

### CENTRE FOR SOCIAL SCIENCE RESEARCH

#### Are Youth Living with HIV in South Africa Reaching the Sustainable Development Goals?

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#### Are Youth Living with HIV in South Africa Reaching the Sustainable Development Goals?

#### Abstract

The Sustainable Development Goals (SDGs) are a commitment by countries worldwide to improving the lives of all, through achieving specific targets related to the promotion of economic, social, and environmental wellbeing by 2030 (Lee et al., 2016).

Many of the 17 goals are linked to poverty and health, focussing on vulnerable, hard-to-reach, and marginalised people. Adolescents are a key target population for the SDGs, but research studies and programmes rarely include their direct perspectives on how to promote health and wellbeing (Hodes et al., 2018a). In the context of HIV research, growing evidence has shown that adolescent populations are particularly vulnerable, with high rates of defaulting (non-adherence) on antiretroviral treatment (ART) (Kim et al., 2017, Cluver et al., 2018b). Research has also shown that adherence to HIV treatment is not just linked to the provision of medication and healthcare, but also to other factors such as the provision of "cash/cash in kind" (e.g. government cash transfers, food security, school fees/materials, school feeding, clothing), and "care" (HIV support groups, sports choir/art positive groups, groups, parenting and parental supervision/monitoring, and access to health facilities) (Young et al., 2014, Singer et al., 2015, Cluver et al., 2016).

The Mzantsi Wakho study, the largest longitudinal, community-traced, mixed methods cohort study of adolescents living with HIV to date, has followed more than 1500 adolescents living in the Eastern Cape, South Africa, over a period of five years. The study looks at their lived experiences in high-HIV prevalence communities, specifically with regard to adherence to ART and sexual and reproductive health.

In this report, we look at longitudinal changes between baseline and the first year of follow-up in this cohort of HIV-positive adolescents as well as 'community controls' (whose HIV-status was negative or unknown), to assess whether their lives are improving in specific relation to the relevant SDGs. This allows us to examine whether existing policies in South Africa are supporting adolescents in achieving the SDGs by 2030.

#### **1.** Introduction

There are an estimated 2.1 million adolescents living with HIV (ALHIV) worldwide, 85% of whom live in sub-Saharan Africa (Idele et al., 2014). The world's largest population of ALHIV live in South Africa (UNAIDS, 2018b, Wamoyi et al., 2016). HIV/AIDS is the second highest cause of death in adolescents worldwide after road traffic accidents (WHO, 2014, Wamoyi et al., 2016).

Between 2013–2018, the Mzantsi Wakho study conducted research to understand sexual practices and ART non-adherence among ALHIV in the Eastern Cape, South Africa. This mixed methods study, designed in collaboration with ALHIV and key partners, aimed to:

- Understand the lived experiences of adolescents and youth;
- Identify how to improve adherence, retention in care, and sexual and reproductive health service use for adolescents living with HIV; and
- Expand the evidence base on adolescents living with HIV, to meet the priorities of development partners and programme implementers.

Given the importance of country alignment with the Sustainable Development Goals (SDGs), we have examined longitudinal cohort changes in the context of the SDGs, investigating whether adolescents in South Africa are attaining these ambitious development goals.

Three waves of quantitative surveys were conducted, in which the same cohort were re-interviewed each year. This report, originally compiled as a summary for partners and funders, examines how these adolescents have fared between the first and second years of data collection (baseline and follow-up) of the study in reaching the SDGs.

#### **1.1** The Sustainable Development Goals (SDGs)

Building on the objectives of the Millennium Development Goals (MDGs) as a global blueprint for development, the SDGs were formulated by the United Nations in 2015 as a set of 17 global goals (Lee et al., 2016). The SDGs broadly cover topics relating to social and economic development, including poverty, hunger, health, education, gender equality, and social justice, with specific targets relating to each goal. They aim to improve the lives of people living in low- and middle-income countries, particularly their poorest and most vulnerable. The majority of state signatories, including South Africa, have committed to attaining

these goals by 2030. Three years subsequent to their adoption, the Goals have been subjected to various critical political analyses, and their targets have been scrutinised by stakeholders as being too vague and numerous (Winkler & Williams, 2017).

In this report, we examine the socio-structural and health outcomes of adolescents in the Mzantsi Wakho study in relation to the SDGs, using qualitative data gathered from 2013 to 2017, and quantitative data collected from baseline and follow-up waves of the study – the largest known longitudinal, community-traced study on adherence to antiretroviral treatment and sexual and reproductive health among adolescents living with HIV. This working paper is structured according to the framework of the SDGs, with primary goals quoted at the beginning of each section, followed by findings based on Mzantsi Wakho data.

#### 2. Methods

#### **2.1** Data collection

This study combines quantitative and qualitative research methods in its design and implementation, with both components informing the adaptation and integration of research tools. The quantitative sample aimed to include all adolescents who had initiated ART in a large urban, peri-urban and rural health subdistrict of the Eastern Cape province of South Africa. Within the first wave of the study (baseline), researchers visited all 52 clinics providing ART to adolescents, located both paper and computerised patient files of all 10- to 19year-old adolescents who had ever initiated ART, and traced them to their homes across the Amathole Health District and the Buffalo City Metropolitan Municipality. Researchers have followed these adolescents over a five-year period. To avoid stigmatising participants, interviews were also conducted with neighbours and with other adolescents ('community controls') in both participants' and neighbouring homes.

At baseline (2014–2015), the study recruited a total of 1,519 10-to-19 year old adolescents. Of this sample, there were 1,063 HIV-positive adolescents who were receiving care in 52 government healthcare facilities, and 456 neighbouring or co-habiting peers whose HIV-status was not known. The study took place in nine hospitals, five community health centres, and 38 primary health clinics. Adolescents were re-traced and re-interviewed in 2016–2017 (follow-up), with a high retention rate of 94%.

The Mzantsi Wakho study has combined qualitative and quantitative research methods since its inception, with qualitative ethnography informing the development of quantitative survey tools and strategies for participant recruitment. As the study progressed, qualitative participants were sampled from the quantitative arm, to explore themes emerging from both qualitative and quantitative research in greater depth. Qualitative methods included interviews, focus groups, observations and participatory research exercises. The aim was to explore firstly how adolescents living with HIV used and adapted medicines and sexual and reproductive health services, and secondly how their caregivers and healthcare workers understood the challenges that adolescents confronted. From the study baseline until the end of follow-up, qualitative research had included 24 months of observations in homes, schools and clinics. Over 150 in-depth interviews had been conducted with youth, healthcare providers and families, with over 1,000 hours of home and clinic observations.

#### **2.2** Cohort demographic characteristics

### 2.2.1 Total study population (adolescents living with HIV and community controls)

A total of 1,519 adolescents and youth were interviewed at baseline, of whom 1,063 (70%) were living with HIV and 456 were 'community controls' whose HIV-status was unknown (Figure 1).

