ADOLESCENT HIV IN TANZANIA

Factors Affecting Viral Load Suppression and the Transition to Adult Care
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# Contents

**Acknowledgments** ........................................................................................................... V

**Abbreviations** .................................................................................................................... vi

**Executive Summary** .......................................................................................................... vii

- Methods ................................................................................................................................. viii
- Results .................................................................................................................................... viii
- Policy Recommendations ...................................................................................................... x

**Introduction** ........................................................................................................................ 1

- Viral Suppression and Viral Load Testing ............................................................................ 1
- Transition to Adult HIV Care .............................................................................................. 4
- Purpose .................................................................................................................................. 7

**Methods** ............................................................................................................................ 7

- Methodology: Quantitative Analysis of Viral Load Testing and Viral Suppression ............ 8
- Methodology: HP+ Pediatric HIV Transition Model (Quantitative) .................................... 9
- Methodology: Qualitative Analysis of Viral Suppression and the Transition to Adult HIV Care ........................................................................................................................................ 11

**Results** ................................................................................................................................ 17

- Policymaker Perspectives ...................................................................................................... 17
- Viral Load Testing and Viral Suppression ............................................................................. 19
- Transition to Adult HIV Care .............................................................................................. 36

**Discussion** .......................................................................................................................... 56

- Viral Load Testing and Viral Suppression ............................................................................. 56
- Transition to Adult HIV Care .............................................................................................. 59
- Study Limitations .................................................................................................................. 61
- Policy Recommendations ...................................................................................................... 62

**References** .......................................................................................................................... 64
List of Tables

Table 1. Study Sites and Site Characteristics, Qualitative Component........................................... 13
Table 2. Demographic and Clinical Characteristics Associated with Viral Load Testing...................... 20
Table 3. Demographic and Clinical Characteristics Associated with Viral Suppression.......................... 23
Table 4. Characteristics of Adolescents and Caregivers Participating in IDIs and FGDs ..................... 25
Table 5. Characteristics of Healthcare Providers Participating in FGDs .............................................. 26
Table 6. Scenarios Used to Estimate the Number of Adolescents Eligible for and Actually Transitioning to Adult Care, 2018–2025 .............................................................................................................. 37
Table 7. Number Expected to Actually Transition, by Scenario, Region, and Year ............................... 39
Table 8. Transition Criteria Used in Study Facilities ................................................................................ 46
Table 9. Preparing for the Transition to Adult Care ............................................................................... 51

List of Figures

Figure 1. Eligibility for Inclusion in Quantitative Analysis of Viral Load Testing and Viral Suppression ............................................................................................................................................... 9
Figure 2. Number of Adolescents Eligible to Transition to Adult HIV Care, by Year (Scenarios 1 and 2) ............................................................................................................................................. 38
Figure 3. Number of Adolescents Ages 15 to 17 Years on ART who Need to Begin Preparing for Transition, by Age and Year ............................................................................................................. 40
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## Abbreviations

<table>
<thead>
<tr>
<th>Abbreviation</th>
<th>Description</th>
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<tbody>
<tr>
<td>AIDS</td>
<td>acquired immune deficiency syndrome</td>
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<tr>
<td>AIM</td>
<td>AIDS Impact Model</td>
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<td>ART</td>
<td>antiretroviral therapy</td>
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<td>ARV</td>
<td>antiretroviral drug</td>
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<tr>
<td>Baylor</td>
<td>Baylor Tanzania Children’s Foundation</td>
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<tr>
<td>CTC</td>
<td>care and treatment center</td>
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<tr>
<td>DBS</td>
<td>dried blood spot</td>
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<tr>
<td>FGD</td>
<td>focus group discussion</td>
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<td>HIV</td>
<td>human immunodeficiency virus</td>
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<td>HP+</td>
<td>Health Policy Plus</td>
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<tr>
<td>IDI</td>
<td>in-depth interview</td>
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<tr>
<td>MDH</td>
<td>Management and Development for Health</td>
</tr>
<tr>
<td>MOHCDGEC</td>
<td>Ministry of Health, Community Development, Gender, Elderly and Children</td>
</tr>
<tr>
<td>NACP</td>
<td>National AIDS Control Programme</td>
</tr>
<tr>
<td>PEPFAR</td>
<td>U.S. President’s Emergency Plan for AIDS Relief</td>
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<tr>
<td>TACAIDS</td>
<td>Tanzania Commission for AIDS</td>
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<tr>
<td>UNAIDS</td>
<td>Joint United Nations Programme on HIV/AIDS</td>
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<tr>
<td>UNICEF</td>
<td>United Nations Children’s Fund</td>
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<tr>
<td>USAID</td>
<td>U.S. Agency for International Development</td>
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<tr>
<td>WHO</td>
<td>World Health Organization</td>
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<td>ZAC</td>
<td>Zanzibar AIDS Commission</td>
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Executive Summary

Although overall HIV prevalence is decreasing in Tanzania, adolescents ages 15–19 years account for a disproportionately high share of new HIV infections in the country (Barker et al. 2016; UNAIDS, 2017; UNAIDS, 2018). Children and adolescents living with HIV who initiate antiretroviral therapy (ART) upon diagnosis and remain on treatment can have normal lifespans (WHO, 2016). With treatment, a growing number of children living with HIV are surviving into adolescence and adulthood — “aging out” of pediatric care and needing to transition into adult care (Dahourou et al., 2017). Adolescents living with HIV have specialized needs and face distinct challenges as they navigate the transition from childhood to adulthood.

In response, the Government of Tanzania is expanding and modifying its programs and approaches to better meet the unique needs of adolescents living with HIV. In 2015, Tanzania adopted the “test and start” strategy (also known as “test and treat”) recommended by the World Health Organization, making all people living with HIV eligible for treatment upon diagnosis and advising the use of viral load testing for treatment monitoring. The sixth edition of Tanzania’s National Guidelines for the Management of HIV and AIDS include test and start and recommend the use of routine viral load testing for all ART clients, regardless of age or disease stage (MOHCDGEC, 2017). Although routine viral load testing is gradually being rolled out nationwide, scale-up is progressing slowly (Roberts et al., 2016). At the time of this study, Tanzania did not have national guidelines or standards of care in place for transitioning adolescents living with HIV to adult models of HIV care. In the absence of standardized guidance, transitioning practices vary, with health facilities using their own processes and criteria to transition adolescents to adult HIV care. However, the National Training Package on Adolescents Living with HIV and AIDS does include content on managing the transition to adult care (MOHCDGEC, 2018). Although the package remains in draft, rollout began in February 2018.

This study was carried out by the Health Policy Plus (HP+) project, funded by the U.S. Agency for International Development (USAID) and the U.S. President’s Emergency Plan for AIDS Relief (PEPFAR). HP+ undertook this study to explore factors influencing viral load testing, viral suppression, and the transition to adult HIV care among adolescents living with HIV in Tanzania. The study also sought to estimate the number of adolescents living with HIV who will be eligible for and actually transitioning to adult HIV care in Tanzania between 2018 and 2025. Findings are intended to inform the development and revision of policies and programs in Tanzania to increase adolescents’ rates of viral suppression and viral load testing and promote successful transitions to adult HIV care. The study used a combination of quantitative and qualitative methods to achieve the following research objectives:

1. Establish baseline estimates and trends for viral load testing and viral suppression among children (ages 0–14 years), adolescents (ages 15–19 years), and young adults (ages 20–24 years) living with HIV in Tanzania who initiated ART at or before 19 years of age

2. Identify potential causes of variance, by demographic and clinical characteristics, in viral load testing and viral suppression among this same population

3. Estimate the number of people who will be eligible for and actually transitioning to adult HIV care in Tanzania each year between 2018 and 2025, at national and regional levels
Adolescent HIV in Tanzania: Factors Affecting Viral Load Suppression and the Transition to Adult Care

4. Identify barriers and enablers that affect viral load testing, viral suppression, and successful transition to adult HIV care in Tanzania

Methods

This was a mixed methods study, consisting of quantitative and qualitative components. Together, these elements provide a comprehensive view of viral load testing, viral suppression, and the transition from adolescent to adult HIV care among children (ages 0–14 years), adolescents (ages 15–19 years), and young adults (ages 20–24 years) living with HIV in Tanzania.

The first quantitative component used secondary analysis of clinic data to explore viral load testing and viral suppression. For this analysis, the team used clinic records from 204 health facilities in three districts in the Dar es Salaam region (Ilala, Kinondoni, and Temeke). Clinic records included 22,622 children, adolescents, and young adults who started ART at or before 19 years of age. Those who had not been on ART for at least six months were excluded, leaving 15,679 individuals. HP+ excluded an additional 196 youth who had been on ART for less than six months at the time of their last viral load test, leaving a sample of 15,483 individuals.

The second quantitative study component focused on the transition to adult HIV care. For this component, HP+ designed and applied the HP+ Pediatric HIV Transition Model to estimate the number of people who will be eligible for and actually transitioning to adult HIV care in Tanzania between 2018 and 2025 (HP+, 2018). The Excel-based model builds upon the AIDS Impact Model (AIM) in Spectrum—an internationally recognized suite of easy-to-use policy models that can estimate numbers on ART by age, sex, regimen, region, and year across multiple scenarios.

The qualitative component of this study sought to identify enablers and barriers affecting viral load testing, viral suppression, and the transition to adult HIV care in Tanzania. The team conducted a series of in-depth interviews (IDIs) and focus group discussions (FGDs) in two regions (Iringa and Tabora): 64 IDIs and eight FGDs with adolescents living with HIV (ages 15–19 years); 64 IDIs with their caregivers; eight FGDs with healthcare providers treating adolescents living with HIV; and 17 IDIs with policymakers and program managers at the national and regional levels.

Results

Policymaker perspectives

Policymakers provided an understanding of the current policy environment surrounding adolescent HIV programming in Tanzania. To improve viral suppression among adolescents, they recommended that the current national HIV management guidelines be followed (MOHCDGEC, 2017) and emphasized the importance of educating adolescents about the importance of treatment adherence. Policymakers identified the lack of national guidance on the transition from adolescent to adult HIV care as a key policy gap. However, national-level policymakers reported that efforts are underway to develop standard operating procedures for the transition to adult care.
**Viral suppression and viral load testing**

This study included both quantitative and qualitative analysis of viral suppression and viral load testing. The quantitative analysis found that only 64.2% of the 15,482 children and adolescents (ages 0–19 years) eligible for viral load test had at least one viral load test in facility records. Of those with a documented viral load test, around two-thirds (65.8%) were virally suppressed, with males less likely to be virally suppressed than females.

IDI respondents and FGD participants highlighted various factors as enablers of viral suppression, including ART adherence and understanding of viral suppression and viral load testing. Adolescents understood the need to adhere to medication regimens but reported occasionally forgetting to take their medication. To keep track of appointments, they commonly reported looking at their clinic cards (where the next appointment date is usually written) or counting their remaining ART medication. Several adolescents reported longer lapses in treatment adherence. Reasons mentioned for such lapses included fear of disclosure, running out of medications while traveling, lack of support, feelings of loneliness, and lack of perceived improvement while on medication. Caregivers mentioned additional challenges affecting adolescents' ability to take ART medication as prescribed, including stigma (at the family level and in institutions such as schools) and economic hardship. Low treatment literacy and understanding of the concept of “viral load” were also identified as barriers to treatment adherence and viral suppression. Adolescents and healthcare providers had contradictory perceptions about providers’ level of engagement with appointment reminders; although few adolescents mentioned being reminded of appointments by healthcare providers or peer educators, providers reported following up with adolescents who missed clinic appointments.

Overall, adolescents and caregivers appeared to have a good understanding of viral suppression, although some adolescents did not know what it meant to be virally suppressed. However, they had limited awareness of the prevention benefits of viral suppression. Although several adolescents and caregivers mentioned that viral suppression substantially reduces the chance of transmitting HIV to others, this awareness was not common. Moreover, there was no recognition that being undetectable could eliminate the risk of sexual transmission. Delayed delivery of test results was the most commonly cited barrier to viral load testing. Participants offered suggestions for improving rates of viral suppression that ranged from ensuring that facilities have adequate supplies and equipment to improving treatment and viral load literacy and expanding outreach activities in communities where health facilities are less accessible.

**Transition to adult HIV care**

The HP+ Pediatric HIV Transition Model used data on the number of adolescents living with HIV, together with current trends in transitioning behavior, to estimate the number of adolescents eligible for and actually transitioning to adult care between 2018 and 2025 under different assumptions. Results show that, if ART coverage is scaled up in line with current trends, the number of 18-year-olds on ART (eligible for transition) would increase from 6,340 in 2018 to 9,486 in 2025. If, instead, ambitious national targets for ART scale-up are met, the number of 18-year-olds on ART would increase from 9,727 in 2018 to 10,328 in 2025.

The study’s qualitative results offer a better understanding of the transition process, including the enabling and hindering factors that affect prospects for a successful transition. According to participants, adolescent and adult clinics are often held in the same building with the same
Adolescent HIV in Tanzania: Factors Affecting Viral Load Suppression and the Transition to Adult Care

Healthcare providers—although on different days and with visits structured differently. Adults meet with clinicians, while adolescents also attend counseling sessions and social activities. Since adult and adolescent clinics are usually operated by the same staff, provider attitudes are similar—although providers are often friendlier to adolescents than they are to adult clients.

Caregivers become less involved in adolescents’ care as they transition to adult HIV clinics. Before transitioning, adolescents must know that they are living with HIV. Otherwise, they would be unable to take control of their own care. When asked about their disclosure experiences, many adolescents did not remember how old they were when first told that they were living with HIV. Of the 52 who did remember, nearly half had been told before the age of 10 years and nearly all by the age of 15 years. Most adolescents were kept unaware of their positive HIV status until caregivers felt it necessary to inform them. Many adolescents said they would have preferred to have learned about their HIV-positive status earlier than they did. Healthcare providers also encouraged disclosure at a young age.

Adolescents’ transition experiences varied, as facilities conduct transition differently. Almost all participants agreed that transition criteria should focus on transition readiness rather than age. Participants offered recommendations for improving the transition process, including doing more to educate adolescents about the transition, preparing adolescents for transition gradually, and making sure that adolescents feel ready for transition before moving ahead with transition. All those interviewed identified peer support as being highly important for adolescents. Healthcare providers requested that they receive training on the transition to adult care, including how to assess transition readiness.

