



**Adolescents and Youth Living with HIV and
the Sustainable Development Goals: Findings
from Mzantsi Wakho Year 2 (2016–2017)**

OCTOBER 2018

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OVERVIEW

This report focuses on new data from the second wave of the Mzantsi Wakho study. It begins with highlights of key findings from the overall study to date, and then comes to focus on these findings in specific relation to the Sustainable Development Goals.

Research aims: Mzantsi Wakho is a mixed-methods study designed in collaboration with adolescents living with HIV (ALHIV) and key partners 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 programmers.

Research sites: Eastern Cape Province of South Africa.

Methodological pluralism: This study integrates quantitative and qualitative methods in design and implementation.

Quantitative methodology and sample: The quantitative sample aimed to include all adolescents who had initiated antiretroviral treatment (ART) in a large urban, peri-urban and rural health district of the Eastern Cape. Research assistants went to all 52 clinics providing ART to adolescents, identified paper and computerized patient files of every adolescent who had ever initiated ART, and traced them to their homes in 180+ neighbourhoods. These adolescents and youth have been followed by us over a 3-year period. To avoid stigmatizing participants,

neighbours and other adolescents in the household are also interviewed.

At baseline (2014–2015), the study recruited a total of 1,519 10–19 year old adolescents: 1,063 HIV+ adolescents who were receiving care in 52 government healthcare facilities, alongside 456 neighbouring or co-habiting peers who were not HIV-infected. The study took place in 9 hospitals, 5 community health centres, and 38 primary health clinics, 35% of which were in rural communities.

Adolescents were re-traced and re-interviewed in 2016–2017 (follow-up), with an exceptionally high retention rate of 94%.

Qualitative methodology and sample size: Interviews, focus groups, observations and other participatory research exercises were conducted to explore: (i) how adolescents living with HIV use and adapt medicines and sexual and reproductive health services, and (ii) how their caregivers and healthcare workers understand the challenges that adolescents confront. From the study baseline until the end of follow-up, qualitative research had included 24 months of home, school and clinic observations. 150 in-depth interviews were conducted with youth, healthcare providers and families, with over 1,000 hours of home and clinic observations.

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| Time frame: Set-up and piloting | 2013 – 2014 |
| Qualitative research | 2013 – 2018 (ongoing) |
| Wave 1 (T1) | 2014 – 2015 (data collection complete) |
| Wave 2 (T2) | 2016 – 2017 (data collection complete) |
| Wave 3 (T3) | 2017 – 2018 (data collection complete) |

HIGHLIGHTS OF MZANTSI WAKHO RESEARCH FINDINGS

Combination social protection for adolescents living with HIV

Following a mixed-methods community audit with lead stakeholders, youth consultations, and a systematic review led, analyses explored which 'cash' and 'care' social protection provisions are associated with reduced sexual risk-taking and lower ART non-adherence (Figure 1). Access to support groups, food security, and strong parental supervision were

associated with improved ART adherence.² Access to free school, adolescent-sensitive clinic care, and strong parental supervision were associated with safe sexual practices.³ Combinations of these interventions had considerable additive effects, especially in reducing sexual risk-taking among adolescent girls living with HIV.

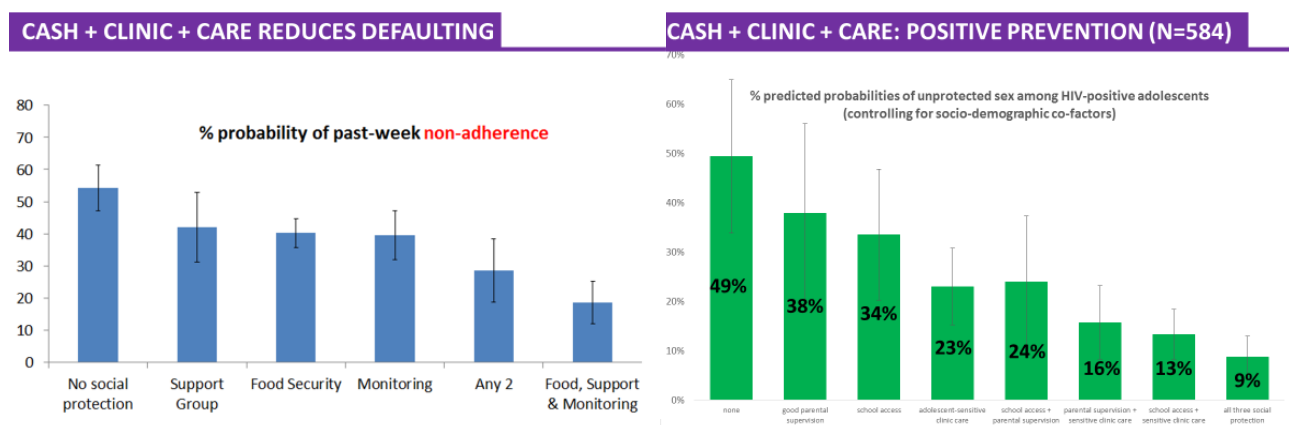


Figure 1. Cash + Care associated with ART non-adherence and safe sexual practices among adolescents living with HIV

Sustainable Development Goals & Adolescent Survival. Evidence to date suggests that certain interventions can contribute to meeting the SDGs for adolescents.⁴ However, little is known about which SDGs are most relevant to adolescents, especially adolescents living with HIV. Quantitative and qualitative analyses of the Mzantsi Wakho data looked at which SDGs protect adolescents living with HIV against mortality risk.

Of the 8 SDGs tested, four SDGs were strongly associated with reduced mortality risk among adolescents living with HIV – which was defined as viral failure or symptomatic untreated TB.⁵ The four SDGs were poverty reduction related (SDG1+2), having a healthy caregiver (SDG3), household employment (SDG8) and protection from child abuse (SDG16). Each individual SDG contributed to reducing high mortality risk, with adolescents who met all the SDGs experiencing the lowest mortality risk (14%) compared to those who accessed none (51%) (Figure 2). These

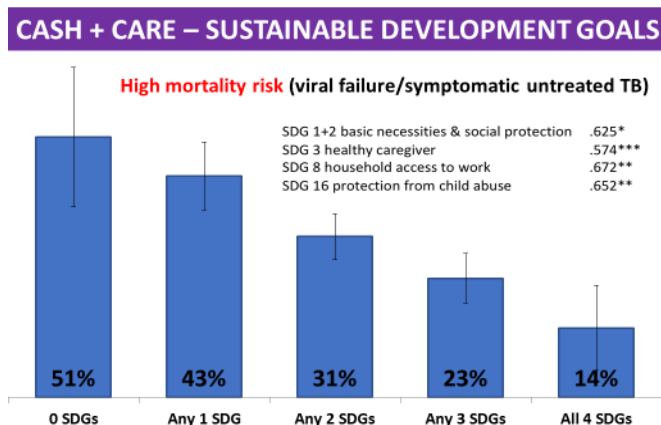


Figure 2. Improving the survival of adolescents living with HIV through Cash + Care SDG provisions

findings shed light on which SDGs we should focus on to support adolescents living with HIV to survive and thrive. In the post-MDG policy era, in which no SDG focuses specifically on adolescents or on HIV, this analysis fills a critical gap in determining the health, education and social outcomes of adolescents living with HIV in relation to the SDG goals.

² Cluver, L. D., Toska, E., Orkin, F. M., Meinck, F., Hodes, R., Yakubovich, A. R., & Sherr, L. (2016). Achieving equity in HIV-treatment outcomes: can social protection improve adolescent ART-adherence in South Africa?. *AIDS care*, 28(sup2), 73–82.

³ Toska, E., Cluver, L. D., Boyes, M. E., Isaacsohn, M., Hodes, R., & Sherr, L. (2017). School, supervision and adolescent-sensitive clinic care: combination social protection and reduced unprotected sex among HIV-positive adolescents in South Africa. *AIDS and Behavior*, 21(9), 2746–2759.

⁴ Cluver, L. D., Orkin, F. M., Meinck, F., Boyes, M. E., Yakubovich, A. R., & Sherr, L. (2016). Can social protection improve sustainable development goals for adolescent health?. *PLoS one*, 11(10), e0164808.

⁵ Cluver, L., Pantelic, M., Orkin, M., Toska, E., Medley, S., & Sherr, L. (2018). Sustainable Survival for adolescents living with HIV: do SDG-aligned provisions reduce potential mortality risk? *Journal of the International AIDS Society*, 21, e25056.

What do adolescents living with HIV want from global development initiatives? How do domains of health and social development intersect, and what are the implications for the SDGs? In a publication lead authored by the study's qualitative principal investigator, Rebecca Hodes, diverse methods and data sources were combined to explore the aspirations of adolescents living with HIV for health and development.⁶ This article focused on two participatory exercises, "Dream Clinics" and "Yummy or crummy? You are the Master Chef". These exercises captured the utility of participatory research with adolescents living with HIV, and revealed synergies between healthcare provision and access, infrastructure, water and sanitation, and nutrition (Figure 3). Findings confirmed that food and water are critical to ART adherence among adolescents living with HIV, interlinking SDGs 2 (food security), 3 (health), and 6 (water and sanitation).

An additional article exploring how adolescents interact with institutions where they access care and HIV interventions was lead-authored by Mzantsi Wakho qualitative investigator, Beth Vale.⁷ Using ethnographic data from a mixed rural-urban sample of adolescents living with HIV, Vale and co-authors

explored how official documents (patient folders, patient cards, health notebook, birth certificates, etc.) bring adolescents living with HIV into state health services. These documents may enable access to essential medicines and other means of social support, including grants. But they may also be a source of fear and doubt among adolescents, particularly if their knowledge about the biomechanics of ART is limited, and if they rely on continued access to social grants as their primary or main means of material support.