Mode of HIV-infection may shape the health and lived experiences of ALHIV, their access to health services and their long-term outcomes (Sherr et al., 2018). In the absence of definitive clinic notes capturing whether the participant was vertically (parent-to-child) or horizontally (sexually) infected, an age-cut-off and a detailed algorithm were used to determine the adolescent's mode of infection (MOI). Participants who began taking ART before the age of 10 were considered vertically infected, whereas those who started treatment after the age of 10 were considered horizontally infected. Other factors, including the age of sexual debut, history of risky sexual behaviour, history of chronic illness and cognitive issues, orphanhood, and report of an HIV-infected parent were used to validate this categorisation. MOI was re-determined in both directions: some HIV-positive adolescents who were determined to be vertically-infected through the algorithm were confirmed to be sexually-infected, and vice-versa (He et al., 2018).

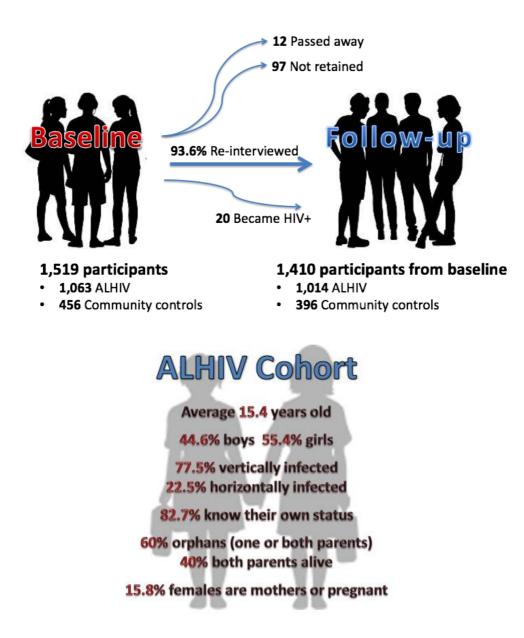


Figure 1: Overview of baseline to follow-up retention and demographics

#### 2.2.2 Retention at follow-up

Of the 1,519 adolescents interviewed at baseline, 1,410 were re-interviewed at the first follow-up. Twelve participants died in the months between baseline and follow up (leaving 93.6% follow up). Of the 97 initial participants who were not retained, 5% were untraceable, and 1.4% declined to participate again (Figure 2).

Of the 1,063 ALHIV interviewed at baseline, 994 were re-interviewed during the follow-up period of data collection. All of the 12 participants who died were ALHIV (leaving 94.6% follow up rates among ALHIV). Of those adolescents interviewed at both baseline and follow-up, an additional 20 adolescents were confirmed to be HIV-positive at follow-up, meaning that 1,014 adolescents from the original sample were HIV-positive at follow-up (Figure 1).

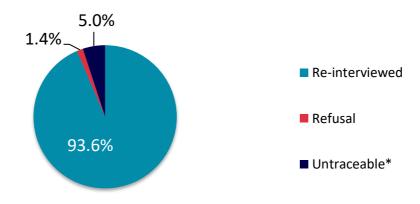


Figure 2: T1  $\rightarrow$  T2 breakdown of individuals re-interviewed or lost to follow-up \*Reasons include leaving home, contact details not working, etc.

Between baseline and follow-up, 6% of participants had moved outside the study setting. The research team traced these participants, travelling to Cape Town and Johannesburg, the main destinations for migrating participants, to conduct interviews (Figure 3).



Figure 3: Baseline  $\rightarrow$  follow-up mobility map showing where adolescents moved to between baseline and follow-up

#### **2.3 Statistical analyses**

Questionnaire responses given at baseline were compared with responses given during the follow-up interview a year later for each individual within the cohort, looking at changes over time.

Key indicators related to selected SDGs were then identified to investigate whether participants were making progress towards reaching these SDGs. For each SDG, only relevant SDG-related targets, for which data were available, were selected for reporting. Findings are clustered by SDG in the next section for SDG1: Ending Poverty, SDG2: Ending Hunger, SDG3: Good Health and Wellbeing, SDG4: Quality education for all, SDG5: Gender Equality, SDG8: Employment and Economic Growth, and SDG16: Peace, Justice and Strong Institutions.

Descriptive analyses stratified by HIV-status and gender were conducted to compare participants within waves of the study. Where additional stratification was undertaken, this is noted in the results sections below.

Pearson's  $\chi^2$  tests were used for categorical variables and two-sample t-tests were used for continuous variables. Additionally, changes between baseline and follow-up were assessed using McNemar Chi-square tests, both overall and with stratification according to HIV-status.

All analyses presented in this report are preliminary descriptive analyses. Further analyses controlling for co-factors are being conducted.

#### 3. Findings

A selection of adolescent-focused SDG indicators is reported in the sections below. For each indicator, changes between baseline and follow-up, and differences between ALHIV and community controls where relevant, are reported. Accessing the same provisions at both baseline and follow-up – sustainable access over the 2-year period – is reported. Qualitative findings from interviews, focus groups, observations and participatory research exercises relate adolescents' experiences and perspectives in relation to these developmental objectives.

### **3.1 SDG 1: Ending poverty in all its forms everywhere**

- SDG 1.1: By 2030, eradicate extreme poverty for all people everywhere
- SDG 1.2: By 2030, reduce at least by half the proportion of men, women and children of all ages living in poverty
- SDG 1.3: Implement nationally appropriate social protection systems and measures for all, including 'floors', and by 2030 achieve substantial coverage of the poor and the vulnerable.

The following indicators were examined in relation to SDG 1:

- The type of housing participants live in
- If households can afford 8 basic necessities
- If households can afford school fees
- If households receive government grants
- If households can afford to travel to the clinic

#### **3.1.1** Where are adolescents living?

Type of housing is a strong indicator of poverty. While the majority of Mzantsi Wakho participants lived in formal housing, one in five lived in informal housing (shacks), in children's homes, or did not have a stable, consistent home (in essence, were homeless). This was similar to the split at baseline (20% informal housing).

Specifically, 276 (19.6%) adolescents were living in informal housing (homeless, in shacks, children's homes, or traditional housing) and 1,134 (80.4%) adolescents were living in formal housing (brick housing or formal constructions).

In this shack in Mdantsane (Figure 4), home to an adolescent participant and her elderly caregiver, there was no running water or electricity. The family had developed a meticulous system for storing water and food in plastic containers.

Commenting on their living circumstances, the caregiver (78 years old) explained: 'Here we are just living on the edge... It is not that we are living or staying in places that we like, but we are living here because we don't have anywhere else to go.'



Figure 4: Participant's home in Mdantsane

### 3.1.2 Do adolescents live in households that can afford the 8 basic necessities?

At follow-up, 78.0% of ALHIV were living in homes that could not afford all 8 basic necessities, which was a significant increase from the 67.9% reporting the same at baseline (P<0.001). The same trend was seen in community controls, with an increase from 65.4% to 82.6% between baseline and follow-up.

