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# HIV, BLAME AND SHAME:

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INTERNALISED HIV STIGMA AMONG  
SOUTH AFRICAN ADOLESCENTS LIVING WITH HIV.

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## APPENDICES

Marija Pantelic  
Department of Social Policy and Intervention  
Green Templeton College  
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## TABLE OF CONTENTS

<b>APPENDIX 1: SYSTEMATIC REVIEW PROTOCOL .....</b>	<b>3</b>
<b>APPENDIX 2: STUDY PROTOCOL .....</b>	<b>20</b>
<b>APPENDIX 3: SAMPLE ETHICS UPDATE LETTER .....</b>	<b>61</b>
<b>APPENDIX 4: OXFORD UNIVERSITY SOCIAL SCIENCES AND HUMANITIES INTER-DIVISIONAL RESEARCH ETHICS COMMITTEE APPROVAL.....</b>	<b>64</b>
<b>APPENDIX 5: UNIVERSITY OF CAPE TOWN CENTRE FOR SOCIAL SCIENCE RESEARCH ETHICS APPROVAL .....</b>	<b>65</b>
<b>APPENDIX 6: EASTERN CAPE DEPARTMENT OF HEALTH ETHICS APPROVAL LETTER ...</b>	<b>66</b>
<b>APPENDIX 7: AMATHOLE DISTRICT DEPARTMENT OF HEALTH ETHICS APPROVAL.....</b>	<b>67</b>
<b>APPENDIX 8: CECILIA MAKIWANE HOSPITAL ETHICS APPROVAL LETTER.....</b>	<b>68</b>
<b>APPENDIX 9: EASTERN CAPE DEPARTMENT OF EDUCATION ETHICS APPROVAL.....</b>	<b>69</b>
<b>APPENDIX 10: CONSENT FORM .....</b>	<b>71</b>
<b>APPENDIX 11: DATA CONFIDENTIALITY AGREEMENT .....</b>	<b>72</b>
<b>APPENDIX 12: MZANTSI WAKHO SAFETY PROTOCOL .....</b>	<b>73</b>
<b>APPENDIX 13: QUANTITATIVE QUESTIONNAIRE .....</b>	<b>81</b>

# APPENDIX 1: SYSTEMATIC REVIEW PROTOCOL

## Systematic review protocol:

### Predictors and Correlates of Internalised HIV-Related Stigma (IHS)

#### in Sub-Saharan Africa

Marija Pantelic<sup>1</sup>, Yulia Shenderovich<sup>2</sup>, Lucie Cluver<sup>1,3</sup>, Mark Boyes<sup>1,4</sup>

<sup>1</sup> Department of Social Policy and Intervention, University of Oxford, Oxford, UK

<sup>2</sup> Department of Psychiatry, University of Cambridge, Cambridge, UK

<sup>3</sup> Department of Psychiatry and Mental Health, University of Cape Town, Cape Town, South Africa

<sup>4</sup> School of Psychology and Speech Pathology, Curtin University, Perth, Australia

## **I. BACKGROUND**

Three decades into the fight against HIV, stigma remains a major ‘road block’ to HIV prevention and treatment (UNAIDS 2007). In 2011, UN member states committed to eliminating HIV/AIDS-related stigma by 2015 (UNAIDS 2011). The literature recognizes two types of HIV-related stigma, enacted and internalized stigma. Existing interventions heavily focus on reducing enacted stigma (Stangl et al. 2013), which refers to negative public attitudes or discrimination towards people living with HIV (Horwitz et al. 2013). Less is known about how to reduce internalised HIV-related stigma (IHS), which occurs when HIV-positive people endorse negative public attitudes associated with HIV and accept them as applicable to themselves (Earnshaw et al. 2013). IHS is characterised by feelings of shame, guilt, worthlessness and difficulties around HIV status disclosure (Lee et al. 2002; Tsai et al. 2012).

Sub-Saharan Africa is home to 70% of the world's HIV-positive people but only two interventions targeting IHS in the region were found in a recent systematic review (Stangl et al. 2013). Both interventions aimed to improve coping through empowerment and knowledge building. Uys et al. (2009) used a multiple-case study approach to evaluate non-standardized programmes designed by small groups of 7-10 nurses and 7-10 HIV-positive patients in 5 healthcare facilities in Lesotho, Malawi, South Africa, Swaziland, and Tanzania. Taken together, the programmes resulted in a significant reduction in negative self-perception among the patients ( $M_1=.82$ ;  $M_2=.36$ ,  $p<.001$ ). By contrast, Tshabalala and Visser (2011) evaluated a structured cognitive-behavioural therapy intervention in a mixed methods randomized trial with HIV-positive women in South Africa ( $n=10$  in the intervention group and 10 in the waitlist control group). The intervention resulted in significantly greater IHS change scores in the intervention group when compared to the control group. Findings from both evaluations should be replicated by large randomized trials before firm inferences are made. Another systematic review of the effectiveness of HIV-related interventions in reducing HIV/AIDS stigma found only one African study and none measuring internalised stigma (Sengupta et al. 2011). Thus, no well-established programs to reduce IHS have been identified in sub-Saharan Africa to date. Moreover, there is no evidence of community or macro-level interventions to reduce internalised stigma, but a growing body of work suggests that stigma and its internalization are entrenched in wider structural inequalities (Parker & Aggleton 2003; Tsai et al. 2013; Campbell & Deacon 2007)

Development of future evidence-based interventions requires knowledge of predictors of IHS in sub-Saharan Africa (Blum & Ireland 2004). Systematic reviews are the gold standard for evaluating intervention effects (Chalmers et al. 1992), and they can also summarize evidence about observational studies (Murray et al. 2009). To our knowledge, to date no comprehensive review on predictors of IHS in sub-Saharan Africa has been conducted, despite the region's disproportionate HIV burden. Logie & Gadalla (2009) conducted a systematic review and meta-analysis of health and demographic correlates of both enacted and internalized HIV-related stigma in North America. However we should be extremely cautious about the transferability of North American studies to sub-Saharan Africa, where HIV is prevalent in the general population rather than over-represented

among otherwise stigmatized populations such as men who have sex with men and racial/ethnic minorities.

## II. OBJECTIVES

The aim of the systematic review proposed in this protocol is to advance theory and inform needed intervention development in Sub-Saharan Africa by synthesizing existing evidence of predictors of IHS in the region. The scope of this review (Table 1) is restricted to observational studies to avoid overlap with the recent systematic review of interventions to reduce HIV-related stigma (Stangl et al. 2013).

If appropriate, the studies will be summarized using meta-analysis. 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 (see Section III.e.).

The scope of the review is summarized in Table 1. See Section III.c. for the full list of inclusion and exclusion criteria.

**Table 1 Scope of the review**

Outcome	HIV/AIDS related internalised or self-stigma, shame, negative self-image, negative self-perception
Population	People living with HIV of all ages
Geographic location	Sub-Saharan Africa

Study design	Cross-sectional surveys, case-control studies, cohort studies, psychometric studies (scale validity and reliability studies)
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### **III. METHODS**

#### **III.a. Search Strategy**

Studies will be identified through electronic searches of bibliographic databases and grey literature sites, examining citations of retrieved studies, and contacting researchers working in the area. The larger databases to be searched through OvidSP (PsycARTICLES, Embase, Global Health, Ovid MEDLINE, and PsycINFO) will use a sensitive search string summarized in Table 2. Smaller databases (CINAHL and WHO Afro Library) will incorporate a simpler, more inclusive search string summarized in Table 3. Key authors will be contacted for unpublished and ongoing studies. References listed in other reviews on HIV/AIDS stigma (Stangl et al. 2013; Logie & Gadalla 2009; Sengupta et al. 2011; Tsai et al. 2013; Brown et al. 2003) and other relevant studies will be screened. The PROSPERO register of systematic reviews will also be searched.

**Table 2 Search string for databases searched in OvidSP (PsychARTICLES, Embase, Global Health, Ovid MEDLINE and PsycINFO)**

1	Population	People living with HIV	(HIV or AIDS or PLWHA or PLWH or ((human or acquired) adj1 (immunodeficiency or immunodeficiency or immuno-deficiency))).ab,hw,ti.
2	Outcome	HIV-related internalised stigma	((stigma adj1 (self or internal* or auto)) or (self adj1 (perception or image)) or (shame adj2 HIV) or (shame adj2 AIDS)).mp. or (shame adj2 antiretroviral*).ab,hw,ti,tx. [mp=ti, ab, tx, ct, sh, hw, tn, ot, dm, mf, dv, kw, bt, nm, kf, ps, rs, an, ui, tc, id, tm]
3	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.

Final search: 1 AND 2 AND 3

**Table 3 Search string used for smaller databases (WHO Afro Library and CINAHL\*)**

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1	Population	People living with HIV	HIV or AIDS
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2	Outcome	HIV-related internalised stigma	stigma OR negative self-perception OR negative self-image OR shame
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Final search: 1 AND 2

\*CINAHL search selected Africa under 'Geographic Subset'

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### **III.b. Study Selection Process**

Following the Cochrane Collaboration Handbook (Deeks et al. 2008), search results will be merged and de-duplicated. The initial screening will involve examination of titles and abstracts to remove irrelevant reports. Full text documents will be retrieved for potentially relevant reports, and these will be examined in detail for compliance with eligibility criteria (see Section III.c.). Where appropriate, authors will be contacted to clarify study eligibility and request additional information.

### **III.c. Inclusion and Exclusion Criteria**

To be eligible for inclusion in the review, the study must meet all of the pre-specified inclusion criteria and none of the exclusion criteria set out in Table 4. The set of screening questions to be used for final inclusion decision-making is included in Appendix 1. Although longitudinal studies are more informative regarding causality than cross-sectional studies, our preliminary review of the literature suggests that there are few

relevant longitudinal studies in sub-Saharan Africa. Therefore this systematic review will include cross-sectional, case-control and psychometric assessment studies, in addition to longitudinal studies.

**Table 4 Systematic Review Inclusion and Exclusion Criteria**

Inclusion criteria	Exclusion criteria
<p>Study population:</p> <ul style="list-style-type: none"> <li>• HIV-positive people</li> </ul>	<ul style="list-style-type: none"> <li>• People whose HIV status is unknown or not specified</li> </ul>
<p>Sampling:</p> <ul style="list-style-type: none"> <li>• Located in sub-Saharan Africa</li> </ul>	<ul style="list-style-type: none"> <li>• Sub-Saharan African immigrants living outside of sub-Saharan Africa</li> </ul>
<p>Study design:</p> <ul style="list-style-type: none"> <li>• Quantitative or mixed methods study design measuring internalised HIV stigma as an outcome, including longitudinal studies, cross-sectional surveys or case-control studies</li> <li>• Psychometric studies validating measurements of internalised HIV stigma</li> <li>• Prevalence studies that assess internalised HIV stigma and report on demographic comparisons (e.g. gender differences in internalised stigma)</li> </ul>	<ul style="list-style-type: none"> <li>• Qualitative studies</li> <li>• Intervention studies</li> </ul>
<p>Outcome measure</p> <ul style="list-style-type: none"> <li>• A measure of internalised HIV stigma</li> </ul>	<ul style="list-style-type: none"> <li>• A multidimensional stigma outcome measure without differentiation between enacted stigma and internalised stigma, making it impossible to infer what factors are associated with internalised stigma.</li> </ul>

### **III.d. Data extraction plan**

The piloted data extraction form is provided in Appendix 1. Study quality will be rated following an adapted version of the Cambridge Quality Checklist (CQC) for systematic reviews of observational studies (see ‘CQC assessment’ in the data extraction form in Appendix 2) (Murray et al. 2009). Two authors will code the data independently. Articles reporting analyses from the same dataset will be checked to avoid data duplication. Where data are duplicated, estimates from the largest sample will be used.

The causal predictor score of CQC is the most important as it assesses the extent to which a predictor is causally related to the outcome. It is determined based on two key features: 1) the extent to which within-individual changes in IHS are associated with within-individual changes in the predictor (analysis of change); and 2) whether the study design and/or statistical analysis take into account and control for alternative explanations of the findings. Models assessing whether variation in the predictor is related to within-individual change in IHS *and* controlling for relevant confounding variables score highest among observational studies.

For the purposes of this systematic review, we adapted CQC to capture reporting quality, in addition to methodological rigor. Studies not reporting reliability of the IHS measure used will be ranked lower than those reporting reliability below 0.70. Response rates will be scored for cross-sectional designs. Our preliminary review of the literature suggests that prospective cohort studies tend to report only retention rates (without response rates at baseline). Therefore only retention rates will be assessed for longitudinal designs.

Studies focusing on people living with HIV in sub-Saharan Africa tend to recruit through healthcare facilities. We therefore adapted CQC sampling scores to assess the method used for the selection of healthcare facilities rather than individual study participants.

CQC will be applied to each observed association between a correlate and IHS instead of the overall study. This will allow for differentiation between the types of study designs

and analyses used for different predictors of IHS. For example, Visser & Sipsma (2013) report a simple correlation between enacted stigma and IHS, whereas other predictors of IHS were assessed in a multivariate model that should receive a higher causality score due to accounting for confounders.

### **III.e. Synthesis plan**

If appropriate, meta-analyses will be undertaken. 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:

- Age
- Gender
- Key populations (paediatric population/ adolescent population/ adult population/ women accessing antenatal services)
- Study quality

## **IV. TIMETABLE**

Task	Complete by
Project planning	November 2013
Testing search strategy	December 2013
Finalizing review protocol	December 2013
Searches	December 2013
Contacting authors for published studies	December 2013
Abstract inclusion/exclusion	December 2013
Full text inclusion/exclusion	December 2013
Data extraction	January 2014
(Data synthesis	January 2014)
Write-up	February 2014

## **V. ACKNOWLEDGEMENTS**

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## **VI. STATEMENTS OF CONFLICT OF INTEREST**

The authors declare they have no competing interests.