Figure 3. The stuff that dreams are made of: using participatory research to explore interlinkages in HIV-positive adolescents' aspirations for development

Transmission risk perceptions and experiences of structural, biomedical and healthcare interventions among adolescents living with HIV

Relevance of HIV disclosure guidelines? Two mixed-methods papers contributed to the relevance and applicability of HIV disclosure guidelines for adolescents living with HIV. First, cross-sectional analyses confirmed that knowing one's own HIV status was strongly linked to improved ART adherence among all adolescents living with HIV (OR 2.18; 95% CI 1.47–3.24).⁸ Among perinatally infected adolescents who knew their status (n=4362/540), disclosure prior to age 12 was associated with higher adherence (OR 2.65; 95% CI 1.34–5.22). Qualitative findings suggested that disclosure was undertaken sensitively in clinical and family settings, but that adolescents' understandings of their HIV-status was partial and, at times transient – with doubts that HIV was a 'permanent' illness, and that ART was the most effective means of maintaining health. The second set of analyses investigated

associations between safe sex and three types of HIV status disclosure: (1) knowledge of own HIV status, (2) knowledge of partner status, and (3) disclosure of HIV-positive status to partner.

Analyses of the full Mzantsi Wakho sample suggests that knowledge of own HIV status is strongly associated with safer sexual practices, while knowledge of partner status is associated with reduced safe sex.⁹ The relationship between disclosing to a partner and safe sexual practices was not significant – potentially due to very low levels of disclosure in this young sample. Qualitative research suggested that adolescents living with HIV feared rejection, stigma and public exposure if disclosing to sexual and romantic partners. Counselling by healthcare workers for adolescents living with HIV focused on benefits of

⁶ Hodes, R., Doubt, J., Toska, E., Vale, B., Zungu, N., & Cluver, L. (2018). The stuff that dreams are made of: HIV-positive adolescents' aspirations for development. *Journal of the International AIDS Society*, 21, e25057.

⁷ Vale, B., Hodes, R., Cluver, L., & Thabeng, M. (2017). Bureaucracies of Blood and Belonging: Documents, HIV-positive Youth and the State in South Africa. *Development and Change*, 48(6), 1287–1309.

⁸ Cluver, L. D., Hodes, R. J., Toska, E., Kidia, K. K., Orkin, F. M., Sherr, L., & Meinck, F. (2015). 'HIV is like a tsotsi. ARVs are your guns': associations between HIV-disclosure and adherence to antiretroviral treatment among adolescents in South Africa. *AIDS*, 29, S57–S65.

⁹ Toska, E., Cluver, L. D., Hodes, R., & Kidia, K. K. (2015). Sex and secrecy: How HIV-status disclosure affects safe sex among HIV-positive adolescents. *AIDS care*, 27(sup1), 47–58.

disclosure, but did not address the fears and risks associated with disclosure. These findings challenge assumptions that disclosure is automatically protective in sexual and romantic relationships for adolescents living with HIV, who may be ill-equipped to negotiate safer sex.

How healthcare workers respond to stock-outs: latent resilience among frontline providers?

Shortages of essential medicines are a daily occurrence in many of South Africa (SA)'s public health facilities, including in the facilities in the Mzantsi Wakho study. Based on observations of the frequency of stock-outs in many of these facilities, this research investigated how actors at the 'front-line' of public health delivery experienced and responded to shortages of essential medicines and equipment in their facilities. Findings are based on focus groups, observations and interviews with healthcare workers and patients at healthcare facilities. This research, published in the *South African Medical Journal*¹⁰, revealed a discrepancy between 'informal' definitions of stock-outs and their reporting through formal stock-out management channels. Front-line healthcare workers designed their own systems for classifying the severity of stock-outs, based on the product in question, and on their potential to access stocks from other facilities. Beyond formal systems of procurement and supply, healthcare workers established vast networks of alternative communication and action, often using personal resources to procure medical supplies. Stock-outs were only reported when informal methods of stock-sharing did not secure top-up supplies. These findings provided new insights into the frequency and severity of stock-outs, and their varied means of management within the public health system.

Challenges in the provision of comprehensive sexual and reproductive healthcare for adolescents?

Interviews and observations in healthcare facilities, and ongoing qualitative and quantitative research with adolescents living with HIV, their relatives, caregivers and friends, provided perspectives into deep-seated challenges in delivering comprehensive sexual and

reproductive healthcare. Papers and book chapters from the study have explored these challenges. These included an overview of women's sexual and reproductive health services in the third decade of South African democracy, which included a discrete section on HIV.¹¹ Additional publications based on primary findings from Mzantsi Wakho included an article about the perception that young women were having 'babies for bling', which focused on the beliefs and practices of healthcare workers. A book chapter on popular perceptions of teenage pregnancy unpacked these ideas further, tracing the history of 'dole mums', and combining the perspectives of healthcare workers, adult caregivers, and adolescents. Numerous other articles and book chapters analysed data collected in the Mzantsi Wakho study to investigate young women's experiences of contraception and termination of pregnancy services.^{12,13,14,15}

Medicines-taking during traditional initiation/circumcision for young men living with HIV.

Mzantsi Wakho is located in a district in which the practice of traditional circumcision has a long history. In recent years, medical male circumcision has been introduced in South Africa's public health sector as a means of HIV-prevention. Qualitative researchers have examined the meanings and practices of circumcision among boys and young men living with HIV, focusing on the effects of traditional circumcision for adherence to medicines. Emerging findings indicate that traditional initiation/circumcision presents a challenge to adolescent boys taking ART because pill-taking is forbidden during initiation. Participants reported feeling stressed and conflicted during this time and reported a range of strategies including (i) hiding medicines (ii) disclosing to a trusted person at initiation school or (iii) ceasing medicines-taking without telling anyone – including biomedical health providers. The 3 months post initiation also represented a challenge for health service access, as boys did not want to be seen in the clinic after coming back from initiation. These findings suggest that boys attending traditional initiation in the Eastern Cape are struggling to take HIV medicines and to remain within the public health

¹⁰ Hodes, R., Price, I., Bungane, N., Toska, E., & Cluver, L. (2017). How front-line healthcare workers respond to stock-outs of essential medicines in the Eastern Cape Province of South Africa. *South African Medical Journal*, 107(9), 738–740.

¹¹ Cooper, D., Harries, J., Moodley, J., Constant, D., Hodes, R., Mathews, C., ... & Hoffman, M. (2016). Coming of age? Women's sexual and reproductive health after twentyone years of democracy in South Africa. *Reproductive health matters*, 24(48), 79–89.

¹² Hodes, R., Toska, E., & Gittings, L. (2016). Babies for Bling: Are teenage girls having children to access grants? *HIV Nursing Matters*, 7(2), 20–23.

¹³ Hodes, R. (2017). Popular perspectives on teenage pregnancy in South Africa. In N. Mkhwanazi & D. Bhana (Eds.), *Young Families: Gender, Sexuality and Care* (pp. 17–30). Cape Town, South Africa: Human Sciences Research Council Press

¹⁴ Hodes, R. (2017). Abortion politics in a state in transition: Contesting South Africa's Choice Act. In S. Stettner, K. Ackerman, K. Burnett & T. Hay (Eds.), *Transcending Borders: Abortion in the Past and Present* (pp. 171–185). New York, USA: Springer.

<https://www.palgrave.com/de/book/9783319483986#aboutBook>

¹⁵ Hodes, R. (2016). The culture of illegal abortion in South Africa. *Journal of Southern African Studies*, 42(1), 79–93.

system. They also point to the creativity and agency of adolescent boys living with HIV as they conform to and subvert hegemonic masculine norms through their medicines-taking practices during the process which serves to legitimize them as men within their society.

Medical pluralism among adolescents living with HIV. Many boys and their families visited traditional health practitioners, demonstrating the presence of traditional health beliefs and practices in the lives of many adolescent boys living with HIV. Products

provided by traditional health practitioners were rarely ingested, but were rather used to bathe in, steam with, wear on the body, or put into the blood via small skin cuts made with a razor. There is a sizeable literature on medical pluralism for people living with HIV in South Africa, to which the emerging findings from this research contribute. Despite documenting the presence of traditional health beliefs and practices in the lives of many adolescent boys living with HIV, this research suggests that this medical pluralism is largely unrelated to their HIV treatment¹⁶.

Reducing secondary HIV transmission – which combination interventions could work?

Poly-victimisation predicts ART non-adherence among adolescents living with HIV. A recent paper in *AIDS* explored which kinds of violence experiences were associated with reduced ART adherence among adolescents living with HIV.¹⁷ Four violence types were independently associated with non-adherence: physical abuse by caregivers; witnessing domestic violence; teacher violence and verbal victimisation by healthcare staff.

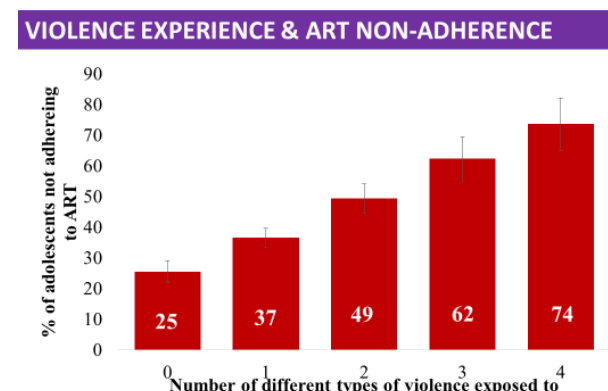


Figure 4. Violence exposure associated with non-adherence for adolescents living with HIV

Past-week non-adherence rose from 25% with no violence, to 73.5% with four types of violence exposure. Violence exposures at home, school and clinic are major and cumulating risks for adolescent antiretroviral non-adherence. Prevention, mitigation, and protection services may be essential for the health and survival of adolescents living with HIV. Evidence-based programmes that address different types of programmes include: parenting programmes, school violence prevention, and healthcare provider training programmes.

