the South African National Department of Health and UNICEF, and explore adolescent views of the Draft National Youth Health Policy and the UNICEF lessons learned report. They take an adolescent-led approach to intervention consultation, adaptation and design.

iv) Semi-structured interviews, ethnographic research and clinic observations with social and health service providers working in ART, SRH, PMTCT and Out Patient Department clinics. Methods iii) and iv) will be integrated with:

v) Quantitative longitudinal survey (n=600, 3 years) to test risk and resilience-promoting factors for adherence and SRH service uptake, and to measure acceptability of the support tools developed in the participatory stage. Data collected during this survey will include: biomarkers (i.e. viral load, CD4-cell count), clinic-level data (i.e. resources, such as counseling, staff/ patient ratio in the clinic) and individual-level panel survey data (i.e. potential individual, family, school and community-level factors) through tablet-administered questionnaires. Survey items were informed by extensive literature reviews as well as the qualitative component of Mzantsi Wakho. Where possible, standardized validated measurements were used. Cognitive interview methods ensured cultural relevance and understandability (37) of key measurements that had not been validated among teens in sub-Saharan Africa. Prior to data collection, the survey was translated, back translated and piloted with 17 HIV-positive teens. More than 20 leading academic and research experts on adolescent health research were consulted on approaches to interviewing HIV-positive adolescents, scales used in interviews and overall study design.

The three-year study combines qualitative, participatory and quantitative approaches. In 2013, research preparation comprised systematic literature reviews of risk and resilience-promoting factors for adolescent adherence and SRH use. It also included extensive consultation with government, NGOs, CBOs and our longstanding AIDS-affected Teen Advisory Group.

Year 1. 2014-15 (underway) will combine qualitative and quantitative approaches. Eighteen months of qualitative research will identify adolescents' medication-taking practices and engagement with HIV and SRH services, and apply participatory methods to develop teen-led support tools. This data directly informs the quantitative survey stage which will interview 600 adolescents to examine risk and resilience-promoting factors in a more generalizable sample. In addition, sampling will allow acceptability-testing of the teen-developed support tool.

South Africa has ART coverage of 52% (38), close to sub-Saharan Africa's median of 49% (39). The study will be conducted in the Eastern Cape, South Africa's poorest province, with 30% antenatal HIV-prevalence (40). The study will be conducted predominantly in the Amathole and Cacadu Districts, as well as Buffalo City Sub-District.

3.1. Preliminary consultations

The study design is based on both a literature review and extensive consultation with government and NGOs. Consultations have taken place with: UNICEF, UNAIDS, SA National

Action Committee for Children Infected and Affected by AIDS, National Departments of Health, Social Development and Basic Education, Health Systems Trust, Keiskamma Trust, Kheth'Impilo, Desmond Tutu HIV foundation, Kidzpositive, and the Treatment Action Campaign, as well as clinics and youth groups, and our Teen Advisory Group of AIDS-affected adolescents, who helped to guide previous qualitative and quantitative research on the previous Orphan Resilience study and Young Carers studies (www.youngcarers.org.za). The TAG group was established in 2008 and includes children and adolescents living in AIDS-affected families as well as HIV+ adolescents aged between 12 and 19, with whom we have conducted collaborative research since 2008 (approved by Oxford IDREC in 2008 and 2012 and included in UCT REC applications in 2009).

3.2. Avoiding stigma

A primary concern of this study is to avoid the potential for the research to stigmatise participants or their families. In light of high levels of HIV-related stigma in South Africa, the quantitative study will be presented within communities and organisations as investigating service access for teenagers who have had any extended contact with the health system. This ethically necessary methodological approach provides an opportunity to identify differences in risk and resilience factors between HIV-positive and HIV-negative adolescents, and to explore the need for targeted support. Recruitment processes and documentation will not mention HIV or AIDS, but will mention adolescent health and access to health services in general. This approach was emphasised as essential in community consultations prior to our past two research studies (Young Carers) in order to avoid unintentional disclosure and stigma, and has been approved for both studies by UCT's Health Sciences REC. In each community or location, both adolescents with HIV and those with other chronic illnesses or disabilities (such as asthma or epilepsy) or those accessing other types of health services such as home-based care will be included in the study, with purposive oversampling of HIV-positive adolescents. This will allow a non-stigmatising research process, as well as 'matching' of participants.

For the qualitative study, participants will be sampled through women's health clinics, trauma clinics, ART clinics, ART support groups and programmes for AIDS-affected and HIV-positive youth. While ART clinics and support groups will necessarily target HIV-positive youth, programmes for AIDS-affected teenagers may also include those not living with HIV. In these instances, all youth in the programme will be eligible to participate in the research, but engaging HIV-negative youth will only serve a comparative and ethical function – allowing researchers to observe similar and different experiences between HIV-positive and HIV-negative youth, and preventing participation-associated stigma.

3.3. Community partners: sampling beyond the clinic

All other known studies of HIV-positive adolescents to date have been based on ART clinic samples, which are necessarily biased towards participants more engaged in the HIV health system. If we are to effectively identify barriers to SRH uptake and ART retention, it is essential that sampling includes adolescents who have never accessed SRH or have ceased ART. Clinic-based samples will include a combination of state and NGO-run clinics (both primary health and antenatal facilities), as well as a variety of types of clinics: primary, ANC, OPD and women's health clinics. Key partners in accessing health facilities are facility managers and senior healthcare workers in 31 clinics, Keiskamma Trust (Hamburg), Small Projects Foundation, Paediatric AIDS Treatment for Africa (PATA) and provincial government departments. Sampling will therefore take place in both clinic and community settings. Adolescents who have been lost to follow-up will be identified from clinic-specific defaulter

lists, ensuring that the sample has an “intention to treat” approach to sampling by including all those that have initiated ART and then stopped. Non-clinic settings will include schools, children’s homes, home-based care organisations and community-based sampling through youth programmes in villages or cities. Similar to qualitative research, the researchers will also be engaging (in a non-research capacity) with broader categories of youth in the community through programme facilitation and workshops. This is to ensure that the researcher team does not become associated only with HIV/AIDS, which could amount to participants incurring stigma through their association with the researchers. The CBO and NGO advisors, and healthcare workers (both clinic and community-based) participating in this research collaboration will guide researchers in selecting, approaching and accessing these community forums.

3.4. Qualitative methods

Why qualitative research?

Public health research and practice has cast the challenge of adolescent ART adherence and SRH service use in predominantly clinical terms, informed by a set of assumptions about youth, risk and compliance (5,18) with medical prescription. Yet the meaning and relevance of these constructs for adolescents on ART and using SRH services remains poorly understood and only superficially accounted for in many HIV treatment, care and support programmes. Exploring young people’s practices of ART-adherence and SRH uptake as expressions of agency will deepen understandings of youth risk-behaviour, providing a potential opportunity to design, implement and integrate health programmes that are more responsive and ultimately more effective approaches to adolescent healthcare.

Public health programmes often position HIV-positive youth both as 'vulnerable victims' and 'reckless risk-takers'. While the former suggests helplessness, positioning youth as ill-equipped for self-care and independence (12), the latter invokes a powerful public health threat. Both assumptions necessitate ongoing, but paternalistic, intervention with the aim of encouraging, even policing, youth compliance (14,41). Constructions of youth irresponsibility and recklessness are in stark contrast to ideals of ‘therapeutic citizenship’ (13,14), now prevalent in HIV and SRH programmes. Here, high demands are placed on teenagers to practice 'responsible lifestyles'. This includes strict adherence to complex treatment regimens, disclosing to intimate partners, negotiating safer sex and accessing and adhering to family planning (often shorthand for avoiding parenthood) - all of which are complicated by context. Public health constructions of the behaviours, needs and desires of young people have powerful effects on the design, implementation, and ultimate efficacy of interventions. Despite the crucial role played by HIV-positive adolescents in their own retention in care and in preventing transmission of HIV, very few of the programmatic responses to improve their health-seeking behaviours incorporate adolescent participation in their design.

In the field of HIV programming, a growing body of anthropological and sociological research has demonstrated that individuals and societies may have entirely different perceptions and priorities to those assumed by public health models (42–45). The standard public health framework often positions human beings as isolated decision-makers, unencumbered by social circumstances. Little attention has been given to the social structures, obligations or uncertainties that shape health behaviours in ways that thwart or contradict medical prescription.

For example, it is possible that considerations of enjoyment, peer acceptance and dignity may supersede those of long-term survival for some adolescents. We need to consider that secrecy may be an ‘embodied practice’ (46) for these teens – in other words, tactically withholding

information regarding sexual practices and HIV status may be integral to negotiating the social world, in which norms of culture, gender, authority and sexuality may mitigate against strict compliance with prescribed health-seeking behaviours such as adherence to ART and contraception. The lived realities of these adolescents may be strikingly different from the adult disclosures necessitated by HIV support groups and ART adherence programmes. This study will consider the hierarchies of power within which adolescents live – of culture, generation and the healthcare system. Without in-depth engagement with the deeply held beliefs and understanding of young people regarding the meanings of SRH, chronic illness and bodily integrity, and their relation to different conceptions of an adult future – including fertility desires – we risk developing ineffective or irrelevant interventions based on inaccurate assumptions that do not account for the centrality of agency and locality in health-seeking behaviours, and that thus have little effect on improving adolescents' adherence to ART and SRH services.

While urgent, evidence-based solutions are required to support ART adherence and improve reproductive health outcomes among adolescents, this research also recognizes the experiential and cultural complexities of living as a teenager in South Africa. This research therefore aims to generate high-quality data on adolescent ART adherence and understandings of SRH through beginning the first phase of the study with in-depth, multi-methods qualitative research.

Qualitative Research Methodology

Qualitative research will take place in two stages: Stage I will consist of a year-long multi-methods qualitative study with 50 adolescents and 70 caregivers, healthcare and social care workers, and will explore the web of contextual and interpersonal factors that inform adolescent ART-adherence and utilisation of SRH services. Data collection methods will include in-depth thematic and narrative interviews, clinic observations, and body-mapping workshops linked with other art-based group work.

Second in Stage II, adolescents will design youth-friendly support tools to promote ART adherence and SRH service uptake, and contribute to planning the National Department of Health's Youth Health Policy through review and activities. Researchers will work with HIV-positive adolescents, as well as with NGOs, CBOs and clinics, to develop adolescent-led programming recommendations for supporting ART adherence and promoting SRH service uptake. While it is difficult to anticipate what form these adolescent-led strategies may take, existing tools and best practice approaches outlined in the UNICEF Lessons Learned (2013) report will be explored with teen research participants. This stage will use a set of participatory workshops, and will be guided by adolescents' decisions on whether to include other stakeholders, for example clinic staff or local leaders, in this process.

Programmatic interventions that include adolescent participation in youth-friendly health promotion tools are starting to be explored in Southern Africa with promising results (47–49). This is in line with global policy trends, which advocate for increased community participation in health service delivery, shifting of health promotion tasks to lay workers in order to address human resource shortages (50), and greater involvement of people living with HIV (PLHIV) (17). By leveraging the participation of HIV-positive adolescents in the design of youth-friendly support tools, the study will aim to further programmatic collaboration between service users and service providers towards a more holistic approach to youth health-seeking behavior.

This qualitative research will inform the development and interpretation of the quantitative survey, and the qualitative and quantitative research team members have planned a set of integrated qualitative and quantitative dissemination activities.

3.5. Quantitative methods

The findings of the qualitative research, for instance relating to the nature and significance of socio-cultural barriers that potentially impede ART adherence and SRH service utilisation, have informed the content of the quantitative survey, which is underway in 2014. Data collection includes both participant self-report and assessment of clinic records. The quantitative study will take place in collaboration with a clinical research study led by Dr Craig Carty and Prof. Gerry Boon at Cecilia Makiwane and Frere hospitals

The first stage of the quantitative survey will interview 600 HIV-positive adolescents. The second and third stages of the quantitative survey will include a one-year and two-year follow-up, and a survey with a sub-sample to test the feasibility of the tool developed through the qualitative participatory workshops.

The annual quantitative surveys will include 1) biomarkers of adherence; 2) a self-report questionnaire that is completed in the supportive presence of an interviewer due to potential low levels of literacy. This questionnaire will collect information about socio-demographics, health service access and potential risk and resilience-promoting factors for ART adherence and SRH service uptake. Questionnaires will be administered using audio mobile-assisted self-interviewing, with language and structures suggested by the Teen Advisory Group and adolescents living with HIV. In addition, 3) clinic-level data will be collected from hospitals and clinics.

The quantitative study will focus on identifying risk and resilience-promoting factors for ART adherence (in comparison to other long-term medication) and understandings and uses of SRH services among adolescents in South Africa. It hypothesises an interactive model of multiple interlinking influences on adolescent adherence, with potential risk and protective factors including neurocognitive, health service-related, financial, psychological, familial, cultural, nutritional and peer-related ones, but will also include factors arising from the qualitative stage. By identifying potentially modifiable intervening factors, this study will aim to inform evidence-based interventions to promote ART adherence and SRH service uptake. Please contact the research team for copies of questionnaire items at mzantsiwakho@gmail.com. A follow-up quantitative survey will assess the feasibility of the adolescent-developed support tool in terms of fidelity, adherence, exposure, and participant satisfaction. The methodology for feasibility testing will follow guidelines for pilot feasibility testing of the Complex Interventions Framework by the MRC (51).

3.6. Characteristics of the Study Population

Sampling

The full mixed-methods study will sample 720 participants (650 adolescents and 70 key informants). The proposed qualitative research will include 50 adolescent respondents on ART, and 50 key informants, including caregivers, social workers and healthcare workers. The quantitative research will include 600 adolescents. Sampling for both the qualitative and the quantitative study will use the WHO definition of adolescents: aged 10-19 (1,52).

Qualitative sampling

The qualitative sample will be comprised of adolescents on ART and HIV-positive adolescents who are using SRH services, recruited from sites that provide health and social support

services for teenagers living with HIV. These include women's health clinics, trauma clinics, ART clinics, youth programmes for AIDS-affected and infected teens and ART support groups. These recruitment sites are likely to produce a biased sample given that all adolescents will be currently accessing services. However, engaging participants over a year-long period will allow for the inclusion of adolescents who are both retained and lost in systems of care.

While the study will be presented to youth as being about 'your life and your engagement with health services', recruitment that is based in ART clinics or programmes for HIV-positive youth implies that the researcher is aware of the HIV-status of prospective participants. Presenting the study as being about 'your life and health' will make room for those who are not particularly open about their HIV-status to participate. Whether or not participants choose to openly disclose their HIV status to the researcher will be left up to them. Presenting the study as being broadly about 'health' will also allow a non-stigmatizing way to present the research to youth groups that include both AIDS-affected and infected teens. To ensure that participants feel comfortable and safe at all times, they will choose the time and place for research-related activities and un-structured engagements.

Additional participants in the qualitative study include healthcare workers, social workers, doctors, counsellors, teachers and caregivers. Adult participants linked to adolescent participants (i.e. their caregivers, health workers or social workers) will only be interviewed with permission from the adolescent.

Quantitative sampling

Due to a lack of data on the population of HIV-positive adolescents and low disclosure rates, identifying the composition of a representative sample of HIV-positive teenagers presents numerous methodological challenges. Extensive review and consultations with the Department of Health and UNICEF have identified poor availability of data. National-level data either excludes under-15 year olds (Statistics South Africa, 2011) or groups by 0-14 and 15-49 years (HSRC, 2009), thus precluding identification of adolescents. The 2012 UNAIDS Country Report for South Africa, using clinic-level data, is unable to distinguish between adults and children – and certainly not adolescents – receiving ART. In addition, there is a lack of data on proportions of adolescents infected postnatally, during childhood or adolescence, and of perinatally-infected adolescents who have been informed of their status (39).

In summary, the 3-stage sampling strategy is as follows: 1) Probability-proportional-to-size selection of ART sites using the Department of Health register and initial clinic mapping results; 2a) Sampling of all adolescents on clinic registers that have initiated treatment including adolescents on treatment and in care, and adolescents who have defaulted or been lost to follow-up; 2b) Sampling of all perinatally-infected adolescents on clinic registers including those lost to follow-up and 3) One-year follow-up interview and 2-year tracking of clinic records.

Stage 1: Selection of ART sites using the DoH register. Using a clinic list from online databases of clinics and the Tier.net system recently established by the National Department of Health, (e.g. DoH, 2012) we consulted with healthcare providers in 84 clinics on the numbers of adolescents on treatment in each clinic. Probability-proportional-to-size random sampling from this list, stratified by area, was applied to reach the intended 600 cases. 32 facilities with more than 5 adolescents on treatment each were stratified in four groups by size: 10 facilities with 5-9 adolescents on treatment, 10 facilities with 10-19 adolescents on treatment and 10 facilities with 20-60 adolescents on treatment. The remaining 2 facilities, Frere and Cecilia Makiwane Hospitals, provide treatment for more than 300 adolescents each and were thus included in a fourth group.

Stage 2a: Sampling of all adolescents on clinic registers that have initiated treatment in the past three years. Using clinic records, all adolescents who have ever initiated treatment will be approached for voluntary participation in the study. These adolescents will include primarily adolescents infected through sexual transmission. Female participants recruited at ANC clinics will be eligible for the study if they are currently on ART as part of a PMTCT programme or if they initiated lifelong ART at pregnancy (based on current protocols in which pregnant women with CD4<350 must initiate lifelong ART). *Stage 2b:* Sampling of all perinatally-infected adolescents on clinic registers. Stage 2 sampling will include patients currently on treatment, as well as those who are lost to follow-up - no longer attending clinics – estimated 14% per year in a recent South African study (22). All other adolescent adherence studies include only clinic attendees (2,23,24), but equally important is the inclusion of adolescents who have started treatment but who are no longer or not currently accessing HIV services (often called 'defaulters' or 'lost to follow-up'). To date, no known adherence studies have included this group, and our sampling approach aims to do so in order to minimise potential bias towards adolescents more engaged in the HIV health system.

Stage 3: Annual follow-up interviews and tracking of clinic records including HI-viral load, pill count records, pharmacy refills, loss to follow-up and mortality for two years. All adolescents will be re-interviewed at one year and adherence will be measured through self-reports. In addition, our clinic-based research staff will work closely with health facilities over 2 years to record viral load measurement and pill counts, and will use clinic records to identify regularity of pharmacy refills, loss to follow-up and mortality. Quality of clinic records ranges from excellent to poor, and those clinics with poor record-keeping have requested assistance with building capacity from our research team to reach Department of Health standards. This capacity-building will have a dual benefit of ensuring adequate records for our research, and providing support to under-resourced health facilities. Refusal rates and socio-demographic characteristics of refusers will be recorded and analysed to estimate the extent of bias in the sample.

All of the very few other known studies to date of adherence amongst adolescents have used clinic-based samples. This is problematic as, by default, it excludes key groups of non-adherent adolescents who do not attend their clinic appointments (similar to examining truancy by using a sample of school-attending children and adolescents) or adolescents who do not actively engage with the healthcare system, for example by sending their caregiver to pick up their medication. In order to access both clinic-attending and other at-risk groups within HIV-positive adolescents, a range of targeted sampling strategies will be used, with recruitment in a range of locations, including antenatal clinics, ART clinics, testing sites and STI clinics, schools, prisons, children's homes, home-based care organisations and community-based sampling.

The research team is aware of the need for extreme sensitivity around disclosure – particularly time since disclosure, and context of disclosure – 20% of pregnant adolescents in South Africa are HIV-positive and most are diagnosed as part of a Prevention of Mother-to-Child Transmission (PMTCT) programme. There are also complexities around partial disclosure (for example adolescents told that they are taking medicine for an unspecified illness), and 'unspoken' disclosure (where adolescents have guessed that they are HIV-positive but have never been told). Some adolescents recruited through clinics will be unaware of their own status, and our research team has developed research protocols (see below) to negotiate this complex ethical issue.

3.7. Recruitment and Enrolment

Recruiting from health facilities: Qualitative and Quantitative Studies

Government approval will be sought to access state clinics and hospitals, while access to NGO-run clinics will be negotiated with NGO management. Healthcare workers at the facilities will be informed of the researchers' presence and purpose in the clinics and will be encouraged to ask questions or make recommendations. Access to potential adolescent participants will be negotiated with the help of doctors, nurses, community healthcare workers/expert patients. While there are clear power inequalities between community healthcare workers and their patients, qualitative research among community healthcare workers suggests that they are more trusted than nurses or doctors (53). Recruitment for the quantitative study in clinics will be conducted by research assistants who will be assigned to work in particular clinics, where they will build rapport with healthcare workers and clinic staff. In the first place, clinic cards and patient rosters, provided with the permission of site staff, the district, and the provincial Department of Health, will provide information about eligible participants, including the numbers of eligible adolescents on treatment and their status (active, transferred or lost-to-follow-up). Adolescents who present for treatment at the ART, women's health, OPD and trauma clinics of healthcare facilities will be approached with information about the study, and a request to participate should they wish to. The process of obtaining assent and consent is clarified in detail in below.

Because teens may not have disclosed their HIV-status or sexual activity to their family, negotiating initial access through caregivers or guardians may risk violating their privacy. It is notable that the consent of a legal guardian is not required in order for a child older than 12 to initiate ART or access a range of SRH services. However, legal guardians will need to provide consent about their child participating in a research project about young people's experience of health services. Community health workers, who interact with families regularly, may also assist in negotiating legal guardian consent.

The question of consent is disputed terrain, especially given that adolescents are situated within the complex power structures of the clinic or hospital, communities and homes. Access and consent will need to be negotiated and re-negotiated on an ongoing basis, with continual re-enforcement that participation is voluntary and may be withdrawn at any time without repercussions. Importantly, researchers will ensure that any sign of discomfort or non-consent (whether verbal or not) will be interpreted as non-consent, following Psychological Society guidelines in working with children.

3.8. Inclusion and Exclusion Criteria

Qualitative study

Participants are eligible for one-on-one research engagements (individual interviews, unstructured participant observation, participatory group workshops) if:

a) They are between the ages of 10-19 years,

b) They are currently initiating/or have previously initiated ART or are accessing SRH services, or they are attending a youth programme for AIDS-affected teens, and

c) If they are below 18 years of age, they, and their legal guardian, have given written, informed and voluntary consent

Participants are eligible for group research activities (body mapping and associated focus groups, workshop-based support-tool development) if:

a) They are between the ages of 10-19 years,

b) They are currently initiating/have initiated ART,

c) If they are below 18, they, and their legal guardian, have given written, informed and voluntary consent,

d) They are part of a pre-existing group of openly-disclosed HIV-positive teenagers,

e) They are willing to discuss their experiences of HIV with the researcher and fellow participants, and

f) They sign a confidentiality agreement stipulating that they will not share what is discussed inside the group-space with others.

Quantitative study

Participants are eligible for the quantitative study if:

a) They are between the ages of 10-19 years old,

b) They have accessed/are accessing treatment for HIV (antiretrovirals), and

c) If they are below 18, they, and their legal guardian, have given written, informed and voluntary consent.

3.9. Qualitative Research Procedures

The qualitative study will engage adolescent participants over an eighteen month period, using multiple methods to explore their treatment decisions and retention in HIV and SRH programmes. A range of participatory and more structured data collection methods will complement observation and un-structured research. Group-based activities will form part of ongoing programme facilitation with HIV-positive youth, which researchers will conduct in collaboration with local HIV/AIDS organisations. In addition to working with youth participants, interviews will be conducted with caregivers and healthcare workers, who may or may not be those caring for or providing services to the teenage participants.

This study design aims towards a minimally invasive, participatory research methodology (54) that will facilitate the collection of triangulated qualitative data. The research methodology, while systematized and well-substantiated, will also be adaptive and responsive to contextual, ethical or practical demands.

Existing qualitative research on adolescent adherence to ART has often been conducted with caregivers (55) producing research *about* children, but rarely *involving* children (56). The reasons for avoiding research with adolescents pertain to ethical considerations over their vulnerability and concerns that data obtained from children may be less reliable. However, there is a growing body of literature arguing that adults cannot serve as proxies of adolescent experience and that young people can be competent participants, as long as researchers facilitate their participation with caution and sensitivity (54).

In South Africa, seminal studies have facilitated focus groups with HIV-positive adolescents on ART (21,57) and conducted qualitative interviews with youth and their caregivers (57). Mixed methods approaches conducted within a more extensive time-frame will facilitate rapport between researchers and respondents, thereby improving the validity of data collected and allowing for triangulation of methods.

Qualitative data for this study will be collected through: ongoing participant observation, semi-structured in-depth interviews, clinic observation, body-mapping, and participatory group workshops. More detail on how, and at what stage, of the research process these methods will be implemented is provided below. The use of a variety of methods, both traditional and innovative, may help to address some of the ethical and methodological issues that arise in conducting research with adolescents (58). It may help sustain participants' interest, guard against the bias of using a single method, triangulate and crosscheck data, determine the

efficacy of different methods (58), and negotiate a balance between non-invasive participation and guided interaction.

Rapport-building and participant observation

Identifying and recruiting participants for this study will require careful, creative and adaptive strategies, which give full consideration to the ethical and methodological challenges of working with teenagers, speaking about sensitive topics like sex, health and illness, and entering the research setting as an outsider. The research team has established partnerships with local HIV/AIDS organisations, primary healthcare clinics, and hospitals, all of which will advise on the most appropriate way to approach potential participants. The research design will also be informed by ongoing consultations with AIDS-affected and HIV-positive teenagers, both through activities with our long-standing Teen Advisory Group and our involvement as volunteer facilitators in a number of programmes for HIV-positive youth. These interactions will provide an opportunity to learn how young people prefer to be engaged, what their interests and concerns are, and what discursive strategies they use to understand and to describe sexuality and health.

Research will begin with an 8-week period of rapport-building, during which researchers will build relationships with HIV-positive adolescents through ongoing participation in NGO programme activities, observation in primary healthcare clinics, and shadowing community health workers. As researchers build relationships with adolescent patients, they may also participate in aspects of their daily life by walking them home, attending extra-curricular activities, meeting friends and family etc. Researchers will also be facilitating a range of extra-curricular programmes, including art-making, health-related workshops and skills-building with HIV-positive young people over this period. The numerous interactions with HIV-positive youth, both inside and outside of health facilities, will allow opportunities to start negotiating future, more structured research participation. During the rapport-building phase, both health-facility and programme-based youth will be aware of the researchers' position as a participant observer. Permission to access state health facilities was obtained from the South African government. Researchers will always introduce themselves as researchers to those who enter the 'scene' of study.

During the period of initial rapport-building and observation, adolescents will decide if they would like to participate in more ongoing (one-on-one un-structured time with the researcher) and/or structured (workshops,, body-mapping or interviews) components of the research, and offer suggestions of how, when and where they would like to engage with researchers. In cases in which participants indicate an interest in participating, the researcher will begin negotiating legal guardian and/or other forms of adult consent in consultation with the adolescent (as explained in the section on consent below). Another key aim of the rapport-building period will be to recruit Xhosa-speaking key informants to assist with access and translation. These may be teenagers or adults, depending on what is appropriate for the setting, and what participants are most comfortable with.

In light of low disclosure rates, the possibility that legal guardians may not know about adolescents' HIV-status or SRH service access, and the fact that some of the recruitment sites may also include HIV-negative teens, recruitment materials and consent forms will not make reference to HIV. One-on-one ethnographic engagements, which will lead from initial rapport-building and group activities, will be guided by participants, and may include walks, visits to the family home or attending the clinic together.

During the period of rapport-building, participants will be informed of a range of upcoming, more structured research activities in which they could choose to participate. Participation will be voluntary and may be withdrawn at any time without consequence. The order in which

activities take place will be negotiated in field and may occur simultaneously for participants who choose to take part in more than one activity. Research activities will be introduced as ways for young people to tell stories about their lives, their bodies and their health, and will not make explicit mention of HIV. The extent to which teenagers reveal their HIV-related experiences will be left up to them, and may depend on the nature and context of the research activity.

Research activity 1: In-depth interviews

Adolescent participants may volunteer to participate in a series of (largely informal) interviews, some more lengthy than others. These interviews will be interspersed and sometimes merged with ethnographic activities, such as visits to adolescents' homes, playing, cooking or visiting the clinic. The participant will chose the interview location and, with their consent, some of these interviews may be recorded, although it is more likely the researchers will take notes. Initial interviews will ask about the *life histories* (59) of respondents, beginning with an open-ended question like, 'Can you tell me the story of your life?' and probing where necessary. These initial interviews will elicit information about respondents' upbringing, when they were diagnosed with HIV, how they discovered their status, their experiences of SRH services, their past experiences of sexuality and intimate relationships, and the current members of their household. Life histories provide a vital context through which to understand respondents' behaviour.

Follow-up interviews will explore participants' daily lives, engagement with HIV and SRH services, treatment practices, and perceptions and experiences of HIV, particularly as they pertain to major health events such as an opportunistic infection or pregnancy, adherence struggles and successes. Where respondents have also taken part in body-mapping, interviews will be informed by the themes and ideas that emerge through these media.

All interviews will explore a list of themes, but will be minimally-structured. Using open-ended questions is more likely to evoke a genuine, spontaneous and un-manipulated narrative as well as eliciting un-anticipated findings (60). Where necessary, gaps will be filled with more follow-up questions or prompts (61). Where feasible and consented to, we will also conduct interviews with respondents' guardians and healthcare workers to explore their perspectives on respondents' health-related practices. Separate interviews will also be conducted with 68 healthcare workers, social service providers and guardians about their experiences of caring for adolescents on ART.

Research activity 3: Body-mapping/focus group discussions

Body-maps are life-size body outlines, filled with visual representations of experiences, feelings and interactions as they relate to the body and the social world. They are useful for research relating to health and illness because they are able to visually represent the interactions between the physical self, perceptions of illness and wellbeing, personal identity and social context.

Body-maps have been used as a therapeutic tool among HIV-positive women in Khayelitsha (62,63) to convey experiences of living with HIV and taking ART. During the 'Mapping Our Lives' workshops, women engaged with medical knowledge, which included anatomical diagrams of organs and representations of the virus. But participants were also encouraged to create spaces for the social - to "think of the body as a museum of life" (62). The PI and other researchers on this project have previous experience facilitating body-mapping workshops. Body-mapping and other research activities that use visual media to explore teenagers' experiences of ART and SRH may be conducted through weekend workshops or through two-hourly sessions connected to support group activities.

This activity will only be undertaken with HIV-positive adolescents who are willing to disclose both to the researcher and to other adolescents in the body-mapping group. Body-mapping workshops will be conducted with pre-existing groups of disclosed adolescents, such as support groups or programmes for HIV-positive youth. Where non-disclosed adolescents participate in these workshops, extreme care will be taken to uphold participant confidentiality. In our past research, this has taken the form of framing questions about illness and medicines in the more general sense of chronic illness and treatment, rather than with specific reference to HIV and ARVs. A confidentiality contract is discussed and signed by the group in the first session of the workshop.

The first hour of each body-mapping session will be spent in open-ended focus group discussions. These discussions will address relevant themes, including living with HIV, taking medication, adherence to medications, and sexual and reproductive decision-making. Respondents will reflect on their experiences in the home, at school and in the clinic, as well as their perceptions of HIV, ART, contraception and other SRH services (such as pregnancy testing and abortion). Reflections generated in these discussions will be mapped in and around the body outline; using symbols, words and pictures.

Given the effect of peer influence on adolescent behaviour, researchers will need to consider the extent to which focus group responses are shaped by peers in the group. Respondents may not be willing to share the intimacies of living with HIV with their peers, in which case body-mapping strategies will be adjusted to accommodate one-on-one as opposed to group reflections.

In this study, the processes of creating body-maps, eliciting the reflection and expression of participants, will be more important than their final product. The maps will be used to elicit discussion in follow-up interviews, as well as to verify and develop emerging themes in this study. Importantly, respondents should provide their own interpretations of their artwork (56). Data will also be collected through the focus group discussions that serve as part of the body-mapping process. As with in-depth interviews, adolescents who participate in body-mapping and diary activities may choose to engage with researchers on more casual terms beyond these semi-structured methods of data collection.

Research Activity 4: Clinic observation and shadowing of healthcare workers

Healthcare workers constitute a vital vanguard in the provision of HIV and SRH care and treatment services to HIV-positive adolescents. Through close and respectful observation of the experiences and practices of healthcare workers, this research will explore the challenges that they experience in their clinical encounters with HIV-positive teens. Permission to 'work-shadow' healthcare workers who encounter HIV-positive adolescents through their work at ART, Women's Health, OPD and Trauma clinics, will be sought from both hospital management, nurse managers, and the healthcare workers themselves. If this permission is granted, researchers will shadow healthcare workers, with a particular focus on nurses, the front-line care providers in most of these clinical contexts. Through clinic observation, supplemented with in-depth interviews, researchers will aim to learn about how nurses experience consulting, treating and supporting the teens in their patient cohorts. It will explore their understandings of the greatest facilitators of, and barriers to, ART adherence and the uptake of SRH services, as well as their intimate and direct knowledge of how the services which they provide may potentially be improved to support better health outcomes among teenagers.

Tool Development 1: Working with adolescents to collaboratively design support tools for adherence and access to sexual and reproductive health services

Through participant observation, interviews, and body-mapping, researchers will identify

adolescents who experience challenges in accessing and adhering to ART and SRH, and who may be interested in exploring ways to circumvent or face these challenges. Researchers will work with these adolescents, as well as with NGOs and clinics, to develop adolescent-led guidance for ART and SRH programming. This part of the study will be focused on adolescent-led strategies and approaches, and it is difficult to anticipate in advance what form these may take. This stage will build on the previous ethnographic and qualitative processes, including a small number of additional adolescents if desirable, and will take place through a set of participatory workshops. Study design will be guided by adolescent's decisions on whether to include other stakeholders – for example clinic staff, or local leaders – in this process. A primary goal of this stage is to allow the direct input of adolescents into the design and programming that is usually undertaken on their behalf. In addition to tool development, the workshops will focus on assessing feasibility in terms of: (i) acceptability of intervention, (ii) barriers to implementation and participation (64) and local contextual issues.

Integrating and linking with quantitative methods

To date, research on ART adherence and SRH decision-making among HIV-positive children and adolescents has been minimal, and what is available has been characterized by a sharp divide between qualitative and quantitative studies. Clinic-based quantitative research has been unable to account for the subtlety and complexity of influences on adolescent ART adherence and SRH decision-making, nor has any known research included adolescent participation in the design of surveys and support tool.

This study has the further aim of directly informing the design of a linked quantitative study of barriers and facilitators for HIV-positive and -negative adolescents, and to utilize this larger sample to test for acceptability the adolescent-designed support tool described above. Sequencing of research has allowed data collected and analysed in the qualitative study to contribute directly to the quantitative study – not only in what questions are asked, but also in how they are asked and in what order. By exploring the cultural, generational and gendered structures of authority in which adolescents are embedded, and by eliciting important information about the way in which adolescents understand, live and speak about key concepts such as HIV testing, ART medication, contraception and fertility desires, the quantitative study design has been guided by its findings in study design, and sensitised to the context in which this data is gathered.

By working as a team with both qualitative and quantitative researchers, projects will be integrated not only in design, but also in the development of inter-disciplinary understandings of the experiences of HIV-positive adolescents, particularly as these relate to and influence their uptake of, and adherence to, ART and SRH. This cooperation has been key during the design of this research protocol and will continue throughout analysis and dissemination.

3.10. Quantitative Research Procedures

The quantitative data collection process will include: (1) participant interviews, (2) secondary data from patient records, and (3) facility-level information.

Quantitative Measures – Questionnaire

The questionnaire has been drafted after consultations with over 20 experts in the field of adolescent health and piloted with HIV-positive youth in South Africa and the region. Measures use (where available) tools validated in Southern Africa (65–67). All measures have been piloted prior to use.

Digital devices – 7-inch tablets – will be provided to participants for completing the questionnaire. Trained research assistants will sit with adolescents to demonstrate how to use the tablet and to guide the participant where necessary. The participant will then be offered the opportunity to complete the questionnaire autonomously. The name or contact details of the participant will not be included in the questionnaire – each individual will only be identified through a unique participant ID. Data will later be collated, but the confidentiality of the participant will be upheld. The use of mobile devices – 7-inch tablets – will increase the accuracy of the answers given by participants. Adolescent participants of multiple studies using mobile devices have reported that this method allows for more truthful answers and greater confidentiality (68–71). A study among students in South Africa concluded that most students perceived the electronic questionnaire to be a more confidential method of answering questions about sex: 77% of those using electronic questionnaires and 51% of those using paper questionnaires (72). The cellphone number made available in recruiting material will only be accessible to the research team. If participants leave a 'please call me' message (a free text message), only the research team will contact them. Should participants share additional contact details with researchers (Facebook, Mxit, etc.), this information will be kept confidential.

(i) *Outcome measures: Adherence.* For adolescents who report having been prescribed any

chronic medication, a triangulated approach to measuring ART adherence, found to be the most reliable method amongst youth (73,74) will be used. It is important to measure adherence across a sufficient but feasible time period. Our systematic reviews of ART adherence amongst adolescents, adults and children (in preparation) found either cross-sectional surveys using retrospective reporting of general adherence (75), or of past 3 days (76,77) with a small number of studies using pharmacy refills up to 24 months (2). Although pharmacy refills are only a moderately reliable indicator of ART adherence, it is important to measure adherence over a longer-term period by identifying change over time. This study therefore proposes the use of three methods for assessment of adherence. 1) each participating adolescent will receive visits, including a questionnaire completed with the help of an interviewer. These will collect information about ART adherence, socio-demographics, service access and potential risk and resilience-promoting factors, using standardised instruments and triangulating measures of adherence (78,79) and used in South Africa (80–82); 2) viral load and CD4 cell-count (where available) measures; 3) medication refill rates (83). Viral load, CD4 and medication refill rates will be recorded from patient files at each facility where they are receiving care.

Sexual and reproductive health outcomes will be measured using standardized tools from similar Southern African studies and studies among HIV-positive adolescents in the region and globally. Sexual health outcomes will include measures of: (i) sexual activity: debut, current levels, (ii) types and number of partners (84) condom use by partner type, (iv) forced sexual experiences/ sexual abuse, (v) transactional sex, and (vi) HIV knowledge and attitudes. Reproductive health outcomes will include (i) parenthood ideations and plans, (ii) pregnancy – past and current, and use of contraception (hormonal, condom, termination of pregnancy, etc.). Through open-ended questions, the survey will explore experiences of adolescents in accessing SRH services and potential reasons for dropping out or defaulting.

Potential risk & resilience factors: (Figure 1) Individual factors include mental health issues (85), HIV-related neurocognitive impairment (23), physical and learning disability (86), level of treatment understanding, and beliefs in myths or fears around HIV or medication (87). *Gender, sexuality and sexual health factors* are highlighted as important by HIV-positive adolescents

(88). Potential factors include transactional sexual relationships and challenges around disclosure to sexual partners, particularly unintended disclosure via taking medication (21). Teenage pregnancy and enrolment into a PMTCT programme may positively or negatively impact adherence. Studies of PMTCT programmes report low adherence, and a qualitative study of teenage mothers reported overwhelming fears of confidentiality breaches by obstetrics staff (89). In addition, contraceptive and sexual health services use may impact adherence, with reports of healthcare staff strongly critical of adolescents wishing to have sexual relationships and plan families.

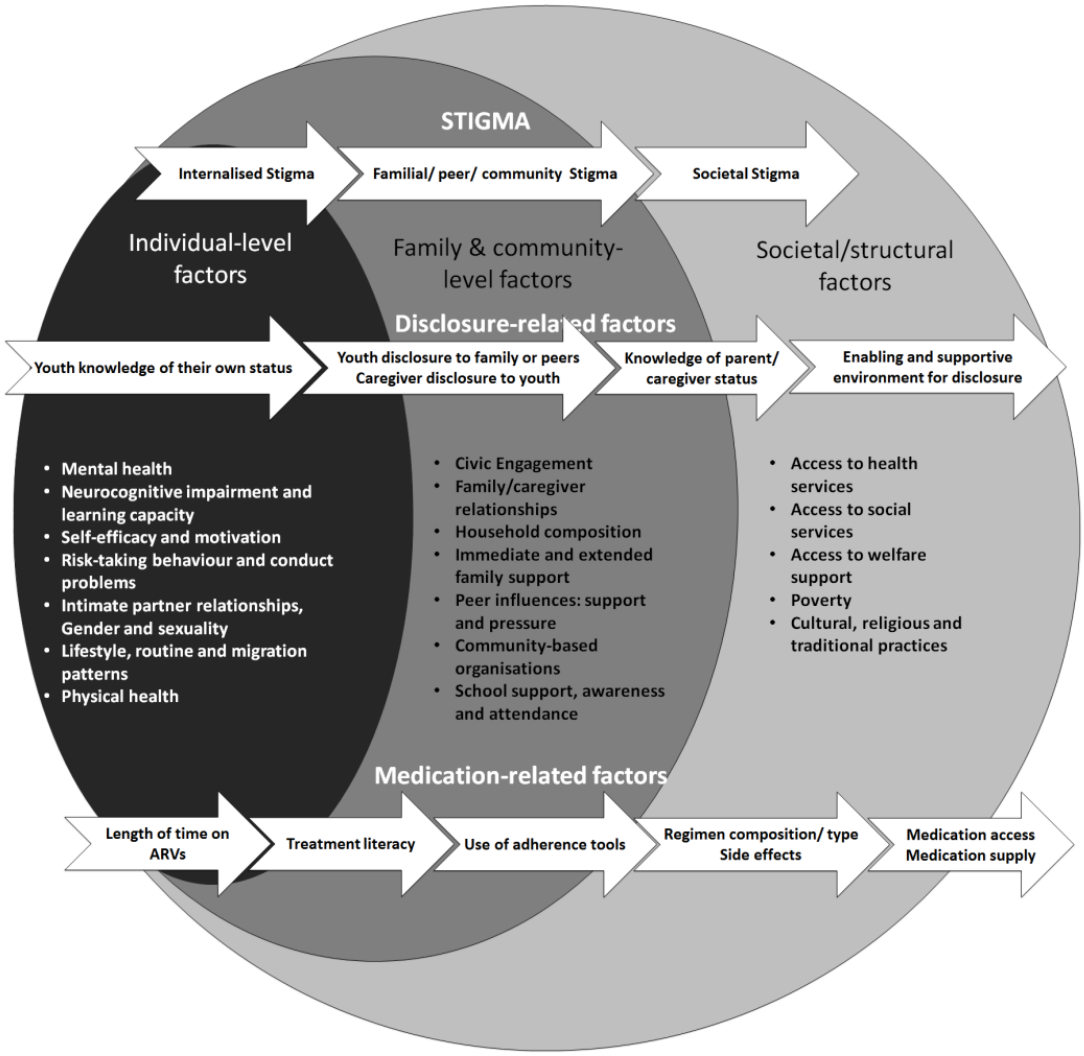
Family and community factors: Qualitative studies suggest that *family relationships* and extent and nature of primary caregiver involvement may be crucial (90). Potential factors will include HIV disclosure by and to families (and timing and nature of disclosure) (91), migration, changes of primary caregiver due to death and illness, physical, emotional and sexual abuse and domestic violence (92).

School, peer & community factors may be particularly important as adolescents develop social identities (93). Potential factors include bullying, stigma and support inside and outside school (94), school attendance and achievement, drug and alcohol use, gang membership and incarceration.

Structural factors: *Social protection and economic factors* include socio-economic status, food security (95) and access to services such as state grants and social services. Distance and transport to clinics have been shown to impact adult adherence (96), and may present even greater difficulties for adolescents with fewer financial resources. *Antiretroviral, HIV treatment, care and support service factors* include use of traditional healers, the social position of those who may recommend alternatives ART (97), complexity of regimens and palatability of medication. Side-effects of medication (such as fat redistribution – lipodystrophy) may be especially embarrassing for adolescents in their peer environment. Prior research indicates that experiencing lipodystrophy and other side effects of HIV medication can affect people's self-esteem, sense of control, social and sexual relations, and can contribute to demoralization, forced disclosure, and the decision to stop treatment (98,99). Access to HIV support services such as support groups, youth clubs and adherence monitors, may be an important predictive factor. In addition, adolescent experiences in health services may be relevant, as qualitative studies report adolescents treated with disapproval and contempt by healthcare staff (100).

Based on the initial findings of the qualitative research and participatory workshops on tool development, the final step of quantitative research will involve testing the feasibility of a tool for young people developed by adolescent participants. A quantitative appraisal of the tool's accessibility, potential for reach and exposure will be conducted with a sub-sample of the expected 600 youth. Based on the main content of the tool, short-term outcome measures shall be selected and measured during the initial data collection and feasibility step. These outcomes will most likely include adherence to ART (past-month recall) and utilization of SRH services (primarily pregnancy, contraceptive use and TOP services).

Figure 1: Hypothesised risk and protective factors for adolescent ART and SRH use



Quantitative Measures – Retrospective and Prospective Patient Records

In light of potential poor treatment and health literacy rates among patients on ART, the questionnaire information on CD4, viral loads and medication refills (2) will be complemented with data recorded from patient files. This data will be recorded using a protocol previously applied in other studies among adolescents on ART (94) adapted to patient files in the facilities that participate in the study. Participant self-reports through the questionnaire and data extracted from patient files will be linked through an anonymous unique identifyer. Data will be extracted from patient files at baseline and on an annual basis for two years (2015-2017).

Quantitative Measures – Clinic-level information

An extensive literature review on factors affecting adherence and access to SRH points to a series of clinic-level factors that affect both. Factors including clinics-based nutrition programmes, staff/patient ratio, provision of counselling, and ease of access to patient records are associated with improved adherence or access to SRH services (literature review is in process). To that end, the research team will develop a clinic-level "profile" of literature-informed indicators, which will be linked to each patient who receives care in that clinic during data analysis. Clinics will not be uniquely identified, but dummy variables will be computed based on the clinic-level factors for participants who receive care in that facility.

3.11. Data entry, safety, monitoring and storage

Data quality will be ensured through rigorous training, spot-checking during data collection and during data entry, which will happen in parallel with data collection. All data collected will be automatically uploaded into a secure server through an open-source software platform – Open Data Kit (www.opendatakit.org), which will be anonymized prior to data analysis to ensure confidentiality of participants. Regular backups of all data will ensure that the database is safe.

Every effort will be made to maintain participants' confidentiality. All data will be identified by a unique participant number and kept in confidential files. Identifiers will be removed from interview transcripts, questionnaires and original recordings, and coded so that only the researchers can access identifiable information. No individual identifying information will be collected or disclosed in reports, publications, or presentations.

Participants will be notified, both verbally and in consent forms, that confidentiality may be breached if the participant is considered to be at significant risk of harm. This includes abuse, neglect or family violence (further details below).

Electronic versions of transcripts, recordings, questionnaires and field notes will be kept in a password-controlled electronic file, accessible only to the researchers. All study documentation including questionnaires and informed consents will be kept in locked cupboards or password protected hard-drives/ computers. Consent documents will be kept separately from questionnaires. Hard-copy data (transcripts, field notes and questionnaires) will be coded – removing identifiers so that only the researchers are able to link it to individuals using a study master list available only to the project investigators and fieldwork project managers.

Data will be stored within the secure offices of the AIDS and Society Research Unit at UCT.

3.12. Data Analysis

Qualitative Study

Qualitative data analysis will adopt key procedural principles from Grounded Theory (101). Data collection and analysis will occur simultaneously, 2.) Analytic codes and categories will be developed from the data and not from preconceived hypotheses, 3.) The analysis will use constant comparison to compare similarities and differences across and within themes, thereby limiting bias, 4) Theoretical memo-making will occur alongside analysis and during the write-up, and 5) The sample will be selected for the purpose of theory construction as opposed to the representativeness of the given population, following theoretical sampling, common to grounded theory (102). Multiple researchers will review the coded data in order to verify findings. The characteristics of the sample recruited will be thoroughly and clearly presented to ensure that others may assess the credibility and transferability of findings (103). Although safeguarding the confidentiality and anonymity of the participants is paramount, analysis will document the overall pool of available teenagers, caregivers and healthcare and social support workers that were deemed eligible for participation, how many refused to participate and their reasons for refusal.

Quantitative Study

Data analysis will be undertaken in SPSS and AMOS (with MPlus if needed). Where relevant, mixed-method data will be used. All analyses will control for socio-demographic co-factors and potential confounders.

Research aim 1: To examine differences in rates of adolescent adherence and access to SRH amongst key subgroups will use descriptive statistics, multivariate regression and ANCOVA.

Research aim 2: to identify which risk and resilience factors predict ART adherence and SRH uptake amongst adolescents, to investigate interactive pathways, interactions and cumulative effects between factors will use multivariate regression, and a set of statistical techniques previously utilised in our longitudinal studies of AIDS-orphaned children. These include log-linear modelling (104), testing of interaction effects in regression models, mediator and moderator analyses in path analysis, and structural equation modelling – which allows simultaneous analysis of multiple predictors, intervening variables and outcomes(105).

Research Aim 3: To examine whether risk and resilience factors and pathways differ among subgroups of HIV-positive adolescents will use ANOVA, SEM and log-linear modelling to compare subgroups;

Research Aim 4: To determine whether HIV-positive and HIV-negative adolescents have different exposure to risk and resilience-promoting factors, and to health services will use multivariate regression and ANCOVA.

Finally, the quantitative study will analyze the feasibility of the tool developed through participatory workshops, focusing on participant satisfaction and potential for adherence/exposure to the tool by HIV-positive adolescents. Descriptive statistics and regression will be used to identify which tool features are most appropriate for HIV-positive adolescents.

1.2.4 Risks and Benefits for Participants

This study aims to investigate risk and protective factors for ART adherence and SRH service uptake among adolescents in South Africa. We will be interviewing adolescents as young as 10 years old, and because the interviewers are adults, this presents a significant power inequality. This power differential is further complicated by class and language distinctions between researchers and study participants. These inequalities will be sensitively and carefully considered. Building trust and rapport with participants, and explicit reflexivity during data collection, data analysis and reporting of the study will all be essential in generating high-quality data and research findings in a non-coercive setting. When fieldworkers are employed and trained for the study, training will focus on building social sensitivity towards unequal power relations. By explicitly encouraging social sensitivity and awareness of our team's roles as researchers and social positions, we will reduce feelings of inequality and prevent coercive work with participants. It is also important to recognise that in a positive and youth-centred research environment, adolescents may benefit from the opportunity to interact with adult facilitators. Adolescents may appreciate a trusted adult to confide in and an opportunity to access information in a confidential setting. We do not anticipate that the interviews will cause any additional distress either to adolescent participants or their caregivers. However, in order to reduce any risk of respondents becoming distressed, guidelines have been developed (see below).

We note that – in all our previous studies – a range of complex cases of children and youth in extreme need have arisen from our research (partly because this is often the first opportunity a child has to discuss in detail their lives, we have very high levels of disclosure regarding rape, abuse and other traumatic life events and conditions). All cases where a child or adolescent may be at risk or is experiencing significant harm are discussed in detail with the qualified South African child protection social worker on the team. Given the very low

availability and variable quality of social services in some low-income areas of South Africa, close supervision by the social worker is provided of all cases, referrals and any supportive action taken by the team.

1) Qualitative data collection tools will be participant-driven and youth-oriented. Quantitative interview materials administered through tablets include teen-friendly images and language designed to engage youth in a comfortable and open style.

2) The majority of adolescents in this study will be HIV-positive and will have disclosed their HIV-status to the researcher in confidence. This study recognises the duty of researchers to uphold participants' constitutional right to privacy and dignity, particularly in a context where HIV remains highly stigmatised. Therefore, in line with the National Health Act (2004) and legal guidelines released by the Open Society Foundation (106) as well as the former AIDS Law Project (2003), researchers will not disclose the status of adolescent participants without their explicit consent. All researchers involved in the project have been trained on strict confidentiality and disclosure guidelines and have signed a fieldwork agreement that includes this information. In cases where HIV-positive participants report having unprotected sex with their partners, resulting in a tension between the participant's right to confidentiality and the public health impetus to protect at-risk partners, researchers will adopt the following procedure as per recent guidelines: 1) advise the adolescent about the risks of unprotected sex for both their own health and the health of their partner, 2) encourage voluntary disclosure and safer sex and provide support to the participant, 3) suggest a joint session with a trained HIV/AIDS counsellor who can assist the adolescent in disclosing or negotiating safer sex, 4) if these approaches are not successful, the researcher will inform the participant that they will be informing a doctor or healthcare worker familiar with the adolescent, explaining the ethical obligation to do so. This is in line with section 14 (80) of the National Health Act, which makes provisions for disclosure if non-disclosure amounts to a serious threat to public health. When consent for participation is sought, participants will be made aware that their confidentiality will be breached only to prevent grave harm and never before consulting with them. If researchers have to resort to informing a healthcare worker of a participant's unsafe sex practices and non-disclosure, it will be recommended that the relevant healthcare worker follow established best practice for HIV disclosure outlined in published legal guidelines (106).

3) Given the complex nature of adhering to long-term medication, this study will identify a number of adolescents who have defaulted or not yet initiated life-saving medication, including ART or TB medication. In cases when participants report non-adherence, the researchers will highlight the importance of adherence to medication and encourage the participant to consult their healthcare workers and adherence buddies. Specific information obtained on the dosage, adherence patterns and other influencing factors for each individual will not be shared with their healthcare worker or legal guardian in order to maintain participant confidentiality. However, adolescents experiencing symptoms of TB, pneumonia or any other opportunistic infection will be referred to a healthcare professional. Given the risk of significant harm, this constitutes a legitimate breach of confidentiality. Participants will be told at the consent stage and in information forms that there are limits to confidentiality when someone is deemed to be at risk of significant harm.

4) In order to protect confidentiality of the participants and protect them from the stigma associated with HIV/AIDS, each interview will be conducted with as much privacy as possible in a space chosen by the participant. In addition the study will be presented within communities as investigating health and social services experiences generally, rather than being an HIV-specific study.

5) As in all research with children and adolescents, there is a possibility that participants

will take the opportunity to disclose difficult living circumstances or abuse. This study recognises that researchers have a responsibility towards children who may disclose information showing them to be at risk of severe harm. Recent research in South Africa has carefully considered these issues. Guidelines are set out by the HSRC/UNICEF study on children's psychological adjustment in South Africa (107) and in the South African Children's Institute/ACESS Child Participatory Poverty Research (108). These promise confidentiality except when a child is shown through the research to be at risk. In cases of risk, and with the consent of the child, they will either be referred to organisations that can provide assistance (ACESS study), or their caregivers will be told (UNICEF study). The choice of these options will be made in consultation with the social worker and psychologist on the research team, and on the basis of best outcomes for the child. Most research with vulnerable children in South Africa considers it an ethical principle to provide help for children whom the research identifies as in need. For example, research undertaken by the Medical Research Council Unit for Anxiety and Stress Disorders routinely refers children to child psychiatric services or to the University of the Western Cape Child Psychology clinic in cases in which there is need for these services (109,110). A University of Cape Town study on child mental health referred children in need to social services, as does research in the Africa Centre on HIV-positive caregivers and infants (111). Researchers on this team have been investigators on three previous studies with AIDS-affected children in South Africa. Based on these studies and on protocols devised from research studies with similarly vulnerable groups (112), the following protocol is proposed:

a) Informing all participants at the consent stage that everything said will be confidential unless it becomes clear that they are at risk of significant harm.

b) If information is disclosed that suggests that the participant, their sexual partner, or a member of the household is at risk of significant harm, the researcher will discuss concerns with the child at the end of the interview before any further action is taken.

c) If the participant or a member of their close network is at risk of severe harm, the researcher will discuss the possibilities for referral with the child participant. If the child does not consent to sharing of information, and the harm is not considered to be significant, the child will be given information about self-referral agencies such as ChildLine SA.

d) However, if the harm is considered to be significant the researcher, assisted by employed fieldwork volunteers, will consult with social services or other organisations. If the decision is made to take action, the participant(s) will be informed (*Please see attached draft referral form*). If referral requires disclosing the child's HIV-status, then the procedure described in 2) above should be followed.

6) This study has an obligation to plan for the possibility of participants, child or adult caregiver, becoming distressed. All interviews will be trained and experienced in working with affected children and families. The research team includes a social worker, a psychologist and HIV counsellors who will be available to supervise researchers and help them to discuss issues with the families and children following the interviews. As discussed above, if there is a need for a participant to access more extensive support (such as consulting a counsellor or attending a clinic) referrals will be made (Please see sample referral letters in the appendices).

The research team is obligated to any participant who may feel distressed following the study or who may reports behaviours that require follow-up counselling. All interviewers are trained and experienced in working with affected children and their families. If a participant becomes distressed, interviewers will be available to discuss any issues he or she may have, and make referrals if required. Interviewers will also contact the project manager by cell phone when they have a particular concern, or when a participant requires more information or their case requires further discussion. Furthermore, in cases laid out in question 13.a (i), additional

sessions might be needed to ensure that risks identified are addressed by participants.

Risks to Researchers

There are general risks in doing fieldwork and we ensure that all research assistants and fieldwork staff are trained in awareness and safety measures. We provide all staff with panic alarms. Staff will not undertake interviews in any situation in which they feel uncomfortable or unsafe. Where there is concern about safety of an area, staff travel in pairs. Where needed, a 'community guide' with strong knowledge of risks will be hired to assist with staff safety. Consulting community organisations about the methods and purpose of the research in each area will also help to ensure that researchers do not face suspicion and mistrust from non-participants in the community. University counselling services will be made available to researchers should they need psychological support. All staff cars are properly equipped and regularly serviced.

Benefits to participants

Participants will have an opportunity to share their experiences and concerns with trusted and sympathetic adults and access referrals where necessary. Fieldworkers and volunteers on the project will assist adolescents in accessing health and social services. Given the network of partners and collaborators and the objectives of this study, the intention if for participants' responses to be used to inform health policy and programming for youth at local, national and regional levels. Health facilities and organisations participating in the study will receive highly specific feedback about the experiences of their youth patients, the aim of which is to have a positive impact on service provision. Finally, this project hopes to develop and test for acceptability an adolescent-driven support tool to benefit youth accessing ART and SRH.

1.2.5 Process of Obtaining Informed Consent and Consent

General Principles

All information sheets and consent forms will be given to potential participants and their legal guardians by the researcher or members of the fieldwork team. All information sheets and consent forms will be read to participants in their preferred language to prevent illiteracy from hindering a participant's understanding of the methods and purpose of the study. All participants will be told they have the right to decline to participate, drop out at any time, and that all the results will remain confidential. Any avoidance of study participation will be understood as a lack or withdrawal of consent.

Participants may consent to participate only after having the information sheet been read to them and been given an opportunity for questions.

Participants will have the opportunity to consider consent for up to a week before interviewers return. However, when we have previously offered participants periods of 24 hours to 1 week to consider consent, the vast majority have requested to participate immediately. In light of this, we propose that participants are offered the choice of whether to consent or refuse immediately, or to have 1-7 days to consider whether they choose to consent.

All participants should be capable of giving their own consent, and we will not interview any adolescent or adults deemed incompetent. Special care will be taken to ensure that all participants are fully aware of and understand the research.

We will obtain written informed consent from each participant in this study.

1) Consent for adolescents to participate

In order to ensure fully informed, voluntary consent for adolescent participants, all adolescents will be provided with information sheets describing the study in their first chosen language, which interviewers will read aloud. If participants are illiterate, they will be able to give verbal consent and indicate with a cross on the signature line. Particular attention will be given to issues surrounding statutory requirements to break confidentiality (i.e. if the adolescent or a member of their household is at significant risk). Only after the purpose of the study and the format of the interview have been explained will the adolescent be asked for their consent to participate.

All attempts will be made to ensure that the research is a positive and participatory experience for all participants, and that consent is both voluntary and informed. All interviewers will have experience in working with vulnerable children affected or infected by HIV/AIDS. If the participants have sensory difficulties, the research team will ensure they can access the questions, for example, a signer will sign the questions to deaf adolescents. Reading the questions out loud will ensure that blind adolescents can participate.