## VII. REFERENCES

- Blum, R.W. & Ireland, M., 2004. Reducing risk, increasing protective factors: findings from the Caribbean Youth Health Survey. *The Journal of adolescent health : official publication of the Society for Adolescent Medicine*, 35(6), pp.493–500. Available at: <http://www.ncbi.nlm.nih.gov/pubmed/15581529> [Accessed December 6, 2013].
- Brown, L., Macintyre, K. & Trujillo, L., 2003. *Interventions to reduce HIV/AIDS stigma: what have we learned?*, New Orleans. Available at: <http://www.ncbi.nlm.nih.gov/pubmed/12627743>.
- Campbell, C. & Deacon, H., 2007. Unravelling the contexts of stigma: from internalisation to resistance to change. *Journal of community & applied social psychology*, 16(6), pp.411–417.
- Chalmers, I., Dickersin, K. & Chalmers, T.C., 1992. Getting to grips with Archie Cochrane's agenda. *BMJ*, 305, pp.786–787.
- Deeks, J.J., Higgins, J. & Altman, D.G., 2008. *Analysing Data and Undertaking Meta-Analyses. Cochrane Handbook for Systematic Reviews of Interventions: Cochrane Book Series* J. P. T. Higgins & S. Green, eds., The Cochrane Collaboration. Available at: [www.cochrane-handbook.org](http://www.cochrane-handbook.org).
- Earnshaw, V. a et al., 2013. HIV stigma mechanisms and well-being among PLWH: a test of the HIV stigma framework. *AIDS and behavior*, 17(5), pp.1785–95. Available at: <http://www.ncbi.nlm.nih.gov/pubmed/23456594> [Accessed December 3, 2013].
- Horwitz, R.H. et al., 2013. No Association Found Between Traditional Healer Use and Delayed Antiretroviral Initiation in Rural Uganda. *AIDS and Behavior*, 17(1), pp.260–265.
- Lee, R.S., Kochman, A. & Sikkema, K.J., 2002. Internalized Stigma Among People Living with HIV-AIDS. *AIDS and Behavior*, 6(4), pp.309–319.
- Logie, C. & Gadalla, T.M., 2009. Meta-analysis of health and demographic correlates of stigma towards people living with HIV. *AIDS care*, 21(6), pp.742–53. Available at: <http://www.ncbi.nlm.nih.gov/pubmed/19806490> [Accessed October 21, 2013].
- Murray, J., Farrington, D.P. & Eisner, M.P., 2009. Drawing conclusions about causes from systematic reviews of risk factors: The Cambridge Quality Checklists. *Journal of Experimental Criminology*, 5(1), pp.1–23. Available at: <http://link.springer.com/10.1007/s11292-008-9066-0> [Accessed December 5, 2013].

- Parker, R. & Aggleton, P., 2003. HIV and AIDS-related stigma and discrimination: a conceptual framework and implications for action. *Social Science & Medicine*, 57(1), pp.13–24. Available at: <http://www.ncbi.nlm.nih.gov/pubmed/12753813>.
- Sengupta, S. et al., 2011. HIV interventions to reduce HIV/AIDS stigma: a systematic review. *AIDS and behavior*, 15(6), pp.1075–87. Available at: <http://www.pubmedcentral.nih.gov/articlerender.fcgi?artid=3128169&tool=pmcentrez&rendertype=abstract> [Accessed October 21, 2013].
- Stangl, A.L. et al., 2013. A systematic review of interventions to reduce HIV-related stigma and discrimination from 2002 to 2013 : how far have we come ? *Journal of the International AIDS So*, 16.
- Tsai, A.C. et al., 2012. Evidence for the reliability and validity of the internalized AIDS-related stigma scale in rural Uganda. *AIDS and behavior*, 17(1), pp.427–33. Available at: <http://www.ncbi.nlm.nih.gov/pubmed/22869104> [Accessed October 29, 2013].
- Tsai, A.C., Bangsberg, D.R. & Weiser, S.D., 2013. Harnessing Poverty Alleviation to Reduce the Stigma of HIV in Sub-Saharan Africa. *PLoS Medicine*, 10(11), p.e1001557. Available at: <http://dx.plos.org/10.1371/journal.pmed.1001557> [Accessed December 4, 2013].
- Tshabalala, J. & Visser, M., 2011. Developing a Cognitive Behavioural Therapy Model to Assist Women to Deal with HIV and Stigma. *South African Journal of Psychology*, 41(1), pp.17–28. Available at: <http://sap.sagepub.com/lookup/doi/10.1177/008124631104100103>.
- UNAIDS, 2011. *2011 United Nations General Assembly Political Declaration on HIV/AIDS: Targets and elimination commitments*, Geneva.
- UNAIDS, 2007. *Reducing HIV Stigma and Discrimination: a critical part of national AIDS programmes*, Geneva.
- Uys, L. et al., 2009. Evaluation of a Health Setting-Based Stigma Intervention in Five African Countries. *AIDS Patient Care and STDs*, 23(12), pp.1059–66.
- Visser, M. & Sipsma, H., 2013. The experience of HIV-related stigma in South Africa. In *Stigma, discrimination and living with HIV/AIDS: A cross cultural perspective*. Dordrecht: Springer, pp. 205–227.

## VIII. APPENDIX 1

### Screening questions

*Note: continue to subsequent question only if the answer to the current question is “yes”.  
Otherwise exclude study from the review.*

1. Does the study sample include HIV positive people?
2. Is the study sample located in sub-Saharan Africa?
3. Does the study measure and report on internalized HIV-related stigma?
4. Does the study use quantitative methods?
5. Does the study fall within one of the following designs?
  - a. Quantitative observational study measuring internalized stigma as a DV
  - b. Psychometric study validating an internalized HIV-related stigma measure
  - c. Prevalence study that assesses level(s) of internalized stigma and reports on at least one demographic comparison (i.e. male/female differences in levels of IHS)

## **IX. APPENDIX 2**

### Data Extraction Form

#### **A. Publication information**

1. Authors
2. Title
3. Year
4. Reviewer (Date of coding)
5. IHS definition:

#### **B. Sample information**

6. Location
7. Population of interest
  - HIV-positive children (specify ages and whether sample consists of perinatally infected, behaviourally infected, combination of both, or not specified)
  - HIV-positive adolescents (specify ages and whether sample consists perinatally infected, behaviourally infected, combination of both, or not specified)
  - HIV-positive adults (specify ages and mode of infection, or not specified)
  - HIV-positive women accessing antenatal care clinics
  - HIV-positive high risk population (MSM, IDU, SW)
  - Other (specify):
8. Gender breakup
  - Female %
9. Other potential stigma markers assessed?
  - Women

- Poverty
- Transactional sex
- Sex work
- MSM
- Other (specify)

### C. CQC Assessment<sup>1</sup>

#### 10. Facility (clinic) sampling

- total population or random sampling
- purposive sampling
- convenience sampling
- not reported

#### 11. Within-facility sampling of individual participants

- total population or random sampling
- purposive sampling
- convenience sampling
- not reported

#### 12. Response rate

- response<sup>2</sup> and retention<sup>3</sup> rates  $\geq 70\%$  and differential attrition<sup>4</sup>  $\leq 10\%$
- response rate  $< 70\%$  or retention rate  $< 70\%$  or differential attrition  $> 10\%$
- not reported

#### 13. Sample size:

- Sample size  $\geq 400$
- Sample size  $< 400$

#### 14. Outcome measure used

- IHS measure

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<sup>1</sup> CQC assessment to be completed separately for each association between a correlate and IHS

<sup>2</sup> Response rate scored for cross-sectional design

<sup>3</sup> Retention rate scored for longitudinal design

<sup>4</sup> Differential attrition scored for case control design

- Enacted stigma measures
- Other outcome measures (specify):

Measure/Scale name:

15. IHS measure validity

- Use of a validated standardized scale with the same target population *OR* use of an adapted scale that had been validated with another target population
- Validation of a newly developed instrument
- Use of a non-validated measurement
- Not reported

16. IHS measure reliability

- Reliability coefficient  $\geq .7$
- Reliability coefficient  $< .7$
- Not reported

17. Study design score

- cross-sectional data
- retrospective data
- prospective data (or study of fixed factor)

18. Causal predictor score

- study without variation in the risk factor, no analysis of change
- study with variation in the risk factor but inadequately balanced, no analysis of change
- study without variation in the risk factor, with analysis of change
- study with variation in the risk factor but inadequately balanced, with analysis of change
- study with variation in the risk factor and adequately balanced, no analysis of change
- study with variation in the risk factor and adequately balanced, with analysis of change

19. CQC total score

## **D. Results**

### 20. Quantitative results

- Correlates/predictors of IHS (include OR, effect size, correlation coefficient, etc)
- Prevalence of internalized stigma
- Prevalence of other types of stigma, if applicable

### 21. Notes

# APPENDIX 2: STUDY PROTOCOL

## MZANTSI WAKHO RESEARCH PROTOCOL

### 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 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).

## **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. Nachege 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 uncleanness – 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 adolescents 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<sup>5</sup>.

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.

### 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 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

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<sup>5</sup> 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).

- 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](http://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 [marija.pantelic@spi.ox.ac.uk](mailto:marija.pantelic@spi.ox.ac.uk). 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 unstructured 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 choose 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).

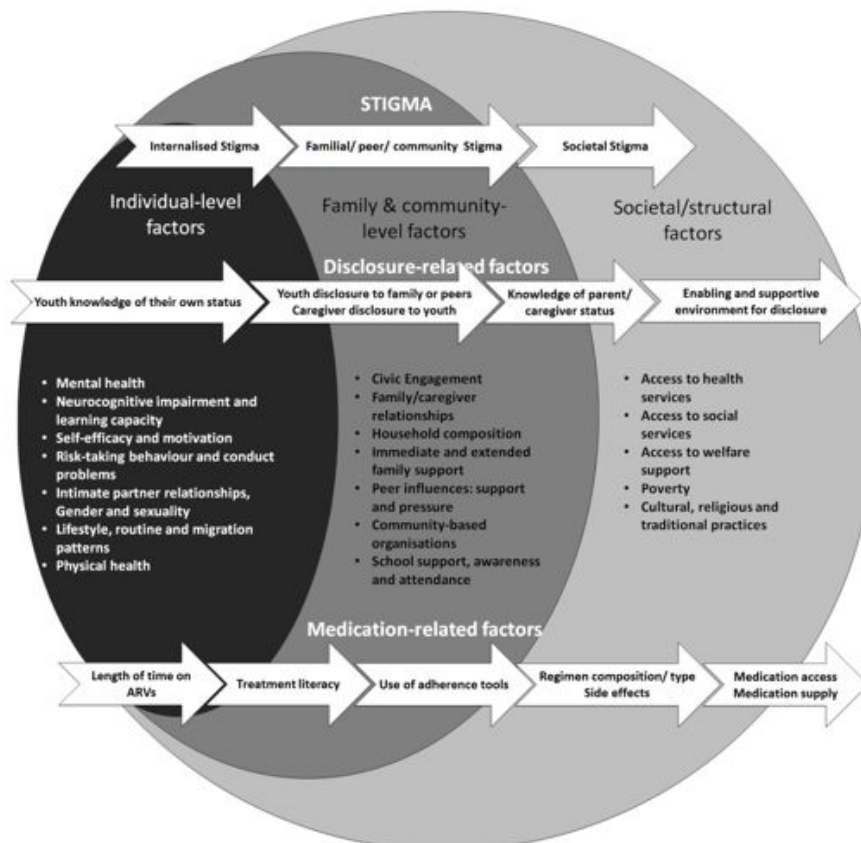
*School, peer & community factors* may be particularly important as adolescents develop social identities

(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 identifier. 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](http://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.

#### **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/ACCESS 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 (ACCESS 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 is 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.

### **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.

## **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.

## **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.

## **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.

## **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](http://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.

## **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.

## **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.

## **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.

## **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.

#### **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 (2<sup>nd</sup> 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).