Clinic-level factors and HIV outcomes. The initial analyses on combinations of social protection interventions for reduced risky behaviours among

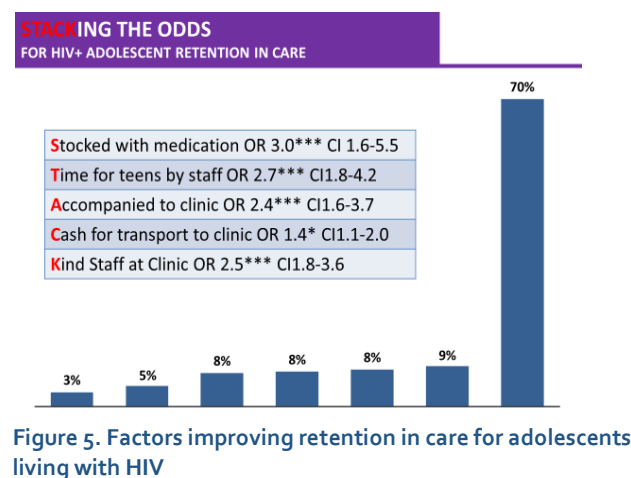


Figure 5. Factors improving retention in care for adolescents living with HIV

adolescents living with HIV, highlighted the importance of clinic-centred provisions to enhance the effect of 'cash' and 'care' interventions.¹⁸ Analyses of clinic-level factors focused on two key outcomes: retention in care and internalised stigma.

Only 56% of adolescents living with HIV reported retention in care (full ART adherence and clinic attendance). Interestingly, retention in care was not significantly associated with the following clinic-related factors: healthcare staff were able to answer adolescent questions, adolescent received information, confidentiality of information, flexible hours, waiting time and travel time to clinic. On the other hand, a stocked clinic, staff with sufficient time to see adolescents, having someone to attend the clinic with, enough cash to get to the clinic, and kind

¹⁶ Gittings, L., Mbula, S. & Kom, P. (2017). Becoming men: HIV-positive adolescent boys' adherence to ART during traditional initiation/circumcision in the Eastern Cape Province of South Africa. Oral poster presented at AIDS Impact in Cape Town, South Africa.

¹⁷ Cluver, L., Meinck, F., Toska, E., Orkin, F. M., Hodes, R., & Sherr, L. (2018). Multitype violence exposures and adolescent antiretroviral nonadherence in South Africa. *AIDS*, 32(8), 975–983.

¹⁸ Cluver, L., Pantelic, M., Toska, E., Orkin, M., Bungane, N., Casale, M., & Sherr, L. (2018; in press) STACKing the odds for adolescent survival: Health service factors associated with full retention in care and adherence amongst adolescents living with HIV in South Africa. *Journal of the International AIDS Society*.

staff were strongly associated with improved retention in care. Combinations of these five interventions helped STACK the odds for HIV+ adolescent retention in care. With access to none only 3% of adolescents were retained, with access to only one 5%–9% while those who accessed all five reported a 70% probability of being retained in care.

Similar factors were associated with internalised stigma: flexible hours, kind staff, and a well-stocked clinic. Adolescents who accessed neither of the three (flexible hours, kind staff and well-stocked clinics) were most likely to report internalised stigma (54%) compared to those who accessed all three (19%) (Figure 6).

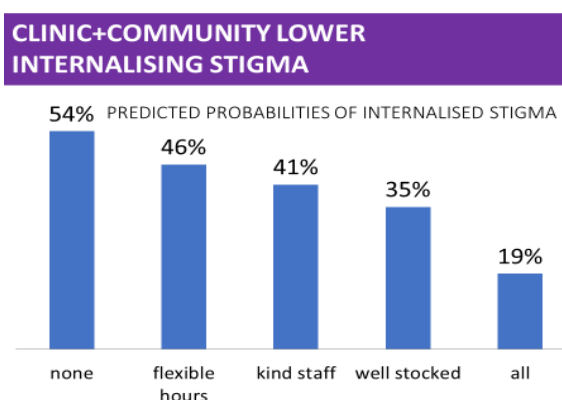


Figure 6. Clinic and community factors associated with reduced internalised stigma (Pantelic et al 2018)

Factors associated with HIV transmission risk.

Longitudinal data analyses (n=983 adolescents living with HIV) explored which adolescents were most at risk of transmitting HIV to sexual partners, or children, and the potential risk factors for HIV transmission. 16% of adolescents reported both past-year sexual risk-taking and viral activity. Factors associated with high HIV transmission risk were mode of infection, poverty, older age, and poor relationship dynamics. Mode of infection moderated the effect of poor relationship dynamics on HIV transmission risk: horizontally-infected adolescents reporting poor relationships dynamics were nearly 5 times more likely to report high HIV transmission risk than vertically infected adolescents in safe relationships (Figure 7).

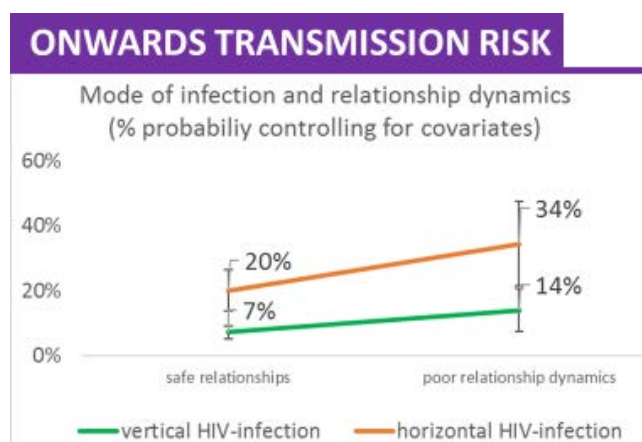


Figure 7. Relationship dynamics associated with onwards transmission risk

THE SUSTAINABLE DEVELOPMENT GOALS (SDGs)

In this section of the report, the socio-structural and health outcomes of the adolescents are examined in relation to the SDGs, using data from two rounds of data from Mzantsi Wakho – the largest known, longitudinal, community-traced study on adherence to antiretroviral treatment and sexual and reproductive health among adolescents living with HIV.

Building on the success of the Millennium Development Goals (MDGs), the SDGs were developed by the United Nations in 2015 as a set of 17 global goals for sustainable development. 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. The SDGs are geared towards improving the lives of those living in low- and middle-income countries, particularly their poorest and most vulnerable citizens. Countries, including South Africa, have committed to attaining these goals by 2030.

Statistical analyses

Descriptive analyses stratified by HIV status and gender were conducted to compare participants within waves of the study. Pearson's χ^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.**

COHORT DEMOGRAPHIC CHARACTERISTICS

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 (ALHIV) and **456** were community controls (Figure 8).

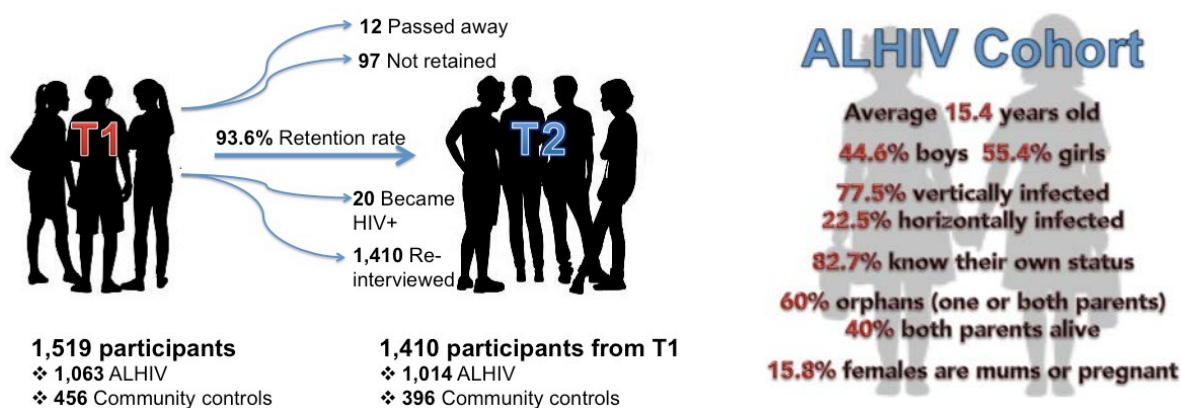


Figure 8. Overview of baseline to follow-up retention and demographics

Retention at follow-up

Of the 1,519 adolescents interviewed at baseline, 1,410 were re-interviewed at follow-up, with 12 adolescents having passed away (93.6% follow-up). The majority of the 97 individuals who were not retained were untraceable (5%), with very low refusal rates (1.4%) (Figure 9). Of the 97 individuals who were not retained were untraceable (5%), with very low refusal rates (1.4%) (Figure 9). Of the ALHIV, 1,063 HIV+ adolescents were interviewed at baseline. Of these, 994 were re-interviewed during the follow-up period of data collection. All of the 12 individuals who had passed away were ALHIV (94.6% follow up rates among ALHIV). Of those adolescents interviewed at both baseline and follow-up, an additional 20 adolescents became HIV+ at follow-up, meaning that 1,014 adolescents from the original sample were HIV+ at follow-up.

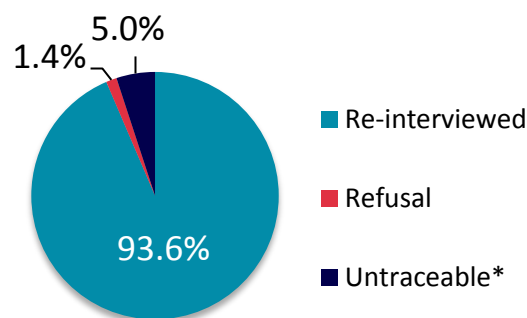


Figure 9. Baseline--> Follow-up breakdown of individuals who were re-interviewed or lost to follow-up.

*Reasons include leaving children's home, contact details not working etc.

Between baseline and follow-up, 6% of participants had moved outside the study setting, so the team traced them, and travelled across South Africa to conduct interviews (Figure 10).