Policy Recommendations

These study findings have direct policy implications, leading HP+ to offer the following recommendations:

1. Peer support groups for adolescents and optional group activities should be incorporated into adult models of HIV care to ensure that adolescents who have transitioned receive ongoing support and continue to benefit from activities similar to those available in adolescent care.

2. Treatment and viral load literacy training and guidance for adolescents, caregivers, and healthcare providers should be developed and rapidly brought to scale—with adolescents living with HIV involved in the development process.

3. Scale-up of routine viral load testing should be continued and implementation strengthened by:
   - Improving turnaround times for delivering test results
   - Ensuring the availability of equipment and supplies
   - Using training and other strategies to enhance providers’ understanding of the benefits of viral load testing and viral suppression and their ability to communicate these benefits to adolescents living with HIV and their caregivers
   - Further developing differentiated models of care for clinically stable and advanced adolescents living with HIV, including expanding outreach activities in communities
where health facilities are less accessible, to enable adolescents and adults to access ARVs and lab tests closer to home

4. Expedite introduction of an age-and developmentally appropriate treatment and viral load literacy strategy for children and adolescents living with HIV and their caregivers.

5. National guidance on disclosure should be crafted and made available to healthcare providers, caregivers, and adolescents, with adolescents living with HIV involved in the development process.

6. Guidelines on the transition from adolescent to adult HIV care should be rapidly finalized and implemented, including ensuring that:
   (a) All providers are trained on the guidelines and on assessing transition readiness
   (b) Adolescents living with HIV are involved in guideline formulation and implementation
   (c) The guidelines:
      - Are written in simple, easily understood language
      - Are available in English and Kiswahili
      - Specify that adolescents should be prepared for and engaged in the transition process well in advance of transition
      - Use readiness, rather than age, as the primary transition criterion—i.e., before transitioning, adolescents must show that they are able to take responsibility for independently managing their condition, including attending appointments as scheduled and taking medications on time; 18-year-olds should remain in adolescent care until they are ready to transition; likewise, younger adolescents who wish to transition should have this option, if they are ready
      - Include guidance for providers on preparing adolescents for transition, discussing test results with adolescents, and assessing transition readiness
      - Emphasize the importance of involving caregivers in the transition process

7. Conduct a rapid policy and guideline scan to determine the status of priority guidelines from conception to implementation. Results can be used as an advocacy tool to prioritize recommendations that need expedited implementation.
Introduction

More than half of Tanzania’s population (54.6%) are under 20 years of age (TACAIDS and ZAC, 2018). Although overall HIV prevalence is decreasing in the country, adolescents ages 15–19 years account for a disproportionately high share of new HIV infections (Barker et al., 2016; UNAIDS, 2017; UNAIDS, 2018). In 2017, there were an estimated 120,000 children (ages 0–14 years) living with HIV in Tanzania, including about 55,000 on antiretroviral therapy (ART) (PEPFAR, 2018), and children accounted for nearly one-fifth (19%) AIDS-related deaths in the country (UNAIDS, 2018). With treatment, a growing number of children living with HIV are surviving into adolescence and adulthood—“aging out” of pediatric care and needing to transition to adult care (Dahourou et al., 2017).

Adolescents living with HIV have specialized needs and face distinct challenges as they navigate the transition from childhood to adulthood. In response, the Government of Tanzania is expanding and modifying its programs and approaches to better meet the unique needs of adolescents living with HIV. In 2015, Tanzania adopted the “test and start” (also known as “test and treat”) strategy recommended by the World Health Organization (WHO)—making all people living with HIV eligible for treatment upon diagnosis and recommending the use of viral load testing for treatment monitoring. The sixth edition of Tanzania’s National Guidelines for the Management of HIV and AIDS include test and start and recommend the use of routine viral load testing for all ART clients, regardless of age or disease stage (MOHCDGEC, 2017). Routine viral load testing is gradually being rolled out nationwide, although scale-up is progressing slowly (Roberts et al., 2016). Currently, Tanzania has no national guidelines or standards of care in place regarding the transition from adolescent to adult HIV care. However, the National AIDS Control Programme (NACP); the Ministry of Health, Community Development, Gender, Elderly and Children (MOHCDGEC); the United Nations Children’s Fund (UNICEF); and implementing partners collaborated to design the National Training Package on Adolescents Living with HIV and AIDS, August 2017, which includes a module on managing the transition to adult care (MOHCDGEC, 2018). Although the package remains in draft, rollout began in February 2018 with trainings in four regions (Arusha, Dodoma, Kilimanjaro, and Tabora). The government is working to finalize the training package and planning for its expanded rollout.

The Health Policy Plus (HP+) project, funded by the U.S. Agency for International Development (USAID) and the U.S. President’s Emergency Plan for AIDS Relief (PEPFAR), undertook this study inform the design of policies and programs related to adolescent HIV in Tanzania. The study used a combination of quantitative and qualitative methods to explore factors influencing viral load testing, viral suppression, and the transition to adult HIV care among adolescents living with HIV in Tanzania, and to estimate the number of people living with HIV in Tanzania who will be eligible for and actually transitioning from adolescent to adult HIV care each year between 2018 and 2025.

Viral Suppression and Viral Load Testing

The primary goal of ART is to achieve viral suppression. People living with HIV who are virally suppressed are less likely to develop AIDS-defining conditions and less prone to comorbidities than those who are not virally suppressed. They also do not transmit HIV to their sexual
partners (WHO, 2016). Viral load testing is the preferred approach recommended for identifying viral suppression and monitoring treatment success (WHO, 2016). The use of routine viral load tests to manage clients’ care (viral load monitoring) has been found to be a cost-effective method of improving life expectancy among people living with HIV (Hyle et al., 2017).

Viral load testing is also used to diagnose and confirm treatment failure (WHO, 2016). Common causes of treatment failure—regardless of age—include challenges accessing ART, poor ART adherence, inadequate dosing, and drug resistance. For children and adolescents, prompt diagnosis and initiation on treatment can result in improved life span and quality of life. Children and adolescents living with HIV who initiate ART upon diagnosis and adhere to their treatment regimen can have near-normal life expectancy (WHO, 2016). Adolescents living with HIV who are not consistently virally suppressed are at greater risk of developing drug resistance and are also more likely to transmit HIV to others—an important concern given that HIV risk behavior tends to be highest in adolescence (Dahourou et al., 2017).

Although 47 of 54 low- and middle-income countries have guidelines that support routine viral load testing (Roberts et al., 2016), in many of these countries viral suppression rates among ART clients are not known because treatment programs do not regularly perform routine laboratory monitoring of HIV viral load. However, this situation is changing rapidly as donors, such as PEPFAR and the Global Fund to Fight AIDS, Tuberculosis and Malaria, have begun supporting viral load testing and gradually diminishing support for the routine use of CD4 cell counts.

**Viral suppression and viral load testing in Tanzania**

The 2016/17 Tanzania HIV Impact Survey found that only 18% of children on ART in Tanzania were virally suppressed (TACAIDS and ZAC, 2018; PEPFAR, 2017). The sixth edition of Tanzania’s National Guidelines for the Management of HIV and AIDS recognize that CD4 cell counts are no longer necessary as a criterion for treatment initiation and recommend that people diagnosed with HIV should start ART as soon as possible—preferably within two weeks of an initial HIV diagnosis. The guidelines recommend the use of routine viral load testing for treatment monitoring and outline algorithms for the use of viral load testing to detect or confirm treatment failure and alter ART regimens among adults, adolescents, and children (MOHCDGEC, 2017).

The guidelines identify the following as the primary goals of combination ART:

- **Maximum and durable suppression of viral load to <50 copies/ml (clinically stable)**
- **Restoration and/or preservation of immunologic function by attainment of CD4 recovery to normal thresholds of ≥500 cells/mm³ for adults; for children younger than five years of age, immunological failure is recognized as developing or returning to a CD4 count of <200 cells/mm³ or CD4 <10%**
- **Reduction of HIV-related morbidity and mortality**
- **Improved quality of life for people living with HIV**

For ART clients above five years of age, the guidelines consider clients to be clinically stable when they meet the following criteria: (1) have been on first-line ART for at least six months; (2) have no adverse drug reactions that require regular monitoring; (3) have no current illnesses (opportunistic infections and comorbidities); and (4) have demonstrated good adherence and
Adolescent HIV in Tanzania: Factors Affecting Viral Load Suppression and the Transition to Adult Care

clinic attendance for the past six months, with viral loads of <50 copies/ml or, in the absence of viral load testing, CD4 counts of >350.

Viral load testing strategies are the same for all ART clients, regardless of age. According to the guidelines, clients should have their first viral load test six months after initiating ART and every six months thereafter, until viral suppression is achieved, after which viral load should be monitored annually to reduce the burden on clients and providers. However, clients who exhibit symptoms of clinical, immunological, or viral failure may be tested at any time. The guidelines set the threshold for treatment failure at 1,000 copies/ml. If a client’s viral load remains at or falls below this threshold, they will continue with their current ART regimen and annual viral load monitoring. However, if at any point a client is found to have a viral load of 1,000 copies/ml or above, they should be referred for enhanced adherence counseling and the test should be repeated after three months. If their viral load remains at or above 1,000 copies/ml, information should be gathered from clinicians and counselors and the client should be switched to a second-line treatment regimen. The guidelines define virologic failure as occurring when a client has a viral load above 1,000 copies/ml (based on two consecutive viral load measurements) after three months of enhanced adherence support (MOHCDGEC, 2017).

The Government of Tanzania is working to expand viral load testing capabilities. The MOHCDGEC plans to increase viral load testing using both dried blood spot (DBS) and plasma samples. To accomplish this, over the next five years the ministry plans to expand testing capacity at national and regional laboratories and create more viral load testing facilities (MOHCDGEC, 2017). Although viral load testing capacity is being scaled up, it will take time before the country is able to meet the demand at scale (Roberts et al., 2016). When the HP+ study team visited Tanzania in October 2017, they noted that scale-up was moving slowly. Moreover, they found that the time elapsed between viral load testing and a client receiving test results varied greatly. However, progress is being made. As of September 2017, Tanzania had the instrument capacity to perform 2,200,000 viral load tests each year in 17 laboratories, with 30 testing platforms nationwide (PEPFAR, 2018).

Current literature identifies several programmatic and policy barriers to the implementation of viral load testing. One major barrier is the complexity of collecting plasma for viral load testing (Dow et al., 2014; Roberts et al., 2016). However, the Tanzanian government anticipates an increased use of DBS rather than plasma collection, particularly in rural areas, which could simplify viral load testing (NACP, 2015). Unlike plasma, DBS can be stored at ambient temperatures for weeks and is therefore—if stored in a dry environment—considered to be reliable under field conditions, including in places without easy access to laboratories (Smit et al., 2014; Dowling et al. 2017). Challenges with specimen transportation and prolonged delays in returning results also reduce demand for viral load testing. These challenges may be improved through the introduction and increased use of DBS (Roberts et al., 2016).

Other factors that contribute to low demand for viral load testing include discomfort with and insufficient knowledge of viral load testing among healthcare providers’ (Roberts et al., 2016). Providers with large workloads and limited knowledge and training may not use viral load testing to manage clients’ care. In addition to limited provider capacity to deliver viral load testing, both providers and clients often lack an understanding of what viral load testing is and of its importance for evaluating treatment success and assessing HIV transmission risks. Often, they lack understanding of the benefits of having an undetectable viral load—both in terms of health outcomes and the fact that virally suppressed individuals are no longer at risk of sexually
transmitting HIV. In the case of pediatric and adolescent clients, this lack of knowledge involves both clients and their adult caregivers. Lack of parental involvement during clinic visits has been strongly associated with suboptimal ART adherence and HIV virologic failure (Lowenthal, 2015).

**Transition to Adult HIV Care**

There is a growing need to ensure that robust policies and standards of care are in place to support successful transitions from adolescent to adult HIV care. Worldwide, due to improved early diagnosis and HIV treatment options, increasing numbers of children and adolescents living with HIV are surviving to adulthood and faced with “aging out” of pediatric and adolescent care and needing to transition to adult care. To ensure that they receive appropriate clinical monitoring and support, as children and adolescents age they need to transition—from child to adolescent care, then from adolescent to adult care. For governments to plan and budget for adequate support to adolescents and young adults who are undergoing transitions in care, it is important to understand how many young people are eligible for transition and actually transitioning each year.

Reiss and Gibson (2002) describe the transition from adolescent to adult HIV care as, “a multifaceted active process that attends to the medical, psychological, and educational or vocational needs of adolescents as they move from the child-focused to the adult-focused health care (p.1309).” Dahourou and colleagues (2017) note that this transition, “involves complex changes of clinics, models of care, and healthcare providers,” and caution that, “If this transition is not well conducted, there is a high risk of non-adherence to ART, emergence of viral resistance and loss to follow-up (p.35).”

Globally, adult care is typically based on adult-centric guidelines that may not be applicable to children or adolescents. Adult care is largely standardized: medication dosages may not vary based on age or weight; the information conveyed during facility visits is standard for all patients; and childhood development goals are not considered—as adults have already reached these goals. In contrast, pediatric and adolescent models of HIV care must take age and other developmental factors into account. In some health systems, pediatricians are available to provide HIV care and treatment, often in settings that are oriented to mothers and younger people. Children under two years of age are seen in maternal and child health clinics; later, they are seen in outpatient departments, other adult-oriented settings, or adolescent clinics. One common model is for adults, children, and adolescents to receive services in the same facility, sometimes from the same providers, but on alternative schedules, such as different days of the week. Tanzania’s HIV and AIDS management guidelines stipulate that clinical HIV care for children and adolescents living with HIV includes monitoring nutrition, growth, and developmental milestones (e.g., weight, height, middle-upper arm circumference), with medication dosages based on weight (MOHCDGEC, 2017). Peer support groups for adults living with HIV deal with different issues than those for children and adolescents. For example, adolescent peer groups include a healthy dose of socialization and broader discussion topics, including laying the foundation for adulthood with HIV and increasing self-management of their condition.

Studies have shown that when the transition from adolescent to adult care is not well conducted, children, adolescents, and young adults are at increased risk for dropping out of care (Dahourou
et al., 2017). Yet, many countries lack transition guidelines and the recommended age of transition varies significantly across, and even within, countries (Dahourou et al., 2017; Lee and Hazra, 2015). Such variation is unsurprising, given the lack of a universally recognized standards defining what successful transition to adult HIV care entails or how it should be achieved (Soeters et al., 2014). Broadly speaking, successful transition from adolescent to adult HIV care means that clients continue to receive care after they have transitioned. However, currently no consensus exists on a precise definition for successful transition (Fair et al., 2015; Davies et al., 2017; Tepper et al., 2017).