#### **15. Appendices**

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

## 16. References

1. Kasedde S, Olson R. Scaling Up National Responses for Adolescents Living with HIV – An Overview of UNICEF , WHO and UNFPA Support. AIDSTAR-ONE Regional Consultation, Gaborone, Botswana. 2012.
2. Nachega JB, Hislop M, Nguyen H, Dowdy DW, Chaisson RE, Regensberg L, et al. Antiretroviral Therapy Adherence, Virologic and Immunologic Outcomes in Adolescents Compared With Adults in Southern Africa. *J Acquir Immune Defic Syndr*. 2009;51(1):65–71.
3. Obare F, Kwaak A Van Der, Birungi H. Factors associated with unintended pregnancy , poor birth outcomes and post-partum contraceptive use among HIV-positive female adolescents in Kenya. *BMC Womens Health*. 2012;12(34).
4. Ferrand RA, Corbett EL, Wood R, Hargrove J, Ndhlovu CE, Cowan FM, et al. AIDS among older children and adolescents in Southern Africa: projecting the time course and magnitude of the epidemic. *AIDS*. 2009;23(15):2039–46.
5. Mergui A, Giami A. La sexualité des adolescents séropositifs: analyse de la littérature et réflexion sur les impensés de la sexualité [The sexuality of HIV-infected adolescents: Literature review and thinking the unthinkable of sexuality]. *Arch Pediatr*. 2011;18:797–805.
6. Patel K, Hernán MA, Williams PL, Seeger JD, McIntosh K, Van Dyke RB, et al. Long-term effectiveness of highly active antiretroviral therapy on the survival of children and adolescents with HIV infection: a 10-year follow-up study. *Clin Infect Dis* [Internet]. 2008;46:507–15. Available from: <http://www.ncbi.nlm.nih.gov/pubmed/18199042>
7. World Health Organization. Antiretroviral therapy for HIV infection in adults and adolescents: Recommendations for a public health approach [Internet]. 2010 Revision. Geneva, Switzerland; 2010. Available from: [http://whqlibdoc.who.int/publications/2010/9789241599764\\_eng.pdf](http://whqlibdoc.who.int/publications/2010/9789241599764_eng.pdf)
8. Hobbs C V, Essajee SM. Early treatment of HIV: implications for resource-limited settings. *Curr Opin HIV AIDS* [Internet]. 2009 May [cited 2014 Apr 28];4(3):222–31. Available from: <http://www.ncbi.nlm.nih.gov/pubmed/19532054>
9. Pillay D. The emergence and epidemiology of resistance in the nucleoside-experienced HIV-infected population. *Antivir Ther* [Internet]. PHLS Antiviral Susceptibility Reference Unit, Division of Immunity and Infection, University of Birmingham Medical School, Birmingham, UK. [d.pillay@bham.ac.uk](mailto:d.pillay@bham.ac.uk); 2001;6 Suppl 3:15–24. Available from: <http://europepmc.org/abstract/MED/11678470>
10. Ajose O, Mookerjee S, Mills EJ, Boule A, Ford N. Treatment outcomes of patients on second-line antiretroviral therapy in resource-limited settings: a systematic review and meta-analysis. *AIDS* [Internet]. 2012 May 15 [cited 2013 Sep 22];26(8):929–38. Available from: <http://www.ncbi.nlm.nih.gov/pubmed/22313953>
11. World Health Organization. HIV drug resistance report 2012 [Internet]. World Health Organization; 2012 [cited 2013 Sep 29]. Available from: <http://www.who.int/hiv/pub/drugresistance/report2012/en/>
12. Persson A, Newman C. When HIV-Positive Children Grow Literature in Developed Countries. *Qual Health Res*. 2012;22(5):656–67.

13. Nguyen V. Antiretroviral globalism, biopolitics and therapeutic citizenship. In: Ong A, Collier SJ, editors. *Global Assemblages: Technology, Politics, and Ethics as Anthropological Problems*. Wiley; 2005. p. 124–44.
14. Robins S. From “Rights” to “Ritual”: AIDS Activism in South Africa. *Am Anthropol* [Internet]. 2006 Jun;108(2):312–23. Available from: <http://doi.wiley.com/10.1525/aa.2006.108.2.312>
15. Bakeera-Kitaka S, Nabukeera-Barungi N, Nöstlinger C, Addy K, Colebunders R. Sexual risk reduction needs of adolescents living with HIV in a clinical care setting. *AIDS Care* [Internet]. 2008 Apr [cited 2013 Sep 29];20(4):426–33. Available from: <http://www.ncbi.nlm.nih.gov/pubmed/18449819>
16. World Health Organization. *A qualitative review of psychosocial support interventions for young people living with HIV*. 2009.
17. (UNAIDS) JUNP on H. *Enhancing the Greater Involvement of People Living with or affected by HIV/ AIDS (GIPA) in sub-Saharan Africa* [Internet]. UNAIDS Best Practice Collection. Geneva, Switzerland; 2000. Available from: [http://data.unaids.org/publications/irc-pub01/jc274-gipa-ii\\_en.pdf](http://data.unaids.org/publications/irc-pub01/jc274-gipa-ii_en.pdf)
18. Arrivillaga M, Martucci V, Hoyos PA, Arango A. Adherence among children and young people living with HIV/AIDS: A systematic review of medication and comprehensive interventions. *Vulnerable Child Youth Stud* [Internet]. 2013 Feb 8 [cited 2013 Sep 27];(February):1–17. Available from: <http://www.tandfonline.com/doi/abs/10.1080/17450128.2013.764031>
19. Abadía-Barrero CE, Castro A. Experiences of stigma and access to HAART in children and adolescents living with HIV/AIDS in Brazil. *Soc Sci Med* [Internet]. 2006 Mar [cited 2013 Sep 26];62(5):1219–28. Available from: <http://www.ncbi.nlm.nih.gov/pubmed/16099573>
20. Hodes R. HIV, abortion and reproductive healthcare for women in South Africa. In: Smith RA, editor. *Global HIV/AIDS Politics, Policy and Activism: Persistent Challenges and Emerging Issues*. ABC-CLIO; 2013.
21. Li RJ, Jaspan HB, O’Brief V, Rabie H, Cotton MF, Nattrass N. Positive futures: a qualitative study on the needs of adolescents on antiretroviral therapy in South Africa. *AIDS Care Psychol Socio-medical Asp AIDS/HIV*. 2010;22(6):751–8.
22. Evans D, Menezes C, Mahomed K, Macdonald P, Untiedt S, Levin L, et al. Treatment Outcomes of HIV-Infected Adolescents attending Public-Sector HIV Clinics across Gauteng and Mpumalanga, South Africa. *AIDS Res Hum Retroviruses*. 2013;29(00):1–13.
23. Lowenthal ED, Lawler K, Harari N, Moamogwe L, Masung J, Masedi M, et al. Rapid psychosocial function screening test identified treatment failure in HIV+ African youth. *AIDS Care Psychol Socio-medical Asp AIDS/HIV*. 2012;24(6):722–7.
24. Bakanda C, Birungi J, Mwesigwa R, Nachega JB, Chan K, Palmer A, et al. Survival of hiv-infected adolescents on antiretroviral therapy in uganda: Findings from a nationally representative cohort in uganda. *PLoS One*. 2011;6.
25. Sharer M, Fullem A. *Transitioning of Care and Other Services for Adolescents living with HIV in Sub-Saharan Africa*. USAID’s AIDS Support and Technical Assistance Resources, AIDSTAR-ONE, Task Order 1. Arlington, VA; 2012.

26. Wiener LS, Battles HB. Untangling the web: a close look at diagnosis disclosure among HIV-infected adolescents. *J Adolesc Heal* [Internet]. 2006;38:307–9. Available from: <http://www.pubmedcentral.nih.gov/articlerender.fcgi?artid=2408712&tool=pmcentrez&rendertype=abstract>
27. Campbell C, Nair Y, Maimane S, Nicholson J. “Dying twice”: a multi-level model of the roots of AIDS stigma in two South African communities. *J Health Psychol*. 2007;12:403–16.
28. Battles HB, Wiener LS. From adolescence through young adulthood: psychosocial adjustment associated with long-term survival of HIV. *J Adolesc Heal*. 2002;30:161–8.
29. Cluver LD, Orkin M, Boyes ME, Gardner F, Nikelo J. AIDS-Orphanhood and Caregiver HIV/AIDS Sickness Status: Effects on Psychological Symptoms in South African Youth. *J Pediatr Psychol* [Internet]. 2012 Sep;37(8):857–67. Available from: <http://www.ncbi.nlm.nih.gov/pubmed/22313551>
30. Cluver LD, Orkin M. Cumulative risk and AIDS-orphanhood: interactions of stigma, bullying and poverty on child mental health in South Africa. *Soc Sci Med* [Internet]. 2009;69:1186–93. Available from: <http://www.ncbi.nlm.nih.gov/pubmed/19713022>
31. Boyes ME, Cluver LD. Relationships Among HIV/AIDS Orphanhood, Stigma, and Symptoms of Anxiety and Depression in South African Youth: A Longitudinal Investigation Using a Path Analysis Framework. *Clin Psychol Sci* [Internet]. 2013 Mar 1 [cited 2014 Apr 29];1(3):323–30. Available from: <http://cpx.sagepub.com/lookup/doi/10.1177/2167702613478595>
32. Cooper D, Moodley J, Zweigenthal V, Bekker L-G, Shah I, Myer L. Fertility intentions and reproductive health care needs of people living with HIV in Cape Town, South Africa: implications for integrating reproductive health and HIV care services. *AIDS Behav* [Internet]. 2009 Jun [cited 2013 Sep 27];13(Suppl 1):38–46. Available from: <http://www.ncbi.nlm.nih.gov/pubmed/19343492>
33. Orner P, Cooper D, Myer L, Zweigenthal V, Bekker L-G, Moodley J. Clients’ perspectives on HIV/AIDS care and treatment and reproductive health services in South Africa. *AIDS Care* [Internet]. 2008 Nov [cited 2014 Apr 29];20(10):1217–23. Available from: <http://www.ncbi.nlm.nih.gov/pubmed/18608082>
34. Bakeera-Kitaka S, McKellar M, Snider C, Kekitiinwa A, Piloya T, Musoke P, et al. Antiretroviral therapy for HIV-1 infected adolescents in Uganda: Assessing the impact on growth and sexual maturation. *J Pediatr Infect Dis* [Internet]. 2008 [cited 2013 Sep 29];3(2):97–104. Available from: <http://iospress.metapress.com/content/j668135704616802/>
35. Barron P, Pillay Y, Doherty T, Sherman G, Jackson D, Bhardwaj S, et al. Eliminating mother-to-child HIV transmission in South Africa. *Bull World Health Organ* [Internet]. 2013 Jan 1 [cited 2013 Sep 27];91(1):70–4. Available from: <http://www.pubmedcentral.nih.gov/articlerender.fcgi?artid=3537246&tool=pmcentrez&rendertype=abstract>
36. Westreich D, Maskew M, Rubel D, Macdonald P, Jaffray I, Majuba P. Incidence of Pregnancy after Initiation of Antiretroviral Therapy in South Africa: A Retrospective Clinical Cohort Analysis. *Infect Dis Obstet Gynecol*. 2012;1–17.
37. Willis GB. Reducing Survey Error through Research on the Cognitive and Decision Processes in Surveys. Meeting of the American Statistical Association. Research Triangle Institute; 1999.

38. Johnson LF. Access to Antiretroviral Treatment in South Africa, 2004-2011. *South Afr J HIV Med.* 2012;(March):22–7.
39. World Health Organization. *Global HIV/AIDS Response: Epidemic update and health sector progress towards Universal Access - Progress Report 2011.* Geneva, Switzerland; 2011.
40. SSA SSA. *Statistical release Mid-year population estimates.* Pretoria, South Africa; 2011.
41. Kelly P. The dangerousness of youth-at-risk: the possibilities of surveillance and intervention in uncertain times. *J Adolesc.* 2000;23:463–76.
42. Heald S. It's never as easy as ABC: Understandings of AIDS in Botswana1. *African J AIDS Res.* 2002;1:1–10.
43. MacPhail C, Campbell C. “I think condoms are good but, aai, I hate those things”: Condom use among adolescents and young people in a Southern African township. *Soc Sci Med.* 2001;52:1613–27.
44. Posel D, Kahn K, Walker L. Living with death in a time of AIDS: a rural South African case study. *Scand J Public Health Suppl.* 2007;69:138–46.
45. McNeill FG, Niehaus IA. *Magic: AIDS Review 2009.* University of Pretoria; 2010.
46. Hardon A, Posel D. Secrecy as embodied practice: beyond the confessional imperative. *Cult Heal Sex An Int J Res Interv Care.* 2012;14(No. S1):S1–S13.
47. Kwaak A Van Der, Obare F, Ormel H. Sexual and reproductive desires and practices of Kenyan young positives: Opportunities for skills building through social media [Internet]. KIT Publishers; 2011. p. 63–70. Available from: <http://www.kit.nl/kit/Publication?item=3133>
48. Collins LM, Hopkins J, Osborne K. Love, life and HIV: Voices of young people living with HIV from around the world. *Proceedings from the 20th World Congress of Sexual Health. Journal of Sexual Medicine;* 2011. p. 84–299.
49. Toroyan T, Reddy PS. Participation of South african youth in the design and development of AIDS photocomics. *Int Q Community Health Educ.* 17(1-2):149–63.
50. World Health Organization. *Task shifting: rational redistribution of tasks among health workforce teams: global recommendations and guidelines.* 2008.
51. Craig P, Dieppe P, Macintyre S, Michie S, Nazareth I, Petticrew M. *Developing and evaluating complex interventions: new guidance* [Internet]. Medical Research Council. 2009. Available from: <http://scholar.google.com/scholar?hl=en&btnG=Search&q=intitle:Developing+and+evaluating+complex+interventions+:+new+guidance#1>
52. World Health Organization. *The sexual and reproductive health of young adolescents in developing countries: Reviewing the evidence, identifying research gaps, and moving the agenda* [Internet]. Geneva, Switzerland: World Health Organization; 2011 [cited 2013 Sep 30]. Available from: [http://www.who.int/reproductivehealth/publications/adolescence/rhr\\_11\\_11/en/index.html](http://www.who.int/reproductivehealth/publications/adolescence/rhr_11_11/en/index.html)
53. Vale B. *From Manual to Makeshift: The practice of community health work in Cape Town.* University of Cape Town; 2012. p. 1–178.