To ensure that children and adolescents do not feel obliged to participate in the research, emphasis will be placed on their ability to refuse to participate, or to cease participation at any point during the research (*See attached Consent and Information Sheets*). Following British Psychological Society Guidelines (113), any avoidance by adolescents of the interview situation will be taken as evidence of failure to consent. Adolescents who refuse to participate, or who stop the interview, will still receive snacks and certificates. All research materials will be provided in English and Xhosa. Interviewers will explain all aspects of the project to adolescents and answer any questions they may have in adolescent's preferred language.

Perinatal HIV-infection can bring with it cognitive delays for children. These can be reflected in a wide range of difficulties, for example a lowered reading age or a lowered cognitive age. The effects and impacts of this for adolescents are still under-researched (52,114), and there are no clear guidelines on how to account for these difficulties in conducting research with children and adolescents who are perinatally-infected with HIV. Many perinatally-infected children look younger than their real age, may have developmental and educational delays (115) but feel and understand themselves to be teenagers. There is also an ethical imperative not to exclude adolescents based on an inappropriate understanding of their potential developmental delays. This study hopes to address this by careful training of research assistants to assess cases in which adolescents do not seem to understand the process or meaning of participation in research, and in these cases will refer to expert partners working within this research collaboration for guidance. We understand that this is a complex issue, and would welcome the advice of ethics committees in addressing this.

*2) Legal guardian consent for adolescent participation**

(**The following process and procedure is applicable to adolescents who have not yet turned 18. Adolescents who are 18-19 years old will be treated as adults with regards to informed consent issues, in compliance with all the of regulations cited in this protocol.*)

Each adolescent's legal caregiver will also provide consent for participation in this study, and will be provided with information describing the study in their first chosen language. Particular attention will be given to issues surrounding statutory requirements to break confidentiality (i.e. where the adolescent or a member of their household is at significant risk).

In some exceptional circumstances related to HIV/AIDS vulnerability, the adolescent may wish to participate but the legal guardian is unavailable (through death, living elsewhere and being

un-contactable, or being too sick to give consent). In these cases, the adolescents will be excluded from the study.

In our prior work with Young Carers and in our orphan resilience study, we identified a small but worrying group of orphaned children who wanted to participate in the study but who explained to us that they lived with a foster carer who was forcing them to undertake large amounts of domestic work against their will, and that the carer would not consent to their participation in the study because of the fear that this abuse would be revealed. When consent was requested from the caregiver, they did refuse. In cases in which children and adolescents experience abuse from caregivers or guardians, consent for the study would be difficult to obtain, as these caregivers would not want to be reported. In light of prior research findings regarding abuse experienced by HIV-affected children in the Young Carers project (116), we expect that similar difficult cases may arise in this study. These cases will be immediately reported to the appropriate authorities. Protocol about reporting the abuse and getting support for the participant will follow legal requirements and include reporting of the case to the social worker for the ward or local administrative unit. The team's co-PI is a trained South African social worker and will provide additional guidance on managing each specific case.

Research team members consulted colleagues at the University of Cape Town Health Sciences REC, the University of Witwatersrand, and Social Workers at Cape Town Child Welfare about this issue. We also consulted South African legislation, particularly the Department of Health Research Ethics Guidelines (2004). The ethics processes and procedures proposed in this research project were reviewed and approved by the following ethics committees and institutions:

(1) Health Sciences REC at University of Cape Town (REC REF 389/2009),

(2) Research Office at the University of KwaZulu-Natal: ethical clearance number HSS/0254/09),

(3) Department of Social Development, Republic of South Africa (date: 15/12/08),

(4) Department of Health, KwaZulu-Natal province (reference HRKM091/09),

(5) Department of Education, KwaZulu-Natal province (Ref. 0048/2009),

(6) Department of Education, Mpumalanga province (date: 13/05/2010),

(7) Department of Health, Mpumalanga province (date: 25/02/2010),

(8) Department of Education, Western Cape province (Ref. 20100225-0034), and

(9) Inter-Divisional Research Ethics Committee (I-DREC) of the Social Sciences and Humanities Division, University of Oxford for the Preventing Abuse of Children in PACCASA study (Ref. No.: SSD/CUREC2/11-40), Young Carers Round 2 study (Ref. No.: SSD/CUREC2/11-02 and SSD/CUREC2/09-52), and most recently

(10) I-DREC of the Social Sciences and Humanities Division, University of Oxford for the study protocol hereby presented (Ref No: SSD/CUREC2/12-21).

(11) Centre for Social Science Research, University of Cape Town (CSSR2013/4)

(12) Department of Health, Eastern Cape Province (29 August 2013)

(13) Department of Education, Eastern Cape Province (4 April 2014)

A growing South African literature (117–120) argues that Section 71 of South Africa's National Health Act, which requires active written consent from a legal guardian where research subjects are under 18, runs the risk of compromising adolescents' constitutional right to privacy, confidentiality and dignity. This is particularly the case with regards to research on

stigmatised subjects such as HIV, ART and SRH (120). It also produces a recruitment bias in favour of respondents who communicate about sexual health with their guardians. Disclosing an HIV-positive status to family members may result in discrimination, violence and social ostracism (121). Hence additional parental or guardian consent may a) be logistically impossible, b) necessitate breaching of confidentiality, and c) place the participant at risk of harm (120)

This presents an ethical dilemma for research with HIV+ adolescents. On the one hand, it is essential that no unintended disclosure is made of an adolescent's HIV-status where they have not chosen to share this with their guardians. On the other hand, it is an ethical responsibility of a research project not to exclude those who are potentially the most vulnerable to non-adherence and other negative outcomes, because they lack family support and knowledge.

In order to ensure that these adolescents can participate in this important study, should they choose to, the research team has consulted with the National Pediatric Technical Working Group based at the National Department of Health and Dr. Galo at Cecilia Makiwane Hospital in East London, Eastern Cape to develop the following solution for such ethically complex, yet crucial participants.

In cases when the research team is aware that an eligible adolescent participant knows their HIV-positive status but the parent/guardian does not, the adolescent or family will not be approached for recruitment through health facilities. Instead, the research team will follow our 'broad community interviewing' approach, whereby we would interview every home including an adolescent within an entire street or small area (or every second home for very crowded locations), using a non-HIV specific questionnaire and using the approach of a general health and social services survey for adolescents.

The study will follow the ethical guidelines for conducting research among adolescents as outlined in the Child Care Act (2005) and the Department of Health Ethics in Health Research (2004). Where the adolescent states that their caregiver will not consent to their participation in the study due to the fear that their abuse of the adolescent will be revealed, or in exceptional cases where the adolescent is unwilling to disclose their HIV-status to their caregiver (and is concerned that the research – whilst not focused only on HIV, will reveal this to the caregiver), the participant will be excluded from the study, but researchers will subsequently make social services referrals for all children and adolescents in abusive situations. Those eligible participants who have not disclosed to their legal guardian, parent or caregiver will be linked with disclosure counselling and support, where available at the local clinic.

Any adolescent who declines to participate before or after the interviewer has explained the project will not be interviewed, even if the legal guardian or nominated adult agrees to or encourages participation.

3) Informed consent for adult caregivers (qualitative study only)

For the qualitative study only, where adolescent participants assent, their caregivers will also be approached as potential interview respondents. This study will obtain informed consent for each adult caregiver. All adults will fill in 'opt-in' consent forms if they agree to participate. All information sheets, consent forms, and interview materials will be translated into participants' first language.

4) Informed consent for professional and community health and social workers (qualitative study only)

Healthcare workers will provide crucial information that will allow the research team to triangulate findings on factors affecting access to treatment (58) during the qualitative part of research. This study will obtain informed consent for each healthcare worker included. They will be given information sheets, consent forms, and interview materials in the participants' first language. Professional and lay health workers will be reminded not to mention their adolescent patients by name or to give any details that might identify patients. No real names (either of healthcare workers or patients they may accidentally mention) will be recorded in interview transcripts. Copies of all information sheets, consent forms and interview materials are attached in the Appendices.

1.2.6 Privacy and Confidentiality

Participants will choose the time, location and nature of their engagement with the research team. In the case of focus groups and other group-based research activities, participants will sign a confidentiality agreement, but will be warned that confidentiality cannot be guaranteed as group members may discuss what was said outside of the group despite having signed this contract. The cell phone number made available in recruiting material will only be accessible to the research team. If participants leave a 'please call me' message, only the research team will contact them. Should participants share their contact details with researchers, this information will be kept confidential.

1.2.7 Reimbursement for Participation

No financial incentives will be provided to participants, however all participants will be given snacks while participating in structured research activities. Participants will choose the site of their interviews to avoid unnecessary transport or child-minding costs, but if the participant chooses to travel for the purpose of maintaining privacy, they will be reimbursed for travel costs and, if necessary, a volunteer made available to assist with child minding. Participants involved in more ongoing research activities (particularly in the qualitative study) may also be offered assistance with homework, or other forms of non-monetary help based on the nature of the engagement. Following participation all participants will receive a Certificate of Participation regardless of completion. As in previous research conducted by members of this research team with HIV-affected communities, financial rewards will not be used. This is for two primary reasons: firstly, as financial incentives can in some cases lead to conflicts within the community or household, and secondly, in order to prevent adolescents agreeing to participate in the study in order to access money – which would reduce the voluntary nature of consent.

1.2.8 Emergency Care and Insurance for Research-related Injuries

Salaries for field staff who are not covered by University insurance include an additional sum to be paid towards medical insurance. In addition, the projects have extensive staff safety protocols, addressing issues from hazardous animals at research sites to road safety risks. All staff are trained in these protocols, which are available and attached.

1.2.9 What Happens at the End of the Study?

The study design, in partnership with government, NGOs and HIV-positive adolescents, has the specific aim of informing policy and programming. This collaborative approach to identifying the research focus and in designing the study is central in ensuring that findings will have direct relevance for HIV programming in South Africa's public health sector and beyond.

Specific policy impacts will include direct input into USAID, UNICEF, UNAIDS and PATA programming (through our regular meetings with these organisations), and national policy commitments such as sub-Saharan African governmental 'National Strategic Plans', National Action Plans for AIDS-affected children and the Department for Social Development's Strategy for Adolescent Sexual and Reproductive Health Services. Research team members have experience in the dissemination of research findings for inclusion in national HIV policies for both academic and advocacy purposes.

Dissemination and outputs will take place throughout the study and will include both peer-reviewed publications and dissemination strategies targeted at policy-makers and programmers. With the research partners PATA, UNICEF, UNAIDS and the South African government, dissemination will include one-page policy briefs (see for example www.youngcarers.org.za/publications), presentations at key policy meetings such as the International AIDS Conference, the International Conference for AIDS and STI's in Africa, as well as smaller, high-level policy forms with government ministers in the Southern African region, funders such as UNAIDS/PEPFAR and the Global Fund. Dissemination of research findings will also take place at study sites, with health services, community meetings, and with local leaders.

Feedback to participants is a key part of a youth-focused research design (122). At each stage of review and data collection, the study will create 'brief reports': summaries of study findings in lay language. These will focus on findings relevant to NGOs, clinics and government in their work with adolescents. Researchers will also report back verbally to adolescent participants, encouraging their thoughts and feedback on emerging findings. For example, the later stages of the qualitative research will ask participants to respond to some of the quantitative findings, which will serve as a form of feedback. Presentations will be made to local NGOs, health services and community groups. No identifiable details will be given in any dissemination or feedback.

1.2.10 Research team

The UK and South Africa-based team builds on established strong working relationships between academics, government and civil society. Dr Cluver (Oxford University & University of Cape Town) has led two longitudinal surveys of 8500 AIDS-affected adolescents in South Africa and acts as an adviser to the SA Government, WHO, USAID, UNICEF and Save the Children; Dr Hodes (University of Cape Town) has conducted qualitative research on partnerships for ART provision and healthcare workers and patients experiences of SRH services with a focus on abortion; Dr Mark is Executive Director of Pediatric AIDS Treatment for Africa, an NGO working with 235 HIV clinics in 23 Sub-Saharan African countries, Dr Boyes (Curtin University) is a psychologist specialising in stress and coping; Dr Kaplan is a sociologist with experience in quantitative and qualitative research on HIV and modeling viral load and other biomarkers (University of Oxford), Professor Orkin (University of Witwatersrand) is the former Chief Statistician of South Africa and is an expert on community

survey analysis. The team includes three Oxford University doctoral students (on Clarendon and Rhodes scholarships: E Toska, B Vale, M Pantelic) and a PhD and MSc student, both officials in the Department of Social Development (M Nxumalo and L Mokotedi), and based at Medunsa and University of Pretoria respectively.

The study includes a 'Methods Advisory Panel' of international experts in adherence research (Dr E Lowenthal, Children's Hospital of Philadelphia, Dr C Luo, Senior HIV Program Adviser, UNICEF and the UN Technical Advisory Group for Adolescents Living with HIV: Dr S Kassede, Dr C Suzuki, Dr D Chamla, Ms P Lim Ah Ken). In addition, the study includes a 'Policy Advisory Panel' (Dr R Yates, Senior Adviser, HIV/AIDS, UNICEF HQ,) UNAIDS (Dr R Jackson, UNAIDS Secretariat), UNICEF South Africa (Dr S Bhardwaj, Senior HIV/AIDS specialist, Dr S Crowley, Chief of Health), The South African Department of Social Development (Dr M Kganakga, Chief Director, HIV/AIDS), Department of Health (Dr L Madisha, Division of Pediatric HIV), Department of Basic Education (G Ndebele, Deputy Director-General of Social Inclusion). In addition, our Teen Advisory Group of AIDS-affected adolescents – with whom we have worked since 2008 – will be actively involved throughout the research in ensuring applicability and teen-friendly approaches.

1.2.11 Stakeholder Participation

Teenagers living with and affected by HIV/AIDS have been key contributors in designing, implementing and reviewing this study. The research team has a longstanding working relationship with a Teen Advisory Group (comprised of AIDS-affected teens and teens on ART, from the Western Cape and Eastern Cape). We will also be facilitating and working within existing programmes for a group of AIDS-affected teenagers linked to the Raphael Centre, Grahamstown, and a group of teenagers on ART linked to the Keiskamma Trust, Hamburg. Questionnaires and data collection tools will be piloted with these groups of young people who will be asked to give suggestions on how the design may be adapted to ensure it is teen-friendly. These groups will also highlight key issues and themes for exploration, suggest sensitive and exciting ways for engaging youth, and provide advice about the appropriate language and terminology to use in relation to sex, illness, medicine-taking and health. Where appropriate, some of these young people may be recruited as key informants or translators for the qualitative research.

The collaboration with adolescent participants will be a crucial aspect of the development of an adolescent-friendly support tool to promote ART adherence and SRH service uptake. Through participatory workshops, adolescent participants will lead the design of a programmatic tool to support their desired retention in care and to help make the healthcare setting more youth-friendly.

The following stakeholders have been involved in ongoing consultations with the research team, focusing our attention on the most relevant and useful questions for practitioners in the field: UNICEF, the South African government, Paediatric AIDS Treatment for Africa, Kidzpositive, the Treatment Action Campaign, Kheth'Impilo, Keiskamma Trust and Raphael Centre. These organisations have contributed to our research design and will be key partners in disseminating findings.

Finally, participants in both the qualitative and quantitative study will be briefed on emerging findings and asked to provide feedback.

1.2.12 Conflicts of Interest

No member of the research staff will receive incentives for recruiting participants or for any other purpose directly related to the study.

1.2.13 Capacity-building and authorship

All of our research studies include active capacity-building approaches, which have been discussed extensively with our Government partner the National Department of Social Development (DSD), and are monitored by the HIV and AIDS Division of DSD via bi-annual reports. We believe that effective capacity-building cannot take place without clear academic benefits of participation for stakeholders, although those benefits have to be tailored to different groups and individuals. The project will take place in collaboration with a research team at Frere & Cecilia Makiwane hospitals in Buffalo City Sub-District, and will work collaboratively with this research team on publications.

Capacity-building within this study occurs on several levels of expertise. Two senior government officials (Mr Lentswe Mokodeti and Ms Zanele Mercedes Nxumalo) will be undertaking MSc and PhD respectively through the research study, and are already being co-supervised by Dr Cluver. We also focus on capacity-building amongst local research assistants, data capturers and community health workers on the study. All fieldwork staff have regular 'training workshops' as part of their paid work time (we usually do them after our weekly team meetings) on a range of topics, including those designed to build their capacity in working with vulnerable families (such as play therapy, counselling skills, gender and sexuality sensitivity) and those designed to help them with future careers (such as CV-writing workshops, interview skills). In this, and all our previous projects, we have a system of a 'capacity-building fund' for every local staff member. This is a sum of money available to all staff but only usable for training or the gaining of qualifications. In the past, our staff have used this for a surprising range of purposes, including completing their Matric (High School certificate) in night school, training as an HIV counsellor, registering for diplomas in nursing and social work, and learning to drive. The provision of the fund worked well as an incentive to staff to find out about training courses and to think in a proactive and strategic way about their careers in their quarterly individual 'capacity-building' meetings with the Project Manager.

In terms of publications, use of data and distribution of results, our approach emphasises providing opportunities for the whole team, including the capacity-building students, local staff, NGOs and government bodies involved to publish from and distribute findings. In our experience, even the most detailed advance-planning of who will first-author publications can require changes (as the study progresses and people's interests and expertise develop) but perhaps more important is the *ethos* of the research team regarding this important area. We believe that all publications should be multiple-authored, to reflect both the collaborative nature of the study but also the collaborative approach we have to the analysis and writing of publications. We also believe that all study members should be encouraged and supported to write first-authored publications using data from the study. However, we should note that this is not always simple – we have in the past had extremely long delays from students who have intended (and very much wanted) to write papers from the studies, but have not managed to do this. We reiterate that – beyond the core research team – other research members only have access to the anonymised version of the dataset, and only then after signing confidentiality agreements with the project investigators. In light of potential collaboration among this research team and other teams, such as the Adolescent Transition Model Project

team based at Frere and Cecilia Makiwane Hospitals in Buffalo City Sub-District, all data sharing will be conducted based on data sharing agreements signed by all parties. These agreements, which will be reviewed and approved by the Principal Investigators and relevant institutions, will outline who can access the anonymised dataset, as well as shared analysis and publication rights and responsibilities.

1.2.14 Ethical and Regulatory Compliance

There is an extensive body of local and international literature on ethical concerns in conducting research with vulnerable children and young people. The ethical guidelines for this study are informed by a number of sources. These include the ongoing academic debate on informed consent and confidentiality (123), the ethical requirements of the universities and research institutions involved in research design, and ethical guidelines from psychological research bodies such as the British Psychological Society (113).

In planning study design and ethical protocols, key research guidelines and legislation in South Africa have been considered, including the Department of Health's Ethics in Health Research Guidelines (2004), the Department of Health, Guidelines for Good Clinical Practice in South Africa (2nd Edition 2006), the Open Society Foundation for South Africa's 'Best Practice Guide to HIV Disclosure' (2009), the AIDS Law Projects' 'HIV and the Law: A Resource Manual' (2003), 'Selected ethical-legal norms in child and adolescent HIV prevention research: Consent, confidentiality and mandatory reporting' (EDCTP 2011), the National Health Act 61 of 2003 (enforced starting 2012), the Children's Act (38 of 2005), the Children's Amendment Act (41 of 2007) and the Sexual Offences Act (32 of 2007). These South Africa specific documents have been supplemented by international guidelines, such as the WHO's Guidelines on HIV Disclosure and Counselling for Children up to 12 Years of Age (124), and the Helsinki Declaration (2008).

1.2.15 Appendices

All appendices can be downloaded here:
https://www.dropbox.com/sh/defzupkm36b76j3/AABRU2oxMlsBglcsLVzfI6qda?dl=0

1. Community and Schools information sheet (quantitative)
2. Information and consent form for adolescent participants (qualitative)
3. Information and consent form for adolescent quantitative questionnaire (quantitative)
4. Information and consent form for participatory workshop on support tools design (qualitative)
5. Guardian consent form for adolescent participation (qualitative)
6. Information and consent forms for caregiver participation (qualitative)
7. Information and consent forms for healthcare and social worker participation (qualitative)
8. Interview guides: adolescent, caregiver, healthcare and social worker participation (qualitative)
9. Adolescent screening sheet
10. Example referral forms for adolescents
11. Adolescent certificate of participation
12. Letter of authorisation: ethics approval from University of Oxford,
13. Letter of authorisation: ethics approval from University of Cape Town
14. Letter of authorisation: Eastern Cape Department of Health
15. Letter of authorisation: Buffalo City Sub-District Department of Health
16. Letter of Authorisation: Eastern Cape Department of Basic Education
17. Letter of support: UNICEF

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1.3 MZANTSI WAKHO PLUS BABY PROTOCOL

Note: this protocol complements the MW overall protocol and sections relevant to both MW and MW+ are not repeated here.

1.3.1 Purpose and Summary

Adolescents in Southern Africa show high rates of defaulting from ART treatment. Little research has been conducted on why adolescents default, how health services respond to defaulting adolescents, and what can be done at health service and community levels to reduce defaulting and re-initiate defaulting adolescents onto ART. This mixed-methods qualitative and quantitative research will build on an existing 3-year longitudinal study 'Mzantsi Wakho': the world's largest community-based study of adolescents on ART. **It will extend beyond the initial study to explore and understand pathways to ART adherence using intensive tracing methods to contact defaulting adolescents.**

The specific research objectives of this project are:

1. To explore *why* HIV-positive adolescents default from ART and become lost to follow-up (LTFU), and what happens once they have 'opted out' of ART programmes, particularly PMTCT.
2. To investigate *if* and *how* adolescent ART-defaulters and LTFU patients are managed by healthcare workers and systems in clinics and communities.
3. To collaborate with HIV-positive adolescents who have defaulted on ART, and with healthcare and social service providers, to *design programmatic responses* to adolescent defaulters with the objective of re-initiating patients onto ART, and motivating better adherence and retention in care.

Mzantsi Wakho Plus will provide additional insights specifically around defaulting and treatment interruptions: a topic of paramount importance identified during the initial findings of the study, but which cannot be addressed within the planned work or budget of Mzantsi Wakho. By building on the initial findings and study cohort, Mzantsi Wakho Plus will explore why adolescents patients default from ART or are lost to follow-up, how this relates to their social and health circumstances, and how they can be re-initiated onto ART.

1.3.2 Background

Sub-Saharan Africa is home to 1.2 million HIV-infected adolescents, who require antiretroviral therapy (ART) to reduce mortality, morbidity and prevent further HIV infections. According to the World Health Organization, HIV is the primary cause of death among adolescents in Sub-Saharan Africa, but there remains very limited research conducted with adolescent ART-users in Sub-Saharan Africa. Existing studies and initial findings from the Mzantsi Wakho study show elevated defaulter and loss to follow-up rates compared to other age groups of ART users. However, the reasons why adolescents are at increased risk of defaulting, and why they are not coming back into care, are insufficiently understood. Clinic-based systems for defaulter tracing, particularly in resource-constrained contexts, remain poorly documented. We do not adequately understand how health workers and systems are responding to adolescent defaulting, and whether these responses are effective in re-initiating adolescents into HIV care, treatment and support.

Based on Mzantsi Wakho initial findings (qualitative and quantitative), **pregnant teens who initiate PMTCT treatment during ante-natal care services** were at an increased risk of LTFU/defaulting from treatment compared to all the other adolescents included in the study.

A systematic review estimated that 49.1% of PMTCT patients became lost to follow up between ANC care and delivery (a pooled proportion of 6 studies) (Sibanda, Weller, Hakim, & Cowan, 2013), though no adolescent-specific data were reported. Due to poor linkages between clinics of various levels, particularly in light of the decentralized ARV treatment programme in South Africa, it is difficult to assess from existing clinical records, whether HIV-positive adolescents on PMTCT regimes have completely interrupted treatment, have self-transferred elsewhere or have died.

In addition to patients who are defaulting or lost to follow-up, preliminary patient file reviews suggest a substantial proportion of adolescents who were having **unscheduled treatment interruptions** before subsequently returning to care. Unstructured treatment interruptions have been linked to greater risk of opportunistic infections, medication resistance, and greater mortality in adult populations (Kranzer et al., 2010). A systematic review of unstructured treatment interruptions reported that factors associated with treatment interruption included: drug toxicity, adverse events, and side-effects; studies from developing countries additionally cited treatment costs and pharmacy stock-outs as concerns, with younger age as a frequently reported risk factor (Kranzer & Ford, 2011). Other risk factors included CD4 count, as well as socioeconomic variables. Studies to date among HIV-positive adolescents have focused either on end-point outcomes (e.g. viral load suppression, opportunistic infections) or self-reported short-term adherence to ART, without combining life events and treatment-taking patterns. Mzantsi Wakho Plus will record the treatment-taking patterns of these young people through participatory research and through reviewing treatment histories recorded in patient files. Research will aim to identify which types of life events are linked to treatment interruptions, and which are linked to re-initiation of ART.

The combination of longitudinal quantitative data sources with in-depth qualitative research will provide a unique perspective on why adolescents default, identifying potential mechanisms for reducing defaulting and improving retention in care.

The proposed study will aim to address pressing gaps in research identified by Mzantsi Wakho baseline research, a project funded by the International AIDS Society's Collaborative Initiative for Pediatric HIV Education (CIPHER) and the Nuffield Foundation in the UK. Building on Mzantsi Wakho strengths, this research **focuses on the health behaviours of HIV-positive teenagers *inside and outside* of the clinical context.** As adolescence is a time of increased risk-taking and experimentation, HIV-positive teenagers represent an especially vulnerable and challenging group for service providers. However, their retention in ART programmes remains under-investigated, and HIV-positive adolescents have rarely been included as partners in the design and operationalization of their own HIV and sexual health services. Our researchers will conduct interviews with teen participants in their homes or at a venue of their choosing, including shack settlements largely devoid of infrastructure and sanitation services. Researchers are locals who have a direct and intimate knowledge of these neighbourhoods. Working with teenage participants in their homes affords rare and valuable insights into the experiences of these adolescents beyond the health sector, in some of the most resource-constrained areas in South Africa.

1.3.3 Definitions

Adolescents refers to 10-19 year olds, using the WHO definition.

Defaulters or defaulting patients are those who are not taking their ART as prescribed. These patients may or may not continue to be involved with the healthcare system, so not all of them are automatically lost to follow-up. A study from South Africa defines patients defaulting from ART as those who had not presented at the pharmacy for refills for more than 30 days (Kranzer et al., 2010).

Lost to follow-up is a general term for largely unknown outcomes of patients who have not returned to a particular clinic to collect their ART or consult a healthcare provider. The exact definition of lost-to-follow-up might differ by clinic, but for this study, an adolescent is defined as lost to follow-up, either when they miss a number of consecutive visits or they do not return for visits over a period of time, primarily three or six months. In a study from the Western Cape (Nglazi et al., 2012), '**lost to follow-up'** referred to patients that had failed to attend the clinic for ≥ 12 weeks and were not known to have died or to have been transferred out to another facility. In second study from South Africa (Evans et al., 2013), **lost to follow-up** was defined as having missed a clinic appointment (clinical assessment, antiretroviral drug pickup or counsellor visit) by ≥ 3 months after the scheduled visit date. These lost to follow-ups were estimated to be approximately half of those on-treatment (Evans2013).

True outcomes for such patients can be divided into three categories: (1) patients who have self-transferred to another facility,[3] (2) those who have died and (3) those who have discontinued treatment (Wilkinson, Skordis-Worrall, Ajose, & Ford, 2015).

Treatment interruptions is defined as a patient-initiated episode of stopping ART but who subsequently resumed treatment. A systematic review of unstructured treatment interruption found that that the definition of treatment interruption varied greatly among the 70 studies included (Kranzer & Ford, 2011).[4]

1.3.4 PMTCT in South Africa

In the revised national ART guidelines, Option B became South Africa's PMTCT regime of choice (DOH 2013). Preceding and following these guidelines, academics and practitioners have debated the benefits of implementing Option B+ (Besada et al., 2012; Coutsoudis et al., 2013; Pillay & Black, 2012). Though the national guidelines, nor the NSP 2012-2016, did not include Option B+ as the country's PMTCT option, the Western Cape Provincial Government and its partners, notably Medecins Sans Frontiers, have been implementing Option B+ in the province since 2013 (Stinson et al., 2014). Since then, though the national guidelines have not been changed, several treatment programmes, facilities and provinces may be implementing Option B+. It is not clear what the Eastern Cape guidelines for Option B/B+ are but facilities visited during MW baseline report applying one of the two guidelines. This makes it harder to know whether a young mother or pregnant teen who is HIV-positive should be on lifelong treatment or prophylaxis for PMTCT.

Eastern Cape facilities that implement Option B+ (as of March 2015):

- Frere Hospital (confirmed by email by Dr. Justus Hofmeyr, January 21, 2015)

National Strategic Plan for 2012-2016 (SANAC, 2011)

[3] Two previous reviews have highlighted the substantial numbers of self-transfers amongst LTFU patients. The first, a systematic review, reported self-transfer rates of 12–54% amongst patients found alive (Brinkhof et al. 2009). The second, a narrative review, estimated a crude unweighted median self-transfer rate of 48.5% amongst those reported in 14 cited studies as LTFU (Geng et al. 2010b).

[4] Twenty-eight did not define the duration of treatment interruption, while of the 42 studies that did specify a definition, duration ranged from 24 h to 1 year (Figure 2). Two cross-sectional studies investigating self-reported treatment interruptions defined interruption as discontinuation of all drugs for more than 24–48 h in the 4 weeks preceding the survey (Glass et al. 2006; Marcellin et al. 2008). Two studies investigating short interruptions defined a maximum duration of treatment discontinuation of 1 month (Oyugi et al. 2007) and 3 months (Taffe et al. 2002).

Initiate all HIV-positive TB patients on lifelong ART, irrespective of CD4 count. In line with WHO recommendations, all HIV-positive TB patients should, with immediate effect, be initiated on ART, irrespective of CD4 count. The same intervention should be considered for pregnant women as evidence becomes available. Until such time, the current guideline of initiating pregnant women on ART at or below CD4 350 will apply, and every effort must be made to initiate pregnant HIV-positive women on ART as early as possible.

National treatment guidelines (published: 24 march 2013; implemented as of 1 April 2013):

Objectives included in the guidelines:

- 1.3 Pregnant women with CD4 < 350cells/mm3 for lifelong ART and CD4 >350cells/mm3 for prophylaxis (Option B)[5]
- 1.5 Introduce FDC ART for HIV positive pregnant women irrespective of CD4 count during pregnancy and during the breastfeeding period

National Eligibility Criteria

Lifelong ART

- CD4 <350 irrespective of WHO clinical stage
- All types of TB
- WHO stage 3 or 4 irrespective of CD4 count

Fast Track Initiation (within7 days of being eligible):

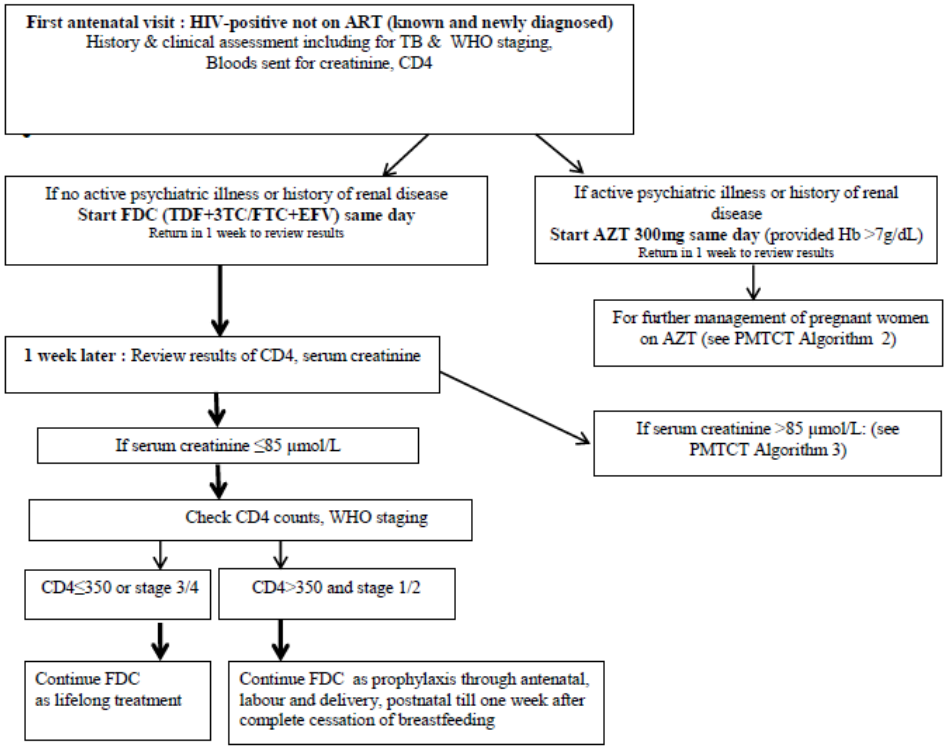
- HIV positive women who are pregnant or breastfeeding OR
- Low CD4 <200
- Stage 4 irrespective of CD4
- TB/HIV co-morbidity with CD<50

[5] Option A promotes: the use of zidovudine (AZT) from 14 weeks' gestation, single-dose nevirapine (NVP) at birth, and 7 days of AZT/ lamivudine (3TC) postpartum for the mother; and daily NVP for the infant until the cessation of breastfeeding or until 4 – 6 weeks of age if the mother is receiving antiretroviral therapy (ART) or is not breastfeeding. Option B recommends ART for the mother from 14 weeks' gestation until birth or the cessation of breastfeeding, and the use of NVP for the infant until 4 - 6 weeks of age. Option B+ advocates lifelong ART, and NVP for the infant as for Option B (Besada et al. 2012).

*Pregnant women assigned to lifelong ART or prophylaxis based on CD4 count (p.8)

Figure 1 PMTCT Algorithm 1 New HIV Positive Diagnosis During Pregnancy

Algorithm 1 is for all women who are newly diagnosed as HIV positive anytime during pregnancy AND women who enter ANC with known HIV positive status and not yet on ART.



1

* If on ART already, then continue ART regimen and if on a compatible regimen (and over 18), switch to FDC. This is relevant particularly to HIV-positive adolescents who initiated ART before they were pregnant, e.g. vertically-infected adolescents.

Most recent published ANC surveillance (2012 data collection, 2013 report DOH):

- Eastern Cape HIV prevalence: 13.5% general population, 29.1% ANC women
- Amathole district: 31.5% in 2012, up from 28.4% in 2011
- Buffalo city sub-district: 33.4% in 2012, down from 34.1 in 2011

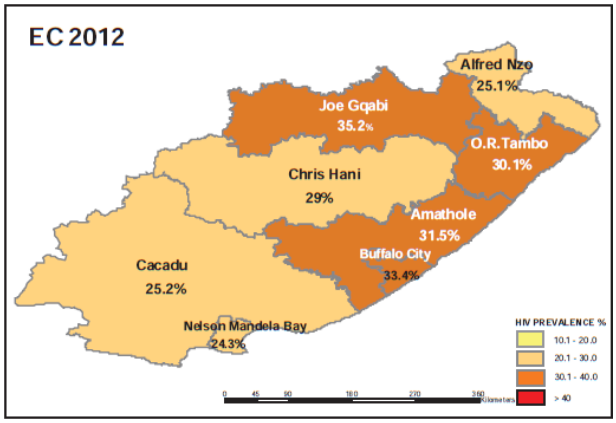
- Prevalence by age groups among the ANC sample recruited (first time goers in October 2012).

Table 9: HIV prevalence among antenatal women by age group, Eastern Cape, 2010 to 2012.

Age group (Years)	2010		2011		2012	
	N	% Prev.	N	% Prev.	N	% Prev.
<15	19	0.0	24	0.0	22	13.6
15 -19	907	12.0	992	11.2	1 080	11.0
*15 - 24	2 097	21.8	2 162	20.7	2 431	19.4

In practice, this means that about 1 in 10 pregnant 10-19 year olds who are pregnant could be HIV-positive, but not necessarily lifelong ART eligible or initiated on life-long treatment.

1.3.5 Methodology



Using both qualitative and quantitative methods, and leveraging the participation both of (a) HIV-positive teenagers and (b) frontline healthcare workers leading, managing and monitoring the ART rollout in South Africa, this mixed-methods research project has four key components:

1) In-depth **qualitative** research with adolescents ART defaulters and key informants (health and social workers) on the causes and consequences of ART defaulting. This component of the research will focus not on the medical effects of ART defaulting, which are well-established in clinical research. Rather, it will explore teenagers' experiences of defaulting from HIV treatment programmes, and their understandings of the effects of this.

2) Participatory workshops to involve adolescents as key stakeholders in the collaborative design of youth-driven support tools to:

a) Support ART adherence and SRH service retention in care,

b) Assist youth in negotiating the barriers that impede retention in care, and

c) Customize ART and sexual health education and support programmes to reduce risk of defaulting.

3) A linked **3-year longitudinal quantitative** study of HIV-positive adolescents who have defaulted from their treatment or are lost to follow-up in the health system. The quantitative arm of the study will combine three data sources: (1) face-to-face interviews, (2) patient medical records and (3) clinical-level data, including *defaulter support and tracking services available* in facilities.

1.3.6 Study Participants

<u>Sampling</u>

The goal of MW+ is to expand the MW sample with hard-to-reach populations. After preliminary analysis, this will involve a three-prong sample expansion:

- Pregnant or young mother teens who are HIV-positive and expected to be on lifelong treatment (ZEBRAS). Because it will be hard to identify those who are meant to be on lifelong ART through screening questions, we will interview **all** HIV-positive 10-19 year olds who are or have ever been pregnant and eligible for ART initiation (PMTCT or lifelong regime). See Screening forms in Appendices 10.1 (pregnant adolescents) and 10.2 (new mothers).
- Female adolescents have been identified through ANC clinics/ hospitals for lifelong PMTCT. Track them in the communities (will be challenging). We only have about 30+ of these in our roster, mostly with missing contact information.
- These pregnant or young mother adolescents could fall into two sub-groups:
    - Those who disclose their status to the project/ Research Assistant

- Those who do not disclose their status to the Research Assistants. During MW baseline, several young women in this group were interviewed and MW+ will follow up with them.

- 15-19 year old adolescents (male and female) – current rates of sexual activity in this age group are 47.5% in our total sample and 43.6% among Giraffes & Elephants.
    - There are about 50 of them as follow-ups or home visits to be done in East London
    - Another 75 are “Go to clinic” so perhaps they can also be tracked by the EL team.
- Male HIV-positive adolescents who interrupt treatment during circumcision school/ camp.
- If we are making good progress on the above three sub-groups, consider tracing participants marked lost to follow-up in the records of the 39 clinics.

1.3.7 Recruitment & Enrolment

Clinic-based recruitment

Overall, MW+ will attempt recruitment from different types of facilities. These sampling strategies complement the sampling of 10-19 year old adolescents eligible for treatment recruited through ARV units (adults or pediatric), happening as part of Mzantsi Wakho. The following table summarizes the types of facilities where we will aim to find the above priority sub-groups.

Sub-group	***ANC clinic***	***Pediatric clinic***	***SRH clinic***	***Male circumcision clinic***	***Labour wards***
Pregnant HIV-positive adolescents					Discussed but not considered ethically and practically feasible
New/ recent mothers HIV-positive adolescents					
Older teens 15-19 years old, including males					
Young males who are attending circumcision school					
LTFU					

Focus in a few facilities in total, but start with one or two:

- CHCs: DVDH and EG – recruit at two locations
    - Pediatric care for teen mothers of HIV-positive babies
    - ANC care for pregnant teenagers
- Hospitals: Frere and CMH

- At days when the younger children come for check-ups or immunization and ask pediatric nurse to refer teenage moms (or grandmas who may be bringing in the babies instead of their young mothers) to the RA for a chat – give toy to all 10-19 year olds mom/ pregnant ones? While they are debates over immunization coverage rates in South Africa[6], immunizations for newborns take place at:
  - 6 weeks: TOPV (1), DTP-HiB (1), Hep B (1)
  - 10 weeks: TOPV (2), DTP-HiB (2), Hep B (2)
  - 14 weeks: TOPV (3), DTP-HiB (3), Hep B (3)
  - 9 months: Measles (1).
- At ANC talk to all 10-19 year old pregnant women who come in and do the screening (NOTE: not before their appointment, but keep in mind that if it is their first ANC appointment they might have just been told they are positive and must initiate ART).

The following section outlines process/ plans for recruitment at each facility type, and will be updated as an organic document of what approaches we use:

Recruitment location 1: ANC clinics

Eligibility criteria:

- 10-19 year old
- HIV-positive
- Pregnant now or recently (in the last year)
- Initiated in the last 1-year on ART

If the adolescents are present in person, the RA will have a screening chat using the questions as guidelines and making sure that the chat is done in as confidential a way as possible given the waiting room set-up.

If the adolescents are not there in person – get contact details from the nurse (Qualitative research suggests that these contacts may be the mother of the adolescent more often than the teen themselves). A draft introduction script for the phone call is included in Annex 10.3, to be adapted by the RAs as they test/ improve it.

*Try the above for 2-4 weeks with one RA for 2 weeks at 2 different locations (one CHC – Empilweni Gompo and one hospital – Frere). Regroup and review process at the end of March when RH/ET/LC are in EL.

** Discuss next steps for the other recruitment locations once ANC clinics have been tested.

Recruitment location 2: Pediatrics clinic

Recruitment location 3: Male circumcision clinics/ nurses

Recruitment location 4: TOP clinic

Challenges to plan/ reflect on:

- Not all TOP patients accept an HIV test
- Not sure about what ART initiation practices take place at TOP clinics. Must investigate further.

<u>Community-based recruitment</u>

Based on the planning skype of February 19, 2015 it was decided that we will postpone starting community-based sampling for MW+ only and focus on tracing into the community young mothers or pregnant teens identified through facilities. This decision will be reviewed in March 2015.

- Mdantsane as a tester for community-based sampling
  - Go to the primary level clinic or start at the counsellor's office? Or at the local church? Support groups? Daycares?

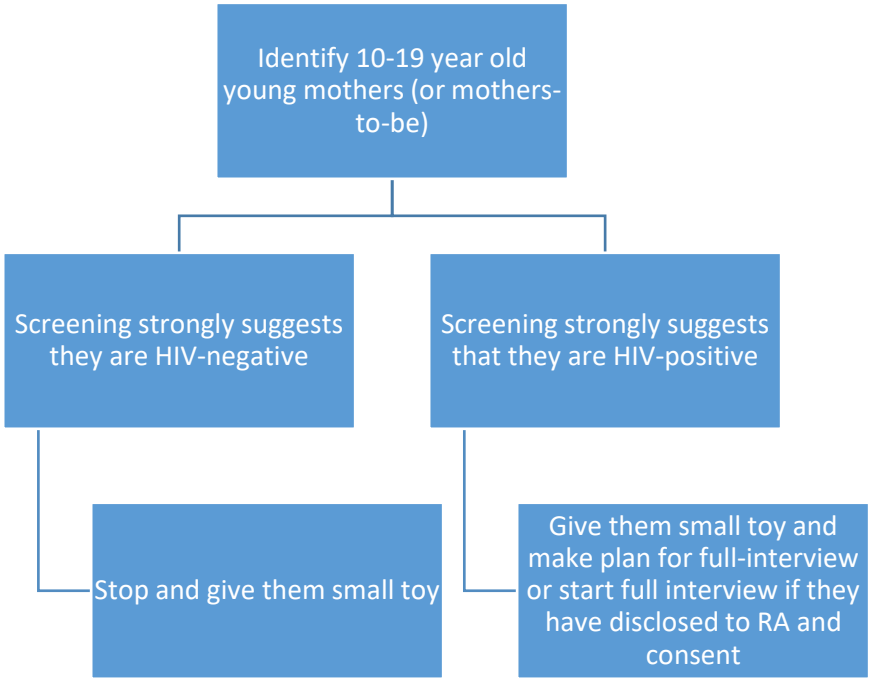
[6] National data sometimes report 96% coverage, and others >100% in provinces such as KZN. UN/WHO estimate 64% fully immunised (data from 2012). Data from 2013 are a bit more hopeful: http://www.data.unicef.org/fckimages/uploads/1421188309_south_africa_rev_13_FINAL.pdf

- Door-to-door with snowballing
- Social workers who work in Mdantsane?

*hold off on testing this unless required by clinic-based recruitment as community-tracing.

Cascade of Recruitment

Community-based recruitment



1.3.8 Eligibility Criteria

- 10-19 year old female adolescents (ZEBRAS)
  - Ever been pregnant (now or before)
  - Tested HIV-positive before, during or after pregnancy
  - Initiated on ART as prophylaxis or lifelong treatment
  - Informed consent from adolescent and caregiver (for those under 18)
- 15-19 year old male and female adolescents
  - HIV-positive
  - Ever initiated or were eligible for ART
  - Informed consent from adolescent and caregiver (for those under 18)

Screening forms are included in Appendices.

1.3.9 Timeline

Activity/ Task	Team Members	Jan	Feb	Mar	April	May	June	July	Aug	Sep	Oct	Nov	Dec
Protocol and Screening/ Recruitment Processes finalised	ET/ RH to draft; Full team to finalise		X										
Clinic-level mapping (add items on defaulter tracking?)	All team, MI to coordinate		X	X									
Administrative arrangements	RH (UTC)/ MP/ ET		X										
Budget review and planning	RH/ET & UCT			X									
QUANTITATIVE COMPONENT													
Quantitative MW+ baseline fieldwork (target n=100 HIV+ pregnant or young mother adolescents)	MP & RAs (ET to support from CT as needed)		X	X	X								
Quantitative MW+ baseline fieldwork (focus on older teens 15-19 year olds, after review of what happens in March-April)	MP & RAs				X	X	X						
Quantitative clinic-level data collection, recording systems for tracing defaulters at various clinics	MP/ MI support from US, ET support from CT				X	X							
Quantitative MW follow-up (MW+ RAs to join MW RAs unless hired for qualitative work with Bex - TBD)	MP & RAs							X	X	X	X	X	X
QUALITATIVE COMPONENT													
Clinic-based interviews/ observations with nurses to record defaulter tracking systems	RH & RA												

1.3.10 Detailed Qualitative Activities

In-depth qualitative work and quantitative analysis will identify (1) reasons for defaulting by HIV-positive adolescents, and (2) health service responses. Focus groups and participatory workshops with adolescents and their care-givers will develop adolescent-friendly tools to reduce defaulting and promote the retention in care and the transition to adult ART programs that are necessary for long-term survival with HIV.

1.3.11 Detailed Quantitative Activities

Clinic-level tracking systems

Integrate a few questions/ items into the clinic-level data collection that is about to happen. Finalize all questions with the field team in February 2015. These items would not necessarily be included in the MW adherence quantitative analysis but will inform the potential interventions that could take place to support retention in care for the hard-to-reach teens included in the study.

Face-to-face interviews

- If the teens disclose during the screening, interview them using the ZEBRA form. Additional proposed questions for Zebras in section **9.2**.
- If teens met by the regular MW team, interview them using the Giraffe or Elephant form, then use the Zebra GAP form. Questions to be finalized
- If HIV-positive pregnant teens or teen moms met by regular MW team but do NOT disclose their status, interview as a BEAR and follow up by more trained MW+ team

Patient-file data extraction

- Using knowledge of current SA treatment guidelines, we would code whether a patient was initiated on PMTCT Option B or B+.

1.3.12 Ethics

Consent Forms/ Processes

- Follow consent-obtaining processes outlined in the MW protocol. Following the MW protocol, consent to participante in MW+ will take place after the initial screening chat with the potential participant.
- Use the same consent form and if team thinks the association with MW logo is harmful, we can remove. Review after a few weeks of testing.
- Ensure consent form includes consent to look at patient files.

1.3.13 Appendices

Screening Sheet – Pregnant Teens

NOTE: similar to the MW screening, these questions are suggestions on how we can get enough information to assess:

2. Whether adolescent mom (or mom-to-be) is HIV-positive OR
3. Whether adolescent mom (or mom-to-be) has ever taken ART or been eligible to take ART.

The purpose of asking these questions is to make the young (future or current) mother comfortable to chat about their baby's and own health. If possible, the goal is to figure out how likely that the mother is HIV-positive and whether they ever were prescribed ART.

Proposed questions & prompts

1. How old are you? _____ (can ask for birthday and calculate)
2. Have you ever been pregnant? (*note how many times, if ever*) _____
3. How many children do you have? How old are they?
    a. Child 1: _____ Age: _____
    b. Child 2: _____ Age: _____
    c. Child 3: _____ Age: _____

YOUR PREGNANCY

4. When will your baby be born?
5. Have you seen a doctor or nurse since you found out that you were pregnant?
6. *We often take special medication when pregnant. This can be for high blood pressure or diabetes or to improve the health of the baby.* Did the nurse give you medicines or injections to take while you are pregnant?
7. What were the medicines that they gave you? _____ If they don't know the name, ask to see the box or have them describe the number of pills, how often they take them, etc.
8. Are you still taking them now?
9. Have you had any side-effects from these medicines?
10. How long will you have to take them for?
    a. Until the baby is born
    b. Until you stop breastfeeding
    c. For a long time, to stay healthy and for the baby to be healthy

YOUR OVERALL HEALTH

11. How has your health been?
12. Do you remember last time you had to go see the nurse/ doctor? What was it for?
13. Have you ever had to take medication for longer than 2 weeks at a time?
    a. If yes, what was it for?
14. Are you still taking any medication?
    a. What is it for?
    b. What is the medication – ask to see it if they have it on them.

Screening Sheet – Teen moms

NOTE: similar to the MW screening, these questions are suggestions on how we can get enough information to assess:

1. Whether adolescent mom (or mom-to-be) is HIV-positive OR
2. Whether adolescent mom (or mom-to-be) has ever taken ART or been eligible to take ART.

The purpose of asking these questions is to make the young (future or current) mother comfortable to chat about their baby's and own health. If possible, the goal is to figure out how likely that the mother is HIV-positive and whether they ever were prescribed ART.

Proposed questions & prompts

15. How old are you? _____ (can ask for birthday and calculate)
16. Have you ever been pregnant? (*note how many times, if ever*) _____
17. How many children do you have? How old are they?
    a. Child 1: _____ Age: _____
    b. Child 2: _____ Age: _____
    c. Child 3: _____ Age: _____

YOUR BABY'S (BABIES') HEALTH

18. Tell us a bit about your child (children)? What are they like? Is the baby sleeping through the night? Is he/she eating well/ crying a lot? And how are you coping?

Note: ask about their favourite food or toy or what are their personalities like? Then ask about their health.

19. *Prompt: We know that all babies get sick sometimes, has (any of) your baby (babies) had to take any medication for a long time?* How has the baby (babies) health been?

_____
_____

20. Were your children able to get their immunizations?
    _____
21. We would love to see their Road to Health cards, if you have them?
22. Has your baby (any of your babies) had to take any medication for longer than 2 weeks at time?
    a. If yes, what was it for?

YOUR HEALTH

23. Did you see a nurse or doctor while you were pregnant?
24. *We often take special medication when pregnant. This can be for high blood pressure or diabetes or to improve the health of the baby.* Did the nurse give you medicines or injections while you were pregnant?

25. What were the medicines that you took?
_____

26. Did you have any side-effects from these medicines?
27. Have you ever had to take medication for longer than 2 weeks at a time?
    a. If yes, what was it for?
28. *Many women take medication (or injections) during labour. This can be to help with the pain of labour or make sure you and the baby are healthy.* Did you have any injections or take any medication in labour? _____
29. What were these medicines for? _____
30. Did you have any side-effects from these medicines?
    _____
31. How long did you have to take them for?
    a. Until the baby was born/ While I was pregnant
    b. Until I stopped breastfeeding
    c. For a long time, to stay healthy and for the baby to be healthy

YOUR OVERALL HEALTH

32. How has your health been?
33. Do you remember last time you had to go see the nurse/ doctor? What was it for?
34. Have you ever had to take medication for longer than 2 weeks at a time?
    a. If yes, what was it for?
35. Are you still taking any medication?
    a. What is it for?
    b. What is the medication – ask to see it if they have it on them.

Phone script for introducing MW+/ Long Journey Beginners to HIV-positive pregnant or new mothers referred from clinic staff

Note: the phone number obtained from the ANC/ pediatric nurses or clinic staff may be of the adolescent or their parent/ caregiver. Be prepared for both possibilities when placing the call. The goal of this call is to connect with pregnant/ new mothers who are HIV-positive and have been referred to us by the clinic staff (so we already know they are HIV-positive and should have initiated ART). A similar phone call can be used if the team meets their mother or grandmother at the clinic.

If the nurse has a relationship with the adolescent or the mother, consider asking them to call them and introduce the RA or briefly the process of chatting about new mother's health.

Greetings: Molo/ Unjani?

Self-introduction: I am Mpondo, working with MW (or whichever name the team prefers). We are researchers talking to young people all over the Eastern Cape about their health and their experiences of health systems. We are looking for female adolescents. Are you a 10-19 year old girl or do you have any 10-19 year old girls in your family/ home?

Once chatting with the adolescent herself:

Thank you for chatting to us, sisi. We are just chatting with lots of young people and asking them about their health and their experiences of getting help for their health.

How has your health been in the last year?

Do you have children? OR Have you ever been pregnant?

What kind of health care services did you get during your pregnancy (let them tell the RA the clinic, ANC care, where they gave birth – if they did, etc.)

How is your baby's health?

Have a longish chat about life, babies and meds (if possible).

Thank you for sharing all this over the phone! We would love to chat to you a bit more in person, meet your baby and give you a thank you certificate and small hamper for your baby. Would you have time to meet with me? I can come where you are or meet in town at a place you prefer.

Additional PMTCT questions – ZEBRA GAP (or new form)

Thank you for chatting to us. We would like to congratulate you on your pregnancy/baby!

We would like to better understand what it is like to be a young mom. We will ask you some questions about your health and medical care but everything you say will be kept confidential. **Your story is important because it will help improve health services for other young women like yourself**.

- How did you find out you were positive?
    - Before I got pregnant
    - During pregnancy
    - During labour/ birth
    - After birth
    - I am not HIV+ (?)
- When did you start ART?
    - During pregnancy
    - During labour
    - After birth
- Which clinic did you start your ARV (PMTCT) treatment at?
    - ANC clinic – clinic where I saw a nurse during my pregnancy
    - Labour ward – while I was waiting to give birth to my baby
    - ARV clinic – the clinic where all other people get their ARV
- How long were you given the ART treatment for?
- How many pills did you have to take every day?
- Did you ever stop taking your medication?
    - Yes, I stopped completely
    - Yes, I stopped and restarted
    - No, I did not stop
- If they stopped: what happened to make you stop taking the medication?
    - The nurse/ doctor told me
    - I decided myself
    - I had to stop for other reasons
- If they stopped: why did you stop taking the medication? [open ended]
- What side-effects did they give you?
- Who else did you tell about taking this medication?
- How long did you take it for?
- Where did you pick up your medications usually?
- Did the father of your child get tested for HIV?
    - Yes, we both got tested together
    - Yes, he got tested but did not go with me
    - No, he did not get tested
    - I don't know if he got tested
- Some women are given PMTCT for a short period of time. Some are offered to start taking it during pregnancy and continue long-term. Did your nurse/doctor ever offer to get you started on life-long treatment?
- Sometimes, nurses or doctors offer young mothers methods to help them decide when and if they want to have another baby. Which of the following were you offered at the end of your pregnancy, during birth or just after giving birth (choose as many as apply):
    - condoms
    - IUD
    - Implant
    - Injection
    - Pill
    - Sterilization

    - None of the above
- Did you choose to use anything to help you decide when and if you want to have another baby? Please choose from the options below:
    - condoms
    - IUD
    - Implant
    - Injection
    - Pill
    - Sterilization
    - None of the above
- Why did you choose this method?
- Is there anything you'd like to say to support other young moms like yourself? [RECORD]

*We already ask questions about what happened with the pregnancy, miscarriage/ abortion, breastfeeding, etc. in the questionnaire. See below:

We'd like to know a bit more about <u>the last time</u> you were pregnant:
*Singathanda ukwazi kancinci malunga **<u>ngexesha elidlulileyo</u>** lokhulelwa kwakho.*

1. How old were you when you were last pregnant? *Wawuneminyaka emingaphi ngexesha lokugqibela kwakho ukukhulelwa?*
   _____ *years old*
   □ I have never been pregnant

2. If you have ever been pregnant, please tell us a bit more about your last pregnancy? Choose all that apply:

Ukuba wakhe wakhulelwa ndiyacela nceda sixelele ngoku khulelwa kwakho kokugqibela. Khetha impendulo kangangoko zifuneka:

□ I was not planning to get pregnant
Ndandinga cwangciselanga ukukhulelwa.
□ I did not want to get pregnant
Bendingafuni ukukhulelwa
□ I wanted to get pregnant
Bendifuna ukukhulelwa
□ I was planning to get pregnant
Bendikucwangcisile ukukhulelwa

3. What happened <u>the last time</u> you were pregnant? *Choose only one answer.*
Kwenzeka ntoni ngexesha wawukhulelwe? Khetha impendulo ibenye.
   □ I have a baby - If yes, **<u>>>Go to Question 31-33.</u>**
   Ndinomntwana >> ukuba ewe, dibanisa umbuzo **<u>olandelayo 31-33</u>**.
   □ My fetus did not live **<u>>>Go to Question 38</u>**
   Umntwana wam akazange aphile
   □ I took some herbs to stop being pregnant **<u>>>Go to Question 38</u>**
   Ndathatha amayeza ukunqanda ukukhulelwa
   □ I went to the hospital to stop being pregnant **<u>>>Go to Question 38</u>**
   Ndaya esibhedlele ukunqanda ukukhulelwa
   □ I went to a doctor's office/ practice to stop being pregnant **<u>>>Go to Question 38</u>**
   Ndaya kwagqirha ukunqanda ukukhulelwa
   □ Other/ *Ezinye* _____ **<u>>>Go to Question 38</u>**

4. How did you give birth to your baby? *Choose only one answer:*
Wambeleka njani umntwana wakho? Khetha impendulo ibenye:
   □ At home
   Ndambelekela ekhaya

□ In the hospital/ clinic
Ndambelekela esibhedlele/ ekliniki
□ I had a caesarean (c-section)
Ndambeleka ngoqhaqho

5. How are you feeding/ did you feed your (youngest) child **in the first 6 months**?
Ingaba ubatyisa njani/wabatyisa njani kwinyanga ezintadathu zabo zokuqala?
□ Breastfeeding mixed with some baby formula
Ukuncancisa ndidibanise nobisi lwabantwana
□ Baby formula only
Ubisi lwabantwana kuphela
□ Breastfeeding only
Ndiyancancisa kuphela
□ Other /Ezinye _____

6. Now, we would like to know about all of your children. If you only have one child, that is ok. Are any of your children HIV positive?
Ngoku singathanda ukwazi malunga konke ngabantwana bakho. Xa emnye khupela kulungile. Ingaba ukhona omnye kubantwana bakho onentsholongwane kagawulayo?
□ Yes/ Ewe
□ No/ Hayi
□ I don't know/ Andazi

1.3.14 References

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2. ETHICS APPROVAL LETTERS

2.1 UNIVERSITY OF OXFORD I-DREC APPROVAL

SOCIAL SCIENCES & HUMANITIES
INTER-DIVISIONAL RESEARCH ETHICS COMMITTEE

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Co-ordinator of the IDREC
Social Sciences Divisional Office

20 December 2012

Dr Lucie Cluver
Department of Social Policy and Intervention

Dear Dr Cluver,

Research Ethics Approval

Ref No: SSD/CUREC2/12-21

Title: **Youth Pulse: Identifying risk and protective factors for adherence to long-term medication amongst adolescents in South Africa**

The above application has been considered on behalf of the Social Sciences and Humanities Inter-divisional Research Ethics Committee (IDREC) in accordance with the procedures laid down by the University for ethical approval of all research involving human participants.