#### 3.1.3 Can adolescents afford to go to school?

As shown in Figure 5, of those who were attending school, at follow-up there was a significant reduction in the number of ALHIV reporting that their household could afford their school fees, from 54.6% at baseline, to 47.6% at follow-up (P<0.01). Community controls between baseline and follow-up did not have a statistically significant change.

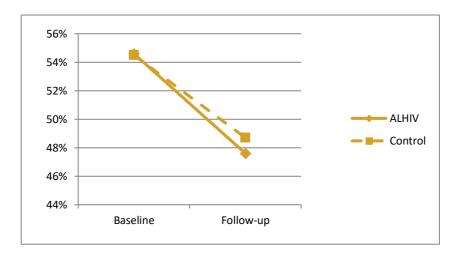


Figure 5: Do adolescents live in households that can afford school fees? Change over time between baseline and follow-up for those attending school

### 3.1.4 How many adolescents live in households that receive government grants?

A very high proportion of the total sample lived in households that received at least one grant (>90%).

Access to government grants were consistent as, over a 2-year period (baseline  $\rightarrow$  follow-up), 90.0% of ALHIV lived in a household that had consistently had access to at least 1 grant. This was similar to community controls, of whom 87% lived in households that had consistently accessed at least one grant over the last 2 years.

#### 3.1.4.1 Grants shopping basket

A participatory research exercise, the 'grants shopping basket' was developed and piloted with youth to investigate how the child support grant was spent. This exercise was conceptualized together with participants, and findings were analysed collaboratively. This exercise documented the financial and material acuity which undergirded how the grant was spent. By examining a couple's grants shopping basket, analysing its contents, and studying the processes through which items were selected, it demonstrated how a young family used the child support grant to provide the nutritious food and sanitation for their child, while simultaneously ensuring their own subsistence.



Figure 6: Contents of a 'child support grant shopping basket', selected by young parents (research conducted in September, 2017)

#### 3.1.5 Can ALHIV afford to get to their clinic?

At follow-up, there was a significant increase in the percentage of ALHIV who were always able to afford to travel to the clinic, from 77.4% at baseline, to 88.8% at follow-up (P<0.001). However, over 10% of ALHIV were still not able to afford to travel to receive the healthcare they needed.

Within qualitative observations at healthcare facilities, a senior trauma nurse, who worked closely with children living with HIV, vented her frustrations over the high cost of transport to clinics, borne especially by rural patients. She spoke of scheduling clinic dates based on social grant disbursements: "*These patients are poor. Sometimes you'll find that they cannot even attend sessions because they will say, 'I don't have money to come'. And then you will just have to wait and say, 'Okay, the grant is on the first, so let me just put my return date on the 3<sup>rd</sup>, or the 5<sup>th</sup> of that month.""* 

At a Day Hospital, a senior antenatal care nurse was alarmed by the transport costs borne by a young, pregnant patient. The patient was admitted to the emergency ward and gave birth that day. The nurse explained: *'This patient has come all the way from [a rural village about 200 kilometres away]. She has taken four taxis to get here. Now, by the time she gets here, she fits [goes into convulsions].... [T]hese people are poor. They use the last bit of money that have to travel through the province to get the services they need.'* 

#### 3.1.5.1 Clinic Report Card

In a participatory research exercise, the 'Clinic Report Card', adolescents assessed and ranked health services that they had identified as crucial to comprehensive care, including transport to clinics (Figure 7 and Figure 8). The majority of participants awarded a poor ranking to the healthcare component: 'free transport to clinic'. Figure 8 shows an excerpt from a clinic report card. It reads: 'If you want to go to the clinic [because you are] very ill, you have to pay a taxi to take you.

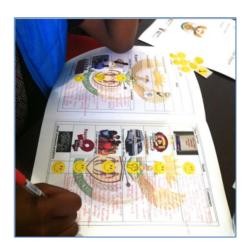


Figure 7: Pages from the 'Clinic Report Card', including assessment sections for youth friendly services, HIV rapid-testing, healthcare workers, and support groups



Figure 8: Excerpt from a clinic report card voices dissatisfaction with inadequate ambulance services. It states: "We don't have free clinic transport in our village. If you want to go to the clinic very ill you have to pay a taxi to take you, so that must change."

### **3.2 SDG 2: End hunger, achieve food security and improved nutrition**

- SDG 2.1: By 2030, end hunger and ensure access by all people, in particular the poor and people in vulnerable situations, including infants, to safe, nutritious and sufficient food
- SDG 2.2: By 2030, end all forms of malnutrition

The following indicators were examined in relation to SDG 2:

- Whether adolescents have access to 3 meals a day (food security)
- Whether adolescents have gone without food in the last week (food insecurity)
- Access to food security support, such as free school meals and food parcels

#### 3.2.1 Do adolescents have access to 3 meals a day?

At follow-up, 88% of both ALHIV and community controls reported living in households that could afford enough food at home to provide 3 meals each day. This was unchanged from baseline.

Of all adolescents, 78% reported consistent food security at both baseline and follow-up (household could afford 3 meals a day). There was no significant difference between ALHIV and community controls, or HIV-positive boys and girls.

### 3.2.2 Have adolescents gone without food in the last week?

At follow-up, more ALHIV were missing at least one meal per week than at baseline (P<0.01) (Figure 9). This difference was not seen in community controls. There was also a significant difference between male and female ALHIV, showing that more girls were consistently going without food than boys at both baseline (P<0.001) and follow-up (P<0.05). Specifically, 21.7% and 25.3% of females at baseline and follow-up respectively were missing at least one meal per week, versus 12.8% and 19.9% of males at baseline and follow-up respectively.

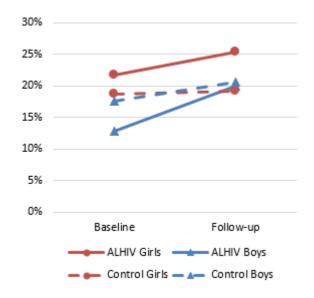


Figure 9: Percentage of ALHIV and community controls who have gone without food at least once a week at baseline and follow-up

Adolescent girls living with HIV were twice as likely as adolescent boys living with HIV to have experienced consistent food insecurity over the course of two years. Specifically, 9.3% of girls vs. 4.6% of boys (P<0.01) responded "yes" to missing a meal in the last week at both baseline and follow-up (Figure 10).

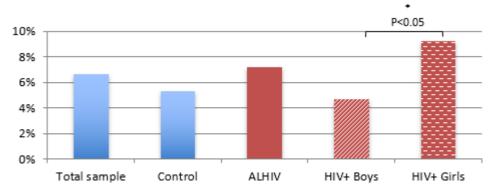


Figure 10: Adolescents who have experienced food insecurity consistently over the last 2 years, and missed a meal regularly

#### 3.2.3 Are adolescents receiving free meals at school?

Over 90% of the total sample who were attending school were accessing at least one free meal at school per day, both at baseline and follow-up.