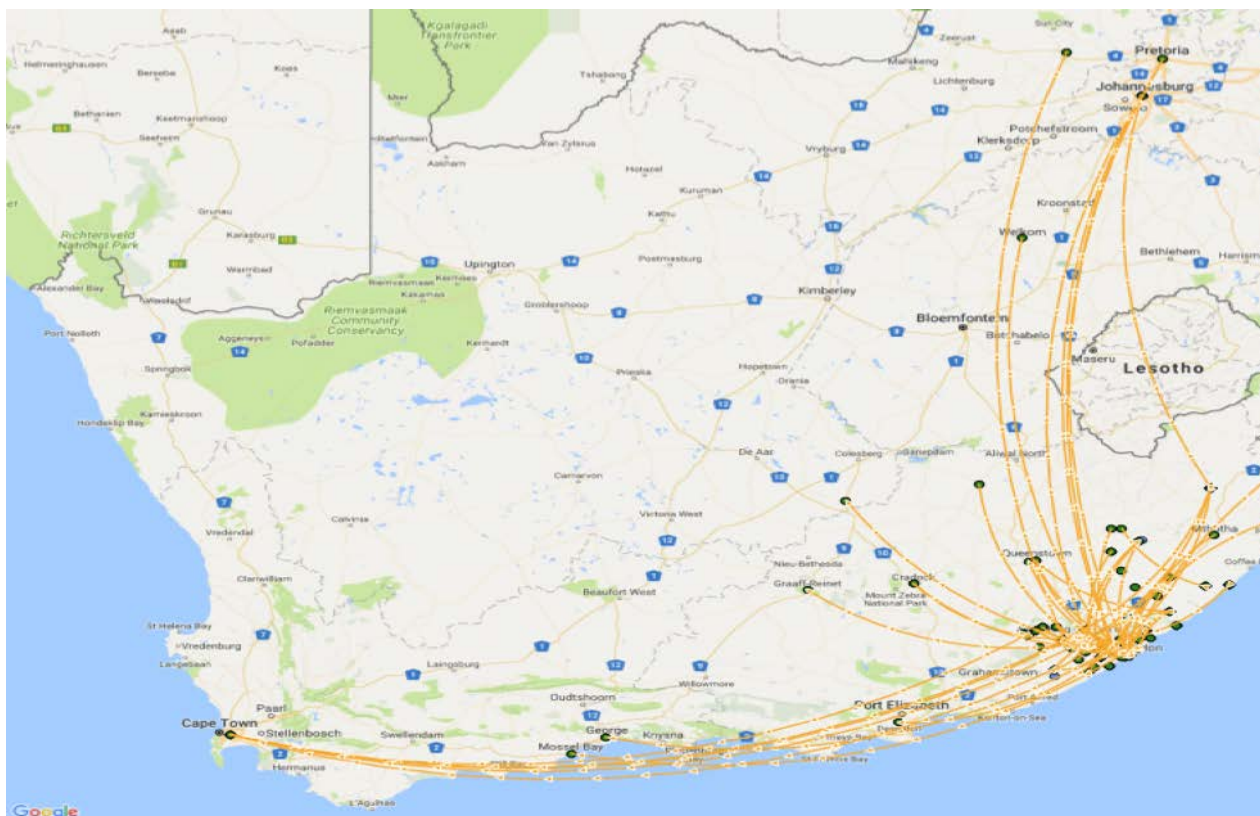


Figure 10. Baseline --> Follow-up mobility map showing where teens moved to between baseline and follow-up

ARE ALHIV ACCESSING THE SDGs?

A selection of adolescent-focused SDG indicators is reported in the section below, using various forms of qualitative data to relate adolescents' experiences and perspectives. For each indicator, changes between

baseline and follow-up, and differences between ALHIV and community controls where relevant, are reported. Where appropriate, sustainable access over the 2-year period is reported.



SDG 1: END POVERTY IN ALL ITS FORMS EVERYWHERE

- 1.1: By 2030, **eradicate extreme poverty** for all people everywhere
- 1.2: By 2030, **reduce at least by half the proportion of men, women and children of all ages** living in poverty
- 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

Where are adolescents living?

Type of housing is a strong indicator of poverty. The majority of Mzantsi Wakho participants live in formal housing, though one in five live on the streets, shacks, or children’s homes.

This is similar to the split at baseline (20% and 80% respectively). In this shack in Mdantsane (Figure 11), home to an adolescent participant and her elderly caregiver, there is no running water and electricity. The family has developed a scrupulous system for storing water and food in plastic containers.



Figure 11: Participant's home in Mdantsane

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.'*

Do teens live in households that can afford the 8 basic necessities?

At follow-up, **78.0%** of ALHIV are living in homes that **cannot** afford all 8 necessities, which is a significant



increase from the **67.9%** reporting the same at baseline ($P < 0.001$). The same negative trend is seen in community controls, with an increase from **65.4%** to **82.6%** between baseline and follow-up.



Figure 12. The eight basic necessities

Can teens afford to go to school?

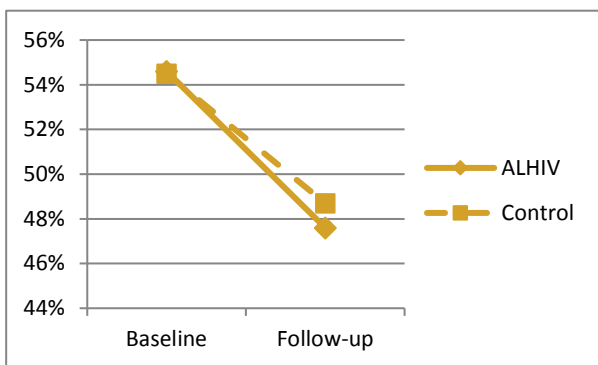


Figure 13. Do teens live in households that can afford school fees? Change over time between baseline and follow-up for those attending school. There was a significant reduction in the number of ALHIV reporting that their household can afford their school fees, from 54.6% at baseline, to 47.6% at follow-up ($P < 0.01$).

As shown in Figure 12, of those who are attending school, at follow-up there has been a significant reduction in the number of ALHIV reporting that their household can 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 have not experienced a significant change.

How many teens live in households that receive government grants?

A very high proportion of the total sample live in households that receive at least 1 grant (>90%). However, there has been a **small but significant reduction** in the number of households receiving grants between baseline and follow-up, for ALHIV ($P < 0.05$). This trend is seen in community controls, but is not significant.

Consistent Access to Government Grants
 Over a 2-year period (baseline → follow-up), 90.0% of ALHIV live in a household that has consistently had access to at least 1 grant. This is similar to community controls, of whom 87% live in households that have consistently accessed at least one grant over the last

Social grants shopping basket

A participatory research exercise, named the 'social 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 informs how the grant is 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 combined the necessity of their household's subsistence, with the objective of providing the most nutritious food and care for their child.



Figure 14. Contents of a 'child support grant shopping basket', selected by young parents (September, 2017)

Can ALHIV afford to get to their clinic?

At follow-up, there has been a **significant increase** in the percentage of ALHIV who are **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 are **still not able to afford to travel** to receive the medical support they need.

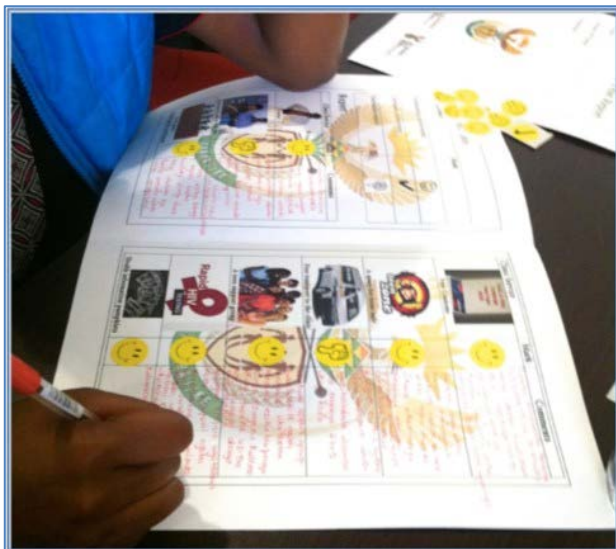


Figure 15. Pages from the 'Clinic Report Card', including assessment sections for youth friendly services, HIV rapid-testing, healthcare workers, and support groups.

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 the scheduling of 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 3rd, or the 5th 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.'

In a participatory research exercise named the 'Clinic Report Card', adolescents assessed and ranked health services that they had identified as crucial to comprehensive care, including transport to clinics (Figures 14–15). The majority of participants awarded a poor ranking for the healthcare component of 'free transport to clinic'. Figure 15 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 16. Excerpt from a clinic report card voicing dissatisfaction with inadequate ambulance services



SDG 2: END HUNGER, ACHIEVE FOOD SECURITY AND IMPROVED NUTRITION

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**

2.2: By 2030, end all forms of malnutrition

Do teens have access to 3 meals a day?

At follow-up, **88%** of both ALHIV and community controls report living in households that **can afford** enough food at home to provide 3 meals each day. This is unchanged from baseline. **78%** of all adolescents have reported consistent food security at both baseline and follow-up (household can afford 3 meals a day). There is no significant difference between ALHIV and community controls, or HIV+ boys and girls.

Have teens gone without food in the last week?

At follow-up more ALHIV are missing at least 1 meal per week than at baseline ($P < 0.01$). This difference is not seen in community controls. There is also a significant difference between male and female ALHIV, showing that girls are consistently going without food than boys at both baseline ($P < 0.001$) and follow-up ($P < 0.05$). **21.7% and 25.3% of females at baseline and follow-up** respectively are missing at least 1 meal per week, versus **12.8% and 19.9% of males at baseline and follow-up** respectively.

Are teens receiving free meals at school?

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

Are teens receiving food parcels?

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

Consistent access to free school meals and food parcels

Over a 2-year period, almost 90% of the total sample have consistently reported accessing free food services at school or receiving food parcels. Significantly fewer adolescent girls living with HIV report 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)**; $P < 0.05$).