I am pleased to inform you that, on the basis of the information provided to the IDREC, the proposed research has been judged as meeting appropriate ethical standards, and accordingly approval has been granted.

Should there be any subsequent changes to the project, which raise ethical issues not covered in the original application, you should submit details to the IDREC for consideration.

Yours sincerely,

Dr Liesl Osman

cc: Dr Mark Boyes
Professor Mark Orkin
Tintswalo Mercy Hlungwani
Rebecca Hodes
Beth Vale
Elona Toska

2.2 I-DREC STUDY AMENDMENT UPDATE

13 Oct 2014

Re: Update on Mzantsi Wakho – Adolescent Health Research Project in the Eastern Cape

Dear IDREC Ethics Committee,

Thank you for the opportunity to send you an update on changes made in the protocol for the Youth Pulse project being implemented by Dr. Lucie Cluver (Approval Ref SSD/CUREC2/12-21). This project has been granted ethical approval by IDREC in December 2012 and the University of Cape Town Research Ethics Committee (Approval Ref CSSR 2013/4) in April 2013.

Since our last update at the end of August 2013, we have been implementing the study in the Eastern Cape province of South Africa. We have developed partnerships with over 20 clinics, community health centres and hospitals that serve adolescents living with HIV, and have interviewed more than 550 adolescents by early October 2014. Qualitative analysis on the ART-taking practices of Eastern Cape adolescents has also begun, using the data collected between August 2013 and April 2014. Our team has been invited to share preliminary findings of Youth Pulse, given the dearth of findings on adolescents on treatment in South Africa. We have presented at UNAIDS' PCB meeting on July 1 (Dr. Cluver), joined a meeting with the Minister of Health, Dr. Motsoaledi on July 10 (Dr. Cluver), and shared preliminary findings at the International AIDS Society in Melbourne on July 20-25 (Dr. Hodes).

We are currently preparing patient file data extraction to match our respondents' self-reported data on ART adherence and sexual and reproductive health, as well as the follow-up data collection phase (see points 6 and 7 below).

This update letter provides information on the changes made in our procedures to ensure a more methodologically and ethically rigorous study.

1. **Public representation of Youth Pulse.** We have added an alternative study name to be shared with the public and our participants, following consultations with youth in the province. The alternative name (Mzantsi Wakho – 'Your South Africa') is meant to denote a study that is *not* HIV-specific. We have used and will continue to use 'Youth Pulse' in publications and policy briefs that refer to the study as one focusing on adolescents living with HIV. We hope that alternating between the two names will protect our research participants from HIV-related stigma and inadvertent disclosure about their HIV status.

2. **Bilingual questionnaire finalised.** Our isiXhosa speaking research assistants translated and back-translated the Baseline questionnaire and tested the final version that is being currently administered. Following a rigorous consent and assent process, we shared the initial draft questionnaire with more than 20 young people in rural and urban areas of the Eastern Cape who agreed to be our Expert Advisors. We finalised

a bilingual Xhosa/ English questionnaire in late February based on their recommendations.

3. **Recruiting a community-based sample of adolescents**. Following multiple coordination meetings with South African medical practitioners: Dr. Luntu Galo (Cecilia Makiwane Complex, East London, South Africaa) and Dr. Gerry Boon (Health Resource Centre, East London, South Africa), we updated our research protocol (attached) to reflect complexities of recruiting adolescents on treatment from communities, with the aim of preventing stigma and managing complex situations of disclosure in the home and (see pg 5. of the revised protocol).

4. **Coordination with partners and researchers**. In early April 2014, we held a coordinating meeting between the Youth Pulse team and the Adolescent Transition Model Project (Executive Director: Craig Carty). Both teams committed to collaborating with the goal of reducing participant burden and maximising the evidence generated from our research. The research team has also held coordination meetings with local NGOs that are likely to benefit from the findings of our research: Beyond Zero (formerly IYDSA) and Kheth'Impilo.
5. **Recruitment from schools**. Many participants are only available in the late afternoons and evenings after they return from school. We have consulted with the Department of Basic Education to enable our research team to meet the adolescents at schools during breaks and free lessons should they choose to. The letter of approval from the Department of Basic Education is attached.
6. **Added consent forms for extracting data from patient files**. During our consultations with the Adolescent Transition Model Project team, we have determined that to enhance the rigor of our study, we should use medical markers such as CD4 counts and viral loads to triangulate self-reported adherence. To that end, we have developed additional consent forms (attached) to allow access to information from the respondents' respective clinics. The consent process was informed by previous research on ART adherence in sub-Saharan Africa, and adheres to the South African National Health Act and the UK Data Protection Act. Details on the secondary data that will be accessed retrospectively and prospectively can be found on pg. 17 of the revised protocol.
7. **Questionnaire updates for follow-up data collection.** Starting December 2014 we will be making changes to the follow-up questionnaire based on consultations with partners.

Please find the attachments enclosed with the letter. If there are any further questions, please do not hesitate to ask.

Lucie Cluver

Dr Lucie Cluver

Associate Professor, Department of Social Policy & Intervention, Oxford University

Department of Psychiatry & Mental Health, University of Cape Town

http://www.spi.ox.ac.uk/people/

2.3 I-DREC APPROVAL FOR STUDY PROTOCOL AMMENDMENTS

SOCIAL SCIENCES & HUMANITIES
INTER-DIVISIONAL RESEARCH ETHICS COMMITTEE

Research Services, University of Oxford, Wellington Square, Oxford OX1 2JD
Tel: +44(0)1865 616576 Fax: +44(0)1865 280467
ethics@socsci.ox.ac.uk

Co-ordinator of the SSH IDREC
Research Services

20 November 2014

Dr Lucie Cluver
Department of Social Policy and Intervention

Dear Dr Cluver

Amendment of research ethics application

Ref No.: SSD/CUREC2/12-21

Title: Youth Pulse: Identifying risk and protective factors for adherence to long-term medication amongst adolescents in South Africa

Subject of amendment: 1) Alternative study name "Mzantsi Wakho – 'Your South Africa'"; 2) Bilingual questionnaire finalised; 3) Change to recruitment protocol for adolescents to reduce stigma; 4) Permission to recruit from schools; 5) Consent form for extracting data from medical notes/clinic files

The above request for amendment has been reviewed on behalf of the Social Sciences and Humanities Inter-Divisional Research Ethics Committee (IDREC).

I am pleased to inform you that, on the basis of the information provided to the IDREC, this amendment has been judged as meeting appropriate ethical standards.

Yours sincerely,

Kate Sahan
Co-ordinator SSH IDREC

cc: Gemma Roche

KS/CK

2.4 UNIVERSITY OF CAPE TOWN, CENTRE FOR SOCIAL SCIENCE RESEARCH

CENTRE FOR SOCIAL SCIENCE RESEARCH
University of Cape Town ▪ Private Bag Rondebosch 7701 ▪ South Africa
Tel: 021 650 4656 ▪ Fax: 021 650 4657 ▪ Web: www.cssr.uct.ac.za

TO: Dr Rebecca Hodes

FROM: Jeremy Seekings
Professor and Director, Centre for Social Science Research, UCT

SUBJECT: Ethics Review CSSR 2013/4.

RESEARCH: Promoting Adolescent Antiretroviral Adherence …

DATE: 17th April 2013

Dr Hodes, a Research Associate in the Centre for Social Science Research, submitted for review relevant documents relating to research that she intends doing, with colleagues from the UCT and Oxford University, on adherence to antiretroviral treatment among adolescent men and women in the Eastern Cape. The documents were scrutinised by the CSSR Research Ethics Review Committee, which included (by invitation) a member of UCT's Health Sciences Faculty Research Ethics Committee.

The Review Committee raised a number of concerns, primarily with respect to the issue of involuntary disclosure of personal information by other participants in discussion groups. The relevant documentation has been reworded, and the researchers have made a clear commitment to pay close attention to this issue. With these changes, the review panel is satisfied that the research will be conducted in a manner that meets the standards of the University of Cape Town.

The proposed research is therefore approved.

Jeremy Seekings

Jeremy Seekings
Professor and Director, Centre for Social Science Research

2.5 EASTERN CAPE DEPARTMENT OF HEALTH APPROVAL

Eastern Cape Department of Health

Enquiries:	Zonwabele Merile	Tel No:	040 608 0830
Date:	29th August 2013	Fax No:	043 642 1409
e-mail address:	zonwabele.merile@impilo.ecprov.gov.za		

Dear Ms Elona Toska

Re: Promoting antiretroviral adherence and sexual and reproductive health service access amongst HIV positive teenagers

The Department of Health would like to inform you that your application for conducting a research on the abovementioned topic has been approved based on the following conditions:

1. During your study, you will follow the submitted protocol with ethical approval and can only deviate from it after having a written approval from the Department of Health in writing.
2. You are advised to ensure, observe and respect the rights and culture of your research participants and maintain confidentiality of their identities and shall remove or not collect any information which can be used to link the participants.
3. The Department of Health expects you to provide a progress on your study every 3 months (from date you received this letter) in writing.
4. At the end of your study, you will be expected to send a full written report with your findings and implementable recommendations to the Epidemiological Research & Surveillance Management. You may be invited to the department to come and present your research findings with your implementable recommendations.
5. Your results on the Eastern Cape will not be presented anywhere unless you have shared them with the Department of Health as indicated above.

Your compliance in this regard will be highly appreciated.

DEPUTY DIRECTOR: EPIDEMIOLOGICAL RESEARCH & SURVEILLANCE MANAGEMENT

2.6 BUFFALO CITY HEALTH SUB-DISTRICT RESEARCH APPROVAL

Province of the
EASTERN CAPE
HEALTH

BUFFALO CITY METRO HEALTH DISTRICT

Buffalo City Sub-district: **Enquiries: Miss. Z. Mntuyedwa**

9 Vincent Road, Vincent, East London, 5200, Eastern Cape
Private Bag x 9015, Main Post Office, East London, 5200, Eastern Cape
Tel No. +27 (0)43 711 1100 Fax No. +27 (0)43 721 1972
Website www.ecdoh.gov.za

To:	Elona Toska
From:	Buffalo City Sub-District Manager
Subject:	**Promoting antiretroviral adherence and sexual and reproductive health service access amongst HIV positive teenagers**
Date:	29/01/2014

Dear Researcher

Permission is herewith granted to you to conduct research in Buffalo City Sub District as requested. Kindly familiarize yourself with the conditions below before commencing with your study.

1. The researcher will conduct the study without compromising client`s confidentiality and the smooth running of the service.

2. The researcher will not provide/publish any reports/statements without prior discussion with and permission of the sub district.

3. A copy of a letter of approval by the ethics committee, Research proposal,Research tools will be submitted to the sub district office before commencing the study.

I accept the conditions as stated in the abbreviated version of Department of Health Agreement Clause for researchers.

ELONA TOSKA	Elona Toska	29 January 2014
Full Name & Surname	Signature	Date
UNATHI NGESI	Unathi	29 January 2014
Witness Name & Surname	Signature	Date

Province of the
EASTERN CAPE
HEALTH

Amathole District

Buffalo City Sub-district:

Enquiries: Miss. Mntuyedwa

9 Vincent Road, Vincent, East London, 5200, Eastern Cape
Private Bag x 9015, Main Post Office, East London, 5200, Eastern Cape
Tel No. +27 (0)43 711 1100 Fax No. +27 (0)43 721 1972
Website www.ecdoh.gov.za

To:	CHC Managers; Clinic Supervisor Operational Managers: Buffalo City Sub District facilities
From:	Buffalo City Sub-District Manager
Subject:	Permission to conduct a research study in Buffalo City Sub District **Promoting antiretroviral adherence and sexual reproductive health service access amongst HIV positive teenagers**
Date:	29/01/2013

This communiqué serves to inform the operational managers of Buffalo City Sub District that Elona Toska and the team have been granted permission to conduct research in the facilities of Buffalo City Sub District.

The sub district office requests that the she be assisted with the information they need without compromising confidentiality of both the consumers of the service and the image of the department.

Your co-operation is always appreciated.

N.V.Nelani

Chairperson: Research Forum

29/01/2013
Date

2.7 EASTERN CAPE DEPARTMENT OF BASIC EDUCATION RESEARCH APPROVAL

Province of the
EASTERN CAPE
EDUCATION

STRATEGIC PLANNING POLICY RESEARCH AND SECRETARIAT SERVICES
Steve Vukile Tshwete Complex • Zone 6 • Zwelitsha • Eastern Cape
Private Bag X0032 • Bhisho • 5605 • REPUBLIC OF SOUTH AFRICA
Tel: +27 (0)40 608 4773/4035/4537 • Fax: +27 (0)40 608 4574 • Website: www.ecdoe.gov.za

Enquiries: B Pamla Email: babalwa.pamla@edu.ecprov.gov.za Date: 04 April 2014

Ms. Elona Toska

10 Princes Road

Vincent

5207

Dear Ms. Toska

PERMISSION TO UNDERTAKE AN INDEPENDENT STUDY: "MZANTSI WAKHO" ADOLESCENT HEALTH RESEARCH

1. Thank you for your application to conduct research.
2. Your application to conduct the above mentioned research in Primary and Secondary School under the jurisdiction of East London and King William's Town Districts of the Eastern Cape Department of Education (ECDoE) is hereby approved on condition that:
    a. there will be no financial implications for the Department;
    b. institutions and respondents must not be identifiable in any way from the results of the investigation;
    c. you present a copy of the written approval letter of the Eastern Cape Department of Education (ECDoE) to the Chief Directors and Directors before any research is undertaken at any institutions within that particular district;
    d. you will make all the arrangements concerning your research;
    e. the research may not be conducted during official contact time, as educators' programmes should not be interrupted;

f. should you wish to extend the period of research after approval has been granted, an application to do this must be directed to Chief Director: Strategic Management Monitoring and Evaluation;

g. the research may not be conducted during the fourth school term, except in cases where a special well motivated request is received;

h. your research will be limited to those schools or institutions for which approval has been granted, should changes be effected written permission must be obtained from the Chief Director: Strategic Management Monitoring and Evaluation;

i. you present the Department with a copy of your final paper/report/dissertation/thesis free of charge in hard copy and electronic format. This must be accompanied by a separate synopsis (maximum 2 – 3 typed pages) of the most important findings and recommendations if it does not already contain a synopsis. This must also be in an electronic format.

j. you are requested to provide the above to the Chief Director: Strategic Management Monitoring and Evaluation upon completion of your research.

k. you comply with all the requirements as completed in the Terms and Conditions to conduct Research in the ECDoE document duly completed by you.

l. you comply with your ethical undertaking (commitment form).

m. You submit on a six monthly basis, from the date of permission of the research, concise reports to the Chief Director: Strategic Management Monitoring and Evaluation.

n. **Special Condition:** Due to the sensitivity of the study, kindly ensure that you adhere to protocol, get consent from parents and ensure confidentiality.

3. The Department reserves a right to withdraw the permission should there not be compliance to the approval letter and contract signed in the Terms and Conditions to conduct Research in the ECDoE.

4. The Department will publish the completed Research on its website.

5. The Department wishes you well in your undertaking. You can contact the Chief Director, Mr. GF Mac Master on the numbers indicated in the letterhead or email greg.macmaster@edu.ecprov.gov.za should you need any assistance.

MR. GF MAC MASTER
CHIEF DIRECTOR: STRATEGIC MANAGEMENT MONITORING AND EVALUATION

FOR SUPERINTENDENT-GENERAL: EDUCATION

2.8 LETTER OF ENDORSEMENT – UNICEF

United Nations Children's Fund
Three United Nations Plaza
New York, New York 10017

Telephone 212 326 7000
Facsimile 212 888 7465
212 888 7454
www.unicef.org

29th October 2012
Direct line 212 326 7520
Ryates@unicef.org

cc: Dr Lucie Cluver

To whom it may concern

Re: Proposed research on factors affecting access and adherence to HIV treatment in South Africa

UNICEF is the lead United Nations agency working children affected by HIV and AIDS and convenes various UN inter-agency working groups on HIV prevention, treatment, protection, care and support. UNICEF works with governments, other UN agencies, civil society and academic researchers to support evidence based policies and programmes for HIV-affected children and youth globally, with a particular focus on Sub-Saharan Africa which has the largest burden of HIV.

Through our discussions with Dr Lucie Cluver and other development partners working in this area, we have identified the issue of determinants of HIV treatment access and adherence amongst HIV-positive adolescents as a significant research gap. Gaining better understanding on this issue will significantly contribute to better policies and programming in this area.

Access to better treatment has saved the lives of many adults and children globally. As well as reducing morbidity and mortality, treatment has reduced the destructive impact that HIV has had on poor households. Antiretroviral adherence is an important priority not only because it prolongs the lives of people living with HIV, but also because it dramatically decreases the likelihood of transmitting HIV to others which is an important public health imperative.

With improved antiretroviral treatment availability, the number of adolescents accessing treatment should increase. However globally, and in South Africa specifically, adolescent treatment access has been disappointing, partly due to the lack of evidence on the comprehensive needs of adolescents in relation to testing and treatment. A strong evidence base on social as well as the clinical determinants of HIV treatment

unite for children

unicef

United Nations Children's Fund
Three United Nations Plaza
New York, New York 10017

Telephone 212 326 7000
Facsimile 212 888 7465
212 888 7454
www.unicef.org

outcomes in young people will help strengthen our existing treatment, care and support programmes and inform new interventions by making them increasingly relevant to the specific needs of this group.

We are therefore pleased to provide our continued support and collaboration for the research project: **Identifying risk and resilience-promoting factors for adherence among adolescents in South Africa**. This important study reflects research priorities identified by UNICEF as well as other development partners working with HIV-positive youth in South Africa. We are looking forward to our continued cooperation with Dr Lucie Cluver and the Adolescent Adherence Team at Oxford University, University of Cape Town and University of Witwatersrand on this highly relevant research project.

We look forward to working with you on this important initiative.

Yours faithfully,

Rachel Yates
Senior Adviser
HIV/AIDS Section
UNICEF HQ

unite for children

unicef

2.9 LETTER OF SUPPORT – PAEDIATRIC AIDS TREATMENT FOR AFRICA (PATA)

www.teampata.org

To Whom it May Concern

15 January 2015

Re: Research Collaboration on the Health of HIV-positive Adolescents with the Mzantsi Wakho study

Since 2013, Paediatric AIDS treatment for Africa (PATA) has been involved in an collaborative effort with 'Mzantsi Wakho' based in East London, South Africa, the University of Oxford, the University of Cape Town, the South African Government Departments of Health, South African Social Development and Basic Education and UNICEF to investigate how South African youth engage with health services. 'Mzantsi Wakho' is investigating antiretroviral adherence, sexual and reproductive health, and retention in care for HIV-positive teenagers in the Eastern Cape province of South Africa. This information is crucial for informing policy and practice.

Paediatric AIDS Treatment for Africa (PATA) is an action network of multidisciplinary teams of frontline healthcare providers and community health workers caring for HIV-infected children. PATA teams are affiliated with 258 health facilities across 24 countries: Burundi, Ethiopia, Kenya, Rwanda, Tanzania, Uganda (East Africa); Burkino Faso, Cote d'Ivoire, Ghana, Nigeria, Togo (West Africa); Angola, Botswana, Lesotho, Malawi, Mozambique, Namibia, South Africa, Swaziland, Zambia, Zimbabwe (Southern Africa); and Cameroon, Republic of Congo, Democratic Republic of Congo (Central Africa). PATA promotes models of care that address the clinical and psychosocial well-being of the child and that offer equitable, integrated and patient- centred services.

Through its involvement with more than 250 facilities across sub-Saharan Africa, PATA is involved in shaping the post-2015 health agenda and has identified access to mother-and-child health as one of the priority areas for young people and for HIV-positive adolescents, specifically. Increasing access to sexual and reproductive health practices to eliminate new HIV infections is key to reaching PATA's mission. Using high-quality evidence to improve practices and services and reduce overall HIV infections among children and their parents is of ultimate priority to PATA's work.

We are therefore pleased to provide our continued support and collaboration for the Mzantsi Wakho research project and any future initiatives or interventions stemming from its inception. Identifying risk and resilience-promoting factors for HIV-positive adolescents in Southern Africa, particularly in the context of sexual and reproductive health is paramount. This important study reflects research priorities identified by PATA and international partners, including WHO, IATT and UN agencies involved in the field. We are looking forward to our continued cooperation with Dr Lucie Cluver, Dr. Rebecca Hodes and the Mzantsi Wakho team at University of Oxford, University of Cape Town and University of Witwatersrand on this highly relevant research project.

For further information please do not hesitate to contact daniella@teampata.org or +27 21 447 9566.

Yours faithfully,

Dr Daniella Mark
Executive Director
Paediatric AIDS Treatment for Africa

Paediatric AIDS Treatment for Africa, NPC, NPO 2007/01297/08, PBO 930034219

Paediatric AIDS Treatment For Africa · PO BOX 12971, Mowbray, 7705 · Cape Town · South Africa
Tel: +27 21 447 9566 · Fax: 086 619 1623 · www.teampata.org

3. INFORMATION SHEETS AND CONSENT FORMS

3.1 ADOLESCENT INFORMATION SHEET AND CONSENT FORM

Filling in Your Details

Name of Participant _____

Age _____

Participant Signature _____ Consent Date _____

ID#/Birthday _____

I, _____, as the legal guardian/parent give consent for the participant to take part in this study.

Signature _____ Consent Date _____

Researcher _____

Questionnaire number _____

Meeting next year

Could you give us the names, addresses and telephone numbers of 2 people (who you don't live with) who you think would know how to contact you in a few years' time?

Person 1 – Name: _____

Address: _____

Phone number _____

Relationship to you _____

Person 2 – Name _____

Address: _____

Phone number _____

Relationship to you _____

Do I want to take part?

I have read and I understand the information sheet for this study and have had a chance to ask questions. ☐

I understand that I have chosen to take part and that I am free to stop at any time, without giving any reason. This will not change any support or help I am getting. ☐

I agree to take part in this study. ☐

I agree that information from my school and clinic records can be added to my questionnaire responses. ☐

I allow Mzantsi Wakho to share this with the PASDP project, at Mater Misericordiae University Hospital, University College Dublin and Walter Sisulu University, who are also working to help adolescent health and well-being. ☐

I don't want to take part in this study. ☐

Would you mind if we contacted you again?
Address:

.....

Telephone number:

.....

What will happen to the results of the study? The results of this study will be used to help the government, and health and welfare organisations, to make better policies for young people and their families.

Make your voice heard

MZANTSI WAKHO

Information and Consent Form

MZANTSI WAKHO is a study about young people in South Africa and how they think about their bodies, their health and their lives.

Your story is important

Why should I take part in this study?
This study will help us to learn more about how to help young people in South Africa.

We are part of a research team from the Universities of Oxford and Cape Town that is trying to learn more about the lives and health of young people in the Eastern Cape. You have been invited to participate in our study. We want to learn from you, share ideas so that we can help government provide better support and services for teens.

Please take time to read this sheet carefully *and decide whether you do or don't want to* take part. Ask the research team if there is anything that is not clear or if you have questions. Thank you for reading this.

Tell me more .

Do I have to take part? Not at all. You can decide if you want to take part or not. If you *don't want to, it won't affect any help you are getting and you won't get into trouble.* If you decide to take part, you are still free to stop at *any time and you won't* have to give a reason. In *one year's time, we will visit you again to see how* you are doing. You can choose then whether you want to talk to us again!

What will you have to do? If you decide to take part, you will sign this consent form, and then spend a couple of hours talking together and doing activities with a researcher. Sometimes we will need to understand things about your health or about school. You might not know these things. With your permission, we might ask your school and clinic for additional information.

What if the questions upset me? You can stop *at any point, and you don't have to give a* reason. You can also contact the research team at any point and say that you want your answers about certain questions to be removed, which we will do straight away.

If you want to talk to someone about anything that has come up from this, you can tell one of the researchers, or you can contact us:

Call the office: 043-7211716

Or send a 'please call me' to 0785034488

contact me

Extra Information

Will what I say be kept confidential? Anything you tell us about yourself will be kept strictly confidential, and will not be told to anyone else. The questionnaire will not include your name and it will be completely anonymous. But during our chat it may become clear that you are suffering from serious challenges. If so, our researchers will explain to you, in private, possibilities for further help. If there is a safety issue, we might contact an organization that can help you. But we will talk to you about it first.

What if I have a complaint? If there is anything to do with the research that you are unhappy with, you can contact Dr Lucie Cluver at University of Oxford (lucie.cluver@spi.ox.ac.uk), or call us on *0437211716 or send a 'please call me'* to 0785034488.

Thank you for reading this sheet. Please let the research team know if you have any questions or if something is not clear.
If you feel comfortable with everything, you can fill in the consent form on the next page.

3.2 FACILITY (CLINIC) INFORMATION SHEET

MZANTSI WAKHO

Promoting Antiretroviral Adherence and Sexual and Reproductive Health Service Access among HIV-positive Adolescents

***NOTE:** This research has been approved by ethics committees at the University of Oxford, University of Cape Town and Eastern Cape Departments of Health and Basic Education. The National Departments of Health (DoH), Social Development (DSD), Basic Education (DoBE) and Women, Children and People with Disabilities, have collaborated in the research design. Individual agreements will be negotiated with every clinic and youth, and their families that are interested in participating.

Research Team

Dr. Lucie Cluver, University of Oxford & University of Cape Town;
Dr. Rebecca Hodes, University of Cape Town; Lesley Gittings, University of Cape Town
Elona Toska, University of Oxford, Marija Pantelic, University of Oxford
Dr. Daniella Mark, Paediatric AIDS Treatment for Africa; Dr. Mark Boyes, University of Oxford; Beth Vale, University of Oxford; and a team of Xhosa-speaking research assistants.

Overview

Research Goals – This study asks the crucial questions: what are the lived experiences of HIV-positive adolescents in relation to ART and SRH, and what obstructs and/or promotes their ART adherence and utilisation of SRH services? It uses mixed qualitative and quantitative methods to achieve two aims:

(3) To identify and investigate risk and resilience-promoting factors for ART adherence and utilization of SRH services amongst HIV-positive adolescents, through linked qualitative and quantitative studies.
(4) To collaborate with HIV-positive adolescents, healthcare workers and social service providers to design support tools to improve adolescent ART adherence and access to SRH services.

Central Research Questions

1) How do adolescents living with HIV perceive and experience antiretroviral treatment (ART) and care, and sexual and reproductive health (SRH) services?
2) What are the risk and protective factors for ART adherence and SRH service utilisation among HIV-positive adolescents?
3) How do service providers and caregivers experience and perceive care for youth on ART?
4) How can adolescents be involved in the design of youth-friendly programmatic interventions for the promotion of ART adherence and SRH service use?

Research Sites – Research will be conducted in ART and SRH clinics, and ART support groups in the Eastern Cape.

Research Participants – Adolescents on ART between the ages of 10-19 years (n=650); health and social services providers for adolescents on ART (n=20); caregivers of adolescents on ART (n=30).

Timeline for Quantitative Study

- Study preparation, design and consultation (October 2012-August 2013)
- Clinic mapping and sampling (August – December 2013)

- Fieldwork and data collection – Baseline Wave 1 (January 2014 – September 2015)
- Fieldwork and data collection – Follow-up Wave 2 (October 2015 – September 2016)
- Fieldwork and data collection – Follow-up Wave 3 (October 2016 – September 2017)
- Data analysis results dissemination (December 2014 – August 2016 ongoing)

Timeline for Qualitative Study

- Study design, preparation and consultation (October 2012-July 2013)
- Ethnographic research with adolescents, caregivers and healthcare providers (August 2013 – April 2014)
- Clinic-based observations and interviews with healthcare providers and adolescents (January 2014 – December 2015)
- Body mapping and participatory tool design workshop camps with adolescents (October 2013 – October 2014)
- Analysis and dissemination (October 2014 – December 2016)

Mzantsi Wakho Plus (February-December 2015)

In 2015, additional mixed-methods qualitative and quantitative research will build on Mzantsi Wakho, focusing on defaulting adolescents, particularly pregnant adolescents/ young moms who have initiated ART. It will extend beyond the initial study to explore and understand pathways to ART adherence and access to PMTCT/ reproductive health services using intensive tracing methods. **The specific research objectives of this project are:**

1. To explore *why* HIV-positive adolescents default from ART and become lost to follow-up (LTFU), and what happens once they have 'opted out' of ART programmes, particularly PMTCT.
2. To investigate *if* and *how* adolescent ART-defaulters and LTFU patients are managed by healthcare workers and systems in clinics and communities.
3. To collaborate with HIV-positive adolescents who have defaulted on ART, and with healthcare and social service providers, to *design programmatic responses* to adolescent defaulters with the objective of re-initiating patients onto ART, and motivating better adherence and retention in care.

Mzantsi Wakho Plus will provide additional insights specifically around defaulting and treatment interruptions: a topic of paramount importance identified during the initial findings of the study, but which cannot be addressed within the planned work of Mzantsi Wakho. By building on the initial findings and study cohort, Mzantsi Wakho Plus will explore why adolescents patients default from ART or are lost to follow-up, how this relates to their social and health circumstances, and how they can be re-initiated onto ART.

Methodology

This mixed-methods research project has four principal components:

1. In-depth **qualitative** research with 50 adolescents and 50 key informants (caregivers, health and social workers) to explore: (i) how HIV-positive adolescents use, adapt and resist HIV care and treatment, and SRH services, and (ii) how those caring for HIV-positive adolescents experience and perceive challenges and facilitators of ART adherence and SRH uptake. A combination of qualitative methods will be used to collect data, including semi-structured in-depth interviews, unstructured participant observation, body mapping, and treatment diaries.
2. Participatory **qualitative** workshops to involve adolescents and care providers as key stakeholders in the collaborative design of youth-driven support tools to:

a) Improve ART adherence and SRH service uptake,

b) Assist youth in negotiating the barriers and challenges that impede their desired retention in care, and
c) Customize ART and SRH interventions for optimized adolescent outcomes.

3. A linked **longitudinal quantitative** study of 800 HIV-positive and an estimated 300 HIV-negative adolescents will assess risk and resilience-promoting factors for ART adherence and SRH utilisation. The survey will include a self-report questionnaire that is completed in the supportive presence of an interviewer. This questionnaire will collect information about socio-demographics, health service access and potential risk and resilience-promoting factors for ART adherence and SRH service uptake. Interview booklets are structured and presented in the style of a teen magazine quiz.
4. Finally, the linked **quantitative** study will test the acceptability of the support tools developed in the participatory workshops, in the larger-scale quantitative sample.

Eligibility Criteria

Qualitative study – Participants are eligible for individual interviews if:

- they are health or social care providers whose patients include HIV-positive adolescents who have initiated or are eligible for HAART.

Participants are eligible for qualitative one-on-one research engagements (individual interviews, unstructured participant observation, diaries) if:

d) They are between the ages of 10-19 years,
e) They are currently initiating/or have previously initiated ART, or they are attending a youth programme for AIDS-affected teens, and
f) They, and their legal guardian, have given written, informed and voluntary consent

Quantitative study – Participants are eligible for the quantitative study if:

d) They are between the ages of 10-19 years old,
e) They have accessed/are accessing treatment for a long-term condition, which may include TB, HIV, blood pressure, diabetes, asthma etc.
f) They have used health services such as: hospitals, clinics, home-based visits, etc.
g) They have been or are pregnant (for girls), and
h) They, and their legal guardian, have given written, informed and voluntary consent.

Ethics

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What will happen at the end of the study?

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For more information on Mzantsi Wakho or Mzantsi Wakho Plus, please contact any of our research team:

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3.3 SCHOOL INFORMATION SHEET

MZANTSI WAKHO

Promoting Access to Health Service Access among Adolescents in the Eastern Cape

***NOTE:** This research has been approved by ethics committees at the University of Oxford, University of Cape Town and Eastern Cape Departments of Health and Basic Education. The National Departments of Health (DoH), Social Development (DSD), Basic Education (DoBE) and Women, Children and People with Disabilities, have collaborated in the research design. Individual agreements will be negotiated with every clinic and youth, and their families that are interested in participating.

Research Team

Dr. Lucie Cluver, University of Oxford & University of Cape Town;
Dr. Rebecca Hodes, University of Cape Town;
Dr. Daniella Mark, Paediatric AIDS Treatment for Africa; Dr. Mark Boyes, University of Curtin;
Beth Vale, University of Oxford; Elona Toska, University of Oxford,
Julia Rosenfeld, Mzantsi Wakho; Maya Isaacsohn; Mzantsi Wakho
Marija Pantelic, University of Oxford, and a team of Xhosa-speaking research assistants.

Overview

Research Goals – This study asks the crucial questions: what are the experiences of adolescents in relation to health services, and what obstructs and/or promotes utilisation to health services such as reproductive and sexual health? It uses mixed qualitative and quantitative methods to achieve two aims:

(1) To identify and investigate risk and resilience-promoting factors for utilization of health services amongst adolescents, through linked qualitative and quantitative studies.
(2) To collaborate with adolescents themselves, healthcare workers and social service providers to design support tools to improve adolescent access to health services, particularly sexual and reproductive health.

Research Sites – Research will be conducted in communities in Buffalo City Sub-District: East London, King Williams Town, and Bhisho in the Eastern Cape.

Research Participants – Adolescents between the ages of 10-19 years (n=650); health and social services providers for adolescents (n=20); caregivers of adolescents (n=30).

Timeline for Quantitative Study

- Study preparation, design and consultation (October 2012-August 2013)
- Facility mapping and sampling (August – December 2013)
- Fieldwork and data collection – Baseline (January – October 2014)
- Fieldwork and data collection – Follow-up (October 2014-September 2015)
- Data analysis results dissemination (October 2014 – August 2016 for both baseline and follow-up)

Timeline for Qualitative Study

- Study design, preparation and consultation (October 2012-July 2013)
- Ethnographic research with adolescents, caregivers and healthcare providers (August 2013 – April 2014)

- Clinic-based observations and interviews with healthcare providers and adolescents (January-February 2014)
- Body mapping and participatory tool design workshop camps with adolescents (October 2013 – October 2014)
- Analysis and dissemination (October 2014 – December 2015)

Methodology

This mixed-methods research project has four principal components:

5. In-depth **qualitative** research with 50 adolescents and 50 key informants (caregivers, health and social workers). A combination of qualitative methods will be used to collect data, including semi-structured in-depth interviews, unstructured participant observation, body mapping, and treatment diaries.
6. Participatory **qualitative** workshops to involve adolescents and care providers as key stakeholders in the collaborative design of youth-driven support tools to:
   a) Improve health service uptake,
   b) Assist youth in negotiating the barriers and challenges that impede their desired retention in care, and
   c) Customize reproductive health interventions for optimized adolescent outcomes.
7. A linked **longitudinal quantitative** study of 600 adolescents will assess risk and resilience-promoting factors for health service utilisation. The survey will include a self-report questionnaire that is completed in the supportive presence of an interviewer. This questionnaire will collect information about socio-demographics, health service access and potential risk and resilience-promoting factors.
8. Finally, the linked **quantitative** study will test the acceptability of the support tools developed in the participatory workshops, in the larger-scale quantitative sample.

Eligibility Criteria

Qualitative study – Participants are eligible for individual interviews if:

- they are health or social care providers whose patients include adolescents who access healthcare services.

Participants are eligible for qualitative one-on-one research engagements (individual interviews, unstructured participant observation, diaries) if:

g) They are between the ages of 10-19 years,
h) They, and their legal guardian, have given written, informed and voluntary consent

Quantitative study – Participants are eligible for the quantitative study if:

i) They are between the ages of 10-19 years old,
j) They have accessed/are accessing treatment for a long-term condition, which may include TB, HIV, blood pressure, diabetes, asthma etc.
k) They have used health services such as: hospitals, clinics, home-based visits, etc.
l) They have been pregnant (for girls), and
m) They, and their legal guardian, have given written, informed and voluntary consent.

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For more information on Mzantsi Wakho, please contact any of our research team:

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Julia Rosenfeld, Quantitative Study Project Manager, julia.b.rosenfeld@gmail.com 0786373709
Maya Isaacsohn, Quantitative Fieldwork Coordinator, maya.isaacsohn@gmail.com 0787298651
Dr. Lucie Cluver, Principal Investigator, lucie.cluver@spi.ox.ac.uk
Dr. Rebecca Hodes, Principal Investigator, rebecca.hodes@gmail.com

4. CERTIFICATES

4.1 ADOLESCENT PARTICIPANT CERTIFICATE

Inkcukatha ezibalulekileyo ekufuneka uzigcine!

Ukuba kukhona into ofuna ukuyithetha engathi ifike koluphando,ungathetha neqela ngokuthi uthumele u Please Call Me kulenombolo 078 503 4488.
If you want to talk about anything that comes up in the study, you can talk to the team by sending a "Please Call Me" to 078 503 4488.

Ukuba kukho abantu abakulimazyo okanye abakoyikisayo kwaye udinga uncedo, ungaqhangamshelana:
If you are being hurt or frightened by other people and need help, you can contact:

Childline:	East London Child Welfare:	Police Station (local)
0800 055 555	043 722 0512	10111

Okanye uqhagamishelane neqela lethu ngokuthi uthumele uPlease Call Me kulenombolo 078 503 4488 okanye ku:
Or you can contact us by sending a "Please Call Me" to the team at 078 503 4488 or to:

_____ at _____

MZANTSI WAKHO

4.2 FACILITY CERTIFICATE

5. ADOLESCENT-FOCUSED DATA COLLECTION TOOLS

5.1 SCREENING FORM

Hello! Thank you so much for helping us with the questionnaire! We wouldn't be able to do it without you, and your story will help make things better for teens in South Africa. To help us decide which questionnaire you are best suited to help us with, we'd like to ask you a few questions.

1. How old are you? *Mingaphi iminyaka yakho?* _____

2. Have you been to a clinic or hospital recently to get help for a broken leg, ear infection, problems seeing or any other health issue?
   - □ Yes
   - □ No

3. Are you taking any medication now?
   - □ Yes
   - □ No

3. Have you ever taken medication for longer than two weeks?
   Wawukhe wathatha amayeza ngaphezulu kweveki ezimbini ebomini bakho?
   - □ Yes
   - □ No

4. What is/was the medication for?

_____

5. Please write the name of the medicine you have taken for longer than two weeks **if you know it** (no problem if you don't ☺). *Sicela ubhale igama leyeza obukhe walithatha ngaphezulu kweveki ezimbini.*

_____
_____

6. If you could be any animal which animal would you be?
Ukuba ungasisilwanyane ungaketha ukuba sesiphi?

_____
_____
_____

RA name: _____ **Date:** _____
Participant Name: _____ **Caregiver Name:** _____
Address: _____ **Phone Number:** _____
School Name: _____ **Grade:** _____
Teacher Name: _____

5.2 ADOLESCENT QUESTIONNAIRE

If you use this questionnaire, please cite: Cluver, L. Toska, E., Boyes, M. Pantelic, M. (2014) Mzantsi Wakho Adolescent Health Baseline Questionnaire – Giraffe.

MZANTSI WAKHO – GIRAFFE QUESTIONNAIRE[7]

STEP 1 – Please do the GET-TO-KNOW EACH OTHER activity with the participant
STEP 2 – Preparation and Consent Process
Dear Research Assistant. Please enter the following information before you start with the participant:
Choose your name (who is conducting the interview)? /Interviewer name

☐ Nomampondo □ Dumile □ Cindy □ Sindi □ Aviwe

☐ Unathi □ Zoe □ Siphesihle □ Thembeka

☐ Julia □ Elona □ Maya □ Becca □ Andre

Choose the clinic where you met/ recruited the participant? /Name of the clinc where recruited

- ☐ Berlin Clinic
- ☐ Bhisho Hospital - ARV clinic
- ☐ Bhisho Hospital - ANC clinic
- ☐ Cecilia Makiwane Hospital - ARV/ adult clinic
- ☐ Cecilia Makiwane Hospital - PMTCT/ ANC clinic
- ☐ Cecilia Makiwane Hospital - Pediatrics
- ☐ Central Clinic
- ☐ Duncan Village Day Hospital
- ☐ Dimbaza Community Healthcare Centre
- ☐ Empilweni Gompo Healthcare Centre
- ☐ Frankfort clinic
- ☐ Frere Hospital - ARV/ adult clinic
- ☐ Frere Hospital - PMTCT/ ANC clinic
- ☐ Frere Hospital - Pediatrics
- ☐ Grey Hospital
- ☐ Grey Gateway Clinic
- ☐ Ilita Clinic
- ☐ Imidange Clinic
- ☐ John Dube Clinic
- ☐ Mt. Coke Community Healthcare Centre
- ☐ Ncerha clinic
- ☐ Needs Camp Clinic
- ☐ Nontyatyambo Clinic
- ☐ NU8 Nobuhle Clinic
- ☐ NU9 Clinic
- ☐ NU12 Eluxolweni Clinic
- ☐ NU13 Siyaphilisa Clinic
- ☐ NU17 Clinic
- ☐ Nonkcampa Clinic
- ☐ Sweetwaters Clinic

[7] The Giraffe version of the questionnaire was used with HIV-positive adolescents who disclosed their HIV-status to the research assistants. The Elephant version of the questionnaire (not included in the Appendices) was used with HIV-positive adolescents who did not know their status and with HIV-status-unknown participants. All items including HIV and ARV in the Giraffe questionnaire were adapted to refer to "sickness", "illness" or "medicine", accordingly. The items not included in the Elephand questionnaire are noted in this document with the note **[ONLY GIRAFFES/ HIV-POSITIVE STATUS-AWARE]**.

- ☐ Qurhu Clinic
- ☐ Tshatshu Clinic
- ☐ Zikhova Clinic
- ☐ Zwelitsha Clinic zone 5
- ☐ Zwelitsha Clinic zone 8
- ☐ Other

Interview Date _____
Participant's Birth Date _____

1. Please choose if the participant is a boy or a girl:

☐ Boy □ Girl

2. How did you confirm the participant is a GIRAFFE?

☐ Giraffe, confirmed by the healthcare provider

☐ Girrafe, confirmed by the caregiver

☐ Giraffe, confirmed by the participant

☐ Animal is unknown

Thank you for this initial information. Please go through the consent form with the participant.

3. Did the participant consent to participate:
   - □ Yes – please continue
   - □ No – stop the interview
4. When was the participant born? _____
5. Where are you conducting this interview?

☐ Participant's Home

☐ Clinic

☐ Hospital

☐ School

☐ Church

☐ Community Centre

☐ Other

Please write the address: _____

5.2.1 Introduction

Isigalo

This questionnaire has 13 parts, each of which will take about 10 minutes. There will be a short break after each part and we will play a small game together. Your answers will be kept confidential and your name will not be written anywhere on this questionnaire. Your experiences will be incredibly helpful to our government and healthcare providers.

Le mibuzo inezigaba ezingamashumi anesithathu, enye kuyo izakuthatha alishumi ukuyiphendula. Kuzakubakho ikhefu emva kwesigaba ngasinye osiphenduleyo kwaye sizakudlala umdlalo omncinci sonke. Iimpendulo zakho zizakuhlala ziyimfihlo yaye igama lakho alizukubhalwa naphi kulemibuzo. Amava akho ayakuba luncedo kakhulu kurhulumente wethu nakwincadelo lezempilo.

If you need a break, just tell the person that is helping you and they will do some activities with you. This is not a test. There are no right or wrong answers! This research aims to help young people in South Africa. Thank you for taking the time to help.

Ukuba ufuna ikhefu, xelela umntu okuncedayo kwaye nabo bazakwenza imidlalo nawe. Oku akulovavanyo. Akukho mpendulo zilungileyo okanye nezingalunganga! Olu phando lujongene nokunceda abantu abatsha baseMzantsi Afrika. Enkosi ngokuthatha ixesha lakho ngokusinceda.

5.2.2 Part 1: About You

Isigendu 1: Malunga ngawe nelizwe lakho

Your answers are important and will help government and other organisations to design better services for young people. But if we need to use something you have said, we will never use your real name. Everything you say is confidential. Can you make up a pretend name that we can use? It can be any name, such as Lerato or Akhona or Beyonce or Zola.

Iimpendulo zakho zibalulekile kakhulu yaye zizakuba luncedo kurhulumente nakwimibutho ekuncedeni abantu abatsha. Kodwa ukuba ufuna ukusebenzisa into oyithetheliyo, asisoze sisebenzise igama lakho. Yonke into oyithethileyo izakuba yimfihlo. Ungakwazi ukusebenzisa igama othe walikha entloko nokuba leliphi esinokuthi silisebenzise. Ingaba lilo nokuba leliphi na igama, Lerato okanye Akhona okanye Beyonce okanye Zola.

1. What nickname would you like us to call you?
   Ingaba sesiphi isiteketiso sakho ofuna sekubizengaso? _____

2. How old are you?
   Mingaphi iminyaka yakho? _____

3. How many villages, towns or cities have you lived in since you were born?
   Zingaphi izixeko okanye idolophu okhe wahlala kuzo koko wazalwa? _____

4. Please tell us what type of house do you live in now [please check one]?
   Nceda ukhethe leyo ifana nekhaya lakho?

   ☐ house made of brick or concrete
   indlu eyenziwe ngezitena okanye yesamente

   ☐ hut made of traditional materials (cow dung, mud, etc.) or a rondavel on its own

plot
indlu eyenziwe ngomhlaba (ubulongwe, udaka, nezinye.) okanye uronta ozemeleyo

☐ living on the street
uhlala esitalatweni

☐ shack in a back yard or a separate plot
ityotyombe elisemva eyadini okanye sigangeni

☐ children's home or shelter for kids
ikhaya labantwana okanye indawo yabantwana basesitratweni

☐ other (what kind?) *enye (chaza?)* _____

5. What language do you mainly speak at home [tick only one]?
Loluphi ulwimi olusebenzisa kakhulu ekhayeni? [KHETHA IMPENDULO IBENYE]?

☐ isiXhosa

☐ isiNgesi/ English

☐ Afrikaans

☐ isiZulu

☐ Other/ *Nezinye*

6. What is the name of the city/ town or village where you live now?
Uhlala kweyiphi idolophu okanye isixeko? _____

7. What is the nicest thing that someone has said to you about yourself?
Yintoni into eyakhe yamnandi umntu owakhe wakuxelela yona? _____

5.2.3 Part 2: Your School

Isigendu 2: Yesikolo sakho

1. What kind of school do you go to:
Loluphi ohlobo lwesikolo ofunda kuso:
   - □ we pay school fees
   Sibhatala intlawulo zesikolo
   - □ the school charges fees but we cannot afford to pay them, so we owe them
   Isikolo siyayifuna intlawulo yesikolo kodwa asi kwazi uhlawulo, ngoku siyabatyala
   - □ it's a free school but we are still asked to pay something
   Isikolo esingahlawulwayo kodwa basafuna sihlawule
   - □ a totally free school, we don't have to pay anything
   Sisikolo ekungahlawula nto tu
   - □ other kids pay school fees but I have special permission from the principal
   Abanye bantwana bayasihlawula kodwa mna ndine mvume eyodwa nenqununu yesikolo
   - □ I don't go to school –>> Go to Question 1a.
   Andihambi sikolo – dlulela kumbuzo 1a.

1a. If you are NOT currently attending school, what is the MAIN REASON for not attending school? [PLEASE CHOOSE ONLY ONE REASON]
Ukuba akuhambi isikolo yintoni isizathu esibangela ungafundi? [KHETA IMPENDULO

IBENYE]

- □ I finished matric
  Ndiphumelele ibanga leshumi
- □ I didn't have enough money to pay fees or uniform
  Bendinge nayo imali eyaneleyo ukuhlawula indleko zesikolo okanye iyunifomu
- □ I had to stop going to school to help at home
  Kwanyanzeleka ndiyeke esikolweni ukuze ndincedise ekhaya
- □ I stopped going because I was too unwell
  Ndayeka kuba ndandi ngaphilanga
- □ I had to stop going because my parent/guardian died
  Kwanyanzeleka ndiyeke kuba umzali wam okanye umqcini wam wasweleka
- □ I had to repeat a grade and I didn't want to.
  Kwanyanzeleka ndiphinde ibanga kodwa ndandinga funi
- □ I was suspended or expelled
  Ndanqunyanyiswa okanye ndagxothwa
- □ I got married
  Ndatshata
- □ I got pregnant or had a child
  Ndakhulelwa okanye ndabanomntwana
- □ I was bullied or treated badly by teachers or friends
  Ndandi xhatshazwa okanye ndandigcugcuthekiswa ngotishala okanye ngabahlobo bam
- □ I did not like school
  Ndandi ngasithandi isikolo
- □ I moved to another place and could not register
  Ndahamba ndaya kwenye idolophu andakwazi ukubhalisa
- □ Other_____
  ezinye

Now go to question 4!

2. What is the name of your school? *Lithini igama lesikolo sakho?*
_____

3. What grade are you in? *Ukwibanga lesingaphi?* _____

4. What is the highest grade you have passed? *Lithini ibanga eliphezulu oliphumeleleyo?*_____

   WELL DONE ☺! *WENZE KAKUHLE ☺!*

5. How many grades have you repeated? *Mangaphi amabanga okhe wawaphinda?*
   _____ grades

6. Why did you repeat grades? *Kwakutheni ukuze uphinde amabanga?*
_____

MY SCHOOL
Please think about THE LAST FULL TERM YOU WENT TO SCHOOL. If you are not sure when this was, please chat with the research assistant.
Nceda ucinge ngethuba <u>usiya esikolweni isiqingatha esipheleleyo.</u> Ukuba awusayi khumbuli ukuba kwakunini, nceda thetha nomncedisi phando.

7. In the last full term of school, how many days did you miss school (not including

weekends, holidays or public strikes)?
Ngexesha lokugqibela esikolweni, zingaphi intsuku zange wakwazi ukuphumelela esikolweni (ungabali impelaveki, okanye holide intsuku zabaqhanqalazi)?

- □ Less than a week in total/ *Ngaphantsi kweveki ubuninzi*
- □ About a week in total/ K*angangeveki ubuninzi*
- □ About 2 weeks in total/ *Ngaphezu kweveki ezembini (2) ubuninzi*
- □ About 3 weeks in total/ *Ngaphezu kweveki ezintathu (3) ubuninzi*
- □ More than a month in total/ *Xa ingadlula inyanga ubuninzi*

8. In the last term of school, which meals did you have for free at school?
Isiqingatha sokugqibela sesikolo zeziphi indidi zokutya ozifumeneyo simahla esikolweni?
   - □ Breakfast/ eBrakfasi
   - □ Lunch/ *Isidlo sasemini*
   - □ Other food/ *Okunye ukutya*
   - □ I don't have any free food at school/ Asifumani nxaso yakutya *esikolweni*

9. How did you get to school during the last term of school?
Isiqingatha sokugqibela sesikolo loluphi uhlobo ubusiya ngalo esikolweni?
   - □ Walk/ *Bendihamba ngenyawo*
   - □ Bus/ *Ndikwela ibhasi*
   - □ Taxi/ *Ndikwela isithuthi sika wonkewonke*
   - □ Driven/ *Bendisiwa yimoto yasekhaya*
   - □ Bicycle/ *ibhayisekile*

10. How long did it take you to get there? *Kuthatha ithuba elingakanani ukufika esikolweni? (inombolo)* _____ hours/ *iyure* _____ minutes/ *imizuzu*

11. How many different schools have you studied in? Please include primary school if you are in secondary school.
Zingaphi izikolo ezohlukileyo othe wafunda kuzo? Nceda ubale nesikolo samabanga aphantsi ukuba ukwisikolo samabanga aphezulu. _____

We would like to know a bit more about your experiences at school. If you are not in school now, please think about when you last went to school. Please tell us how true these statements are for you:

Singathanda ukwazi banzingamava akho esikolweni. Ukuba awusafundi ngoku nceda ucinge kwakunini ngoko wawugqibelisa. Nceda usixelele ukuba kuyinyani kangakanani na kuwe oku:

	Never *Zange*	Sometimes *Ngamanye amaxesha*	Always *Rhoqo*
12. I like school. *Ndiyasithanda isikolo.*			
13. I look forward to going to school. *Ndinomdla wokuya esikolweni.*			
14. I try hard to do well in school. *Ndiyazama kakhulu ukwenza kakuhle esikolweni.*			
15. I have been hit, beaten or slapped by a teacher at school. *Ndakhe ndabethwa okanye ndaqhwatywa ngempama ngutitshala esikolweni.*			

	Never *Zange*	Sometimes *Ngamanye amaxesha*	Always *Rhoqo*
16. I like the way my school looks. *Ndiyayithanda indlela esijongeka ngayo isikolo sam.*			
17. I feel safe at school. *Ndiziva ndikhuselekile esikolweni.*			

18. What has been your favourite subject at school (now or before)?
Zeziphi izifundo ozithandayo esikolweni [ngoku okanye ngaphambile]
_____

This is the end of Section 2!!!

5.2.4 Part 3: Me and My Health

Isiqendu 3: Wena nempilo yakho

We all get sick sometimes. This section asks about how your health has been in the past 6 months.
Sonke siyagula ngamanye amaxesha. Elicandelo libuza ngempilo yakho ibinjani kwezinyanga 6 zidlulileyo:

1. How has your overall health been in the last 6 months?
Besinjani isimo sempilo yakho kwezinyanga 6 zidlulileyo?
□ Very poor health/ *Ibingentlanga kakhulu*
□ It has been OK (not too good, not too bad)/ *Ibingcono (ibingentlanga, ibingembanga)*
□ Excellent health/ *Ibintle kakhulu*

The next questions are about problems you have had while doing certain activities because of your health, in the past 6 months.
Lemibuzo ilandelayo ibuza malunga nengxaki okhe wadibana nazo malunga nempilo yakho.

In the last six months… *Kwezinyanga 6 zidlulileyo…*	No, no difficulty *Hayi, bekungekho bunzima*	Yes, some difficulty *Ewe, bebukhona ubunzimana*	Yes, a lot of difficulty Ewe, bekunzima kakhulu	Cannot do it at all *Bendinga kwazi kwaphela*
2. Did you have difficulty seeing, hearing, walking or climbing steps, washing yourself or getting dressed, speaking or being understood? *Ingaba ubukhe wanobunzima ekuboneni, ekuveni, ekuhambeni, ekunyukeni amanqwanqwa,*				

ekuzivaseni okanye ekuzinxibiseni, ekuthetheni okanye de ungaviwa nanga bantu?				
3. Did you have difficulty remembering things or following a story or conversation? *Ingaba ubukhe wanobunzima ekukhumbuleni izinto okanye ekulandeleni amabali okanye iingxoxo?*				

Which one of the following illnesses have you had <u>in the past 6 months</u>? Please tell us how often you have felt them: *never, sometimes* or *often*.
Kwezinyanga 6 zidlulileyo zeziphi izigulo ezake zakufumana kwezi zilandelayo? Nceda usixelele kukangaphi uziva: zange, ngamanye amaxesha, njalo.

In the past sixth months…	Never *Zange*	Sometimes *Ngamanye amaxesha*	Often *Njalo*
4. Ear problems: pains and infections *Ingxaki zendlebe: intlungu kunye nosuleleko*			
5. Asthma, lung problems and trouble breathing for more than two days *Isifuba, ingxaki yemiphunga kunye nokuphefumla nzima ngaphezu kwentsuku 2.*			
6. Fits or epilepsy *Ukuxhuzula okanye isifo sokuwa*			
7. Shingles or rash in the skin *Wakhe wanebhanti (ishingles) okanye irhatshalala emzimbeni wakho*			
8. Sores on the hands, mouth, feet or other parts of the body *Izilonda emlonyeni, ezandleni nasezinyaweni, nasemzimbeni wakho wonke*			
9. A cough where you spit up green or yellow stuff			
10. A bad cough lasting three weeks or longer			
11. Pains in your chest			
12. Night sweats			
13. Coughing up blood			
14. Ulcers, white patches on your mouth or problems swallowing food *Amaqhakuva amancinci emlonyeni wakho okanye emilebeni, abangela kubenzima ukuginya ukutya*			
15. Diarrhoea or a runny tummy for more than 2 days *Utyatyazo okanye isisu esihambisayo ngaphezu kwentsuku ezimbini (2)*			
16. Nausea or vomiting *Uziva ngongathi uzakugabha okanye uyagabha*			
17. Headaches *Intloko ebuhlungu*			
18. Back pain / aches *Intlungu emqolo*			

19. Fever U*mkhuhlane*			
20. Tire easily, little energy *Ndindinwa msinyane, ndibenamandla amancinci*			
21. Stomach problems / difficulties with digesting food *Ingxaki zesisu/ ubunzima ekuginyeni ukutya*			
22. Dizziness *Isiyezi*			
23. Bad dreams or problems sleeping well *Amaphupha amabi okanye ukungalali kakuhle*			
24. Lost a lot of weight, or could not put on weight *Ukwehla emzimbeni okanye ukungatyebi*			
25. Sores or warts in your private parts *Izilonda okanye iintsumpa kumalungu akho angasese*			
26. Burning while urinating / peeing *Umchamo otshisayo*			
27. Itching and redness in your private / intimate parts *Urhawuzelelo kunye nobubomvu kumalungu akho angasese*			
28. Itching, soreness or bleeding from your bum *Urhawuzelelo, izilonda okanye ukopha ezimpundwini zakho*			

29. Have you ever been tested for TB?
Ingaba ubukhe wayo vavanyelwa isifo sephepha (TB)?
□ No, I've never been tested
Hayi, andizange ndivavanywe
□ Yes, I was tested, I had TB in the past, but I am ok now
Ewe, ndavavanywa ndandi nesifo sephepha kodwa ndiphilile ngoku
□ Yes, I was tested, I have TB now
Ewe, ndavavanywa, ndinesifo sephepha ngoku.
□ Yes, I was tested, I did not have TB
Ewe, ndavavanywa, andina sifo sephepha
□ Yes, I was tested, but I don't know the results
Ewe, ndavavanywa, kodwa andizazi iziphumo zam

30. Have you ever had an HIV test?
Ingaba ubukhe wavavanyelwa isandulela sentsholongwane kagawulayo (HIV)?
□ Yes, I got my results/ Ewe, ndazifumana iziphumo zam
□ Yes, but I never got the results/ Ewe, kodwa zange ndizifumane iziphumo zam
□ No <u>>> Go To Question 31/ *Hayi* >> *dlulela kumbuzo 31.*</u>

30a. How old were you when you had your first test? _____
Wawuneminyaka emingaphi ngethuba wawuqala ukuvavanywa?

31. [ONLY GIRAFFES/ HIV-POSITIVE STATUS-AWARE] What is your most recent CD4 count? If you don't know, please write 0 (zero):___
Buthini ubume bakho be CD4 count bamvanje? [Xa ungayazi pendula ngo (o) zero

32. [ONLY GIRAFFES/ HIV-POSITIVE STATUS-AWARE] What was the result of your most recent viral load?
Zazithini iziphumo zakho zamvanje ze viral load?
□ There is still some virus in my body
Isekhona enye intsholongwane emzimbeni wam

□ The doctor or nurse said my viral load is low
Ugqirha okanye umongikazi uthe intsholongwane yam isezantsi.
□ I don't know my viral load results
Andizazi iziphumo ze viral load yam

Sometimes when we are not feeling well, we go to see a doctor or a nurse. Sometimes we go straight to the pharmacy or we visit a sangoma or a herbalist.
Ngamanye amaxesha asiziva siphilile, siyahamba siyobona ugqirha okanye umongikazi. Ngamanye amaxesha siyahamba siyobona ifamasisti okanye isangoma okanye inyanga.