54. Morrow V, Richards M. The Ethics of Social Research with Children: An Overview. *Child Soc* [Internet]. 1996;10:90–105.
55. Merzel C, Vandevanter N, Irvine M. Adherence to Antiretroviral Therapy among Older Children and Adolescents with HIV: A Qualitative Study of Psychosocial Contexts. *AIDS Patient Care STDS*. 2008;22(12):977–87.
56. Kirk S. Methodological and ethical issues in conducting qualitative research with children and young people: A literature review. *Int J Nurs Stud*. 2007;44:1250–60.
57. Petersen I, Bhana A, Myeza N, Alicea S, John S, Holst H, et al. Psychosocial challenges and protective influences for socio-emotional coping of HIV adolescents in South Africa: a qualitative investigation. *AIDS Care*. 2010;22(8):970–9.
58. Punch S. Research with children: the same or different from research with adults? *Childhood*. 2002;9(3):321–41.
59. Hagemaster JN. Life history: a qualitative method of research. *J Adv Nurs*. 1992;17:1122–8.
60. Docherty S, Sandelowski M. Focus on qualitative methods: Interviewing children. *Res Nurs Health* [Internet]. 1999 Apr;22(2):177–85. Available from: <http://doi.wiley.com/10.1002/%28SICI%291098-240X%28199904%2922%3A2%3C177%3A%3AAID-NUR9%3E3.3.CO%3B2-8>
61. Steward MS, Steward DS. Interviewing young children about body touch and handling. *Monogr Soc Res Child Dev*. 1996;61:1–214.
62. MacGregor HN. Mapping the body: tracing the personal and the political dimensions of HIV/AIDS in Khayelitsha, South Africa. *Anthropol Med* [Internet]. 2009 Apr [cited 2014 Apr 29];16(1):85–95. Available from: <http://www.tandfonline.com/doi/abs/10.1080/13648470802426326>
63. Vasquez G. *Body perceptions of HIV and AIDS: the memory box project*. Cape Town, South Africa; 2004.
64. Diclemente RJ, Wingood GM, Rio C del, Crosby RA. Prevention interventions for HIV positive individuals. *Sex Transm Infect* [Internet]. 2002 Dec 1 [cited 2013 Sep 30];78(6):393–5. Available from: <http://sti.bmj.com/content/78/6/393.short>
65. Boyes ME, Cluver LD. Performance of the Revised Children’s Manifest Anxiety Scale in a Sample of Children and Adolescents from Poor Urban Communities in Cape Town. *Eur J Psychol Assess*. 2013;29(2):113–20.
66. Boyes ME, Mason SJ, Cluver LD. Validation of a brief stigma-by-association scale for use with HIV/AIDS-affected youth in South Africa. *AIDS Care*. 2013;25(2):215–22.
67. Boyes ME, Cluver LD, Gardner F. Psychometric properties of the child PTSD checklist in a community sample of South African children and adolescents. *PLoS One* [Internet]. 2012 Jan [cited 2013 Sep 27];7(10):e46905. Available from: <http://www.pubmedcentral.nih.gov/articlerender.fcgi?artid=3463511&tool=pmcentrez&rendertype=abstract>

68. Gorbach PM, Mensch BS, Husnik M, Coly A, Masse B, Makanani B, et al. Effect of Computer-Assisted Interviewing on Self-Reported Sexual Behavior Data in a Microbicide Clinical Trial. *AIDS Behav.* 2013;17:790–800.
69. Ochieng F, Wyckoff S, Ochura J, Mboi P, Odera W, Adipo D, et al. Audio computer-assisted self-interview (ACASI) for sexual risk assessment and risk-reduction communication with families in rural Western Kenya. *AIDS 2006 - XVI International AIDS Conference.* 2006. p. CDD133.
70. Malotte C, Cutting A, Huettner S, Matson P, Ellen J. P2-S8.12 Feasibility of using cell phones for daily data collection within adolescent cohort studies. *Sex Transm Infect [Internet].* 2011 Jul 10 [cited 2013 Oct 3];87(Suppl 1):A260–A261. Available from: <http://sti.bmj.com/cgi/doi/10.1136/sextrans-2011-050108.386>
71. Jaspan HB, Flisher AJ, Myer L, Mathews C, Seebregts C, Berwick JR, et al. Brief report: Methods for collecting sexual behaviour information from South African adolescents — a comparison of paper versus personal digital assistant questionnaires. *J Adolesc.* 2007;30:353–9.
72. Mukoma W, Mathews C, Flisher AJ, Seebregts C, Jansen S, Ahmed NA, et al. Use of electronic questionnaires on handheld devices to evaluate the effects of a school-based HIV prevention programme on adolescent sexual behaviour. *The XV International AIDS Conference.* 2004. p. TuPeC4886.
73. Llabre MM, Weaver KE, Durán RE, Antoni MH, McPherson-Baker S, Schneiderman N. A measurement model of medication adherence to highly active antiretroviral therapy and its relation to viral load in HIV-positive adults. *AIDS Patient Care STDS [Internet].* 2006;20:701–11. Available from: <http://www.ncbi.nlm.nih.gov/pubmed/17052140>
74. Valdivia Vadell C, Soler-Palacín P, Martín-Nalda A, Cabañas Poy MJ, Clemente Bautista S, Espiau Guarner M, et al. Evaluación de un programa de valoración de adherencia al tratamiento antirretroviral [Evaluation of a program for assessing adherence to antiretroviral treatment]. *An pediatría [Internet].* 2011;75(6):380–95. Available from: <http://www.ncbi.nlm.nih.gov/pubmed/21757410>
75. Rudy BJ, Murphy DA, Harris DR, Muenz L, Ellen J. Patient-related risks for nonadherence to antiretroviral therapy among HIV-infected youth in the United States: a study of prevalence and interactions. *AIDS Patient Care STDS.* 2009;23:185–94.
76. Malee K, Ph D, Williams P, Montepiedra G, McCabe M, Nichols S, et al. Medication Adherence in Children and Adolescents with HIV Infection : Associations with Behavioral Impairment. 2011;25(3).
77. Williams PL, Storm D, Montepiedra G, Nichols S, Kammerer B, Sirois PA, et al. Predictors of adherence to antiretroviral medications in children and adolescents with HIV infection. *Pediatrics.* 2006;118:e1745–e1757.
78. Naar-King S, Templin T, Wright K, Frey M, Parsons JT, Lam P. Psychosocial factors and medication adherence in HIV-positive youth. *AIDS patient care and STDs.* 2006 p. 44–7.
79. Maneesriwongul WL, Tulathong S, Fennie KP, Williams AB. Adherence to antiretroviral medication among HIV-positive patients in Thailand. *J Acquir Immune Defic Syndr.* 2006;43 Suppl 1:S119–S122.

80. Bailly D. Issues related to consent to healthcare decisions in children and adolescents. *Arch Pediatr* [Internet]. 2010;17 Suppl 1:S7–S15. Available from: <http://www.ncbi.nlm.nih.gov/pubmed/20172456>
81. Peltzer K, Preez NF, Ramlagan S, Anderson J. Antiretroviral treatment adherence among HIV patients in KwaZulu-Natal, South Africa. *BMC Public Health*. 2010;10(111):1–10.
82. Parienti J-J, Massari V, Descamps D, Vabret A, Bouvet E, Larouzé B, et al. Predictors of virologic failure and resistance in HIV-infected patients treated with nevirapine- or efavirenz-based antiretroviral therapy. *Clin Infect Dis*. 2004;38:1311–6.
83. Lyimo RA, van den Boogaard J, Msoka E, Hospers HJ, van der Ven A, Mushi D, et al. Measuring adherence to antiretroviral therapy in northern Tanzania: feasibility and acceptability of the Medication Event Monitoring System. *BMC Public Health*. 2011;11:92.
84. DiClemente RJ, Wingood GM, Crosby R, Sionean C, Cobb BK, Harrington K, et al. Parental monitoring: association with adolescents' risk behaviors. *Pediatrics*. 2001;107:1363–8.
85. Farley J, Hines S, Musk A, Ferrus S, Tepper V. Assessment of adherence to antiviral therapy in HIV-infected children using the Medication Event Monitoring System, pharmacy refill, provider assessment, caregiver self-report, and appointment keeping. *J Acquir Immune Defic Syndr*. 2003;33:211–8.
86. Antinori A, Arendt G, Becker JT, Brew BJ, Byrd DA, Cherner M, et al. Updated research nosology for HIV-associated neurocognitive disorders. *Neurology*. 2007;69:1789–99.
87. Keyser RE, Peralta L, Cade WT, Miller S, Anixt J. Functional aerobic impairment in adolescents seropositive for HIV: A quasiexperimental analysis. *Arch Phys Med Rehabil*. 2000;81:1479–84.
88. Steinberg J. *Three Letter Plague: A Young Man's Journey Through a Great Epidemic*. Random House; 2011.
89. Almeleh CJ. *The Longlife AIDS-advocacy Intervention: An Exploration into Public Disclosure*. 2004.
90. Vreeman RC, Nyandiko WM, Ayaya SO, Walumbe EG, Marrero DG, Inui TS. Factors Sustaining Pediatric Adherence to Antiretroviral Therapy in Western Kenya. *Qual Health Res*. 2009;19(1716-1729).
91. Hammami N, Nöstlinger C, Hoérée T, Lefèvre P, Jonckheer T, Kolsteren P. Integrating adherence to highly active antiretroviral therapy into children's daily lives: a qualitative study. *Pediatrics*. 2004;114:e591–e597.
92. Vreeman RC, Nyandiko WM, Ayaya SO, Walumbe EG, Marrero DG, Inui TS. The perceived impact of disclosure of pediatric HIV status on pediatric antiretroviral therapy adherence, child well-being, and social relationships in a resource-limited setting. *AIDS Patient Care STDS*. 2010;24(10):639–49.
93. Jewkes R, Abrahams N. The epidemiology of rape and sexual coercion in South Africa: An overview. *Soc Sci Med*. 2002;55:1231–44.
94. Nglazi MD, Kranzer K, Holele P, Kaplan R, Mark D, Jaspan H, et al. Treatment outcomes in HIV-infected adolescents attending a community-based antiretroviral therapy clinic in South Africa.

BMC Infect Dis [Internet]. BioMed Central Ltd; 2012;12(1):21. Available from: <http://www.biomedcentral.com/1471-2334/12/21>

95. Fox MP, Mazimba A, Seidenberg P, Crooks D, Sikateyo B, Rosen S. Barriers to initiation of antiretroviral treatment in rural and urban areas of Zambia: a cross-sectional study of cost, stigma, and perceptions about ART. *J Int AIDS Soc.* 2010;13:8.
96. Weiser SD, Gupta R, Tsai AC, Frongillo EA, Grede N, Kumbakumba E, et al. Changes in food insecurity, nutritional status, and physical health status after antiretroviral therapy initiation in rural Uganda. *J Acquir Immune Defic Syndr* [Internet]. 2012;61:179–86. Available from: [http://imp-primo.hosted.exlibrisgroup.com/openurl/44IMP/44IMP\\_services\\_page?sid=OVID&isbn=&issn=1525-4135&volume=61&issue=2&date=2012&title=Journal+of+Acquired+Immune+Deficiency+Syndromes&atitle=Changes+in+food+insecurity,+nutritional+status,+and+physical+health+status+after+antiretroviral+therapy+initiation+in+rural+Uganda&aulast=Weiser+S.D.&spage=179](http://imp-primo.hosted.exlibrisgroup.com/openurl/44IMP/44IMP_services_page?sid=OVID&isbn=&issn=1525-4135&volume=61&issue=2&date=2012&title=Journal+of+Acquired+Immune+Deficiency+Syndromes&atitle=Changes+in+food+insecurity,+nutritional+status,+and+physical+health+status+after+antiretroviral+therapy+initiation+in+rural+Uganda&aulast=Weiser+S.D.&spage=179)
97. Emenyonu N, Muyindike W, Habyarimana J, Pops-Eleches C, Thirumurthy T. Cash transfers to cover clinic transportation costs improve adherence and retention in care in a HIV treatment program in rural Uganda. 17th Conference on Retroviruses and Opportunistic Infections. San Francisco, CA; 2010. p. 16–9.
98. Collins E, Wagner C, Walmsley S. Psychosocial impact of the lipodystrophy syndrome in HIV infection. *AIDS Read.* 2000;10:546–50.
99. Kremer H, Ironson G, Schneiderman N, Hautzinger M. To Take or Not to Take: Decision-Making About Antiretroviral Treatment in People Living with HIV/AIDS. *AIDS Patient Care STDS.* 2006;20(5):335–49.
100. Hodgson I, Ross J, Haamujompa C, Gitau-Mburu D. Living as an adolescents with HIV in Zambia - lived experiences, sexual health and reproductive needs. *AIDS Care Psychol Socio-medical Asp AIDS/HIV.* 2012;24(10):1204–10.
101. Glaser BG, Strauss AL. The discovery of grounded theory. *International Journal of Qualitative Methods.* Chicago: Aldine; 1967.
102. Popay J, Rogers a., Williams G. Rationale and Standards for the Systematic Review of Qualitative Literature in Health Services Research. *Qual Health Res* [Internet]. 1998 May 1 [cited 2012 Mar 9];8(3):341–51. Available from: <http://qhr.sagepub.com/cgi/doi/10.1177/104973239800800305>
103. Whittemore R, Chase SK, Mandle CL. Validity in Qualitative Research. *Qual Health Res* [Internet]. 2001 Jul 1 [cited 2012 Mar 1];11(4):522–37. Available from: <http://qhr.sagepub.com/cgi/doi/10.1177/104973201129119299>
104. Davies M-A, Boulle A, Fakir T, Nuttall J, Eley B. Adherence to antiretroviral therapy in young children in Cape Town, South Africa, measured by medication return and caregiver self-report: a prospective cohort study. *BMC Pediatr* [Internet]. 2008 Jan [cited 2013 Sep 27];8:34. Available from: <http://www.pubmedcentral.nih.gov/articlerender.fcgi?artid=2533648&tool=pmcentrez&rendertype=abstract>
105. Kline RB. Principles and Practice of Structural Equation Modeling. 3rd ed. Little TD, editor. New York: The Guilford Press; 2011.