#### **3.2.4** Are adolescents receiving food parcels?

At baseline, 18% of adolescents reported living in households that have received food parcels or free meals, either from a church or clinic/hospital. At follow-up this had dropped (P<0.001) by half, from 18.4% at baseline (for both ALHIV and controls) to 9.2% and 6.6% for ALHIV and community controls respectively.

Over a 2-year period, almost 90% of the total sample had consistently reported accessing free meals at school or receiving food parcels. Significantly fewer adolescent girls living with HIV reported accessing free food or food parcels than adolescent boys living with HIV at both baseline and follow-up (87.7% (Females) vs. 91.8% (Males); P<0.05).

### **3.3 SDG 3: Ensure healthy lives and promote wellbeing for all at all ages**

- SDG 3.3: By 2030, end the epidemics of AIDS, tuberculosis, malaria and neglected tropical diseases and combat hepatitis, water-borne diseases and other communicable diseases
- SDG 3.7: By 2030 ensure universal access to sexual and reproductive health-care services, including for family planning, information and education
- SDG 3.8: Achieve universal health coverage, including financial risk protection, access to quality essential health-care services and access to safe, effective, quality and affordable essential medicines and vaccines for all

The following indicators were examined in relation to SDG 3:

- General mental and physical health
- Appropriate monitoring of viral load and CD4 counts in HIV-positive adolescents
- Adherence to antiretroviral treatment (ART) for HIV-positive adolescents
- Condom use
- Experience at the clinic when accessing contraception

#### **3.3.1** How healthy are adolescents?

When HIV is treated and monitored well, ALHIV can expect similar life expectancy to their HIV-negative peers (Johnson et al., 2013). However, poor adherence to ART increases the risk of opportunistic infections and of HIV-related mortality (Kranzer and Ford, 2011, Cluver et al., 2016). Through monitoring the health status of ALHIV, including through annual viral load measurements and CD4 counts, healthcare providers can track the health outcomes of ALHIV, including the efficacy of ART regimens. They can also identify and treat adverse health events.

More ALHIV in the sample experienced poor physical and mental health than community controls; a trend observed at both baseline and follow-up (P<0.001). At follow-up, 21.6% of ALHIV reported experiencing poor physical or mental health, compared with 13.1% of community controls (P<0.001). However, for ALHIV, this was a significant improvement from physical and mental health reported at baseline, in which 24.5% reported poor physical or mental health (P<0.001). There was no significant difference between baseline and follow-up for community controls.

### 3.3.2 Are HIV-positive adolescents receiving regular CD4 and viral load monitoring?

As shown in Figure 11, regular monitoring of HIV-positive patients via annual CD4 counts and viral load levels was limited for adolescents in the Mzantsi Wakho study. Although 89.1% of ALHIV had a patient file, and of those, 92.5% contained information about viral load, only about half had any viral load data from the last two years. At each level of the "treatment cascade", HIV-positive adolescents were falling out of the system of healthcare monitoring. At the end of the cascade, only 48.5% of ALHIV (513 out of 1,058) had a medical file indicating that their viral load was undetectable.

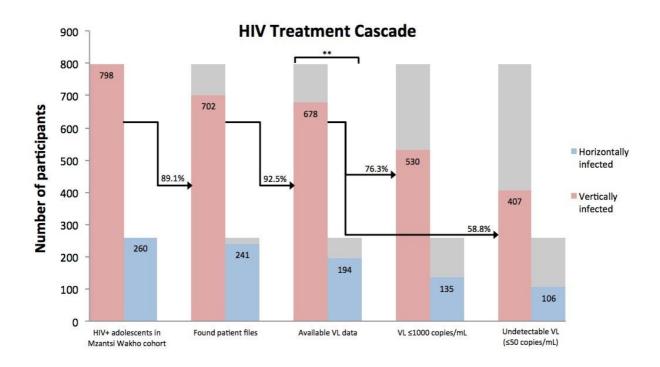


Figure 11: The gaps in viral load and CD4 count monitoring (Haghighat, 2018)

In an interview with a highly-adherent adolescent who had moved from the Eastern Cape in search of work, and who was staying in Khayelitsha in Cape Town, she explained that she was receiving information about her CD4 count results at clinic visits, but not her viral load results. The interviewer asked if she had been given information about the meaning of biomarkers: 'Did they tell you about what they [CD4 count and viral load] are doing, what is means for your body? The participant replied: 'No, they didn't tell us about that'.

#### 3.3.3 Are ALHIV adhering to their antiretroviral treatment?

At follow-up, 42.6% of ALHIV reported that, in the last week, they had not been fully adherent to their ART regimens. This was significantly higher than at baseline, in which 35.9% of adolescents had reported that, in the last week, they had not been fully adherent (P<0.001).

Within the qualitative sample, essentially all participants reported periods of nonadherence to ART. Interestingly, they did not use words such as 'adherence' or 'defaulting' to describe their medicines-taking practices. Rather, they understood periods of non-adherence as temporary, and explained that they would return to their regimens in the future, after a 'break' from the routine demands of compliance (follow-up qualitative interviews) (Hodes et al., 2018b).

#### 3.3.4 Are adolescents consistently using condoms?

Of ALHIV (boys and girls) who had had sex in the past year, there was a significant increase in condom use from 50.0% at baseline to 64.1% at follow-up (P<0.05). A small increase (46.6% at baseline to 53.4% at follow-up) was also seen in community controls, though this was not statistically significant.

Interestingly, there was also a significant difference in consistent condom use between HIV-positive boys and HIV-positive girls at both baseline and followup. As shown in Figure 12, over 75% of HIV-positive males reported using condoms consistently when having sex, compared to under 60% of HIV-positive females. Looking at the total HIV-positive sample at follow-up, this meant that over 35% of HIV-positive adolescents were at risk of a secondary HIV-positive infection or STIs, or transmitting HIV to their partner.

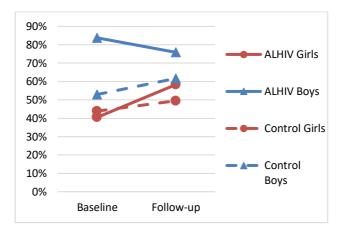


Figure 12: Consistent condom use in HIV-positive adolescents at baseline and follow-up by sex

### 3.3.5 What are adolescents' experiences of accessing contraception?

At both baseline and follow-up, clinics were the place that adolescents used most to access contraception. At follow-up, 89.0% of those accessing contraceptives reported obtaining it from the clinic.