33. In the last year, where have you gone to get help? Please choose all options that apply.
Kunyaka ophelileyo, ubulifunephi uncendo? *[KHETHA IMPENDULO KANGANGOKO ZIFUNEKA]*
□ Chemist/Pharmacy *Indawo yamayeza/ ifamasisti*
□ Public Clinic / *Ikliniki ka wonkewonke*
□ Private Doctor (Ugqirha) / *Ugqirha wabucala*
□ Traditional Healer (Sangoma) / *Isangoma*
□ A healer at church or medicines from the church / *Umthandazeli wasecaweni okanye amayeza asecaweni*
□ Traditional Pharmacy / *Ixhwele inyangi yesintu*
□ A public hospital / *Isibhedlele sika wonkewonke*
□ Private Hospital / *Isibhedlele sabucala*

34. How do you usually get to your local clinic/ hospital?
Ingaba uhamba njani xa usiya kwikliniki / isibhedlele
□ Walk/ *Ndiyahamba*
□ Taxi/ *Itekisi*
□ Bus/ *Ibhasi*
□ Driven
Ndiyasiwa ngemoto yasekhaya/ imoto yasesibhedlele/ umbutho wasekuhlaleni
□ Other/ *Ezinye*

34a. If "other", how do you get there? _____

35. How long does it take to get there? _____ hours _____ minutes
Ithatha ixesha elingakanani ukuyofika? Iyure imizuzu

36. How much does it cost to get to your clinic (in Rand)? If you don't pay any money, please enter 0 (zero): _____
Ibiza malini ukuya eklinikini yakho? (imali) Ukuba uyahamba ukuya ekliniki, nceda ubeke 0 (iqanda)

37. Who goes to the above places with you usually? CHOOSE ONLY ONE ANSWER
Ngubani lo usoloko uhamba naye kwezi ndawo zinga phezulu? KHETA IMPENDULO IBENYE
□ I go alone / *Ndihamba ndedwa*
□ My parent/ caregiver goes *Umzali wam/ umntu ondigcinayo*
□ Another family member / *Elinye ilungu losapho lwam*
□ My friend / *Umhlobo wam*
□ My boyfriend/ girlfriend *Isinqanda mathe sam/ iqabane lam*
□ My village or community healthcare worker
Unompilo wasesixekweni okanye wase kuhlaleni kwam
□ Someone else / *Omnye umntu*

AT THE CLINIC

38. Who did you talk to about your health at the clinic during the last year? Choose as many as apply.
    Ngubani othethe naye ekliniki malunga nempilo yakho kunyaka odlulileyo? Khetha impendulo kangangoko zifuneka.
    - □ Nurse/ *Mongikazi*
    - □ Doctor/ *Ugqirha*
    - □ Counsellor/ *Umcebisi ngempilo*
    - □ Pharmacist/ *Umniki mayeza*
    - □ Village or Community healthcare worker
      Unompilo wasesixekweni okanye wase kuhlaleni kwam
    - □ Someone else who works at the clinic who is living with HIV
      Omnye umntu osebenza ikliniki ophila nentsholongwane kagawulayo (HIV).

39. How long do you wait to see someone at the clinic usually?
    Lixesha elingakanani usoloko ulinda ngalo ukuze ubone ababantu abangentla?
    _____ hours *Iyure* _____ minutes *imizuzu*

Going to the clinic/ hospital in the past year

Ukuya ekliniki/ esibhedlele kunyaka odlulileyo

Now we would like to hear about your experience at the clinic or hospital where you went to get help or where you go when you are sick. Your answers will be completely confidential and will not in any way impact the help or support you are getting.

Ngoku singathanda ukuva malunga ngamava akho ekliniki okanye esibhedlele apho wayakhona uyofuna uncedo okanye apho uyakhona xa ugula. Iimpendulo zakho zizakuhlala ziyimfihlo kwaye azizukuchaphazela uncendo nenxaso oyifumanayo.

Please tell us how often you experienced any of the following in the past year: *Nceda ke usixelele ukuba kukangaphi ufumana ezizinto zilandelayo kunyaka odlulileyo.*	Never	Once or Twice	Several Times	Most of the time
40. I didn't have enough money for transport to get to the clinic *Andikhange ndibenayo imali yokukhwela ukuya ekliniki.*				
41. No one was available to go with me Bekungekomntu wondikapha.				
42. It was not safe for me to go to the clinic/ hospital. *Bendingakhuselekanga okanye ukuba ndingaya ekliniki.*				
43. I did not get the help that I needed *Akange ndilufumane ncedo ebendiludinga.*				
44. The clinic/ hospital staff were too busy to give me the help I needed *Abasebenzi bebexakeke kakhulu ukuba bangandibona.*				
45. I felt my information would be kept safe and confidential Ndizive inkcukacha zam zizokugcinwa zikhuselekile kwaye ziyimfihlo.				

46. They did not know the answers to my questions *Khange babenazo impendulo kwimibuzo yam.*				
47. They got angry with me about how I take my pills and they scolded me *Bacaphuka ngehlobo endizithatha ngalo ipilisi zam de bagxininisa.*				
48. I had to miss school to go to the clinic *Ndaphosa isikolo ngenxa yokuba bendisiya ekliniki.*				
49. I felt comfortable talking to the healthcare worker about getting something to prevent pregnancy *Ndaziva ndikhululekile ukuthetha nonompilo malunga nokuthatha izicwangcisi zam.*				
50. They got angry with me because I am having sex and they scolded at me *Baye bacaphuka de bandingxolisa kuba ndisabelana ngesondo.*				
51. I could get condoms when I needed them *Ndingazifumana izikhuseli (icondoms) xa ndizifuna.*				

52. How often do you go to a support group at your clinic?
Kukangaphi usiya kwiqela lenxaso elibanjwelwa ekliniki okanye esibhedlele?
   - □ Weekly/ *Ngeveki*
   - □ Monthly/ *Ngenyanga*
   - □ Every year/ Qho *ngonyaka*
   - □ Once in a while/ *Kanye ethubeni*
   - □ I don't go to one/ *Andiyi ndawo* >> Go to Question 54.

53. What kind of support group do you go to?
Leliphi iqela lenkxaso ohamba kulo?
   - □ A group for anyone who is HIV positive
     Iqela labantu abaphila nentsholongwane kagawulayo (HIV positive)
   - □ A group for HIV positive youth/ teens only
     Iqela labantu abatsha abaphila nentsholongwane kagawulayo (HIV positive)
   - □ The group changes
     Iqela litshintshatshintsha njalo.

54. Does your family have a person who visits you at least once a month to help with health issues, who is not a family member, like a nurse, community health worker, home-based carer, village health worker or social worker?
Ingaba kusapho lwakho ukhona umntu okhe akutyelele kanye enyangeni othi akuncedise ngezempilo. Ongenguye umntu wosapho lwakho, kodwa njengo nompilo, unontlalontle, umntu onjongene nempilo ekuhlaleni?
   - □ No/ *Hayi*
   - □ Yes/ *Ewe*

55. Imagine you get a special meeting with the Minister of Health. What would you like to tell him about young people and their health in South Africa?
Khawufane ucinge usentlanganisweni nomphathiswa wezempilo. Yintoni ongathanga ukumxelela yona malumnga nabantu abatsha nempilo yabo Emzantsi Afrika?
You can write your message. Ungabhala umyalezo wakho.

You can record your message. Ushicelele umyalezo wakho.
You can video-record your message. Ushicelele (video) umyalezo wakho.

5.2.5 Part 4: You and Your Medicine

Isigendu 4: Wena namayeza akho

Sometimes we get sick and we need to take medication to get better. Other medication helps us stay healthy.

The following questions ask about any pills you take. We know that taking medicine regularly can be a big job, and that it is challenging.
Ngamanye amaxesha siyagula kwaye sidinga ukuthatha amayeza ukuze sibengcono. Amanye amayeza ayasinceda ukuze sihlale sisempilweni. Lemibuzo ilandelayo ibuza ngepilisi ozithathayo noba zeziphi na. Siyazi ukuba ukuthatha amayeza rhoqo ingangumsebenzi omkhulu kwaye ongumcelimngeni.

1. Which medication are you currently taking? Choose as many answers as apply.
Ngawaphi amayeza owathathayo ngoku? Khetha impendulo kangangoko zifuneka
□ I am not taking any medication >> Please ask the research assistant for the "D" booklet and skip to question 2d
Andithathi nawaphi na amayeza
□ Medicines for my chest/ *Amayeza esifuba sam*
□ Medicines for my diarrhoea/ *Amayeza otyatyazo*
□ TB medication/ *Amayeza esifo sephepha*
□ Medicines for HIV/AIDS – antiretrovirals, ARV/ *Amayeza eHIV/ iARVs*
□ Pill to prevent pregnancy/ *Ipilisi zokukhusela ukukhulelwa*
□ Medicines for my ear/ *Iyeza lendlebe*
□ I don't know what my medication is about/ *Andiyazi ukuba amayeza wam ngawantoni*

2. Please write the name of the medicine you are currently taking. If you don't know, please write "I don't know":
Sicela ubhale igama lamayeza owathathayo ngoku. [Xa ungayazi, bhala "andiyazi".]
_____

3. How old were you when you started taking this medication?
Wawunangaphi ukuqala kwakho ukuthatha amayeza?
_____ years old
□ I don't know

4. How many pills in total do you take every day?
Zingaphi ipilisi ozithathayo rhoqo ngosuku?
_____ pills

5. How many times a day do you have to take pills (antiretrovirals, pills for your tummy, TB or other illness)?
Mangaphi amaxesha ngosuku othi uthathe ngazo ipilisi? (iARVs, ipilisi zesisu, zesifo sephepha okanye ezinye izifo)?
_____ times

Taking HIV medication – ARV pills

Amayeza eHIV – ipilisi zeARV

Now we'd like to talk about one kind of medicine only: your antiretrovirals or ARVs.
Ngoku sifuna ukuthetha malunga ngodidi olunye lamayeza: aniretrovirals okanye iARVs.

Do not worry about telling us if you are not taking all of your medicines. We need to know what is really happening, not what you think we may want to hear.
Ungaxhali ngosixelela ukuba awuwathathi wonke amayeza wakho. Sidinga ukwazi kanye okwenzekayo hayi lento ucinga ukuba sifuna ukuyiva.

6. How many antiretrovirals or ARV pills do you have to take every day?
Zingaphi ipilisi ekufanele (iARVs) uzithathe rhoqo?
_____ pills

7. How many times a day do you have to take antiretrovirals or ARV pills?
Mangaphi amaxesha ngemini ekufanele uthathe ipilisi zeARVs?
_____ pills

8. When do you need to take your pills? Choose as many as apply:
Kufuneka uzithathe nini ipilisi zakho? [Impendulo ezininzi zivumelekile]
- □ In the morning / *Ekuseni*
- □ During the day/ *Emini*
- □ In the evening/ *Ebusuku*
- □ Anytime/ *Nanini na*
- □ I don't know/ *Andiyazi*

Dumile did not manage to take his ARVs last Tuesday because he was very busy with school. We would like to understand if you have similar experiences when you take your ARVs so we can help other teens.

We need to know what is really happening, not what you think we want to hear. Nobody will get angry at you and your answers.
uDumile akazithathanga iARVs kulwesibini odlulileyo kuba ebexakekile ngumsebenzi wesikolo. Singafuna uqonda ngehlobo othatha ngalo iARVs ukuze sikwazi ukunceda abanye abantwana abalingana nawe. Sifuna ukuqonda ukuba yintoni eyenzekayo, hayi lento ucinga ukuba sifuna ukuyiva. . Akukho mntu oyakucaphuka ngeempendulo zakho

In the past three days…
Kwintsuku ezinthathu ezidluleyo…

9. How many times did you take your ARV pills yesterday?
Mangaphi amaxesha othathengawo iARVs izolo?
_____ times

10. How many times did you take your ARV pills on the day before yesterday?
Mangaphi amaxesha uthathengawo iARVs izolo elinye?
_____ times

11. How many times did you take your ARV pills three days ago?
Mangaphi amaxesha othathengawo iARVs kwintsuku ezintathu (3) ezidlulileyo?
_____ times

Andiwe knows he is supposed to take his ARVs every day at the same time(s). Even if he tries his best, sometimes unexpected things get in the way and prevent him from taking them. So some days Andiwe does not take his ARVs or he doesn't take them at the right time.

This is not his fault.
uAndiwe uyayazi ukuba kufanelekile athathe iARVs rhoqo ngalo lonke ixesha. Nokuba uyazama ngamanye amaxesha izinto ezingacwangcisekanga zimbangela angakwazi ukuthatha ipilisi zakhe. Ngezinye imini uAndiwe akazithathi iARVs okanye akazithathi ngexesha elilungileyo.

Lena asiyongxaki yakhe

We would like to ask you about the times you were not able to take your ARVs.We simply want to better understand why teens have a hard time taking their HIV medication/ ARVs.
Siza kuthanda ukubuza malunga namaxesha apho ungakwazanga ukuthata iARVs. Sifuna ukwazi ngcono kutheni ulutsha lifumana ubunzima ekuthatheni amayeza abo HIV/iARVs

12. How many days did you take all of your ARVs at the right time *last week?*
Zingaphi iintsuku kwiveki ephelileyo othathe amayeza wakho ngexesha elililo?
- □ I didn't take my medication at the right time last week/ Andikhange ndiwathathe amayeza
- □ One day/ Usuku lwalunye
- □ Two days/ Intsuku zambini
- □ Three days/ Intsuku zantathu
- □ Four Days/ Intsuku zane
- □ Five Days/ Intsuku zantlanu
- □ Six Days/ Intsuku zantandathu
- □ I took my medication at the right time every day last week.
Ndiwathathile amayeza am ngexesha elifanelekileyo kwiveki ephelileyo.

Remember, your answers to our questions will help us understand what makes it easier or harder to take ARV pills. Please answer as truthfully as you can. Your answers are completely confidential and we will not judge you.
Khumbula, impendulo nemibuzo yakho iya kunceda ekuqondeni okwenza kube lula okanye kubenzima ukuthatha iARVs zakho. Nceda uphendule ngokunyanisekileyo kangangoko. Impendulo zakho ziza kuhlala ziyimfihlo kwaye akho mntu uyaku gweba.

13. When was the last time you missed taking any of your ARV pills?
Kwakunini ngoko wawuphose uthatha ipilisi zakho iARVs?

- ☐ in the last week/ *Kwiveki ephelileyo*
- ☐ in the last month/ *Kwinyanga ephelileyo*
- ☐ in the last year/ *Kunyaka ophelileyo*
- ☐ I've never missed a pill/ *Andizange ndaphosa ipilisi*

14. Please think back to the last time you missed taking your ARVs. Why was it?
Nceda ucinge ngexesha apho waphosa khona ukuthatha iARVs zakho. Kwakutheni?

_____

_____

Record Audio 1

Sometimes the medicine we get from the doctor changes. They also tell us to take different numbers of pills and at different times. We would like to know if your ARV pills have changed in the last year.
Ngamanye amaxesha amayeza esiwathathayo kwagqirha aye atshintshe. Baye basixelele ukuba masithathe ipilisi ezohlukileyo kwaye ngamaxesha ahlukileyo. Sifuna ukuqonda ukuba ingaba ipilisi zakho ziye zatshintsha kunyaka ophelileyo.

15. In the past year, have you changed the type of ARV treatment you take, for example: name of medicines, number of pills, times you had to take them?
Kunyaka odlulileyo ubukhe wawatshintsha amayeza owasebenzisayo. Umzekelo igama leyeza, inani leepilisi, ixesha lokuzithatha?
□ No / Hayi <u>>> Go to Question 17</u>
□ Yes/ Ewe

16. How many times?/ *Amaxesha amangaphi?* _____

17. Who picks up your ARV pills from the clinic or hospital usually?
Ngubani okuthathela amayeza ekliniki okanye esibhedlele usoloko?
□ I get it myself/ *Ndiyazithathela ngokwam*
□ Someone in my family goes without me/ *Ilungu losapho liyandithathela ngaphandle kwam*
□ I go together with someone from my family/ *Ndihamba nomntu kusapho lwam*
□ A health worker brings them to my home/ *Onompilo bayawazisa apha ekhaya.*
□ My treatment buddy collects my meds/ *Lomntu undincedisa ekuwaseleni nguye ondithathelayo*
□ I don't know who gets my medicine/ *Andiyazi ukuba athathwa ngubani amayeza am.*
18. How often do you go to fetch your ARV pills? *Uya kangaphi uyothatha amayeza wakho?*
□ Every month/ *Qho ngenyanga*
□ Every two months/ *Qho emveni kwenyanga ezimbini*
□ Every three months/ *Qho emveni kwenyanga ezintathu*
□ I don't know/ *Andiyazi*
□ Other/ *Enye* _____

19. How many times <u>last year</u> were you not able to fetch your pills from the clinic?
Mangaphi amaxesha ongakhange ukwazi ukuyolanda amayeza wakho ekliniki kulonyaka udlulileyo?
□ I always got my medicine/ *Ndiwalanda rhoqo amayeza wam*
□ 1-2 times/ *Kanye-kabini*
□ More than three times/ *Ngaphezulu kwesithathu*

20. How many times in the last year were you not able to get to your clinic appointment?
Uphose kangaphi kunyaka ophelileyo ukuya kwidinga lakho ekliniki?
□ I always went to my appointment/ *Ndihamba rhoqo kumadinga am ekliniki.*
□ 1-2 times/ *Kanye-kabini*
□ More than three times/ *Ngaphezulu kwesithathu*

21. How many times in the last year were you not able to get your medications because the clinic had run out of medication (stock-out)?
Mangaphi amaxesha kunyaka odlulileyo apho ungakhange ukwazi ufumana amayeza ngenxa yokuba engekho ekliniki (ephelile)
□ I always got my medicine/ *Ndiwalanda rhoqo amayeza wam*
□ 1-2 times/ *Kanye-kabini*
□ More than 3 times/ *Ngaphezulu kwesithathu*

Taking medication can make us feel better or worse. It can also change over time. Please tell us how often you have felt or thought the following about your medication <u>in the last year</u>.
Ukuthatha amayeza kungasenza sizive ngcono okanye sigula nangakumbi, kuyatshintsha exesheni. Khawusixelele indlela obuziva ngayo nobucinga ngayo ngamayeza wakho kunyaka odlulileyo.

	Never Zange	Sometimes Ngamanye amaxesha	Often Njalo
22. I don't need medication anymore, because I can stay healthy without it. *Andiwadingi amayeza kwakhona, kuba ndiyakwazi uhlala ngaphandle kwawo.*			
23. I remember to take my medication when I do something else, for example, brush my teeth or eat breakfast. *Ndiye ndikhumbule ukuthatha amayeza am xa ndenza enye into umzekelo, xa ndihlamba amazinyo okanye ndisitya isidlo sakusasa*.			
24. Taking medication caused me to have other physical symptoms (e.g. rash, headache, getting fat in unusual places, nausea, vomiting, diarrhoea). *Ukuthatha amayeza kwenze ukuba ndibe neempawu emzimbeni (umzekelo: irhatshalala, intloko ebuhlungu, ndityebe kwiindawo endingazifuniyo, ndibene siyezi, ndigabhe, ndityatyaze.)*			
25. Taking medication makes me feel stronger and healthier. *Ukuthatha amayeza kundenza ndizive ndisemandleni kwaye ndiphilile.*			
26. I don't take my medication because I run out of them. *Andiwathathi amayeza kuba endiphelele.*			
27. I forget to take my medication. *Ndiyalibala ukuthatha amayeza wam.*			
28. I remember to take my pills because a soapie or a TV programme starts on TV. *Ndiyakhumbula ukuthatha amayeza kuba kudlala inkqubo kumabona kude (iTV).*			
29. My medication gets in the way of my daily life, school and friends. *Ipilisi zam ziyandiphazamisa kwinkqubo zam zemihla, esikolweni kwakunye nakubahlobo bam.*			
30. I feel fed up taking my medication and need a break. *Ndiziva ndidiniwe ekuthatheni amayeza wam kwaye ndifuna ikhefu.*			
31. It has been hard to take my medication when I have changed homes or schools. *Kubanzima ukuthatha amayeza xana nditshintsha indawo yokuhlala okanye izikolo.*			
32. Taking my medication is hard because I am worried people would find out about my HIV. *Ukuthatha amayeza kubanzima kuba ndibanexhala labantu bangandibona ukuba ndine HIV.*			
33. I use an alarm to remember to take my pills.			

	Never Zange	Sometimes Ngamanye amaxesha	Often Njalo
Ndisebenzisa ialamu ukuze ndikhumbule ukuthatha ipilisi zam.			
34. I struggle to take my medication when I get sick with another illness. *Ndibanobunzima ekuthatheni amayeza am xa ndigula sesinye isigulo.*			
35. It is hard to take my medication when my family and/or friends don't help me remember. *Kubanzima ukuthatha amayeza xa usapho lwam / okanye izihlobo zam zingandi ncedisi ekukhumbuleni.*			
36. I carry my medication with me all the time. *Ndiyawaphatha amayeza am ngalo lonke ixesha.*			
37. I do not have anywhere to keep my medicine at school or home. *Andinayo indawo yokuwagcina amayeza am esikolweni okanye ekhaya.*			
38. I understand why I have to take my medicine *Ndiyaqonda ukuba kutheni kunyanzelekile ukuthatha amayeza am.*			
39. I keep getting sick even when I do take it. *Ndisoloko ndigula nokuba ndithatha amayeza.*			
40. My girlfriend/ boyfriend helps me to remember to take my pills. *Isinqanda mathe sam siyandinceda ekukhumbuleni ekuthatheni amayeza am.*			
41. Taking my medication reminds me of HIV. *Ukuthatha amayeza am kundikhumbuza ngeHIV.*			
42. My doctor/ nurse has told me to stop taking medicine for some time. *Ugqirha/ umongikazi undixelele ukuba mandiyeke ukuthatha amayeza okwethutyana.*			
43. It has been difficult for me to take my medicine when I haven't eaten. *Kubanzima ukuthatha amayeza xana ndingatyanga.*			
44. I feel like the pills are toxic or harmful. *Ndiziva ngathi ipilisi zinobungozi.*			
45. I have too many pills to take. *Ndinepilisi ezinizi ekumele ndizithathe.*			
46. When I have a boyfriend/ girlfriend, I struggle to take my medication. *Xa ndinesinqanda mathe kubanzima ukuthatha ipilisi.*			
47. I use a cellphone to remember to take my pills. Ndisebenzisa *imfonomfono ukukhumbula ukuthatha ipilisi.*			

	Never Zange	Sometimes Ngamanye amaxesha	Often Njalo
48. When I was in circumcision camp, it was hard to take my medication. *Xeshikweni ndisentabeni kwakunzima ukuthatha ipilisi zam.*			
49. I have not been able to take my medicine because my pills got damaged or lost. *Andikwazi ukuthatha ipilisi zam kuba zimoshakele okanye zalahleka.*			
50. It was difficult to take my medication because I drank too much alcohol. *Bekunzima ukuthatha amayeza kuba bendinxile kakhulu.*			
51. Someone at the clinic/ hospital has told me that I should not take medicine when I drink alcohol or take other drugs. *Umntu ekliniki/ esibhedlele undixelele ukuba mandingathathi amayeza ndisele utywala okanye iziyobisi.*			

>>Go to Question 52

Taking medication in the past
Uthatha amayeza kwixesha elidluleyo

2d. Have you ever taken any medication for longer than 2 weeks in your life? Choose as many answers as apply:
Wawukhe wathatha amayeza ngaphezulu kweveki ezimbini ebomini bakho? Khetha impendulo kangangoko zifuneka:

- □ I have never taken any medication/ *Andizange ndathatha mayeza ngaphezulu kweveki ezimbini.*
- □ Medicines for my chest/ *Amayeza esifuba sam*
- □ Medicines for my diarrhoea/ *Amayeza otyatyazo*
- □ TB medication/ *Amayeza esifo sephepha*
- □ Medicines for HIV/AIDS – antiretrovirals, ARV/ *Amayeza eHiv-iARVs*
- □ Pill to prevent pregnancy/ *Ipilisi zokukhusela ukukhulelwa*
- □ Medicines for my ear/ *Iyeza lendlebe*
- □ I don’t know what my medication is about/ *Andazi ukuba amayeza wam ngawantoni*

3d. Please write the name of the medicine you have taken for longer than two weeks:
Sicela ubhale igama leyeza obukhe walithatha ngaphezulu kweveki ezimbini:

_____

Now we would like to ask you about the time when you were taking antiretrovirals, HIV/AIDS pills (ARVs) in the past.
Ngoku singathanda ukubuza malunga nexesha elo ubuthatha ngalo ipilisi zentsholongwane kagawulayo (HIV) antiretrovirals, HIV / AIDS pills.

You told us you took ARVs in the past, but not now.
Ubusixelele ukuba wawuthatha amayeza ngaphambili kodwa, hayi ngoku

4d. How old were you when you first started taking ARVs?
Wawuneminyaka emingaphi ngexesha wawuqala ukuthatha iARVs? _____ years old

- □ I don’t know

5d. When did you last take ARVs?
Wagqibela nini ukuthatha ARVs?

- □ A long time ago, I don’t remember/ *Kudala/andisakhumbuli*
- □ In the last year/ *Kunyaka ophelileyo*
- □ More than a year ago/ *Ngaphezu konyaka*

Taking medication can make us feel better or worse. It can also change over time. Please tell us how you felt about taking your ARV pills/ medication?
Ukuthatha amayeza kungasenza sizive singcono kakhulu okanye sigula. Inako ukutshintsha emveni kwexesha. Nceda usixelele waziva njani ngokuthatha amayeza okanye iARVs?

	True for me *Kuyinyani kum*	Not true for me Akuyonyani kum
6d. I didn’t needed medication anymore, because I could stay healthy without it. *Khange ndisawadinga amayeza, kuba ndiyakwazi ukuhlala ndisempilweni ngaphandle kwawo.*		

	True for me *Kuyinyani kum*	Not true for me Akuyonyani kum
7d. Taking medication caused me to have other physical symptoms (e.g. rash, headache, getting fat in unusual places, nausea, vomiting diarrhoea). *Ukuthatha amayeza kundibangela ukuba mandibe neempawu emzimbeni (irhatshalala, intloko ebuhlungu, isiyezi, amaphupha amabi, notyatyazo.)*		
8d. I stopped taking my medication because I ran out of them. *Ndiyekile ukuthatha amayeza kuba andiphelele.*		
9d. Sometimes I forgot to take my medication. *Ngamanye amaxesha ndiyalibala ukuthatha amayeza*.		
10d. My medication got in the way of my daily life, school and friends. *Amayeza ayandiphazamisa kubomi bam bemihla ngemihla, eskolweni naku bahlobo bam.*		
11d. I felt fed up taking my medication and needed a break. *Ndiziva ndidikiwe ukuthatha amayeza kwaye ndifuna uphumla.*		
12d. It was hard to take my medication when I changed homes or schools. *Bekunzima ukuthatha amayeza am ngexesha nditshintsha ikhaya nesikolo.*		
13d. Taking my medication was hard because I was worried people would find out about my HIV. *Ukuthatha amayeza kwakunzima ngoba ndandinexhala ukuba abantu bazokwazi ngeHIVyam.*		
14d. I struggled to take my medication because I got sick with another illness. *Ndasokola ukuthatha amayeza ngoba ndagula sesinye isigulo.*		
15d. It was hard to take my medication when my family and/or friends didn't help me remember. *Kwakunzima ukuthatha amayeza xa usapho lwam/izihlobo zazingandikhumbuzi.*		
16d. I did not have anywhere to keep my medicine at school or home. *Andinayo enye indawo yokugcina amayeza am esikolweni okanye ekhaya.*		
17d. I didn't understand why I had to take my medicine. *Ndandingaqondi ukuba kutheni kufuneka ndithathe amayeza.*		
18d. I kept getting sick even when I did take it. *Ndaqhubeka ndigula nangona ndadiwathatha amayeza.*		
19d. Taking my medication reminded me of HIV. *Ukuthatha amayeza kundikumbuza ngentsholongwane kagawulayo (iHIV).*		
20d. My doctor/ nurse told me to stop taking medicine for some time. *Ugqirha wam/ umongikazi wandixelela ukuba ndime ukuthatheni amayeza okwethutyana.*		

	True for me *Kuyinyani kum*	Not true for me Akuyonyani kum
21d. It was difficult for me to take my medicine on an empty stomach. *Kwakunzima ukuthatha amayeza ndingatyanga.*		
22d. I felt like the pills were poisonous or harmful. Ndandisiva ingathi ipilisi (ARVs) zinobungozi*.*		
23d. I had too many pills to take. *Ndandi nepilisi ezininzi endandizithatha.*		
24d. I got a new boyfriend/ girlfriend, and I struggled to take my medication around them. *Ndafumana isinqandamathe esitsha, ndandisokola ukuthatha amayeza xa bekhona*.		
25d. When I was in circumcision camp it was hard to take my medication. *Xa ndandisentabeni kube kunzima ukuthatha amayeza.*		
26d. I was not able to take my medicine because my pills got damaged or lost. *Bendingakwazi ukuthatha amayeza kuba onakala okanye zalahleka.*		
27d. It was difficult to take my medication because I drank too much alcohol. *Kwakunzima ukuthatha amayeza ngoba ndandisela kakhulu ubutywala.*		
28d. Someone at the clinic/ hospital has told me that I should not take medicine when I drink alcohol or take other drugs. *Kukho umntu ekliniki /esibhedlele owandixelela ukuba akufanelanga ndithathe amayeza xa ndisel'ubutywala okanye ndithathe ezinye iziyobisi.*		

Thanks for answering these question. Please pass this booklet to the research assistant and return to the main questionnaire, starting again at Question 52, Section 4

[Both on ARVs and Defaulters]

Sometimes we take other medicines to make our body and soul feel better. We visit sangomas, healers, preachers, or local doctors and pharmacists to help us. Sometimes they give us medication or advice to help us feel better.
Ngamanye amaxesha siye sisebenzise amanye amayeza ukwenza imizimba ibengcono. Siye sindwendwele, kwizangoma, iinyangi, abefundisi, oogqirha okanye ikhemisti ukuze zisincede. Ngamanye amaxesa basinika amayeza okanye ingcebiso ukusinceda sizive ngcono.

52. In the last year, how often did you go to a sangoma, traditional healer or a healer in your church? / Kunyaka odlulileyo uyekangaphi kwisangoma okanye exhweleni okanye kumthandazeli wasecaweni?
    - □ I did not go to a sangoma or healer / Andikhange ndiye kwisangoma okanye kumthandazeli
    - □ Once/ Kanye
    - □ 2-3 times/ Kabini-kathathu exesheni
    - □ 4 or more times/ Kane nangaphezulu emaxesheni

53. If you went to a sangoma or a traditional healer in the last year, did they tell you to: / Ukuba ubuyile kwisangoma okanye exhweleni kunyaka odlulileyo ingaba bakuxelela ukuba:

□ I did not go to a sangoma
□ Take ARVs / Thatha iARVs kuphela
□ Take ARVs together with traditional meds / Thatha iARVs namayeza esintu
□ Stop taking your ARVs / Yeka uthatha iARVs zakho

54. If you went to a healer at church in the last year, did they tell you to: / Ukuba ubuyile kumthandazeli wasecaweni kunyaka odlulileyo, ingaba bakuxelela ukuba:

□ I did not go to a healer
□ Take ARVs / Thatha iARVs kuphela
□ Take ARVs with prayer / Thatha iARVs zakho unomthandazo
□ Stop taking your ARVs / Yeka uthatha iARVs zakho

55. Have you taken any other medicine to help keep you healthy and happy over the last year?

Ingaba akhona amayeza okhe wawasebenzisa ukuzigcina usempilweni kwaye wonwabile kunyaka odlulileyo?

- □ Medicine my sangoma gave me/ *Amayeza endawanikwa sisangoma sam*
- □ Herbal medicine to eat or drink/ *Iingcambu endazinikwa ukuba ndizitye okanye ndizisele*
- □ Herbal medicine to use on my skin as a cream/ *Iingcambu endazinikwa ukuba ndiziqabe kulusu lwam*
- □ Vitamin pills/ *Ipilisi zakhamzimba*
- □ Nutritional supplement/ *Izongezi zakhamzimba*
- □ I did not take any other medicine/ *Akhange ndithathe amanye amayeza*
- □ Other / *ezinye* _____

Andiwe is confused about how to take his ARVs. Can you please help him and tell him whether he is doing the right thing?
uAndiwe udidekile ukuba azithathe njani iARVs zakhe. Ungamnceda umxelele ukuba ingaba wenza into elungileyo?

	Right *Ilungile*	Wrong *Ayilunganga*
56. Andiwe can only take ARVs if he has eaten food.		

	Right *Ilungile*	Wrong *Ayilunganga*
uAndiwe angazithatha iARVs zakhe akuba etyile qha.		
57. It is important that Andiwe takes his ARVs at the exact time. *Kubalulekile ukuba uAndiwe athathe iARVs zakhe ngexesha elililo.*		
58. It is ok for Andiwe to share ARVs with other people in his family or friends. *Kulungile uAndiwe abelane nabanye abantu ngeARVs kusapho lwakhe okanye kuzihlobo.*		
59. Andiwe is two hours late in taking his ARV medication. He should still take it. *uAndiwe usemva ngeeyure ezimbini ekuthatheni iARVs zakhe. Kusafanele azithathe.*		
60. Andiwe has gone out and has had some drinks with his friends. He shouldn't take his ARVs. *uAndiwe uphumile nabahlobo bakhe bayosela utywala. Akufanelanga azithathe iARVs zakhe.*		
61. If Andiwe misses his ARVs one day, it is ok to take two doses the next day. *Ukuba uAndiwe ukuphosile ukuthatha iARVs zakhe ngezolo, kulungile ukuba athathe imilinganiselo imibini ngengomso.*		
62. Andiwe has just vomited up his ARV pill. He should take another pill. *uAndiwe ugabhe iARVs zakhe. Kufanele athathe enye pilisi.*		

A treatment buddy is someone who was there when you started medication, who often attends clinic appointments with you, knows information about your pills, reminds you to take your treatment, and the clinic contacts them when they need to contact you. They can be your parent/ caregiver, friend, sibling, support group member or another patient. They can be taking ARVs or they can be HIV-negative.
Itreatment buddy ngumntu owayekho ukuqala kwakho ukuthatha amayeza, oya nawe kumadinga akho ekliniki, onolwazi ngepilisi zakho akukhumbuze futhi ukuzithatha. Ingangumzali wakho, umntu okugcinayo, umhlobo, isalamane, ilungu leqela elixhasayo, okanye esinye isigulane. Basenokuba nabo bayazithatha iARVs okanye basenokuba abanayo iHIV.

63. Do you have a treatment buddy?
Ingaba unaye umntu okuncedisayo ekuthatheni amayeza?
□ Yes/ Ewe
□ No/ Hayi

64. Do you also assist them with treatment?
Ingaba uyabancedisa nabo ekuthatheni amayeza?
□ Yes, I help them take their ARVs
Ewe, ndiyabancedisa ukuthatha iARVs zabo
□ Yes, I help them take other pills
Ewe, ndiyabancedisa ukuthatha ezinye ipilisi.
□ No, they are not on medication/ *Hayi, akukho mayeza mawathathayo*
□ No/ *Hayi*

Let's take a break!

5.2.6 Part 5: More About You

Isigendu 5: Okuninzi ngawe

1. What are you most proud of about yourself? *Yintoni ozingca ngayo ngobuwena?*

Record Audio 2

[Body and Looks]

Now we would like to ask you a bit about your body. Please tell us how often have you felt these things about your body in the past year?
Ngoku sifuna ukubuza kancinci ngomzimba wakho. Cela usixelele ukuba wena uzive njani ngomzimba wakho kulonyaka ophelileyo?

2. I look as good as others my age.
Ndibonakala ndimhle njengo ntanga bam.
- *Never / Azange*
- *Sometimes / Ngalomaxesha*
- *Always / Rhoqo*

3. I like how my skin looks.
Ndiyaluthanda uhlobo olubonakala ngalo ulusu lwam.
- *Never / Azange*
- *Sometimes / Ngalomaxesha*
- *Always / Rhoqo*

4. My body is small for my age.
Umzimba wam ukhangeleka umncinci kuneminyaka yam.
- *Never / Azange*
- *Sometimes / Ngalomaxesha*
- *Always / Rhoqo*

5. I would like to put on weight.
Ndingathanda ukutyeba.
- *Never / Azange*
- *Sometimes / Ngalomaxesha*
- *Always / Rhoqo*

6. Other young people think I am sexy/ attractive.
Abanye abantu abatsha bacinga ukuba ndinomtsalane.
- *Never / Azange*
- *Sometimes / Ngalomaxesha*
- *Always / Rhoqo*

7. Some of my body parts have changed since I started taked ARVs.
Amanye amalungu omzimba wam atshintsha sukela oko ndaqala iARVs.
- *Never / Azange*
- *Sometimes / Ngalomaxesha*
- *Always / Rhoqo*

How you Think and Feel

Ucinga kanjani kwaye uziva njani

This part of the questionnaire looks at sadness and challenges that all of us face in our lives sometimes. For each group of 3 statements, pick out which best describes how you have felt in the last 2 weeks.
Esisigaba semibuzo sijongene nqo nokukhathazeka kwakunye nemicelimngeni ethi uninzi lwethu luhlangabezane nayo ngamanye amaxesha. Kwizivakalisi ezintathu ezahlukileyo khetha kanye ezo zichaza indlela ozive ngayo kwiveki ezimbini ezidlulileyo.

8.

☐Nothing will ever work out for me
Akukho nto inokundihambela kakuhle

☐I am not sure if things will work out for me
Andiqinisenkanga ukuba izinto ziza kundihambela kakuhle

☐Things will work out for me OK
Izinto ziza kundihambela kakuhle.

9.

☐I am sad once in a while
Ndikhathazeka kanye exesheni

☐ I am sad many times
Ndikhathazeka amaxesha amaninzi

☐I am sad all the time
Ndikhathazeka ixesha lonke.

10.

☐I look OK
Ndijongeka kakuhle

☐There are some bad things about my looks
Zikhona izinto ezimbi kwinkangeleko yam

☐I look ugly
Ndijongeka ndimbi.

11.

□ I hate myself
Ndiyazicaphukela
□ I do not like myself
Andizithandi
□ I like myself
Ndiyazithanda.

12.

□ I do not feel alone
Andiziva ndililolo
□ I feel alone often
Ndiziva ndililolo njalo
□ I feel alone all the time
Ndiziva ndililolo lonke ixesha.

13.

□ I do most things OK
Phantse zonke izinto ndizenza kakuhle
□ I do many things wrong
Izinto ezininzi andizenzi kakuhle

□ I do everything wrong
Zonke izinto ndizenza ngokungalunganga.

14.
□ I have enough friends
Ndinabahlobo aboneleyo
□ I have some friends but wish I had more
Ndinabo abahlobo kodwa ndinqwenela ukuba ndinganabanye
□ I don't have any friends
Andinabo abahlobo.

15.
□ I feel like crying every day
Ndiziva ingathi ndingalila yonke imihla
□ I feel like crying many days
Ndiziva ingathi ndingalila intsuku ezininzi
□ I feel like crying once in a while
Ndiziva ingathi ndingalila kanye emva kwexeshana.

16.
□ Nobody really loves me
Akukho mntu ondithanda ngenene
□ I am not sure if anybody loves me
Andiqinisekanga ukuba ukhona umntu ondithandayo
□ I am sure that somebody loves me
Ndiqinisekile ukuba ukhona umntu ondithandayo.

17.
□ Things bother me all the time
Izinto ziyandikhathaza lonke ixesha
□ Things bother me many times
Izinto ziyandikhathaza amaxesha amanizi
□ Things bother me once in a while
Izinto ziyandikhathaza kanye emva kwexeshana.

Sometimes we get extremely sad. In the past month did you:
Ngamanye amaxesha siziva sikhathazeke kakhulu. Kwinyanga edlulileyo ubukhe wa:

	Yes *Ewe*	No *Hayi*
18. Wish you were dead? *Unqwenele ukuba wawufile?*		
19. Want to hurt yourself? *Ufune ukuzenzakalisa?*		
20. Think about killing yourself? *Ucinge ngokuzibulala?*		
21. Think of a way to kill yourself? *Ucinge ngendlela zokuzibulala?*		
22. Try to kill yourself? *Ukuzama ukuzibulala?*		

[Social Activities]

23. Are you a member of any youth and/or health organisations, political or activist groups? Tick as many as apply.
Ngaba ulilungu lolutsha okanye wombutho wezempilo okanye ezepolitiki okanye ezamatsha ntliziyo? Khetha ezingenayo.

☐ A youth centre where I can do things like use computers and play sports >> Go to Question 23a

Iziko labantu abatsha apho ndithi ndisebenzise khona ikhompiyutha kwaye sidlale nezemidlalo

- ☐ A youth club or homework club at school >>Go to Question 23a
  Umbutho wabantu abatsha okanye umbutho wokwenza umsebenzi wasekhaya wesikolo
- ☐ Gospel Choir/ Singing Group/ *Iqela legosipile okanye iqela lomculo* >>Go to Question 23a
- ☐ Sports team/ *Iqela lezemidlalo* >>Go to Question 23a
- ☐ Music/ Arts performance group/ *Umculo nezo nxentso* >>Go to Question 23a
- ☐ Volunteering/ *Ukuncedisa simahla* >>Go to Question 23a
- ☐ Career Development and advice/ *Umbonisi ngekamva* >>Go to Question 23a
- ☐ Other/ *Ezinye* _____ >>Go to Question 23a
- ☐ No, I am not a member of a group/ Hayi, andilolungu naliphi na iqela

23a. What is the name of your club or group or activity? _____
Yintoni igama lombutho okanye leqela lakho?

24. How often do you go out to a night club, tavern or shebeen?
Kukangaphi uphuma usiya kwindawo zentselo?

- ☐ A few times a week/ *Kanye nanga phezulu evekini*
- ☐ Every week/ *Rhoqo evekini*
- ☐ Once in a while / Kanye emva kwexeshana
- ☐ Never/ *Andizange*

Weekends
Impelaveki

On weekends, Andiwe spends time with friends and family. Sometimes he travels to visit family members, or stays out late with his friends. Some weekends he stays at home, goes to church and helps out his parents and grandparents. It is not always easy for him to take his medication during Saturdays and Sundays, but he does his best. Think about last weekend – Saturday and Sunday.
Ngeempela veki, uAndiwe ucitha ixesha lakhe nabahlobo nosapho lwakhe. Ngamanye amaxesha uye ayokutyelela amanye abantu basendlini, okanye ahlale nabahlobo bakhe kude kubesebusuku kakhulu. Ngezinye impela veki uye ahlale ekhaya, okanye aye ecaweni ayokunceda abazali kunye nomakhulu notamkhulu wakhe. Akuhlali kulula ukuba athathe amayeza wakhe ngoMgqibelo nangeCawa, kodwa uyazama kangangoko. Ngoku cinge ngempela veki yakho edlulileyo - ngoMgqibelo nangeCawa.

25. What did you do last weekend?
Ube uyenza ntoni empela eveki edluliyeo?
    - □ Stayed at home/ Ndlala endlini
    - □ Visited relatives/ Vakashele abanye abantu abasendlini
    - □ Played sports with friends/ udlale emidlalo nechomi zakho
    - □ Go out with friends/ uphumile nechomi zakho
    - □ Other/ Ezinye: _____

26. How many times did you not take your medication last weekend?

Mangaphi amaxesha ongakhange uwathathe amayeza wakho kwimpela veki edlulileyo?
_____ times

27. How many days in the last month did you want to take your ARVs but you couldn't?
Zingaphi intsuku kwinyanga edlulileyo ubufuna ukuthatha iARV's zakho kodwa ungakwazi?
_____ days

28. Were there times in the past (when you were younger) that you couldn't take your ARVs?
Ingaba ayekho amaxesha(ngoku wawumncinci) apho wawufuna ukuthatha amayeza wakho kodwa ungakwazi?
□ No/ Hayi >> Go to Question 30
□ Yes/ Ewe >> Go to Question 29

29. Can you tell us a bit more why? *Ungasixelela kabanzi ukuba kwakutheni?*
_____Record Audio 3

30. Were there times in your life when it was easy to take ARVs?
Ingaba ayekhona amaxesha ebomini bakho apho bekulula ukuthatha iARV's zakho?
□ No/ Hayi
□ Yes/ Ewe

31. Can you tell us a bit more about what made it easier? *Ungasixelela banzi ukuba yintoni eyenza kwalula?*
_____Record Audio 4

32. Think back to Andiwe, who is struggling to take his ARVs regularly. What advice would you give him to make it easier to take his ARVs?
Cinga ngoAndiwe ofumana ubunzima ekuthatheni iARV's zakhe rhoqo. Ngcebiso zini ongamnika zona ukwenza kubelula ukuthatha iARV's zakhe?
_____Record Audio 5

Akhona loves going to school and helping out at home. But sometimes it is difficult for her to sit still, concentrate or finish the work that she has been asked to do by her teacher or parents. Some days, she can get bored or tired or even angry. Could you tell us a bit more about whether you have felt these in the last 6 months?
uAkhona uyathanda ukuya esikolweni kwaye ancedise nasekhayeni. Kodwa ngamanye amaxesha kunzima kuye ukuba ahlale azinze aphula-phule okanye agqibe umsebenzi awunikiweyo ngutitshala okanye ngabazali bakhe. Ngezinye intsuku uye adikwe okanye adinwe de abenomsindo. Ungasixelela ukuba kwezinyanga zintandathu zidlulileyo ubukhe waziva oluhlobo.

In the last sixth months…	Not true for me *Akunjalo*	Somewhat true *Ngathi kunjabo*	Certainly true *Ngokuqinisekileyo kunjalo*
33. I am restless, I cannot stay still for very long. *Andizinzanga, andikwazi ukukhlala ndingagungqi ixesha elide.*			
34. I am constantly moving around and turning. *Ndisoloko ndiphatha ndiyeka okanye ndiyagushugushuza.*			
35. I am easily distracted, I find it			

difficult to concentrate. *Ndiphazamiseka lula. Ndikufumana kunzima ukuzikisa ingqondo.*			
36. I think before I do things. *Ndiyaqiqa phambi kokuba ndenze izinto.*			
37. I finish the work I am doing. My attention is good. *Ndiyawugqiba umsebenzi endiwenzayo. Ndingumntu oqaphelisisayo.*			

38. Who is your favourite famous person? *Ngubani usaziwayo wakho omthandayo?*
_____

Memory Game

Umdlalo wokucinga
During this questionnaire we are going to play a couple of games. They will last a few minutes but don't take any of this too seriously, just see what you can do.
Ngethuba sisaphendula lemibuzo sizakudlala imidlalo embalwa. Izakuthatha imizuzwana kodwa ungayithatheli ngqalelo, bona ukuba ungenzantoni.

We will tell you 5 words. Please repeat them as you read them. We will ask you for them in a little bit of time:
Sizakuxelela amagama abemahlanu. Sicela uwaphinda phinde ukuwafunda. Sizakubuza ngawo exesheni.

- □ Apple iapile
- □ Red Ubomvu
- □ Car imoto
- □ Ball ibhola
- □ Hope ithemba

39. Imagine that you are in a taxi with the President. What is the first question you will ask him?
Ngoku, khawubenomfanekiso wakho usemotweni nomongameli. Ungathetha naye umele bonke abantwana abanjengawe. Ngowuphi umbuzo onokumbuza wona kuqala?

_____
_____

MEMORY GAME: Please write down any of the words that you remember from our word game:
Sicela ubhale phantsi amagama owakhumbulayo kumdlalo wethu wamagama:

- □ _____
- □ _____
- □ _____
- □ _____
- □ _____

40. How many of the words did you need help remembering?
Mangaphi kulamagama othe wadinga uncedo ukuwakhumbula?
_____ words

5.2.7 Part 6: My Friends and Free Time

Isigendu 6: Abahlobo bakho nexesha lakho

Thobeka likes to spend her free time with friends from school, while Sipho likes to play sports with his friends to relax. Sometimes, Thobeka likes to go to a shebeen or a party with her friends. Sipho also goes to the shebeen after soccer games.
uThobeka uyathanda ukuchitha ixesha lakhe nabahlobo bakhe basesikolweni, xeshikweni uSipho yena ethanda ezemidlalo nabahlobo bakhe kuze aphole. Ngamanye amaxesha, uThobeka uyathanda ukuya eshebeeni okanye epatini nabahlobo bakhe. uSipho naye uyaya eshebeeni emva komdlalo webhola ekhatywayo.

1. What do you like to do with your friends in your free time or when you are not in class? *Nithanda ukwenza ntoni nabahlobo bakho ngexesha lenu okanye xa ningekho emgumbini lokufundela?*

   _____

   _____

Sipho has gotten drunk in the past. Thobeka smokes dagga sometimes. A few of their friends also use drugs: dagga, sniff glue or petrol, use pills, or take other drugs like tik.
USipho wayekhe washusha ngaphambili. UThobeka utshaya intsangu ngamanye amaxesha. Abanye babahlobo babo basebenzisa iziyobisi: intsangu, bafunxa iglu, okanye ipetroli, basebenzisa ipilisi, baye basebenzise nezinye iziyobisi ezifana neetiki.

2. In the last three months, have you ever drunk enough alcohol or taken enough drugs to make you forget what happened, or you couldn't walk or talk properly? *Kwezinyanga zintanthu zidlulileyo ubukhe wasela utywala okanye wathatha iziyobisi kangangokuba ude ulibale ukuba kwenzeka ntoni okanye ungakwazi ukuhamba okanye ukuthetha kakuhle?*

   ☐ Never/ *Andizange*

   ☐ Sometimes/ *Ngamanye amaxesha*

   ☐ Often / *Njalo*

   ☐ Every day/ *Rhoqo*

Teen Confidential

Teenagers have different ideas and feelings about sex. Nobuhle often discusses with her girlfriends their thoughts about relationships, pregnancy and HIV. Sithembele and his friends sometimes chat about other teens he is attracted to and his ideas about sex.
Abantu abaselula banembono ezahlukileyo kwaye baziva ngokwahlukileyo ngeze sondo. uNobuhle usoloko exoxa nabahlobo bakhe ngengcinga zabo malunga ngezothando ukukhulelwa nange HIV. Ngamanye amaxesha uSithembele nabahlobo bakhe baye bancokole ngabanye abaselula abancwasileyo nangembono zakhe ngeze sondo.
Can you tell us how your friends at school and home feel about these things?

3. How many of your friends think that having sex at my age with as many people as possible is a cool thing for a boy or girl to do?
   Bangaphi kubahlobo bakho abacinga ukuba ukwabelana ngesondo kulentanga yakho nabantu abaninzi kuyinto elungileyo kumntana [oyinkwenkwe/ intombazana].

   ☐ None / *Akekho*

   ☐ Some / *Abanye*

   ☐ Most / *Uninzi*

   ☐ All / *Bonke*

4. How many of your friends have had sex because they were drunk or high on drugs?
   Bangaphi kubahlobo bakho abakhe babelana ngesondo kuba besele utywala okanye besebenzise iziyobisi (beqhunyiwe)?
   - None / *Akekho*
   - Some / *Abanye*
   - Most / *Uninzi*
   - All / *Bonke*

5. Do you have friends who have had sex because they were drunk or high on drugs?
   Bangaphi kubahlobo bakho abakhe babelana ngesondo kuba besele utywala okanye besebenzise iziyobisi (beqhunyiwe)?
   - None / *Akekho*
   - Some / *Abanye*
   - Most / *Uninzi*
   - All / *Bonke*

6. How many of your friends have been pregnant or have gotten someone pregnant?
   Bangaphi kubahlobo bakho ocinga ukuba babekhe bakhulelwa okanye benza omnye umntu wakhulelwa?
   - None / *Akekho*
   - Some / *Abanye*
   - Most / *Uninzi*
   - All / *Bonke*

Could you tell us a little bit about what people in your community think about HIV?
Khasixelele kancinci ukuba abantu bokuhlala kwakho bacinga njani ngentsholongwane kagawulayo (HIV)?

7. People in the community think that a person with HIV is disgusting.
   Abantu ekuhlalini bacinga ukuba umntu onentsholongwane kagawulayo (HIV) uyonyanyeka.
   - Never/ Zange
   - Sometimes / Ngamanye amaxesha
   - Most of the time/ Ixesha elininzi

8. People in my community think that HIV is a punishment from God or from ancestors.
   Abantu ekuhlalini bacinga ukuba nentsholongwane kagawulayo (HIV) sisohlwayo esisuka kuThixo okanye izinyanya.
   - Never/ Zange
   - Sometimes / Ngamanye amaxesha
   - Most of the time/ Ixesha elininzi

9. Do you play or did you play a sport at school, like soccer, netball, running, rugby, drum majorettes, or cricket?
   Yeyiphi imidlalo oyidlalayo okanye owawuyidlala esikolweni, njenge bhola ekhatywayo, ibhola yomnyazi, ukubaleka, umbhoxo, iimajorenzi, okanye iqakamba?

   ☐ Yes/ *Ewe*

   ☐ I don't/ didn't play any sports at school. *Andidlali/ khange ndidlale namye umdlalo esikolweni*

☐ I was told not to play sports at school. *Ndaxelelwa ukuba ndingadlali mdlalo esikolweni.*

Other teens and you

Abanye abaselula kunye nawe

Other kids and teenagers can be great. They can also be really mean to each other. Think about how things have been for you in the last 6 months. It would help if you answered all the questions even if you are not certain or it seems silly!
Abanye abantwana nabaselula balungile. Yaye bakhe bangcolelane omnye komnye. Kunganceda ukuba uphendule yonke imibuzo nokuba awuqinisekanga okanye ikhangeleka isisigezo!

In the past 6 months have other kids: *Kwezinyanga zintandathu zidlulileyo ingaba abanye abantwana bakhe ba:*	Not at all *Zange*	Once *Kanye*	2-3 Times *Kabini-Kathathu exesheni*	4 or more times *Kane nangaphezulu emaxesheni*
10. Called me names or swore at me. *Bandibiza ngamagama okanye bandithuka.*				
11. Tried to get me into trouble with my friends. *Bazama ukundifaka enkathazweni nezihlobo zam.*				
12. Took something without permission or stole things from me. *Bathatha into ngaphandle kwemvume yam okanye baba izinto zam.*				
13. Made fun of me for some reason. *Bahlekisa ngam ngenxa yezizathu ezithile.*				
14. Made me uncomfortable by standing too close or touching me. *Bandenza ndizive ndingakhululekanga ngokuthi basondele kum okanye bandibambe.*				
15. Punched, kicked or beat me up. *Bandibetha ngenqindi, bandikhaba okanye bandibethe.*				
16. Hurt me physically in some way. *Bandivisa ubuhlungu ngedlela ethile emzimbeni.*				

17. Tried to break or damaged something of mine. *Bazama ukophula okanye ukumosha into yam.*				
18. Refused to talk to me or made other people not talk to me. *Bala ukuthetha nam okanye benza abanye abantu bangathethi nam.*				

19. What do you like most about your best friend?
Yintoni oyithanda kakhulu ngomhlobo wakho osenyongweni?

_____

_____

Acting and Reacting

Izenzo nendlela owenza ngayo izinto

Sometimes, Buliswa and Themba get upset, or just plain angry. They react by doing things that show their anger. Can you tell us about your actions in the past 6 months?
Ngamanye amaxesha, uBuliswa noThemba baye bakhathazeke, okanye babenomsindo. Baye benze izinto ezibonakalisa umsindo wabo. Ungasixelela ngezenzo zakho kwezinyanga zintandathu zidlulileyo?

In the past six month…	Not true *Ayonyani*	Somewhat true *Ingayinyani*	Definitely true *Yeyona nyani*
20. I cut or bunk classes, or skip school. *Ndiyeka phakathi eklasini okanye nditsiba amasuku esikolo.*			
21. I run away from home. *Ndibalekile ekhaya.*			
22. I drink alcohol to have a good time, without my parents or caregivers knowing or approving. *Ndiyabusela utywala kuba ndifuna ukonwaba, ngaphandle kwemvume yabazali bam okanye omntu ondigcinayo engayazi.*			
23. I don't feel guilty after doing something I shouldn't. *Andiziva ndinesazela emva kokuba ndenze into ebekungafanelekanga ndiyenzile.*			
24. I hang around with kids who get in trouble. *Ndonwaba nabantwana abasoloko bezifaka engxakini.*			
25. I would rather be with older kids than with kids my own age. *Ndikhetha ukuhlala nabantwana abadala kunam kunokuhlala nentanga zam.*			
26. I steal at home. *Ndiyeba ekhaya.*			
27. I steal things from places other than home. *Ndiyeba izinto kwezinye indawo kodwa hayi ekhaya.*			

In the past six month…	Not true *Ayonyani*	Somewhat true *Ingayinyani*	Definitely true *Yeyona nyani*
28. I swear or use dirty language. *Ndiyathuka okanye ndisebensize ulwimi olungcolileyo.*			
29. I lie or cheat. *Ndiyaxoka okanye ndisebenzise amaqhinga.*			
30. I get very angry and often lose my temper. *Ndiba nomsindo kakhulu kwaye ndingakwazi ukuzibamba.*			
31. I fight a lot. I can make other people do what I want. *Ndithanda ukulwa. Ndiyakwazi ukwenza abantu benze into endiyifunayo.*			
32. I usually do as I am told. *Ndisoloko ndisenza into endiyixelelweyo.*			
33. I try to be nice to other people. *Ndiyazama ukulunga kwabanye abantu.*			
34. I carry a knife on me for protection. *Ndisoloko ndiphethe imela kum kuba ndifuna ukuzikhusela.*			
35. I carry a gun on me for protection. *Ndisoloko ndiphethe umpu kum kuba ndifuna ukuzikhusela.*			
36. I am part of a gang. *Ndiyinxalenye yeqela lemigulukudu.*			
37. I bet money or gamble. *Ndiyancakaza ngemali yam.*			

Special Friends and Relationships

Abahlobo abakhethekileyo nezothando

Now we would like to know a bit more about any romantic relationship that you might have or want to have in the future.
Ngoku ke singathanda ukuva ngendlela ohambisana ngayo wena kwindima yezothando okuzo okanye obawela ukuba kuzo njengoba ixesha lihamba.

38. Do you currently have a boyfriend or girlfriend?
Ingaba unaso isinqanda mathe?
□ No/ *Hayi* □ Yes/ *Ewe*

39. Do you know your boyfriend's or girlfriend's HIV status?
Ingaba uyasazi isimo se HIV seqabane lakho?
□ Yes, they are positive / *Ewe, ndiyayazi bosulelekile*
□ Yes, they are negative / *Ewe, ndiyayazi abosulelekanga*
□ I don't know / *Hayi, andiyazi*

40. Have you ever had a romantic or sexual experience (that is more than friends) with someone of the same gender?
Ingaba wawukhe wabelana ngesondo nomntu okwisini esinye nawe (ongapha komhlobo wakho)?

□ Yes/ *Ewe* □ No/ *Hayi*

41. If you could choose a famous person to be your boyfriend or girlfriend, who would it be?
Ukuba ungakhetha umntu ongusaziwayo onohambisana naye, ungakhetha bani?

_____
_____

5.2.8 Part 7: Sharing and Caring

Isiqendu 7: Ukwabelana nokukhathalelana

Learning about our positive status can be difficult but also valuable. We would like to know more about your experience so we can make it better for other teenagers in the future.
Ukufunda ngesimo sethu seHIV kunganzima kodwa kubalulekile. Singathanda ukwazi ngamava akho ukuze sizokwazi ukwenza ngcono kwabanye abantwana abaselula.