To improve retention and viral suppression rates among adolescents transitioning to adult HIV care, there is a pressing need to develop a transitioning policy that can be universally applied across Tanzania and in other countries. Developing such policy guidance entails devising standard transition criteria that are relevant and feasible to implement. The literature highlights several factors as important to successful transition:

- **Disclosure:** Several international guidelines on transitioning include full disclosure and an understanding of one’s HIV status as prerequisites for transitioning from pediatric or adolescent to adult HIV care (Rosen et al., 2003; Sharer and Fullem, 2012).

- **Advance preparation:** Experts recommend preparing adolescents and their caregivers for the transition to adult care, beginning at least one year before the transition itself (Committee on Pediatric AIDS, 2013; Soeters et al., 2014; Bunupuradah et al., 2015).

- **Agency:** Adolescents who are taught to take an active role in their own healthcare are more likely to transition successfully (Sharer and Fullem, 2012). Adolescents who feel a sense of responsibility and maturity and view living with HIV positively have a higher likelihood of being retained in care after the transition (Masese et al., 2017).

- **Knowledge, skills, and emotional readiness:** Research suggests that adolescents should have certain knowledge and skills, such as self-management of medication, before they are ready to transition (Sharer and Fullem, 2012). Such knowledge and skills may be more important than chronological age in ensuring retention in HIV care after the transition (Fair et al., 2010). Researchers at Duke University developed a checklist to determine whether adolescents are ready for the transition (Dow, 2017). However, in practice, this checklist may not be sufficient, as it measures actions (such as taking medications on time) but not emotional readiness, which some researchers and clinicians have identified as a key ingredient for successful transition (Dow, 2017).

- **Peer support groups:** Peer support groups have been identified as a successful method for improving the uptake of health services by adolescents (Busza et al., 2013). Group transitioning, in which all members of a support group transition together, can promote a successful and maintained transition to adult care (Hansudewechakul et al., 2015; Masese et al., 2017). Establishing a support group at the adult clinic for adolescents who are in the process of transitioning has also been shown to provide adolescents with essential peer support, retain them in care, and improve adherence (Masese et al., 2017).
The literature also identifies a variety of barriers faced by adolescents and their families on the road to a successful transition to adult HIV care. Recognizing that studies define successful transition differently, these barriers include:

- Adolescents’ unwillingness to leave healthcare providers with whom they are comfortable (Katusiime et al., 2013; Kung et al., 2016).
- Healthcare providers’ desire to keep adolescents (whom they may have cared for since they were children) in their clinics, rather than transitioning them to adult clinics (Katusiime et al., 2013; Kung et al., 2016).
- Features of adult HIV care that make transition to adult clinics less appealing, including decreased support for clients, less supportive provider attitudes, and lower quality of care (Inzaule et al., 2016; Kung et al., 2016; Mark et al., 2017; Masese et al., 2017).
- Fear of encountering greater stigma when attending adult HIV clinics (Kung et al., 2016; Masese et al., 2017).
- Lack of guidance to help adolescents and their families successfully navigate the transition (Katusiime et al., 2013; Mark et al., 2017).

**Transition to adult care in Tanzania**

A systematic loss analysis conducted in Tanzania in 2015 revealed that, of 2,411 children who were on ART at the beginning of the reporting period and categorized as lost to follow-up by the end of the reporting period, 74% (1,778) had aged out—moving from the under-15 years age band to the 15–19 years age band; 14% (331) had transferred out, 12% (299) were lost to follow-up, and 0.1% (3) had died (PEPFAR, 2017). This information, coupled with the cognitive, emotional, and physical development of children and adolescents as they age, suggests a need to identify and continually assess essential factors that support the transition from adolescent to adult HIV care in the Tanzania context, to minimize young people’s risk of falling out of care and off of successful ART.

Currently, Tanzania has no national guidelines or standards of care for transitioning adolescents to adult HIV care, nor is there specific guidance in place regarding the recommended age or criteria for transition. As a result, transition practices vary throughout the country. However, the draft *National Training Package on Adolescents Living with HIV and AIDS* (MOHCDGEC, 2018) includes content on managing the transition of adolescents to adult care. The package emphasizes the importance of transitioning adolescents when they are ready. Providers may assess readiness to transition based on emotional, developmental, and physical maturity. Module 13 of the package is designed to ensure that healthcare providers are aware of the transition process and equipped with the knowledge they need to ensure a smooth transition of care. The module identifies key considerations when transitioning adolescents to adult care and describes providers’ role as supporting adolescents by encouraging them to advocate for themselves and increase their capacity to manage their own care (MOHCDGEC, 2018). This study helps expand the understanding of transition readiness and provides crucial input into the development of standardized guidance for the transitioning of care in Tanzania.
Adolescent HIV in Tanzania: Factors Affecting Viral Load Suppression and the Transition to Adult Care

**Purpose**

This study was designed to explore factors influencing viral load testing, viral suppression, and the transition from adolescent to adult HIV care in Tanzania. Information generated by the study is intended for use in target setting, planning, and evaluation. Its objectives were to:

1. Establish viral load suppression baseline estimates and trends in children (ages 0–14 years), adolescents (ages 15–19 years), and young adults (ages 20–24 years) living with HIV who initiated ART at or before 19 years of age.
2. Identify potential causes of variance, by demographic and clinical characteristics, in viral load testing and viral suppression among children, adolescents, and young adults living with HIV who initiated ART at or before 19 years of age.
3. Develop projections (at the national and regional levels) of how many adolescents and young adults will be eligible for and actually transitioning to adult care each year from 2018 to 2025.
4. Identify barriers to and enablers of viral suppression among adolescents living with HIV.
5. Identify barriers to and enablers of successful transition from adolescent to adult care.

To achieve these objectives, HP+ conducted a range of quantitative and qualitative research activities. Results of this study are intended to inform the development of national policy guidelines and programs (both facility- and community-based) to increase the proportion of adolescents living with HIV in Tanzania who achieve viral suppression, are retained in care, and successfully transition to adult care.

**Methods**

This was a mixed methods study, consisting of both quantitative and qualitative elements:

1. **Quantitative analysis of viral load testing and viral suppression.** Established baseline estimates and trends for viral load suppression in children, adolescents, and young adults (ages 0–24 years) living with HIV who initiated ART at or before 19 years of age.

2. **HP+ Pediatric HIV Transition Model (Quantitative).** Estimated the number of people (at national and regional levels) eligible for and actually transitioning to adult treatment from 2018 to 2025.

3. **Qualitative analysis of viral suppression and transition of care.** Identified barriers and enablers affecting viral load testing, viral suppression, and successful transition from adolescent to adult care.

Together, these components provided a comprehensive picture of viral suppression and transition of care among adolescents and young adults in Tanzania to inform programming and policy design and implementation.
Methodology: Quantitative Analysis of Viral Load Testing and Viral Suppression

Research questions

This study component was designed to establish baseline estimates of viral suppression among children (ages 0–14 years), adolescents (ages 15–19 years), and young adults (ages 20–24 years) living with HIV in Tanzania. Due to limited data availability, analysis was limited to facilities using electronic medical records in three districts in the Dar es Salaam region (Ilala, Kinondoni, and Temeke). For children, adolescents, and young adults in this region (see “study population” below for details), HP+ used secondary data to respond to the following questions:

1. What proportion have received at least one viral load test (disaggregated by demographic and clinical characteristics)?
2. What proportion are virally suppressed (disaggregated by demographic and clinical characteristics)?
3. What demographic and clinical characteristics are associated with having received at least one viral load test?
4. What demographic and clinical characteristics are associated with viral suppression?

Study population

The population of interest was children (0–14 years), adolescents (15–19 years), and young adults (20–24 years) living with HIV who started ART at or before 19 years of age, had been on ART for at least six months, and were accessing ART at facilities supported by Management and Development for Health (MDH) in one of three districts in the Dar es Salaam region (Ilala, Kinondoni, and Temeke). Our analysis included the clients of all the facilities that were using electronic medical records. As shown in Figure 1, 204 facilities met these criteria, providing services to 22,622 children and adolescents. Those who had been on ART for less than six months were excluded, leaving 15,679 individuals. A further 196 individuals were excluded because they had been on ART for less than six months at the time of their viral load tests, leaving a sample of 15,483 children and adolescents eligible for inclusion in the quantitative analysis.
Data sources

The study team used data from Tanzania’s health facility-based electronic medical records system, CTC2, extracting patient care and treatment records from individual health facilities’ CTC2 databases. During data extraction, patient records were de-identified, removing all fields that could be traceable to individual clients, including names, phone numbers, and physical addresses. The care and treatment clinic number, facility name, and council names were maintained to facilitate merging facility-based datasets into one consolidated dataset for Dar es Salaam. After extraction, individual health facilities’ datasets were merged by facility name and patient identifier. The final dataset contained de-identified data for each client on viral load tests and results, demographic and clinical characteristics, and treatment outcomes.

Analysis

Statistical analyses were performed using SAS version 9.4 (SAS Institute Inc., Cary, North Carolina). All variables were initially examined for distribution, range, outliers, and the extent of missing data. Descriptive analyses were then conducted. Chi-squares and T-tests were computed for categorical and continuous variables, respectively (95% confidence interval). All statistical tests were two-sided and p-values less than 0.05 were considered significant. Descriptive analyses were followed by multivariate analysis (logistic regression) using binary outcomes (had at least one viral load test or not; virally suppressed or not) to examine the association between various demographic and clinical characteristics and viral load testing and viral suppression.

Methodology: HP+ Pediatric HIV Transition Model (Quantitative)

Research questions

To plan and budget appropriately to provide adequate support to young people transitioning to adult HIV care, governments need to know the number who will be eligible for and actually transitioning each year. In response, HP+ developed a Pediatric HIV Transition Model and
Adolescent HIV in Tanzania: Factors Affecting Viral Load Suppression and the Transition to Adult Care

applied it in Tanzania and Mozambique to estimate the number of adolescents and young adults living with HIV who will be eligible for and actually transitioning to adult HIV care each year between 2018 and 2025. The model can estimate the number of people on ART by age, sex, ART regimen, region, and year across multiple scenarios. In Tanzania, in consultation with key pediatric HIV stakeholders, HP+ developed two ART coverage scenarios:

1. ART coverage increases based on recent trends in identification, linkage to care, and retention in care
2. National ART coverage targets are met

For these two scenarios, HP+ used the model to respond to the following questions:

1. How many adolescents and young adults living with HIV (ages 18–24 years) will be eligible to transition to adult HIV care between 2018 and 2025?
2. How many people are expected to actually transition to adult HIV care based on recent trends?
3. How many adolescents ages 15 to 17 years will need to start preparing for the transition to adult HIV care?

Data sources

The model estimates the number of people on ART by subnational unit, gender, and single-year age band and projects. It allows for the adjustment of various assumptions, making it flexible and easily adapted to other settings. The model builds upon the AIDS Impact Model (AIM) in Spectrum—an internationally recognized suite of easy-to-use policy models (Stover et al., 2017). AIM estimates the number of people living with HIV each year based on data from population surveys, sentinel surveillance, and other sources. It is a dynamic model that considers changes in underlying demography and impacts of ART on HIV-related mortality. The HP+ Pediatric HIV Transition model uses official country-specific AIM files to estimate the number of people living with HIV. To estimate the number of people on ART each year, the transition model uses programmatic data on trends in HIV testing coverage, yield rates, rates of linkage to care and retention. In Tanzania, HP+ used regional Spectrum files updated with 2017 programmatic data and publicly available PEPFAR data (PEPFAR, 2017a; 2017b).

For the first scenario—ART coverage increases based on recent trends—the number of infants under one year old on ART was based on linear extrapolation of four years of trend data on early infant diagnosis, including the number of infants tested each year, the percentage of those tested identified as living with HIV, the percentage of those identified as living with HIV who were linked to care, and the percentage of those on ART who were retained in care after 12 months. The number of children, adolescents, and young adults on ART each year was based on linear extrapolation of four years of trend data on HIV testing, testing yields, number linked to ART, and number retained in care after 12 months of treatment—using the number of children, adolescents, and young adults on ART in 2017 as a baseline. This scenario used publicly-available PEPFAR data, disaggregated by region, sex, and age band (0–14 years vs. over 15 years. For select indicators, where data were available, HP+ examined trends specifically for young people ages 15–24 years (PEPFAR, 2017a; 2017b).
The model requires selecting age criteria for transitioning, as many countries stipulate a minimum age for transition. For Tanzania, 18 years was selected, based on stakeholder recommendations, current practice, and NACP guidance (MOHCDGEC, 2018, Chapter 13). The model is flexible, allowing for other factors, such as viral suppression, to be included in its calculations. Viral suppression was not included in this model application, as Tanzania does not require clients to be virally suppressed before transitioning to adult care.

In Tanzania, data on transitioning data are not routinely collected or reported. Therefore, HP+ used 2014–2017 cohort data from the Baylor Tanzania Children’s Foundation—a patient-centered pediatric HIV prevention and treatment program that seeks to reduce AIDS-related morbidity and mortality among infants, children, and adolescents. In Tanzania, Baylor runs hospitals and clinics using a model of pediatric excellence, supporting pediatric care and treatment services in six regions in the Southern Highlands and eight regions in the Lake Zone (Baylor, n.d.).

**Methodology: Qualitative Analysis of Viral Suppression and the Transition to Adult HIV Care**

The qualitative component of this study involved primary data collection, in contrast with the quantitative elements, which relied on secondary data. Data were collected through a combination of in-depth interviews (IDIs) and focus group discussions (FGDs) in selected facilities.