106. Open Society Foundation for South Africa. A best practice guide to HIV disclosure. Jossel L, editor. Cape Town, South Africa; 2009.
107. Dawes A, Bray R, Kvalsvig J, Kafaar Z, Rama S, Richter LM. Going Global with Indicators of Child Well-Being: Indicators of South African Children's Psychosocial Development in the Early Childhood Period [Internet]. Cape Town, South Africa; 2004. Available from: <http://www.hsrc.ac.za/en/research-data/view/1783>
108. Alliance for Children's Entitlement to Social Security, Soul City, The Children's Institute. Children speak out on poverty: Report on the ACCESS (Alliance for Children's Entitlement to Social Security) Child Participation Process. Cape Town, South Africa; 2002.
109. Seedat S, Van Nood E, Vythilingum B, Stein DJ, Kaminer D. School survey of exposure to violence and posttraumatic stress symptoms in adolescents. *South African J Child Adolesc Ment Heal* [Internet]. 2000;12:38–44. Available from: <http://ezproxy.antiochne.edu/login?url=http://search.ebscohost.com/login.aspx?direct=true&db=psyh&AN=2002-13288-002&site=ehost-live&custid=s3217437>
110. Seedat S, Nyamai C, Njenga F, Vythilingum B, Stein DJ. Trauma exposure and post-traumatic stress symptoms in urban African schools: Survey in CapeTown and Nairobi. *Br J Psychiatry* [Internet]. 2004;184:169–75. Available from: <http://bjp.rcpsych.org/cgi/doi/10.1192/bjp.184.2.169>
111. Stein A, Krebs G, Richter LM, Tomkins A, Rochat TJ, Bennish ML. Babies of a pandemic: Infant development and maternal HIV. *Arch Dis Child* [Internet]. 2005 Feb [cited 2013 Oct 3];90(2):116–8. Available from: <http://www.pubmedcentral.nih.gov/articlerender.fcgi?artid=1720268&tool=pmcentrez&rendertype=abstract>
112. Bostock L. God, She's Gonna Report Me': The Ethics of Child Protection in Poverty Research. *Child Soc*. 2002;16:273–83.
113. The British Psychological Society. Code of Ethics and Conduct - Guidance published by the Ethics Committee of the British Psychological Society [Internet]. The British Psychological Society; 2009. Available from: [http://www.bps.org.uk/system/files/documents/code\\_of\\_ethics\\_and\\_conduct.pdf](http://www.bps.org.uk/system/files/documents/code_of_ethics_and_conduct.pdf)
114. Fair C, Wiener LS, Zadeh S, Albright J, Mellins CA, Mancilla M, et al. Reproductive Health Decision-Making in Perinatally HIV-Infected Adolescents and Young Adults. *Matern Child Health J*. 2012;1–12.
115. Lowick S, Sawry S, Meyers T. Neurodevelopmental delay among HIV- infected preschool children receiving antiretroviral therapy and healthy preschool children in Soweto, South Africa. *Psychol Health Med*. 2012;17(5):599–610.
116. Cluver LD, Orkin M, Boyes ME, Gardner F, Meinck F. Transactional Sex Amongst AIDS-Orphaned and AIDS-Affected Adolescents Predicted by Abuse and Extreme Poverty. *JAIDS Journal of Acquired Immune Deficiency Syndromes*. 2011. p. 336–43.
117. Mason-jones AJ. Ethical issues in adolescent health research. Bergen, Norway: "PREPARE" Consortium; 2010.
118. Singh JA, Karim SSA, Karim QA, Mlisana K, Williamson C, Gray C, et al. Enrolling Adolescents in Research on HIV and Other Sensitive Issues: Lessons from South Africa. *PLoS Med* [Internet].

Public Library of Science; 2006 Jul [cited 2013 Sep 30];3(7):984–8. Available from:  
<http://dx.plos.org/10.1371/journal.pmed.0030180>

119. Strode A, Slack C, Grant C, Mushariwa M. Ethical and legal challenges in enrolling adolescents in medical research in South Africa: implications for HIV vaccine trials. *South African J Sci.* 2005;101(May/June 2005):224–8.
120. Zuch M, Mason-jones AJ, Mathews C, Henley L. Changes to the law on consent in South Africa : implications for school-based adolescent sexual and reproductive health research. *BMC Int Health Hum Rights* [Internet]. BioMed Central Ltd; 2012;12(3):5. Available from: <http://www.biomedcentral.com/1472-698X/12/3>
121. Norman A, Chopra M, Kadiyala S. HIV Disclosure in South Africa: Enabling the Gateway to Effective Response. 2005 p. 17.
122. Herth K. Hope as seen through the eyes of homeless children. *J Adv Nurs* [Internet]. 1998;28:1053–62. Available from: <http://www.ncbi.nlm.nih.gov/pubmed/9840877>
123. Alderson P, Morrow V. Ethics, social research and consulting with children and young people. Barnardo's; 2004.
124. World Health Organization. Guideline on HIV disclosure counselling for children up to 12 years of age. Geneva, Switzerland; 2011.

## **APPENDIX 3: SAMPLE ETHICS UPDATE LETTER**

### **Re: Quarterly update on Mzantsi Wakho – Adolescent Health Research Project in the Eastern Cape**

Dear Mr. Merile,

Thank you for the opportunity to present our preliminary findings on our research study on adolescent health in the Eastern Cape at Unathi House, 10<sup>th</sup> of April 2015. Since our last update in December, we have continued establishing the study in various facilities and communities, started collecting viral load and CD4 count data from patient files, and established a questionnaire for collecting information on the types of services available in partner healthcare facilities (questionnaire attached for your review). We are pleased to announce that we have so far completed 1066 baseline quantitative interviews with 10-19 year olds.

This update letter includes information on the following: (1) qualitative research on medication-taking practices and access to sexual and reproductive health services, (2) Preliminary findings of ethnographic research and youth camps in rural and urban Eastern Cape on medication taking practices, (3) a summary of quantitative interviews completed so far, (4) a summary of our attempts to collect viral load and CD4 count data from patient files, and (6) an updated questionnaire for surveying clinics to establish which services they offer.

#### **1. Qualitative research on medication-taking practices and access to sexual and reproductive health services**

In the course of 2015, the qualitative research team conducted 72 in-depth interviews with 43 HIV-positive teenagers, and 30 interviews with 22 caregivers of HIV-positive adolescents. Four focus groups were conducted with (i) adolescent girls, (ii) adolescent boys, (iii) adolescent girls and boys combined and (iv) caregivers of HIV-positive adolescents. Interviews with healthcare workers were conducted at the family planning, antenatal care, antiretroviral and trauma units of five public health facilities (three hospitals and two health centres).

#### **2. Preliminary findings of ethnographic research and youth camps in rural and urban Eastern Cape on medication taking practices**

Participatory research with teens provided a more comprehensive view of the various psychosocial and medical challenges that adolescents confront, including at home, at school, and at the clinic. Key findings included the association between substance abuse and HIV risk transmission behaviours, and the difficulties that families from rural areas face in paying for transport to health facilities.

#### **3. So far, 1066 quantitative interviews have been conducted.** Of these, 737 teens were HIV-positive and had initiated ART. We also interviewed another 329 negative youth and youth whose status was unknown in order to prevent stigma associated

with participation in the study.

**Table 5 Mzantsi Wakho interviews completed so far**

<b>Positive</b>		<b>Status unknown</b>	
Child aware of status	482	Never been on chronic medication	298
Child unaware of status	255	Clarifications needed	31
<b>Total positive</b>	<b>737</b>	<b>Total negative / status unknown</b>	<b>329</b>

- 4. Difficulties with accessing biological markers of adherence.** We obtained full parental and participant consent to access information from participants' patient files. Here, viral load and CD4 count data are essential in order to validate self-reported ART adherence.

We attempted to extract viral load and CD4 count data from patient files from 80 of our participants. However, our preliminary findings suggest that many clinics are missing viral load and CD4 count data from patient files.

We discussed this at the meeting at EC DoH with you and your colleagues, where it was established that Tier.net will not have more reliable data due to different implementation stages in healthcare facilities. As we continue to investigate how to access this information, we welcome any additional suggestions you or your colleagues might have.

- 5. Surveying healthcare facilities.** We developed the attached survey that we will start implementing in healthcare facilities to assess which services are available to adolescent participants. We have piloted the tool with one nurse, and are in the process of recruiting a designated data collector, who will visit each of our 39 partner healthcare facilities and collect information on the services available. The list of these 39 facilities is provided in the Appendix. In addition, we intend to launch partnerships with NU 3 and Frere Gateway clinics.

Thank you for your continued support for our research. If there are any further questions, please do not hesitate to ask.



Dr Lucie Cluver  
Principal Investigator (Quantitative)  
University Lecturer  
Department of Social Policy and  
Intervention  
32 Wellington Square  
University of Oxford  
[lucie.cluver@spi.ox.ac.uk](mailto:lucie.cluver@spi.ox.ac.uk)



Dr. Rebecca Hodes  
Principal Investigator (Qualitative)  
Director, AIDS and Society Research Unit  
Centre for Social Science Research  
Leslie Social Science Building  
University of Cape Town 7701  
[rebecca.hodes@gmail.com](mailto:rebecca.hodes@gmail.com)



### **Appendix: Mzantsi Wakho Partner Healthcare Facilities**

1. Berlin Clinic
2. Bhisho Hospital - ARV clinic
3. Bhisho Hospital - ANC clinic
4. Bhisho Gateway Clinic
5. Cecilia Makiwane Hospital - ARV/ adult clinic
6. Cecilia Makiwane Hospital - PMTCT/ ANC clinic
7. Cecilia Makiwane Hospital – Pediatrics
8. Central Clinic
9. Duncan Village Day Hospital
10. Dimbaza Community Healthcare Centre
11. Empilweni Gompo Healthcare Centre
12. Frankfort clinic
13. Frere Hospital - ARV/ adult clinic
14. Frere Hospital - PMTCT/ ANC clinic
15. Frere Hospital – Pediatrics
16. Grey Hospital
17. Grey Gateway Clinic
18. Ginsberg clinic
19. Ilita Clinic
20. Imidange Clinic
21. John Dube Clinic
22. Mt. Coke Community Healthcare Centre
23. Ncerha clinic
24. Ndevana
25. Needs Camp Clinic
26. Nontyatyambo Clinic
27. NU8 Nobuhle Clinic
28. NU9 Clinic
29. NU12 Eluxolweni Clinic
30. NU13 Siyaphilisa Clinic
31. NU17 Clinic
32. Nonkcampa Clinic
33. Sweetwaters Clinic
34. Qurhu Clinic
35. Tshatshu Clinic
36. Tyutyu Clinic
37. Zikhova Clinic
38. Zwelitsha Clinic zone 5
39. Zwelitsha Clinic zone 8

#### **Planned additional partnerships:**

1. NU3 clinic
2. Frere Gateway clinic



## APPENDIX 4: OXFORD UNIVERSITY SOCIAL SCIENCES AND HUMANITIES INTER-DIVISIONAL RESEARCH ETHICS COMMITTEE APPROVAL

SOCIAL SCIENCES & HUMANITIES  
INTER-DIVISIONAL RESEARCH ETHICS COMMITTEE

Hepple Street, 75 George Street, Oxford OX1 2DP  
Tel: +44(0)1865 274911 Fax: +44(0)1865 274912  
[IDREC@social.ox.ac.uk](mailto:IDREC@social.ox.ac.uk) [www.social.ox.ac.uk](http://www.social.ox.ac.uk)

Co-ordinator of the IDREC  
Social Sciences Divisional Office



20 December 2013

Dr Leslie Owen  
Department of Social Policy and Intervention

Dear Dr Owen,

**Research Ethics Approval**

**Ref No: 100/00062/13-11**

**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 Leslie Owen

cc: Dr Mark Boyes  
Professor Mark Drent  
Tinae's Mary Hungwen  
Rebecca Hodges  
Beth Vale  
Gina Tshepo

LD/CK



## APPENDIX 5: UNIVERSITY OF CAPE TOWN CENTRE FOR SOCIAL SCIENCE RESEARCH ETHICS APPROVAL

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](http://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: 17<sup>th</sup> 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  
Professor and Director, Centre for Social Science Research



## APPENDIX 6: EASTERN CAPE DEPARTMENT OF HEALTH ETHICS APPROVAL LETTER

  
Eastern Cape Department of Health

Enquiries:	Zonwabele Merlie	Tel No:	043 608 0000
Date:	29 <sup>th</sup> August 2013	Fax No:	043 642 1400
e-mail address:	zonwabele.merlie@impilo.ecprov.gov.za		

---

Dear Ms Elna 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





# APPENDIX 7: AMATHOLE DISTRICT DEPARTMENT OF HEALTH ETHICS APPROVAL



## 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 <b>Promoting antiretroviral adherence and sexual reproductive health service access amongst HIV positive teenagers</b>
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



## APPENDIX 8: CECILIA MAKIWANE HOSPITAL ETHICS APPROVAL LETTER

Province of the Eastern Cape  
**Department of Paediatrics and Child Health**  
**East London Hospital Complex**  
Cecilia Makiwane Hospital & Fries Hospital  
Private Bag X3047  
East London, 5200, South Africa  
Ph: Cell 083 378 1584  
Fax: 044 878 0900  
eMail: [gerald.boon@ecpc.hc.gov.za](mailto:gerald.boon@ecpc.hc.gov.za)  
Cecilia Makiwane Hospital Ph: 043-7082111 Fries Hospital Ph: 043-7082077/1111



11<sup>th</sup> April 2014

Mrs J Schok, Dr L Gels, Dr D Russion and Dr K Haper,  
Cecilia and Fries Hospitals  
Buffalo City

Dear Colleagues,

**Research Request : Title: Youth Puber: Identifying risk and protective factors for adherence to long-term medication amongst adolescents in South Africa / Promoting antiretroviral adherence and sexual and reproductive health service access amongst HIV positive teenagers.**

I have reviewed the research proposal and the ethical approvals for this study from the point of view of the Department of Paediatrics and Child Health and our patients.

On the basis of conflict with current research – I have been reassured by the other developing areas of research related to adolescents who are HIV positive that the two research groups are collaborating and have indicated to me in writing (attached) that the projects will not interfere with each other.