1. How did you learn about your HIV the first time?
Wazi njani okokuqala ukuba unentsholongwane kagawulayo (uneHIV)?
   - □ I guessed myself/ *Ndazicingela ngokwam*
   - □ I was told at the clinic by a doctor or nurse/ *Ndaxelelwa ekliniki ngugqirha okanye ngumongikazi*
   - □ I was told at home by my family/ *Ndaxelelwa ekhaya lusapho lwam*
   - □ I was told at the clinic by my family and a doctor or nurse/ *Ndaxelelwa ekliniki lusapho lwam kunye nogqirha okanye nomongikazi*
   - □ I overheard people talking about my HIV status/ *Ndeva abantu bethetha ngesimo sam sentsholongwane kagawulayo (seHIV).*
   - □ I never guessed

2. [ONLY GIRAFFES/ HIV-POSITIVE STATUS-AWARE] At which age did you first suspect you were HIV-positive?
Wawuneminyaka emingaphi uqala kwakho ukuzikrokrela ukuba uneHIV? _____ years old

3. At which age did someone first tell you were HIV positive?
Wawuneminyaka emingaphi ukuxelelwa kwakho ukuba unentsholongwane kagawulayo (uneHIV)? _____ years old

4. [ONLY GIRAFFES/ HIV-POSITIVE STATUS-AWARE] Did you ever take pills without knowing what they are for?
Wawukhe wathatha ipilisi ungazazi ukuba zezantoni?
   - □ Yes/ *Ewe*
   - □ No/ *Hayi*

5. [ONLY GIRAFFES/ HIV-POSITIVE STATUS-AWARE] How did you feel when you learned about your HIV status? Choose as many options as apply:
Waziva njani wakuva ukuba unentsholongwane kagawulayo (HIV)?
   - □ Surprised/ Ndothuka
   - □ Upset/ Ndaba nomsindo
   - □ Relieved/ Ndakhululeka
   - □ I didn't care/ Zange ndikhathale
   - □ I don't remember/ Andikhumbuli
   - □ Other/ Ezinye: _____

FOR BOYS ONLY: This is Lundi. Living with HIV is difficult for him sometimes. Some days

Lundi feels ashamed and he struggles to feel good about himself. Could you say how much these things have been true for you in the past year?

AMAKHWENKWE ODWA: Lona nguLundi. Ukuphila nentsholongwane kagawulayo (HIV) kunzima kuye ngamanye amaxesha. Ngezinye imini uLundi uziva enentloni kwaye uyasokola ukuba azive kakuhle ngaye. Ungasixelela ukuba ezizinto bezinyani kangakanani nakuwe kunyaka odlulileyo?

FOR GIRLS: This is Nosizi. Living with HIV is difficult for her sometimes. Some days Nosizi feels ashamed and she struggles to feel good about herself. Could you say how much these things have been true for you in the past year?

AMANTOMBAZANA ODWA: Lona nguNosizi. Ukuphila nentsholongwane kagawulayo (HIV) kunzima kuye ngamanye amaxesha. Ngezinye imini uNosizi uziva enentloni kwaye uyasokola ukuba azive kakuhle ngaye. Ungasixelela ukuba ezizinto bezinyani kangakanani nakuwe kunyaka odlulileyo?

6. Lundi/ Nosizi is very careful who he/she tells that he/she has HIV. Are you careful who you tell?
   uLundi/ uNosizi umlumkele umntu amxelelayo ukuba unentsholongwane kagawulayo (HIV). Wena ukhe uzive njalo?
   - Never/ *Zange*
   - Sometimes/ *Ngamanye amaxesha*
   - Most of the time/ ixesha elininzi

7. Sometimes Lundi/Nosizi feels that he/she is not as good as other kids because he/she has HIV. Do you ever feel this way?
   Ngamanye amaxesha uLundi/ uNosizi uziva engafani nabanye abantwana kuba enentsholongwane kagawulayo (HIV). Wena ukhe uzive njalo?
   - Never/ *Zange*
   - Sometimes/ *Ngamanye amaxesha*
   - Most of the time/ ixesha elininzi

8. Sometimes Lundi/Nosizi feels like he/she would rather die than live with HIV. Do you ever feel this way?
   Ngamanye amaxesha uLundi/ uNosizi uziva ingathi angafa kunoba aphile nentsholongwane kagawulayo (HIV). Wena ukhe uzive njalo?
   - Never/ *Zange*
   - Sometimes/ *Ngamanye amaxesha*
   - Most of the time/ ixesha elininzi

9. Sometimes Lundi/ Nosizi feels like he/she is a bad person because he/she has HIV. Do you ever feel this way?
   Ngamanye amaxesha uLundi/ uNosizi uziva engumntu ombi kuba enentsholongwane kagawulayo (HIV). Wena ukhe uzive njalo?
   - Never/ *Zange*
   - Sometimes/ *Ngamanye amaxesha*
   - Most of the time/ ixesha elininzi

10. Sometimes Lundi/ Nosizi feels ashamed that he/she is HIV-positive. Do you ever feel this way?
    Ngamanye amaxesha uLundi/ uNosizi uziva enentloni kuba enentsholongwane kagawulayo (HIV). Wena ukhe uzive njalo?
    - Never/ *Zange*
    - Sometimes/ *Ngamanye amaxesha*

- Most of the time/ ixesha elininzi

11. Sometimes Lundi/Nosizi feels that it is his/her fault that he/she is HIV-positive. Do you ever feel this way?
    Ngamanye amaxesha uLundi/ uNosizi *uzive ingathi nguye lo uzenze ukuba abenentsholongwane kagawulayo (HIV)*. *Wena ukhe uzive njalo?*
    - Never/ *Zange*
    - Sometimes/ *Ngamanye amaxesha*
    - most of the time/ ixesha elininzi

12. Sometimes having HIV makes Lundi/Nosizi feel contaminated and dirty inside. Do you ever feel this way?
    Ngamanye amaxesha uLundi/ uNosizi uziva egcolile/ emdaka kuba enentsholongwane kagawulayo (HIV). Wena ukhe uzive njalo?
    - Never/ *Zange*
    - Sometimes/ *Ngamanye amaxesha*
    - Most of the time/ ixesha elininzi

FOR BOYS: If you could say anything to Lundi to make him feel better, what would it be? You can even share with him your own difficulties and how you've overcome them.
AMAKHWENKWE ODWA: Ukuba ungathetha nantoni kuLundi ezomenza azive engcono, ingayintoni? Ungamxelela ngobunzima othe wahlangabezana nazo nangendlela oye wazoyisa ngazo.

FOR GIRLS: If you could say anything to Nosizi to make her feel better, what would it be? You can even share with her your own difficulties and how you've overcome them.
AMANTOMBAZANA ODWA: Ukuba ungathetha nantoni kuNosizi ezomenza azive ngcono, ingayintoni? Ungamxelela ngobunzima othe wahlangabezana nazo nangendlela oye wazoyisa ngazo.

_____
_____
_____

Thank you for answering these difficult and private questions.
Enkosi ngokuphendula lemibuzo inzima kunye nale ifihlakeleyo.

<u>For boys and girls:</u>
Some teens have parents who were ill for some time before they died. Or their parent is unwell at the moment. It's difficult for teens to handle sometimes. Could you say how much these things have been true for you <u>in the past year</u>?

Abanye abantu abaselula babenabazali ababegula ithutyana phambi kokuba basweleke. Okanye umzali uyagula ngalomzuzu. Kunzima ebantwini abaselula ukumelana nesisimo. Ungasichazela ukuba zinyaniseke kangakanani kuwe ezizinto <u>kunyaka odlulileyo</u>?

Because someone in my family is sick or has died... *Ngenxa yokuba kukho ilungu losapho lwam eligulayo okanye eliye lasweleka:*	Not at all	Sometimes	All the time
13. I've been teased about my family member. *Bendigezelwa ngenxa yelungu losapho lwam.*			
14. I've been treated badly because of my family member. *Bendiphetheke kakubi ngenxa yelungu losapho lwam.*			
15. People have gossiped about my family behind my			

back *Abantu bahlebile ngosapho lwam.*			
16. I worry about being rejected. *Ndibanexhala lokungamkeleki.*			
17. I avoid making new friends. *Ndiyakubaleka ukwenza abahlobo abatsha.*			
18. I feel different and alone. *Ndiziva ndahlukile kwaye ndindodwa.*			

19. Which music or sports star are you most similar to?
Yeyiphi imvumi okanye umdlali obona ufana naye? _____

Each of us has different people who we share secrets with and go to when we need help or support.

Umntu ngamnye unaye umntu amxelela imfihlelo zakhe, athi aye kuye xa edinga uncedo nenkxaso.

20. Please tell us how many people know about your HIV? [CHOOSE AS MANY ANSWERS THAT APPLY]
Sicela usixelele ukuba bangaphi abantu abaziyo ngeHIV yakho? [KTHETHA IMPENDULO KANGANGOKO ZIFUNEKA]
- □ Parent or person who cares for me/ *Umzali okanye umntu ondigcinayo*
- □ Rest of my family / abanye abantu kusapho lwam
- □ Friends at home/ abahlobo bam ekhaya
- □ Friends at school/ abahlobo bam esikolweni
- □ Teachers/ principal at school/ootitshala okanye inqununu esikolweni
- □ People at church/abantu ecaweni
- □ Others who live near my house/Abamelwane bam

We would like to know how much information about your health you share with others in your life.
Sicela usixelele ukuba wabelene nabo kangakanani abasebomini bakho.

Please tell us how much you have shared with each person in your life:
Sicela usixelele ukuba wabelene nabo kangakanani abasebomini bakho:

21. Parent or Caregiver/ *Umntu okugcinayo*
- □ I don't have a parent or caregiver/ *Andinaye umntu ondigcinayo okanye umzali*
- □ They don't know anything about my health, illness or medication
Abazinto ngesimo sempilo yam, ukugula okanye amayeza am
- □ They suspect something/ know from other sources
Bayakrokra/bazi ngokuva kwabanye abantu
- □ They know I am sick but they don't know what I have
Bayazi ndiyagula kodwa abazi ndigula yintoni
- □ They know I am taking medication, but not what type of medication
Bayazi nditya amayeza kodwa abawazi ngawantoni
- □ They know about my HIV status
Bayazi ngesimo sam seHIV
- □ I talk to them about my HIV status
Ndiyathetha nabo ngesimo sam seHIV
- □ They know that I am taking ARVs
Bayazi ukuba ndithatha iARVs
- □ I talk to them about my struggles with taking medicine

Ndithetha nabo ngobunzima bokuthatha lamayeza

22. My Best Friends/ *ABAHLOBO BAM*
    - □ They don't know anything about my health, illness or medication
      Abazinto ngesimo sempilo yam, ukugula okanye amayeza am
    - □ They suspect something/ know from other sources
      Bayakrokra/bazi ngokuva kwabanye abantu
    - □ They know I am sick but they don't know what I have
      Bayazi ndiyagula kodwa abazi ndigula yintoni
    - □ They know I am taking medication, but not what medication
      Bayazi nditya amayeza kodwa abawazi ngawantoni
    - □ They know about my HIV status
      Bayazi ngesimo sam seHIV
    - □ I talk to them about my HIV status
      Ndiyathetha nabo ngesimo sam seHIV
    - □ They know that I am taking ARVs
      Bayazi ukuba ndithatha iARVs
    - □ I talk to them about my struggles with taking medicine
      Ndithetha nabo ngobunzima bokuthatha lamayeza

23. My boyfriend/ girlfriend/ *ISINQANDAMATHE SAKHO*
    - □ I don't have a boyfriend/ girlfriend
      Andinaso isinqandamathe
    - □ They don't know anything about my health, illness or medication
      Abazinto ngesimo sempilo yam, ukugula okanye amayeza am
    - □ They suspect something/ know from other sources
      Bayakrokra/bazi ngokuva kwabanye abantu
    - □ They know I am sick but they don't know what I have
      Bayazi ndiyagula kodwa abazi ndigula yintoni
    - □ They know I am taking medication, but not what medication
      Bayazi nditya amayeza kodwa abawazi ngawantoni
    - □ They know about my HIV status
      Bayazi ngesimo sam seHIV
    - □ I talk to them about my HIV status
      Ndiyathetha nabo ngesimo sam seHIV
    - □ They know that I am taking ARVs
      Bayazi ukuba ndithatha iARVs
    - □ I talk to them about my struggles with taking medicine
      Ndithetha nabo ngobunzima bokuthatha lamayeza

24. My Church Leader or Priest/ *INKOKHELI YAM ENKONZWENI OKANYE UMFUNDISI*
    - □ I don't go to church
      Andihambi cawa.
    - □ They don't know anything about my health, illness or medication
      Abazinto ngesimo sempilo yam, ukugula okanye amayeza am
    - □ They suspect something/ know from other sources
      Bayakrokra/bazi ngokuva kwabanye abantu
    - □ They know I am sick but they don't know what I have
      Bayazi ndiyagula kodwa abazi ndigula yintoni
    - □ They know I am taking medication, but not what medication
      Bayazi nditya amayeza kodwa abawazi ngawantoni
    - □ They know about my HIV status
      Bayazi ngesimo sam seHIV
    - □ I talk to them about my HIV status

Ndiyathetha nabo ngesimo sam seHIV

- □ They know that I am taking ARVs
  Bayazi ukuba ndithatha iARVs
- □ I talk to them about my struggles with taking medicine
  Ndithetha nabo ngobunzima bokuthatha lamayeza

25. Teachers and school principal/ *OOTITSHALA OKANYE INQUNUNU YESIKOLO*

- □ I don't go to school
  Andisihambi isikolo
- □ They don't know anything about my health, illness or medication
  Abazinto ngesimo sempilo yam, ukugula okanye amayeza wam
- □ They suspect something/ know from other sources
  Bayakrokra/bazi ngokuva kwabanye abantu
- □ They know I am sick but they don't know what I have
  Bayazi ndiyagula kodwa abazi ndigula yintoni
- □ They know I am taking medication, but not what medication
  Bayazi nditya amayeza kodwa abawazi ngawantoni
- □ They know about my HIV status
  Bayazi ngesimo sam seHIV
- □ I talk to them about my HIV status
  Ndiyathetha nabo ngesimo sam seHIV
- □ They know that I am taking ARVs
  Bayazi ukuba ndithatha iARVs
- □ I talk to them about my struggles with taking medicine
  Ndithetha nabo ngobunzima bokuthatha lamayeza

Similarities and Differences

Ukufana nokohluka

BOYS: Remember Lundi? He is having a hard time because of his HIV status. Lundi knows that people often think bad things about HIV-positive people. Sometimes people treat Lundi differently from other kids just because he is HIV-positive. This is not fair. Could you say how much these things have been true for you in the past year?

AMAKHWENKWE ODWA: Usamkhumbula uLundi? Ufumana amaxesha anzima kuba nentsholongwane kagawulayo (HIV). uLundi/ uNosizi uyayazi ukuba abantu basokolo becinga izinto ezimbi ngabantu abanentsholongwane kagawulayo (HIV). Ngamanye amaxesha abantu bamphatha ngendlela eyahlukileyo kunabanye abantwana uLundi/ uNosizi kuba enentsholongwane kagawulayo (HIV). Oku akulunganga. Ungatsho ukuba zinyaniseke kangakanani ezizinto kuwe kunyaka odlulileyo?

GIRLS: Remember Nosizi? She is having a hard time because of her HIV status. Nosizi knows that people often think bad things about HIV-positive people. Sometimes people treat Nosizi differently from other kids just because she is HIV-positive. This is not fair. Could you say how much these things have been true for you in the past year?

AMANTOMBAZANA ODWA: Usamkhumbula uNosizi? Ufumana ubunzima ngenxa yesimo sakhe seHIV. uNosizi uyazi ukuba abantu bahlala njalo becinga izinto ezingalunganga ngabantu aba neHIV. Ngamanye amaxesha abantu bamphatha ngendlela eyahlukileyo uNosizi kunabanye abantwana ngenxa yokuba eneHIV. Oku akulunganga. Ungatsho ukuba zinyaniseke kangaka nani ezizinto kuwe kunyaka odlulileyo?

FOR EVERYONE:

UMNTU WONKE:

26. I have been hurt by how people reacted when they found out I have HIV.
    Ndiziva kabuhlungu ngendlela abantu abazi bonakalisa ngayo xabefumanisa ukuba ndinentsholongwane kagawulayo (HIV).
    - Never/ Zange
    - Sometimes / Ngamanye amaxesha
    - Most of the time/ Ixesha elininzi

27. I have stopped spending time with some kids because of their reactions to my HIV status.
    Ndiyekile ukuchita ixesha nabanye abantwana, ngenxa yendlela abenzengayo bakuva ngesimo sam sentsholongwane kagawulayo (HIV).
    - Never/ Zange
    - Sometimes / Ngamanye amaxesha
    - Most of the time/ Ixesha elininzi

28. I have lost friends by telling them I have HIV.
    Ndilahlekelwe ngabahlobo ngokuba xelela ukuba ndinentsholongwane kagawulayo (HIV).
    - Never/ Zange
    - Sometimes / Ngamanye amaxesha
    - Most of the time/ Ixesha elininzi

29. I've been teased because of my HIV.
    Ndigezelwe ngenxa yokuba ndinentsholongwane kagawulayo (HIV).
    - Never/ Zange
    - Sometimes / Ngamanye amaxesha
    - Most of the time/ Ixesha elininzi

30. That was great! Now say you're still in the taxi with the President. What if the President told you they were resigning and you would become the next president of South Africa? What would be the first thing you would do?
    Bekukuhle ke oku, ngoku masithi usetekisini noMongameli.Ungathini ukuba uMongameli angakuxelela uyehla esikhundleni sakhe kwaye wena uzokuba nguMongameli walapha eMzantsi Afrika. Ingayintoni into yokuqala onokuyenza?

_____

5.2.9 Part 8: Stuff That Has Been Hard

Isigendu 8: izinto ezikhe zanzima

Scary things may also happen in our neighbourhood, community or city. Buntu has been robbed and had his things stolen.
Izinto ezoyikisayo zingenzeka apho uhlala khona okanye kwidolophu yakho.uBuntu wayekhe warojwa kwaye wabelwa nezinto zakhe.

1. How many times have you had things stolen in the last year?
   Kunyaka odlulileyo izinto zakho zibiwe amatyeli amangaphi? _____ times

2. Buntu was attacked and hit when he was out. Have you ever been hit or attacked outside?
   uBuntu ukhe wahlaselwa waze wabethwa xeshikweni ephumile. Ingaba wakhe wabethwa waze wahlaselwa uphumile?
   - □ Yes, more than a year ago/ *Ewe, ngaphezulu konyaka odlulileyo*

- □ Yes, in the last year/ *Ewe, kunyaka odlulileyo*
- □ Never/ *Zange*

3. Buntu saw someone in his neighbourhood being shot. Have you seen someone being shot?
   uBuntu ukhe wabona umntu edutyulwa apho ahlala khona. Ingaba wakhe wabona umntu edutyulwa?
   - □ Yes, more than a year ago/ *Ewe, ngaphezulu konyaka odlulileyo*
   - □ Yes, in the last year/ *Ewe, kunyaka odlulileyo*
   - □ Never/ *Zange*

4. Lindiwe saw someone being stabbed one evening. Have you seen someone stabbed?
   uLindiwe ukhe wabona umntu ehlatywa ngobunye ubusuku. Ingaba wakhe wabona umntu ehlatywa?
   - □ Yes, more than a year ago/ *Ewe, ngaphezulu konyaka odlulileyo*
   - □ Yes, in the last year/ *Ewe, kunyaka odlulileyo*
   - □ Never/ *Zange*

5. If you could invite any famous person to your neighbourhood, village or city, who would it be?
   Ukuba ungamema usaziwayo apho uhlala khona okanye esixekweni okanye kwidolophu yakho, ingangu bani? _____

Young people in many parts of the world experience bad treatment and violence by family members, at school, in their communities, or at work. This is an important problem for youth in many places, even though many times they don't speak about this. We would like to ask you about your experiences of violence.

Abantu abatsha baye bafumane impatho mbi nobundlobongela kumalungu osapho lwabo kwindawo ezininzi apha elizweni, esikolweni, esixekweni, okanye emsebenzini. Oku kuyingxaki ebalulekileyo kubantu abatsha kwindawo ezininzi, nangona ixesha elininzi bengathethi ngako oku. Singathanda okubuza ngamava akho ngobu ndlobongela.

Has anyone in your family or who is living in your home or someone at school done any of these to you: *Ingaba ukhona umntu kusapho lwakho okanye ohlala kokwenu okanye umntu esikolweni owakhe wenza oku kuwe:*	Weekly *Ngeveki*	Monthly *Ngenyanga*	At least once this year *Noko ibikhe yenzeka Kanye kulonyaka*	Has happened, but not in the last year *Yenzeka kodwa hayi kunyaka ophelileyo*	Never *Zange*
6. Used a stick, belt or other hard item to hit you *Basebenzise uswazi, ibhanti okanye izinto eziqinileyo xa ekubetha*					
7. Slap, punch, hit, pinch or pull your ear/hair so that you were hurt or had marks *Bandibethe ngempama, ngenqindi okanye wakutswikila okanye wakutsala ngendlebe/ ngenwele ukuba uve ubuhlungu okanye ube namabala?*					
8. Threaten to hurt you. *Bakugrogrisa ngokwenzakalisa.*					
9. Say they would call ghosts or evil spirits, or harmful people *Bathi bazakubizela izithunzela okanye imimoya emdaka okanye abantu abanobungozi.*					
10. Tell you they wished they did not have to look after you or make you feel you are a burden. *Bakuxelele ukuba banqwenela ukuba bangaze baphinde bakungcine okanye bakwenze uzive ngokungathi ungumqobo.*					
11. Make you feel unwelcome in the home *Bakwenze uzive ungamkelekanga ekhayeni.*					
12. Say that you would be sent away or kicked out of the house *Bathi uza kusiwa kwenye indawo okanye ugxothwe endlini?*					
13. Call you dumb, lazy, or other names *Bakubize ukuba usisidenge, udangele okanye bakubize amagama amabi.*					
14. Insult members of your family that have passed away *Banyelise amalungu osapho lwakho abhubhayo.*					
15. Threaten to leave you and never come back *Bakugrogrisa ngokukushiya bangaze baphinde babuye.*					
16. Threaten to hurt or kill a person or an animal that you care about					

Has anyone in your family or who is living in your home or someone at school done any of these to you: *Ingaba ukhona umntu kusapho lwakho okanye ohlala kokwenu okanye umntu esikolweni owakhe wenza oku kuwe:*	Weekly *Ngeveki*	Monthly *Ngenyanga*	At least once this year *Noko ibikhe yenzeka Kanye kulonyaka*	Has happened, but not in the last year *Yenzeka kodwa hayi kunyaka ophelileyo*	Never *Zange*
Bakugrogrisa ngokwenzakalisa okanye ngokubulala umntu okanye isilwanyana osikhathaleleyo.					
17. Withhold a meal to punish you *Bakohlwaya ngokuvimba ukutya.*					

Let's take a break!

18. Has anyone made you look at their private parts or wanted to look at yours when you did not want to?
Ingaba ukhona umntu owakwenza ukuba ujonge amalungu akhe angasese okanye afune ukujonga awakho ungafuni?
    - □ Yes, more than a year ago/ *Ewe, ngaphezulu konyaka odlulileyo*
    - □ Yes, in the last year/ *Ewe, kunyaka odlulileyo*
    - □ Never/ *Zange*

19. Has anyone touched your private parts, or made you touch theirs, or tried to have sex with you when you did not want to?
Ingaba ukhona umntu owakhe wakuphatha kumalungu akho angasese, okanye wakwenza uphathe awakhe, okanye wazama ukwabelana ngesondo nawe ungafuni?
    - □ Yes, more than a year ago/ *Ewe, ngaphezulu konyaka odlulileyo*
    - □ Yes, in the last year/ *Ewe, kunyaka odlulileyo*
    - □ Never/ *Zange*

20. Has anyone had sex with you when you did not want them to?
Ingaba ukhona umntu owabelana nawe ngesondo wabe wena ungafuni?
    - □ Yes, more than a year ago/ *Ewe, ngaphezulu konyaka odlulileyo*
    - □ Yes, in the last year/ *Ewe, kunyaka odlulileyo* - [*If happened in the last three days, please tell me if you would like me to help you access emergency contraception and post-exposure medication] [ukuba oku kwenzekile kwintsuku ezintathu ezidlulileyo, nceda undixelele ukuba ungathanda ndikuncede ufumane unyango olukhawulezileyo lokukhusela ukukhulelwa nokosuleleka zizifo]
    - □ Never/ *Zange*

21. Did you tell anyone if someone touched you when you didn't want it?
Ingaba ukhona umntu owakhe wamxalela ukuba kukho ubani ebekhe wakuphatha ungafuni?
    - □ YES >>Go to Question 22
    - □ NO <u>>> Go to Question 24</u>

22. Who did you ask for help? *Ingaba ucele bani akuncede?*
    _____

23. How did the person you first told about this react?
Ingaba lomntu wamxelela oku wenza njani?

    - □ They believed me and supported me / Bandikholelwa yaye bandixhasa
    - □ They believed me, but did not care / Bandikholelwa kodwa abakhathala
    - □ They blamed me for causing it / Bandisola ngoku kwenzekayo
    - □ They did not believe me at all / Azange bandikholelwe kwaphela
    - □ They took me to the clinic, police or social worker / Bandisa ekliniki, emapoliseni, okanye kunontlalontle

<u>Responding to Challenges</u>

<u>Ukumelana nemicelimngeni</u>

We'd like to know how you feel about challenges you may face and how you have responded to them. Your answers will help us support other teens who might be facing the same difficulties. Let's think about this and answer these questions.

Sifuna ukuqonda ukuba uziva njani malunga nemicelimngeni othi ujongane nayo kwaye umelene njani nazo. Impendulo zakho zizakusinceda ekuxhaseni abanye abantwana abaselula abajongene nobunzima obufana nobakho. Masicingeni ke ngoko siphendule le mibuzo ilandelayo.

	Not at all *Zange nakancinci*	A little bit true *Inyanisile kancinci*	Sort of true *Inakho unyanisa*	Exactly true *Inyanisile*
24. I can always manage to solve difficult problems if I try hard enough. *Ndinakho ukuzisombulula ingxaki zam ukuba ndizama kakhulu.*				
25. I am certain that I can achieve/reach my goals. *Ndiqinisekile ndinakho ukuwafezekisa amaphupha wam okanye imigomo yam.*				
26. I can stay calm because I have ways of solving problems when they come up. *Ndingazinza ukuba ndinakho ukuzisombulula iingxaki zam xa zisiza.*				
27. I can handle whatever comes my way. *Ndingamelana nayo nantoni na endithi ndidibane nayo endleleni.*				

28. Remember the words we told you at the end of Part 5? Let's see if we can remember them together.
Usawakhumbula amagama besikuxelele wona ekupheleni kwecandelo lesihlanu (5)? Masibone ukuba singawakhumbula sobabini na?

□ _____
□ _____
□ _____
□ _____
□ _____

29. How many of the words did you need help remembering? _____words
Mangaphi kulamagama othe wadinga uncedo ukuwakhumbula?

5.2.10 Part 9: Home and Family

Isigendu 9: Ekhaya no sapho

We'd like to understand what living in your home is like. Can you please answer the following to the best of your ability? If there's anything you don't understand just ask the research assistant.
Sifuna ukwazi kunjani uhlala ekhayeni lakho. Nceda uphendule imibuzo ilandelayo kangangokho unakho. Xa unento ungayiqondiyo ubuze umncedisi phando.

1. Do you have a parent, guardian or caregiver staying with you and taking care of you at home?
   Unaye umzali, umntu okungcinayo, umntu ophantsi kwakhe uhlala naye kwaye okukhathaleleyo?
   - □ YES/ Ewe >>Go to Question 2
   - □ NO/ Hayi >> Go to Question 1a

1a. If you don't have anyone that takes care of you at home, who is the main person that supports you?
Ukuba akhomntu okugcinayo ekhayeni, ngubani oyenamntu okuxhasayo?

_____

2. Who is the person that takes care of you at home?
   Ngubani lomntu okugcinayo ekhayeni?
   - □ Biological mother/ umama okuzalayo
   - □ Biological father/ utata okuzalayo
   - □ Grandmother/ umakhulu
   - □ Grandfather/utatomkhulu
   - □ Aunt/ makazi
   - □ Brother/ bhuti
   - □ Sister/ sisi
   - □ Uncle/ malume
   - □ Other/ Omnye >> Go to Question 2a

2a. Please tell us who takes care of you at home?
Sixela usixelele ngubani lomntu okugcinayo ekhayeni khathalelayo?

_____

3. How old is this person? Uneminyaka emingaphi lomntu? _____ years

4. How many different caregivers [parents or guardians] have you had?
   *Abangaphi abantu abakhe bakhulisa [abazali okanye abantu ophantsi kwabo]?*_____ .

5. How many other people live in the same home as you? _____ people.
   Bangaphi abanye abantu ohlala kunye nabo ekhaya?

6. How many of them are working? _____ .
   Bangaphi abasebenzayo?

7. Please tick the things which you can afford at home: (choose as many as apply)
   Nceda ukhethe izinto ukwazi ufikelela kuzo ekhaya: (kthetha impendulo kangangoko ezifuneka)
   - □ 3 meals a day/ *ukutya kathathu ngemini*
   - □ School fees/ *intlawulo yesikolo*

- □ Visit to the doctor when you are ill, and all the medicines you need/ *uyakwazi uyobona uGqirha xa ugula, ufumane onke amayeza owadingayo*
- □ School uniform/ *impahla zesikolo*
- □ Enough clothes to keep you warm and dry/ *impahla ezaneleyo ezithi zikwazi ukugcina uhlale ufudumele kwaye womile*
- □ Toiletries to be able to wash every day/ *izinto zokuthambisa ukuze ndikwazi ukuvasa yonke imihla*
- □ School equipment/ *izixhobo zesikolo*
- □ More than one pair of shoes/ *ngaphezulu kwepere enye yezihlangu*

8. Sometimes kids don't have enough food in their home. How many days in the past week (7 days) did you not have enough food in your home?
   Ngamanye amaxesha abantwana abanakutya okwaneleyo emakhayeni abo. Zingaphi intsuku kwiveki edlulileyo (7 intsuku) bungenakutya okwaneleyo ekhayeni lakho?
   _____ days.

9. Are you or your household receiving any grants?
   Ingaba wena okanye ekhayeni lakho kukhona ofumana sibonelelo mali sikarhulumente?
   □ Yes/ Ewe >> Go to Questions 10-15
   □ No/ Hayi >> Go to Question 16

10. How many child support grants does your household receive?
    Zingaphi izibonelelo mali zabantwana sikarhulumente zizonke enizifumanayo kowenu?
    _____

11. How many foster care grants does your household receive?
    Zingaphi izibonelelo mali sokuncedisa ukukhathalela sikarhulumente (foster care) zizonke enizifumanayo kowenu? _____

12. How many disability grants does your household receive?
    Zingaphi izibonelelo mali zokhubazeka sikarhulumente zizonke enizifumanayo kowenu?
    _____

13. How many pension grants does your household receive?
    Zingaphi izibonelelo mali sobudala sikarhulumente zizonke enizifumanayo kowenu?
    _____

14. How many care dependency grants does your household receive?
    Zingaphi izibonelelo mali zokugcina umntwana okhubazekhileyo zikarhulumente zizonke enizifumanayo kowenu? _____

15. Do you get food parcels or free meals at church or clinic/ hospital at least once a month?
    Ingaba uyazifumana ipasile zokutya okanye ukutya kwasimahla ecaweni, okanye isebele lezempilo (ikliniki) okanye esibhedlele noba kukanye enyangeni?
    □ Yes/ Ewe No/ Hayi

Some kids grow food to eat or have animals to take care of. Can you tell us about what plants you grow or which animals you care for?
Abanye abantwana bazilimela ukutya okanye banemfuyo abathi bayikhathalele. Ungasixelela ngezozityalo ozilimayo okanye imfuyo leyo uyikhathalelayo?

16. Do you or your family grow food in a school garden, community garden or at home?
    Ingaba wena okanye usapho lwakho kukhona ukutya enikutyalileyo egadini yesikolo, egadini yoluntu, okanye ekhayeni?
    □ Yes/ Ewe
    □ No/ Hayi

17. What is the name of your favourite soapie?
    Ntoni gama lengqubo oyithandayo? _____

We would like to find out about experiences that happen to children at home, in the family. These questions may seem strange or hard to answer. Please try to answer them as best you can, this is not a test. There is no right or wrong answer, just say what you remember happened to you. If at any point you feel too uncomfortable to continue you can stop.
Singathanda ukwazi malunga nezinto ezithi zenzeke ebantwaneni ekhaya okanye kusapho. Akho mphendula elungileyo okanye engalunganga, sixelele okukumbulayo okwenzekayo kuwe. Xa uziva ungakhululekanga nokuqhubeka ungayeka.

If you want to get help about any of the things we ask about, talk to the research assistant. Buntu's family has lots of arguments. Sometimes adults shout at each other and sometimes there is fighting.
Xa ufuna uncedo malunga nayiphina into, thetha nomcedisi phando.

18. How many days in the last week were there arguments with adults shouting in your home?
    Zingaphi iintsuku kwiveki ephelileyo ebekukho iingxabano nabantu abadala bengxolisana ekhayeni lakho? _____ >>Go to Question 20, if 0 (zero).

19. What were these arguments mostly about? *Bezi ngantoni ezingxabano?*
    _____

20. How many days in the last week were there arguments with adults hitting each other in your home?
    Zingaphi iintsuku kwiveki ephelileyo apho bekukhe kwakhona iingxabano nabantu abadala bebethana ekhayeni lakho? _____ days.

Zoli really admires her aunt Yandiswa. She wants to grow up and become a teacher like her. This makes Zoli study harder and think about the subject she would like to teach most.
uZoli enyanisweni uyakholwa ngumakazi wakhe uYandiswa. Ufuna ukhula abe ngutitshalakazi njengaye. Lento ibangela uZoli azimisele ekufundeni okunye acinge ngezifundo anothanda ukuzifundisa.

21. Who do you really admire in your life: a role model? *Ngubani okholwa nguye ebomini bakho?* _____

5.2.11 Part 10: Your Past, Your Present, and Your Future

Part 10: Odlulekuko, Okuko, Nekamva lakho

Many kids go through things that are very upsetting or frightening. Now, think about something upsetting or frightening that has happened in your life. Please tell us how often you have felt the following things when you think about what happened.

Abantwana abaninzi badlula kwizinto ezibuhlungu okanye ezoyikisayo. Ngoku kumbula ngokwakwehlelayo okucaphukisayo okanye okwakoiukisayo ebomini bakho. Nceda sixelele kukangaphi uziva ngalendlela ilandelayo (ibhokisi), xa ucinga ngokwakwehlelayo kwinyanga edlulileyo.

	Never *Zange*	Some of the time *Ngamanye amaxesha*	Most of the time *Ixesha elininzi*	All of the time *Rhoqo*
1. Do you get upset when you think about what happened? *Uyakhathazeka xa ucinga ngokwenzekayo?*				
2. When something reminds you of what happened, do you get tense or upset? *Xa kukho into ekukhumbuza ngokwenzekayo, uyaxhalaba okanye uyakhathazeka?*				
3. Do you go over and over what happened in your mind? *Uyaphinda – phinda ukucinga ngokwenzekayo engqondweni?*				
4. Do you think about (or see pictures in your head of) what happened even when you don't want to? *Uneengcinga okanye umfanekiso – ngqondweni ekufikelayo ngento eyenzekayo, noxa ungafuni?*				
5. Do you worry that it might happen again? *Unexhala lokuba lonto ingenzeka kwakhona?*				
6. Do you try not to think about what happened? *Uyazama ukungacingi ngokwenzekayo?*				
7. Do you try to stay away from things that remind you of what happened? *Uyazama ukuziphepha izinto ezithi zikukhumbuze ngento eyenzekayo?*				
8. Do you feel like it's happening all over again even when it's not? *Uva ngathi lo nto iyenzeka kwakhona noxa ingenzeki?*				
9. Do you feel it's hard to have any feelings any more, like you feel numb? *Uva ngathi kunzima uvakalelwa, uva udangele emphefumlweni?*				
10. Do you make yourself very busy and do things so you won't think about what happened? Uzigcina uxakekile usenza izinto ukuze ungacingi ngento eyenzekayo?				

Other Teens and You
Abanye abaselula kunye nawe

Many teenagers feel nervous or anxious at times. Please say which of these are true for you.

Abantwana abaselula bazifumana benomva ndendwa okanye bexhalabile ngamaxesha athile.

Nceda usixelele ukuba yeyiphi kwezi zinto eyinyani kuwe.

11. I worry a lot of the time.
    Ndibanexhala amaxesha amaninzi.
    - Yes / *Ewe*
    - No / *Hayi*
12. I worry about what my carers will say to me.
    Ndibanexhala ukuba bazokuthini na abagcini bam.
    - Yes / *Ewe*
    - No / *Hayi*
13. I feel that others do not like the way I do things.
    Ndiziva ngokungathi *abanye abantu abaluthandi uhlobo endenza ngalo izinto.*
    - Yes / *Ewe*
    - No / *Hayi*
14. It is hard for me to get to sleep at night.
    Kunzima kum ukulala ebusuku.
    - Yes / *Ewe*
    - No / *Hayi*
15. I worry about what other people think about me.
    Ndibanexhala yindlela abanye abantu abacinga ngayo ngam.
    - Yes / *Ewe*
    - No / *Hayi*
16. I feel alone even when there are people with me.
    Ndiziva ndililolo nangona bekhona abanye abantu.
    - Yes / *Ewe*
    - No / *Hayi*
17. I worry about what is going to happen.
    Ndibanexhala yinto ezakuthi yenzeke.
    - Yes / *Ewe*
    - No / *Hayi*
18. Other children are happier than I am.
    Abanye abantwana bonwabile kunam.
    - Yes / *Ewe*
    - No / *Hayi*
19. I have bad dreams.
    Ndinamaphupha amabi.
    - Yes / *Ewe*
    - No / *Hayi*
20. I wake up scared sometimes.
    Ndivuka ndisoyika ngamanye amaxesha.
    - Yes / *Ewe*
    - No / *Hayi*
21. I worry when I go to bed at night.
    Ndibanexhala xa ndiyokulala ebusuku.
    - Yes / *Ewe*
    - No / *Hayi*
22. I am nervous.
    Ndinomvandedwa.
    - Yes / *Ewe*
    - No / *Hayi*
23. A lot of people are against me.
    Abantu abaninzi abekho ngakwicala lam.
    - Yes / *Ewe*

 No / *Hayi*

24. I often worry about something bad happening to me.
Ndisoloko ndinexhala ngento embi enothi indehlele.
 Yes / *Ewe*
 No / *Hayi*

Thank you for answering these difficult questions. Now lets talk about your goals and plans for the future.

Enkosi kakhulu ngophendula le mibuzo inzima. Ngoku masithethe ngemingqweno kwakunye nezicwangciso zekamva lakho.

25. What job do you want to do when you grow up?
Ngowuphi umsebenzi owufunayo xa ukhulile? _____

Please tell us whether the following statements are true for you.
Nceda usixelele ukuba yeyiphi kwezi zilandelayo eyinyani kuwe.

	Agree	Disagree
26. Finishing high-school is important to me. *Kubalulekile kum ukugqibezela izifundo eziphakamileyo.*		
27. I have plans for my future. *Ndine zicwangciso ngekamva lam.*		
28. I think I will have many opportunities in life. *Ndicinga ukuba ndizokuba namathuba amaninzi ebomini.*		

5.2.12 Part 11: Let's Talk About Sex

Isiqendu 11: Masithethe ngezesondo…

The following section has a lot of personal questions in it. Remember that everything is confidential, no one will know what you have said, and when you share your experiences with us we will use it to help healthcare workers and the government understand the needs of youth such as yourself better. Your answers will help us find out how to make health services better for youth.

Elicandelo lilandelayo linemibuzo emininzi eqonde nqo kuwe. Impendulo zakho zizokusincedisa ukuba singenza njani inkonzo zempilo zibengcono kubantu abatsha.

Please answer the following questions to the best of your ability. For each sentence, please tell us if you think it is 'true', 'false' or if you 'don't know'.

Sicela uphendule le mibuzo ilandelayo kangangoko unakho. Kwezi zivakalisi zilandalayo nceda usixelele ukuba 'yinyani', 'asiyonyani' okanye 'akuyazi'.

7. If you are HIV positive, you cannot become infected with HIV again.
Xa unentsholongwane kagawulayo, awukwazi uphinda usuleleke yintsholongwane kagawulayo kwakhona.
   - □ True/ Yinyani
   - □ False/ Asiyonyani
   - □ I don't know/ Andiyazi

8. HIV cannot be passed from an HIV-positive mother to her unborn child.
Abantu abatsha abangomama abaphila nentsholongwane kagawulayo akumelanga

ukuba bakhulelwe kuba bazakusulela abantwana ngentsholongwane.
- □ True/ Yinyani
- □ False/ Asiyonyani
- □ I don't know/ Andiyazi

9. If an HIV-positive adolescent has sex, they need to use a condom.
   Umntu omtsha ophila nentsholongwane kagawulayo kumele abelane ngesondo xa efuna, kodwa ufuneka esebenzise isikhuseli (icondom).
   - □ True/ Yinyani
   - □ False/ Asiyonyani
   - □ I don't know/ Andiyazi.

10. People living with HIV who are using the injection, pills or implant to prevent pregnancy, do not need to use condoms.
    Abantu abaphila nentsholongwane kagawulayo abo basebenzisa inalithi okanye pilisi okanye implant zokukhusela ekukhulelweni, abafanelanga ukusebenzisa isikhuseli (icondom).
    - □ True/ Yinyani
    - □ False/ Asiyonyani
    - □ I don't know/ Andiyazi

We know that sex can mean a lot of things. Girls can have sex with boys, girls with girls, or boys with boys. Sometimes we choose to kiss, other times to have sex. Remember that your name is not recorded anywhere on this questionnaire.

Siyazi ukuba ukwabelana ngesondo kuthetha izinto ezininzi. Amantombazana angabelana ngesondo namakhwenkwe, amantombazana namanye amantombazana okanye inkwenkwe nenye inkwenkwe. Ngamanye amaxesha siye khethe ukuphuzana, abanye babelane ngesondo. Khumbula ukuba igama lakho alishicilelwangwa.

Let's talk about sex…
Masithethe ngezesondo…

First time experiences
Amava am okuqala

For boys only:
11. How old were you when you first kissed someone with tongue?
    Igaba wawuneminyaka emingaphi ngexesha wawuqala ukuphuzana nomntu nifakane ulwimi?
    _____years old
    - □ Never

12. How old were you when you touched someone else's private parts because you wanted to *or* someone else touched your private parts because you wanted them to?
    Ingaba wawuneminyaka emingaphi ngexesha wawuphatha amalungu angasese womntu kuba ufuna okanye umntu abambe amalungu wakho angasese kuba wena ufuna
    _____years old
    - □ Never

13. How old were you when you first had sex?
    Wawuneminyaka emingaphi ngexesha wawuqala ukwabelana ngesondo?

    _____years old

 Never

14. How old were you when someone first used their mouth to kiss your private parts (penis)?
Wawuneminyaka emingaphi ngexesha wawuphuzwa ngumntu okokuqala kumalungu wakho angasese (ubudoda)?

_____years old
 Never

15. How old were you when you had sex in your bum or put your penis in someone else's bum?
Wawuneminyaka emingaphi ngethuba usabelana ngesondo ezimpundwini okanye ufake ubudoda bakho ezimpundwini zomnye umntu?

_____years old
 Never

For Girls only:

16. How old were you when you first kissed someone with tongue or deep kissed?
Igaba wawuneminyaka emingaphi ngexesha wawuqala ukuphuzana nomntu nifakane ulwimi?

_____years old
 Never

17. How old were you when you touched someone else's private parts because you wanted to *or* someone else touched your private parts because you wanted them to?
Ingaba wawuneminyaka emingaphi ngexesha wawuphatha amalungu angasese womntu kuba ufuna okanye umntu abambe amalungu wakho angasese kuba wena ufuna

_____years old
 Never

18. How old were you when you first had sex?
Wawuneminyaka emingaphi ngoku wawuqala ukwabelana ngesondo?

_____years old
 Never

19. How old were you when someone first used their mouth to kiss your private parts (vagina)?
Wawuneminyaka emingaphi ngexesha wawuphuzwa ngumntu okokuqala kumalungu wakho angasese?

_____years old
 Never

20. How old were you when you had sex in your bum?
Wawuneminyaka emingaphi ngethuba wawusabelana ngesondo ezimpundwini zakho?

_____years old
 Never

For boys and girls:
Now we would like to ask you about having sex in the last year.

When we say 'sex' we mean when a boy inserted his penis into a girl's vagina.
Ngoku sizokubuza ngokugqibela kwakho ukwabelana ngesondo kunyaka odlulileyo. Xa sithetha ngesondo sithetha xa inkwenkwe ifaka ubudoda bayo ebuntombini bakho.

21. Now think back to the first time you had sex with someone. What was it like for you?
Ngoku cinga ngexesha wawuqala ukwabelana ngesongo nomntu. Kwakunjani?
Choose as many answers as apply:
Khetha impendulo kangangoko zifuneka:
- □ I was scared / Ndandisoyika
- □ I enjoyed it / Bekumnandi
- □ I felt shy / Ngandinentloni
- □ It was painful / Kwakubahlungu
- □ It was something I wanted / Yayinto endandiyifuna
- □ It was something I was forced to do against my will / Yayinto endanyanzelwa ukuba ndiyenze ndingafuni
- □ I have never had sex / Zange ndabelana ngesondo

22. Did you or your partner use any of the following the first time you had sex?
Ingaba wena okanye nomlingane wakho ngezesha lokuqala nisabelana ngesondo nayisebenzisa enye yezi zilandlelayo.
Choose as many answers as apply:
Khetha impendulo kangangoko zifuneka:
- □ Nothing/ Akho nasinye
- □ Male condom/ Icondom yamadoda
- □ Female condom/ Icondom yabafazi
- □ Birth control pill/ Ipilisi ekhusela ukukhulelwa
- □ Injection/ Inaliti
- □ Having sex with only one person / Ukwabelana ngesondo nomntu omnyo kuphela
- □ Implant/ implant
- □ Pulling out / Ukuchamela ngaphandle
- □ Intrauterine Device (IUD - loop)/ Iluphu
- □ Sterilization/ ukuvalwa
- □ Not having sex at all / Ungabelani ngesondo namntu
- □ Having sex only during certain times of the month / Ukwabelana ngesondo ngalooma xesha enyangeni

23. Now think about the last time you had sex - how old was your partner?
Ngoku ncinga ngexesha lokugqibela usabelana ngesondo - lalineminyaka emingaphi iqabane lakho?
- ☐ Same age as me / Wayenguntanga wam
- ☐ Older than me / Wayemdala kunam >> Go to Question 17a.
- ☐ Younger than me / Wayemncinci kunam >> Go to Question 17a.
- ☐ I don't remember / Andisakhumbuli
- ☐ I don't know / Andiyazi

17a. How old was your partner? _____years old
Lalineminyaka emingaphi iqabane lakho?

24. Did you use a condom the last time you had sex?

Ingaba ubuyisebenzisile na isikhuseli (icondom) ngethuba lokugqibela usabelana ngesondo?

- □ Yes, during the entire time we had sex/*Ewe, lonke ixesha sisabelana ngesondo*
- □ For a part of the sex/ *Ngamanye amaxesha sisabelana ngesondo*
- □ No, we did not use a condom/ *Hayi, asizange siyisebenzise isikhuseli (icondom)*

Only those who are sexually active
Kwabo sebabelana ngesondo

(If you are not sexualy active Go to Question 38)

Now we will ask you some questions about condoms and other ways to prevent a girl from getting pregnant, in the past year.
Ngoku sizakubuza imibuzo malunga nesikhuseli nakunye nendlela yokukhusela intombazana ingakhulelwa.

Your answers will help us understand how youth preferences change over time.
Impendulo zakho zizakusinceda sazi ukuba abantu abatsha batshintsha njani njengoba ixesha lihamba.

25. How often have you had sex <u>in the last year</u>?
    Kwinyanga ezintandathu ezidlulileyo wabelane kangaphi ngesondo*?*
    - □ Never/ *Andizange*
    - □ Monthly/ *Qho ngenyanga*
    - □ Weekly/ *Qho ngeveki*
    - □ Daily/ *Ntsukuzonke*

26. How many people have you had sex with <u>in the past year</u>?
    Bangaphi abantu owabelane nabo ngesondo <u>ngonyaka odlulileyo</u>? _____

27. In <u>the last year</u>, how often did you use condoms for the whole time that you were having sex?
    <u>Kwezinyanga zitandathu zidlulileyo</u>, ingaba usisebenzise kangaphi isikhuseli (icondom) ekuqaleni ukuya ekupheleni?
    - □ Never/ *Zange*
    - □ Less than half the time
    - □ Half the time/ *Ngamanye amaxesha*
    - □ More than half the time
    - □ Every time/ *Ngalo lonke ixesha*

28. Which of the following did you and your partner(s) use over the last year? Choose as many answers as apply
    Ingaba sesiphi isikhuseli enisisebenzisileyo neqabane lakho kwezinyanga zintandathu? [khetha zonke ezingenayo]
    - □ Nothing/ Akho nasinye
    - □ Male condom/ Icondom yamadoda
    - □ Female condom/ Icondom yabafazi
    - □ Birth control pill/ Ipilisi ekhusela ukukhulelwa
    - □ Injection/ Inaliti
    - □ Pulling out
    - □ Having sex with only one person
    - □ Intrauterine Device/ Iluphu
    - □ Implant/ implant
    - □ Sterilization/ ukuvalwa

□ Not having sex at all
□ Having sex only during certain times of the moth
□ Other/ Ezinye _____

29. Why did you use the above method? Choose as many answers as apply.
Kwakutheni ukuze usebenzise ezindlela zingentla? Khetha impendulo kangangoko zifuneka.
□ I don't know
Andiyazi
□ To prevent pregnancy
Ukukhusela ukukhulelwa
□ To prevent passing on my HIV to my partner
Ukukhusela iqabane lam ekulosuleleni ngentsholongwane kagawulayo
□ To prevent getting infected with STIs
Ukukhusela ukosuleleka ngezifo ezosulela ngokulalana.
□ To prevent getting re-infected by HIV
Ukunqanda ukosuleleka kwakhona ngentsholongwane kagawulayo.

30. Where did you get the method you used? *Choose only one answer.*
Uyifumene phi lendlela ubuzikhusela ngayo? Khetha impendulo ibenye.
□ Shop/ Evenkileni
□ Pharmacy/drug shop/ Ekhemesti
□ Clinic/ hospital - Esibhedlele/ isebe lezempilo
□ HIV/AIDS treatment centre/ Kwindawo yentsholongwane kagawulayo
□ Other health centre/ Kwamanye amaziko empilo
□ Friends/ Kwizihlobo
□ Shebeen / Eshebeeni
□ Other (specify)/ Enye indawo(chaza) _____

Sometimes, people give or receive presents from their partner because they are having sex with him or her.
Ngamanye amaxesha abantu bafumana izipho kumaqabane abo ngenxa yokuba besababelana ngesondo.

31. Have you had any of these presents given to you because you had sex with someone OR did you decide to have sex with someone in exchange for these gifts? Choose as many answers as apply:
Ingaba ubukhe wazifumana ezi zipho zilandelayo kumntu okhe wabelana naye ngesondo okanye ukhethe ukwabelana ngesondo uzokwazi ufumana izipho? Khetha zeziphi:
□ Money/ Imali
□ Buying you clothes/ Akuthengele impahla
□ Hair extensions or weave at the salon / Ukwenza inwele esaluni
□ Drinks when you were out at a shebeen or club/ukuthengelwa ubutywala xa siseshebeen okanye kwindawo zesiyolo
□ Cosmetics and jewelry/izinto zothambisa okanye ubucwebe
□ Airtime/ iairtime
□ Cellphone/ imfonomfono
□ A place to stay/ Indawo yokuhlala
□ Transportation: bus tickets, lifts in a car or taxi/ Ukukhweliswa emotweni simahla
□ Better marks at school/ Amanqaku angcono esikolweni
□ School fees/ Ukubhatalelwa intlawulo yesikolo
□ Food/ Ukutya
□ Anything else? >>Go to Question 25a.
□ None of the above/ Ayikho nanye kwezi zingentla

25a. Anything else? _____
Ezinye izinto?

25b. Has this happened in the last 6 months?
Ingaba lento ibikhe yenzeka kwezinyanga zintandathu zidlulileyo?
□ Yes/ Ewe □ No/ Hayi

This section asks questions about pregnancy, having children and what you would like your family to look like.
Elicandelo libuza ngokukhulelwa, ngokuba nabantwana nangokuba ufuna lubenjani usapho lwakho.

32. How many times have you been pregnant or made someone pregnant?
Ukhulelwe amatyeli amangaphi okanye wenza omnye umntu wakhulelwa?
_____ times
□ I don't know / I have never been pregnant

33. How many children do you have? *Unabantwana abangaphi?*
_____ children

For girls only (boys skip to question 34)
Amantombazana kuphela…

Noxolo got pregnant when she was 16. She was not sure when it happened or how, but she decided to keep the baby with her grandmother's help. Nomvula got pregnant at 15, but decided that she could not have the baby. Some friends told her to take some herbs, other friends suggested she go to the hospital to end the pregnancy.
Noxolo ukhulelwe xa eneminyaka eyi 16. Wayengaqinisekanga ukuba yenzeke nini kodwa wathatha isigqibo sokumgcina umntwana ngoncedo lukamakhulu wakhe. Nomvula wakhulelwa ena 15 kodwa wagqiba ekukhupheni isisu. Abanye babahlobo bakhe bamxelela ngokusebenzisa amayeza abanye babonisa ukuba aye esibhedlele ayokhupha isisu.

We'd like to know a bit more about the last time you were pregnant:
Singathanda ukwazi kancinci malunga ngexesha elidlulileyo lokhulelwa kwakho.

34. How old were you when you were last pregnant? *Wawuneminyaka emingaphi ngexesha lokugqibela kwakho ukukhulelwa?*
_____ *years old*
□ I have never been pregnat

35. If you have ever been pregnant, please tell us a bit more about your last pregnancy? Choose all that apply:
Ukuba wakhe wakhulelwa ndiyacela nceda sixelele ngoku khulelwa kwakho kokugqibela. Khetha impendulo kangangoko zifuneka:
□ I was not planning to get pregnant
Ndandinga cwangciselanga ukukhulelwa.
□ I did not want to get pregnant
Bendingafuni ukukhulelwa
□ I wanted to get pregnant
Bendifuna ukukhulelwa
□ I was planning to get pregnant
Bendikucwangcisile ukukhulelwa

36. What happened the last time you were pregnant? *Choose only one answer.*
Kwenzeka ntoni ngexesha wawukhulelwe? Khetha impendulo ibenye.

□ I have a baby - If yes, >>Go to Question 31-33.
Ndinomntwana >> ukuba ewe, dibanisa umbuzo olandelayo 31-33.
□ My fetus did not live >>Go to Question 38
Umntwana wam akazange aphile
□ I took some herbs to stop being pregnant >>Go to Question 38
Ndathatha amayeza ukunqanda ukukhulelwa
□ I went to the hospital to stop being pregnant >>Go to Question 38
Ndaya esibhedlele ukunqanda ukukhulelwa
□ I went to a doctor's office/ practice to stop being pregnant >>Go to Question 38
Ndaya kwagqirha ukunqanda ukukhulelwa
□ Other/ *Ezinye* _____ >>Go to Question 38

37. How did you give birth to your baby? *Choose only one answer:*
Wambeleka njani umntwana wakho? Khetha impendulo ibenye:

□ At home
Ndambelekela ekhaya
□ In the hospital/ clinic
Ndambelekela esibhedlele/ ekliniki
□ I had a caesarean (c-section)
Ndambeleka ngoqhaqho

38. How are you feeding/ did you feed your (youngest) child in the first 6 months?
Ingaba ubatyisa njani/wabatyisa njani kwinyanga ezintadathu zabo zokuqala?

□ Breastfeeding mixed with some baby formula
Ukuncancisa ndidibanise nobisi lwabantwana
□ Baby formula only
Ubisi lwabantwana kuphela
□ Breastfeeding only
Ndiyancancisa kuphela
□ Other /Ezinye _____

39. [ONLY GIRAFFES/ HIV-POSITIVE STATUS-AWARE] Now, we would like to know about all of your children. If you only have one child, that is ok. Are any of your children HIV positive?
Ngoku singathanda ukwazi malunga konke ngabantwana bakho. Xa emnye khupela kulungile. Ingaba ukhona omnye kubantwana bakho onentsholongwane kagawulayo?

□ Yes/ Ewe
□ No/ Hayi
□ I don't know/ Andazi

For boys only…
Amakhwenkwe kuphela…

Jongile has had a girlfriend for a long time. His girlfriend got pregnant last year. Jongile decided to support the child. Jongile's friend Fikile likes lots of girls and has had sex with many of them. Some of these girls have told Fikile they got pregnant, but he is not sure what happened with the baby. What about you?
uJongile wayene qabanekazi ithuba elide. Qabanekazi lakhe lakhulelwa kunyaka odlulileyo. uJongile ubenesigqibo sokumondla mntwana. Mhlobo ka Jongile uFikile uyawathanda kakhulu amantombazana kwaye wakhe wabelana ngesondo nabaninzi babo. Abanye balamantombazana bamxelela ukuba bakhulelwe, kodwa akanasiqiniseko sokuba kwenzeka ntoni ngomntwana. Uthini ngawe?

34. How old were you when you last got someone pregnant? Wawuneminyaka emingaphi ngexesha elinye lamaqabanekazi akho efumanisa ukuba likhulelwe?

_____

□ I have never gotten someone pregnant

35. Please tell us a bit more about the last time you got one of your girlfriends pregnant. Choose all that apply:
Nceda usixelele ngokusinabisela ngethuba wenze iqabanekazi lakho lakhulelwa. [khetha impendulo kangangoko zifuneka]

□ I was not planning to get my girlfriend pregnant
Andizange ndicwangcisela iqabanekazi lam likhulelwe.
□ I did not want to get my girlfriend pregnant
Bendingafuni iqabanekazi lam likhulelwe
□ I wanted to get my girlfriend pregnant
Bendifuna iqabanekazi lam likhulelwe
□ I was planning to get my girlfriend pregnant
Bendikucwangcisile ukukhulelwa kweqabanekazi lam

36. What happened the last time you got your girlfriend pregnant? *Choose only one answer: Kwenzeka ntoni ngexesha lokugqibela ufumaniseka ukuba iqabanekazi lakho likhulelwa? Khetha impendulo ibenye:*

□ I have a baby
Ndinomntwana
□ The fetus did not live
Umntwana wam akazange aphile
□ My girlfriend took some herbs to stop being pregnant
Iqabanekazi lam lathatha amayeza ukunqanda ukukhulelwa
□ My girlfriend went to the hospital or a doctor's office to stop being pregnant
Iqabanekazi lam laya esibhedlele okanye kugqirha ukunqanda ukukhulelwa
□ I don't know what happened/ Andiyazi kwenzeka ntoni….
□ Other/ Ezinye _____

37. [ONLY GIRAFFES/ HIV-POSITIVE STATUS-AWARE] Now, we would like to know about all of your children. If you only have one child, that is ok. Are any of your children HIV positive?
Ngoku singathanda ukwazi malunga konke ngabantwana bakho. Xa emnye khupela kulungile. Ingaba ukhona omnye kubantwana bakho onentsholongwane kagawulayo?

□ Yes/ Ewe
□ No/ Hayi
□ I don't know/ Andiyazi

For boys and girls:
Amakwenkwe kunye namantombi

Please answer these questions, whether you have had sex or not. Remember that all your answers will be kept private and that your name is not attached to this questionnaire.
Nceda uphendule lemibuzo, nangona ungazange wabelane ngesondo, okanye usabelana ngesondo. Khumbula ukuba zonke impendulo zakho zizagcinwa ziyimfihlo kwaye negama lakho alibhalwangwa kulemibuzo.