**Research questions**

This qualitative part of the study was designed to provide in-depth understanding of key stakeholders’ perceptions on the enablers of and barriers to achieving viral suppression in children and adolescents (ages 0–19 years) living with HIV and successfully transitioning adolescents and young adults from pediatric/adolescent to adult HIV care. Stakeholders included adolescents (ages 15–19 years) living with HIV, their adult caregivers (parents/guardians), policymakers and high-level program managers, and healthcare providers. Healthcare providers invited to participate in the study were involved in providing care to adolescents at care and treatment center (CTC) clinics. Question guides were designed to elicit in-depth views and perceptions from respondents to answer the following questions:

1. What factors reduce barriers to viral suppression and increase ART adherence in children and adolescents living with HIV?
2. What factors and practices improve programming and policies for children and adolescents living with HIV and can be used to inform national guidance and implementation?
3. What are commonly identified transition experiences among adolescents living with HIV transitioning to adult care?
4. What factors need to be in place for an adolescent to be considered “ready” to transition from adolescent to adult HIV care?
Site selection

Qualitative data were collected in two regions, Iringa and Tabora. These regions were selected after consultations with USAID, NACP, and implementing partners, taking into consideration selection criteria, which included higher HIV prevalence and higher volumes of children and adolescents on ART. To allow for comparison, one district in each region was designated as “high-performing” and one as “low-performing.” The study team used a proxy indicator (percentage of adolescents on ART who received viral load testing) to categorize districts as high- or low-performing. To ensure access to enough adolescents on ART at study sites, districts were considered for inclusion only if they had at least four facilities that serve 50 or more children/adolescents currently on ART. The study team planned to recruit adolescent FGD participants from among the members of adolescent support groups (teen clubs). Therefore, only districts with at least two facilities that operate teen clubs were considered for inclusion. In the Iringa region, Mufindi and Iringa districts were selected, with viral load testing coverage among adolescents of 51% and 33%, respectively (see Table 1). In the Tabora region, Igunga and Nzega districts were selected, with viral load testing coverage among adolescents of 38% and 21%, respectively.

Within each district, four facilities (two high-performing and two low-performing) were selected as study sites, for a total of 16 facilities, eight in each region. There was no strict definition for “high” or “low” performance. Facilities were defined as high- or low-performing based on their relative performance in comparison with other facilities in the district. High-performing facilities had a relatively higher proportion of adolescents on ART, with viral load tests, and retained in care than low-performing facilities. Districts/facilities that are hard to access were not considered for inclusion, largely due to budget constraints. Facilities were selected to ensure that at least one facility in each district was a hospital or health center and at least one was a dispensary. Table 1 shows the characteristics of study facilities, by region.
### Table 1. Study Sites and Site Characteristics, Qualitative Component

<table>
<thead>
<tr>
<th>Region</th>
<th>District</th>
<th>Facility Name</th>
<th>Performance Level¹</th>
<th>Currently on Treatment (#)</th>
<th>Viral Load Tests (%)</th>
<th>Virally Suppressed (%)</th>
<th>Teen Clubs (Y/N)</th>
</tr>
</thead>
<tbody>
<tr>
<td>Iringa</td>
<td>Iringa</td>
<td>Tosamaganga Hospital</td>
<td>Higher</td>
<td>157</td>
<td>67</td>
<td>52</td>
<td>Y</td>
</tr>
<tr>
<td>Iringa</td>
<td>Iringa</td>
<td>Wasa Dispensary</td>
<td>Higher</td>
<td>44</td>
<td>100</td>
<td>55</td>
<td>N</td>
</tr>
<tr>
<td>Iringa</td>
<td>Iringa</td>
<td>Ifunda Roman Catholic Health Center</td>
<td>Lower</td>
<td>79</td>
<td>4</td>
<td>100</td>
<td>Y</td>
</tr>
<tr>
<td>Iringa</td>
<td>Iringa</td>
<td>Nzihi Health Center</td>
<td>Lower</td>
<td>89</td>
<td>2</td>
<td>100</td>
<td>Y</td>
</tr>
<tr>
<td>Iringa</td>
<td>Mufundi</td>
<td>Mdagulo Dispensary</td>
<td>Higher</td>
<td>168</td>
<td>99</td>
<td>49</td>
<td>Y</td>
</tr>
<tr>
<td>Iringa</td>
<td>Mufundi</td>
<td>Usokami Health Center</td>
<td>Higher</td>
<td>389</td>
<td>74</td>
<td>60</td>
<td>Y</td>
</tr>
<tr>
<td>Iringa</td>
<td>Mufundi</td>
<td>Mgololo Health Center</td>
<td>Lower</td>
<td>61</td>
<td>11</td>
<td>57</td>
<td>N</td>
</tr>
<tr>
<td>Iringa</td>
<td>Mufundi</td>
<td>Mlangali Health Center</td>
<td>Lower</td>
<td>91</td>
<td>22</td>
<td>50</td>
<td>N</td>
</tr>
<tr>
<td>Tabora</td>
<td>Igunga</td>
<td>Igunga Hospital</td>
<td>Higher</td>
<td>141</td>
<td>51.8</td>
<td>68.5</td>
<td>Y</td>
</tr>
<tr>
<td>Tabora</td>
<td>Igunga</td>
<td>Choma Health Center</td>
<td>Higher</td>
<td>62</td>
<td>56.5</td>
<td>68.6</td>
<td>Y</td>
</tr>
<tr>
<td>Tabora</td>
<td>Igunga</td>
<td>Simbo Health Center</td>
<td>Lower</td>
<td>57</td>
<td>12.3</td>
<td>28.6</td>
<td>Y</td>
</tr>
<tr>
<td>Tabora</td>
<td>Igunga</td>
<td>Ziba Dispensary</td>
<td>Lower</td>
<td>51</td>
<td>19.6</td>
<td>60.0</td>
<td>N</td>
</tr>
<tr>
<td>Tabora</td>
<td>Nzega</td>
<td>Nzega Hospital</td>
<td>Higher</td>
<td>183</td>
<td>27.3</td>
<td>78.0</td>
<td>Y</td>
</tr>
<tr>
<td>Tabora</td>
<td>Nzega</td>
<td>Itobo Health Center</td>
<td>Higher</td>
<td>93</td>
<td>29.0</td>
<td>70.4</td>
<td>Y</td>
</tr>
<tr>
<td>Tabora</td>
<td>Nzega</td>
<td>Mwanhala Dispensary</td>
<td>Lower</td>
<td>48</td>
<td>8.3</td>
<td>25.0</td>
<td>N</td>
</tr>
<tr>
<td>Tabora</td>
<td>Nzega</td>
<td>Ndala Mission Hospital</td>
<td>Lower</td>
<td>106</td>
<td>22.6</td>
<td>54.2</td>
<td>Y</td>
</tr>
</tbody>
</table>

Source: Deloitte and Elizabeth Glaser Pediatric AIDS Foundation program monitoring data, 2017

¹ Facilities were defined as high- or low-performing based on their relative performance in comparison with other facilities in the district. High-performing facilities had a relatively higher proportion of adolescents on ART, with viral load tests, and retained in care than low-performing facilities.
Data collection and study population

The qualitative portion of this study consisted of IDIs and FGDs. IDIs were held with adolescents (ages 15–19 years) living with HIV and their caregivers (parents/guardians), as well as with policymakers at the national and regional levels. FGDs were conducted with adolescents living with HIV who were participating in teen clubs, and with healthcare providers working in the study facilities. Staff from each selected facility assisted the study team in recruiting study participants. The study was undertaken in facilities operating under the northern zone of the Boresha Afya (“Improving Health”) program—a USAID-funded program working to control the HIV epidemic in Tanzania.

Interviews and focus group discussions were conducted between June 25 and July 24, 2018. Data collection was carried out by a team of interviewers and facilitators with experience in qualitative interviewing and facilitation techniques and working with adolescents. The team received training on relevant topics, including qualitative research techniques (refresher), study aims and objectives, screening and recruitment of study participants, ethics for research with human subjects, data management, and quality assurance procedures. They were also oriented on skills for interviewing vulnerable populations, including issues to consider when interviewing adolescents living with HIV.

Each IDI lasted about one hour. FGDs were longer—the longest lasted 3 hours, 19 minutes. Whenever possible, interviews and group discussions were undertaken in places that offered visual and audio privacy, such as rooms in the facility. Interviews with policymakers were mostly held in their offices. In some cases, no space was available, and interviews were conducted outdoors (e.g., in project vehicles or under a tree), with specific outdoor locations selected keeping privacy and confidentiality in mind.

IDIs: Adolescents and caregivers. Overall, 164 interviews were held—64 with adolescents living with HIV and 64 with caregivers (half in each study region). Adolescent IDI participants were identified from the clinical records of each facility. Adolescents who were interviewed were asked to bring their parents or guardians, 64 of whom were also interviewed. Facility staff contacted adolescents and caregivers—either via phone call or during home-based care—to invite them to participate in the study and, if they were interested, to schedule a time to come to the facility to meet the interviewers, be consented/assented, and be interviewed (if they agreed to participate). Originally, HP+ intended to conduct half of the interviews with adolescents who acquired HIV before 10 years of age and half with adolescents who acquired HIV later in life. However, for many respondents, it was impossible to ascertain age at infection. Many adolescents did not know how old they were when they contracted HIV, as HIV-positive status is often not disclosed to children and adolescents until they are older. Health facility records, which may contain this information, were not available to the study team.

Adolescent FGDs. The study team conducted eight FGDs with 48 adolescents—two FGDs in each district (one with female adolescents and one with male adolescents). Each discussion group included six adolescents. The recruitment process for FGDs resembled the process used for IDIs, except that adolescents were selected from a list of teen club members at each facility.

Healthcare provider FGDs. The team held eight FGDs (two in each district) with 59 healthcare providers. Four healthcare providers were selected from each facility. Providers were
invited to participate in the FGDs if they were working at the HIV clinic (CTC) in one of the study facilities and providing care to adolescents.

**Policymaker IDIs.** The study team held interviews with 17 policymakers and program managers involved in HIV care and treatment and influential in drafting, amending, or implementing policies and guidelines—11 at national level, four in the Iringa region, and three in the Tabora region. Policymakers were identified by the study team based on personal contacts received from the research team and co-investigators.

**Ethical considerations**

Before fieldwork began, ethical approval for the protocol, instruments, and all study procedures was obtained from institutional review boards in Tanzania and the United States. In Tanzania, ethical approval was obtained from the National Health Research Ethics Committee of the National Institute for Medical Research, the Commission for Science and Technology, and the Mbeya Medical Research and Ethics Committee. In the United States, ethical approval was received from Health Media Labs institutional review board. In addition, permission to conduct research activities in the respective regions and districts was obtained from the President’s Office–Regional Administration at Local Government. All study activities adhered to international and Tanzania guidelines governing research with human subjects and prioritized the privacy, confidentiality, and safety of all research subjects.

Before the start of each interview or FGD, the informed consent script (in Kiswahili) was read to participants. The script described the study and included all pertinent information about their rights as research subjects. Participants were then given the opportunity to ask questions. Those who agreed to participate acknowledged their agreement by signing the informed consent form. Under-age participants signed a similar informed assent form and their adult parent or guardian signed the consent form. FGD participants were consented/assented individually, not in the group setting, to avoid peer pressure to participate. After participants and caregivers signed consent/assent forms, they received a copy of the informed consent/assent script, which included phone numbers to call in case they had questions or concerns.

IDIs and FGDs were conducted in locations where the conversation could not be observed or overheard, and where interruptions were minimized. Transcripts included no information that could identify an individual respondent.

**Analysis**

All IDIs and FGDs were conducted and audio recorded in Kiswahili, then transcribed directly into English. Trained research team members verified the transcripts against the original recordings to ensure that the transcriptions and translations were accurate. Transcripts were then uploaded to the ATLAS.ti (version 7.0) software for analysis.

Data analysis began by developing an a-priori codebook, comprising preset codes derived from questions in the question guides. The preliminary codebook was used by eight research team members to code a single transcript. The coders then compared the assigned codes under similar text segments and resolved any disagreements, proposed new codes, and refined or merged the preset codes. This process was repeated three times, until there were minimal or no disagreements in the understanding and application of the codes. This process was repeated for
every interview category. The finalized codes were used to code the remaining transcripts. The coding process was immediately followed by synthesis of the coded data materials, guided by the key research questions. Data analysis also involved exploration of any potential differences in responses based on participants’ background (e.g., Tabora vs. Iringa regions, males vs. females, high-performing vs. low-performing facilities).

The HP+ analysis focused specifically on barriers to and enablers of viral suppression and successful transition to adult care. Results of adolescent IDIs and FGDs are presented jointly, as this analysis does not distinguish between results from these two sources. HP+ analyzed the data of female and male participants, and of participants from high- and low-performing facilities, jointly—only pointing out significant differences when observed.
Results

Policymaker Perspectives

The presentation of results begins with insights garnered from policymaker interviews. Policymakers’ observations describe the current policy environment, providing a backdrop against which to discuss our findings. The qualitative portion of this study included IDIs with 17 policymakers and program managers: 11 at the national level, four in the Iringa region, and three in the Tabora region. Respondents included regional and district AIDS control coordinators, as well as department heads and program officers in positions that support pediatric and adolescent HIV care. Interviewees were asked to share their perceptions of the current state of adolescent HIV care in Tanzania and their suggestions for how it could be improved.

Policymaker interviews established that, although Tanzania has no national guidelines dedicated to adolescent care, issues related to adolescent HIV care are integrated into the National Guidelines for the Management of HIV and AIDS (MOHCDGEC, 2017). However, these guidelines focus on the physical aspects of care and treatment and do not sufficiently address other issues in adolescent care, such as the importance of involving adolescents in their own care. Twelve policymakers acknowledged this weakness in the guidelines as a gap, recognizing that adolescents may need to be treated differently than adults or children. Specifically, policymakers identified age of consent as a barrier to care. Like children, adolescents require parental consent for medical treatment until they reach the legal age of consent (18 years). Adolescents can be given information and education but cannot receive care without parental consent. Yet, some adolescents below 18 years of age are capable of making their own care decisions and need to be involved in their own care.

“On my side, the biggest challenge I see when trying to provide services to adolescents is on some of the existing policies, which are somehow discriminative against adolescents. For example, we were told that anybody below the age of 18 [years] is a minor. There are issues of consenting towards some of these services, including testing, or providing other services, where an adolescent need to come with a parent or a guardian, so that the issue of consent is adhered to. That is a challenge in terms of policy.”

—National-level policymaker

Policymakers identified the lack of guidelines on transitioning adolescents to adult care as an important policy gap. Some policymakers had ideas about how transition should be approached; others were less clear. Overall, their views did not present actionable recommendations.

“The great challenge is that you find most of the adolescents don’t like it. You make a lot of efforts to educate them, but you find that they are going to adult clinic out of their will. They wish to continue attending the adolescent clinics and this makes us worry regarding their adherence. They can decide to stop using medications, something which is very bad.”