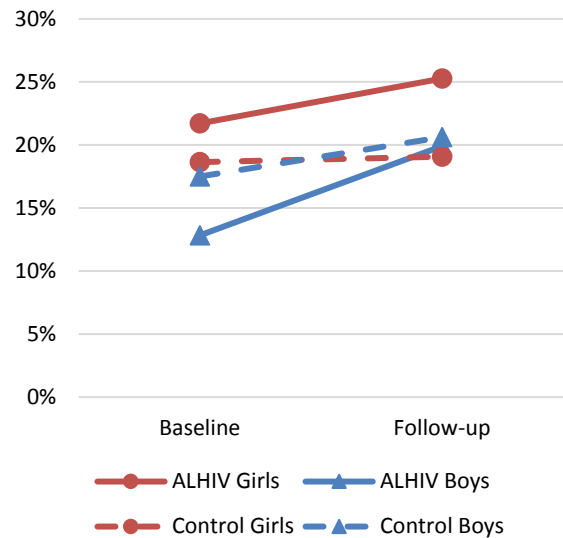


Figure 17. Percentage ALHIV and community controls who had gone without food at least once a week at baseline and follow-up. There was a significant increase in number of adolescents who had gone without food among the entire ALHIV sample ($p < 0.01$), among ALHIV boys ($p < 0.001$), and ALHIV girls ($p < 0.05$).

Consistent Food insecurity by Sex

Looking at a 2-year period, **adolescent girls living with HIV are twice as likely to have experienced consistent food insecurity than adolescent boys living with HIV (4.6% vs. 9.3% respectively; $P < 0.01$)**, responding "yes" to missing a meal in the last week at both baseline and follow-up (Figure 17).

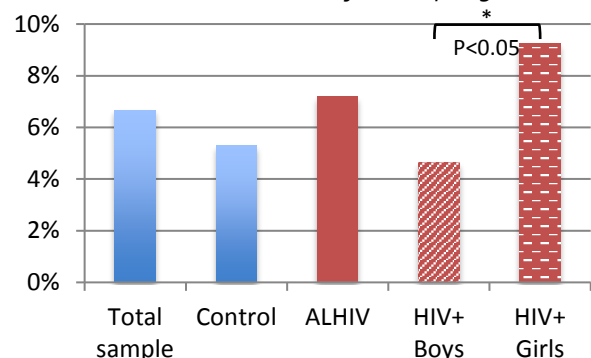


Figure 18. Adolescents who have experienced food insecurity consistently over the last 2 years, and missed a meal regularly



SDG 3: ENSURE HEALTHY LIVES AND PROMOTE WELLBEING FOR ALL AT ALL AGES

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

3.5: Strengthen the **prevention and treatment** of substance abuse, including narcotic drug abuse and harmful use of alcohol

3.7: By 2030 ensure **universal access to sexual and reproductive health-care services, including for family planning, information and education**

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**

How healthy are teens?



When treated and monitored appropriately, teens can live a healthy life with HIV. Poor adherence to ART increases the risk of opportunistic infections

and of HIV-related mortality. Through monitoring the health status of ALHIV, including viral load, healthcare providers can track the health outcomes of ALHIV, including the efficacy of ART regimens, and can identify and treat adverse health events.

More of the ALHIV in the sample experience poor physical or mental health than community controls; a trend observed at both baseline and follow-up ($P < 0.001$). At follow-up, **21.6%** of ALHIV report experiencing poor physical or mental health, compared with **13.1%** of community controls ($P < 0.001$). However, for ALHIV, this is a significant improvement from physical and mental health

reported at baseline, where **24.5%** reported poor physical or mental health ($P < 0.001$). There is no significant difference between baseline and follow-up for community controls.

Are HIV+ teens in the sample receiving regular CD4 and viral load monitoring?

As shown in Figure 18, regular monitoring of HIV+ patients via annual CD4 counts and viral load levels is, in reality, very limited for adolescents in the current study. **89.1%** of ALHIV have a patient file, and of those, **92.5%** contain information about viral load. At each level of the "treatment cascade", HIV+ adolescents are falling out of the system, meaning their chances of effectively monitoring their disease are lessened. At the end of the cascade, only **48.5%** of ALHIV (513 out of 1,058) have a medical file indicating their viral load is undetectable and their HIV infection is being managed.

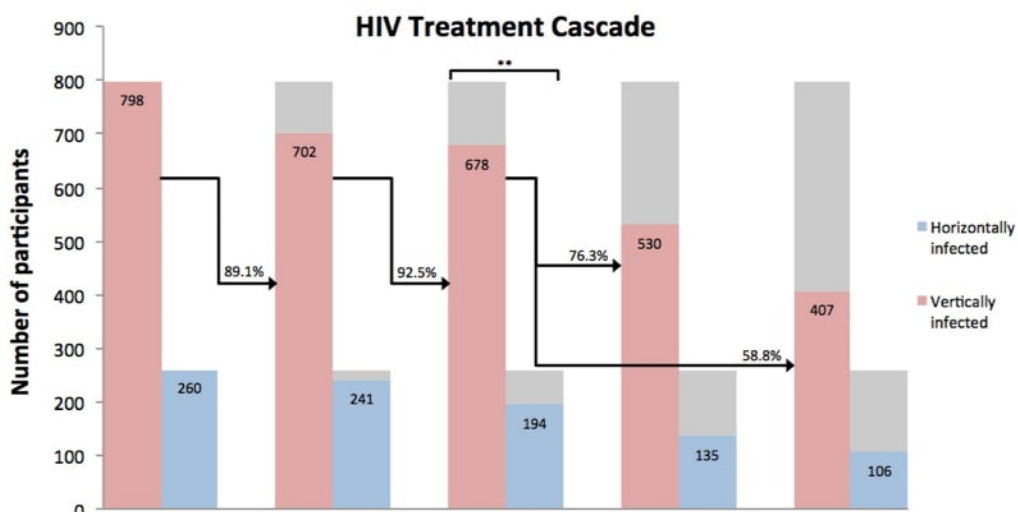


Figure 19. The gaps in viral load and CD4 count monitoring (from Haghghat, R., Toska, E., Bungane, N., & Cluver, L. 90–90–48: *The Reality of Viral Suppression among ART-initiated Adolescents in South Africa*. Presentation at AIDS2018 in Amsterdam, Netherlands.)

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, she explained that she was receiving information about her CD4 count results at clinic visits, but not 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 it means for your body?'* The participant replied: *'No, they didn't tell us about that.'*

Are ALHIV adhering to their ARV treatment?



At follow-up, **42.6%** of ALHIV are reporting that in the last week they have **not** been fully adherent to their ART regimens. This is significantly

higher than at baseline, where **35.9%** of teens report self-report that in the last week they haven't been fully adherent ($P < 0.001$).

Within the qualitative sample, essentially all participants reported periods of non-adherence 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 'taking a break' and described that they would return to their regimens 'in the future' (follow-up qualitative interviews).¹⁹

Are teens consistently using condoms?

Of ALHIV who had had sex in the past year, there is 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**) is also seen in community controls, though this is not statistically significant.



Interestingly, there is also a significant difference in consistent condom use between HIV+ boys and HIV+ girls at both baseline and follow-up. As shown in Figure 18, over **75% of HIV+ males** are reporting using condoms consistently when having sex, compared to **fewer than 60% of HIV+ females**. Looking at the total

HIV+ sample at follow-up, this means that **over 35%** of HIV+ teens are at risk of



a secondary HIV+ infection or STIs.

What are teens' experiences of accessing contraception?

At both baseline and follow-up, clinics were the place that teens used most to access contraception. At follow-up, of those accessing contraceptives, **89.0%** reporting they obtained contraception from the clinic.

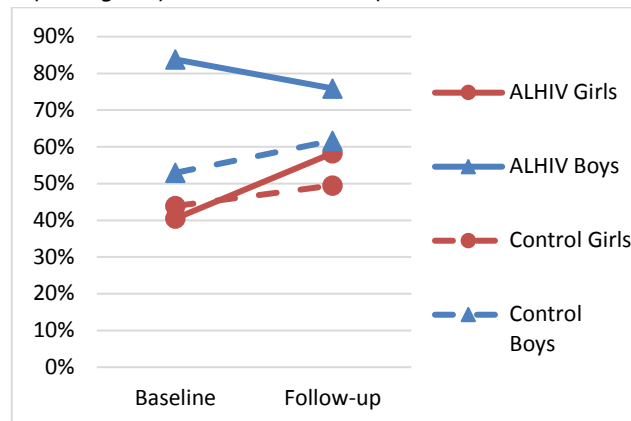


Figure 20. Consistent condom usage in ALHIV at baseline and follow-up by sex. Rates of condom use are significantly higher among ALHIV boys than ALHIV girls at baseline ($p < 0.001$), and at follow-up ($p < 0.01$). For ALHIV girls, there was a significant increase in rates of consistent condom use between baseline and follow-up ($p = 0.04$), whereas for the other groups, the changes between baseline and follow-up were not significant.

Teens 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, requiring time and travel costs to get to this facility, and that they had come for family planning. The nurse explained: *'They won't give teenagers family planning there. They will chase them out of the clinic!'*

Do teens drink or take drugs?

At follow-up, **5.6%** of the total sample report drinking harmful levels of alcohol or taking drugs, which is a small but significant increase from the total sample at baseline (**4.6%**; $P < 0.001$). This difference between baseline and follow-up is significant for both ALHIV and community controls, but with no difference between HIV+ boys and girls

¹⁹ Hodes, R., Hatane, L., Gittings, L., Ronan, A., Malunga, S., Cluver, L., Mark, D., Toska, E., Bloch, K., & Haghghat, R. (2018). Adherence misfits: Divergent perspectives on ART-defaulting among healthcare providers, caregivers, peer navigators and adolescents living with HIV. Poster presented at AIDS2018 in Amsterdam, Netherlands.