38. Next time you have sex, do you plan to use a condom?
Xa uphinda usabelana ngesondo ingaba uzaku sisebenzisa isikhuseli (icondom)?

- □ Definitely yes/ *Ewe ngokuqinisekileyo*
- □ Probably yes/ *Mhlawumbi ewe*
- □ Not sure/ *Andiqinisekanga*
- □ Probably no/ *Mhlawumbi hayi*
- □ Definitely no/ *Hayi*

Khwezi uses condoms correctly but only with some girlfriends. Babalwa does not like condoms because she is embarrassed to ask her boyfriend to use them.

What about you? Can we talk about condoms? Thank you!
uKhwezi usebenzisa isikhuseli (icondom) kakuhle, kodwa namanye amaqabanekazi. uBabalwa akasithandi isikhuseli (icondom) kuba unentloni ukubuza iqabane lakhe ngokusisebenzisa. Uthini ngawe? Singathetha ngesikhuseli (icondom)? Enkosi!

	Never True for me *Akuyonyani kum*	Sometimes true for me *Kuyinyani ngamanye amaxesha*	Always true for me *Kuhlala kuyinyani oku kum*
39. I can use a condom and make sure it's put on the whole way down every time I have sex. *Ndingasisebenzisa kakuhle isikhuseli (icondom) ndiqiniseke ndisifake sonke uyofika ezantsi rhoqo ndisabelana ngesondo.*			
40. If the guy or girl I'm with refuses to use a condom, I can say no to sex. *Ukuba umntu (inkwenkwe/ intombi) endihambisana nayo iyala ukusebenzisa isikhuseli (icondom), ndingathi andifuni ukwabelana ngesondo.*			
41. I would be too embarrassed to get condoms at the local shop. *Ndinganentloni ukuyothenga isikhuseli (icondom) evenkileni esekuhlaleni.*			
42. Condoms make sex less good. *Isikhuseli (icondom) senza ukwabelana ngesondo kungabi mnandi.*			
43. If I use a condom when I have sex this will make my partner think that I do not trust them or I am cheating on them. *Xa ndisebenzisa isikhuseli (icondom) neqabane/ neqabanekazi lam oku kwenza acinge ukuba andimthembanga okanye ndiyakrexeza.*			
44. My religion does not support using condoms. *Inkolo yam ayikuxhasi ukusetyenziswa kwesikhuseli (kwecondom).*			
45. Condoms are too expensive to buy for every time I have sex. *Andibinayo imali yokuba ndithenge isikhuseli (icondom) lonke ixesha*			

ndizokwabelana ngesondo.			
46. Using contraception is my partner's problem and responsibility, not mine. *Ukusebenzisa isicwangcisi kuyingxaki kwaye kuluxanduva lweqabane/lweqabanekazi lam hayi olwam.*			

For boys only:
Amakhwenkwe kuphela…

Xolani is 18. He was invited to initiation school when he was 17. His friend Zweli decided to get circumcised at the hospital when he was 18. What about you?
uXolani uneminyaka eyi 18. Wayemenywe kwisikolo solwaluko xa wayeneminyaka eyi 17. Umhlobo wakhe, uZweli, wathatha isigqibo sokwaluka esibhedlele xa wayeneminyaka eyi 18. Uthini ngawe?

47. How did you get circumcised?
Woluka njani?
- □ I have not been circumcised yet
  Andikoluki
- □ I was initiated through a traditional ceremony
  Ndeluka ngesiko lesintu
- □ I went to a clinic or hospital
  Ndalukela esibhedlele/ isebe lezempilo

For boys and girls:
<u>Getting and using contraception</u>

Ukufumana nokusebenzisa izicwangcisi

48. What are you doing to prevent getting pregnant? *Choose as many answers as apply:*
Wenza ntoni ukuqanda ukukhulelwa? Khetha impendule kangangoko: ZIFUNEKA
- □ Nothing/ Andenzinto
- □ Male condoms/ icondom yabantu yamadoda
- □ Female condoms/ icondom yabantu yabafazi
- □ Birth control pill/ ipilisi endiyithatha rhoqo
- □ Injection/ inaliti
- □ Pulling out/ Ukuchamela ngaphandle
- □ Having sex with only one person / Ukwabelana ngesondo nomntu omnye
- □ Intrauterine Device (IUD-loop)/ iluphu
- □ Implant/ implant
- □ Sterilisation/ ukuvalwa
- □ Not having sex/ Ungabelani ngesondo namntu
- □ Only having sex during certain times of the month/ ukwabelana ngesondo ngalooma xesha enyangeni
- □ Other/ Enye _____

49. Which method to prevent pregnancy do you think is best for you? *Choose only one answer.*
Yeyiphi indlela yokukhusela ukukhulelwa ocinga ukuba ikulungele wena? Khetha impendulo ibanye.
- □ Nothing/ Akho nasinye
- □ Male condom/ Isikhuseli (icondom) yamadoda

□ Female condom/ Isikhuseli (icondom) yabafazi
□ Birth control pill/ Ipilisi ekhusela ukukhulelwa
□ Injection/ Inaliti
□ Pulling out/ Ukuchamela ngaphandle
□ Having sex with only one person/ Ukwabelana ngesondo nomntu omnye
□ Intrauterine Device/ Iluphu
□ Implant/ implant
□ Sterilisation/ ukuvalwa
□ Not having sex at all (abstinence)/ kungabelani ngesondo konke konke
□ Only having sex during certain times of the month/ ukwabelana ngesondo ngalooma xesha enyangeni.
□ Other/ Ezinye _____

50. If you were going to use something to prevent pregnancy, where would you feel <u>most</u> comfortable getting it? Choose only one answer.
Ukuba ubuzakusebenzisa isicwangcisi yeyiphi eyona ndawo ongaziva ukhululekile, ukuyifumana khona? Khetha impendule ibenye.
□ Shop/ Evenkileni
□ Pharmacy/drug shop/ Ekhemesti
□ Clinic/ hospital - Esibhedlele/ isebe lezempilo
□ HIV/AIDS treatment centre/ Kwindawo yentsholongwane kagawulayo
□ Friends/ Kwizihlobo
□ School/ Eskolweni
□ Shebeen

Andisiwe went to the clinic to get condoms last week. It was terrible. But Siphesihle said her clinic is fine and the nurses are really nice!

What is it like for you to go to the clinic to get condoms, the pill or other ways of preventing pregnancy?
uAndisiwe waya eklinik eyokufumana isikhuseli (icondom) kwiveki edlulileyo. Kwakukubi! Kodwa uSiphesihle uthe eklinik yakhe ilungile okanye abongikazi balunge kakhulu. Sizakufuna ukuva ngamava akho ekliniki okanye ngesibhedlele apho ufumana khona izicwangcisi zakho (icondom, ipilisi okanye ezinye indlela zokucwagcisa).

51. What method has someone at the clinic offered you to prevent pregnancy for you or your partner? Choose as many answers as apply.
Zeziphi indlela zokucwangcisi athe umntu wakunika zona ekliniki eziqanda ukukhulelwa wena okanye isiqanda mathe? Khetha impendule kangangoko zifuneka.
□ Nothing / Azikho
□ Male condoms/ Yicondom yabantu yamadoda
□ Female condoms/ Yicondom yabantu yabafazi
□ Birth control pill/ Yipilisi endiyithatha rhoqo
□ Injection/ Yinaliti
□ Implant/ Implant
□ Intrauterine Device (IUD)/ Yiluphu
□ Sterilisation/ ukuvalwa
□ Other/ Enye _____

52. Think back to the first time you or your partner used a method to prevent pregnancy (pill, injection, IUD, implant, condom or sterilisation). How did you first start using it? Choose only one answer:

Cinga ngexesha elidlulileyo apho okanye nesanqa wakhe waqala ukusebenzisa indlela yokukhusela ukukhulelwa (ipilisi, iluphu, inaliti, implant okanye uvalwa). Waqala njani ukuyisebenzisa? Khetha impendulo ibenye:

□ I asked the nurse for the method to prevent pregnancy that I or my partner wanted/ *Ndazicelela indlela yokukhusela ukukhulelwa endandi yifuna*
□ The nurse/ doctor offered me some choices and I chose one method for me or my partner/ *Umongikazi/ Ugqirha wandinika emandi khethe kuzo*
□ The nurse/ doctor told me which method my partner or I should start/ *Umongikazi/ Ugqirha wandixelela ukuba mandiqale ngeyiphi*
□ The nurse gave me something without telling me what it was/ *Umongikazi/ Ugqirha wandinika into engakhange andinike nkcazelo*
□ My partner or I are not using any contraception
□ Other/ *Ezinye*: _____

53. How did you feel when you went to the clinic to get methods to prevent pregnancy in the last six months? Choose as many answers as apply.
Waziva njani xa wawuye ekliniki uyothatha izicwangcisi zakho kwinyanga ezintandathu ezidlulileyo. Khetha impendule kangangoko zifuneka.

□ Welcomed/ Ndamkelekile
□ Ashamed/ Ndinentloni
□ Respected/ Ndihloniphekile
□ Worried/ Ndinexhala
□ Listened to carefully and professionally/ Ndimanyelwe kakuhle kakhulu
□ Scared/ Ndisoyika
□ Scolded/ Ndinqonqoziswa
□ Annoyed/ Ndicaphuka
□ Bored/ Ndidikiwe
□ I have not been to the clinic to get contraception

54. Did anyone at the clinic ever tell you about the side-effects of contraception?
Ngaba ukhona umntu ekliniki owakhe wakuxelela ngemiphumela yokusebenzisa izicwangcisi?

□ Yes/ Ewe □ No/ Hayi

55. Have you ever used contraception before? *Wawukhe wazisebenzisa izincwagcisi?*

□ Yes/ Ewe >>Go to Question 55a □ No/ Hayi >>Go to Question 56

55a. Have you experienced any of these side-effects from contraception?
Ingaba ubukhe wafumana eminye yalemiphumela yokusebenzisa izicwangcisi?

□ Nausea/ *Uziva ngongathi uzakugabha*
□ Bloating/ *Ukuqunjelwa sisisu*
□ Headaches/ *Intloko ebuhlungu*
□ Sore breasts/ *Amabele abuhlungu*
□ Painful periods/ *Isiluma*
□ Weight gain/ *Ukutyeba*
□ Depression or feeling low/ *Idepression okanye uzive uphantsi*
□ Sore, dry or itchy vagina/ *Ubuhlungu okanye ukoma okanye urhawuzelelo ebuntombini bakho*
□ Not wanting to have sex/ *Ungafuni ukwabelana ngesondo*

56. How can we improve sexual or reproductive health services for adolescents at the clinic?
Singayiphucula njani imeka yeze sondo kunye ne zozalo kumaziko ezempilo kubantu abaselula?

- □ Staff (nurses, doctors or counsellors) need to be more sensitive and respectful towards youth
  Abasebenzi ekliniki (omongikazi, ogqirha okanye okanisila) badinga ukuba nentlonipho kubantu abatsha.
- □ More information on different contraceptive methods should be given to teens (boys and girls) in a non-judgmental way
  Abantu abaselula (kumankwenkwe namantombanzana) kumele banikwe ulwazi oluninzi kwindlela ezohlukileyo zokucwangcisa ngaphandle kokugwetywa.
- □ More information on sexual and reproductive health (pregnancy) should be given to teens (boys and girls)
  Abantu abaselula (amankwenkwe namantombanzana) kumele banikwe ulwazi oluninzi ngempilo yezesondo nezozalo
- □ Specific times and days when teenagers can come for their appointments and visits
  Amaxesha nentsuku ezithile apho abantu abaselula bangeza kumadinga wabo
- □ Enough consultation time with the staff
  Ithuba elaneleyo lokubonana nabasebenzi basekliniki
- □ Dedicated nurse or staff for providing contraception or family planning
  Omongikazi nabasebenzi abazinikeloyo benikeza ngezingcwagcisi ezosapho
- □ Contraceptives (condoms, pills, injection, implant, etc.) available when I need them
  Izingcwagcisi (iikhondoms ,nepilisi, inaliti, implant, nezinye) zikhona xandizifuna
- □ Cleaner and nicer waiting area and visiting rooms at the clinic/ hospital
  Amangumbi asekliniki okanye esibhedlele okulinda okanye okundwendwela acocekileyo.
- □ More private waiting area
  Indawo zabucala zokulinda
- □ Better equipped examination room
  Indawo zokuxilongwa zabucala
- □ Non-health activities/ services at the waiting area, for example: access to internet, social media, or web-surfing stations, or a TV with youth-friendly programmes
  Iindawo zokuhambisa ixesha kumagumbi okulinda umzekelo:ufumana internet simahla, amakhasi onxulumelwano, izitishi zeweb okanye inkqubo ezinobuhlobo kubantu abatsha.
- □ Materials to help me plan my future and improve my life
  Izixhobo zokundinceda ekucwangciseni ikamva lam okanye zindincede ekuphuculeni ubomi bam
- □ Other/ Ezinye

57. Were you told to return for your next appointment for contraception at an exact time?
  Waxelelwa ukuba uze uphinde ubuye kwidinga lakho lozokuthatha izicwangcisi ngexesha elililo?
  □ Yes/ Ewe □ No/ Hayi

Every two months, Neliswa goes to the clinic to get the injection. One day, she misses her appointment because she is studying for an exam.
Rhoqo kwinyanga ezimbini, uNeliswa uya ekliniki uyokufumana inaliti. Ngenye emini waliphosa idinga lakhe kuba waye ufunda imviwo zakhe.

58. If you miss your appointment (return date), what will happen?
  Ukuba uliphosile idinga lakho, kuza kwenzeka ntoni?
  - □ I will not be able to reschedule another appointment at that clinic
    Andizokwazi ukulifumana elinye idinga ekliniki
  - □ I will be able to reschedule another appointment at that clinic. There will be no bad consequences.
    Ndizakukwazi ukwenza elinye idinga ekliniki. Akuzubakho mephumela emibi.

- □ I will reschedule another appointment but there will be bad consequences (the nurse will scold me)
  Ndizakukwazi ukwenza elinye idinga ekliniki, kodwa kuzakho bakho imiphumela emibi (umongikazi uyakundihawula).
- □ I have never had clinic appointments

59. How many children would you like to have in the future?
Ungathanda ukuba nabantwana abangaphi kwixesha elizayo? _____ children

Almost finished!

5.2.13 Part 12: Needs and Support

Isiqendu 12: Iimfuno nenkxaso

Remember the difficult thing that we were thinking about before? Please think about it again.
Khumbula into enzima ebesikhe sayicinga ngaphambili? Sicela uphinde ucinge ngayo kwakhona.

Please tell us if you have felt this way 'not at all', 'some of the time', most of the time' or 'all the time' in this past month.
Nceda usixelele ukuba ubukhe waziva ngalendlela 'hayi nakanye', 'ngamaxesha athile', 'ngamaxesha amaninzi,' okanye 'ngamaxesha onke' kulenyanga idlulileyo.

In the past month…	Not at all *Hayi nakanye*	Some of the time *Nagmaxesha athile*	Most of the time *Ngamaxesha amaninzi*	All of the time *Ngamaxesha onke*
1. Do you get physically upset when something reminds you of what happened – like getting sweaty, shaking, your heart pounding, getting short of breath, or stomach aches? *Uva iintshukumo zomzimba xa kukho into ekukhumbuza ngokwenzekayo (umzekelo: usuke ubile ungcangcazele, intliziyo ibethe nagamandla, uphelelwe ngumphefumlo, isisu sibebuhlungu*?				
2. Do you have trouble falling asleep or staying asleep? *Uba nengxaki yokulala okanye uyaphuthelwa?*				
3. Is it hard for you to pay attention – like listening to your teacher, or doing your work – because you can't concentrate well? *Uba nengxaki yokumamela ngenyameko – umzekelo:*				

In the past month…	Not at all *Hayi nakanye*	Some of the time *Nagmaxesha athile*	Most of the time *Ngamaxesha amaninzi*	All of the time *Ngamaxesha onke*
ukumamela utitshala, okanye ukwenza umsebenzi- kuba ungakwazi ukuzikisa ukucinga?				
4. Do you get jumpy or startle easily? *Uba phaku-phaku okanye wothuka msinya?*				
5. Do you get annoyed (grouchy) or irritable (kind of angry) really easily? *Uba nomsindo okanye ucaphuka msinya?*				
6. Do you get angry or upset at people for no reason? *Uba nomsindo okanye ucaphukiswe ngabantu ngaphandle kwesizathu?*				
7. Do you feel it's hard to have fun doing things? *Ingaba uziva kunzima ukonwaba usenza izinto?*				
8. Do you ever feel it's hard to feel happy? *Ingaba ukhe uzive ngathi kunzima ukuba wonwabe?*				
9. Do you feel alone even when other people are around? *Ingaba uziva uwedwa nokuba uhleli nabanye abantu?*				

Sometimes the people we live with, our parents, grandparents, siblings or aunts/uncles, they get sick and they need our help and support to get better. At other times, we need their help to get healthy again.

In this section, we will ask you about your parents the person or people that take care of you at home.
Ngamanye amaxesha abantu esihlala nabo, abazali bethu, ootatomkhulu, izalamane zakho, okanye oomakazi/oomalume, baye bagule badinge uncedo nenkxaso yethu ukuze babe ngcono. Ngelinye ixesha, nathi siye siludinge uncedo lwabo ukuze siphile kwakhona. Kwelicandelo, sizakubuza ngomntu okanye ngabantu abakukhathaleleyo ekhaya kunye nabazali bakho.

10. Has your parent or person who cares for you been sick for more than 2 weeks in the last year?
Ingaba umzali wakho okanye umntu ukugcinayo ebekhe wagula ngaphezu kweveki ezimbini kunyaka odlulileyo?
    - □ Yes/ Ewe
    - □ No/ Hayi >>Go to Question 14

11. Could we ask you about some of the symptoms of sickness your parent or person who cares for you most, have had when they are sick? Choose all the symptoms that they have - please scroll down.
Singakubuza malunga nezinye zempawu zesigulo ebenaso umzali wakho okanye umntu okugcinayo ngoku ebegula? Khetha zonke impawu ebenazo - nceda wehle.
    - □ Lost weight and become very thin/ *Ingaba behla ngokomzimba wade wabhitya*
    - □ Diabetes/ *Bebeneswekile*
    - □ Asthma/ *Isifuba*
    - □ Any of these: very pale, hair changing colour, legs swelling up, burning feelings in feet, skin very dry
    Ingaba bakhe banazo ezi zinto: aphatshe, okanye kutshintshe umbala wenwele, okanye adumbe inyawo, okanye ave kutshisa inyawo, okanye ome ulusu.
    - □ Emotional problems/ *Ingaba bakhe banengxaki ngokwasemphefumlweni*
    - □ Eyes yellow, and fever, or itching/ *Ingaba amehlo abo ayethyeli, kwaye benomkhuhlane okanye ukurhawuzelela.*
    - □ Shingles or a rash on the skin/ *Ingaba babenebhanti (shingles) okanye irhashalala kulusu lwabo*
    - □ High blood pressure/ *Ingaba bebenengxaki yokunyukelwa (yihigh high)*
    - □ Sores on body/ *Ingaba babenezilonda emzimbeni*
    - □ Ulcers, white patches on mouth, or problems swallowing food/ *Ingaba bebenamaqhakuva elwimini okanye izinto ezimhlophe emlonyeni, okanye ingxaki xa beginya ukutya*
    - □ Do they drink alcohol too much/ *Babesela utywala kakhulu*
    - □ Cancer/ *Ingaba bebenesifo somhlaza*
    - □ Trouble breathing, or a cough for more than two days with fever/ *Ingaba bebenengxaki xa bephefumla, okanye bakhohlele ngaphezu kwentsuku ezimbini benomkhuhlane*
    - □ TB in the past 5 years/ *Ingaba bebenesifo sephepha (TB) kwiminyaka emihlanu edlulileyo*
    - □ Arthritis/ *Ingaba bebenesifo samathambo*
    - □ Have they been bewitched/ *Ingaba babethakathiwe*
    - □ Diarrhoea or a runny tummy for more than 2 days/ *Ingaba bebenesifo sotyatyazo okanye isisu esihambisayo ngaphezu kwentsuku ezimbini*
    - □ HIV/ *ntsholongwane kagawulayo*
    - □ Other / *Ezinye*

12. Is your parent or caregiver taking ARVs?
Ingaba umzali wakho okanye umntu okugcinayo uyazithatha na iARVs?
    - □ Yes/ Ewe
    - □ Yes, but they don't take them every day / *Ewe, kodwa abazithathi ntsuku zonke*
    - □ No >> Go to Question 14
    - □ I don't know / Andiyazi >> Go to Question 14

13. [ONLY GIRAFFES/ HIV-POSITIVE STATUS-AWARE] Do you take ARVs together?
Ingaba nizithatha nobabini iARVs?
    - □ Yes/ Ewe
    - □ No/ Hayi
    - □ Sometimes/ Ngamanye amaxesha

Confidential stories

Amabali ayimfihlelo

Langa and Sebenzile's parents both passed away in the last three years. They don't not know why their mom passed away, but they know thier dad has TB and many headaches.

We would like to ask you about your mom and dad. Thank you for helping us with this. These questions are totally confidential.
Ngoku singathanda ukubuza ngomama notata wakho. Enkosi ngokusinceda ngoku. Yonke lemibuzo iyimfihlelo.

14. Is your mom alive?
Ingaba usaphila umama wakho?
    - □ Yes/ *Ewe* >> Go to Question 19
    - □ Yes but she doesn't live with me/ *Ewe, kodwa akahlali nam* >> Go to Question 19
    - □ I don't know/ *Andiyazi* >> Go to Question 19
    - □ No/ *Hayi*

15. How old were you when your mom passed away? _____ years old
Wawuneminyaka emingaphi ukusweleka kuka mama wakho?

16. Do you know what happened?
Uyayazi ukuba kwenzeka ntoni?
    - □ Road accident / *ingozi yendlela*
    - □ Illness / *wayegula* >> Go to Question 17
    - □ Attacked / *wahlaselwa*
    - □ Something else >> Go to Question 16a

16a. Could you tell us what else? *Ungasixelela enye into?* _____

17. Could we ask you about some of the symptoms of sickness your mother had before they died? Choose all the symptoms that they had - please scroll down.
Singakubuza malunga nezinye impawu zesigulo ebenaso phambi kokuba asweleke?
Khetha zonke impawu ebenazo - nceda wehle.
    - □ Lost weight and become very thin/ *Ingaba behla ngokomzimba wade wabhitya*
    - □ Diabetes/ *Bebeneswekile*
    - □ Asthma/ *Isifuba*
    - □ Any of these: very pale, hair changing colour, legs swelling up, burning feelings in feet, skin very dry
    Ingaba bakhe banazo ezi zinto: aphatshe, okanye kutshintshe umbala wenwele, okanye adumbe inyawo, okanye ave kutshisa inyawo, okanye ome ulusu.
    - □ Emotional problems/ *Ingaba bakhe banengxaki ngokwasemphefumlweni*
    - □ Eyes yellow, and fever, or itching/ *Ingaba amehlo abo ayethyeli, kwaye benomkhuhlane okanye ukurhawuzelela.*
    - □ Shingles or a rash on the skin/ *Ingaba babenebhanti (shingles) okanye irhashalala kulusu lwabo*
    - □ High blood pressure/ *Ingaba bebenengxaki yokunyukelwa (yihigh high)*
    - □ Sores on body/ *Ingaba babenezilonda emzimbeni*
    - □ Ulcers, white patches on mouth, or problems swallowing food/ *Ingaba bebenamaqhakuva elwimini okanye izinto ezimhlophe emlonyeni, okanye ingxaki xa beginya ukutya*
    - □ Did she drink alcohol too much/ *Babesela utywala kakhulu*
    - □ Cancer/ *Ingaba bebenesifo somhlaza*
    - □ Trouble breathing, or a cough for more than 2 days with fever/ *Ingaba bebenengxaki xa bephefumla, okanye bakhohlele ngaphezu kwentsuku ezimbini benomkhuhlane*
    - □ TB in the past 5 years/ *Ingaba bebenesifo sephepha (TB) kwiminyaka emihlanu edlulileyo*

- □ Arthritis/ *Ingaba bebenesifo samathambo*
- □ Was she bewitched? / *Ingaba babethakathiwe*
- □ Diarrhoea or a runny tummy for more than 2 days/ *Ingaba bebenesifo sotyatyazo okanye isisu esihambisayo ngaphezu kwentsuku ezimbini*
- □ HIV/ *ntsholongwane kagawulayo*

18. Was your mother taking ARVs?
    Ingaba umama wakho wayethatha iARVs?
    - □ Yes
    - □ No
    - □ I don't know

19. Is your dad alive?
    Ingaba usaphila utata wakho?
    - □ Yes >> Go to Question 24
    - □ Yes but he doesn't live with me / *Ewe, kodwa akahlali nam* >> Go to Question 24
    - □ No
    - □ I don't know >> Go to Question 24

20. How old were you when your dad passed away? _____ years old.
    Wawuneminyaka emingaphi ukusweleka kukatata wakho?

21. Do you know what happened?
    - □ Road accident / *ingozi yendlela*
    - □ Illness / *wayegula* >> Go to Question to 22
    - □ Attacked / *wahlaselwa*
    - □ Something else >> Go to Question 21a

21a. Could you tell us? ..... / enye into Ungasixelela?

22. Could we ask you about some of the symptoms of sickness your father had before he died? Choose all the symptoms that they had - please scroll down.
    Singakubuza malunga nezinye impawu zesigulo ebenaso phambi kokuba asweleke?
    Khetha zonke impawu ebenazo - nceda wehle.
    - □ Lost weight and become very thin/ *Ingaba behla ngokomzimba wade wabhitya*
    - □ Diabetes/ *Bebeneswekile*
    - □ Asthma/ *Isifuba*
    - □ Any of these: very pale, hair changing colour, legs swelling up, burning feelings in feet, skin very dry
      Ingaba bakhe banazo ezi zinto: aphatshe, okanye kutshintshe umbala wenwele, okanye adumbe inyawo, okanye ave kutshisa inyawo, okanye ome ulusu.
    - □ Emotional problems/ *Ingaba bakhe banengxaki ngokwasemphefumlweni*
    - □ Eyes yellow, and fever, or itching/ *Ingaba amehlo abo ayethyeli, kwaye benomkhuhlane okanye ukurhawuzelela.*
    - □ Shingles or a rash on the skin/ *Ingaba babenebhanti (shingles) okanye irhashalala kulusu lwabo*
    - □ High blood pressure/ *Ingaba bebenengxaki yokunyukelwa (yihigh high)*
    - □ Sores on body/ *Ingaba babenezilonda emzimbeni*
    - □ Ulcers, white patches on mouth, or problems swallowing food/ *Ingaba bebenamaqhakuva elwimini okanye izinto ezimhlophe emlonyeni, okanye ingxaki xa beginya ukutya*
    - □ Did he drink alcohol too much/ *Babesela utywala kakhulu*
    - □ Cancer/ *Ingaba bebenesifo somhlaza*
    - □ Trouble breathing, or a cough for more than 2 days with fever/ *Ingaba bebenengxaki xa bephefumla, okanye bakhohlele ngaphezu kwentsuku ezimbini benomkhuhlane*

- □ TB in the past 5 years/ *Ingaba bebenesifo sephepha (TB) kwiminyaka emihlanu edlulileyo*
- □ Arthritis/ *Ingaba bebenesifo samathambo*
- □ Was he bewitched/ *Ingaba babethakathiwe*
- □ Diarrhoea or a runny tummy for more than 2 days/ *Ingaba bebenesifo sotyatyazo okanye isisu esihambisayo ngaphezu kwentsuku ezimbini*
- □ HIV/ *ntsholongwane kagawulayo*

23. Was your father taking ARVs?
Ingaba utata wakho ebethatha iARVs?
- □ Yes/ *Ewe*
- □ No/ *Hayi*
- □ I don't know/ *Andiyazi*

Thank you for answering these difficult questions. Would you like to draw or write something for your parents?
Enkosi ngokuphendula lemibuzo inzima. Ungathanda ukuzoba okanye ubhalele abazali bakho into?

_____

_____

_____

_____

People sometimes look to others for friendship and support.
Ngamanye amaxesha abantu baye bakhangele ubuhlobo nenkxaso kwabanye abantu.

How often do you have:
Ingaba uyifumana kangakanani inkxaso xa uyidinga?

24. Someone you can count on to listen when you need to talk.
Umntu onokumamela xa ufuna ukuthetha.
- □ Never / *Azange*
- □ Sometimes / *Ngamanye amaxesha*
- □ Always / *Rhoqo*

25. Someone to give you good advice about a crisis.
Umntu okunika ingcebiso xa usengxakini.
- □ Never / *Azange*
- □ Sometimes / *Ngamanye amaxesha*
- □ Always / *Rhoqo*

26. Someone to share your most private worries and fears with.
Umntu ongakwazi ukuba uthethe naye imfihlo nokoyika kwakho.
- □ Never / *Azange*
- □ Sometimes / *Ngamanye amaxesha*
- □ Always / *Rhoqo*

27. Someone to turn to for suggestions about how to deal with personal problems.
Umntu ongamthemba ukuba uyakwazi ukuthetha nawe nengxaki zakho.
- □ Never / *Azange*
- □ Sometimes / *Ngamanye amaxesha*
- □ Always / *Rhoqo*

28. Someone to help you if you were confined to bed.
Umntu ongakunceda xa ungakwazi ukuvuka ebhedini.

- Never / *Azange*
- Sometimes / *Ngamanye amaxesha*
- Always / *Rhoqo*

29. Someone to take you to the doctor if you needed it.
Umntu onokusa kwagqirha xa kufuneka njalo.

- Never / *Azange*
- Sometimes / *Ngamanye amaxesha*
- Always / *Rhoqo*

30. Someone to prepare your meals if you were not well.
Umntu ongakulungisela ukutya xa unokuthi ungakwazi ukuzenzela wena.

- Never / *Azange*
- Sometimes / *Ngamanye amaxesha*
- Always / *Rhoqo*

31. Who is the person that supports you the most with advice, help to solve problems or make sure you are ok when you are sick?
Ngubani umntu okuxhasa kakhulu ngeengcebiso, okusombululela iingxaki zakho, okanye oqinisekisa ukuba yonke into ilungile xa ugula?

☐ Parent or other family member / Umzali okanye elinye ilungu losapho

☐ Friends / *Abahlobo*

☐ Teachers / *ootitshala*

☐ Healthcare provider (doctor, nurse or village/ community health worker) / *Abenyango lezempilo (ugqirha, umongikazi, okanye unompilo wasekuhlaleni)*

☐ Social worker / *unontlalontle*

☐ Someone from church / umntu wasecaweni

☐ Other / omnye_____

Your relationship with your family
Buhlobo bakuyo nesapho lwakho

Please answer these questions about stuff that happens at home in the past two months – just choose the best answer.

How have things at home bee in the past two months?

Nceda uphendule le mibuzo malunga nezinto ezithe zenzeka ekhaya kwinyanga ezimbini ezidlulileyo – khetha eyona mpendulo ichanekileyo:

	Never / *Azange*	Rarely/ *Nqabile ukuba kwenzeki*	Sometimes / *Ngamanye amaxesha*	Often / *Njalo*	Always/ *Rhoqo*
32. Your parents or caregiver says you have done something well *Umzali okanye umntu okugcinayo uthi wenze into kakuhle.*					
33. Your parent or caregiver					

	Never / *Azange*	Rarely/ *Nqabile ukuba kwenzeki*	Sometimes / *Ngamanye amaxesha*	Often / *Njalo*	Always/ *Rhoqo*
compliments you when you have done something well. *Umzali okanye umntu okugcinayo uyakuncoma xa wenze into kakuhle.*					
34. Your parent or caregiver praises you for behaving well. *Umzali okanye umntu okugcinayo uyakuncoma xa uziphethe kakuhle.*					
35. Your parent or caregiver tells you that they like it when you help out around the house. *Umzali okanye umntu okugcinayo uyakuxelela ukuba uyathanda xa uncedisa ekhaya.*					
36. Your parent or caregiver rewards or gives something extra to you for behaving well. *Umzali okanye umntu okugcinayo uyakuvuza ngokuziphatha kakuhle.*					
37. Your parents or caregivers hug you or kiss you when you have done something well. *Umzali okanye umntu okugcinayo uyakwanga okanye akuphuze xa uthe wenza kakuhle.*					
38. You go out without a set time to be home. *Uyahamba ungabekelwanga xesha lokuba ubuye ekhaya.*					
39. You stay out in the evening past the time you are supposed to be at home. *Awubuyi ngexesha olibekelweyo endlini.*					
40. You fail to leave a note or let your parent or caregiver know where you are going.					

	Never / *Azange*	Rarely/ *Nqabile ukuba kwenzeki*	Sometimes / *Ngamanye amaxesha*	Often / *Njalo*	Always/ *Rhoqo*
Awumbhaleli okanye umxelele umzali okanye umntu okugcinayo ukuba uyaphi.					
41. Your parent or caregiver does not know who you are friends with. *Umzali okanye umntu okugcinayo akazazi izihlobo zakho.*					
42. You go out after dark without an adult with you. *Uhamba ebusuku kungekho mntu mdala.*					
43. Your parent or caregiver gets so busy that they forget where you are and what you are doing. *Umzali okanye umntu okugcinayo uye axakeke kakhulu de alibale nokuba uphi kwaye wenza ntoni apho ukhoyo.*					
44. You stay out later than you are supposed to and your caregiver doesn't know it. *Awubuyi ekhaya kude kutshone ilanga kwaye umntu okugcinayo engayazi.*					
45. Your parent or caregiver leaves the house and doesn't tell you where they are going. *Umzali okanye umntu okugcinayo uyahamba angakuxeleli nokuba uyaphi.*					
46. You come home from school more than an hour past the time your parent or caregiver expects you to be home. *Awubuyi ngexesha akulindele ngalo mzali okanye mntu okugcinayo ukuphuma kwesikolo.*					
47. You are at home without					

	Never / *Azange*	Rarely/ *Nqabile ukuba kwenzeki*	Sometimes / *Ngamanye amaxesha*	Often / *Njalo*	Always/ *Rhoqo*
an adult with you. *Uyahlala ekhaya engekho umntu omdala.*					

We'd like to know more about how you feel talking to your parents or caregivers. Could you tell us about how much you've shared with your caregiver in the past two months?

Singathanda ukuva ukuba uziva njani ngokuthetha nomzali okanye nomntu okugcinayo. Ungasixelela ukuba wabelene kangakanani nomzali okanye nomntu okugcinayo kwezinyanga zimbini zidlulileyo?

	Strongly disagree	Disagree	Don't know	Agree	Strongly agree
48. I have no fear in discussing problems with my parent or caregiver. *Andinaloyiko ngokuxoxa ingxaki zam nomzali okanye nomntu ondigcinayo.*					
49. I am comfortable talking about sex or medication with my parents or caregivers. *Ndikhululekile ngokuthetha ngezesondo okanye ngamayeza wam nomzali okanye nomntu ondigcinayo.*					
50. I am relaxed with my parent or caregiver, I can talk to them openly. *Ndikhululekile nomzali okanye nomntu ondigcinayo, ndithetha naye ngokuphandle.*					
51. When I talk to my parent or caregiver, I am anxious and careful about what I say. *Xa ndithetha nomzali okanye nomntu ondigcinayo, ndiyaqaphela ukuba mandithethe ntoni.*					
52. I have no fear telling my parents or caregivers exactly how I feel. *Andinaloyiko lokumxelela umzali okanye umntu ondigcinayo ukuba ndiziva njani na.*					

5.2.14 Part 13: Tell Us What You Think

Part 13: Sixelele ucinga ntoni?

Thank you for taking part in our research project.

We would appreciate it if you could take an extra few minutes to tell us your thoughts about our research. We will use your answers to improve our future work.
Enkosi ngothatha inxaxheba kwiprojethi yethu yophando. Singathanda ukuba unokuthatha imizuzu usixelela ngengcinga zakho malunga nophando lwethu. Sizakusebenzisa impendulo zakho ekuphuculeni ikusasa lethu lophando projethi.

What did you think about taking part in this research project? Choose as many answers as apply.
Ucinga ntoni ngokuthatha inxanxeba kuphando lwethu? Khetha impendulo kangangoko zifuneka.

- ☐ It felt good to be open and honest about myself.
  Kuvakale mnandi ukuziva ndikhululekile okanye ndinyanisekile malunga nam.
- ☐ It helped me to share the bad things that I've been through.
  Indincede ndabelana ngezinto ezimbi endidlule kuzo.
- ☐ It made me feel distressed (sad, upset, or angry).
  Indenze ndaziva ndingahluphekanga (ukukhathazeka, ukuhlupheka, okanye ukubanomsindo).
- ☐ This research will help others.
  Oluphando luzakunceda nabanye.
- ☐ The questions were too private/ personal.
  Lemibuzo ibifihlakele/ ibinzulu.
- ☐ I learnt stuff that I did not know before.
  Ndifunde izinto ebendingazazi ngaphambili.
- ☐ It was hard to understand the questions.
  Kubenzima ukuyiqonda lemibuzo.
- ☐ I know my answers won't be told to other people
  Ndiyazi impendulo zam azizokuxelelwa abanye abantu.

We'd like to come back and speak to you again next year. Do you have any advice or questions for us?
Singathanda ukubuya kwakhona sithethe nawe kulonyaka uzayo. Ingaba unazo naziphi ingcebiso okanye imibuzo ebhekisa kuthi?

_____

Thank you very much for your time. Please pass this questionnaire back to the Research Assistant so they can give you your certificate.
Enkosi kakhulu ngexesha lakho. Nceda udlulise imfonomfono/ itablet kumncedisi phando azokwazi ukunikeza ikhephekhephe.

Questionnaire Number _____

5.3 SCALES AND MEASURES SUMMARY

These measures reflect our literature review and consultations with an advisory panel and experts in South Africa and sub-Saharan Africa. When possible, measures already used and validated in South Africa are presented. This document includes the measures and constructs used in the Mzantsi Wakho baseline questionnaire organized in five groups: (1) outcome measures; (2) complex multi-level factors specifically related to the adolescent's HIV status; (3) individual level factors; (4) family and community level factors; (5) societal and structural factors.

OUTCOME MEASURE 1 – ADHERENCE TO ANTIRETROVIRAL TREATMENT
Adherence to medication
ART adherence was measured by adolescent self-report (Evans et al, 2015), using the standardized Patient Medication Adherence Questionnaire (Duong et al, 2001) and measures developed in Botswana (Lowenthal et al. 2014) for adolescents for past week, past 3 days and past weekend adherence. The following measures were included on adherence to ARV (giraffes)/ medication (elephants/ bears): 1. How many pills? 2. How many times a day? 3. When do you take pills: morning, day, evening? 4. Missed doses over past three days (worded as the correct number of doses each day: yesterday, day before and two days ago). 5. How many days participant took all ARVs at the right time in last week 6. Last missed dose: past week, past month, past year, never. 7. Weekend missed doses 8. Number of doses missed in the last 30 days
Reasons for non-adherence were measured using i) the Adult AIDS Clinical Trials Group Adherence Instruments: Adherence Follow-up Questionnaire and Adherence Barriers Follow-up Questionnaire (Chesney et al., 2000; Murphy, 2003) and ii) Section 2 of the Adolescent Adherence Questionnaire developed by the Pediatric AIDS Clinical Trials Group (Naar-King, 2006) which measures 21 reasons for missing medications over the past month (e.g. didn't have medication with self, fell asleep or slept through dose time, simply forgot, etc.). The scale of 24 items was adapted to HIV-positive adolescents in the South African setting, based on consultations with experts and the Teen Advisory Group (α=.60)
COMPLEX MULTI-LEVEL HIV-SPECIFIC FACTORS
Sexual and Reproductive Health
Love & relationships 1. Do you currently have a boyfriend or girlfriend? 2. Do you know their HIV status? (Answer options: yes, they are HIV+/ yes, they are HIV-/ no, I don't know) 3. Have you ever had a romantic sexual experience with someone of the same gender?
High-risk sexual behavior will be measured through a combination of questions:

Items from the PREPARE trial (Mathews, 2013) and the National survey of HIV and risk behaviour amongst young South Africans (RHRU, 2005) were used to measure sexual activity (screening item), HIV risk knowledge, self-efficacy/agency in relation to condom use, age of sexual debut, concurrent sexual partners, frequency of condom use, transactional sex, sexual activity under the influence of alcohol and under the influence of drugs. Items from this survey will also be used to measure forced sex (by verbal and physical force), pregnancy and sex with older partners. Included items were: **First sexual experience** (7 items) recorded age of first sexual experience using research from South Africa (unpublished) and a US-based study ("Dolezal_2006_Adolescent Sexual Behavior Assessment - Male Version," n.d.) for sexual practices (5 items): Kissed someone with tongue, touched private parts when wanted to, vaginal sex, oral sex, and anal sex. The type of first-time sexual experiences were measured through 1 multiple-response item based on research with adolescents in South Africa adapted through qualitative research (1 item) (Maharaj & Munthree, 2007), while contraception use was measured through a multiple-response item listing barrier contraception (male condom, female condom, IUD), non-barrier hormonal contraception (injection, pill, implant), non-barrier medical contraception (sterilization), traditional contraception (withdrawal, cyclical sex), and no contraception use by adolescent or sexual partner.
Most recent sexual experience measured two items: partner age (2 items) and condom use at last intercourse (1 item).
Sexual practices over the last year were documented through 8 items: frequency of sexual activity, number of sexual partners, frequency of condom use, contraception use, reasons for contraception use, location where adolescent obtained contraception, and transactional sex (ever and past six months). **Reasons for safe sex** were recorded through a multiple-response question, adapted from the only other study among HIV positive adolescents in Southern Africa to record these motivations quantitatively (Birungi 2009). **Transactional sex** was measured through two items, used in two other studies with HIV/AIDS affected youth in South Africa: the first asked adolescents to choose what items they have ever had sex in exchange for from a list including food, airtime, cell phones, transport, etc. Items recorded whether the participant had engaged in transactional sex ever and in the last 6-months.
HIV transmission risk Knowledge consisted of a 4 item scale (Futterman 2013, personal consultation) including knowledge of parent-to-child-transmission, risk of re-infection, whether condoms were necessary if on non-barrier contraception, and on the importance of condom use. It demonstrated internal consistency (α) of .59 for the whole sample and the 0.58 for the HIV+ individuals.
Reproductive practices, intentions and decision-making were explored through questions on parenthood ideation, desires and plans applied among HIV-positive adolescents in the US and Kenya (Fair et al., 2012; Obare et al., 2010). Additional questions on planning of pregnancy and type of birth were explored based on recent models of reproductive behavior proposed by South African demographers and studies among HIV-positive women in South Africa (Cooper, Harries, Myer, Orner, & Bracken, 2007). **Both boys and girls** were asked how many times they had been or made someone pregnant, how many children they had, and how many children they would like to have. **Adolescents girls** were asked age of last pregnancy, whether it was planned/ wanted, both or neither, the outcome of the pregnancy, type of childbirth, mode of child-feeding for the first 6 months

and whether any of their children were positive. **Adolescent boys** were asked how old they were when they last got someone pregnant, if the pregnancy was wanted/ planned, both or neither, the outcome of the pregnancy, and whether any of their children were positive. All participants were asked whether they intended to use condoms next time they had sex, using a 5-point Likert scale: definitely yes, probably yes, maybe, probably not, definitely not.

Circumcision – 1 item explored whether participants have been circumcised and whether this took place as part of a traditional initiation ceremony or at a clinic or hospital. A further question will explore the effect of circumcision camp (part of the initiation ceremony) on ability to take medication as part of the larger medication factors scale described above.

Condom use self-efficacy was measured through a 7-item scale created by combining concepts from the Condom Use Self-Efficacy Scale-Ghana (CUSES-G) and high-loading items condom self-efficacy measures used in the only longitudinal study of perinatally-infected HIV-positive adolescents in the United States, which showed high internal consistency at both times – Cronbach's alpha = 0.78 at T1 and 0.76 at T2 (Wiener, Battles, & Wood, 2007). CUSES-G was validated in a sample of Ghanean youth with high internal consistency (α=0.93) and had satisfactory construct validity using condom use at last sexual encounter (r=0.733, p<0.01) (Asante & Doku, 2010). The scale has been used among South African youth showing good internal validity (Sayles et al., 2006; Schaalma et al., 2009), but it showed poor internal consistency in our sample (α=0.56).

Experiences of and access to contraception and sexual health services was measured through 11 items: current contraception use, preferred method of contraception, location adolescents would feel most comfortable accessing contraception, types of contraception offered at the clinic, experience of first accessing contraception, experience of accessing contraception at the clinic in the last 6-months, knowledge of and experiences of contraception side-effects, a multiple-response question on how sexual and reproductive health services can be improved, whether adolescents women are given appointments for accessing contraception and consequences of missing these appointments. These items were developed in consultation with the qualitative team and adolescents participating in the questionnaire piloting.

Medication-related Factors – Individual level

General questions on medication

1. Which medications are you currently taking? (I am not taking any medicine/medicines for my chest/medicines for my diarrhea/TB medication/medicines for HIV/AIDS – antiretrovirals/medicines for my ear/I don't know what my medication is about)
2. Name of medicine (free recall)
3. Photo of medicine
4. Age started taking medication
5. Pill burden – number of pills every day
6. How many times a day do you take pills

Treatment and Health Literacy: was measured through 10 items developed based on the work of Treatment Action Campaign (TAC) and Medecins Sans Frontiers (MSF) in South Africa (Coetzee et al., 2004; Skhosana, Struthers, Gray, & McIntyre, 2006; TAC, 2012). Items explored the knowledge of participants on the following topics: (i) own treatment regime (1 item - at least one medicine name recalled), (ii) most recent CD4 count (1 item) (iii) most recent viral load (1 item) (iv) treatment adherence literacy(7 items) with a scale

adapted from the Baylor clinic adolescent support groups treatment adherence game (BIPAI, 2009).

Family and Community Level Factors (9 items) included the type of adherence support the adolescents receive. 5 items (α = .64) were added to the medication factors scale described above, to measure community level factors that might affect adherence including the use of alarms, cellphone reminders, boyfriend/girlfriend, a TV programme, or a normal activity of daily life to remind participants to take their medication, based on items from the Adolescent Adherence Questionnaire (Naar-King, 2006). 2 items measured whether participants received support from treatment adherence buddies, 2 items measured participant attendance to clinic support groups and 1 item measured home visits.

Structural/ Societal Level

Two major factors related to medication were explored (10 items): (i) type of regime: first line, second line, PMTCT; (ii) access/ supply to medication. Type of ARV regime will be verified through visual confirmation of medicine, while access/supply to ARVs will be assessed through a tool adapted from TAC's Road to Good Adherence on participants' experiences of obtaining ARVs: time, frequency, location, type of provider and frequency of stock-outs (TAC, 2011).

Disclosure

Disclosure is a complex factor that is fluid across age-groups, ranging from non-disclosure, partial disclosure, disclosure through 3rd parties, future plans to disclosure and full disclosure (Greene & Faulkner, 2002). However, quantitative research to date explores disclosure among HIV-positive adolescents as a simple dichotomous outcome. The following disclosure measurements are the first of its kind among HIV-positive adolescents.

Adolescent **knowledge of HIV-status** was assessed in steps: first through healthcare worker report, then with primary caregivers during the consent process. Discrepancies between healthcare worker and caregiver reports requited that interviewers check whether adolescents understood their status while obtaining consent, to prevent recent disclosure. Adolescents were screened on their recent history of illness and medication-taking. Those who did not know their status were asked about "illness" and "medication" instead of "HIV" and "ART" respectively.

Disclosure TO adolescents was explored through a series of questions;

1. How you learnt about your HIV status (options – guessed myself, told at clinic by family, told at home by family, told at clinic by family, overheard people talking, never guessed)
2. What age you first suspected you were HIV-positive?
3. What age someone told you were HIV positive
4. Did you ever take pills without knowing what they are for?
5. How did you feel when you learnt about your status?

Disclosure BY adolescents was measured to tease out the complex patterns of sharing information about HIV status and medication-taking across different types of relationships. Based on previous research among HIV-positive adolescents, the types of relationships explored included: 1-caregiver, 2-rest of family, 3-best friend, 4-boyfriend/ girlfriend, 6-church, 7-teachers and school principal, where they live (Lam, Naar-King, & Wright, 2007; Michaud et al., 2009; Peele, D'Angelo, Chandwani, Abramowitz, & Koenig, 2012). Levels of disclosure were conceptualized as incremental based on qualitative literature and piloting

with HIV-positive youth in the Eastern Cape. For each of these relationships, disclosure was therefore explored on a scale as follows (0=They don't know anything about my health, illness or medication, 1=They suspect something/ know from another sources, 2=They know I am sick but they don't know what I have, 3=They know I am taking medication, but not what medication, 4=They know about my HIV-positive status, 5=I talk to them about my HIV-positive status, 6=They know what medicines I am taking (ARVs), or 7=I talk to them about my struggles with taking medicines).

Stigma

Primary stigma among HIV-positive adolescents was measured through the 10-item ALHIV-SS measuring internalized (5 items), anticipated (2 items) and enacted HIV stigma (3 items). The scale was cross-culturally adapted from a stigma scale previously used with HIV-positive adolescents in the US (Wright, Naar-King, Lam, Templin, & Frey, 2007). We adapted the scale through cognitive interviews with 9 South African adolescents and validated it within the present study, using the baseline sub-sample of HIV-positive adolescents who were aware of their status (n=721). ALHIV-SS demonstrated good psychometric properties, with internal consistency (α) of .70, .57 and .75 for anticipated, enacted and internalized stigma respectively. (Pantelic et al., under preparation).

Secondary stigma due to HIV in the family or household was measured through the Stigma-By-Association (SBA) scale. SBA was used in our two previous studies with HIV/AIDS-affected youth in South Africa. The scale has been validated for use in South Africa (Mark E. Boyes, Mason, & Cluver, 2012) and demonstrated good reliability (6 items). In this population it demonstrated reliability of .60 for HIV+ individuals and 0.63 across the whole sample.

INDIVIDUAL-LEVEL RISK AND PROTECTIVE FACTORS

Mental health

Depressive symptoms: The Child Depression Inventory (short form) (Kovacs, 1992) (10 items). This form was used in our previous studies examining AIDS-affected children in South Africa with good acceptability. The CDI is a widely-used and well-validated measure with strong psychometric properties, and has been used in multiple other South African populations (Suliman, 2002). Here it demonstrated reliability of .64 among the HIV+ individuals and .68 across the whole sample.

Anxiety symptoms: Children's Manifest Anxiety Scale – Revised (Reynolds & Richmond, 1978).The RCMAS is a widely-used scale that has been standardized in US populations, shows good internal consistency and test-retest reliability (Gerard & Reynolds, 1999; Reynolds & Richmond, 1978). An abrevieated version with 14 items has been validated with good internal consistency in our previous South African studies of AIDS-affected children (M. Boyes & Cluver, 2012). In this sample α=0.80 for both the entire sample and HIV+ individuals.

Post-traumatic stress symptoms:

The Child PTSD Checklist (Amaya-Jackson, McCarthy, Newman & Cherney, 1995) has been widely used in Black African youth in South Africa (Seedat, Nyamai, Njenga, Vythilingum, & Stein, 2004; Seedat, Van Nood, Vythilingum, Stein, & Kamlner, 2000). The checklist was restructured using the new DSM-V criteria and factor analysis from previous studies of familial AIDS, in which it was validated and demonstrated excellent validity (M. E. Boyes, Cluver, Gardner, & Seedat, 2012). The included scale was formed of 19 items with α of 0.90 and 0.89 for the full sample and HIV+ individuals respectively.

Suicidality/self-harm:

Mini International Psychiatric Interview for Children and Adolescents Suicidality and self-harm subscale (D. Sheehan, Shytle, & Milo, 2004) (5 items). The MINI-Kid has been extensively validated in developed world populations, and shows strong internal consistency and test-retest reliability (Lecrubier et al., 1997; D. V. Sheehan et al., 1997). In this population α = .87 and .88 for the full sample and HIV+ individuals respectively

Neurocognitive development and learning capacity

Neurocognitive development and learning capacity was measured through a memory sub-test derived from the WISC-IV and WAIS-III tools (Wechsler, 2004) which have been validated among Xhosa speakers (Van der Merwe 2008): *Immediate and delayed recall* of 5 words was tested.

Hyperactivity was measured using a subscale (5 items, α= 0.53 for all, =0.54 for HIV+) from a version of the Strength and Difficulties Questionnaire adapted and validated in the Xhosa language (Goodman 2004).

Physical health

Physical health was measured through a combination of tools. First, 1 item on self-reported health over the past month and a 2 item scale on physical disability (α = .57 for all, .60 for HIV+) adapted from The International Classification of Functioning, Disability and Health (ICF) (WHO, 2001).

Severity of health issues was assessed using 25 items based on the Verbal Autopsy questionnaire (Lopman et al., 2006) adapted into a verbal symptomology checklist in consultation with HIV-positive youth, clinicians and our qualitative team. The revised 25-item verbal symptomology scale included 8 items on TB symptoms, 17 items linked to AIDS-related opportunistic infections and antiretroviral treatment side-effects, and 4 items on STI symptoms.

The TB symptomology items were adapted from the South African Demographic and Health Survey (2003) (Department of Health Medical Research Council OrcMacro, 2007) the World Health Organization Stop Tuberculosis Team, and the Kwa-Zulu Natal Department of Health TB symptom guidelines, to assess symptoms of active pulmonary TB.

The symptoms checklist was adapted to include questions on other long-term illness, including epilepsy and asthma (2 items). Further items were added to detect whether participants were STI symptomatic (4 items: burning whilst urinating, genital itching/ redness, anal itching/ soreness/ bleeding) in the last 6 months, following WHO guidelines for symptomatic diagnosis of STIs (WHO, 2004).

My Future!

3 items were measured to explore attitudes toward the future, focusing on goals to finish high-school, plans for the future and future opportunities. The scale demonstrated good reliability with α= .84 and =.82 among the whole and HIV+ sample respectively.

Self Efficacy

Perceived self-efficacy was measured using 4 items based on questions from the internationally validated General Self-Efficacy Scale (Schwarzer & Jerusalem,1995), α = .81 and .82 for entire and HIV+ sample respectively

Risk taking behavioUr and conduct problems

Behaviour problems and peer relationships

To measure child behaviour and child relationships, measures were combined from the Child Behaviour Checklist (CBCL) (Achenbach 1992, Achenbach, 2000) and the Strengths and Difficulties Questionnaire (SDQ) (Goodman,2004). Rule-breaking was measured with a 10 item subscale from CBCL. The CBCL-YSR has been normed on a mixed-ethnicity US population, and was used in the Family Health Project study of orphan well-being in the USA (Forehand et al., 2002) and in South Africa (Barbarin, Richter, & DeWet, 2001) as well as in our two studies among HIV/AIDS-affected youth in South Africa. The CBCL-YSR is commonly used as a 'gold standard' measure of child behaviour. A small adaptation is necessary - replacing the item 'I set fires' (included in the CBCL as a sign of destructive tendencies but commonly a task undertaken by children in South Africa in order to cook). 5 items from the conduct problems and pro-social subscales of SDQ were added. Two devised items on carrying of weapons are also added – these were adapted from the National Primary Schools Violence Survey (Burton, 2008), to include carrying of weapons both inside and outside school (2 items). A final 2 items were developed to measure gang membership and gambling.

Alcohol and substance use:

Screening for **hazardous alcohol use** (1 item) was based on an item adapted from the Alcohol Use Disorders Identification Test (AUDIT), a 10-item, self-rating questionnaire that assesses hazardous drinking. The AUDIT was developed and validated by the World Health Organisation for international use and has been validated for a variety of community and primary health care settings (Cohen et al., 2011; Jaspan, Mueller, Myer, Bekker, & Orrell, 2011). The scale showed very high sensitivity and specificity among HIV-positive people in South Africa (Myer et al., 2008).

Demographic information

Child age, gender, nationality and basic demographic information was asked using items from the South African Census (2001) (SSA, 2001). 1 item measured migration (number of towns lived in).

Community involvement and Migration

Community involvement was measured with 1 item asking participants to indicate all community groups that they are involved with and 1 item asked for frequency of nightclub/ tavern/ shebeen use.

Body Image

Six items were used to measure body image-related issues among participants'. They evaluated thoughts and beliefs about their physical appearance in the last year. The items were developed using concepts derived from qualitative research which included three general items: "I look as good as others my age," "I like how my skin looks," and "Other young people think I am sexy/ attractive," and three HIV-specific items: "My body is small for my age.' [stunting], "I would like to put on weight" [weight loss], and "Some of my body parts have changed since I started taking ARVs/ medicine" [lipodystrophy].

FAMILY and COMMUNITY-LEVEL FACTORS

Caregiver Status

Existence of primary caregiver, and relationship the adolescents to primary caregiver, was identified using items from the National survey of HIV and risk behaviour amongst young South Africans (RHRU 2005). Primary caregiver was identified as the person who 'stays with you and takes care of you at home'. Relationships of caregiver to children was categorized as the following: biological parent, grandparent, other extended family member

(aunts, uncles, cousins, adult siblings etc), non-family member (social worker/ careworker, foster carer), living in a child-headed or youth-headed households. (5 items)

Education and School Experiences

Education items were developed with the South African Department of Education. Some items from the 'Young Lives' study (Boyden & Dercon, 2008) were used to determine some education outcomes, others were identified by the National Action Committee for Children Affected by AIDS (NACCA) and NGOs. Items include: age of school enrolment, current grade, repetition of grades and reasons for repetition, failure of grades and reasons for failure, school dropout and reasons, number of different schools attended, ability to pay school fees, free schools, and access to school fees exemption. An item documented access to school feeding by asking which meals participants received for free at school (breakfast, lunch, other or combination). Six items on school experience were developed by adapting a scale of the PREPARE trial (Mathews, 2013) and items from qualitative research in the Young Carers study including experience of school violence, safety, and positive expectations of schooling.

Parental and caregiver morbidity and mortality

Caregivier morbidity was assessed using an adapted version of the verbal autopsy questionnaire (Lopman et al., 2006) (18 items), as used in our previous studies. Further questions measured general health and knowledge of caregiver ARV use (3 items).

Where children identified parental death, cause of death was recorded, a verbal autopsy questionnaire completed and any ARV use prior to death noted. These items were developed as port of a South African national survey of AIDS-affected children (Cluver et al., 2013). 22 items for each caregiver.

Bullying

Bullying was measured with the 9-item, standardised 'Social and Health Assessment Peer Victimization Scale' (Ruchkin, Schwab-Stone, & Vermeiren, 2004), used in research with vulnerable children in Cape Town (Ward, Martin, Theron, & Distiller, 2007) and in our previous studies of AIDS-affected children. This scale was adapted from the Multidimensional Peer Victimization Scale, which was validated in the US (Mynard & Joseph, 2000). Items include; being called names, being hit or threatened and having possessions broken or stolen. This measure generates a total global score of exposure to bullying. It demonstrated good internal consistency (α) of .81 for the entire sample and .79 for the HIV+ sample.

Peer norms

Peer norms were measured through 4 items adapted from a study of adolescents living with HIV in the United States (Bauermeister, Elkington, Brackis-Cott, Dolezal, & Mellins, 2009). The scale assesses how many peers within participants' social networks perceived being-sexually active makes someone "cool" or "popular". Items were derived from two sub-scales: norms about expected sexual activity of peers (2 item) and perceived peer sexual behaviour (2 items), adapted to the South African context. One of the items on expected sexual activity of peers: "How many of your friends think that using condoms is like eating sweets in their wrapper?," while one of the items on perceived peer sexual behaviour was "Do you have friends who have had sex because they were drunk or high on drugs?" (α= .73 for all, .76 for HIV+)

Parenting and Home Environment

Positive parenting (6 items, α=.89 for all, .90 for HIV+) – including items on praise, positive reinforcement and support from caregiver and *good parental supervision* (10 items, α=.92 for all, .93 for HIV+))– including monitoring of adolescent social activities and home rule setting – were measured using the positive parenting and parental supervision sub-scales of the Alabama Parenting Questionnaire (Elgar, Waschbusch,Dadds & Sigvaldason, 2007).