—District-level policymaker
Policymakers at the national level reported that there are currently efforts underway to address this gap by developing a standard operating procedure to guide healthcare providers in transitioning adolescents to adult HIV care. To design these guidelines, however, policymakers noted that they need more information than is currently available to them.

“We need to know what are the challenges that the healthcare providers face as they prepare the adolescents for transition. So, before we get this SOP, we need to hear from those who have ever succeeded in preparing the adolescents for transition into adult model of care. We think of two years before transition, but who knows? Through their experience, they may recommend four years back. We have to know on how to prepare them.”

—National-level policymaker

Although policymakers were not asked to recommend a specific age for transition, seven interviewees suggested that transition should occur at 18 years of age, since this is the legal age of emancipation in Tanzania. However, policymakers emphasized that the transition process should be gradual and should involve sufficient preparation of adolescents. They also mentioned preparation in relation to adult clinics, recommending that adult clinics should prepare to receive transitioning adolescents to ensure that they are able to meet their needs.

“Providers should introduce the issue of transition to these adolescents as they age, telling them that they will move from adolescent to adult or from pediatric to adolescents, so it should be a continuous process.”

—National-level policymaker

While policymakers acknowledged the need for guidelines on adolescent care, some suggested that transition counseling should be tailored to individual adolescents and that such tailoring is more important than following standard guidelines.

With respect to viral load testing and viral suppression, policymakers recommended that providers should follow current testing guidelines and that adolescents should be educated about the importance of adherence to medication, viral load testing, and the benefits of viral suppression.

“There is a guideline, when an adolescent attends clinic and if the time of getting viral load test has reached, they will be tested.”

—District-level policymaker

“I wish to provide them a message on how they are doing with their treatment. The message should let them know that this test shows how right are the treatments they receive. [...] They should know that the test proves how right is the treatment they get, so that even if you educate them on that message, it may be easy for them to understand to what extent is their treatment right. Then they should be told on what to do so that they may have good results regarding medication adherence. That it is not only by taking the medications, but taking them correctly, and not getting involved in unprotected sex that can predispose them to getting new infections.”

—District-level policymaker
Policymakers also commented on the issue of disclosure. Some saw nondisclosure as a challenge to reaching viral suppression.

“The biggest problem is that many adolescents do not get early disclosure. The challenge that we see in our setting is that many children use medication without knowing why and many parents believe their children use medication properly. It is possible that a child started to use medication when they were 3/4/5/6/7 years old, when they reach 8/9/10 years old they start to get tired, some of them avoid taking medication and many things start to happen as you know, adolescents have their issues, like one asking oneself, ‘Why I am using medication without knowing?’, etc. A mother might think that her child is taking medications well because they are matured and be confident about it only because they (the child) visits the clinic every month to get their medication while in reality, the child isn’t doing what is required. But also, the child is not disclosed to their condition and many other challenges, so the biggest issue is poor adherence to medication and disclosure issue, and many when you test them, you find the viral load is still high.”

—District-level policymaker

When asked what he hoped would result from the updated national treatment guidelines, one respondent said:

“Regarding treatment, the clients are not delayed being started on treatment. This is the first good thing. The second thing is disclosure the adolescents, one should at least be told about his HIV status earlier. This enhances good management unlike delaying to tell them about it. I see there have been more improvement on the treatment aspect.”

—District-level policymaker

Viral Load Testing and Viral Suppression

This section includes results relating to viral suppression and viral load testing, beginning with results of the quantitative analysis.

Quantitative results

Our analysis included 15,483 children, adolescents, and young adults (0–24 years) living with HIV who started ART at or before 19 years of age, had been on ART for at least six months, and were accessing ART at MDH-supported facilities in one of three districts in the Dar es Salaam region (Ilala, Kinondoni, and Temeke). Around 57% were female. All 15,483 were eligible to receive a viral load test. However, only 9,937 (64.2%) had at least one viral load test in the facility records. Table 2 shows the demographic and clinical characteristics of those who were tested, compared to those who were not, as well as a logistic regression analysis of the association between these demographic and clinical characteristics and having been tested. The dependent variable was coded one if tested, otherwise it was coded zero.
## Table 2. Demographic and Clinical Characteristics Associated with Viral Load Testing (n=15,483)

<table>
<thead>
<tr>
<th>Characteristic</th>
<th>Viral Load Test Uptake</th>
<th>Odds Ratios of Having At Least One Viral Load Test</th>
</tr>
</thead>
<tbody>
<tr>
<td></td>
<td>Eligible¹</td>
<td>Tested (%)</td>
</tr>
<tr>
<td><strong>Sex</strong></td>
<td></td>
<td></td>
</tr>
<tr>
<td>Female (56.7%)</td>
<td>8,775</td>
<td>63.0</td>
</tr>
<tr>
<td>Male (43.3%)</td>
<td>6,708</td>
<td>65.7</td>
</tr>
<tr>
<td><strong>Age at ART Initiation</strong></td>
<td></td>
<td></td>
</tr>
<tr>
<td>&lt;1 year</td>
<td>1,303</td>
<td>59.2</td>
</tr>
<tr>
<td>1–9 years</td>
<td>6,976</td>
<td>66.5</td>
</tr>
<tr>
<td>10–14 years</td>
<td>3,486</td>
<td>65.7</td>
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<tr>
<td>15–19 years</td>
<td>3,718</td>
<td>60.0</td>
</tr>
<tr>
<td><strong>Age at Last Clinical Encounter⁴</strong></td>
<td></td>
<td></td>
</tr>
<tr>
<td>0–4 years</td>
<td>1,603</td>
<td>38.9</td>
</tr>
<tr>
<td>5–9 years</td>
<td>2,814</td>
<td>60.2</td>
</tr>
<tr>
<td>10–14 years</td>
<td>3,497</td>
<td>71.6</td>
</tr>
<tr>
<td>15–19 years</td>
<td>4,126</td>
<td>71.6</td>
</tr>
<tr>
<td>≥20 years</td>
<td>3,443</td>
<td>70.7</td>
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<tr>
<td><strong>Point of Entry into HIV Care</strong></td>
<td></td>
<td></td>
</tr>
<tr>
<td>PMTCT⁵</td>
<td>1,229</td>
<td>59</td>
</tr>
<tr>
<td>VCT⁶</td>
<td>6,352</td>
<td>64.7</td>
</tr>
<tr>
<td>PITC/OPD/IPD⁷</td>
<td>2,666</td>
<td>69</td>
</tr>
<tr>
<td>Other⁸</td>
<td>1,416</td>
<td>61.7</td>
</tr>
<tr>
<td>Not Documented</td>
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<td>62.6</td>
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<tr>
<td><strong>Transfer-in on ART</strong></td>
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<td></td>
</tr>
<tr>
<td>No</td>
<td>11,910</td>
<td>63.9</td>
</tr>
<tr>
<td>Yes</td>
<td>3,573</td>
<td>65</td>
</tr>
<tr>
<td><strong>WHO Stage at ART Initiation</strong></td>
<td></td>
<td></td>
</tr>
<tr>
<td>WHO Stage 1 or 2</td>
<td>6,462</td>
<td>65.8</td>
</tr>
<tr>
<td>WHO Stage 3 or 4</td>
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<td>64</td>
</tr>
<tr>
<td>Not Documented</td>
<td>515</td>
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<tr>
<td><strong>Diagnosed with Tuberculosis (TB) at ART Initiation</strong></td>
<td></td>
<td></td>
</tr>
<tr>
<td>No</td>
<td>14,385</td>
<td>63.9</td>
</tr>
<tr>
<td>Yes</td>
<td>1,098</td>
<td>68</td>
</tr>
<tr>
<td><strong>Diagnosed with TB after Six Months on ART</strong></td>
<td></td>
<td></td>
</tr>
<tr>
<td>No</td>
<td>14,606</td>
<td>63.9</td>
</tr>
<tr>
<td>Yes</td>
<td>877</td>
<td>68</td>
</tr>
<tr>
<td>Characteristic</td>
<td>Viral Load Test Uptake</td>
<td>Odds Ratios of Having At Least One Viral Load Test</td>
</tr>
<tr>
<td>---------------</td>
<td>-----------------------</td>
<td>--------------------------------------------------</td>
</tr>
<tr>
<td></td>
<td>Eligible1</td>
<td>Tested (%)</td>
</tr>
<tr>
<td>Duration on ART9</td>
<td>6-12 months</td>
<td>1,925</td>
</tr>
<tr>
<td></td>
<td>13-24 months</td>
<td>2,540</td>
</tr>
<tr>
<td></td>
<td>25-36 months</td>
<td>1,898</td>
</tr>
<tr>
<td></td>
<td>37-120 months</td>
<td>7,461</td>
</tr>
<tr>
<td></td>
<td>&gt;120 months</td>
<td>1,659</td>
</tr>
<tr>
<td>Reported Adherence</td>
<td>Good</td>
<td>14,109</td>
</tr>
<tr>
<td></td>
<td>Poor</td>
<td>837</td>
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<tr>
<td>Antiretroviral Drug (ARV) Regimen at ART Initiation</td>
<td>Tenofovir (TDF)-based</td>
<td>2,553</td>
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<tr>
<td></td>
<td>Zidovudine (AZT)-based</td>
<td>8,468</td>
</tr>
<tr>
<td></td>
<td>Stavudine (d4T)-based</td>
<td>2,459</td>
</tr>
<tr>
<td></td>
<td>Abacavir (ABC)-based</td>
<td>417</td>
</tr>
<tr>
<td></td>
<td>Protease inhibitor (PI)-containing</td>
<td>465</td>
</tr>
<tr>
<td></td>
<td>Other10</td>
<td>969</td>
</tr>
</tbody>
</table>

1 Eligible for viral load test: on ART for at least six months
2 CI indicates confidence interval
3 Reference indicates “reference group”
4 Age at last recorded visit before data extraction—for patients alive and still on ART; or age before termination event—for patients who died, were lost to follow-up, or transferred to another clinic
5 Prevention of mother-to-child transmission
6 Voluntary counseling and testing
7 PITC (provider-initiated testing and counseling), OPD (outpatient department), IPD (inpatient department)
8 Includes referred from another clinic (transfer-in), community-based testing, index testing, etc.
9 Time (in months) from ART initiation to date of data extraction or date patient dropped out of care due to loss to follow-up, death, or transfer to another clinic
10 Includes other first- and second-line combinations
HP+ found statistically significant differences between children, adolescents, and young adults who had at least one documented viral load test and those who did not. Males were significantly more likely to have a viral load test than females. Earlier ART initiation—in terms of both age and clinical stage—was positively associated with viral load testing. Those who initiated ART between 15 and 19 years of age were significantly less likely to have received a viral load test than those who started treatment before the age of 15 years. Those who started ART at a more advanced disease stage (during WHO clinical stage three or four) were less likely to have a documented viral load test than those who started treatment earlier (during stage one or two). Duration on ART had a highly significant positive association with testing—the odds of having received at least one test increased with duration on ART. Those who reported poor adherence to their medication regimen were much more likely to have received a viral load test than those who reported good adherence.

Of those tested, 6,539 (65.8%) were virally suppressed. Table 3 shows the demographic and clinical characteristics of those who were virally suppressed, compared to those who were not. The table also shows the results of the logistic regression analysis of the association between these demographic and clinical characteristics and being virally suppressed. The dependent variable was coded one if virally suppressed, otherwise it was coded zero.

As Table 3 shows, HP+ found highly significant associations between several demographic and clinical characteristics and viral suppression. Males were less likely to be virally suppressed than females. The likelihood of viral suppression increased with age of ART initiation. Not surprisingly, patients who started ART at a more advanced disease stage (during clinical stage three or four) were less likely to be virally suppressed than those who started treatment earlier (during clinical stage one or two). Likewise, patients with good treatment adherence were six times as likely to be virally suppressed as patients with poor adherence.
<table>
<thead>
<tr>
<th>Characteristic</th>
<th>Count (n)</th>
<th>Virally Suppressed (%)</th>
<th>Odds Ratios of Viral Suppression</th>
</tr>
</thead>
<tbody>
<tr>
<td></td>
<td></td>
<td></td>
<td>Tested</td>
</tr>
<tr>
<td><strong>Sex</strong></td>
<td></td>
<td></td>
<td></td>
</tr>
<tr>
<td>Female</td>
<td>5,531</td>
<td>67.9</td>
<td>Reference(^2)</td>
</tr>
<tr>
<td>Male</td>
<td>4,406</td>
<td>63.1</td>
<td>0.81(0.74–0.88)</td>
</tr>
<tr>
<td><strong>Age at ART Initiation</strong></td>
<td></td>
<td></td>
<td></td>
</tr>
<tr>
<td>&lt;1 year</td>
<td>772</td>
<td>59.8</td>
<td>0.51(0.43–0.61)</td>
</tr>
<tr>
<td>1–9 years</td>
<td>4,642</td>
<td>64.5</td>
<td>0.62(0.56–0.70)</td>
</tr>
<tr>
<td>10–14 years</td>
<td>2,292</td>
<td>62</td>
<td>0.56(0.50–0.64)</td>
</tr>
<tr>
<td>15–19 years</td>
<td>2,231</td>
<td>74.4</td>
<td>Reference</td>
</tr>
<tr>
<td><strong>Age at Last Viral Load Test</strong></td>
<td></td>
<td></td>
<td></td>
</tr>
<tr>
<td>0–4 years</td>
<td>750</td>
<td>56</td>
<td>0.56(0.48–0.67)</td>
</tr>
<tr>
<td>5–9 years</td>
<td>1,738</td>
<td>66.8</td>
<td>0.89(0.78–1.02)</td>
</tr>
<tr>
<td>10–14 years</td>
<td>2,553</td>
<td>66.5</td>
<td>0.88(0.78–1.00)</td>
</tr>
<tr>
<td>15–19 years</td>
<td>2,744</td>
<td>66.5</td>
<td>0.80(0.71–0.90)</td>
</tr>
<tr>
<td>≥20 years</td>
<td>2,152</td>
<td>69.3</td>
<td>Reference</td>
</tr>
<tr>
<td><strong>Point of Entry into HIV Care</strong></td>
<td></td>
<td></td>
<td></td>
</tr>
<tr>
<td>PMTCT(^3)</td>
<td>725</td>
<td>67.6</td>
<td>Reference</td>
</tr>
<tr>
<td>VCT(^4)</td>
<td>4,110</td>
<td>66.1</td>
<td>0.93(0.79–1.11)</td>
</tr>
<tr>
<td>PITC/OPD/IPD(^5)</td>
<td>1,839</td>
<td>66.9</td>
<td>0.97(0.81–1.16)</td>
</tr>
<tr>
<td>Other(^6)</td>
<td>873</td>
<td>65.3</td>
<td>0.90(0.73–1.11)</td>
</tr>
<tr>
<td>Not Documented</td>
<td>2,390</td>
<td>64.1</td>
<td>0.86(0.72–1.02)</td>
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<tr>
<td><strong>Transfer-in on ART</strong></td>
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<td></td>
<td></td>
</tr>
<tr>
<td>No</td>
<td>7,615</td>
<td>66.5</td>
<td>Reference</td>
</tr>
<tr>
<td>Yes</td>
<td>2,322</td>
<td>63.4</td>
<td>0.87(0.79–0.96)</td>
</tr>
<tr>
<td><strong>Disease Stage at ART Initiation</strong></td>
<td></td>
<td></td>
<td></td>
</tr>
<tr>
<td>Stage 1 or 2</td>
<td>4,249</td>
<td>68.4</td>
<td>Reference</td>
</tr>
<tr>
<td>Stage 3 or 4</td>
<td>5,442</td>
<td>63.8</td>
<td>0.81(0.75–0.89)</td>
</tr>
<tr>
<td>Not documented</td>
<td>246</td>
<td>63.8</td>
<td>0.81(0.62–1.07)</td>
</tr>
<tr>
<td><strong>TB at ART Initiation</strong></td>
<td></td>
<td></td>
<td></td>
</tr>
<tr>
<td>No</td>
<td>9,190</td>
<td>65.8</td>
<td>Reference</td>
</tr>
<tr>
<td>Yes</td>
<td>747</td>
<td>66.1</td>
<td>1.02(0.87–1.19)</td>
</tr>
<tr>
<td><strong>TB after Six Months on ART</strong></td>
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<td></td>
<td></td>
</tr>
<tr>
<td>No</td>
<td>9,319</td>
<td>65.7</td>
<td>Reference</td>
</tr>
<tr>
<td>Yes</td>
<td>618</td>
<td>67</td>
<td>1.06(0.89–1.26)</td>
</tr>
</tbody>
</table>
## Adolescent HIV in Tanzania: Factors Affecting Viral Load Suppression and the Transition to Adult Care