SDG 4: ENSURE INCLUSIVE AND EQUITABLE QUALITY EDUCATION AND PROMOTE LIFELONG LEARNING OPPORTUNITIES FOR ALL

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**

4.3: By 2030, ensure **equal access for all women and men to affordable and quality technical, vocational and tertiary education**, including university

4.4: By 2030, **eliminate gender disparities in education** and ensure **equal access to all levels of education and vocational training for the vulnerable**

Are teens attending school full-time?

Over 10% of teens at baseline and follow-up are 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 are at risk of falling behind their peers with their studies, and ultimately missing out on attaining effective learning outcomes and prospective opportunities.

This level of school absence is consistent between baseline and follow-up, but what is striking is the significant difference between the attendance records of HIV+ boys and HIV+ girls, as well as control boys and girls (**Error! Reference source not found.**). At both baseline and follow-up, over twice the number of girls than boys (both ALHIV and community controls) report 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).

This difference could be explained by girls needing to take more time out of school when pregnant and

Do teens attend free schools, or fee-paying schools?



The number of teens attending free schools has remained constant between baseline and follow-up, with no significant difference seen between boys and girls, or ALHIV and controls at either timepoint. Only 30% of teens attend free schools, with the remaining teens attending schools that charge fees (even if they are fee-exempt).

looking after children, but 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 girls and young women, boys and young men, and adult caregivers^{20,21}

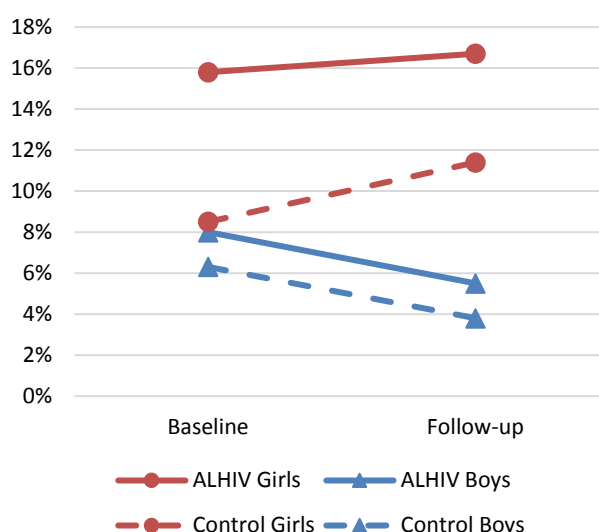


Figure 21. School absence (missing 2 weeks or more in the last term, or not enrolled due to reasons other than matriculation). School absence was significantly more common among ALHIV girls than ALHIV boys at baseline ($p < 0.001$) and follow-up ($p < 0.001$), and among control girls than control boys at follow-up ($p < 0.01$).

Do teens like school and look forward to going?

At both baseline and follow-up, **over 80%** of all teens report that they always like going to school and look forward to attending. At follow-up this is significantly higher than at baseline overall, at and **84.7%** and **81.7%** respectively ($P < 0.05$).

²⁰ Hodes, R. (2017). Popular Perspectives on Teenage Pregnancy in South Africa. In *Young Families: Gender, Sexuality and Care* (pp. 17–30). Cape Town, South Africa: HSRC Press.

²¹ Hodes, R., Toska, E., & Gittings, L. (2016). Babies for Bling: Are Teenage Girls Having Children to Access Grants? *HIV Nursing Matters*, 7(2), 20–23.

How are teens doing at school?

Reasons for failing a grade or needing to repeat a grade are numerous, including not being able to afford to go, needing to stay home to help, being ill, getting expelled, becoming pregnant, not liking school, or being bullied.

As indicated in Figure 20, a significantly higher proportion of teens report failing or repeating their last

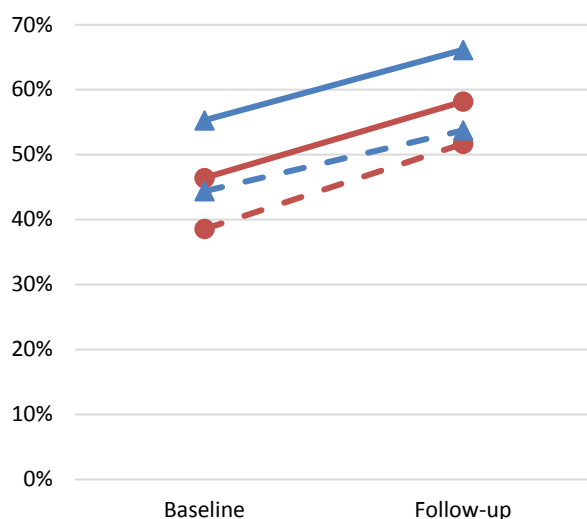


Figure 22 – Percentage of teens who have failed their last grade, or have needed to repeat a grade due to reasons other than matriculating. A significantly higher percentage of ALHIV had failed their last grade, as compared to controls at baseline ($p=0.001$) and follow-up ($p<0.01$).

Do teens like school and look forward to going?

At both baseline and follow-up, over 80% of all teens report that they always like going to school and look forward to attending. At follow-up this is significantly higher than at baseline overall, at and 84.7% and 81.7% respectively ($P<0.05$).

Do teens feel safe at school?

At both baseline and follow-up, around 80% of all teens report feeling safe at school.

Have teens experienced violence at the hands of their teacher at school?

Worryingly, the number of teens, both ALHIV and controls who report being beaten or slapped by a teacher in the last full term at school has more than doubled between baseline and follow-up (**Error! Reference source not found.**). At baseline, 41.7% of all teens attending school reported being slapped or beaten by a teacher in the last full term, which increased to 87.0% at follow-up ($P<0.001$). This significant trend between baseline and follow-up is

grade at follow-up versus baseline ($P<0.001$ for ALHIV, control, and whole sample).

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

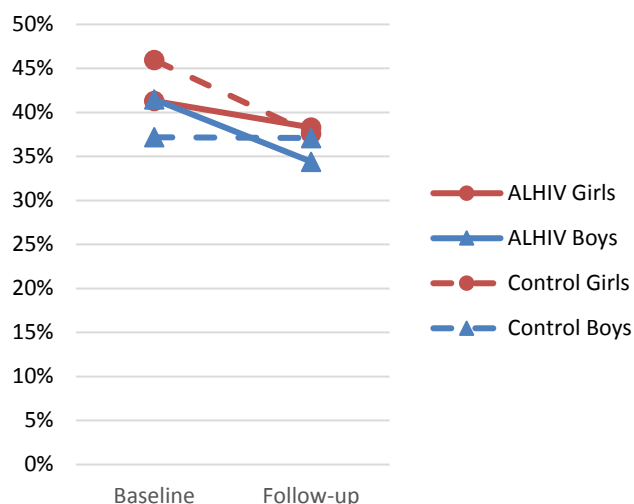
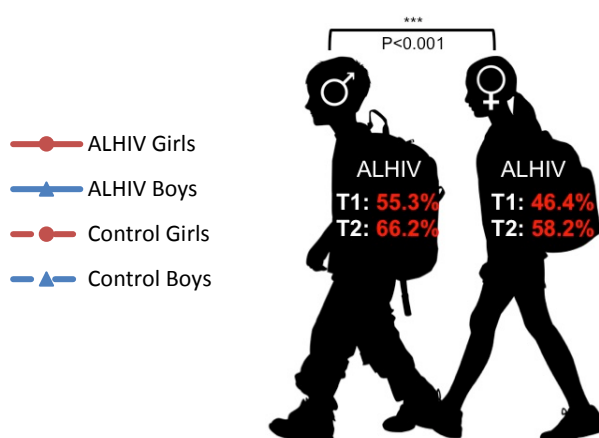


Figure 23. Teens attending school who have been beaten or slapped by a teacher in the last term.

seen in both HIV+ teens and community controls. There is no significant difference between ALHIV and controls at either time point.²²

²² For more information see: Cluver, L., Meinck, F., Toska, E., Orkin, F. M., Hodes, R., & Sherr, L. (2018). Multitype violence exposures and adolescent antiretroviral nonadherence in South Africa. *Aids*, 32(8), 975–983.

SDG 5: ACHIEVE GENDER EQUALITY AND EMPOWER ALL WOMEN AND GIRLS

5.1: End all forms of discrimination against all women and girls everywhere

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



Sexual abuse (including rape)

There has been 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 is seen in both ALHIV and community control girls ($P < 0.001$ for both groups) (Figure 21).

Rape

At follow-up, the number of adolescent girls and young women who report ever being raped is significantly higher at follow-up than at baseline ($P < 0.001$), with **6.3%** of females reporting they have ever been raped at follow-up. In real numbers, **50 additional girls** have experienced this trauma.

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 21 shows this information broken down by HIV status.

Abuse victimization experiences among adolescent boys and young men



Physical, emotional, and sexual abuse is 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, over 40 boys reported that they had ever been sexually abused or raped.