5 items form the Child- Parent Communcation Apprehension Scale for use with Young adults (Lucchetti, Powers, & Love, 2002) were adapted to measure communication between adolescents and their caregiver. The revised scale showed strong reliability in the full sample (α=.93), but poor reliability among the HIV+ sub-sample (α=.45).

Negative family processes and child trauma

Exposure to family conflict and domestic violence was measured using items from the UNICEF Measures for National-level Monitoring of Orphans and Other Vulnerable Children (2 items) (Snider & Dawes, 2006).

Physical abuse (2 items) and emotional abuse (10 items) were measured using items from the UNICEF Measures for National-level Monitoring of Orphans and Other Vulnerable Children (Snider & Dawes, 2006) which have been successfully used previously in two other studies of HIV/AIDS affected adolescents in South Africa (Meinck, Cluver, Boyes, & Loening-Voysey, 2016; Meinck, Cluver, Boyes, & Ndhlovu, 2015). Exposure to sexual abuse was measured using three items from the Juvenile Victimization Questionnaire (JVQ) (Finkelhor, Hamby, Ormrod, & Turner, 2005)and used in our previous studies in South Africa. Access to help and reactions to disclosure of abuse were measured using three items from the ISPCAN International Child Abuse Screening Tool (Zolotor et al., 2009).

Community-level trauma was measured using 4 items from the Child Exposure to Community Violence (CECV) Checklist (Martinez & Richters, 1993), adapted to reflect commonest community traumas in South Africa, as identified by national police statistics (SAPS, 2005).

Structural/ Societal Hypothesised Risk and Protective Factors

Experiences with Health Care Services

Health care utilization (9 items) was measured through Items from the REACH study – a 4-province study of health care utilization amongst HIV+ people. Additional open items included reporting of reasons for non-access to healthcare (including affordability of transport, time spent travelling, whether adolescent accessed healthcare alone or accompanied, if they had to miss school, and mode of transport). We also recorded the **type of clinic** where adolescents are accessing their antiretroviral treatment: primary care, adolescent-specific services, pediatric care, adult care.

Interactions with Healthcare Providers (12 items) were explored and piloted with our TAG team using items from the PREPARE trial and qualitative research among HIV-positive adolescents in Sub-Saharan Africa, including : communication style, perceived stigma, information on treatment, health services and products offered (family planning, HIV/ STI testing and counselling) (Busza, 2011; Obare, van der Kwaak, & Birungi, 2012).

Household poverty

Poverty was measured using a range of tools. Items from the South African Census (SSA 2001) will determine whether children live in formal, informal (i.e. shacks) or traditional structures. Food insecurity will be measured using 2 items from the South African National Food Consumption Survey (1999) (Labadarios et al., 2003). Poverty will also be measured by measuring access to the top 8 socially-perceived necessities for children, as identified

by the Centre for South African Social Policy in the 'Indicators of poverty and social exclusion project' (Wright, 2008), and endorsed by over 80% of the South African population in a nationally-representative survey (the South African Social Attitudes Survey 2006) (Pillay, Roberts, & Rule, 2007). These include items such as 'enough clothes to keep you warm and dry' and '3 meals a day'. 8 items α=.27 for all, .72 for HIV+). Household employment will be measured as number of people cohabiting with the child who are employed (part-time or full-time).
Social Support
Social support was measured using a 9 items from the Medical Outcome Study (MOS) Social Support Survey (Sherbourne & Stewart, 1991), with a mixture of 3 items from the material support subscale and 4 from the psychological support subscale. This scale has been widely used in the developing world, including in South Africa (Casale 2015) 1 item was added to measure the relationship of the person from whom the child receives the most support. The scale demonstrated good reliability of α=.86 for the whole sample and 0.85 for the HIV+ sample.
Support from state and NGOs
Receipt within the household of the major forms of *social security transfers* (Child Support Grant, Foster Care Grant, Pension, Disability Grant and Care Dependency Grant) were measured. 5 items asked if the participants receive foster care, child support, pensions, disability and care dependency grants. 1 item measured if participants receive food parcels or free meals and 1 item measured the receipt of any home-based care. Items described above in the education section will determine whether their school is a no-fees school or whether they have fees exemption and whether their school provides food.
Traditional practices and forms of support
Items in the healthcare utilization section will determine utilization of non-biomedical care: traditional healers, faith healers, etc.. Social support and family contact with traditional healers is measured with four devised items. It has been determined that the subtlety and complexity of the support given to adolescents in long-term medication by traditional practices will be difficult to capture in a quantitative study, and so the qualitative component of the study will be undertaken to examine this in more detail.
Feedback on questionnaire
Two items on adolescent experiences of participating in the research were included at the end of the questionnaire. Results were used to inform the follow-up questionnaire.

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5.4 REFLECTION FORM

RA Name _____ Participant Name _____
Interview date _____ Date of completing _____

Location and Interview Process:

1. How did you **FIRST** contact the participant? (CHECK ONLY ONE BOX):
   □ ***Clinic*** □ ***Home-visit*** □ ***Phone-call*** □ ***Other:***
   _____

Notes:
_____

2. Where did you do the interview?
   _____
   _____

3. If you did the interview at the participant's home, please answer the following:
   a. How did you get there (walked, taxi, drove, how long did it take, etc.?)

   b. Please write any helpful directions that will help us find the home again next year.

_____
_____

4. Who else was present during the interview – family member, friends or partner?
   _____
   _____

5. How much were the other people involved? (Overheard answers, participated, commented on questions or answers, they talked to a second RA)

_____
_____

6. Was the interview interrupted by anything? □ Yes □ No

If yes, please explain what happened:

_____
_____

7. How much support did you provide to the participant?
   □ None, the participant used the tablet her/himself (they read and answered themselves)
   □ I read out all the questions but the participant used device
   □ I read out all of the questions AND put in the answers given by the participant
   □ Other
   _____
   _____

8. Did the participant have any difficulty answering the questions? (e.g. distracted, difficulty hearing or concentrating, not taking interview seriously)

_____
_____
_____

   a. Anything else that may affect the answers given:
   _____
   _____

9. Overall interview – please write a brief summary. Please include if participant was a neighbour, an Elephant that didn't take ART, an Elephant that turned into Giraffe during interview, etc.

_____
_____
_____

IF PARTICIPANT WAS AN ELEPHANT, did they:

- Know they were HIV-positive (giraffe)----□ Yes □ No
- Know they took ARVs ----------□ Yes □ No
- Know ARVS are for HIV----------□ Yes □ No

Caregiver Conversation:

1. Did anyone speak with a caregiver or family member *during the interview*? □ Yes □ No

a. Who spoke with the family member? (RA name)

_____

b. Who did s/he speak with? (Family member name and relationship)

_____
_____
_____

c. Please write a brief summary of points discussed **WITH THE CAREGIVER:**

_____
_____
_____
_____

Referrals:

1. Did the teen tell you anything that concerned you or requires follow up?

Data Inconsistency:

Did the participant tell you different things at different times? Or did the participant and the parent say conflicting things? Please describe what was said and how you know that there was a conflict? (e.g. About school, family, sex, condom use, medication, or anything else)

_____
_____
_____
_____

6. CLINIC-BASED DATA COLLECTION

6.1 CLINIC MAPPING TOOL

***NOTE: *This data will be collected during 20-25 minute conversations with the clinic manager. The introduction to the clinic will be informal (but we will have an ethics letter if they require it) saying that we are trying to have a better understanding of their experiences with HIV-positive adolescents. This is not an evaluation but a chat to better understand what the overall status of HIV-positive adolescents in care is and the particular experiences of clinics. The following items will be expanded upon in later visits for the selected PARTNER CLINICS.*

INTRODUCTION: We know that they are having a difficult time with adolescents on ARVs, maybe they struggle to adhere to their medicines, maybe you have stock outs, or high rates of lost-to-follow-up. We would like to understand better the issues that you face so we have designed a study. The team from the Universities of Oxford and Cape Town have coordinated with DOH, DSD and DBE, UNICEF and other partners who will want to hear the experiences that you have. This information will be kept confidential and if we share it with partners, we will use codes such as *Urban Clinic, Buffalo City District*.

Clinic Information – completed by team prior or post visit

1. Clinic Name: _____	2. District: _____
3. Contact Name: _____	4. Sub-district: _____
5. Clinic phone number _____	6. Contact person phone number _____
7. Email address:	8. Directions to finding the clinic: _____ _____
9. Type: □ Pediatric clinic (if Yes, at which age do teens ACTUALLY transition to adults? _____) □ General clinic □ Ante natal care clinic □ ARV clinic (pediatric and adult) □ Other _____	10. Partner/ Support organization: □ IYDSA support □ Keth'impilo support □ PATA clinic □ Keiskamma clinic □ SPF clinic □ South to South Clinic □ Other _____

Clinic Size & Practices (data available)

11. Number of patients on ARVs (overall) _____
12. Adolescents on ARVs (10-19 years old) _____
    If ANC clinic, how many adolescents are on lifelong ART (10-19 years old)

    _____
13. Children (<10 years old) on ARV _____
14. What is your adolescent retention rate (who continue to attend clinic appointments)

    _____
15. Do you do pill counts? □ Yes □ No
16. How frequently do adolescent patients get refills?
    □ Monthly □ every two months □ other:

    _____
17. How often are adolescent patients expected to come for clinic visits?

    _____

□ Monthly □ every two months □ other:
_____

18. Do you have a specific time when adolescents can come for appointments?
□ No, they can come any time □ Yes, they come on
_____

We have heard that many clinics have had issues with getting viral load tests done through the national laboratory. What about your clinic?

19. Do you conduct viral loads? □ Yes □ No
20. Do you do CD4 counts? □ Yes □ No
21. What is the proportion/ percent/ rate of adolescents on second line treatment?
_____
22. What is the proportion/ percent/ rate of adolescents 10-19 years old know their status?
_____

Human Resources

23. Number of staff
□ Total: _____
□ Doctors _____
□ Nurses _____ □ Assistant Nurses _____
□ Lay Counsellors _____ □ Community Health Workers _____
□ Expert Patients/ PLHIV _____ □ Peer educators _____

24. Do you have a person dedicated to managing patient files/ data clerk? □ Yes □ No
If yes, please add details (# people, full-time)
_____
25. Do you have a pharmacist? □ Yes □ No
If yes, please add details (# people, full-time)
_____

Services Offered at the clinic/ hospital

What are the services that you offer at your clinic *for adolescents*?

26. ART initiation □ Yes, at clinic □ Yes, they refer □ No
27. VCT □ Yes, at clinic □ Yes, they refer □ No
28. FP/ contraception □ Yes, at clinic □ Yes, they refer □ No
29. ANC services □ Yes, at clinic □ Yes, they refer □ No
30. TB services □ Yes, at clinic □ Yes, they refer □ No
31. Nutritional support □ Yes, at clinic □ Yes, they refer □ No
32. Transition support for adolescent patients
□ Yes, at clinic □ Yes, they refer □ No
33. Adolescent support group □ Yes, at clinic □ Yes, they refer □ No
34. Support group (all ages) □ Yes, at clinic □ Yes, they refer □ No
35. Termination of pregnancy □ Yes, at clinic □ Yes, they refer □ No
36. Outreach for Lost-to-follow-up □ Yes, at clinic □ Yes, they refer □ No

CLOSING UP: Introduce the study in more detail and ask if they would be interested in taking part. □ Yes □ No

Is the clinic taking part in any other research projects? □ Yes □ No
If yes, what is the research project on? _____

If yes, ask what the process of getting approval is. Thank them for their time.
Notes from visit:
_____

6.2 LIST OF PARTICIPATING FACILITIES

6.2.1 Clinics selected for inclusion in the study following 2013 clinic mapping

Clinic name	*Facility Type*	*Estimated number of adolescents on antiretroviral treatment*	*Location*
1. Frere Hospital	Paediatric clinic, ANC clinic, ARV unit	363	Urban
2. Cecilia Makiwane Hospital		456	Peri-urban
3. Bhisho Hospital - ARV clinic	ARV clinic	20	Urban
4. Grey Hospital	ARV clinic	39	Urban
5. Tshatshu Clinic	Primary clinic	30	Rural
6. Berlin	Primary clinic	20	Rural
7. NU17	Primary clinic	20	Peri-urban
8. Duncan Village Day Hospital	Paediatric clinic, ANC clinic, ARV unit	20	Peri-urban
9. Dimbaza Community Health Care Clinic	ARV clinic	21	Peri-urban
10. NU13 - Siyaphilisa	Primary clinic	21	Peri-urban
11. Zwelitsha Zone 5	Primary clinic	34	Peri-urban
12. Empilweni Gompo	ARV clinic, Paediatric clinic,	60	Peri-urban
13. Grey Gateway Clinic	Primary clinic	17	Peri-urban
14. Bhisho Hospital – ANC clinic	ANC clinic	15	Peri-urban
15. Needs Camp Clinic	Primary clinic	12	Peri-urban
16. Nonkcampa	Primary clinic	10	Peri-urban
17. Zwelitsha Zone 8	Primary clinic	10	Rural
18. Central Clinic	Primary clinic	11	Rural
19. Qurhu Clinic	Primary clinic	12	Rural
20. Ilitha Clinic	Primary clinic	15	Rural
21. NU2 – Nontyatyambo	ARV clinic, ANC clinic	18	Urban
22. NU8 (Nobuhle)	Primary clinic	15	Urban
23. Ncera	Primary clinic	5	Rural
24. Zikhova	Primary clinic	7	Rural
25. Mt. Coke CHC	ARV clinic, Paediatric clinic	9	Rural
26. NU9 - Luyolo	Primary clinic	9	Peri-urban
27. NU12 - Eluxolweni	Primary clinic	7	Peri-urban
28. Rabula Clinic	Primary clinic	7	Peri-urban
29. Imidange Clinic	Primary clinic	6	Peri-urban
30. John Dube Clinic	Primary clinic	6	Peri-urban
31. Frankfort Clinic	Primary clinic	5	Peri-urban
32. Sweetwaters	Primary clinic	5	Peri-urban

6.2.2 Final list of facilities which participated in the study

Clinic name	*Facility Type*	*Location*
1. Beacon Bay clinic	Primary clinic	Urban
2. Berlin clinic	Primary clinic	Rural
3. Bhisho Gateway clinic	Primary clinic	Urban
4. Bhisho Hospital – ANC clinic	ANC clinic	Peri-urban
5. Bhisho Hospital – ARV clinic	Hospital	Urban
6. Braelyn Clinic	Primary clinic	Peri-urban
7. Breidbach Clinic	Primary clinic	Peri-urban
8. Bulembu clinic	Primary clinic	Rural
9. Cata Clinic	Primary clinic	Peri-urban
10. Cecilia Makiwane Hospital – ANC Clinic	Hospital	Peri-urban
11. Cecilia Makiwane Hospital – ARV Clinic	Hospital	Peri-urban
12. Cecilia Makiwane Hospital – Paediatric Clinic	Hospital	Peri-urban
13. Central Clinic	Primary clinic	Rural
14. Dimbaza Community Health Care Clinic	Community Healthcare Centre	Peri-urban
15. Duncan Village Day Hospital	Community Healthcare Centre	Peri-urban
16. Empilweni Gompo	Community Healthcare Centre	Peri-urban
17. Ethembeni clinic	Primary clinic	Rural
18. Frankfort Clinic	Primary clinic	Peri-urban
19. Frere Gateway clinic	Primary clinic	Urban
20. Frere Hospital – ANC clinic	Hospital	Urban
21. Frere Hospital – ARV unit	Hospital	Urban
22. Frere Hospital – Paediatric clinic	Hospital	Urban
23. Ginsberg clinic	Primary clinic	Peri-urban
24. Grey Gateway Clinic	Primary clinic	Peri-urban
25. Grey Hospital – ARV clinic	Hospital	Urban
26. Ilitha Clinic	Primary clinic	Rural
27. Imidange clinic	Primary clinic	Peri-urban
28. John Dube Clinic	Primary clinic	Peri-urban
29. Mt. Coke CHC	Community Healthcare Centre	Rural
30. Ncerha clinic	Primary clinic	Rural
31. Ndevana clinic	Primary clinic	Rural
32. Needs Camp clinic	Primary clinic	Peri-urban
33. Nonkcampa	Primary clinic	Rural
34. NU12 - Eluxolweni	Primary clinic	Peri-urban
35. NU13 - Siyaphilisa	Primary clinic	Peri-urban
36. NU17 clinic	Primary clinic	Peri-urban
37. NU2 – Nontyatyambo CHC	Community Healthcare Centre	Urban
38. NU3 clinic	Primary clinic	Peri-urban
39. NU5 clinic	Primary clinic	Peri-urban
40. NU7 clinic	Primary clinic	Peri-urban
41. NU8 (Nobuhle)	Primary clinic	Urban
42. NU8 clinic	Primary clinic	Peri-urban

Clinic name	*Facility Type*	*Location*
43. NU9 - Luyolo	Primary clinic	Peri-urban
44. Philani clinic	Primary clinic	Peri-urban
45. Qurhu Clinic	Primary clinic	Rural
46. Sweetwaters	Primary clinic	Peri-urban
47. Tshatshu Clinic	Primary clinic	Rural
48. Tyutyu clinic	Primary clinic	Peri-urban
49. Tyutyu village clinic	Primary clinic	Rural
50. Zanempilo clinic	Primary clinic	Rural
51. Zikhova	Primary clinic	Rural
52. Zwelitsha Zone 5	Primary clinic	Peri-urban
53. Zwelitsha Zone 8	Primary clinic	Rural

6.3 PATIENT FILE DATA EXTRACTION FORM

Current Clinic: _____
Person extracting data from files: _____
Serial Number – (*This is the ID# in the roster*). _____

Was a patient file found for this patient? *If there was no patient file found for this patient, you have completed the Patient File Data Extraction Form for this participant.* ***But please ensure you offer the data capturer or nurse to help look for the file.***

- □ Yes
- □ No

You may have found more than one patient file for this patient. ***Please use the most recent file you have found.*** *Note all of the following information. Please do not write the participant's name, address, or phone number on this form.*

Patient File Number – *If there is no patient file number please write 666. Write 999 when you cannot read the answer, such as when the question is in the folder, the answer is there, but not legible.*

_____

When was this patient file opened? *Remember: You should be recording this for the most recent patient file you have found. Write 666 if the question is blank. Write 999 when you cannot read the answer, such as when the question is in the folder, the answer is there, but not legible.*

_____

HIV DIAGNOSIS and ART INITIATION

Year HIV diagnosed – *Year that participant got diagnosed with HIV. Year of their FIRST HIV-positive test. If the question is blank, write 666. Write 999 when you cannot read the answer, such as when the question is in the folder, the answer is there, but not legible.*

_____

ART start date – *The first date when they started taking antiretroviral (ART) in THIS clinic. If there is no date written in page 1 of the patient files, please write the date of the first visit they picked up antiretroviral (ART).*

_____

Pre-ART experience – Antiretroviral (ART, HAART, PMTCT, sdNVP, dual RX pMTCT, PEP) use before the above date? *Did the participant take antiretrovirals before starting this round of treatment?*

- □ Yes
- □ No
- □ Answer missing (left blank)
- □ Question not in file

FIRST VISIT RECORDS

Please find the following information about the first visit from the patient file. It might be in more than one place in the file. If there is no section in the patient file about the first visit, please write information from the first row in the visit/ observation list.

Date of First Visit – *Please write the date of the first visit recorded in THIS clinic.*

_____

WHO stage at first visit – *Please write a number 1-4 when the patient file is complete. Write 333 when question is not applicable, when the question is NOT in the folder at all. Write 666 when data is missing, so when the question is in the folder, but there is no data available. Write 999 when you don't know the answer, such as when the question is in the folder, the answer is there, but not legible.*

_____

CD4 count at first visit – *Check the value in the laboratory report when possible. Please offer the nurse or the data capturer to update this information from laboratory reports to the patient files. Also offer to search for the laboratory reports yourself. Write 333 when question is not applicable, when the question is NOT in the folder at all. Write 666 when data is missing, so when the question is in the folder, but there is no data available. Write 999 when you don't know the answer, such as when the question is in the folder, the answer is there, but it is not legible. If the CD4 count is 333, 666 or 999, please add 1, so write 334, 667, or 1,000.*

_____

Viral load at first visit- Write 888 if the viral load was non-detectable (LDL) – *Check the value in the laboratory report when possible. Please offer the nurse or the data capturer to update this information from laboratory reports to the patient files. Also offer to search for the laboratory reports yourself. Write 333 when question is not applicable, for example, when the question is NOT in the folder at all. Write 666 when data is missing, so when the question is in the folder, but there no data available. Write 999 when you don't know the answer, such as when the question is in the folder, answer there, but not legible. If the viral load is 333, 666 or 999, please add 1, so write 334, 667, or 1,000.*

_____

MOST RECENT INFORMATION

Date of the most recent CD4 count in the patient file – *Please write the date of the most recent CD4 count **IN** the patient file. If there is a laboratory report **IN** the patient file, please use that. If there is a laboratory report outside of the patient file do **NOT** record it yet (the tablet will ask for this later).*

_____

Most recent CD4 count – *Please write the most recent CD4 count **IN** the patient file. If there is a laboratory report **IN** the patient file, you may use that. If there is a laboratory report outside of the patient file do **NOT** record it yet (the tablet will ask for this later). Write 333 when question is not applicable, when the question is NOT in the folder at all. Write 666 when data is missing, so when the question is in the folder, but there is no data available. Write 999 when you don't know the answer, such as when the question is in the folder, the answer is there, but it is not legible. If the CD4 count is 333, 666 or 999, please add 1, so write 334, 667, or 1,000.*

_____

Date of the most recent Viral Load in the patient file – *Please write the date of the most recent viral load found **IN** the patient file. If there is a laboratory report **IN** the patient file, you*

*may use that. If there is a laboratory report outside of the patient file do **NOT** record it yet (the tablet will ask for this later).*

_____

Most recent Viral Load in the patient file – *Please write the most recent Viral Load found **IN** the patient file. If there is a laboratory report **IN** the patient file, you may use that. If the viral load is non-detectable (LDL) write 888. Write 333 when question is not applicable, for example, when the question is NOT in the folder at all. Write 666 when data is missing, so when the question is in the folder, but there no data available. Write 999 when you don't know the answer, such as when the question is in the folder, answer there, but not legible. If the viral load is 333, 666, 888 or 999, please add 1, so write 334, 667, 889, or 1,000.*

_____

Current ART medication – medication names – *Please choose the names of the medications included in the treatment regimen that the patient is currently taking.*

- □ FDC(TDF&FTC&EFV)
- □ 3TC – lamivudine
- □ TDF – tenofovir
- □ AZT or ZDV – azythromycin or zidovudine
- □ ABC – abacavir
- □ FTC – emtricitabine
- □ d4T – stavudine
- □ EFV – efavirenz
- □ NVP – nevirapine
- □ LPV/r – lopinavir & ritonavir/aluvia
- □ RTV – ritonavir
- □ ddl – didanosine
- □ other: _____ *(please write the name of the medication if it is not listed)*

Ever had TB before?

- □ Yes
- □ No
- □ Answer missing (left blank)
- □ Question Not in File

Has preventive TB treatment been reported? *Please check whether a date, checkmark or number of months is given under IPT or INH. This might also be listed in medications as Isoniazid, IPT or INH.*

- □ Yes
- □ No

Has TB treatment been reported in THIS clinic? *Please check whether a date, checkmark or number of months is given under TB treatment or TB Rx. This might also be listed in medications as Rifafour, Rimstar or all of: ethambutol/isoniazid/pyrazinamide/rifampicin. DO NOT record TB treatment from TB History section in this question.*

- □ Yes
- □ No

Has there been a TB test reported? *Please check the lab reports for GeneXpert, AFB, sputum culture, or sputum smear. This might also be listed in the patient file under investigations, examinations or TB screen as: sputum smear, sputum culture, Mantoux, TST, GeneXpert or AFB.*

- □ Yes
- □ No

If yes, please indicate the type of TB test:

- □ Mantoux/TST
- □ Sputum

If yes, please indicate the results of the test:

- □ Positive for TB/ TB detected
- □ Negative for TB/ TB not detected

Has the patient ever had monitoring for TB symptoms reported?

- □ Not reported/blank
- □ Yes and the patient HAS NOT had TB symptoms
- □ Yes and the patient HAS had TB symptoms. *Please check which symptoms:*
  - □ Cough
  - □ Weight loss
  - □ Fever
  - □ Night sweats
  - □ Haemoptysis (coughing blood)
  - □ Swollen lymph nodes
  - □ Respiratory symptoms/ chest pains
  - □ Fatigue

LAB REPORTS OUTSIDE OF PATIENT FILE

Please ask the nurse or the data capturer if they keep laboratory reports somewhere in the office outside of the patient files. Clinic staff tend to be busy – please offer to input this data into the patient files as a thank you.

Did you find another CD4 count lab report outside of the patient file for this patient? *If you did not find another CD4 count lab report outside of the patient file for this patient please skip the next two questions.*

- □ Yes
- □ No

What was the CD4 count? – *If you found multiple lab reports outside of the patient file, please only look at the most recent one. Please write the CD4 count listed on the **MOST RECENT** lab report that was found **OUTSIDE OF THE PATIENT FILE**. Write 333 when question is not applicable, when the question is NOT in the folder at all. Write 666 when data is missing, so when the question is in the folder, but there no data available. Write 999 when you don't know the answer, such as when the question is in the folder, the answer is there, but it is not legible. If the CD4 count is 333, 666 or 999, please add 1, so write 334, 667, or 1,000.*

_____

What was the date the CD4 count was taken on? – *Please write the date the CD4 count was taken on.*

_____

Did you find another Viral Load lab report outside of the patient file for this patient? *If you did not find another Viral Load lab report outside of the patient file for this patient please skip the next two questions.*

- □ Yes
- □ No

What was the Viral Load? – *If you found multiple lab reports outside of the patient file, please only look at the most recent one. Please write the Viral Load listed on the* ***MOST RECENT*** *lab report that was found* ***OUTSIDE OF THE PATIENT FILE****. Write 888 if the Viral Load is non-detectable (LDL). Write 333 when question is not applicable, for example, when the question is NOT in the folder at all. Write 666 when data is missing, so when the question is in the folder, but there no data available. Write 999 when you don't know the answer, such as when the question is in the folder, answer there, but not legible. If the viral load is 333, 666, 888 or 999, please add 1, so write 334, 667, 889, or 1,000.*

_____

What was the date the Viral Load was taken on? – Please write the *date the Viral Load was taken on.*

_____

Once you have filled out this form, please double check that you did not forget to fill in information. THANK YOU for filling out this data from the patient file! ☺

7. REFERRAL LETTERS – EXAMPLES

UNIVERSITY OF OXFORD
Department of Social Policy and Social Work

BARNETT HOUSE, 32 WELLINGTON SQUARE,
OXFORD OX1 2ER, ENGLAND.
TEL 01865 270326 FAX 01865 270324

Dear Sir or Madam: DD/MM/2013

Child at risk of becoming homeless

Youth Pulse is currently undertaking mental health research with vulnerable young people in the Eastern Cape. Where we feel that a young person is at risk of significant harm, we make referrals to relevant organisations.

XXXXXX was abandoned at a young age by both mother and father. He does not know father's whereabouts. Mother visited in 2002 but has no contact. XXXXX previously lived with his maternal grandmother, but was told to leave by aunts and uncles. He is currently staying with his 18-yr old sister and her boyfriend in a shack in XXXXX. His sister is unwilling for him to stay there permenantly. He has a grandmother living in the Transkeii.

It seems that there are potential options for this child, but that these need to be explored with the help of Social Services (perhaps a Family Group Conference?). I am concerned that this child is at immediate risk of becoming homeless if this is not addressed.

Please do not hesitate to contact me if you require any further details, or wish to discuss this in more detail.

Sincerely,

Name Surname
Youth Pulse Programme Manager
Cell: (0XX) XXX-XXXX

Youth Pulse is a research collaboration between the South African Government and a number of universities and non-governmental organizations. For this research project our interviewers travel from house to house in selected areas to interview adolescents in order to learn more about their health, daily lives, experiences and feelings. The data collected in this project will be used to assist government in developing social policies relating to children.

UNIVERSITY OF OXFORD
Department of Social Policy and Social Work

BARNETT HOUSE, 32 WELLINGTON SQUARE,
OXFORD OX1 2ER, ENGLAND.
TEL 01865 270326 FAX 01865 270324

Dear Sir or Madam: DD/MM/2013

Child reporting suidical thoughts

Re: **XXXXXXX**
Date of Birth: **XXXXXX**
Address:**XXXXXX, Site C, XXXXX**
School: **XXXXX Primary School**

Youth Pulse is currently undertaking mental health research with vulnerable young people in the Eastern Cape. Where we feel that a young person is at risk of significant harm, we make referrals to relevant organisations.

Zukiswa is living with her grandmother, after her mother's death. She identified in the research that she is unhappy living with her grandmother, and extremely upset by her mother's death. We are concerned that she identified a desire to commit suicide. We request that this be allocated to a social worker for further investigation.

Please do not hesitate to contact me if you require any further details, or wish to discuss this in more detail.

Sincerely,

Name Surname
Youth Pulse Programme Manager
Cell: (0XX) XXX-XXXX

Youth Pulse is a research collaboration between the South African Government and a number of universities and non-governmental organizations. For this research project our interviewers travel from house to house in selected areas to interview adolescents in order to learn more about their health, daily lives, experiences and feelings. The data collected in this project will be used to assist government in developing social policies relating to children.

UNIVERSITY OF OXFORD
Department of Social Policy and Social Work

BARNETT HOUSE, 32 WELLINGTON SQUARE,
OXFORD OX1 2ER, ENGLAND.
TEL 01865 270326 FAX 01865 270324

Dear Sir or Madam: DD/MM/2013

Social Services support for Child-headed Household

Re: **XXXXXXX**
Date of Birth: **XXXXXX**
Address:**XXXXXX, Site C, XXX**
School: **XXXXX Primary School**

XXXXXXX
Date of Birth: **XXXXXX**
Address:**XXXXXX, Site C, XXXXX**
School: **XXXXX Primary School**

And
XXXXXXX
Date of Birth: **XXXXXX**

Address:**XXXXXX, Site C, XXXX**
School: **XXXXX Primary School**

Youth Pulse is currently undertaking mental health research with vulnerable young people in the Eastern Cape. Where we feel that a young person is at risk of significant harm, we make referrals to relevant organisations.

This set of children's parents are both deceased, and they live in a Child-Headed Household, headed by XXXXXXX. XXXXX and XXXX are both attending school, but XXXX has dropped out of school due to inability to pay school fees. The family are in dire financial circumstances, and are not receiving any grants or income. We request that this family be allocated to a social worker (if Social Services are not already aware of this case) for further investigation and support.

Please do not hesitate to contact me if you require any further details, or wish to discuss this in more detail.

Sincerely,

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universities and non-governmental organizations. For this research project our interviewers travel from house to house in selected areas to interview adolescents in order to learn more about their health, daily lives, experiences and feelings. The data collected in this project will be used to assist government in developing social policies relating to children.

Name Surname
Youth Pulse Programme Manager
Cell: (0XX) XXX-XXXX

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BARNETT HOUSE, 32 WELLINGTON SQUARE,
OXFORD OX1 2ER, ENGLAND.
TEL 01865 270326 FAX 01865 270324

Dear Principal and Governing Body DD/MM/2013

Child Eligible for School Fee Exemption

Re: **XXXXXXX**
Date of Birth: **XXXXXX**
Address: **XXXXXX, Site C, XXXXX**
School: **XXXXX Primary School**

Youth Pulse is currently undertaking mental health research with vulnerable young people in the Eastern Cape. Where we feel that a young person is at risk of significant harm, we make referrals to relevant organisations.

XXXX's father is deceased, and the family do not have a regular income or receive and social grants. XXXXX completed Grade 7, and was forced to leave school due to lack of money to pay school fees.

We request that the school and Governing Body consider re-admitting XXXXXXXX, with allowance for the family's lack of ability to pay school fees in full.

Please do not hesitate to contact me if you require any further details, or wish to discuss this in more detail.

With many thanks for your consideration of this matter.

Sincerely,

Name Surname
Youth Pulse Programme Manager
Cell: (0XX) XXX-XXXX

Youth Pulse is a research collaboration between the South African Government and a number of universities and non-governmental organizations. For this research project our interviewers travel from house to house in selected areas to interview adolescents in order to learn more about their health, daily lives, experiences and feelings. The data collected in this project will be used to assist government in developing social policies relating to children.

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BARNETT HOUSE, 32 WELLINGTON SQUARE,
OXFORD OX1 2ER, ENGLAND.
TEL 01865 270326 FAX 01865 270324

Dear XXXXXX DD/MM/2013

Thank you again for taking part in the Youth Pulse research this year. When you were doing the worksheet, you said that you had been raped outside your house. We wanted to say that you are a very brave girl and that you must remember that it was not your fault. If you ever want to talk to someone about this, these are telephone numbers, which might be able to help.

Rape Crisis XXX
- +27 (0)21 361 9228
Counselling line - +27 (0)21 361 9085

LifeLine XXX
(021)461 1111

Childline
08000 55555

AIDS Helpline
0800 012322

Wishing you all the best for the future.

Sincerely,

Name Surname
Youth Pulse Programme Manager
Cell: (0XX) XXX-XXXX

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Department of Social Policy and Social Work

BARNETT HOUSE, 32 WELLINGTON SQUARE,
OXFORD OX1 2ER, ENGLAND.
TEL 01865 270326 FAX 01865 270324

Dear Sir or Madam: DD/MM/2013

The following adolescent was interviewed on **DD/MM/2013** and the interviewer noted that he/she might be in need of **home-based care services**. The following particulars were noted:

Name of child: B.
D.O.B: 10/1/1997
Name of guardian: M (biological mother)
Address: Stand no xxx, Vodacom Park, on top of the hill, Matsulu C.
Phone number: xxxxx
School: Funindlela Primary, 7

B is in the later stages of AIDS and is also infected with TB. She is struggling with compliance on her medications with no support at home. B was first referred to this office in July 2011 and was urgently referred a second time because she was seriously ill in September. When the social worker met her, she agreed that she needed better support than B's mother was willing to give and agreed to move her. However, she later spoke to B's mother, at which point she decided that the move was not necessary. The same day, B was admitted to Themba Hospital for very severe miliary TB. When she was discharged, she was initiated on ARV's, but her mother has not supported her in taking them. Her mother has never been to a clinic appointment. B and her mother were then referred to the supervising social worker at Matsulu for adherence support, but no one has done an assessment with them or met with the family, and no counseling or further action has been done in spite of continuous, urgent referrals from the Youth Pulse Research Project. Without urgent support from social services, B is going to be dead within six months. This death could easily be prevented if someone was supporting B in taking her medication and attending clinic and hospital visits regularly.

B has had no support in taking her medication. Her mother is non-cooperative, beats her up regularly and is often away from the house, and B does not have enough food at home. B's mother is also HIV+, but she refuses to initiate treatment in spite of having promised B that she will. B would really benefit from social support services, especially home-based care.

If you need any more information, please do not hesitate to contact us.

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Sincerely,

Name Surname
Youth Pulse Programme Manager
Cell: (0XX) XXX-XXXX

Youth Pulse is a research collaboration between the South African Government and a number of universities and non-governmental organizations. For this research project our interviewers travel from house to house in selected areas to interview adolescents in order to learn more about their health, daily lives, experiences and feelings. The data collected in this project will be used to assist government in developing social policies relating to children.

8. SYSTEMATIC REVIEW DOCUMENTS

8.1 SYSTEMATIC REVIEW PROTOCOL

The State of the Evidence of sexual risk-taking among Adolescents and Youth living with HIV in sub-Saharan Africa: A Systematic Review of Prevalence, Determinants and Interventions

Elona Toska[1, 2], Marija Pantelic[1], Lucie Cluver[1, 3], Franziska Meinck[1], Katharina Keck[1]

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2 AIDS and Society Research Unit, Centre for Social Science Research, University of Cape Town

3 Department of Psychiatry and Mental Health, University of Cape Town, Cape Town, South Africa

Keywords: sexual behaviours, HIV-positive, adolescents, youth, sub-Saharan Africa, systematic review, prevalence, risk factors, interventions

BACKGROUND

As access to antiretroviral (ARV) treatment in Sub-Saharan Africa has improved, the number of children vertically-infected with HIV who survive to adolescence has increased (1). Coupled with sustained high HIV-incidence among youth in the region, improved survival has resulted in more than 2 million adolescents living with HIV globally. Eighty five per cent of these adolescents, nearly 1.7 million, live in Sub-Saharan Africa, with adolescent girls representing nearly two-thirds of total (2,3). Adolescents living with HIV are not only more vulnerable due to potential re-infection by HIV or other STIs compared to their HIV-negative peers, they are also at risk of passing the virus on to their partners or children (4). Furthermore, adolescents living with HIV are more likely than adults or younger children to adhere poorly to their medication (5), particularly treatment regimens to prevent mother-to-child-transmission, thus developing resistance to available antiretroviral therapies, eventually risking running out of treatment options, or infecting others with resistant strains of the virus (6,7). Adolescents living with HIV in Sub-Saharan Africa are particularly vulnerable to these risks due to poor access to healthcare services such as family planning, HIV testing, and treatment (8–12).

The only longitudinal study among vertically-infected HIV-positive adolescents, conducted in the United States, suggests initial delays in puberty and sexual activity due to living with HIV (22). Biomedical and behavioural research shows that HIV-positive youth on antiretroviral treatment report similar levels of sexual activity to HIV-negatives ones by late adolescence (23,24). Despite similar levels of activity, HIV-positive adolescents might be even more vulnerable than other adolescents, with higher levels of unprotected sex and poorer sexual health outcomes reported in the United States and some Sub-Saharan African countries (19,25–29).

The small number of studies on adolescents living with HIV report high rates of unprotected sex with other adolescents (27–90%), and very low rates of disclosure of HIV-status to sexual partners (13,14). Little is known about rates of other high-risk behaviours such as transactional sex, sex with older partners, multiple concurrent sexual partners, and sex on drugs or alcohol (15). In addition, HIV-positive adolescents experience a range of vulnerabilities that reduce the efficacy of generalised prevention programmes, including cognitive and mental health issues (16,17), family-related challenges (18,19) and material deprivation (20,21). This group has been neglected in HIV-prevention efforts in the region,

with no known studies testing interventions aimed at supporting HIV-positive adolescents to reduce sexual and onwards vertical transmission.

Evidence on the effectiveness and feasibility of low-cost interventions to reduce HIV transmission from adolescents, both vertically and horizontally, is urgently needed. Behavioural interventions to reduce HIV transmission among HIV-negative youth in Sub-Saharan Africa have had mixed effects when implemented on their own (30). Since 2013, evidence from Kenya, Malawi and South Africa has shown HIV-risk reduction associated with social protection: unconditional cash transfers (31–33) and, most recently, combinations of 'cash plus care' (34) that include economic social protection plus psychosocial support such as positive parenting. However, to our knowledge, no studies to date have examined how these programmes may reduce HIV-transmission risk behaviours among HIV-positive adolescents, or how they may work in combination with healthcare preventions to promote risk reduction.

Though some interventions have been conducted among HIV-positive adolescents in the United States (35–39), there is a dearth of research and interventions to meet the need gap of HIV-positive adolescents in the developing world, where most of them live. A 2010 WHO review of behavioural interventions for HIV Positive Prevention in middle and lower-income countries found 19 studies, none of which focused on young people (40). Our preliminary literature review located a handful of interventions that have addressed sexual practices among adolescents living with HIV: (1) Adolescent Hemophilia Behavioral Intervention Evaluation Project (35), (2) Teens Linked to Care (38), (3) Healthy Choices (36), (4) +Click among perinatally and postnatally-infected adolescents (39) and (5) Adolescent Impact (37).

Among those interventions that have been tried, there is a dearth of interventions that show positive impact for key behaviours such as self-reported condom use, abstinence, reduced numbers of sexual partners, delayed sexual initiation, etc. This lack of intervention evidence is exacerbated by the overall lack of research on these outcomes among HIV-positive adolescents in Sub-Saharan Africa. To fill the above evidence gap in effective interventions for HIV-positive adolescents, a 2012 consultation on research on sexual and reproductive decision-making of HIV-positive adolescents concluded that further research is needed to elucidate adolescent sexual and reproductive health needs, as well as hypothesize models of sexual and reproductive decision-making among HIV-positive youth (41). In particular, it is important to understand how HIV-positive youth initiate sexual relationships and how they protect themselves and others in these relationships from the outset. Studies located through our preliminary literature review suggest that the effect of age (42), gender, mode of infection (43), disclosure to partners (27), medication adherence (44), mental health, and other factors may be key to reducing sexual risk-taking among adolescents living with HIV. It is crucial for intervention development research to document the prevalence of risk behaviours and guide intervention development through improved understanding of the problem theory (determinants and theories of change) of sexual and reproductive practices of adolescents living with HIV in South Africa.

OBJECTIVES

The aim of the systematic review proposed in this protocol is to advance theory and inform needed intervention development. It will synthesize existing evidence of prevalence, predictors and programmes that aim to reduce sexual risk-taking among HIV-positive adolescents and youth in Sub-Saharan Africa. The scope of this review is summarised in Table 1. This protocol presents the plan to assess the state of the evidence for two research questions:

1. What is the prevalence of sexual risk-taking among HIV-positive adolescents and youth in Sub-Saharan Africa?

2. What are determinants[8] of sexual risk-taking among HIV-positive adolescents and youth in Sub-Saharan Africa?
3. What interventions have aimed at reducing sexual risk-taking among HIV-positive adolescents and youth in Sub-Saharan Africa and how effective were they?

Table 1. Scope of the review

Population	Adolescents and Youth living with HIV Age range: 10-24 years old
Outcome	Individual risk behaviours: early sexual debut, inconsistent condom use, having an older partner, transactional sex, having multiple sexual partners, sex drunk or on drugs, sexually transmitted infections, and unwanted adolescent pregnancies. OR Composite risk behaviours consisting of any of the above behaviours combined.
Geographic location	Sub-Saharan Africa
Study Design	Randomised controlled trials (individual or cluster), Quasi-experimental studies including quasi-randomized trials, controlled before-after studies, pre- and post-test studies, longitudinal cohort studies, cross-sectional studies (prevalence only)

METHODS

Search strategy

The systematic review will focus on prevalence, determinants, and interventions to reduce risk of HIV-transmission behaviours amongst adolescents and youth living with HIV, and studies that identify determinants of high-risk sexual behaviours among HIV-positive adolescents and youth. Given the lack of evidence in the region, the review may be expanded to include worldwide research, and will extend Cochrane Collaboration guidelines for systematic reviews of randomised controlled trials, to include rigorous quasi-experimental studies and longitudinal cohort studies. Cross-sectional surveys will be included to allow for prevalence rates to be documented. The systematic review research question and inclusion criteria have been extended to include studies among youth living with HIV, given the overlap in age groups between adolescents (10-19 year old) and youth (15-24 year old).

Studies will be identified through electronic searches of bibliographic databases, grey literature sites and citations in retrieved studies and reviews. The search strategy follows guidelines outline in the Cochrane Handbook of systematic reviews (45). Large databases such as PsycARTICLES, Embase, Global Health, MEDLINE, and PsycINFO will be consulted using sensitive search terms and free-text search terms for people living with HIV and HIV-transmission risk behaviour using the OvidSP platform. The search strings for OvidSP are included in Table 2, and were test-run in early September 2015. PubMed will be searched using MeSH and search terms listed in Table 3. Popline[9], the world's largest reproductive health library will be searched using the search strings in Table 4, and through manual searching of the relevant subject headings. Other databases: CINAHL, ProQuest, and WHO

[8] Determinants are factors associated with the outcome through longitudinal research. For this review, risk and protective factors will be documented, following definitions laid out by Murray and colleagues (48).

[9] http://www.popline.org/advancedsearch

Afro Library[10] will be searched using a simpler and more inclusive search string (Table 3). Searches in CINAHL, conducted through the Ebscohost platform, will select Africa under Geographic Area. ProQuest[11] will be searched to increase the likelihood of locating dissertations and abstracts, using the search term in Table 3. The PROSPERO register of systematic reviews, Cochrane database of systematic reviews, and the Campbell Collaboration records will also be searched. Conference abstracts and presentations will be searched, using conference websites for key events in the field, including: IAS, AIDSImpact, SAAIDS and ICASA, using simple sensitive search terms. References listed in the included studies as well as in other relevant reviews will also be screened for eligibility. Email requests for unpublished and ongoing investigations will be sent to key relevant researchers.

Websites of major international and regional organisations, such as the World Health Organization (WHO), Joint UN Program for HIV/AIDS (UNAIDS), the UN Children's Fund (UNICEF), United States Agency for International Development (USAID), UN Family Planning Agency (UNFPA), International Planned Parenthood Federation (IPPF), and Population Council will be consulted to identify relevant publications.

[10] http://indexmedicus.afro.who.int/

[11] http://search.proquest.com/socialsciences/advanced?accountid=13042

Table 2. Search string for databases searched in OvidSP (PsychARTICLES, Embase, Global Health, Ovid MEDLINE and PsycINFO)[12]

1	Population	Adolescents or youth living with HIV	(((HIV or AIDS or ((human or acquired) adj1 (immunodeficiency or immune-deficiency or immuno-deficiency))) adj2 (child* or adolescen* or teen* or you*)) or ALHIV or PHIV or BHIV).ab,ti,hw.
2	Outcome(s)	Early sexual debut	(early adj1 sexual adj1 (debut or initiation)).ab,hw,ti. Or
3		Unprotected sex	(((safe or unsafe or protected or unprotected) adj1 (sex or intercourse)) or abstinen*).ab,hw,ti.
4		Contraception use	(condom or IUD or implant* or contracepti* or hormon* or inject* or spermicide or diaphragm or (dual adj1 (protection or method))).ab,hw,ti.
5		Sex with an older partner	(((old* or age$disparate or intergenerational) adj1 sex* adj1 partner)).ab,hw,ti.
6		Transactional sex	(((sugar adj1 (daddy or daddies)) or ((transactional or survival) adj1 sex))).ab,ti,hw.
7		Multiple partners	(MCP or ((multiple or concurrent) adj2 partner*)).ab,hw,ti.
8		Sex drunk or on drugs	((sex adj1 drunk) or (sex adj2 drug*)).ab,hw,ti.
9		Sexually Transmitted Infections	(sexually transmitted infection* or STI* or chlamydia or gonorrh$ea or syphilis or (herpes simplex virus or HSV) or HPV).ab,hw,ti.
10		pregnancy	Pregnan*.ab,hw,ti.
11	Final outcome search string		2 OR 3 OR 4 OR 5 OR 6 OR 7 OR 8 OR 9 OR 10
12	Location	Sub-Saharan Africa	((sahara* adj1 africa) or Angola or Benin or Botswana or Burkina Faso or Burundi or Cameroon or Cape Verde or Central African Republic or Chad or Comoros or Congo or Brazzaville or Democratic Republic of Congo or Cote d'Ivoire or Djibouti or Equatorial Guinea or Eritrea or Ethiopia or Gabon or

[12] .ab. denotes a word in the abstract; hw. denotes head words; .pt. denotes a Publication Type term; .ti. denotes a word in the title.

		Gambia or Ghana or Guinea or Guinea$Bissau or Kenya or Lesotho or Liberia or Madagascar or Malawi or Mali or Mauritania or Mauritius or Mozambique or Namibia or Niger or Nigeria or (Reunion adj3 africa) or Rwanda or Sao Tome or Senegal or Seychelles or Sierra Leone or Somalia or South Africa or Sudan or Swaziland or Tanzania or Togo or Uganda or Western Sahara or Zambia or Zimbabwe).ab,cp,hw,ti.
19	FINAL SEARCH STRING	1 AND 11 AND 12

Table 3. Search Strings for PubMed & Proquest

Database	PubMed	Proquest
Search String	((((("HIV"[Mesh] OR "Acquired Immunodeficiency Syndrome"[Mesh] OR "HIV-1"[Mesh]) AND ("Child"[Mesh] OR "Adolescent"[Mesh] OR "Young Adult"[Mesh]) AND ("Sexual Behavior"[Mesh] OR "Sexual Partners"[Mesh] OR "Sexual Abstinence"[Mesh] OR "Social Behavior"[Mesh] OR "Reproductive Health"[Mesh] OR "Coitus"[Mesh] OR "Contraception"[Mesh] OR "Contraception, Postcoital"[Mesh] OR "Contraception, Barrier"[Mesh] OR "Contraception, Immunologic"[Mesh] OR "Contraception Behavior"[Mesh] OR "Sexually Transmitted Diseases/epidemiology"[Majr] OR "Sexually Transmitted Diseases/prevention and control"[Majr] OR "Sexually Transmitted Diseases/psychology"[Majr] OR "Pregnancy in Adolescence"[Mesh] OR "Pregnancy"[Mesh] OR "Pregnancy, Unplanned"[Mesh] OR "Pregnancy, Unwanted"[Mesh]) AND ("Randomized Controlled Trial"[Publication Type] OR "Non-Randomized Controlled Trials as Topic"[Mesh] OR "Multicenter Studies as Topic"[Mesh] OR "Cross-Over Studies"[Mesh] OR "Evaluation Studies as Topic"[Mesh] OR "Program Evaluation"[Mesh] OR "Evaluation Studies"[Publication Type] OR "Pilot Projects"[Mesh] OR "Cohort Studies"[Mesh] OR "Lost to Follow-Up"[Mesh] OR "Epidemiologic Studies"[Mesh] OR "Odds Ratio"[Mesh]) AND	(((HIV OR AIDS OR ((human OR acquired) adj1 (immunodeficiency OR immunodeficiency OR immunodeficiency))) adj2 (child* OR adolescent* OR teen* OR you*)) OR ALHIV OR PHIV OR BHIV) AND ((early adj1 sexual adj1 (debut OR initiation)) OR ((safe OR unsafe OR protected OR unprotected) adj1 (sex OR intercourse)) OR abstinen* OR (condom OR IUD OR implant* OR contraception* OR hormone* OR inject* OR spermicide OR diaphragm OR (dual adj1 (protection OR method))) OR ((old* OR age disparate OR intergenerational) adj1 sex* adj1 partner) OR (sugar adj1 (daddy OR daddies)) OR ((transactional OR survival) adj1 sex) OR (MCP OR (multiple or concurrent) adj2 partner*) OR ((sex adj1 drunk) OR (sex adj2 drug*)) OR (sexually transmitted infection* OR STI* OR chlamydia OR gonorrhoea OR gonorrhea OR syphilis OR (herpes simplex virus OR HSV) OR HPV) OR Pregnan*) AND ((sahara* adj1 africa) OR Angola OR Benin OR Botswana OR Burkina Faso OR Burundi OR Cameroon OR Cape Verde OR Central African Republic OR Chad OR Comoros OR Congo OR Brazzaville OR Democratic

	("Africa"[Mesh] OR "Africa South of the Sahara"[Mesh] OR "South Africa"[Mesh] OR "Africa, Western"[Mesh] OR "Africa, Southern"[Mesh] OR "Africa, Eastern"[Mesh] OR "Africa, Central"[Mesh])	Republic of Congo OR Cote d'Ivoire OR Djibouti OR Equatorial guinea OR Eritrea OR Ethiopia OR Gabon OR Gambia OR Ghana OR guinea OR guinea bissau OR Kenya OR Lesotho OR Liberia OR Madagascar OR Malawi OR Mali OR Mauritania OR Mauritius OR Mozambique OR Namibia OR Niger OR Nigeria OR (Reunion adj3 africa) OR Rwanda OR Sao Tome OR Senegal OR Seychelles OR Sierra Leone OR Somalia OR South Africa OR Sudan OR Swaziland OR Tanzania OR Togo OR Uganda OR Western Sahara OR Zambia OR Zimbabwe)
Publication Types	n/a	AND stype.exact("Conference Papers & Proceedings" OR "Scholarly Journals" OR "Dissertations & Theses" OR "Working Papers" OR "Government & Official Publications")
Language	AND (English[lang] OR French[lang] OR Spanish[lang] OR Portuguese[lang])	AND la.exact("English" OR "Portuguese" OR "French" OR "Spanish")
Timeline	AND (("1983/01/01"[PDAT] : "3000/12/31"[PDAT])	AND pd(>19830101)

Table 4. Search strings for other smaller databases (PopLine, WHO Africa, and CINAHL)

	Search terms		Popline	WHO Africa	CINAHL
1	Population	Adolescents or youth living with HIV	Title: (((HIV or AIDS) AND (child* OR adolescen* OR teen* OR you*)) OR ALHIV OR BHIV OR PHIV) OR Keyword: (((HIV or AIDS) AND (child* OR	(HIV OR AIDS) AND (child OR adolescent OR teenager OR youth)	((HIV or AIDS) AND (child* OR adolescen* OR teen* OR you*)) OR ALHIV OR BHIV OR PHIV)

			adolescen* OR teen* OR you*)) OR ALHIV OR BHIV OR PHIV)		
2	Outcome(s)	Early sexual debut Unprotected sex Contraception use Sex with an older partner Transactional sex Multiple partners Sex drunk or on drugs Sexually Transmitted Infections Unwanted pregnancy	N/A	sex	(((early N1 sexual N1 (debut or initiation)) OR (((safe or unsafe or protected or unprotected) N1 (sex or intercourse)) or abstinen*) Or (condom or IUD or implant* or contracepti* or hormon* or spermicide or diaphragm or (dual N1 (protection or method))) Or (((old* or age$disparate or intergenerational) N1 sex* N1 partner)) Or (((sugar N1 (daddy or daddies)) or ((transactional or survival) N1 sex))) OR ((MCP or (multiple or concurrent) N2 partner*)) OR ((sex N1 drunk) or (sex N2 drug*)) OR (sexually transmitted infection* or STI* or chlamydia or gonorr$ea or syphilis or (herpes simplex virus or HSV) or HPV) OR Pregnan*)
3	Location	Sub-Saharan Africa	(sahara* and africa) or (south* and Africa) or (east* or Africa)	N/A	selected Africa under ‘Geographic Subset’
Final search		1 AND 3		1 AND 2	1 and 2

Study selection process

All results will be merged and duplicates will be removed following processes outlined in the Cochrane Handbook (46). The authors will review all titles and abstracts to remove irrelevant search results, using the screening questions in Appendix 1. Full text documents will be retrieved for potential relevant search results, and checked against eligibility criteria outlined in section 3c. Authors will be contacted for additional information as necessary and appropriate. References of the included studies will also be reviewed to harvest any relevant studies not located through the above search process.

Inclusion and Exclusion Criteria

Only studies that meet all of the pre-specified inclusion and none of the exclusion criteria will be included in the review's findings. Two authors will review all titles and abstracts for inclusion using a set of screening questions for final decision-making (Appendix 1). Randomised controlled trials (RCTs) provide the strongest form of evidence about intervention impact. However, due to the small number of RCTs identified in preliminary searches, this review also includes studies with less rigorous designs, including pre–post intervention comparisons, and post-intervention comparisons with "control" populations, and longitudinal cohort studies. All searches will be conducted within the publication date limits of 1983 or the closest date limit available, reflecting the time since HIV has been diagnosed in adolescents and youth. Reports in English, French and Portuguese will be reviewed to allow for publications from Western and Central Africa, and reports in Spanish will be reviewed as one of the official languages of the United Nations.

Table 5. Study inclusion and exclusion criteria

Topic	Inclusion criteria	Exclusion criteria
Study population	• HIV-positive • Any of the sample in the 10-24 year old range	HIV-exposed adolescents or youth
Study design	• Intervention studies: randomised control trials, pilot studies, pre-post intervention studies (controlled and not). • Quantitative or mixed methods reports of longitudinal cohort studies. • Cross-sectional studies	• Qualitative studies • Case-control studies
Sampling	• Located in sub-Saharan Africa • Single or multi-country • Random or non-random sampling • Community and facility-based sampling	Sub-Saharan African immigrants living outside of sub-Saharan Africa
Outcome measure	• Any of the sexual behaviours listed above or a combination of these sexual behaviours, either as primary or secondary outcome; • Biological markers: STI test results and pregnancy.	• Combination risk methods where data on individual sexual behaviours are not reported

		• Studies reporting proxy behaviours, intentions, knowledge, or awareness related to the outcomes of interest.
Publication type	• Peer-reviewed journal article • Grey literature • Conference abstracts and presentations • Dissertations	• Conference abstracts without additional information
Language	• English • French • Portuguese • Spanish	• Any other language

Data extraction plan

Data from included studies will be independently extracted by two authors for each study using the data extraction form in Appendix 3. The data extraction form will be piloted by two independent coders. Discrepancies will be resolved by discussion following a pre-agreed protocol. Articles reporting analyses from the same dataset will be checked for data duplication, with the largest sample taken if multiple reports are located. The studies' internal and external validity will be assessed in accordance with the Cochrane Handbook of systematic reviews. The authors have adapted a risk assessment form to assess the included studies internal validity, i.e. whether the study answers the question free of potential biases (Table 6). The adapted quality checklist (Appendix 2) combines guidance on assessing systematic bias from the Cochrane Handbook for experimental designs (RCTs, non-randomised controlled trials and pre- and post-test experimental design) (47) presented in Table 6, and the Cambridge Quality Checklist for systematic reviews of risk factors (48). Following the Cochrane Handbook guidance, risk of bias will be noted as unclear in cases when: (1) insufficient detail is reported of what happened in the study, (2) what happened in the study is known, but the risk of bias is unknown; or (3) an entry is not relevant to the study at hand.

Table 6. Internal Validity Assessment Criteria for Included Studies adapted from the Cochrane Handbook of Systematic Reviews

Risk criteria	**Randomised controlled trials**	**Non-randomised controlled trials, pre-post test, experimental designs**	**Non-experimental longitudinal designs**
Random sequence generation (selection bias)	☐ low risk ☐ high risk ☐ not clear	☐ low risk ☐ high risk ☐ not clear	☐ low risk ☐ high risk ☐ not clear

Allocation concealment (selection bias)	☐ low risk ☐ high risk ☐ not clear	☐ low risk ☐ high risk ☐ not clear	☐ low risk ☐ high risk ☐ not clear
Blinding of participants and personnel (performance bias)	☐ low risk ☐ high risk ☐ not clear	☐ low risk ☐ high risk ☐ not clear	☐ low risk ☐ high risk ☐ not clear
Blinding of outcome assessment (outcome bias)	☐ low risk ☐ high risk ☐ not clear	☐ low risk ☐ high risk ☐ not clear	☐ low risk ☐ high risk ☐ not clear
Incomplete outcome data (attrition bias)	☐ low risk ☐ high risk ☐ not clear	☐ low risk ☐ high risk ☐ not clear	☐ low risk ☐ high risk ☐ not clear
Selective reporting (reporting bias)	☐ low risk ☐ high risk ☐ not clear	☐ low risk ☐ high risk ☐ not clear	☐ low risk ☐ high risk ☐ not clear
Other bias	☐ low risk ☐ high risk ☐ not clear	☐ low risk ☐ high risk ☐ not clear	☐ low risk ☐ high risk ☐ not clear

The Cambridge Quality Checklist focuses on identifying studies of correlates, risk-factors and causal risk factors for systematic review (48), including experimental designs. The checklist will be completed following the careful identification of the determinants (risk factors and causal risk factors) and the outcome measures for each included study.