Adolescents were asked about their experiences in clinics when seeking access to contraception. Both positive and negative responses were recorded. A notable trend was that youth sought out contraceptive services in clinics that had reputations for respectful treatment of adolescents. While this incurred material

and opportunity costs, adolescents were assured that they would receive contraception rather than being turned away.

In the waiting area at a contraceptive clinic, a nurse addressed a group of adolescents. She asked: 'Where are you from? Why are you here?' They responded that they were from different neighbourhoods to that in which the clinic was located, requiring time and travel costs to get to this facility, and that they had come for family planning. In relation to patients' failures to access to contraception from their most proximate healthcare facilities, the nurse explained: 'They won't give teenagers family planning there. They will chase them out of the clinic!' This clinic had acquired a good reputation for providing contraceptive services timeously and also to adolescent patients, who travelled there specifically to access a friendlier and more efficient service. Some of these patients avoided their local clinics, despite their greater proximity, because of the hostility of healthcare workers who were opposed to providing contraception to school girls.

# **3.4 SDG 4: Ensure inclusive and equitable quality education and promote lifelong learning opportunities for all**

- SDG 4.1: By 2030, ensure that all girls and boys complete free, equitable and quality primary and secondary education leading to relevant and effective learning outcomes
- SDG 4.3: By 2030, ensure equal access for all women and men to affordable and quality technical vocational and tertiary education, including university
- SDG 4.4: By 2030, eliminate gender disparities in education and ensure equal access to all levels of education and vocational training for the vulnerable

The following indicators were examined in relation to SDG 4:

- Whether adolescents are attending school full-time
- If adolescents ever failed or repeated a grade at school
- Whether adolescents have to pay school fees, or if they have access to free education

#### **3.4.1** Are adolescents attending school full-time?

Over 10% of adolescents at baseline and follow-up were missing more than 2 weeks of school in the last term, or not enrolled in school for reasons other than

matriculating (completing high school). Even if just temporary, these individuals were at risk of falling behind their peers with their studies.

This level of school absence was consistent between baseline and follow-up, but what was striking was the significant difference between the attendance records of boys and girls (both HIV-positive participants and community controls) (Figure 13). At both baseline and follow-up, over twice the number of girls than boys (both ALHIV and community controls) reported missing more than 2 weeks of school in the last term, or not attending school due to reasons other than matriculation (P<0.001 for both time points for ALHIV; P<0.01 for community controls).

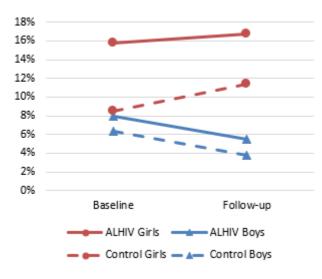


Figure 13: School absence (missing 2 weeks or more in the last term, or not enrolled due to reasons other than matriculation)

This difference could be explained by girls needing to take more time out of school when pregnant and looking after children, or to undertake household chores or carer responsibilities. Further quantitative analysis is needed to understand the differences between the sexes. Qualitative research documented vastly different perspectives on the causes and implications of teenage pregnancy among young women, young men, and adult caregivers (Hodes 2018; Hodes et al., 2016).

#### 3.4.2 How are adolecents doing at school?

Reasons for failing a grade or needing to repeat a grade were numerous, including not being able to afford to go to school, needing to stay home to help with household duties, being ill, getting expelled, becoming pregnant, not liking school, or being bullied. As indicated in Figure 14, a significantly higher proportion of adolescents reported failing or repeating their last grade at follow-up versus baseline (P<0.001 for ALHIV, control, and whole sample).

A significant difference was also seen between ALHIV boys and ALHIV girls at both baseline and follow-up (P<0.001 at both time points), and between HIV+ and control adolescents at both baseline and follow-up (P<0.01 for both time points), with more boys than girls reporting failing or repeating a grade.

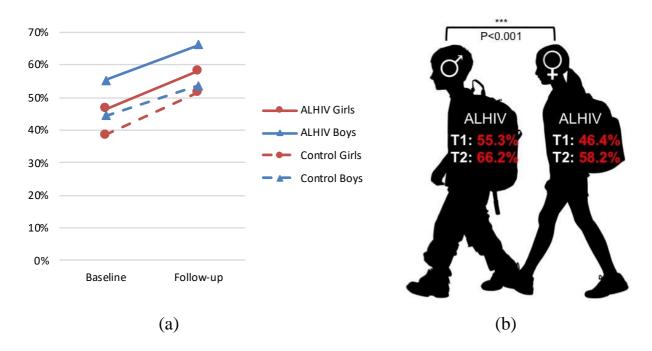


Figure 14: Percentage of adolescents who have failed their last grade, or have needed to repeat a grade due to reasons other than matriculating. (a) ALHIV compared with control at baseline and follow-up; (b) ALHIV only, stratified by sex at baseline and follow-up

### **3.5 SDG 5: Achieve gender equality and empower all women and girls**

- SDG 5.1: End all forms of discrimination against all women and girls everywhere
- SDG 5.2: Eliminate all forms of violence against all women and girls in the public and private spheres, including trafficking and sexual and other types of exploitation

The following indicators were examined in relation to SDG5:

- Incidence of sexual abuse, including rape
- Incidence of transactional sex (sex in exchange for gifts or money)

#### 3.5.1 Sexual abuse (including rape)

There was a significant increase in girls reporting ever being sexually abused, including rape, from 7.9% at baseline, to 11.5% at follow-up (P<0.001). This trend was seen in both ALHIV and community control girls (P<0.001 for both groups) (Figure 15).

#### 3.5.2 Rape

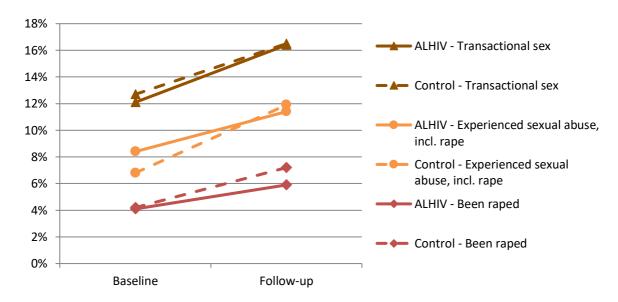
At follow-up, the number of adolescent girls and young women who reported ever being raped was significantly higher at follow-up than at baseline (P<0.001), with 6.3% of females reporting they had ever been raped at follow-up. In real numbers, an additional 50 girls in the Mzantsi Wakho study reported having been raped in the twelve months between baseline and follow-up. The team followed a rigorous protocol supervised by social workers and in collaboration with nurses and service providers from the study area to offer these young people referrals to health and counselling services.

#### 3.5.3 Transactional sex

Over 10% of girls reported having sex in exchange for gifts, such as money, clothes, somewhere to stay or better marks at school – "transactional sex". At baseline, 12.3% of all sexually active girls (ALHIV and controls) reported ever having had transactional sex. At follow-up this figure has significantly increased, with 16.4% of all sexually active girls reporting ever having had transactional sex (P<0.001). Figure 15 shows this information broken down by HIV-status.