Abuse victimization experiences among adolescent girls and young women

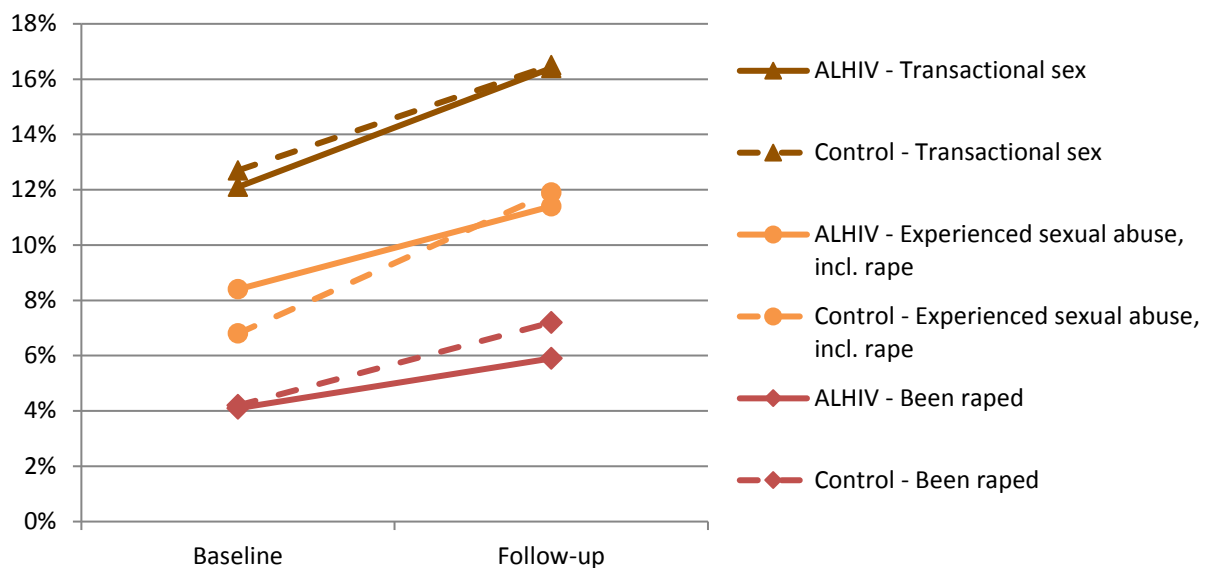
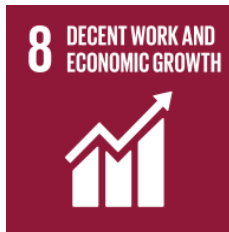


Figure 24. Girls reporting sexual abuse or rape, or transactional sex. There was a significant increase between baseline and follow-up for control groups ($p < 0.001$ for all), and for ALHIV ($p < 0.01$ for all).



SDG 8: PROMOTE SUSTAINED, INCLUSIVE AND SUSTAINABLE ECONOMIC GROWTH, FULL AND PRODUCTIVE EMPLOYMENT AND DECENT WORK FOR ALL

8.5: By 2030, achieve full and productive employment and decent work for all women and men

8.6: By 2020, substantially reduce the proportion of youth not in employment, education or training

Are teens receiving any career development advice or support?



Adolescents were asked if they have access to any career advice, or have any support with doing their homework. Of those who are 15 and over, which is an age at which teens 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.

How many teens live in households where no adults are working?

For the overall sample at both baseline and follow-up, **30–40%** of teens live in households where no adults are working, suggesting that these teens are living in households entirely dependent on government grants or other financial means of survival.



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

16.1: Significantly reduce all forms of violence and related death rates everywhere

16.2: End abuse, exploitation, trafficking and all forms of violence against and torture of children

Are teens experiencing any form of violence or abuse, including physical or emotional, or domestic violence?

As shown in **Error! Reference source not found.**, more teens (both ALHIV and community controls) are experiencing emotional abuse at follow-up than at baseline ($P < 0.001$). **28.3%** and **31.6%** of ALHIV and community controls respectively report 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 are experiencing significantly less physical violence than at baseline ($P < 0.001$). **33.6%** and **35.1%** of ALHIV and community controls respectively report experiencing emotional abuse in the past year at **baseline**, compared with **26.2%** and **25.8%** at **follow-up**.

There is no significant difference between ALHIV and community controls at the different time-points, or between HIV+ boys and girls. Domestic violence has remained constant between baseline and follow-up for both ALHIV and community control teens, with

12% of ALHIV experiencing recent domestic violence (within the last week at the time the interview was conducted).

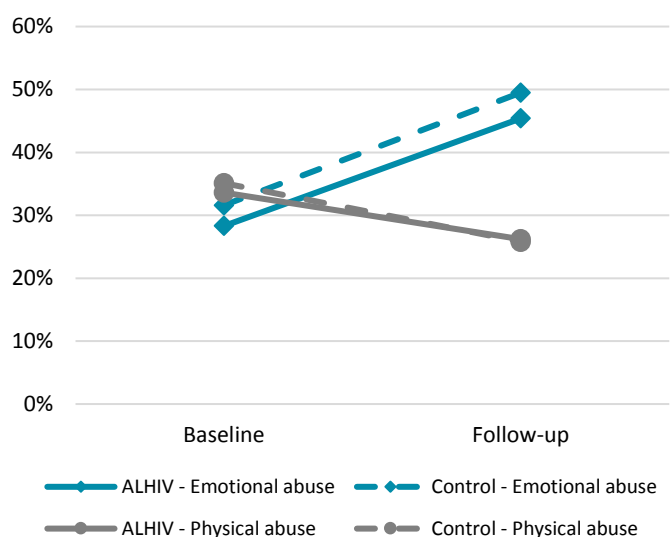


Figure 25. Physical and emotional abuse at baseline and follow-up. There was a significant increase between baseline and follow-up in having experienced emotional abuse for ALHIV ($p < 0.001$) and the control group ($p < 0.001$), whereas for physical abuse there was a significant decrease for ALHIV ($p < 0.001$), and the control group ($p < 0.01$).



SDG 17: STRENGTHEN THE MEANS OF IMPLEMENTATION AND REVITALIZE THE GLOBAL PARTNERSHIP FOR SUSTAINABLE DEVELOPMENT

SDG 17 looks more broadly at the international community, and how they are supporting developing countries in particular to reach the SDGs. We have focused on the following targets in this section:

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

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



The Mzantsi Wakho study, the world's largest cohort of adolescents living with HIV, has provided high quality evidence on the lived experiences of adolescents living with HIV in South Africa. Through dissemination at the international, regional, national, and local level, the research team has shared study findings widely with the goal of informing government policies and programming, contributing to SDG 17. Most recently, the study's findings contributed to UNAIDS' Global Response to HIV report²³.



Figure 26. Mzantsi Wakho in numbers

²³ *Global AIDS Update 2018 – Miles to Go: Closing Gaps, Breaking Barriers, Righting Injustices*. Retrieved July 23, 2018, from UNAIDS website: <http://www.unaids.org/en/resources/documents/2018/global-aids-update>.

CONCLUSION

Figure 26 shows an overview of the findings of this report. For each of the SDGs examined in the report, this figure indicates how many teens responded positively to **none** of the questions relating to that SDG in this report, **at least one** of the questions, or

at least 2 of the questions. This enabled us to quantify how many teens have essentially reached a particular SDG target, how many were partially reaching the SDG target, and how many weren't reaching that SDG target at all.

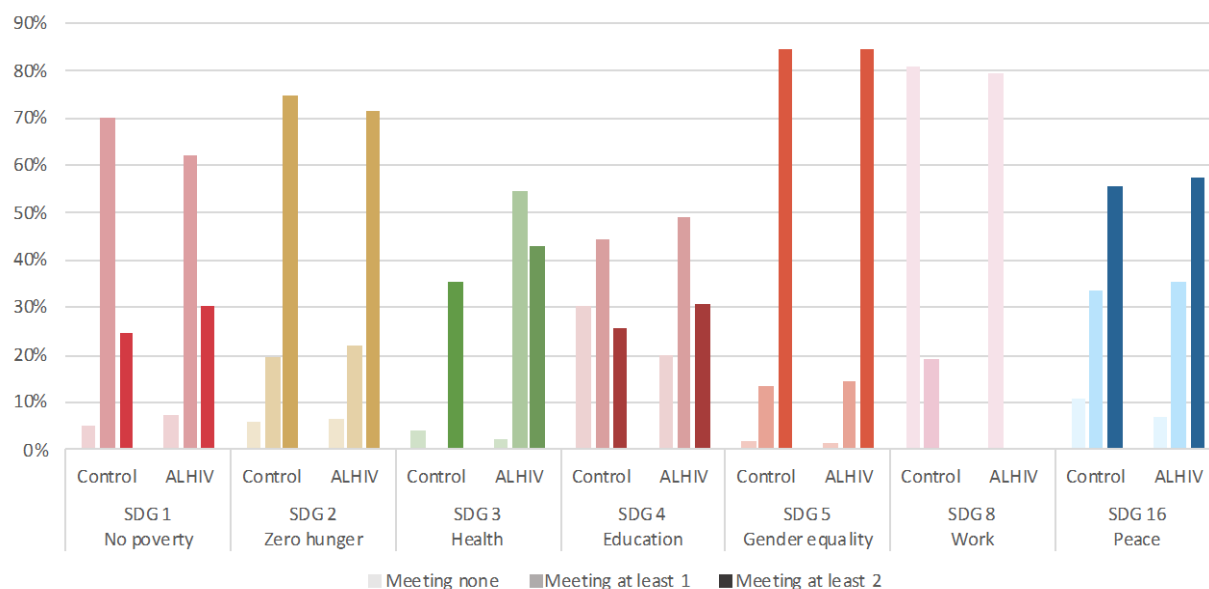


Figure 27. Overview of report findings at follow-up timepoint, including how many teens responded positively to each of the questions asked for each SDG. Criteria used for this graph: SDG 1 – Living in formal housing / Can afford all 8 necessities / Can afford to go to the clinic. SDG2 – Have access to 3 meals a day / Haven't gone without food in the last week. SDG3 – Report good physical and mental health / Consistently using condoms / Don't drink excessively or take drugs / For HIV+ only – full past-week adherence. SDG4 – 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. SDG5 – Have NOT experienced any sexual abuse including rape ever / Have NOT had an older partner or had transactional sex EVER. SDG8 – Have reported living in a house where at least one adult is working / Have received career advice. SDG16 – Have never experienced physical or emotional abuse / Have never experienced domestic violence.

Figure 24 suggests that teens are doing better at reaching SDG2 and SDG5 at follow-up, with **>70%** of teens responding positively to at least 2 of the indicators relating to ending hunger, and **>80%** of teens responding positively to at least 2 of the indicators relating to gender equality and empowerment of women.

A low percentage of teens are achieving SDG4 (access to an inclusive and equitable quality education), with **20–30%** of teens 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 teens have received no help with getting a job, and live in a household in which no adults work.