With respect to ethical issues – I have asked them to correct the protocol of the situation where the guardian is not able or willing to be asked to give consent, such that the protocol and consent form are altered to conform to South African law in this matter. I understand that this has been done and also that in such circumstances where problems might relate to abuse of a child that suitable processes have been put in place to manage such situations in line with legal and ethical expectations.

I otherwise consider the ethical issues appropriately taken care of.

On this basis I as head of Paediatrics and Child Health am satisfied to approve the research be conducted as per protocol.

I attach to this and following communications the protocols and various ethical and research approvals already received.

If the hospital management is satisfied please could they inform the researcher, Ekona Tsoke, appropriately (email address [ekona.tsoke@epl.ec.gov.za](mailto:ekona.tsoke@epl.ec.gov.za)).

Yours Sincerely  
  
Gerald Boon  
Head Paediatrics and Child Health: East London Hospitals

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## APPENDIX 9: EASTERN CAPE DEPARTMENT OF EDUCATION ETHICS APPROVAL



STRATEGIC PLANNING POLICY RESEARCH AND SECRETARIAT SERVICES  
Steve Tshwete Complex • Zone 6 • Zwelitsha • Eastern Cape  
Private Bag X0032 • Bheke • 5605 • REPUBLIC OF SOUTH AFRICA  
Tel: +27 (0)40 808 4773/4035/4527 • Fax: +27 (0)40 808 4574 • Website: [www.ecdoe.gov.za](http://www.ecdoe.gov.za)

Enquiries: @ Pama Email: [tsutshwete.pama@ecdoe.gov.za](mailto:tsutshwete.pama@ecdoe.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.ecpmv.gov.za](mailto:greg.macmaster@edu.ecpmv.gov.za) should you need any assistance.



**MR. GF MAC MASTER**  
**CHIEF DIRECTOR: STRATEGIC MANAGEMENT MONITORING AND EVALUATION**  
**FOR SUPERINTENDENT-GENERAL: EDUCATION**



## APPENDIX 10: CONSENT FORM

**Participant Information**

Name of Participant \_\_\_\_\_

Age: \_\_\_\_\_

Participant Signature: \_\_\_\_\_ Consent Date: \_\_\_\_\_

DOB/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 like to meet you in a year's time?

Person 1 - Name: \_\_\_\_\_

Address: \_\_\_\_\_

Phone number: \_\_\_\_\_

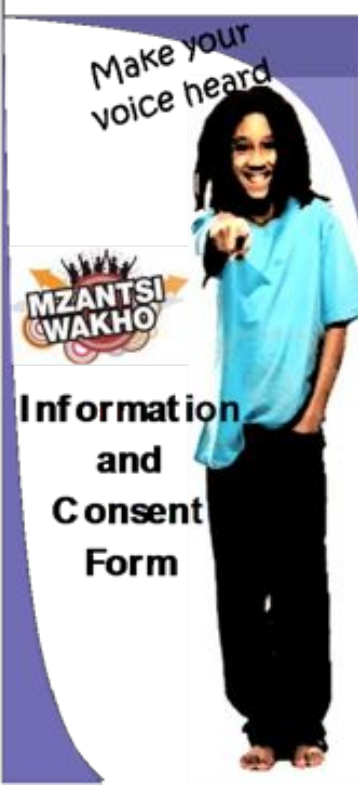

Relationship to you: \_\_\_\_\_

Person 2 - Name: \_\_\_\_\_

Address: \_\_\_\_\_

Phone number: \_\_\_\_\_


Relationship to you: \_\_\_\_\_

**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.

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*

**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 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.



## APPENDIX 11: DATA CONFIDENTIALITY AGREEMENT

Thank you for being part of this training.

As a participant of this training, I understand and acknowledge that:

1. Any and all references to HIV testing and HIV status are specifically protected under law and release of information about someone's HIV status may make me subject to legal and/ or disciplinary action. **I understand that it is illegal to disclose any minor, adolescent, or adult's HIV status to anyone without his or her permission.** I understand that it is my responsibility to be discrete and mindful of this in all interactions or discussions about this training workshop and the research project.
2. I shall only refer to the research project as an Adolescent Health Research project and not one that specifically focuses on HIV positive teens. This is done to protect the confidentiality of participants and reduce potential stigma associated with participation in the study. **I understand that saying that the research project focuses on HIV positive teens puts all participants at risk of stigma. Because of this, I will not discuss the project as being HIV-related in any conversation, including in my personal life and with all people not directly involved in the project.**
3. I shall respect and maintain the confidentiality of all information about the research project or potential participants that were shared in the training. This includes, but is not limited to:
  - HIV Status of the study participants
  - Details about the questionnaire
  - Details about recruitment strategies
  - Referral information

I hereby acknowledge that I have read and understood this information and that my signature below signifies my agreement to comply with the above terms. In the event of a breach or threatened breach of this Confidentiality Agreement, I acknowledge that Mzantsi Wakho may, as applicable and as it deems appropriate, pursue legal disciplinary action including my termination from the project.

### Trainee:

Name: \_\_\_\_\_ Signed: \_\_\_\_\_ Date: \_\_\_\_\_

### Project Manager:

Name: \_\_\_\_\_ Signed: \_\_\_\_\_ Date: \_\_\_\_\_



## APPENDIX 12: MZANTSI WAKHO SAFETY PROTOCOL

Note: This is the version of the safety protocol used while this DPhil candidate was conducting fieldwork. It is a working document and continues to be updated.

### 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). Included in this document are also safety procedures put in place regarding personal safety, driving safety, health safety, substance misuse, tablet use and safety, fire and floods (and other natural disasters), as well as climate safety. Please read the whole document carefully before submitting a signed copy to your Project Manager.

### 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 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.
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). 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 between the Project Managers, 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 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.

## SAFETY PROCEDURES

Please note that every person working in the field in South Africa on Mzantsi Wakho is required to have travel insurance.

While many of these safety procedures involve common-sense, please read the personal safety guidelines carefully. Note that they are relevant across all safety domains.

### ***Personal Safety in the field:***

- All staff and volunteers should carry a well-charged cell phone at all times in case of accident or emergency.
- Where there is an immediate emergency and Project Managers are not in the 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.
- If requested, all *Mzantsi Wakho* staff will be provided with a personal safety alarm.
- Staff should carry Project ID cards and a safety alarm where they are easily accessible (eg around the neck).



- Staff should know the closest location to the local authorities to seek refuge if danger arises.
- If possible, never leave a team member behind. It is best to intervene as a team.
- If interviewing in a community in which you feel unsafe:
  - Inform your Project Manager
  - Form 'Interviewer Groups' (and include a male field worker if possible)
  - If necessary a CPF escort can be arranged
- If needed, staff should discuss emergency SMS or telephone code.
- Staff should always work in teams of two (preferably with a male RA on each team) and within viewing distance of each other.
- Staff should carry maps of the areas in which they work to facilitate orientation and giving directions.

#### ***Dealing with Participants:***

- Violent Participants:
  - 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 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:
  - RAs should be aware of escalating emotions.
  - 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.
  - 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.
  - Contact and inform Project Manager of the encounter.

#### ***Driving Safety:***

- Extreme caution should be used at all times when driving and all rules of the road should be obeyed.
- In rural areas there may be a significant number of cattle on the road and drivers should be wary of this.
- There may also be a significant number of school children on the road who have a tendency to dash into traffic
- If requested, any person who will be driving a *Mzantsi Wakho* project car will be provided with defensive driving training.
- 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.
- 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 *Mzantsi Wakho* team should always be informed about your destination and estimated time of return.
- Valuables should never be left in the car.
- Your personal safety is more important than the car!

### ***Health of staff members***

- All staff members are required to have some form of health insurance
- All staff members are highly advised to practice safe sex
- 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, unless they have drug-resistant TB.
  - 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.
- Staff members with existing medical conditions:
  - All staff with chronic medical conditions are required to alert the Project Managers of their 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.

### ***Tablet use and safety***

- All research assistants must comply with and sign the Tablet Use for Fieldwork protocol.
- Tablets are to be used for work purposes only. Specifically, the tablets will be used to:
  - Collect questionnaire data; and
  - Collect video and photo answers from participants.
- Tablets will be delivered to the field each morning and picked up at the end of each day by a project manager or volunteer in the project vehicle. Any changes to this policy will be discussed in team meetings.



- 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. 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 case of loss or theft of a tablet you are required to report it missing at the nearest police station and to your Project Manager

### ***Crime***

South Africa has high crime rates. We strongly advise all staff to take the following steps if they are attacked or threatened:

- If you are threatened with a weapon, hand over whatever valuables you have been asked to hand over. Do not fight the person your life is more important.
- Should you be close to another group of people try to seek refuge by asking them directly for help – bystanders can be powerful protection. If you are in the vicinity of the car try to get into it and drive away. If you are being followed, try to find a safe place (i.e. corner shop).

### ***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. Do not ever try to kill a snake.
- 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.
- Stay clear off all areas where lions, cheetahs and leopards have been spotted.

### ***Climate:***

- Heat: fieldworkers will be provided with water bottles, sun umbrellas and sunblock during the summer months.
- Rain: fieldworkers will be provided with umbrellas and/or rain jackets.

### ***Fire, Floods, and Natural Disasters***

- In any case of environmental hazard, consider your own safety and that of your team first.
- The Project Manager and Principal Investigator will make a decision, in consultation with the fieldwork team, about how best to deal with these.

### ***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.



**Miscellaneous:**

In various sites fieldworkers have been accused of being Satanists

- This is being 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 kept on box.net so they are easily accessible for all members of the project.

**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.
- If re-addressing the objectives of the study has not always 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.
  - If necessary, give RAs crisis prevention training or safety training.

“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 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

*Principal Investigators:*

Dr Lucie Cluver (quantitative)  
Email: [lucie.cluver@socres.ox.ac.uk](mailto:lucie.cluver@socres.ox.ac.uk)  
Phone: +44 1865 2 80370 (Oxford)  
SA cell: +27 826 505 815

Dr Rebecca Hodes (qualitative)  
Email: [rebeccahodes@gmail.com](mailto:rebeccahodes@gmail.com)  
Phone: +27 794 268 682

*Research Officer:*

Franziska Meinck  
Email: [franziska.meinck@spi.ox.ac.uk](mailto:franziska.meinck@spi.ox.ac.uk)  
<mailto:mark.boyes@socres.ox.ac.uk>  
Phone: +44 (0)752 610 8460 (Oxford)

*Quantitative Project Manager:*

Elona Toska  
Email: [elona.toska@spi.ox.ac.uk](mailto:elona.toska@spi.ox.ac.uk)  
<mailto:Casale@ukzn.ac.za>  
Phone: +27 81 862 9611

Marija Pantelic  
Email: [marija.pantelic@spi.ox.ac.uk](mailto:marija.pantelic@spi.ox.ac.uk)

Julia Rosenfeld  
Email: [julia.b.rosenfeld@gmail.com](mailto:julia.b.rosenfeld@gmail.com)  
Phone: +27 78 637 3709

*Qualitative Project Manager:*

Beth Vale  
Email: [beth.nosizwe.vale@gmail.com](mailto:beth.nosizwe.vale@gmail.com)  
<mailto:Casale@ukzn.ac.za>  
Phone: +27 82 309 3945  
+27 71 040 9285



## APPENDIX 13: QUANTITATIVE QUESTIONNAIRE



# Mzantsi Wakho Giraffe Questionnaire



Interviewer name: \_\_\_\_\_

Interview date: \_\_\_\_\_

Name of clinic: \_\_\_\_\_

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       Giraffe, confirmed by the participant  
 Giraffe, confirmed by the caregiver       Giraffe, confirmed by participant themselves  
 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 to the next page  
 No - please ask additional questions below

**4. When was the participant born? \_\_\_\_\_**

Questionnaire Number: clinic.datetoday.interviewer.participantbirthday  
 Please write this questionnaire number in the consent form.

**5. Where are you conducting the interview?**

- Participant's Home  
 clinic  
 Hospital  
 School  
 Church  
 Community Centre  
 Other

Please write address: \_\_\_\_\_



## Introduction

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



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.



## ABOUT YOU

1. What nickname would you like us to call you? \_\_\_\_\_
2. What age are you? \_\_\_\_\_
3. How many villages, towns or cities have you lived in since you were born, including where you are living now? \_\_\_\_\_
4. When were you born? \_\_\_\_\_

5. Please tell us what type of house do you live in now! [please check one]

- house made of brick or concrete
- hut made of traditional materials (cow dung, mud, etc.) or a rondavel on its own plot
- living on the street
- shack in a back yard or a separate plot
- children's home or shelter for kids
- other (what kind?) \_\_\_\_\_

6. What language do you mainly speak at home [tick only one]?

- isiXhosa
- isiNgesi/ English
- Afrikaans
- isiZulu
- other

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**



7. What is the name of the city/ town or village where you live now?

\_\_\_\_\_

8. WHAT IS THE NICEST THING ANYONE HAS SAID TO YOU ABOUT YOURSELF?

.....  
 .....  
 .....

# SECTION 2: My school

## 1. What kind of school did you go to?

- we pay school fees
- the school charges fees but we cannot afford to pay them, so we owe them
- it's a free school but we are still asked to pay something
- a totally free school, we don't have to pay anything
- other kids pay school fees but I have an special permission from the principal to go there for free
- don't go to school – go to **question 1a.**

2. WHAT IS THE NAME OF YOUR SCHOOL?

\_\_\_\_\_

3. WHAT GRADE ARE YOU IN?

\_\_\_\_\_



1a. If you are NOT currently attending school, what is the MAIN REASON for not attending school? [PLEASE CHOOSE ONLY ONE] REASON]

- |  |  |
|--|--|
| <input type="checkbox"/> finished matric                                   | <input type="checkbox"/> was suspended or expelled                           |
| <input type="checkbox"/> didn't have enough money to pay fees or uniform   | <input type="checkbox"/> got married   |
| <input type="checkbox"/> had to stop going to school to help at home       | <input type="checkbox"/> got pregnant or had a child                         |
| <input type="checkbox"/> stopped going because I was too unwell            | <input type="checkbox"/> was bullied or treated badly by teachers or friends |
| <input type="checkbox"/> had to stop going because my parent/guardian died | <input type="checkbox"/> did not like school                                 |
| <input type="checkbox"/> had to repeat a grade and I didn't want to        | <input type="checkbox"/> moved to another place and could not register       |
|  | Other _____  |



6

4. How many grades have you repeated?

- 1     2     3  
 4     5 or more     None

...