### 3.5.4 Abuse victimization experiences among adolescent boys and young men

Physical, emotional, and sexual abuse was not limited to female participants. At follow-up, 6.9% of teen boys report ever experiencing sexual abuse, including rape: a significant increase from the 4.1% at baseline (P<0.001). In real numbers, at follow-up, more than 40 boys reported that they had ever been sexually abused or raped.



### 3.5.5 Abuse victimization experiences among adolescent girls and young women

Figure 15: Girls reporting sexual abuse or rape, or transactional sex

Figure 15 reports rates of transactional sex, sexual abuse – including rape – among adolescent girls in the study. Notably, rates did not vary by HIV status, but increased between baseline and follow-up. At follow-up more than one in ten adolescent girls had experienced sexual abuse, including rape, and more than one in six reported having sex in exchange for money or material goods.

# **3.6 SDG 8: Promote sustained, inclusive and sustainable economic growth, full and productive employment and decent work for all**

- SDG 8.5: By 2030, achieve full and productive employment and decent work for all women and men
- SDG 8.6: By 2020, substantially reduce the proportion of youth not in employment, education or training

The following indicators were examined in relation to SDG 8:

- Provision of career advice or support
- Employment status of household

### 3.6.1 Are adolescents receiving any career development advice or support?

Adolescents were asked if they had access to any career advice, or had any support with doing their homework. Of those who were 15 and over, which is an age at which adolescents may be starting to think about what their career options or ambitions are, fewer than 3% of boys and girls answered yes to receiving this support at baseline or follow-up.

### 3.6.2 How many adolescents live in households where no adults are working?

For the overall sample at both baseline and follow-up, 30-40% of adolescents lived in households in which no adults were working, suggesting that these adolescents were living in households primarily dependent on government grants for income.

# 3.7 SDG 16: Promote peaceful and inclusive societies for sustainable development. Provide access to justice for all and build effective, accountable and inclusive institutions at all levels

- SDG 16.1: Significantly reduce all forms of violence and related death rates everywhere
- SDG 16.2: End abuse, exploitation, trafficking and all forms of violence against and torture of children

The following indicators were examined in relation to SDG 16:

- Exposure to physical, emotional, or domestic violence
- Whether adolescents are safe at school, or exposed to violence

## 3.7.1 Are adolescents experiencing any form of violence or abuse, including physical or emotional, or domestic violence?

As shown in Figure 16, more adolescents (both ALHIV and community controls) were experiencing emotional abuse at the follow-up timepoint than they were at baseline (P<0.001). Specifically, 28.3% and 31.6% of ALHIV and community

controls respectively reported experiencing emotional abuse in the past year at baseline, compared with 45.4% and 49.5% at follow-up.

However, by contrast, both ALHIV and community controls were experiencing significantly less physical violence than at baseline (P<0.001). Specifically, 33.6% and 35.1% of ALHIV and community controls respectively reported experiencing physical abuse in the past year at baseline, compared with 26.2% and 25.8% at follow-up.

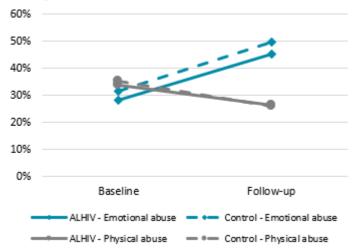


Figure 16: Physical and emotional abuse at baseline and follow-up

There was no significant difference between ALHIV and community controls at the different time-points, or between HIV-positive boys and girls. Domestic violence remained constant between baseline and follow-up for both ALHIV and community control adolescents, with 12% of ALHIV experiencing recent domestic violence (within the last week at the time the interview was conducted).

### 3.7.2 Have adolescents experienced violence at the hands of their teacher at school?

The number of adolescents who reported corporal punishment from a teacher in the last full term at school remained stable between baseline and follow-up, with no significant difference between the two time points (Figure 17). At baseline, 41.7% of all adolescents attending school reported being slapped or beaten by a teacher in the last full term, which decreased slightly to 36.7% at follow-up. This trend was observed for all teenagers, without no significant difference between ALHIV and controls at either time point.

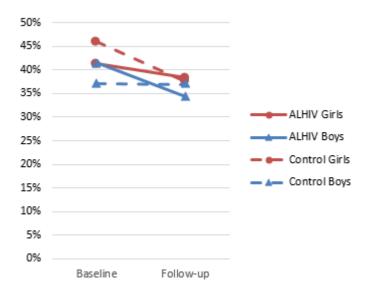


Figure 17: Adolescents who have been beaten or slapped by a teacher in the last term

# **3.8 SDG 17: Strengthen the means of implementation and revitalize the global partnership for sustainable development**

- SDG 17.9: Enhance international support for implementing effective and targeted capacity-building in developing countries to support national plans to implement all the Sustainable Development Goals, including through North-South, South-South and triangular cooperation
- SDG 17.18: By 2020, enhance capacity-building support to developing countries, including for least developed countries and small island developing states, to increase significantly the availability of high-quality, timely and reliable data disaggregated by income, gender, age, race, ethnicity, migratory status, disability, geographic location and other characteristics relevant in national contexts

SDG 17 focuses broadly on the international community, and how it is supporting developing countries in particular to reach the SDGs. This section reports on how the Mzantsi Wakho project has helped to contribute to SDG 17.

Through dissemination at the international, regional, national, and local levels, the Mzantsi Wakho research team has shared study findings widely with the goal of informing policies and programming, contributing to SDG 17 (Figure 18).

Most recently, the study's findings contributed to UNAIDS' Global Response to HIV report (UNAIDS, 2018a). In seeking to document the workings of the study from a range of perspectives, a podcast about Mzantsi Wakho was recorded in 2018, and is available on the study homepage at <u>http://www.mzantsiwakho.org/</u>.

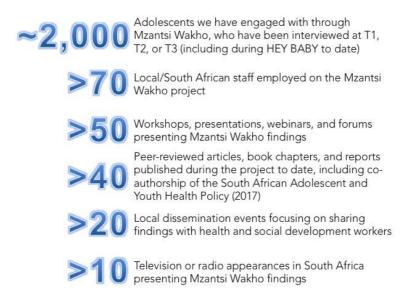


Figure 18: Mzantsi Wakho in numbers

#### 4. Summary

#### 4.1 SDG 1 – Ending poverty

Indicators for study participants for SDG 1, linked to eradicating extreme poverty for all (SDG 1.1), and reducing at least by half the proportion of men, women and children living in poverty (SDG 1.2) showed overall that adolescents were moving further away from attaining SDG 1 at follow-up compared with baseline.

20% of adolescents were still living in informal housing, most likely because they had no alternative housing and no financial means of improving their living arrangements (Figure 4), with no improvement between baseline and follow-up.