Participatory qualitative research on adolescents' experiences in relation to the SDGs has revealed their

aspirations for development across the domains of health and social development.²⁴ It has demonstrated how adolescents conceive of health and social services as interconnected, especially in regard to sanitation, education, nutrition and health.

Participants emphasized the importance of food and water as pre-requisites for adherence to medicines, and hunger and thirst were associated with non-adherence and defaulting. This suggests an important interlinkage between SDGs 2 (food security), 3 (health), and 6 (water and sanitation). Rather than a silo'ed service, participants imagined healthcare as part of a developmental lattice that connects sound infrastructure, access to food and education, a ready supply of water, and medical supplies (Figure 27). Adolescents conceived of their inclusion as partners in the design, conceptualization and implementation of development initiatives.

²⁴ Hodes, R., Doubt, J., Toska, E., Vale, B., Zungu, N., & Cluver, L. (2018). The stuff that dreams are made of: HIV-positive adolescents' aspirations for development. *Journal of the International AIDS Society*, 21, e25057.

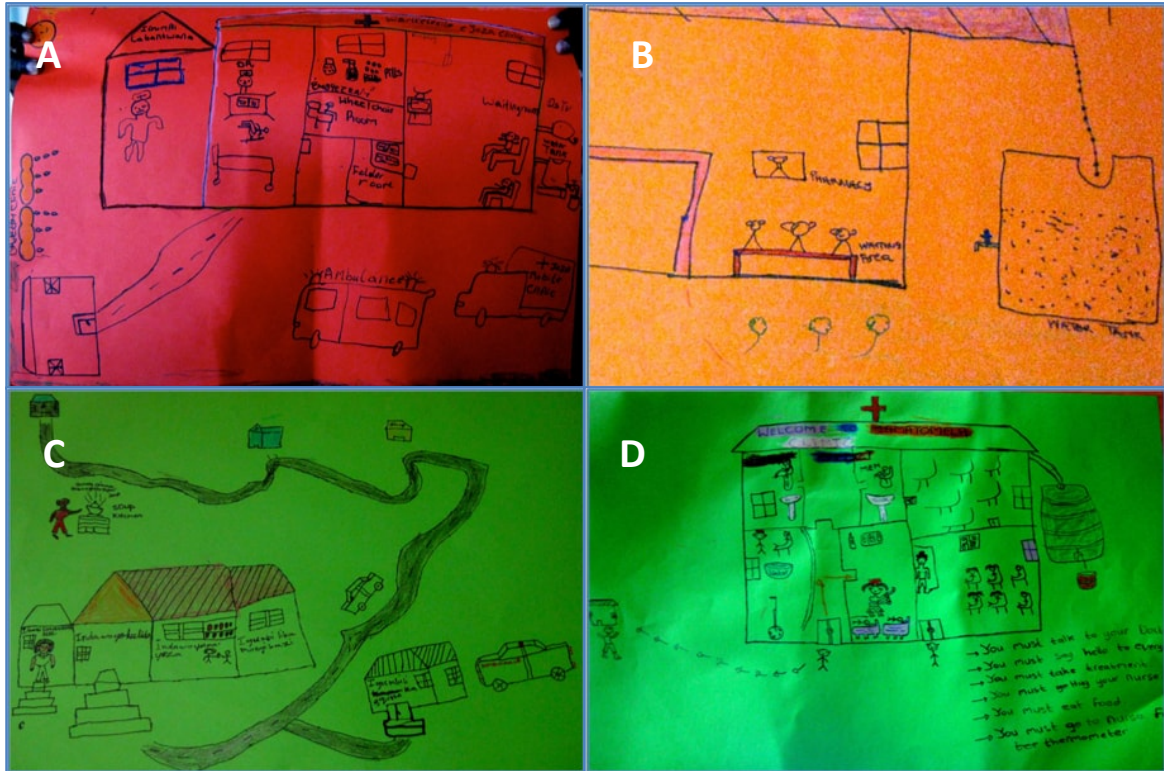


Figure 28. Images drawn by participants showing the basic facilities they believe a clinic should provide. Food and water are a common theme. A – A “dream clinic” (November 2013), including water tanks and taps (far right), a wheelchair room (centre) and an ambulance and mobile clinic (bottom right); B – Detail from a “dream clinic” (November 2013) shows a large and full water tank and a tap adjacent to the patient’s waiting area; C – Detail from a “dream clinic” (February 2014) shows the route to the clinic from participants’ homes. The first stop on the route is a soup kitchen, the second is a school; D – A “dream clinic” (November 2013) features a water tank and a bucket for easy distribution (far right), separate and well-appointed ablutions for men and women (with taps and toilets, centre top), and a basin with water in the consulting room (centre).

2018–2019

T3 data

T3 data collection was completed in June 2018, with data cleaning currently underway. A short report outlining key findings will be compiled in 2019.

Mzantsi Wakho Podcasts

A series of podcasts showcasing different facets of the Mzantsi Wakho research project has recently gone live, and can be accessed at <http://www.mzantsiwakho.org.za/news/mzantsi-wakho-podcast-episode-01>

| | |
|------------------|---|
| Episode 1 | HIV, democracy and adolescents in South Africa: An introduction to the Mzantsi Wakho study, by Rebecca Hodes |
| Episode 2 | Framing quantitative findings in the Mzantsi Wakho study, by Elona Toska |
| Episode 3 | Framing qualitative findings in the Mzantsi Wakho study, by Beth Vale |
| Episode 4 | Revelations and challenges within the qualitative team, by Mildred Thabeng, Kanya Makabane and Sinebhongo Mbula |
| Episode 5 | A project manager and community liaison explains the complexities of her work in the Eastern Cape, by Nokubonga Philiswa Mjo |
| Episode 6 | A project co-ordinator describes the importance of the study locally and globally, by Mavis Nobuhle |
| Episode 7 | The study's clinics co-ordinator describes the challenges and possibilities of collaborating with healthcare workers and adolescents living with HIV, by Nonhuthuzelo Bungane |
| Episode 8 | Up close and in focus: Why we did the study, and what we have learnt, by Lucie Cluver |
| Episode 9 | Thanks to our partners, funders and supporters, by Mildred Thabeng, Kanya Makabane and Sinebhongo Mbula |

Launch of new study: HEY BABY (Helping Empower Youth Brought Up in Adversity with their Babies and Young children): 2018–2021

In 2016–2017, it became clear that adolescent mothers living with HIV were struggling to disclose their status to research assistants, dropping out of HIV care, and more likely to be defaulting from ART. We have developed a new study – closely linked to Mzantsi Wakho and sharing much of the sample – of adolescent mothers living with HIV and uninfected adolescent mothers, as well as their children. HEY BABY study tools were piloted in 2017 and 2018. Funding applications were successful for two rounds of mother-child data collection (2018 and 2020). Ethical approval was given from the Universities of Oxford (IDERC Ref No: R48876/RE001) and Cape Town (HREC REF 226/2017), and the South African Department of Health.



The study aims to understand resilience promoting factors for HIV-infected and affected adolescent parents. It includes an adolescent parent questionnaire, which investigates experiences of pregnancy and parenthood, as well as infants' health, nutrition and care, and uses the Mullen Scales of Early Learning, which measures child cognitive ability and motor development. The study was officially launched in March 2018.

Analysis conducted and compiled by Dr Clare E F Dyer and Laurence Campeau, with co-authorship by Principal Investigators Dr Elona Toska, Dr Rebecca Hodes and Prof Lucie Cluver.

Suggested citation: Mzantsi Wakho Year 2 Report: Adolescents and Youth Living with HIV and the Sustainable Development Goals (2018). Available at www.mzantsiwakho.org.



Figure 29. A typical morning in the Mzantsi Wakho offices. From top left: Amanda Mbiko, Sinebhongo Mbula, Philiswa Mjo, Babalwa Mkati, Nisso Nurova and Anna Carlqvist (11 May 2017). (Photograph by Rebecca Hodes)



Figure 30. The East London and King William's Town teams at the launch of the new HEY BABY study (photograph by Laurence Campeau)

The team

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Clinic team: *Pumza Bellem, Nontuthuzelo Bungane, Zoliswa Marikeni, and Amanda Mbiko.*

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Publications

The following is a full list of the publications lead-authored or co-authored by the Mzantsi Wakho investigators until September 30, 2018. While some of the publications do not report directly on the data collected during this period (marked with an *), they draw on the shared investigator team expertise and experiences during this research project.

1. Cluver, L., Pantelic, M., Toska, E., Orkin, M., Casale, M., Bungane, N., Sherr, L. (2018). STACKing the odds for adolescent survival: health service factors associated with full retention in care and adherence amongst adolescents living with HIV in South Africa. *J Int AIDS Soc.* 21(9):e25176.
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5. Cluver, L., Pantelic, M., Orkin, M., Toska, E., Medley, S., & Sherr, L. (2018). Sustainable Survival for adolescents living with HIV: do SDG-aligned provisions reduce potential mortality risk?. *Journal of the International AIDS Society*, 21, e25056.
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12. Vale, B., Hodes, R., Cluver, L., & Thabeng, M. (2017). Bureaucracies of Blood and Belonging: Documents, HIV-positive Youth and the State in South Africa. *Development and Change*, 48(6), 1287–1309.
13. Natukunda, H. P. M., Cluver, L. D., Toska, E., Musiime, V., & Yakubovich, A. R. (2017). Beyond clinical trials: Cross-sectional associations of combination antiretroviral therapy with reports of multiple symptoms and non-adherence among adolescents in South Africa. *South African Medical Journal*, 107(11), 965–975.
14. Hodes, R. (2017). Contesting the Choice Act: Abortion politics in a state in transition. In T. P. Light & S. Stettner (Eds.), *Abortion in Transcultural Perspective*. London: Palgrave.
15. Pantelic, M., Boyes, M., Cluver, L., & Meinck, F. (2017). HIV, violence, blame and shame: pathways of risk to internalized HIV stigma among South African adolescents living with HIV. *Journal of the international AIDS society*, 20(1), 21771.
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