4.a Why did you repeat grades?

\_\_\_\_\_

\_\_\_\_\_

\_\_\_\_\_



- Tax     Bicycle     Drive

7.a. How long did it take you to get to school in the last term?

\_\_\_\_\_ hours \_\_\_\_\_ minutes

## 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.

5. In the last full term of school, how many days did you miss school (not including weekends, holidays or public strikes)?

- Less than a week in total     About 3 weeks in total  
 About a week in total     4 or more weeks in total  
 About 2 weeks in total

6. In the last term of school, which meals did you have for free at school?:

- Breakfast     Other food  
 Lunch     I don't have any free food at school

7. What is the main way you got to school during the last term of school?

- Walking     Bus

- Bicycle     Drive



8. How many different schools have you been to? Please include primary school if you are in secondary school

\_\_\_\_\_

7

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:

- 11. I like school
- 12. I look forward to going to school
- 13. I tried hard to do well in school
- 14. I have been beaten/slapped by a teacher at school
- 15. I like the way my school looks
- 16. I feel safe at school

Never	Sometimes	Always



17. What has been your favorite subject now or before?

\_\_\_\_\_

This is the  
end of  
Section 2!!!



7

Section 5: Me and My Health

We all get sick sometimes. This section asks about how your health has been in the past 6 months.

1. How has your overall health been in the last 6 months?
- Very poor health
  - It has been OK (not too good, not too bad)
  - Excellent health!



The next questions are about problems you have had while doing certain activities because of your health. Please check the boxes below

In the last six months...

1. Did you have difficulty seeing, hearing, walking or climbing steps, washing yourself or getting dressed, speaking or being understood?
2. Did you have difficulty remembering things or following a story or conversation?

	No - no difficulty	Yes - some difficulty	Yes - a lot of difficulty	Cannot do it at all



Which one of the following illnesses have you felt in the past 6 months? Please tell us how often you have felt them: never, sometimes or often.



In the past six months...	Never	Sometimes	Often
1) Ear problems: pains and infections			
2) Asthma, lung problems or difficulty breathing for more than two days			
3) Fits or epilepsy			
4) Shingles or rash on the skin			
5) Sores on the hands, mouth, feet or other parts of the body			
6) Tuberculosis (TB)			
7) ulcers on your mouth or lips, white patches on your mouth or difficulty swallowing food			
8) Diarrhea or a runny tummy for more than 2 days			

	Never	Sometimes	Always
9) Nausea or vomiting			
10) Headaches			
11) Back pain			
12) Fever			
14) Tire easily / little energy			
15) Stomach problems, difficulty digesting food			
16) Dizziness			
17) Bad dreams or problems sleeping well			
18) Lost a lot of weight or could not put on weight			





Which one of the following illnesses have you felt in the past 6 months? Please tell us how often you have felt them: never, sometimes or often.



In the past six months...	Never	Sometimes	Often
19) Sores or warts in your private parts			
20) Burning while urinating			
21) Itching or redness in your private intimate parts?			
22) Itching, soreness or bleeding from your bum			

23. Have you ever been tested for TB?

No, I've never been tested

Yes, I was tested, I had TB in the past, but I am ok now

Yes, I was tested, I have TB now

Yes, I was tested, I did not have TB

Yes, I was tested, but I don't know the results

24. Have you ever been tested for HIV?

Yes, but I didn't get my results

Yes, I got my results

No (skip to Q26)

25. How old were you when you were first tested for HIV [year]?

26. What was your most recent CD4 count?  
.....  
\_\_\_\_\_

27. What was the results of your most recent viral load?

There is still some virus in my body

The doctor or nurse said my viral load is low

I don't know my viral load results



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

### MY SCHOOL

28. In the last year, where have you gone to get help?

<input type="checkbox"/> Chemist/Pharmacy	<input type="checkbox"/> A healer at church or medicine from the church
<input type="checkbox"/> Public Clinic	<input type="checkbox"/> Traditional Pharmacy
<input type="checkbox"/> Private Doctor	<input type="checkbox"/> Public Hospital
<input type="checkbox"/> Traditional healer	<input type="checkbox"/> Private Hospital

29. What is the main way you got to school during the last term of school?

- Walking  Bus  
 Bicycle  Drive  
 Taxi  Other: \_\_\_\_\_

30. How long does it take to get there?

\_\_\_\_\_ hours \_\_\_\_\_ minutes

31. How much does it cost to get to your clinic (in Rand)? If you don't pay any money, please enter 0 (zero): \_\_\_\_\_

32. Who goes to the above places with you usually?  
**CHOOSE ONLY ONE ANSWER**

- I go alone
- My parent/ caregiver comes
- Another family member
- My friend /
- My boyfriend/ girlfriend
- My village or community healthcare worker
- Someone else



**MY SCHOOL**

23. 4. Who did you talk to about your health at the clinic during the last year? CHOOSE AS MANY AS APPLY

<input type="checkbox"/> Nurse	<input type="checkbox"/> Village or community health worker
<input type="checkbox"/> Doctor	<input type="checkbox"/> Someone else who is working at the clinic living with HIV
<input type="checkbox"/> Counselor	
<input type="checkbox"/> Pharmacist	

30. How long does it take to get there?

\_\_\_\_\_ hours \_\_\_\_\_ minutes



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.



Please tell us how often you have experienced these in the past year...	Never	Once or twice	Several Times	Most of the time
1) I didn't have enough money to get transport to the clinic				
2) No one was available to go with me				
3) It was not safe for me to go to the hospital/ clinic				
4) I did not get the help I needed				
5) The clinic/hospital staff were too busy to help me				
6) I felt my information would be kept safe and confidential				
7) They did not know the answers to my questions				

	Never	Sometimes	Always
9) They did know the answers to my questions			
10) They got angry with me about how I take my pills and scolded me			
11) I had to miss school to go to the clinic			
12) I felt comfortable talking to the healthcare worker about getting something to prevent pregnancy			
14) They got angry with me because I am having sex and they scolded me			



15. How often do you go to a support group at your clinic or hospital?

Weekly

- Monthly
- Every Year
- Once in a while
- don't go to one (skip to question XXXX)



16. 4. What kind of support group do you go to?

- A group for anon who is HIV positive
- A group for HIV positive youth/teens only
- The group changes

17. 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

- No
- Yes



18. 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?



## GAME TIME

6. Who is your favourite sports player?



7. Do you support a team?



8. What are your favourite soapies?

1  
2  
3



9. Which soapie star are you most like?

10. Why are you like them?



## Section 5: More About You

1. What are you most proud of about yourself?

\_\_\_\_\_

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?



...

2. I look as good as others my age

- Never
- Sometimes
- All of the time

3. I like how my skin looks

- Never
- Sometimes
- All of the time

4. My body is small for my age

- Never
- Sometimes
- All of the time

5. I would like to put on weight

- Never
- Sometimes
- All of the time

6. Other young people think I am sexy/ attractive

- Never
- Sometimes
- All of the time

7. Some of my body parts have changed since I started taking ARVs

- Never
- Sometimes
- All of the time



## How I Think and Feel - SECTION 7

*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.*

1.  Nothing will ever work out for me  
 I am not sure if things will work out for me  
 Things will work out for me OK

2.  I do most things OK  
 I do many things wrong  
 I do everything wrong

3.  I am sad once in a while  
 I am sad many times  
 I am sad all the time

4.  I look ok/good!  
 There are some bad things about my looks  
 I look ugly

5.  I feel like crying every day  
 I feel like crying many days  
 I feel like crying once in a while

6.  I have enough friends  
 I have some friends but wish I had more  
 I don't have any friends

7.  I hate myself  
 I do not like myself  
 I like myself

8.  Nobody really loves me  
 I am not sure if anybody loves me  
 I am sure that somebody loves me

9.  I do not feel alone  
 I feel alone many times  
 I feel alone all the time

10.  Things bother me all the time  
 Things bother me many times  
 Things bother me once in a while






Sometimes we get extremely sad. In the past month did you

	Yes	No
1. Wish you were dead	<input type="checkbox"/>	<input type="checkbox"/>
2. Want to hurt yourself	<input type="checkbox"/>	<input type="checkbox"/>
3. Think about killing yourself	<input type="checkbox"/>	<input type="checkbox"/>
4. Think of a way to kill yourself	<input type="checkbox"/>	<input type="checkbox"/>
5. Try to kill yourself	<input type="checkbox"/>	<input type="checkbox"/>



1. Are you a member of any youth and/or health organisations, political or activist groups?

- A youth centre where I can do things like use computers and play sports
- A youth club or homework club at school
- Gospel Choir/ Singing Group
- Sports team
- Music/ Arts performance group
- Volunteering
- Career Development and advice
- Other/ Ezinye \_\_\_\_\_

23a. What is the name of your club or group or activity?  
\_\_\_\_\_

24. How often do you go out to a night club, tavern or shebeen?

- A few times a week
- Every wee
- Once in a while
- Never



## WEEKENDS

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.

### 1. What did you do last weekend?

- Stayed at home
- Visited relatives
- Played sports with friends
- Go out with friends
- Other

### 2. How many times did you not take your medication last weekend?



6. 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?



### 3. How many days in the last month did you want to take your ARVs but you couldn't?

### 4. Were there times in the past (when you were younger) that you couldn't take your ARVs?

- No
- Yes

4.a Can you tell us a bit more why?

### 5. Were there times in your life when it was easy to take ARVs?

- No
- Yes

Can you tell us what made it easier?



## My Social Network



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?

In the last sixth months...	Not true for me	Somewhat true for me	certainly true for me
1. I am restless, I cannot stay still for very long			
2. I am constantly moving around and turning			
3. I am constantly distracted and find it difficult to concentrate			
4. I think before I do things.			
5. I finish the work I am doing. My attention is good			

**Circle your favorite celebrity**



**Memory Game**

Apple Car Red  
 Hope Bell

ALTERNATIVE CONTACTS



6. Imagine that you are in a taxi with the President. You can talk to him on behalf of all teens like yourself. What is the first question you will ask him?

**MEMORY GAME:** Please write down any of the words that you remember from our word game



## MY FRIENDS AND FREE TIME

Section 6



*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 sometimes goes after school to soccer games.*

1. What do you like to do with your friends in your free time or when you are not in class?

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.

### How many times in the past 3 months have you...

1. Have you ever drunk enough alcohol or taken enough drugs to forget what happened or you couldn't walk or talk properly?	Never	Once or twice	Every week or Weekend	Every Day
--	-------	---------------	-----------------------	-----------

## Teen Confidential



Can you tell us how your friends at school and home feel about sex and relationships? Remember it's totally confidential and no one will know what your responses are, it's just important that you tell us how you really feel.

a) 1. How many of your friends think that having sex at your age with as many people as possible is a cool thing for a [boy/girl] to do.

None  Some

Most  All

b) How many of your friends think that using condoms is like eating sweets in their wrapper?

None  Some

Most  All

c) 1. How many of your friends have had sex because they were drunk or high on drugs?

None  Some

Most  All

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.



d) How many of your friends have been pregnant or have gotten someone pregnant?

None  Some

Most  All

e) Could you tell us a little bit about what people in your community think about HIV?

f) People in the community think that a person with HIV is disgusting?

Most of the time

Sometimes

Never

g) People in my community think that HIV is a punishment from God or from ancestors.

Most of the time

Sometimes

Never

h) Do you play, or did you play, a sport at school, like soccer, netball, running, rugby, drum majorettes, or cricket?

Yes

I don't/didn't play sports at school

I was told not to play sports at school

Other kids and teenagers can be great. They can also be really mean to each other. It would really help if you could answer all these questions even if you not certain or they seem silly. In the past 6 months...

Never

Once

2-3 times

Four or more times

1. Called me names or swore at me

2. Tried to get me into trouble with my friends

3. Took something with out permission or stole something from me

4. Made fun of me for some reason

5. Made me uncomfortable by standing too close or touching me.

6. Punched, kicked or beat up

7. Hurt me physically in some way

Who's the best dancer?



Never

Once

2-3 times

Four or more times

8. Tried to break or damage something of mine

9. Refused to talk to me or made other people not talk to me

10. What do you like most about your best friend?

## Section 3

Remember that your answers here are completely confidential - we won't tell people what you say

In the past month, can you say if this is...

1. I cut or bunk classes, or skip school

- Not true  
 Somewhat or sometimes true  
 Very true or often true

2. I run away from home

- Not true  
 Somewhat or sometimes true  
 Very true or often true

3. I drink alcohol to have a good time, without my parents or caregivers knowing or approving

- Not true  
 Somewhat or sometimes true  
 Very true or often true

### MY BEHAVIOUR

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?