Across the first 2 years of the study, an alarming percentage of adolescents reported that their household could not afford at least one of the 8 basic necessities, with a worsening trend evident. The 8 basic necessities, which include access to warm clothing, toiletries, as well as affording school uniforms and school equipment, underpin a sense of wellbeing, good health, dignity, confidence, and chances of good future prospects (Wright, 2007). That almost 80% of adolescents lived in homes without at least one of these basic necessities is deeply concerning. Access to food, clothing and school fees for children are

imperatives of a decent standard of living (Wright, 2007). Furthermore, access to these basic provisions has been shown to improve ART adherence among ALHIV (Cluver et al., 2016). Linked to this, a worsening trend over the 2 years was also seen with ability to afford school fees – fewer than 50% of households were able to afford school fees at follow-up, which was significantly less than at baseline. The onwards impact of this cannot be underestimated, affecting the likelihood of future employment and wellbeing, as well as impacting on ART adherence among the ALHIV (Cluver et al., 2016). The South African government does provide an exemption system for pupils who cannot afford school fees, whereby a full or partial reduction in fees may be applied for. Further research is needed to understand how school fees waivers or reductions impact on adolescents' school retention and, conversely, on the impacts of compulsory fees on learner absenteeism and drop-out.

Indicators linked to the existence of nationally appropriate social protection systems (SDG 1.3) remained unchanged over the 2-year period, with 90% of households accessing at least 1 grant. Social grants play a key role in alleviating poverty, and South Africa has a well-developed system of social support grants (Seekings, 2004, 2015, 2016). Findings from the Mzantsi Wakho study suggest that there was a high uptake of social support grants among this cohort, which is positive evidence that families were accessing social support, but also a strong indicator that many families lacked a subsistence income, and were thus eligible for grants.

Apparent improvement in affordability to clinic transport is a good indicator that ALHIV should be able to access clinic and medical support when required. Findings from both quantitative and qualitative components of this study support the urgent need for provision of better, and free, transport and access to clinics, especially for individuals living in rural areas. Indeed, research has shown that cash-in-kind support, such as transport to clinics, positively influenced ALHIV adherence to medication (Cluver et al., 2016).

These observations indicated that adolescents in South Africa still have a long way to go to reach SDG 1.

#### 4.2 SDG 2 – Ending hunger

Findings from this study show that almost 90% of households could afford three meals a day. However, this figure remained constant over the two-year period rather than improving.

ALHIV, especially girls, were seemingly worse off with regards to food security, with a quarter of those interviewed missing at least one meal per week; significantly more so than community controls. Further work is needed to understand the reasons for these differences between the sexes, as well as associations between HIV-status and food security, especially as food security has been shown to be an important cofactor for ART adherence in ALHIV (Cluver et al., 2016, Young et al., 2014). This trend with girls faring worse than boys was also observed consistently over the two-year period, with the same ALHIV girls reporting missing meals at both time points, indicating that for these individuals, food security has remained low, and has not improved.

Ending hunger and ensuring access by all people, in particular the poor and people in vulnerable situations ... to safe, nutritious and sufficient food (SDG 2.1), and ending malnutrition (SDG 2.2), are goals not yet achieved for young people in South Africa, and policies specifically directed at adolescents, especially adolescent girls living with HIV, are needed.

#### 4.3 SDG 3 – Good health and wellbeing

Findings from Mzantsi Wakho indicate that overall the physical and mental health of ALHIV had slightly improved over the two-year period, though was still worse than community controls. However, there are worrying findings that both adherence and regular monitoring of CD4 and viral load were poor and worsening. Regular monitoring of these biomarkers in ALHIV was limited, with adolescents falling out of the system at each step of the "treatment cascade" (Haghighat et al., 2018). Self-reported full adherence to ART was also diminishing, with only 42% of adolescents in the study reporting full past-week adherence. Qualitative findings suggest that not understanding the importance of full adherence could be one such reason for defaulting, with adolescents viewing non-adherence as providing a much-needed break from the 'boring', distasteful or even oppressive ritual of medicines-taking (Hodes et al., 2018c). Participants perceived breaks in ART-adherence as providing their bodies with a break from medicines, as well as giving them a sense of relief and ease from the demands of their pill-taking routines. Many did not understand the impact of non-adherence on HIV disease progression. Indeed, published guidelines on best practice for initiating ART and retaining HIV-positive patients in care focus on the importance of education and counseling as factors to improve adherence (Thompson et al., 2012).

Condom use improved over the two-year period, especially among HIV-positive males, where 75% use in the past year was reported at follow-up. However, condom use among HIV-positive females was still relatively low, with fewer than

60% of HIV-positive females reporting having always used a condom. This is leaving a vulnerable group of adolescents at risk of contracting secondary HIV infections, contracting other STIs, and transmitting HIV and other STIs onwards to sexual partners and, potentially, to infants. Patriarchal social norms prevent girls and women from negotiating or insisting on safe sex. Girls and women who have been abused, who are economically dependent on their male partners, or who are in relationships with partners who are 10 years older or more, are less likely to be able to negotiate condom use and to thereby prevent HIV transmission or unwanted pregnancy (Langen, 2005).

Data from this study has shown that clinics were the most common place to access contraception, and that youth sought out contraceptive services in clinics that have a reputation for respectful treatment of adolescents. Supporting healthcare workers to provide adolescent-responsive health services centred on confidentiality, and respectful, non-judgmental communication in clinical consultation, may promote increased contraceptive access and use.

Achieving the targets linked to SDG 3 is a significant undertaking, particularly for states such as South Africa with high HIV prevalence. In this report, specific areas of concern were highlighted, in which creative interventions and policies are urgently needed to significantly reduce HIV infection (SDG 3.3), ensuring regular monitoring of biomarkers of HIV infection (CD4 count and viral load), and improving ART adherence for all HIV-positive people. Young people were accessing family planning information and contraception via clinics (SDG 3.7). However, more needs to be done to ensure that clinics staff are adequately trained to provide non-judgmental, accurate and factual advice to young people This may require improving HIV-education and ART literacy, including the importance of ART adherence and viral monitoring.

#### 4.4 SDG 4 – Quality education for all

SDG 4.1 states that all girls and boys should be able to complete free, equitable, and quality primary and secondary education by 2030. Data from this study shows that a high percentage of adolescents were attending school full-time, however, 10% were still missing significant periods of school time. It was highlighted that girls were particularly at risk of missing school, which could be due to domestic responsibilities such as caring for children, or due to pregnancy. However, it was shown that girls were doing better than boys in their educational achievements, with fewer girls than boys failing or needing to repeat a grade. Additional work will be needed to understand the causes for these gender differences, in order to meet SDG 4.4.