The quality assessment checklist was modified along the following lines:

1. Sampling method is assessed as total/ random sampling vs. convenience or case-control sampling in the original checklist. Our preliminary literature review indicates that studies in our population, HIV-positive adolescents, usually recruit from healthcare facilities. We have adapted the checklist to assess included studies' sampling strategy at the cluster (facility, community, school, etc.) and individual participant-level.
2. Sample size adequacy – the Cambridge Quality Checklist uses a cut-off N=400 for adequate sample size for findings of correlates to be able to detect small enough effect sizes (48). In light of the dearth of research among HIV-positive adolescents, we may change this cut-off to N=200 for RCTs and quasi-experimental trials, which would allow the inclusion of studies that can detect medium effect sizes.
3. Outcome measurements – as sexual behaviours do not involve psychometric measurements, the internal validity of the outcome measure will be assessed by whether methodological practices were in place to improve its reporting. These approaches were ranked in terms of rigour: (4) self-report triangulated through biomarkers, (3) self-report validated through other measures, e.g. self-reported

unprotected sex validated through self-reported pregnancy, (2) self-report using interview technologies or research approaches known to improve reporting of stigmatised behaviours, (1) for studies with self-reported outcomes collected without special research approaches, and (0) no information reported. Multiple studies have contended that audio computer-assisted interviews increase the accuracy of reported stigmatised behaviours (primarily sexual activity and substance use) compared to face-to-face-interviews and self-administered questionnaires (49), including one among adolescents living with HIV in the United States (50). A 2004 study among school goers in South Africa reported fewer mistakes among those using electronic questionnaires compared to paper ones (51).

The quality checklist and data extraction forms were piloted by the first two authors using studies among HIV-positive adolescents the United States (35–37,39).

Synthesis plan

The systematic review will be conducted and reported as guided by one of the existing standards of conducting systematic reviews: the Critical Appraisal Skills Programme (CASP 2001), the tool to assess systematic reviews or AMSTAR (Shea et al. 2007) or the PRISMA statement for reporting Systematic Reviews and Meta-Analyses of Studies (Moher et al. 2009), based on requirements of the publication where the review will be submitted. If possible and appropriate, meta-analysis will be conducted for systematic review findings. If meta-analysis is warranted, statistical analyses will be carried out using the Comprehensive Meta-Analysis software, version 2 (52). Random and fixed-effects models will be checked for consistency as is recommended by the Cochrane Handbook for Systematic Reviews (53). Homogeneity will be assessed to estimate bias due to sampling error or reflecting true differences between effect sizes (53). Sensitivity analysis will identify whether individual effect sizes distort the aggregated effects (54). To assess the possibility of publication bias, the 'trim and fill' procedure will be conducted for the study outcome. In the case that is possible, as a secondary objective, the review will investigate how the associations between risk and protective factors and outcomes differ according to pre-specified moderators. This objective is contingent upon the quality, amount and variability of available data, as well as the compatibility of outcome measures used. Where possible, moderator analysis will assess whether findings significantly differ by:

1. Mode of infection (vertical/ horizontal)
2. Age group: younger (10-14), older adolescents (15-19), youth (20-24)
3. Gender (female/ male)
4. Treatment status (ART naïve, ever initiated, lost to follow up, defaulting, etc. – defined based on data extraction from included studies)
5. Disclosure of HIV status (knowledge of own status, disclosure of HIV-status to others – categories to be confirmed based on data extraction from included studies)
6. Study quality
7. Intervention type: single or combination of interventions

TIMETABLE

Task	*Complete by*
Project planning	June-July 2015

Testing search strategy	August 2015
Finalizing review protocol	September 2015
Searches run and collated	September 2015
Contacting authors for published studies	September 2015
Abstract inclusion/exclusion	September 2015
Full text inclusion/exclusion	September 2015
Data extraction	September-October 2015
Data synthesis	October 2015
Write-up	October 2015
Submission for publication	November 2015
Review, revise and submit as needed[13]	December 2015-June 2016

ACKNOWLEDGEMENTS

This research is funded by Evidence for HIV Prevention in Southern Africa (EHPSA), a DFID programme managed by Mott MacDonald (MM/EHPSA/UCT/05150014), the Clarendon-Green Templeton College Scholarship, and the Nuffield Foundation (CPF/41513), all of whom have funded the authors' to work on this research project. The research leading to these results has also received funding from the John Fell Fund and the European Research Council under the European Union's Seventh Framework Programme (FP7/2007-2013) / ERC grant agreement n°313421.

STATEMENTS OF CONFLICT OF INTEREST

The authors declare they have no competing interests.

[13] Once submitted for publication, the timeline will be out of the authors' control.

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8.2 SYSTEMATIC REVIEW PROTOCOL APPENDICES

8.2.1 Screening Questions

Note: continue to subsequent question only if the answer to the current question is "yes". Otherwise exclude study from the review.

Study Characteristics	Eligibility criteria	Eligibility criteria met? Yes	No	Unclear
Participants and setting	Adolescents (10-19 year old) Youth (15-24 years old)	☐ ☐	☐ ☐	☐ ☐
Location of study	Study samples in at least one country in sub-Saharan Africa	☐	☐	☐
Type of study	Experimental study including randomized controlled trials (RCTs) or cluster-randomized trials (CRTs).	☐	☐	☐
	Quasi-experimental studies including quasi-randomized trials, controlled before-after studies (CBAs) and interrupted time series studies (ITSs).	☐	☐	☐
	Observational longitudinal cohort studies	☐	☐	☐
Types of outcome measures	<u>Primary outcome:</u> 1. Early sexual debut 2. Unprotected sex 3. Contraception use 4. Sex with an older partner 5. Transactional sex 6. Multiple partners 7. Sex drunk or on drugs 8. Sexually Transmitted Infections 9. Unwanted pregnancy 10. Combination of any of the above <u>Secondary outcomes:</u> Any of the above outcomes	☐ ☐ ☐ ☐ ☐ ☐ ☐ ☐ ☐ ☐ ☐ ☐	☐ ☐ ☐ ☐ ☐ ☐ ☐ ☐ ☐ ☐ ☐ ☐	☐ ☐ ☐ ☐ ☐ ☐ ☐ ☐ ☐ ☐ ☐ ☐
INCLUDE ☐	Reason for exclusion:			

8.2.2 Study Quality Checklist

Quality Assessment[14]
Study design score[15]
1 Study without a comparison group – No analysis of change
2 Inadequately controlled study – No analysis of change
3 Study without a comparison group – With analysis of change
4 Inadequately controlled study – With analysis of change
5 Controlled non-experimental study – No analysis of change
6 Controlled non-experimental study – With analysis of change
7 Randomised experiment targeting a risk factor
Cluster sampling (cluster= facility, community, school or other)
3 Total population or random sampling
2 Purposive sampling
1 Convenience sampling
0 Not reported
Within-cluster sampling of participants
3 Total population or random sampling
2 Purposive sampling
1 Convenience sampling
0 Not reported
Response rates
2 Response *or* retention rates ≥70% *or* differential attrition ≤10%[16]
1 Response rate <70% *or* retention rate <70% *or* differential attrition >10%
0 Not reported
Sample size score
1 Sample size ≥400 (cohort studies) and ≥200 (experimental designs)
0 Sample size <400 (cohort studies) and <200 (experimental designs)
Outcome measures (*complete for each different outcome***)**
3 Self-reported measure validated through biomarker
2 Self-reported measure validated through other measurements
1 Self-reported measure collected through special techniques to improve response rate (e.g. AUDIO-ACASI/ AMASI, ACASI/ AMASI, sealed envelopes, etc.)
0 Not reported
Determinant measures (*complete for each different determinant***)**
3 Reliability coefficient ≥.75 and reasonable face validity *or* criterion or convergent validity coefficient ≥ 0.3 *or* more than one instrument or information source used
2 Use of an instrument used in previous studies with the same sample
1 Use of a non-validated measure
0 Not reported
Determinant (causal risk factor/ risk factor) score (*complete for each different determinant***)**
6 Analysis with variation in the predictor and adequately balanced, with analysis of change
5 Analysis with variation in the predictor and adequately balanced, no analysis of change
4 Analysis with variation in the predictor but inadequately balanced, with analysis of change
3 Analysis without variation in the predictor, with analysis of change
2 Analysis with variation in the predictor but inadequately balanced, no analysis of change
1 Analysis without variation in the predictor, no analysis of change
Risk of Bias Assessment score (*complete for each study based on the Risk Assessment Checklist below***) – add sum of all bias criteria using the following scoring system:**
2 Low risk
1 High risk
0 Not reported

Risk of Bias Assessment – adapted from the Cochrane Handbook of Systematic Reviews

[14] Scoring to be completed separately for each analyzed association between an outcome and an associated factor.

[15] Items 1 and 2 will be scored for cross-sectional study designs.

[16] Response rate scored for cross-sectional study designs. Retention rate scored for longitudinal study designs.

Risk of Bias criteria ↓/ Study Design →	Randomised controlled trials	Non-randomised controlled trials, pre-and post-test, experimental designs	Non-experimental longitudinal or cross-sectional designs	Notes
Random sequence generation (selection bias)	☐ high risk ☐ low risk ☐ not clear	☐ high risk ☐ low risk ☐ not clear	☐ high risk ☐ low risk ☐ not clear	For non-RCTs, consider sampling strategy, e.g. total or random sampling, purposive, or unknown.
Allocation concealment (selection bias)	☐ low risk ☐ high risk ☐ not clear	☐ high risk ☐ low risk ☐ not clear	☐ high risk ☐ low risk ☐ not clear	
Blinding of participants and personnel (performance bias)	☐ low risk ☐ high risk ☐ not clear	☐ high risk ☐ low risk ☐ not clear	☐ high risk ☐ low risk ☐ not clear	For cross-sectional studies, review type of interview to improve reporting of measures, e.g. age/ gender matching of RAs, mobile vs. paper questionnaires, etc.
Blinding of outcome assessment (outcome bias)	☐ low risk ☐ high risk ☐ not clear	☐ high risk ☐ low risk ☐ not clear	☐ high risk ☐ low risk ☐ not clear	For non-RCTs, consider outcome measurements methods.
Incomplete outcome data (attrition bias)	☐ low risk ☐ high risk ☐ not clear	☐ high risk ☐ low risk ☐ not clear	☐ high risk ☐ low risk ☐ not clear	For non-RCTs, consider reporting of (1) missing data, (2) response rate.
Selective reporting (reporting bias)	☐ low risk ☐ high risk ☐ not clear	☐ high risk ☐ low risk ☐ not clear	☐ high risk ☐ low risk ☐ not clear	
Other bias	☐ low risk ☐ high risk ☐ not clear	☐ high risk ☐ low risk ☐ not clear	☐ high risk ☐ low risk ☐ not clear	Contamination in cluster RCTs.
Other bias notes				

8.2.3 Data extraction form

Notes:

- Complete this form only for included studies.
- Be consistent in the order and style you use to describe the information for each report.
- Record any missing information as unclear or not described, to make it clear that the information was not found in the study report(s), not that you forgot to extract it.

General Information

Study ID *(surname of first author and year first full report of study was published e.g. Smith 2001)*	
Date form completed *(dd/mm/yyyy)*	
Name of person extracting data	
Study author contact details	
Publication type *(e.g. full report, abstract, presentation, grey literature)*	☐ peer-reviewed article ☐ conference abstract ☐ published report ☐ conference presentation ☐ unpublished report ☐ other _____
Notes:	

Characteristics of included studies

Methods

	Descriptions as stated in report/paper	
Outcome measures	Primary outcomes: 1. Early sexual debut 2. Unprotected sex 3. Contraception use 4. Sex with an older partner 5. Transactional sex 6. Multiple partners 7. Sex drunk or on drugs 8. Sexually Transmitted Infections 9. Unwanted pregnancy 10. Combination of any of the above Secondary outcomes: Any of the above outcomes	☐ ☐ ☐ ☐ ☐ ☐ ☐ ☐ ☐ ☐ ☐ ☐
	Reliability coefficient or convergent validity coefficient	
Study design	Study without a comparison group – No analysis of change Inadequately controlled study – No analysis of change Study without a comparison group – With analysis of change Inadequately controlled study – With analysis of change Controlled non-experimental study – No analysis of change Controlled non-experimental study – with analysis of change Randomized experiment – Targeting a risk factor	☐ ☐ ☐ ☐ ☐ ☐ ☐ ☐
Unit of observation	☐ individual ☐ dyad (couple/ parent-child) ☐ other	
Types of intervention[17]	Behavioural Biomedical	☐ ☐

[17] For intervention trials only.

	Structural Social protection Combination of interventions	☐ ☐ ☐
	If combination of interventions, please describe the intervention:	
Comparison	☐ multiple arms/ comparison groups ☐ another intervention ☐ treatment as usual ☐ no comparison	
	Please describe comparison group/ arms:	
Duration of intervention[18]		
Duration of participation	From recruitment to last follow-up: _____ months Follow-up duration: _____ months *(from intervention to follow-up)* ***Notes on follow-up:***	

Participants

	Description	Details
Population of interest	• HIV-positive adolescents (10-19 year old) only • HIV-positive youth (15-24 years old) • Some HIV-positive adolescents or youth included in the overall sample	☐ ☐ ☐
Demographics/ characteristics of population of interest	Mode of infection	Vertical _____ % Horizontal _____% ☐ Not reported (NR)
	Gender (Report gender composition for all arms)	female _____%
	Treatment status	☐ ART naïve ☐ On ART treatment ☐ Special groups (defaulters, lost-to-follow-up, PMTCT patient) ☐ NR
	Disclosure	Know own status _____ % ☐ NR Disclosure to others: _____ % ☐ NR
Setting and context	Location	
	Community or facility (clinic) sampling	☐ community-based sampling ☐ health facility-based sampling ☐ NR
	Sampling of individual participants	☐ total population or random sampling ☐ purposive sampling ☐ convenience sampling ☐ NR

[18] For intervention trials only

Sampling	Inclusion criteria	
	Exclusion criteria	
	Method of recruitment of participants *(e.g. phone, mail, clinic patients)*	
	Sample size	
	Cluster-RCTs – Inter cluster correlation	_____ % ☐ NR
	Non-RCTs – Response rate	_____ % ☐ NR
	RCTs – Retention rate – differential attrition	_____ % ☐ NR _____ % ☐ NR

Results

Results – overview	Baseline imbalances *(if applicable)*	
	Withdrawals and exclusions (%)	
	Analysis type	ITT ☐ Completers ☐ Not reported ☐
	Missing data (rate and analysis method)	
	Confounding factors/ effect modifiers accounted for	

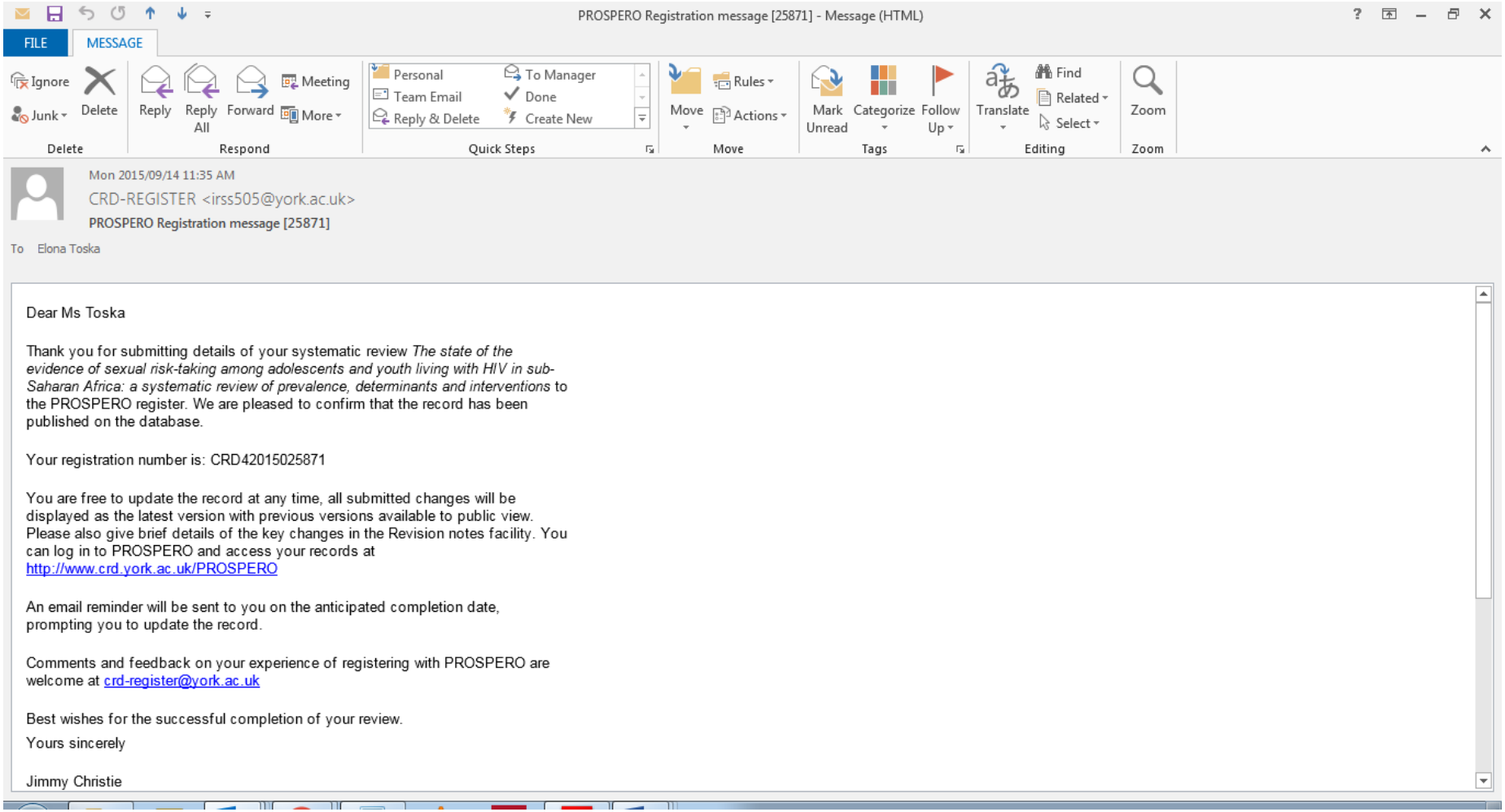
OUTCOMES

Outcome	Prevalence	Crude (specify, e.g. OR, RR, IRR and specify the reference group)	Adjusted (specify, e.g. OR, RR, IRR and specify the reference group)	Intervention effect (if relevant)	Notes

DETERMINANTS

Determinant	Prevalence (N=?)	Outcome 1				Outcome 2			
		Relationship to outcome (delete as appropriate)	Crude (specify, e.g. OR, RR, IRR and specify the reference group)	Adjusted (specify, e.g. OR, RR, IRR and specify the reference group)	Notes	Relationship to outcome (delete as appropriate)	Crude (specify, e.g. OR, RR, IRR and specify the reference group)	Adjusted (specify, e.g. OR, RR, IRR and specify the reference group)	Notes
		correlate risk factor causal risk factor				correlate risk factor causal risk factor			
		correlate risk factor causal risk factor				correlate risk factor causal risk factor			
ADD AS MANY AS APPLY		correlate risk factor causal risk factor				correlate risk factor causal risk factor			

8.3 SYSTEMATIC REVIEW REGISTRATION ON PROSPERO



8.4 SYSTEMATIC REVIEW APPENDICES

8.4.1 Study inclusion and exclusion criteria

Topic	Inclusion criteria	Exclusion criteria
Study population	• HIV-positive • Any of the sample in the 10-24 year old range	HIV-exposed adolescents or youth
Study design	• Intervention studies: randomised control trials, pilot studies, pre-post intervention studies (controlled and not). • Quantitative or mixed methods reports of longitudinal cohort studies. • Cross-sectional studies	• Qualitative studies • Case-control studies
Sampling	• Located in sub-Saharan Africa • Single or multi-country • Random or non-random sampling • Community and facility-based sampling	Sub-Saharan African immigrants living outside of sub-Saharan Africa
Outcome measure	• Any of the sexual behaviours listed above or a combination of these sexual behaviours, either as primary or secondary outcome; • Biological markers: STI test results and pregnancy.	• Combination risk methods where data on individual sexual behaviours are not reported • Studies reporting proxy behaviours, intentions, knowledge, or awareness related to the outcomes of interest.
Publication type	• Peer-reviewed journal article • Grey literature • Conference abstracts and presentations • Dissertations	• Conference abstracts without additional information
Language	• English • French • Portuguese • Spanish	• Any other language

8.4.2 Search string for databases searched in OvidSP (PsychARTICLES, Embase, Global Health, Ovid MEDLINE and PsycINFO)[1]

1	Population	Adolescents or youth living with HIV	(((HIV or AIDS or ((human or acquired) adj1 (immunodeficiency or immune-deficiency or immuno-deficiency))) adj2 (child* or adolescen* or teen* or you*)) or ALHIV or PHIV or BHIV).ab,ti,hw.
2	Outcome(s)	Early sexual debut	(early adj1 sexual adj1 (debut or initiation)).ab,hw,ti. Or
3		Unprotected sex	(((safe or unsafe or protected or unprotected) adj1 (sex or intercourse)) or abstinen*).ab,hw,ti.
4		Contraception use	(condom or IUD or implant* or contracepti* or hormon* or inject* or spermicide or diaphragm or (dual adj1 (protection or method))).ab,hw,ti.
5		Sex with an older partner	(((old* or age$disparate or intergenerational) adj1 sex* adj1 partner)).ab,hw,ti.
6		Transactional sex	(((sugar adj1 (daddy or daddies)) or ((transactional or survival) adj1 sex))).ab,ti,hw.
7		Multiple partners	(MCP or ((multiple or concurrent) adj2 partner*)).ab,hw,ti.
8		Sex drunk or on drugs	((sex adj1 drunk) or (sex adj2 drug*)).ab,hw,ti.
9		Sexually Transmitted Infections	(sexually transmitted infection* or STI* or chlamydia or gonorrh$ea or syphilis or (herpes simplex virus or HSV) or HPV).ab,hw,ti.
10		pregnancy	Pregnan*.ab,hw,ti.
11	Final outcome search string		2 OR 3 OR 4 OR 5 OR 6 OR 7 OR 8 OR 9 OR 10
12	Location	Sub-Saharan Africa	((sahara* adj1 africa) or Angola or Benin or Botswana or Burkina Faso or Burundi or Cameroon or Cape Verde or Central African Republic or Chad or Comoros or Congo or Brazzaville or Democratic Republic of Congo or Cote d'Ivoire or Djibouti or Equatorial Guinea or Eritrea or Ethiopia or Gabon or Gambia or Ghana or Guinea or Guinea$Bissau or Kenya or Lesotho or Liberia or Madagascar or Malawi or Mali or Mauritania or Mauritius or Mozambique or Namibia or Niger or Nigeria or (Reunion adj3 africa) or Rwanda or Sao Tome or Senegal or Seychelles or Sierra Leone or Somalia or South Africa or Sudan or Swaziland or Tanzania or Togo or Uganda or Western Sahara or Zambia or Zimbabwe).ab,cp,hw,ti.
19	FINAL SEARCH STRING		1 AND 11 AND 12

[1] .ab. denotes a word in the abstract; hw. denotes head words; .pt. denotes a Publication Type term; .ti. denotes a word in the title.

8.4.3 Search Strings for PubMed & Proquest

Database	PubMed	Proquest
Search String	((((("HIV"[Mesh] OR "Acquired Immunodeficiency Syndrome"[Mesh] OR "HIV-1"[Mesh]) AND ("Child"[Mesh] OR "Adolescent"[Mesh] OR "Young Adult"[Mesh]) AND ("Sexual Behavior"[Mesh] OR "Sexual Partners"[Mesh] OR "Sexual Abstinence"[Mesh] OR "Social Behavior"[Mesh] OR "Reproductive Health"[Mesh] OR "Coitus"[Mesh] OR "Contraception"[Mesh] OR "Contraception, Postcoital"[Mesh] OR "Contraception, Barrier"[Mesh] OR "Contraception, Immunologic"[Mesh] OR "Contraception Behavior"[Mesh] OR "Sexually Transmitted Diseases/epidemiology"[Majr] OR "Sexually Transmitted Diseases/prevention and control"[Majr] OR "Sexually Transmitted Diseases/psychology"[Majr] OR "Pregnancy in Adolescence"[Mesh] OR "Pregnancy"[Mesh] OR "Pregnancy, Unplanned"[Mesh] OR "Pregnancy, Unwanted"[Mesh]) AND ("Randomized Controlled Trial"[Publication Type] OR "Non-Randomized Controlled Trials as Topic"[Mesh] OR "Multicenter Studies as Topic"[Mesh] OR "Cross-Over Studies"[Mesh] OR "Evaluation Studies as Topic"[Mesh] OR "Program Evaluation"[Mesh] OR "Evaluation Studies"[Publication Type] OR "Pilot Projects"[Mesh] OR "Cohort Studies"[Mesh] OR "Lost to Follow-Up"[Mesh] OR "Epidemiologic Studies"[Mesh] OR "Odds Ratio"[Mesh]) AND ("Africa"[Mesh] OR "Africa South of the Sahara"[Mesh] OR "South Africa"[Mesh] OR "Africa, Western"[Mesh] OR "Africa, Southern"[Mesh] OR "Africa, Eastern"[Mesh] OR "Africa, Central"[Mesh])	(((HIV OR AIDS OR ((human OR acquired) adj1 (immunodeficiency OR immunodeficiency OR immunodeficiency))) adj2 (child* OR adolescent* OR teen* OR you*)) OR ALHIV OR PHIV OR BHIV) AND ((early adj1 sexual adj1 (debut OR initiation)) OR ((safe OR unsafe OR protected OR unprotected) adj1 (sex OR intercourse)) OR abstinen* OR (condom OR IUD OR implant* OR contraception* OR hormone* OR inject* OR spermicide OR diaphragm OR (dual adj1 (protection OR method))) OR ((old* OR age disparate OR intergenerational) adj1 sex* adj1 partner) OR (sugar adj1 (daddy OR daddies)) OR ((transactional OR survival) adj1 sex) OR (MCP OR (multiple or concurrent) adj2 partner*) OR ((sex adj1 drunk) OR (sex adj2 drug*)) OR (sexually transmitted infection* OR STI* OR chlamydia OR gonorrhoea OR gonorrhea OR syphilis OR (herpes simplex virus OR HSV) OR HPV) OR Pregnan*) AND ((sahara* adj1 africa) OR Angola OR Benin OR Botswana OR Burkina Faso OR Burundi OR Cameroon OR Cape Verde OR Central African Republic OR Chad OR Comoros OR Congo OR Brazzaville OR Democratic Republic of Congo OR Cote d'Ivoire OR Djibouti OR Equatorial guinea OR Eritrea OR Ethiopia OR Gabon OR Gambia OR Ghana OR guinea OR guinea bissau OR Kenya OR Lesotho OR Liberia OR Madagascar OR Malawi OR Mali OR Mauritania OR Mauritius OR Mozambique OR Namibia OR Niger OR Nigeria OR (Reunion adj3 africa) OR Rwanda OR Sao Tome OR Senegal OR Seychelles OR Sierra Leone OR Somalia OR South Africa OR Sudan OR Swaziland OR Tanzania OR Togo OR Uganda OR Western Sahara OR Zambia OR Zimbabwe)
Publication Types	n/a	AND stype.exact("Conference Papers & Proceedings" OR "Scholarly Journals" OR "Dissertations & Theses" OR "Working Papers" OR "Government & Official Publications")
Language	AND (English[lang] OR French[lang] OR Spanish[lang] OR Portuguese[lang])	AND la.exact("English" OR "Portuguese" OR "French" OR "Spanish")
Timeline	AND (("1983/01/01"[PDAT] : "3000/12/31"[PDAT])	AND pd(>19830101)

8.4.4 Search strings for other smaller databases (PopLine, WHO Africa, and CINAHL)

	Search terms		Popline	WHO Africa	CINAHL
1	Population	Adolescents or youth living with HIV	Title: (((HIV or AIDS) AND (child* OR adolescen* OR teen* OR you*)) OR ALHIV OR BHIV OR PHIV) OR Keyword: (((HIV or AIDS) AND (child* OR adolescen* OR teen* OR you*)) OR ALHIV OR BHIV OR PHIV)	(HIV OR AIDS) AND (child OR adolescent OR teenager OR youth)	((HIV or AIDS) AND (child* OR adolescen* OR teen* OR you*)) OR ALHIV OR BHIV OR PHIV)
2	Outcome(s)	Early sexual debut Unprotected sex Contraception use Sex with an older partner Transactional sex Multiple partners Sex drunk or on drugs Sexually Transmitted Infections Unwanted pregnancy	N/A	sex	(((early N1 sexual N1 (debut or initiation)) OR (((safe or unsafe or protected or unprotected) N1 (sex or intercourse)) or abstinen*) Or (condom or IUD or implant* or contracepti* or hormon* or spermicide or diaphragm or (dual N1 (protection or method))) Or (((old* or age$disparate or intergenerational) N1 sex* N1 partner)) Or (((sugar N1 (daddy or daddies)) or ((transactional or survival) N1 sex))) OR ((MCP or (multiple or concurrent) N2 partner*)) OR ((sex N1 drunk) or (sex N2 drug*)) OR (sexually transmitted infection* or STI* or chlamydia or gonorr$ea or syphilis or (herpes simplex virus or HSV) or HPV) OR Pregnan*)
3	Location	Sub-Saharan Africa	(sahara* and africa) or (south* and Africa) or (east* or Africa)	N/A	selected Africa under 'Geographic Subset'
Final search		1 AND 3		1 AND 2	1 and 2

9. FULL BASELINE STUDY RESEARCH TEAM

Listed alphabetically but will group by job type

Name	Title	Role
Amanda Mbiko	Research Assistant	Clinic and community-based interviews. Piloting of clinic data collection.
Amol Naik	International volunteer	Adherence measures literature review
Andre Robb	Fieldwork Coordinator	Team capacity building, financial reporting
Aviwe Mboyiya	Research Assistant	Clinic and community-based interviews
Bulelani Kinana	Research Assistant	Clinic and community-based interviews
Babalwa Makwenkwe	Research Assistant	Clinic and community-based interviews
Becca Jopling	Fieldwork coordinator	Recruitment and interview logistics
Blessing Madondo	Project Manager Trainee	Project management, fieldwork logistics, capacity building
Bongiwe Saliwe	Research Assistant	Clinic and community-based interviews
Christin Gilmer	International volunteer	Clinic mapping coordinator
Carly Hudelson	International Volunteer	Adherence factors systematic review
Chunyiswa Kama	Research Assistant	Clinic and community-based interviews
Dumile Mhlauli	Research Assistant	Clinic and community-based interviews
Elona Toska	Project Manager	Quantitative investigator and manager
Izidora Skracic	Fieldwork Coordinator	Administrative support and financial reporting
Janina Steinert	Fieldwork Coordinator	Quantitative fieldwork coordinator
Jessica Sandelson	Fieldwork Coordinator	Fieldwork logistics and referrals
Julia Rosenfeld	Project Manager	Fieldwork manager, referrals
Khameer Kidia	International Volunteer	Disclosure literature review and analyses
Marija Pantelic	Project manager	Quantitative investigator, manager and referrals
Lauren Parmley	Fieldwork Coordinator	Roster management, clinic-based research
Louis Pilard	Fieldwork Coordinator	Roster management, fieldwork logistics, capacity building
Mavis Mpumlwana	Ass. Project Manager	Roster management, fieldwork logistics, recruitment of young moms and pregnant adolescents, recruitment of initial refusals, capacity building
Maya Isaacsohn	Project Manager	Fieldwork and Clinic-based research coordinator
Moses Neel	Research Assistant	Clinic and community-based interviews
Nomampondo Sotsonga	Research Assistant	Clinic and community-based interviews
Nolusindiso Gwebecimele	Research Assistant	Clinic and community-based interviews
Nonkumbuzo Galela	Research Assistant	Clinic and community-based interviews
Beauty Kamile	Research Assistant	Community guide for Kwalini initially. Clinic and community-based interviews.
N Nduvana	Research Assistant	Clinic and community-based interviews

Niklas Bobrowitz	International volunteer	Clinic factors literature review & profile draft
Philiswa Nokubonga Mjo	Community Liaison Officer	Clinic and community-based interviewer. Coordinated relationships with local community contacts and referrals. Fieldwork logistics.
Phumla Nobatye	Research Assistant	Clinic and community-based interviews
Rachel Smith	International Volunteer	Fieldwork logistics
Siyavuya Mqalo	Research Assistant	Clinic and community-based interviews
Sally Medley		
Sindiswa Mona	Research Assistant	Community-based interviews
Siphesihle Tshaka	Research Assistant	Clinic and community-based interviews
Thembani Mampangashe	Research Assistant	Clinic and community-based interviews. Fieldwork logistics
Thembeka Tsiba	Research Assistant	Clinic and community-based interviews
Tom Walker	Fieldwork Coordinator	Roster management, paper-based questionnaire design
Unathi Mgweba	Fieldwork Coordinator	She quit after one day of work ☺
Unathi Ngesi	Research Assistant	Clinic and community-based interviews
Vuyiseka Luke	Research Assistant	Trainer, Interviewer
Yasmin Dunkley	Fieldwork Coordinator	Fieldwork logistics
Zoliswa Marikeni	Research Assistant	Clinic and community-based interviewer, referrals, piloting of clinic data collection.

10. RESEARCH PARTNER ORGANISATIONS

http://teampata.org/#

Paediatric AIDS Treatment for Africa (PATA) is an NGO based in South Africa working with over 250 multi-disciplinary health teams in 23 countries to ensure that all children and adolescents living with HIV in sub-Saharan Africa receive optimal treatment, care and support and live long, healthy lives. PATA's mission is to mobilize and strengthen a network of frontline healthcare providers to improve paediatric and adolescent HIV prevention, treatment, care and support in sub-Saharan Africa. PATA was a key partner during the study design, sharing contact details from partners in the Eastern Cape, providing feedback on study design and measures. The research team has also collaborated with PATA to disseminate preliminary findings through presentations and workshops at PATA's continental, regional, and youth summits.

http://keiskamma.com/health/

The Keiskamma Trust is a South African NGO working in rural Eastern Cape focusing on uplifting vulnerable communities through art-based, music-based, health-focused and education-centred programmes. The Keiskamma Trust Health programme was key to increasing access to ART to thousands of people in rural Eastern Cape communities. The Mzantsi Wakho research team collaborated with the Keiskamma Trust in several key ways: (1) participatory workshops with HIV-positive adolescents, (2) piloting of quantitative questionnaire, (3) in-depth qualitative research.

http://www.therelevancenetwork.com

The Relevance Network is a South Africa-based consulting firm that seeks to support human rights and access to quality services through multisectoral, integrated partnerships. The Relevance Network's Executive Direction, Craig Carty, has been a key investigator in the Mzantsi Wakho team, focusing on building relationships with facilities and improving access to and quality of available patient file data such as viral loads, CD4 counts, etc. The Relevance Network team, based in East London, is a close collaborator of the Mzantsi Wakho fieldwork team.

http://www.spf.org.za/

Small Projects Foundation is a local partner of PATA. Small Projects Foundation (SPF) is a non-governmental organisation that has contributed to community empowerment and development in the Eastern Cape and nationally since 1988. The Foundation now specialises in the areas of project management, social marketing, development facilitation, training, innovative development, research and evaluations.Their HIV/AIDS team, Ms. Rose Ewing and Executive Director, Mr. Paul Cromhout, provided crucial advice during the design of the study, referred the study team to potential partner facilities and organisations, and suggested important research topics based on their experience providing support to HIV-affected children and adolescents in the Eastern Cape.

11. HEALTH AND SAFETY FORMS

11.1 RISK ASSESSMENT FORM: ELONA TOSKA

Date updated: 4 October 2013

All incidents will be documented and this risk assessment and the attached safety protocol will be updated on an annual basis by the Project Manager.

Hazard	Risks involved	Control measure
Personal (e.g. theft, violence, crime, personal heath)	South Africa has high crime rates (car theft, house break-ins, theft of personal possessions, and violence to person). We have developed a safety protocol for the Mzantsi Wakho project that is followed by all staff (including Project Managers and PIs when in South Africa – **see Appendix 12**).	Drive with car doors locked at all times. Drive with car windows closed (use air conditioning instead). Do not drive in dangerous areas at night; if have to drive in dangerous areas by day do so with caution and follow advice in anti-hijacking literature distributed by SA Police which we possess. Always travel with a fully charged cellphone with emergency numbers in the address book. Do not flaunt possessions e.g. laptop/cell phone/ jewellery/handbag in the street and ensure they are not visible in the car when driving or car is parked. Ensure that place where staying is safely secured at all times. Our accommodation has a burglar alarm, burglar bars at the windows, and panic buttons. Ensure approved and confirmed Travel Insurance from University of Oxford covers stolen items and health costs. University of Oxford students and staff attend courses offered from the University Safety Office.

Hazard	Risks involved	Control measure
	HIV and infectious disease risk in areas with high prevalence and deprivation.	Care will be taken to minimize exposure to HIV and TB. Post-exposure prophylaxis will be sought in cases when exposure is suspected in compliance with South African treatment protocols.
	High prevalence of bacterial and viral infections.	A first aid kit with over-the-counter prophylaxis for common infections will be carried in each project site at all times.
	Malaria is also present in some parts of South Africa.	Take appropriate preventative measures against malaria (prophylactics, cover up in the evenings, close the windows at night to avoid being bitten).
Travel (e.g. remote location, driving)	South Africa has high numbers of road deaths (appox. 1000 people per month). Roads in remote areas can be of poor quality, particularly in the winter. Access to mechanics for car breakdowns may be limited in rural areas.	Ensure that the car is not faulty and can withstand poor road conditions (e.g. gravel) if driving in such an area. Ensure that the driver is not tired or under the influence of drugs or alcohol and is fit to drive. Drive within the speed limits, keep distance from car in front, be vigilant about poor drivers or pedestrians or animals on the road. Use reputable car hire companies and take out max insurance available for theft and car damage caused by accident (unfortunately they all have an excess these days). Costs of damage to other people on the road (if involved in a crash) are covered by the Road Accident Fund. Whenever travelling, inform someone else of where you are going, when you are due there, contact details, and when you are due back.

Hazard	Risks involved	Control measure
		Project vehicle is maintained and serviced regularly. Updated car documents and maintenance profile passed on to every driver. Use public vehicles only in areas of known safety and after consulting with local knowledge and experience.
Location (e.g. extreme weather, temperatures,)	It can get hot in the summer months.	Ensure protective clothing and sun screen is worn when in field. Accommodation has air conditioning. Direct sunlight is to be avoided wherever possible to avoid sunburnt and heat stroke. First aid kit to include oral rehydration salts for such situations.
Work environment (e.g. lone working, cultural differences)	Our research is conducted in informal settlements in Eastern Cape and the Western Cape. Due to the nature of these settlements there are potential risks to staff safety – including theft and violence to person.	We have developed a safety protocol for reporting and responding to safety issues as they arise in field. All Young Carers staff (including PIs) adhere to this protocol when in South Africa. The safety protocol is attached to this risk assessment form. Consultations with local partners: Paediatric AIDS Treatment for Africa (based in Cape Town), Small Projects Foundation (based in East London), Keiskamma Trust (based in Hamburg, Eastern Cape), and Raphael Centre (based in Grahamstown). Researchers will be accompanied in the field by Xhosa speaking field assistants who is familiar to the neighbourhoods and will facilitate cultural translation. The U. of Oxford research team will also attend a basic isiXhosa course before going on fieldwork.

Hazard	Risks involved	Control measure
Other (e.g. manual lifting, sanitation, diet, hazardous substances, water-borne diseases)	Water quality in the main cities is largely fine but does vary.	Boil water or drink bottled water if in a rural area or in an area known to have poor water quality. Avoid salad, buffet food and ice unless in safe areas.

11.2 MZANTSI WAKHO SAFETY PROTOCOL

Overview:

This document aims to outline a general procedure that will be implemented to ensure the safety of all Mzantsi Wakho South Africa staff. All staff should read this document and sign the declaration included. The structure for the reporting and documenting of any safety issues that might arise is outlined in the diagram below (contact details for the Principal Investigator and all Mzantsi Wakho Project Managers are included at the end of this document). Appended to this document are also procedures put in place regarding personal safety, what to do in the event of being a victim of crime or violence, driving safety, health safety, substance misuse, tablet use and safety, fire and floods (and other natural disasters), as well as climate safety.

The safety of our team members is the paramount concern of the project. All team members are briefed on how to respond to situations of crime and violence. The first goal is to remove yourself from the situation as quickly as possible, and to seek a place of safety. Avoid any further confrontation with criminals. In cases of robbery, **comply without hesitation and** do not try to recoup stolen property or to apprehend criminals.

Hierarchy for the reporting and documenting of any safety concerns

Procedure:

1. Any staff safety concerns should be raised with Project Managers immediately. Project Managers (PMs) will make a decision about whether to deal with this immediately, to discuss with the Principal Investigator, or to discuss in the weekly staff meeting at each provincial site. Research Assistants (RAs) in East London report to the Project Manager. RAs in King Williams Town report to the Project Manager, but should raise concerns with their Fieldwork Coordinators, who will forward them to the Project Manager.

The qualitative team report to Dr. Rebecca Hodes directly. If she is unavailable and there is an emergency, qualitative RAs report to Dr. Lucie Cluver.

2. Project Managers and their team should determine whether the safety concern is likely to be a local issue, or whether this issue might impact other sites. If it is deemed that the concern may impact other sites the Principal Investigator and all other Project Managers should be informed immediately. Project Managers and staff at all sites should discuss the issue and any possible safety procedures that could be implemented to address it

3. If the concern is deemed to be relevant only to the local site, the Project Manager and staff should discuss the issue and any possible safety procedures that could be implemented to address the issue. The Project Manager should also contact the Project Managers of the other sites to determine whether the concern has been a problem in other provinces and, if so, what procedures were put in place to address it.

4. If a safety procedure is decided upon, the initial concern and the proposed procedure should be documented (using a copy of the attached Safety Documentation Form). This form should be sent to the Principal Investigator (cc Dr. Franziska Meinck and Katherine Gardiner). If the Principal Investigator has any suggestions, recommendations, or concerns these will be communicated directly to Project Managers

   If a safety procedure cannot be decided upon the Principal Investigator should be informed and a conference call will be arranged so that the issue can be discussed between the Principal Investigator and all Project Managers

5. Once the safety procedure has been approved by the Principal Investigator the Safety Documentation Form should be appended to the office copy of the safety protocol (this document), this way a record of all safety concerns and staff responses is maintained**.** The other Project Managers and the department's admin team (Katherine Gardiner) should be emailed a copy of the form to append to their office copy of the safety protocol, this way if the same issue arises at another site the approved response is immediately available.

6. All accidents need to be reported to the department. Information should be provided to the project manager who will email Katherine Gardiner.

"I declare that I have read and understood this document. I am aware of the procedure that has been put in place to ensure the safety of *Mzantsi Wakho South Africa* staff"

Name: _____

Site: _____

Signed: _____

Date: _____

SAFETY PROCEDURES

The following safety procedures are to be followed by all Mzantsi Wakho staff:

Personal Safety:

- **Staff should carry a well-charged cell phone at all times in case of accident or emergency.** The project will purchase car chargers for phones of each coordinator/driver. These chargers and their cables must never be removed from the car. **The phone should have emergency numbers and your project manager's and field co-ordinator's numbers pre-programmed in. Check the phone will have signal.**
- **If possible also discreetly carry a cheap phone as a back-up (with emergency numbers pre-programmed) which can be used if your main phone is stolen.**
- Where there is an immediate emergency and project managers are not on field or easily contactable, staff (eg RAs) should inform their field coordinators, who will inform the project managers
- **Always inform another member of the *Mzantsi Wakho* team about your destination and estimated time of return. Have an agreed course of action if they don't hear from you.**
- If requested, all *Mzantsi Wakho* staff will be provided with a personal safety alarm
- Staff should carry safety alarm where they are easily accessible
- Staff should know the closest location to the local authorities to seek refuge if danger arises
- If danger arises, staff should remove themselves from danger immediately, without taking time to inform the Project Manager. Inform the Project Manager only once you are in a safe space to make a phone call.
- If possible, never leave a team member behind.
- Your life is more important than project property such as tablets and cars. In the event of robbery, do not put yourself at risk for project materials. Give project materials away.
- We also recommend that in the event of robbery you give up your own belongings, but the project will not be able to cover the loss of personal belongings. **It is a good idea to keep a small amount of cash in a couple of places about your person so you have some sacrificial cash to give up but still have cash some to get help with after.**
- **If interviewing in a community in which you feel unsafe:**
    - **Inform your Project Manager before starting work in the community, as early as possible**
    - Form 'Interviewer Groups' (and include a male field worker if possible)
    - If necessary an agreed upon community guide can be arranged (i.e. committee ward members)
- When inside a house, make sure you are close to the door and there are no obstacles standing in the way between you and the door.
- **Have a pre-prepared exit excuse so you can withdraw tactfully and quickly if you start to feel uncomfortable or unsafe**

- **Staff will always work in teams of two or more**

Dealing with Participants:

- Violent Participants:
    - Staff should carry a well-charged cell phone at all times in case of violence or danger **(with pre-programmed emergency numbers)**
    - If staff encounter someone who is violent, they should immediately remove themselves to a safe place (ie. Clinic, school, policy office, garage, shop, rand office)
    - Staff should **not** solve the matter independently
    - Staff should **not** respond violently (*so as not to promote escalating emotions*)
    - Do **not** confront a mob
    - Walk away and ignore the accusations
    - Inform the project manager as soon as possible
    - If violent accusations result in physical harm, project managers should open an assault case at the police station
- Unhappy Participants and Caregivers/Family members:
    - RAs should be aware of escalating emotions. If a participant or caregiver is becoming emotional or upset/suspicious about the project, stop and remind them that their participation is voluntary
    - When possible, re-address the objectives of the study, privacy guidelines for disclosure, and remind the participants that authorities in the areas are aware of the project study
    - Always carry Department of Education permission letter, to prove the legitimacy of Mzantsi Wakho. It is also helpful to point to the contact number provided in the letter and offer the participant to call this number (they may use your project airtime)
    - If participant is not satisfied with the explanation, offer to make appointment with the project manager
    - Appease the unhappy participant by ensuring that their concerns will be heard and handled
    - Give the participant packs regardless of refusing to participate.
    - Contact and inform project manager of the encounter

If a team member is the victim of crime or violence, the following protocol must be observed:

- If the incident happened during work hours, Contact your Project Manager immediately. This is Marija Pantelic for the quantitative team, and Dr. Rebecca Hodes for the qualitative team. If the Project Manager is unavailable, Dr. Lucie Cluver is the point person for all emergencies.
- Do not give any written statements to the police without seeking legal advice. Henry van Breda is a reliable criminal lawyer in East London.
- **You are not required to make statements to the police without legal counsel**. Any statements made may be used against you in court.

- Ensure that you take photos of any statements that you make, so that you have evidence of the written content of the statement.
- Report all stolen goods to the police and photograph this report.
- Staff must consider interventions very carefully, and no actions must be taken without consulting with managers.
- Emergency funds are available to buy airtime and possibly a cheap cell phone to remain in contact if your phone has been stolen. At the very least, team members must share the number of a friend with a manager in the aftermath of crime.

Driving Safety:

- Extreme caution should be used at all times when driving and all rules of the road should be obeyed
- Always ensure that you drive with locked doors and wearing your seatbelt.
- As you approach the car be aware of possible people lurking, waiting or observing around or behind the car.
- **Park the car in an open well lit area**
- Have the keys ready in your hand so that you don't spend time looking for them in front of the car.
- Lock the car as soon as you enter.
- As you enter the car, leave your bag and phone somewhere that is not visible (i.e. under the seat next to you).
- Open the window by 1.5 inches so that nobody can reach their hand through and so that it is harder to smash through.
- While driving, make sure you leave about 10 meters of space in front of you and the car ahead of you.
- If you see anyone walking with hands in pockets, this is usually a sign of someone carrying a gun. Drive yourself away from this person immediately. Do not get out of the car
- If someone jackknives you, try to drive yourself away immediately even if it means driving on the curb. Do not get out of the car.
- **Do not stop to help a seemingly stranded motorist – it might be a ploy to make you stop. If you are concerned for their welfare you can stop a safe distance away and call the police to assist them.**
- Be alert for people and animals crossing the road unexpectedly, including on the highway
- If requested, any person who will be driving a *MzantsiWakho* project car will be provided with up to three defensive driving lessons
- No speaking on phones or texting. Using a mobile phone while driving (texting or calling) is a criminal offence in South Africa
- Staff should carry a well-charged cell phone at all times in case of accident or emergency. **Pre-programe emergency numbers into the phone**
- Always get enough rest before you drive the car to avoid falling asleep behind the wheel

- When using the car for work purposes, another member of the *MzantsiWakho*team should always be informed about your destination and estimated time of return
- Valuables should never be left in the car
- Project cars are maintained and insured. However before leaving check that the car is road worthy and suitable for the terrain.
- If the car is showing any sign of trouble including unusual noises, dysfunctional fuel/oil gauge, tire problems, etc, inform the Project Manager immediately and do **not** drive the car.
- Make daily checks on the vehicle to ensure that there is sufficient petrol/oil/water.
- Take spare provisions (eg water) and consider how you will get assistance in an emergency (eg break down)
- Observe the speed limit and rules regarding safe overtaking (two second safe following distance).
- On the highway, put the headlights on no matter the time of day.
- **Where possible avoid travelling alone at night.** No driving on highways or outside the cities of East London or King Williams Town at night.
- Avoid leaving valuables in cars. If you must leave valuables inside a car, ensure that it is locked and that the windows are closed. Never leave valuables in the back of the Bakki.
- Your personal safety is more important than the car!

Health of staff members

All staff from overseas is required to make an appointment with their local travel clinic prior to their departure. Oxford DPhil students can make an appointment with the Oxford University Occupational Health Service or their GP. All overseas staff should be up-to-date with their recommended vaccinations including Hepatitis A and rabies.

- There is a high risk of exposure to TB during interviews. It is important to note the following:
  - Interviews should be conducted in well-ventilated areas. Outside under a tree would be best (weather permitting). If the interview must be conducted inside then make sure all the windows are open and that the RA sits at the open door.
  - Research participants who have been on treatment for 2 weeks are no longer infectious.
  - Contact with infectious participants who are not on treatment should be limited. Interviews should be scheduled for a later time when the participant is on treatment. If a participant tells you that they have TB and are not on treatment or have been on treatment for less than 2 weeks, stop the interview immediately and reschedule.

- The areas in which research is conducted have high HIV prevalence. HIV is not transmitted by touching or kissing someone. HIV is transmitted through unprotected contact with bodily fluids.
  - Staff should practice safer sex wherever possible and get tested regularly
  - If members of staff think they may have been exposed to HIV it is vital they seek post-

exposure prophylaxis from the nearest hospital as soon as possible and not longer than 72 hours after the exposure

- Staff members with existing medical conditions:
  - All staff with chronic medical conditions such as epilepsy or diabetes are requested to wear medical alert bracelets
  - All staff are responsible to carry their medication with them at all times and show their team members where it is kept and how to administer it in an emergency

Alcohol and substance use

- Mzantsi Wakho is a drug-free and alcohol-free programme. This means that the consumption or possession of alcohol and illicit drugs whilst at work is unacceptable and volunteers/employees should present themselves for work and remain, while at work, capable of performing their work duties safely.
- The effects of drugs and alcohol abuse (ie hangovers or any other affects that will lead to impairment) will furthermore not be tolerated.
- Any employee found to be under the influence of alcohol or drugs may not enter or remain on the project premises and will be released from employment immediately.

Wildlife

- *Mzantsi Wakho* team members should treat homes with dogs with caution
- Do NOT approach wildlife. Do not attempt to feed baboons!
- In rural areas you may encounter snakes. Snakes are most likely to bite when they feel threatened, are startled, are provoked, or have no means of escape when cornered. Encountering a snake is always considered dangerous and it is recommended that you leave the vicinity
- Wear long trousers and covered shoes in areas where there is a risk of snakes
- If requested, one member of each field work team will be provided with First Aid training
- Staff should carry a well-charged cell phone at all times in case of accident or emergency. **Check the phone will have a signal where you are going.**
- Stay clear of all areas where lions, cheetahs and leopards have been spotted
- Identify the nearest health centre before each new journey into a rural location

Climate:

- Heat: fieldworkers will be provided with coolers and water bottles during the summer months
- Rain: fieldworkers will be provided with umbrellas and rain boots

Fire, Floods, and Natural Disasters

- In any case of environmental hazard, consider your own safety and that of your team first and remove yourself from danger

- Do not attempt to cross a floods or fire in order to get yourself to interviews. **If there is any doubt check local news before setting out.**
- The Project Manager and Principal Investigator will make a decision for longer-term work in areas undergoing natural disasters. This will be done in consultation with the fieldwork team and we will think together about how best to deal with these issues

Taxi wars, riots, political violence

- In the event of taxi wars, riots, or political violence discuss any safety issues with Project Managers, but in any case where there is risk to staff, fieldwork will suspend or move to another area.
- Do not attempt to cross a riot or protest in order to get yourself to interviews.
- In the event of taxi war, inform the Project Manager immediately, and we will help you arrange alternative transport to work.

Local elections 2016: In preparation for the local elections of August 3rd, 2016, the research team took additional precautions, including but not limited to:

1. No bright t-shirts or clothes in any of the party colours to avoid mistaken identity;
2. Everyone to have MW approval/ introductory letters (laminated) and badges to explain that a) we are part of a community project and b) we are not allowed to talk about politics;
3. No discussion of politics in any work hours, with staff or participants;
4. Team members to immediately inform PMs/ PIs if they hear about any planned demonstrations, protests, etc., so that we can plan for everyone to be in safe areas, and
5. If there is any risk, leave the area immediately.

Election-related violence and unrest was monitored through a unique Twitter account: **kwcelmonitor**, and regular monitoring of Facebook sites of local media and agencies, such as the Daily Dispatch, the Herald, and ENCA.

Miscellaneous:

- In various sites fieldworkers have been accused of being Satanists. This should be addressed through: addressing concerns that have lead to negative impressions of the project (e.g. that we're taking away legitimate/fraudulent grants), praying with the people who have accused fieldworkers of Satanism, working with local religious leaders to prevent any confusion about our affiliation.
- All staff members are requested to register a telephone number of a relative or friend which can be contacted in case the member of staff is involved in an accident at work. Emergency numbers are to be emailed to Franziska Meinck and the Oxford team (Lizzy Button and Sarah Hoeksma).
- For foreign nationals, don't travel around with your passport on your person. Make a copy when you arrive in South Africa, and have this certified at a local police station. Travel with this on your person as a means of identification. Leave your passport and other valuables locked at home in a suitcase.
- Don't walk around with earphones in. You must be able to hear and be aware of your surroundings at all times.

- Avoid expensive-looking jewellery, shoes or clothing.
- Avoid visible valuables such as wallets or cell phones in pockets, and laptop bags.
- Follow your intuition. If it doesn't feel right, don't worry about manners or about causing offense. Get out of the situation.

For Project Managers

- Project managers should make sure all field staff have a copy of documented safety procedures amongst field protocols and ask staff to sign for confirmation of having read and accepted adherence to them. Staff should also be encouraged to provide suggestions or highlight guidelines that are not working at team meetings. Project managers are also responsible for reporting accidents to the department.
- If re-addressing the objectives of the study has not worked to calm down violent participants:
    - Inform the Indunas and ward councillors about the encounter and request another community meeting (with Indunas and local authorities -Community Development Forum staff, CDFs present)
    - Address some of the issues encountered and explicitly and patiently explain the **reason** for each questions (i.e. Who lives in my home) if necessary
    - Prior assessments of communities is crucial (get information on safety, crimes, witchcraft, etc.), and know the village and culture
    - Monitor your RAs, violent encounters can be traumatic. Offer psychological counselling (with local psychologists in hospitals) or debrief team members
    - Provide reminder trainings on the safety protocol for all fieldwork staff

MOBILE DEVICES (TABLET) USE PROTOCOL

Tablet Use

Report all problems with tablets while in field to a project manager immediately. Tablets should only be used for work purposes. Specifically, tablets are used to: 1) collect questionnaire data; 2) collect video and photo answers from participants.

***Your* Safety**

- Only take tablets out when you are ready to do an interview with a participant and in a space where you feel safe.
- When traveling on foot or public transport with tablets, keep the tablet in your bag at all times.
- When travelling by car, ensure that tablets are concealed from view at all times. Do not leave tablets in the car unattended. Ensure that the car does not move off until the tablet is safely stored away, tablets are not allowed to ride by themselves in the back of the car (even if concealed from view).
- It is important to avoid exposing tablets in public.
- If you are not sure of your safety, get to a nearby safe place (tuck shop, participant's home, school or clinic) and phone a project manager.

- In the event of a threat and where you do not have time to report this to a manager, avoid harm to yourself by any means necessary, even if that involves giving away the tablet.

***Participant* Safety**

- Make sure that interview sites are safe and secure. If you struggle to find a safe place, phone a project manager to make an alternative plan.
- Make sure that participants feel safe and comfortable in the place where you will interview her/him. Participants cannot go off on their own with tablets or share tablets with friends or family.
- If a participant wants to input the answers themselves, they must stay somewhere near the RA (in direct eyesight as the tablet is still the RA's responsibility during this time).
- Assist the participant any time. “Choose a Photo” or “Choose a Video” is used to ensure that they do not see other participants’ information.
- Never share data on the tablets with anyone other than a project manager or fieldwork coordinator in the team. Failing to do so could result in criminal prosecution.

***Tablet* Safety**

- Tablets will be delivered to the field each morning and picked up at the end of each day by a Project Manager or Fieldwork Co-ordinator in the project vehicle. Any changes to this policy will be discussed at team meetings.
- The tablets stay at the office when not in use by the project, unless authorised by a PM.
- Tablets will be kept in a locked cabinet and charged onsite every night.
- Each tablet will have applications that will help the team leaders to check where the tablet is and how the data is being used. No applications, such as Facebook or YouTube are to be used or downloaded on the tablets.
- Report any/all problems with the tablet whilst in field to a Project Manager immediately. Problems may include tablet running out of battery, crashing or issues saving questionnaire data.
- Tablets are to remain in their cases at all times and the pens should be given placed in the elastic bands on the tablets cases when they are delivered back to the office.

I have read, understood and discussed these terms and conditions with the Project Managers. I commit to follow these guidelines whilst using tablets for data collection.

Research Assistant Name

_____

Project Manager Name

_____

Safety Concern Documentation and Response Form

Date concern raised: _____

1) Safety Concern:

2) Proposed Response:

Response approved by PI: Yes/No

Site: _____

Signed by Project Manager: _____

Date Approved: _____

Mzantsi Wakho South Africa – Contact Details

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International Team Member Information Sheet

Name: _____

Planned fieldwork dates: Start _____ End _____

Have you sent the following to elizabeth.button@spi.ox.ac.uk and/or sarah.hoeksma@spi.ox.ac.uk?

Travel itinerary	□ Yes	□ No
Travel and medical insurance	□ Yes	□ No
Visa details	□ Yes	□ No
Passport details	□ Yes	□ No
Driving License	□ Yes	□ No

Emergency Contact Details:

Name: _____

Address: _____

Phone: _____

Email: _____

Relationship to you: _____

Medical History:

Will you be taking any long-term medication while in South Africa?

□ Yes □ No

If yes, what are the names of the medications? _____

Are you bringing the refills or will you obtain them in South Africa?

_____

Do you have any long-term health issues?

□ Yes □ No

If yes, please let us know what they are: _____

Do you have any allergies?

□ Yes □ No

If yes, what are they? _____

Do you have any special dietary requirements?

□ Yes □ No

If yes, what are they? _____