4. I don't feel guilty after doing something I shouldn't

- Not true  
 Somewhat or sometimes true  
 Very true or often true

5. I hang around with kids who get in trouble

- Not true  
 Somewhat or sometimes true  
 Very true or often true

6. I would rather be with older kids than kids my own age

- Not true  
 Somewhat or sometimes true  
 Very true or often true





*In the past 6 months...*

**7. I steal at home**

- Not True    Sometimes or somewhat true    Very often or often true

**8. I steal from places other than home**

- Not True    Sometimes or somewhat true    Very often or often true

**9. I swear or use dirty language**

- Not True    Sometimes or somewhat true    Very often or often true

<p><b>10. I lie or cheat</b>  <input type="checkbox"/> Not True  <input type="checkbox"/> Sometimes or somewhat true  <input type="checkbox"/> Very often or often true</p>	<p><b>11. I get very angry and often lose my temper</b>  <input type="checkbox"/> Not True  <input type="checkbox"/> Sometimes or somewhat true  <input type="checkbox"/> Very often or often true</p>
---	--

**12. I fight a lot. I can make other people do what I want**

- Not True    Sometimes or somewhat true    Very often or often true

**13. I usually do as I am told**

- Not True    Sometimes or somewhat true    Very often or often true

**14. I try to be nice to other people**

- Not True    Sometimes or somewhat true    Very often or often true

**14. I carry a knife on me for protection**

- Not True    Sometimes or somewhat true    Very often or often true

<p><b>15. I carry a gun on me for protection</b>  <input type="checkbox"/> Not true  <input type="checkbox"/> Somewhat or sometimes true  <input type="checkbox"/> Very true or often true</p>	<p><b>16. I am part of a gang</b>  <input type="checkbox"/> Not true  <input type="checkbox"/> Somewhat or sometimes true  <input type="checkbox"/> Very true or often true</p>	<p><b>17. I bet money or gamble</b>  <input type="checkbox"/> Not true  <input type="checkbox"/> Somewhat or sometimes true  <input type="checkbox"/> Very true or often true</p>
--	---	---

## Special Friends and Relationships

How we would like to know a bit more about any romantic relationship that you might have or want to have in the future

1. Do you currently have a boyfriend or girlfriend?

No  Yes

2. Do you know your boyfriend's or girlfriend's HIV status?

Yes, there are positive  Yes, they are negative  No

3. Have you ever had a romantic or sexual experience (that is more than friends) with someone of the same gender?

No  Yes

4. Have you ever had a romantic or sexual experience (that is more than friends) with someone of the same gender?

No  Yes

5. If you could choose a famous person to be your boyfriend or girlfriend, who would it be?



# SHARING AND CARING

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.

1. How did you learn about your HIV the first time?
- I guessed myself
  - I was told at the clinic by a doctor or nurse
  - I was told at home by my family
  - I was told at the clinic by my family and a doctor or nurse
  - I overheard people talking about

SECTION V



2. At which age did you first suspect you were HIV-positive

3. At which age did someone first tell you were HIV positive?

4. Did you ever take pills without knowing what they are for?  
 Yes  No

5. How did you feel when you learned about your HIV status?  
 Surprised  
 Upset  
 Relieved  
 I didn't care  
 I don't remember  
 Other \_\_\_\_\_



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?



1. Lundi is very careful who he tells that he has HIV. Are you careful who you tell?

- Not at all  
 Sometimes  
 All the time

2. Sometimes Lundi feels that he is not as good as other kids because he has HIV. Do you ever feel this way?

- Not at all  Sometimes  All the time

3. Sometimes Lundi feels like he would rather die than live with HIV. Do you ever feel this way?

- Not at all  Sometimes  All the time

4. Sometimes Lundi feels like he is a bad person because he has HIV. Do you ever feel this way?

- Not at all  Sometimes  All the time

5. Sometimes Lundi feels ashamed that he is HIV-positive. Do you ever feel this way?

- Not at all  Sometimes  All the time

6. Sometimes Lundi feels that it is his fault that he is HIV-positive. Do you ever feel this way?

- Not at all  Sometimes  All the time

7. Sometimes having HIV makes Lundi feel contaminated and dirty inside. Do you ever feel this way?

- Not at all  Sometimes  All the time

Thank you for answering these difficult and private questions

8. 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.

---



---



---



Many people in our community are sick or someone in their family is sick or has died. Sometimes people treat us differently because of this and sometimes it makes us feel bad about ourselves.

Because someone in the family is sick or has died...

- 1. I've been teased  
 Not at all    Sometimes    All the time
- 2. I've been badly treated  
 Not at all    Sometimes    All the time
- 3. People have gossiped behind my back  
 Not at all    Sometimes    All the time
- 4. I worry about being rejected  
 Not at all    Sometimes    All the time
- 5. People who know don't want me around them  
 Not at all    Sometimes    All the time
- 6. I avoid making new friends  
 Not at all    Sometimes    All the time
- 7. I feel different and alone  
 Not at all    Sometimes    All the time

Which music or sport star are you most similar to?

## Sharing and Caring

Each of us has different people who we share secrets with and go to when we need help or support



1. Please tell us how many people know about your HIV?

Parent or person who cares for me  
 Rest of my family  
 Friends at home  
 Friends at school  
 Teachers/ principal at school  
 People at church  
 Other: \_\_\_\_\_

We would like to know how much information about your health you share with others in your life.

2. Parent or Caregiver  
 I don't have a parent or caregiver  
 They don't know anything about my health, illness or medication  
 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,  
 They know I am taking medication, but not what type of medication,  
 They know about my HIV status  
 I talk to them about my HIV status  
 They know that I am taking (ARVs).  
 I talk to them about my struggles with taking medicine

3. My best friends
- They don't know anything about my health, illness or medication
  - 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.
  - They know I am taking medication, but not what type of medication.
  - They know about my HIV status
  - I talk to them about my HIV status.
  - They know that I am taking (ARVs).
  - I talk to them about my struggles with taking medicine

4. My boyfriend/ girlfriend
- I don't have a boyfriend/ girlfriend
  - They don't know anything about my health, illness or medication
  - 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.
  - They know I am taking medication, but not what type of medication.
  - They know about my HIV status
  - I talk to them about my HIV status.
  - They know that I am taking (ARVs).
  - I talk to them about my struggles with taking medicine

5. My church leader or priest
- I don't go to church
  - They don't know anything about my health, illness or medication
  - 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.
  - They know I am taking medication, but not what type of medication.
  - They know about my HIV status
  - I talk to them about my HIV status.
  - They know that I am taking (ARVs).
  - I talk to them about my struggles with taking medicine

33

5. Teachers and school principal
- I don't go to school
  - They don't know anything about my health, illness or medication
  - 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,
  - They know I am taking medication, but not what type of medication.
  - They know about my HIV status
  - I talk to them about my HIV status,
  - They know that I am taking (ARVs),
  - I talk to them about my struggles with taking medicine

## Similarities and Differences

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?

1. I have been hurt by how people react when they find out that I have HIV

Never    Sometimes    Most of the time

2. I have stopped spending time with some kids because of their reactions to my HIV status

Never    Sometimes    Most of the time

3. I have lost friends by telling them I have HIV

Never    Sometimes    Most of the time

4. I've been teased because of my HIV

Never    Sometimes    Most of the time

5. 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?

33



34

Scary things may also happen in our neighborhood, community or city. Buntu has been robbed and had his things stolen

1. How many times have you had things stolen in the last year?			
2. Buntu was attacked and hit when he was out. Have you ever been attacked or hit when you are out?	Yes, more than a year ago	Yes, in the last year	Never
3. Buntu saw someone in his neighborhood being shot. have you ever seen anyone being shot?	Yes, more than a year ago	Yes, in the last year	Never
14. Lindewi saw someone being stabbed on evening. Have you even seen anyone get stabbed?	Yes, more than a year ago	Yes, in the last year	Never
Who of the following would you most like to be your neighbour?			

TOM - INSERT SOME PICTURES OF CELEBS



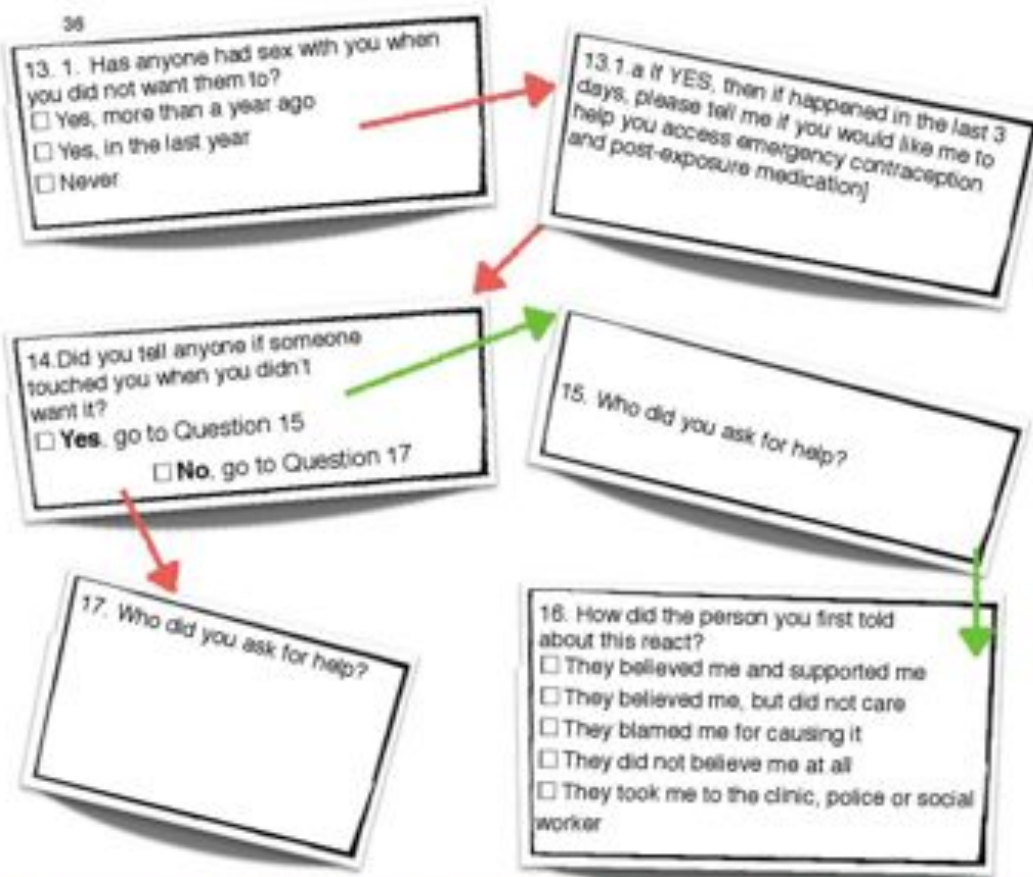
	Weekly	Monthly	At least once a year	Has happened but not in the last year	Never
1. Used a stick, belt or other hard item to hit you					
2. Slap, punch, hit, pinch or pull your ear/hair so that you were hurt or had marks					
3. Threaten to hurt you.					
4. Say they would call ghosts or evil spirits, or harmful people					
5. Tell you they wished they did not have to look after you or make you feel you are a burden					
6. Make you feel unwelcome in the home.					
7. Say that you would be sent away or kicked out of the house					
8. Call you dumb, lazy, or other names					

Has anyone in your family or who is living in your home or someone at school every done any of these things to you?

	Weekly	Monthly	At least once a year	Has happened but not in the last year	Never
9. Insult members of your family that have passed away					
10. Threaten to leave you and never come back.					
11. Threaten to hurt or kill a person or an animal that you care about.					
12. Withhold a meal to punish you.					

13. Has anyone made you look at their private parts or wanted to look at yours when you did not want to?  
 Yes, more than a year ago  
 Yes, in the last year

14. 1. Has anyone touched your private parts, or made you touch theirs, or tried to have sex with you when you did not want to?  
 Yes, more than a year ago



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.

	Weekly	Monthly	At least once a year	Has happened but not in the last year	Never
9. I can always manage to solve difficult problems if I try hard enough					
10. I am certain that I can achieve/reach my goals					
11. I can stay calm because I have ways of solving problems when they come up.					
12. I can handle whatever comes my way					

13 Remember the words we told you at the end of Part 5! Let's see if we can remember them together.

14. How many of the words did you need help remembering?

### Part 9: Home & Family

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

\*\*\*

1. Do you have a parent, guardian or caregiver staying with you and taking care of you at home?

- Yes (skip question 3)  
 No

3. If you don't have anyone that takes care of you at home, who is the main person that supports you?



5. How old is this person?

7. How many different caregivers (parents or guardians) have you had?

8. How many other people live in the same home as you?

9. How many of them are working?

10. Please tick the things which you can afford at home

- 3 meals a day  
 Costs of going to school even if you go to a no-fees school (transport, books, exams)  
 Visit to the doctor when you were ill, getting there and buying all the medicines you need  
 School uniforms.  
 Enough clothes to keep you warm and dry.  
 Toiletries to be able to wash every day  
 School equipment (pencils, exercise books...)  
 More than 1 pair of shoes.

### CAREGIVER

4. Who is the person that takes care of you at home?

- Biological Mother  
 Biological Father  
 Stepfather / Stepmother  
 Brother / Sister / Stepbrother / Stepsister  
 Grandmother / Grandfather  
 Great-grandfather / Great-grandmother  
 Aunt / Uncle  
 Cousin  
 Foster Parent  
 Other:

## Home and Family

1. 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?

\*\*\*

2. Are you or your household receiving any grants?

- Yes  
 No (skip to \_\_\_\_FILL THIS IN)

3. How many child support grants does your household receive?

4. How many foster care grants does your household receive?

3. How many disability grants does your household receive??

4. How many pension grants does your household receive?

5. In the past month, how many days was there not enough food in the house for you to eat?

- Yes  
 No



**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?**

6. Do you or your family grow food in a school garden, community garden or at home?

- Yes  
 No

7. What is the name of your favourite soapie?

INSERT SOME SOAPIE IMAGES HERE

## Your thoughts on the future of South Africa

We would like to find out about experiences that happen to children at home, in the family. 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.

1. What are your thoughts about the future of South Africa?

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2. What are your hopes for King Williams Town?

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3. If you could be the minister of families for one day, what is the first change you would make?

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