#### 4.5 SDG 5 – Gender equality

The Optimus Study on the sexual victimisation of children in South Africa examined the prevalence of child sex abuse and maltreatment (Artz et al., 2016). Within the study, over 35% of young people – one in three boys and girls – reported experiencing some form of sexual abuse. As with the Optimus Study, Mzantsi Wakho also examined experiences of physical, emotional, and sexual abuse among both girls and boys.

The incidence of sexual abuse, including rape, had increased between baseline and follow-up for both boys and girls. There is a chasm between the objectives of SDG 5, specifically SDG 5.1 and 5.2 (end all forms of discrimination against all women and girls, and eliminate all forms of violence against all women and girls ... including sexual and other types of exploitation), and the experiences of South African children and youth.

Transactional sex, described as engaging in sexual intercourse in exchange for gifts or money, is common in sub-Saharan African countries such as South Africa (Wamoyi et al., 2010). Research has shown that transactional sex increases risk of HIV infection in women 1.5 to 2-fold (Wamoyi et al., 2016, Ranganathan et al., 2016). Again, an increase in the incidence of transactional sex was observed between baseline and follow-up among study participants, meaning more girls are at risk of contracting primary or secondary HIV infection. In the context of SDG 5.2, this indicates that a significant percentage of girls – over 10% at follow-up – have experienced sexual exploitation and violence.

#### 4.6 SDG 8 – Employment and economic growth

South Africa has one of the highest unemployment rates in the world, and it continues to increase. In 2018, unemployment rates had increased from 26.7% in Quarter 1 to 27.2% in Quarter 2 (Moya, 2018).

Young people in South Africa face an even worse job market, and many struggle to gain employment upon leaving school. As such, it is even more important for them to receive help and support in job-seeking, through careers advice from school, homework clubs in the community, job skills training, or having regular access to computers.

Fewer than 3% of participants aged 15 or over reported that they ever received career advice or attended a homework club. Furthermore, 40% of young people were living in households in which no adults worked. These findings remained constant between baseline and follow-up, suggesting there has been little progress

towards reaching SDG 8.5 and SDG 8.6 (by 2030 achieve full and productive employment and decent work for all ... and reduce the proportion of youth not in employment, education or training).

#### 4.7 SDG 16 – Peace justice and strong institutions

Violence is one of South Africa's greatest health and social challenges (Ward, 2012). Many adolescents are abused by caregivers or parents in their homes, or by other adults and youth in educational settings in which they are subject to corporal punishment, psychological punishment, sexual and gender-based violence, and bullying (DSD et al., 2012). The period of adolescence is also a time of increased independence, which is associated with a greater risk of experiencing violence in the community (Ward, 2012, Cluver et al., 2018a). Physical, verbal, and emotional abuse may also be experienced at schools and in clinics (Toska et al., 2015) at the hands of teachers and clinic staff respectively (Artz et al., 2016).

Findings from the current study related to SDG 16 were mixed, with a decrease in physical violence between baseline and follow-up, but an increase in emotional abuse. Domestic violence rates stayed the same. However, over 25% of participants reported experiencing either physical or emotional abuse.

Among the most concerning findings is that levels of teacher-on-pupil violence in schools has more than doubled between baseline and follow-up, with a staggering 87% of adolescents reporting being slapped or beaten by a teacher in the last school term at follow-up.

Exposure to violence in a community setting such as school has been shown to reduce ART adherence (Cluver, 2018a). Urgent work is needed to understand the cause of such a dramatic increase in violence in schools.

Those findings indicate that there is still a long way to go in order for South Africa to achieve SDG 16.1 and SDG 16.2 (significantly reduce all forms of violence and related death rates ... and end ... all forms of violence against and torture of children).

#### 5. Conclusion

This working paper aimed to summarise how young people in South Africa are doing in relation to achieving or making progress in relation to key SDGs. Figure 19 shows an overview of the findings of this report. For each of the SDGs examined in the report, the figure indicates how many adolescents responded positively to none of the questions relating to that SDG in this report, at least one of the questions, or at least two of the questions. This enabled us to quantify how many adolescents have essentially reached a particular SDG target, how many were partially reaching the SDG target, and how many were not reaching that SDG target. In most cases, there were no significant differences by HIV-status, suggesting that by reaching SDGs for all adolescents, we are also supporting ALHIV thrive.

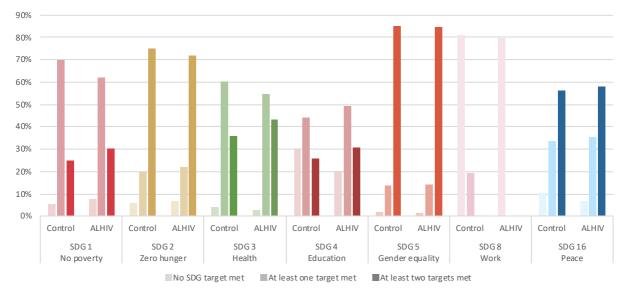


Figure 19: Overview of report findings at follow-up timepoint, including how many adolescents responded positively to each of the questions asked for each SDG.

Criteria used for this graph:

*SDG 1 - Living in formal housing / Can afford all 8 necessities / Can afford to go to the clinic.* 

SDG 2 - Have access to 3 meals a day / Haven't gone without food in the last week.

SDG 3 - Report good physical and mental health / Consistently using condoms / Don't drink excessively or take drugs / For HIV-positive only – full past-week ART adherence.

SDG 4 - Attending school full time (if school age) / Haven't failed a grade or needed to repeat / Have NOT been hit or slapped by a teacher.

SDG 5 - Have NOT experienced any sexual abuse including rape ever / Have NOT had an older partner or had transactional sex EVER.

SDG 8 - Have reported living in a house where at least one adult is working / Have received career advice.

*SDG 16 - Have never experienced physical or emotional abuse / Have never experienced domestic violence.* 

Figure 19 shows that, from the analysis at follow-up, adolescents were doing better at reaching SDG2 and SDG5, with more than 70% of adolescents responding positively to at least two of the indicators relating to ending hunger, and more than 80% of adolescents responding positively to at least two of the indicators relating to gender equality and empowerment of women.

A low percentage of adolescents were achieving SDG 4 (access to an inclusive and equitable quality education), with 20-30% of adolescents responding negatively to all of the indicators relating to SDG4. Similarly, a targeted approach to improving access to SDG 8 (employment and sustained economic growth) is needed, as 80% of adolescents have received no help with getting a job, and live in a household in which no adults work.

Of particular concern are the high levels of rape, sexual violence and other forms of physical and emotional abuse documented in the study. Rates of violence are notoriously difficult to quantify at population-level, and elements of the Mzantsi Wakho study – including reaching young people in the communities in which they live, and its long duration – provide an empirical evidence-base for the commonality of violence among participants. Moreover, the gender disparities in key findings – including in the greater frequency of food insecurity and absence from school among girls – point directly to the ongoing experiential, socio-economic and structural vulnerabilities persisting in the lives of young South Africans, especially young women.

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