<table>
<thead>
<tr>
<th>Characteristic</th>
<th>Virally Suppressed</th>
<th>Odds Ratios of Viral Suppression</th>
</tr>
</thead>
<tbody>
<tr>
<td></td>
<td>Tested</td>
<td>Unadjusted Odds Ratios (95% CI)</td>
</tr>
<tr>
<td></td>
<td>Virally Suppressed (%)</td>
<td></td>
</tr>
<tr>
<td><strong>Duration on ART</strong></td>
<td></td>
<td></td>
</tr>
<tr>
<td>6–12 months</td>
<td>1,007</td>
<td>74.1</td>
</tr>
<tr>
<td>13–24 months</td>
<td>1,374</td>
<td>62.9</td>
</tr>
<tr>
<td>25–36 months</td>
<td>1,157</td>
<td>67.9</td>
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<tr>
<td>37–120 months</td>
<td>5,217</td>
<td>63.5</td>
</tr>
<tr>
<td>&gt;120 months</td>
<td>1,182</td>
<td>64.3</td>
</tr>
<tr>
<td><strong>Reported Adherence</strong></td>
<td></td>
<td></td>
</tr>
<tr>
<td>Good</td>
<td>9,267</td>
<td>68.4</td>
</tr>
<tr>
<td>Poor</td>
<td>559</td>
<td>25.4</td>
</tr>
<tr>
<td><strong>ARV Regimen at Viral Load Test</strong></td>
<td></td>
<td></td>
</tr>
<tr>
<td>Tenofovir (TDF)-based</td>
<td>2,709</td>
<td>70.1</td>
</tr>
<tr>
<td>Zidovudine (AZT)-based</td>
<td>5,286</td>
<td>63.3</td>
</tr>
<tr>
<td>Stavudine (d4T)-based</td>
<td>484</td>
<td>63.4</td>
</tr>
<tr>
<td>Tenofovir (TDF) + protease inhibitor (PI)</td>
<td>437</td>
<td>70.3</td>
</tr>
<tr>
<td>Zidovudine (AZT)+PI</td>
<td>89</td>
<td>65.2</td>
</tr>
<tr>
<td>Abacavir (ABC)+PI</td>
<td>874</td>
<td>66.9</td>
</tr>
<tr>
<td>Other8</td>
<td>48</td>
<td>62.5</td>
</tr>
</tbody>
</table>

1 Confidence interval
2 Reference indicates “reference group”
3 Prevention of mother-to-child transmission
4 Voluntary counseling and testing
5 PITC (provider-initiated testing and counseling), OPD (outpatient department), IPD (inpatient department)
6 Includes referred from another clinic (transfer-in), community-based testing, index testing, etc.
7 Time (in months) from ART initiation to date of data extraction or date patient dropped out of care due to loss to follow-up, death, or transfer to another clinic
8 Includes other first- and second-line combinations
Qualitative results

This section presents qualitative findings related to viral load testing and viral suppression drawn from IDIs and FGDs with adolescents living with HIV, IDIs with their caregivers, and FGDs with healthcare providers.

HP+ conducted 64 IDIs with adolescents living with HIV (ages 15–19 years) in the Iringa and Tabora regions and 64 IDIs with caregivers of adolescents living with HIV—half in each region. Of the adolescents interviewed, only seven had already transitioned to adult care, as study facilities generally transition adolescents to adult care when they are 19 years of or older. About half of adolescents interviewed (31) had primary education only; the rest (33) had secondary education. Around half (33) were living with their own parents, while the rest (31) lived with close relatives such as aunts, uncles, grandparents, or siblings. Most adolescents were not employed; rather, they were either studying or had just graduated from school. Some adolescents were helping with income generating activities at the family level, including small-scale farming, taking care of livestock, or helping in family businesses such as retail shops.

In addition to interviews, HP+ conducted eight FGDs with adolescents, two in each district (one with female adolescents, one with males). Each FGD included six adolescents. Participants were drawn from teen clubs at the study facilities. Adolescents participating in IDIs and FGDs had similar characteristics (see Table 4 for details on the characteristics of adolescents and caregivers participating in IDIs and FGDs).

<table>
<thead>
<tr>
<th>Characteristic</th>
<th>Adolescent IDIs (n=64)</th>
<th>Adolescent FGDs (n=48)</th>
<th>Caregiver IDIs (n=64)</th>
</tr>
</thead>
<tbody>
<tr>
<td>Region</td>
<td></td>
<td></td>
<td></td>
</tr>
<tr>
<td>Iringa</td>
<td>32 (50%)</td>
<td>—</td>
<td>32 (50%)</td>
</tr>
<tr>
<td>Tabora</td>
<td>32 (50%)</td>
<td>—</td>
<td>32 (50%)</td>
</tr>
<tr>
<td>Gender</td>
<td></td>
<td></td>
<td></td>
</tr>
<tr>
<td>Male</td>
<td>30 (47%)</td>
<td>24 (50%)</td>
<td>15 (23%)</td>
</tr>
<tr>
<td>Female</td>
<td>34 (53%)</td>
<td>24 (50%)</td>
<td>49 (77%)</td>
</tr>
<tr>
<td>Age</td>
<td></td>
<td></td>
<td></td>
</tr>
<tr>
<td>15–17 years</td>
<td>34 (53%)</td>
<td>29 (60%)</td>
<td>—</td>
</tr>
<tr>
<td>18–19 years</td>
<td>30 (47%)</td>
<td>19 (50%)</td>
<td>—</td>
</tr>
<tr>
<td>20–30 years</td>
<td>—</td>
<td>—</td>
<td>8 (13%)</td>
</tr>
<tr>
<td>31–50 years</td>
<td>—</td>
<td>—</td>
<td>37 (58%)</td>
</tr>
<tr>
<td>50+ years</td>
<td>—</td>
<td>—</td>
<td>18 (28%)</td>
</tr>
<tr>
<td>Don’t know</td>
<td>—</td>
<td>—</td>
<td>1 (2%)</td>
</tr>
<tr>
<td>Education</td>
<td></td>
<td></td>
<td></td>
</tr>
<tr>
<td>Primary</td>
<td>31 (48%)</td>
<td>—</td>
<td>—</td>
</tr>
<tr>
<td>Secondary</td>
<td>33 (52%)</td>
<td>—</td>
<td>—</td>
</tr>
<tr>
<td>Occupation</td>
<td></td>
<td></td>
<td></td>
</tr>
<tr>
<td>Small-scale farmer</td>
<td>—</td>
<td>—</td>
<td>40 (63%)</td>
</tr>
<tr>
<td>Employed</td>
<td>—</td>
<td>—</td>
<td>8 (13%)</td>
</tr>
<tr>
<td>Own business</td>
<td>—</td>
<td>—</td>
<td>13 (20%)</td>
</tr>
<tr>
<td>Other</td>
<td>—</td>
<td>—</td>
<td>3 (5%)</td>
</tr>
</tbody>
</table>
HP+ also held eight FGDs (two in each district) with 59 healthcare providers working at CTCs in our study facilities. Participants were ages 20–60 years, with a median age of 38 years. Most participants were nurses or doctors and most had at least three years of experience working with adolescents. However, only about one-third had received specific training on pediatric and adolescent HIV care. At the time of the study, some—but not all—partners were beginning to provide such training. See Table 5 for details on the characteristics of healthcare providers participating in focus groups.

Table 5. Characteristics of Healthcare Providers Participating in FGDs

<table>
<thead>
<tr>
<th>Characteristic</th>
<th>Providers (n=59)</th>
</tr>
</thead>
<tbody>
<tr>
<td><strong>Age</strong></td>
<td></td>
</tr>
<tr>
<td>20–30 years</td>
<td>17 (29%)</td>
</tr>
<tr>
<td>31–40 years</td>
<td>19 (32%)</td>
</tr>
<tr>
<td>41–50 years</td>
<td>13 (22%)</td>
</tr>
<tr>
<td>51–60 years</td>
<td>6 (10%)</td>
</tr>
<tr>
<td>No response</td>
<td>4 (7%)</td>
</tr>
<tr>
<td><strong>Position at health facility</strong></td>
<td></td>
</tr>
<tr>
<td>Nurse (working with youth)</td>
<td>26 (44%)</td>
</tr>
<tr>
<td>Medical doctor/clinical officer (youth)</td>
<td>6 (10%)</td>
</tr>
<tr>
<td>Nurse assistant</td>
<td>7 (12%)</td>
</tr>
<tr>
<td>Health assistant – peer educator</td>
<td>8 (14%)</td>
</tr>
<tr>
<td>Laboratory technician (conducting HIV tests—viral load, CD4, etc.)</td>
<td>8 (14%)</td>
</tr>
<tr>
<td>Data manager/health information staff (working with CTC data)</td>
<td>4 (7%)</td>
</tr>
<tr>
<td><strong>Years of experience</strong></td>
<td></td>
</tr>
<tr>
<td>&lt;1 year</td>
<td>1 (2%)</td>
</tr>
<tr>
<td>1–3 years</td>
<td>15 (25%)</td>
</tr>
<tr>
<td>3–5 years</td>
<td>14 (24%)</td>
</tr>
<tr>
<td>5–10 years</td>
<td>13 (22%)</td>
</tr>
<tr>
<td>&gt;10 years</td>
<td>16 (27%)</td>
</tr>
<tr>
<td><strong>Trained in adolescent HIV care and treatment</strong></td>
<td></td>
</tr>
<tr>
<td>Yes</td>
<td>21 (36%)</td>
</tr>
<tr>
<td>No</td>
<td>30 (51%)</td>
</tr>
<tr>
<td>Non-response</td>
<td>8 (14%)</td>
</tr>
<tr>
<td><strong>Total</strong></td>
<td>59</td>
</tr>
</tbody>
</table>
**ART adherence**

Viral suppression, which is monitored using viral load testing, can only be achieved with appropriate adherence to ART. This section looks at barriers and enablers affecting ART adherence and viral load testing among adolescents living with HIV, as described by adolescents, caregivers, and healthcare providers.

All the adolescents who participated in this study were on ART at the time of their interview or focus group. Healthcare providers said that they generally give adolescents ART medications on a monthly basis. When adolescents come to the facility for a refill, they are required to bring their medication container so the remaining pills can be counted. Providers reported that their counseling sessions with adolescents are long enough to discuss the importance of adherence, assess whether the adolescent is having any difficulties taking their medication daily and on time (at home and at school), and explore ways for the adolescent to overcome barriers to ART adherence. Providers emphasized the importance of engaging caregivers in adolescents’ care and treatment, noting that caregivers’ position enables them to ensure, not only that adolescents adhere to ART, but also that they maintain good nutrition and self-care.

> “When you explain things to do to the parents and they understand well, it becomes easier for them to help their children. If the parents don’t understand, that means you are making life hard for the child. They may get side effects due to bad use of medication, poor nutrition and their progress in general.”
> —FGD, healthcare provider

Adolescents reported using a variety of techniques to remember to take their medication. Those most frequently mentioned were having caregivers remind them, using a mobile phone alarm or an alarm clock, and associating medication with mealtimes. Less frequently reported methods included receiving an SMS message reminder from the clinic and being reminded by a peer educator or a friend.

> “My mother reminds me. She wakes me up in the morning and tells me it is time to take my medication.”
> —IDI, female adolescent, 18 years old

> “I have a wall clock. It reminds me at seven o’clock. Alternatively, I use the alarm on my phone. At seven, it sounds. Then I know it is already time.”
> —IDI, male adolescent, 19 years old

Although many adolescents had been on treatment for a long time, they still reported occasionally forgetting to take their medication—mentioning various reasons for these lapses. While some of these reasons were circumstantial, others happened because of a disruption in adolescents’ routine.

> “There was a day I went to my aunt, and we were late in coming back. So, we had to sleep over and I had not taken the medication with me.”
> —IDI, male adolescent, 19 years old
Several adolescents reported not taking their ART medication for longer periods at some point in their lives. Adolescents mentioned several reasons for these longer lapses in adherence, including fear of disclosure, running out of stock while traveling, lack of support, feelings of loneliness, and lack of perceived improvement while on medication.

“Several adolescents reported not taking their ART medication for longer periods at some point in their lives. Adolescents mentioned several reasons for these longer lapses in adherence, including fear of disclosure, running out of stock while traveling, lack of support, feelings of loneliness, and lack of perceived improvement while on medication.

“I was staying at the place where there were many students. Then you could find that we are telling stories and I forget to take the medications.”

—IDI, female adolescent, 17 years old

“I just didn’t have someone to take care of me and to encourage me. Someone to even tell me to go with my medication to Dar-es-salaam. I had gone for work. Then life was hard, things did not work out well. I did not even remember to go for medication. I did not even take my transfer card for the medication.”

—IDI, female adolescent, 18 years old

“They fear they will lose their respect in the streets if they are discovered to be taking medication.”

—FGD, male adolescent

Caregivers mentioned additional challenges affecting adolescents’ ability to take ART medication as prescribed, including stigma (both at the family level and in institutions such as schools) and economic hardship—which meant adolescents had limited access to food and had to take medications on an empty stomach.

“When you look at him, you find that he receives the services with hardship. Taking the medication where he is, he is not free; he is looking around to see who is present, and he fails to be open. He is still afraid. Even where we stay, because I have many children, when he comes, he waits until all of his fellows have left, and then he goes and takes the medication.”

—IDI, female caregiver

“But I think these medications need someone to eat well and most schools serve breakfast at 10am, and if someone needs to take the medication at 6am it’s a very long time to wait, and instead of the medication causing relief, they cause suffering.”

—IDI, female caregiver

Adherence to ART may depend on keeping clinic appointments. Most adolescents and caregivers reported that they are able to keep their appointments and that clinic hours generally work well with their schedules, especially in clinics with Saturday hours. However, respondents reported that sometimes clinic schedules conflict with weekend school activities.
Adolescent HIV in Tanzania: Factors Affecting Viral Load Suppression and the Transition to Adult Care

“...on other Saturdays, we are told to go to school. Therefore, you decide not to go to school so that you can come to the clinic.”

—IDI, female adolescent, 18 years old

Adolescents gave several reasons for missing clinic appointments, including forgetting about the appointment, not wanting to be seen attending the HIV clinic, not having money for bus fare, and having scheduling conflicts with school or work. Stigma appears to be a significant barrier to clinic attendance and treatment adherence. When asked about why their peers miss clinic appointments, the reason most commonly mentioned by adolescents was peers’ not wanting to be seen attending HIV care. Caregivers confirmed the reasons for missing appointments mentioned by adolescents, adding that, when adolescents miss an appointment, caregivers sometimes pick up medications on their behalf.

“Some fear that if they come to a place like this, someone living in the same neighborhood may see them and spread the news and discriminate against them. Their fear may extend to a point whereby if they walk in the streets, they may be nervous that someone is talking behind their back.”

—FGD, female adolescent

“The first thing is the family where this person comes from. If the family stigmatizes this person, definitely this person will be depressed...They can even give up coming to the clinic...There should be providers who move around and visit these people, even once per week, to encourage them. The people surrounding this patient will learn to do this gradually as well, and later it will be okay. You find that you are just coming to the clinic to take medication and go away without receiving any advice. When you go back home, and you come across such things it makes you give up.”

—IDI, male adolescent, 19 years old

Neither adolescents nor caregivers cited stockouts or provider attitudes as reasons for not going to the clinic. Some adolescents mentioned that their peers sometimes stop going to the clinic when they feel better—they do not see any reason to continue to visit the facility when they do not feel sick.

“When they look at themselves, they see themselves as healthy, and they don’t even look sick. They say, ‘First of all, I am not sick, what am I going to do at the hospital?’”

—FGD, female adolescent

Ways of keeping track of appointments most commonly mentioned by adolescents include looking at their clinic cards—where the date of their next scheduled clinic visit is usually written—and counting their remaining ART medication. If they only have few pills remaining, they know their appointment must be soon. Some adolescents reported writing the date of their next appointment in a diary or a physical calendar. Few reported using a phone (theirs or their parents’) to keep track of appointments.

Adolescents and healthcare providers had conflicting perceptions about providers’ level of engagement with appointment reminders. From the adolescent perspective, it seems that providers do not sufficiently follow up with appointment reminders. Few adolescents (mostly
female) reported being reminded of appointments by healthcare providers or peer educators. However, healthcare providers reported following up on adolescents who miss their appointments, by calling their caregivers or the leaders of their teen clubs (for those who participate). According to providers, some clinics use outreach workers working in the area to follow up on adolescent clients. All facilities reported collecting clients’ contact information (home addresses and phone numbers [of adolescents and/or their caregivers]) so that they are able to follow up on them. Adolescents appear to appreciate it when they are contacted by healthcare providers.

“When you come here you must write down your chairman and the place where you live... When they see that I have stayed away for too many months, they will follow your chairman. And there is a nurse who deals specifically with following up with adolescents who take medication. So, she usually knows, and she goes to their home to see how they are doing...”

—FGD, female adolescent

Good quality of care can be an important enabler of treatment adherence. Adolescents identified good quality of care as a factor in their coming to the clinic for services. They emphasized privacy and confidentiality, both during and after being seen by providers, as important considerations. They suggested that reimbursing some of their transportation expenses would facilitate adolescents’ clinic attendance, as transportation costs can be prohibitive for adolescents who live far from the facility. Similarly, adolescents appreciated getting lunch at the facility, a practice that some facilities include as part of their adolescent services. Healthcare providers also recommended that adolescents be offered food or an allowance, regardless of whether they were attending the adolescent or the adult clinic, because they may live far from the facility.

“When the services are good, the adolescents will be attending every day.”

—FGD, male adolescent

“We appreciate, now that they are moving village to village to provide medicine, because you find someone walking for 30km when they are hungry. So, giving them food will help and encourage them. Even water is appreciated.”

—FGD, healthcare provider

**Understanding viral suppression**

Understanding what it means to be virally suppressed, as well as the health and lifestyle advantages of viral suppression, can be an important enabler of obtaining viral load testing. Overall, although some adolescents did not know the meaning or implications of being virally suppressed, both adolescents and their caregivers appeared to have a good understanding of viral suppression. They correctly described being virally suppressed as having low levels of HIV or inactive/suppressed viruses in the blood. When asked how one becomes virally suppressed, almost all adolescents and caregivers said that viral suppression results from the proper use of ART medications.
“When you adhere to medication, the viruses get suppressed. When you stop, the viruses get strong and it brings you problems.”

—FGD, female adolescent

“They told us when you take medication, viruses run to the glands and they become weak and sleep. They cannot attack due to immunity [immune suppression].”

—IDI, male adolescent, 19 years old

Many adolescents and caregivers associated viral suppression with clinic attendance because visiting the clinic is the only way for them to access ART medications. However, some caregivers pointed out that clinic attendance, on its own, does not lead to being virally suppressed. Instead, being virally suppressed also requires taking ART medications as directed by clinicians.

“Going to clinic without adhering to medication will not make someone to be virally suppressed. So, there must be a person to make close follow ups that you are taking the medication after coming from the clinic.”

—IDI, female caregiver

Awareness of the prevention benefits of viral suppression was limited among adolescents and caregivers. While several adolescents and caregivers recognized that viral suppression reduces the chance of transmitting HIV to others, this awareness was not common. Moreover, there was no recognition that being undetectable could prevent sexual transmission of the virus. However, many adolescents and caregivers did mention that viral suppression leads to better health, longer life, and higher energy levels.

“Because, the one whose viruses are not suppressed, they [viruses] can spread at any time to any location, but, the one whose virus are suppressed, it becomes difficult for the person to spread and receive because their immunity [immune system] is stronger.”

—IDI, male adolescent, 19 years old

“Because, as I said earlier, they become healthier, charming and happy, and can cooperate with the society to do developmental activities.”

—IDI, female caregiver

Healthcare providers echoed these sentiments about the health benefits of viral suppression. They noted that viral suppression leads to longer life, fewer opportunistic infections, and increased ability to participate in economic activities at the community level. For pregnant women living with HIV, viral suppression reduces HIV risk faced by the unborn child—this advantage of viral suppression was only mentioned by healthcare providers. None of the providers mentioned the benefits of viral load suppression for preventing horizontal sexual transmission.

Almost all adolescents and caregivers described viral suppression in terms of its advantages. The only disadvantage mentioned was that people may to stop taking their medication once they learn that they are virally suppressed because they perceive themselves to be healthy. None of the respondents mentioned the risk of ART resistance as something to be considered when stopping treatment.
“I can say that the disadvantage of viral suppression is, when you stop taking medication.”

—IDI, male adolescent, 19 years old

Healthcare providers also expressed concern that adolescents might stop treatment once they are virally suppressed. To minimize this risk, providers explained that they emphasize to clients the need to continue taking their medication after they become virally suppressed.

“For someone, if you tell them that way, they would think they are healed and become lazy on taking medicines.”

—FGD, healthcare provider

As for being “undetectable,” many adolescents had a good grasp of the term’s meaning, some had not heard of it, and others had an incorrect understanding of the term. A few adolescents confused being undetectable with being cured, but most understood the difference.

“I heard it’s when they test the blood for HIV and don’t see anything.”

—FGD, female adolescent

“Being undetectable means a person has adhered to medication until maybe no longer infected and all the HIV is gone, while viral load suppression means viruses are suppressed but they are still there, and a person has to adhere to medication lest they become active again.”

—IDI, male caregiver

Caregivers were less informed about the concepts of viral suppression and being undetectable than their adolescent children. Some did not believe that HIV can actually be undetectable. Others linked the concepts to religious beliefs about healing HIV through prayer. Yet others believed myths and misconceptions about viral suppression. One parent even thought that being undetectable was a disadvantage.

“...some say that if someone drinks a lot of alcohol, ‘they’ [the viruses] get drunk a lot, so being detected is not easy. They are barely seen, those are the ones termed as suppressed.”

—IDI, female caregiver

“We have heard of it, but I always disagree to it. We were once told that, ‘Your fellows have tested, and viruses are not there.’ I always disagree.”

—IDI, female caregiver

“There aren’t any benefits of being undetectable with virus because people think that they have recovered. So, there is not any benefit, instead it’s a loss.”

—IDI, female caregiver

Overall, adolescents and caregivers in higher performing districts had a better understanding of viral suppression, including the concept of being undetectable, than their counterparts in lower
performing districts. Male and female adolescents had a similar grasp of these concepts; no significant differences based on sex were observed.

**Viral load testing**

More than half of adolescents interviewed reported having heard the term “viral load testing,” although some incorrectly referred to viral load testing as “CD4 testing.” Adolescents receiving care in higher performing facilities and districts had greater awareness and understanding of viral load testing than those in lower performing facilities and districts. In one FGD held in a lower performing district, participants had either not heard of viral load testing or did not know what it meant.

Adolescents and caregivers observed that facilities offer viral load testing free of charge. They did not perceive viral load testing to be either time consuming or inconvenient. They did, however, identify several barriers to viral load testing, of which the most commonly mentioned was delayed delivery of test results. Sometimes, they observed, getting viral load test results takes so long that adolescents are asked to take another test before they have received the results of the earlier one. Adolescents and caregivers also reported instances where their initial sample coagulated before being processed. These observations were echoed by healthcare providers.

“There was a day I wanted to refuse, because they tested me last month and they wanted to test me in the coming month ... I didn’t get the previous results and they want to test again, getting injection frequently.”

—IDI, male adolescent, 19 years old

“I remember, sometime back, we took several blood samples and the results never came back until today. So, there are some patients who think negatively already. Whenever blood samples are taken from them, they will comment that we are taking their blood samples, but they won’t know the results for the tests. Such comments are disheartening to us too because it is true that when the blood samples don’t return, we are the ones to blame and they lose hope with this.”

—FGD, healthcare provider

Adolescents and caregivers commonly identified fear of test results as a reason for adolescents to avoid viral load testing. They explained that some adolescents, particularly older ones, are afraid to be told that they have a high viral load, which they perceive as being linked to poor disease prognosis. Fear of results was also identified as a common reason for avoidance of viral load testing among adolescents who are not adhering to their ART regimens. Conversely, adolescents who are adhering to their treatment regimens sometimes do not see a need for viral load testing, because they are in good health. Some adolescents perceive healthcare providers as only requesting viral load tests for sick individuals.

“Others don’t have a good adherence to medications, so they are afraid that if they go and get tested they will be found with many viruses.”

—IDI, male adolescent, 16 years old
“In many cases, the people taking the tests are those who are frequently ill. They will be the ones to go take the tests.”

—FGD, female adolescent

Other barriers mentioned, although rarely, by adolescents and caregivers included poor quality of care, unavailability of viral load testing, lack of awareness of viral load testing, and fear of injections. A few adolescents and caregivers said that some adolescents do not get viral load tests because of long queues for the test at their facilities. This observation was echoed by healthcare providers.

“...currently there is testing for viral load. I tell him, ‘Go and get tested.’ He says he has gone and there are too many people, ‘So, mother, I wasn’t tested.’”

—IDI, female caregiver

Healthcare providers identified additional reasons for adolescents not taking viral load tests. They reported that some providers are negligent and do not order the test for their clients. They also observed that, instead of coming to the facility themselves, many clients send others to collect their medication, which means that there is no opportunity for providers to test their viral loads.

Both adolescents and their caregivers reported that clinics encourage them to take viral load tests by educating them about the importance of the test. Specifically, they said providers told them that viral load testing helps increase ART clients’ awareness of how well they are doing and whether their treatment is working. In addition, some facilities were reported as putting up billboards about the availability of viral load testing.

“To tell the truth, every time we attend [clinic], they try to speak on this. They say, ‘People, let us test and ascertain the viral count and our progress.’ I doubt if any at all have not heard, since even on your attendance day, they start by speaking of this.”

—IDI, female caregiver

**Participant suggestions for improving rates of viral suppression**

Adolescents, caregivers, and healthcare providers gave specific suggestions about how to promote viral load testing and improve rates of viral suppression among adolescents. These suggestions are listed below, even though some relate to measures that are already in place. For example, #7 below refers to the time of day at which ART medications are taken. This should not be an issue because ART medications can be taken at any time of day. However, respondents perceived this as a problem. Some participant suggestions have clear programmatic implications, while others do not.

1. Ensure that all facilities offer viral load testing and have the equipment needed to provide it.
2. Ensure that facilities always have adequate supplies of medications, as stockouts lead to missed doses or to a change in treatment regimens. Adolescents mentioned that they do not like to switch antiretroviral drug (ARV) regimens because it takes their bodies time to get used to the new medications.
“They [HIV program] should make sure ARVs are available all the time. When ARVs are available, people will take them, and hence achieve viral suppression.”

—IDI, male adolescent, 19 years old

3. Improve facility and health system procedures to reduce long lines and expedite delivery of test results. For example, install testing machines in all health centers and allow healthcare providers to see results of earlier tests, not just the latest one, ideally in a dedicated database.

4. Make certain that providers:
   - Convey to adolescents the importance of viral load testing and treatment adherence, including making sure that adolescents understand the purpose and utility of viral load testing and the importance of viral suppression
   - Offer adolescents more education to improve their understanding of ART and medication usage (i.e., treatment literacy)
   - Address beneficiaries’ worries about test results and their fear of injections
   - Educate adolescents about risky behaviors, and how to avoid them

“It [HIV program] should provide education to adolescents. Many adolescents are not willing to use medication. They have that attitude, so, more education on medication usage should be provided.”

—IDI, female adolescent, 16 years old

5. Improve quality of care, including ensuring appropriate provider attitudes and safeguarding privacy and confidentiality. To achieve this, providers recommended increasing the number of facility staff. Providers also requested additional training, as some of them had never been trained in caring for adolescents living with HIV.

“Health programs should keep on supporting the staff and give them different skills on how to educate and help adolescents psychologically so that they can have a good adherence to medicines.”

—FGD, healthcare provider

6. Create teen clubs or support groups in facilities where these are not yet available, as such groups were deemed useful for improving adolescents’ overall well-being, as well as providing a good venue for educating adolescents about treatment adherence, viral load testing, and viral suppression. Providers also mentioned the economic skills learned in these groups, which give adolescents important skills and a little capital which can make it easier for them to adhere to their treatment regimens.

“Mostly, they have topics which they teach their fellows, like how to live, how to take medications and also things about meals, so, there are a lot of things they talk about with them.”

—FGD, healthcare provider
7. Prescribe to adolescents ART medications that can be taken in the evening, rather than during the day, because when adolescents are at school they are more likely to forget to take their medication and often do not have food with which to take their medications.

8. Organize “test days” around sporting events and other activities that attract adolescents.

9. Refund adolescents the cost of transportation to the facility.

10. Involve caregivers in the conversation, rather than talking to adolescents only, especially for younger adolescents. This could reduce stigma toward adolescents at home and help adolescents better deal with the practicalities of treatment. For older adolescents and young adults (who may still be in adolescent care when they are older than 18 years), participants recommended encouraging them to make their own decisions and take greater responsibility for their care.

11. Ensure the availability in health facilities of viral load testing guidelines, including guidance on how to share viral load test results with different clients and clear instructions regarding treatment and counseling of clients with different test results. The guidelines should be written in simple language and, ideally, should be available in Kiswahili. These materials should be available to both healthcare providers and peer educators.

12. Ensure that healthcare providers receive enough airtime on their mobile phones to call clients to follow up on their clinic appointments. Although some providers receive phones from the facility for client follow-up, these phones do not always have airtime.

13. Expand community outreach activities in places where health facilities are less accessible, to enable adolescents to get viral load and other lab tests nearer their homes.

“Another thing is that the programs should keep on supporting the outreaches or the outside clinic visits, so that people would continue to receive lab services and medications nearer to where they are.”

—FGD, healthcare provider

“I suggest being supported in transport, or the service providers should reach out to our areas. They may be bringing the medications right to my home when I cannot afford transport costs.”

—FGD, male adolescent

### Transition to Adult HIV Care

**Quantitative results**

HP+ used the Pediatric HIV Transition Model to estimate the number of adolescents who will be eligible for and actually transitioning to adult HIV care each year between 2018 and 2025. Results are shown for four scenarios, which vary by assumptions about ART coverage and age of transition (see Table 6). Scenario 1 and Scenario 2 assume that adolescents transition at 18 years of age, while Scenario 3 and Scenario 4 assume that transition behavior follows trends observed in cohort data from Baylor Tanzania’s Children’s Foundation (see Methodology section for additional details). Baylor cohort data (2014–2017) show that each year approximately 13% of 18-year-olds, 12% of 19- and 20-year-olds, 4% of 21-year-olds, 3% of 22-year-olds, and 6% of 23-
year-olds transition to adult HIV care (Baylor, n.d.). Scenario 1 and Scenario 3 assume that current trends in HIV identification, linkage to care, and retention in care continue, while Scenario 2 and Scenario 4 assume that national ART coverage targets are met.

Table 6. Scenarios Used to Estimate the Number of Adolescents Eligible for and Actually Transitioning to Adult Care, 2018–2025

<table>
<thead>
<tr>
<th>Age of Transition</th>
<th>Trends in HIV Identification, Linkage to Care, and Retention in Care</th>
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</thead>
<tbody>
<tr>
<td>Adolescents Transition at 18 Years of Age</td>
<td>Current Trends Continue</td>
</tr>
<tr>
<td>Transitions Follow Current Trends (Baylor Data)</td>
<td>Scenario 1</td>
</tr>
<tr>
<td></td>
<td>Scenario 3</td>
</tr>
</tbody>
</table>

Adolescents eligible to transition to adult care

**Scenario 1: Adolescents are eligible to transition at 18 years of age; current trends in HIV identification, linkage, and retention continue**

If Tanzania scales up ART coverage for children and adolescents in line with recent trends in identification, linkage to care, and retention in care, HP+ estimates that the number of 18-year-olds on ART will increase from 6,340 in 2018 to 9,486 in 2025—representing a 50% increase in the number of adolescents eligible to transition to adult care and treatment. Under this scenario, males represent between 35% and 38% of adolescents eligible to transition (18-year-olds on ART), depending on the year. Regions estimated to have the largest numbers of adolescents eligible for transition (percentage of 18-year-olds on ART in 2025) include Dar es Salaam (16%), Mbeya (11%), and Kagera (9%).

**Scenario 2: Adolescents are eligible to transition at 18 years of age; national targets for HIV identification, linkage, and retention are met**

HP+ also estimated the potential range in numbers on ART if coverage targets are met, taking into account underlying uncertainty about the number of people living with HIV. If national targets are met, there will be an estimated 9,727 18-year-olds on ART (i.e., eligible to transition) in 2018—representing a significant increase over 2017, due to ambitious assumptions about ART coverage increases to reach national targets by 2020. National targets assume a gradual increase in ART coverage from 2020 to 2024. As a result, the estimated number of adolescents eligible to transition increases only slightly, to 10,328, by 2025. However, given underlying uncertainty about the number of people living with HIV, the number of adolescents eligible to transition in 2025 could range from 5,264 to 13,508. Under this scenario, males represent 38% to 45% of adolescents eligible to transition, depending on the year. Regions estimated to have the largest numbers of adolescents eligible to transition (percentage of 18-year-olds on ART in 2025) include Dar es Salaam (11%), Mwanza (8%), and Tabora (7%).

Figure 2 shows the numbers of adolescents eligible to transition under Scenario 1 and Scenario 2, by year, from 2018 to 2025.
Adolescent HIV in Tanzania: Factors Affecting Viral Load Suppression and the Transition to Adult Care

Figure 2. Number of Adolescents Eligible to Transition to Adult HIV Care, by Year (Scenarios 1 and 2)

Source: HP+ calculations
Note: Percentages shown are the percentage of people living with HIV on ART. The number of people living with HIV is based on point estimate from AIM.

Adolescents expected to transition to adult HIV care
Scenario 1 and Scenario 2 assume that all adolescents transition to adult care when they are 18 years of age. In reality, however, many do not, instead continuing to receive care in adolescent services well into their adult years. As a result, fewer people are likely to transition to adult care each year than are eligible. To reflect this reality, the next two scenarios assume that age of transition follows recent trends.

Scenario 3: Age of transition follows current trends; current trends in HIV identification, linkage, and retention continue
In this scenario, the number of adolescents and young adults actually transitioning each year is estimated to increase from 3,916 in 2018 to 5,362 in 2025 if the country scales up ART coverage in line with recent trends in identification, linkage to care, and retention in care. Nearly one-fifth (17%) of those expected to transition in 2025 are predicted to live in Dar es Salaam (see Table 7).

Scenario 4: Age of transition follows current trends; National targets for HIV identification, linkage, and retention are met
In this scenario, the number of adolescents and young adults actually transitioning is estimated to decrease slightly, from 6,028 in 2018 to 5,884 in 2025. This decrease is due to high coverage levels under this scenario and slight declines in underlying estimates of the number of people living with HIV. Under this scenario, Dar es Salaam also accounts for the largest proportion (12%) of those estimated to actually transition by 2025, followed by Mwanza (9%) and Tabora (7%).
Under both Scenario 3 and Scenario 4, 20-year-olds represent the greatest proportion of those transitioning to adult care and treatment (approximately 24% each year). Table 7 shows figures for all four scenarios, by region.

### Table 7. Number Expected to Actually Transition, by Scenario, Region, and Year

<table>
<thead>
<tr>
<th>Region</th>
<th>Scenario 1</th>
<th>Scenario 2</th>
<th>Scenario 3</th>
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<td></td>
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<td><strong>Total</strong></td>
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<td><strong>9,486</strong></td>
<td><strong>9,727</strong></td>
<td><strong>10,444</strong></td>
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</table>
Preparing for the transition to adult HIV care

Ideally, providers and caregivers start preparing adolescents for transitioning to adult care and treatment well before they actually transition. Such advance preparation helps adolescents better understand why a transition is needed and gives them time to adjust to the idea of transitioning and cope with potential challenges in the transition process. The number of adolescents ages 15 to 17 years who are on ART and may need to be prepared for the transition to adult HIV care is large and expected to increase each year—from 16,215 in 2018 to 24,865 in 2025 under Scenario 3, or from 24,816 to 27,638 over the same period under Scenario 4.

Figure 3. Number of Adolescents Ages 15 to 17 Years on ART who Need to Begin Preparing for Transition, by Age and Year

Qualitative results

Qualitative results related to viral load testing and viral suppression and details of IDI and FGD participants are included in the previous section. During focus groups and interviews, participants were also asked about the transition to adult care. Healthcare providers said that they consider an adolescent’s transition to adult care to be successful if they continue taking ART medications as prescribed and attend adult clinic appointments as scheduled.

“I can know if the transition is [successful] when I see the attendances are going well, that every date that [is scheduled] is written, they come on the same date. The second thing are the tests, when they perform the tests like the viral load then I will find the number of viruses is decreasing instead of increasing and then I will know that this person is taking medications appropriately.”

— FGD, healthcare provider
Adolescent HIV in Tanzania: Factors Affecting Viral Load Suppression and the Transition to Adult Care

Adolescent versus adult HIV care

This section begins with participants’ observations about how adolescent care compares with adult care. Understanding how these models of care differ offers a clear picture of where adolescents are starting, and where they are heading, as they transition to adult care.

Study participants reported that adolescent and adult clinics are commonly (but not always) held in the same building, using the same healthcare providers and consultation rooms—although on different days of the week and offering quite different services. Usually, adult clinics operate on weekdays, while adolescent clinics are held on Saturdays. This difference may have implications for scheduling appointments, especially when clinic hours conflict with school or work. Typically, adolescents visit the facility once a month, while adults attend clinic every two or three months.

To ensure that children and adolescents receive age-appropriate counseling, many clinics separate children and adolescents into age-based groups (the age groups used varied across facilities), which attend the facility on different Saturdays. Healthcare providers reported that, when adolescents transition to adult care, they usually continue visiting the facility on a monthly basis until providers are satisfied with their ART adherence and clinic attendance. At that point, providers begin giving adolescents medications for two months, then three months, so that they can begin scheduling clinic visits every two to three months, as other adults do.

Healthcare providers also reported that adolescent clinic visits take longer than adult visits because they include group counseling and social activities in addition to time spent with clinicians. A typical Saturday adolescent visit would start at 8 a.m., with sports, followed by a group educational session, usually led by a healthcare provider with the help of peer educators. The group session would be followed by clinical activities, such as taking weight and height measurements and prescribing or dispensing ARVs, then a meal at the facility. In contrast, adult visits usually include only the clinical elements, sometimes accompanied by seminars. Where offered, these seminars are shorter than the education sessions for adolescents. Food is not offered to adults in health facilities. While this is consistent with the adolescent recommendation that food be offered when they come to the facility to be tested (see qualitative results in previous section), not all adolescents appreciated spending extra time at the facility.

“The adolescent clinic is good, but I suggest that for us who come from afar, we should be provided with services as soon as we get here so that we may return home early.”

—FGD, male adolescent

In clinics that do not have teen clubs, adolescent visits are similar to adult visits, including only clinical services.

When respondents who had already transferred to adult care were asked to compare the time they spent in adolescent and adult care, they gave mixed responses. Many said that they spent less time at the adult clinic, but this response was not universal. When the same question was posed to healthcare providers, they all said that waiting time is longer at adult clinics because they serve too many clients, which increases overall time spent at the facility—although not time spent with clinicians. Providers also reported prioritizing adolescents who have transferred to adult care by attending them first, especially in the first few weeks after they have transitioned.
“You should not make them wait for long because they are used to getting tea and food. We usually do this in the first months. If they are 20 people ahead of them, you try to put their files up so that they leave early so that they don’t hate their new services.”

—FGD, healthcare provider

When asked to comment on provider attitudes in adolescent and adult clinics, most adolescents and caregivers said that provider attitudes are similar, because both clinics are being run by the same providers. Providers, they observed, are often friendlier to adolescents because they want to build adolescents’ trust so that they will talk and ask questions more freely.

“When you talk to adolescents the same way you talk to adults, they become afraid of you and they won’t be very open. If you want to speak to an adolescent and become very open to you, then you must be like them. You act as though you are not a doctor. You become low and friendly and try to give them hope and confidentiality and when you do that, they open up and start explaining lots of things to you.”

—FGD, healthcare provider

Caregivers said that providers give more information to adolescents than to adult clients because adolescents need more information than adults, including information on bodily changes, maturing, and how HIV is transmitted. On the other hand, caregivers said that some information is given to adults only, not to adolescents—specifically, information about condom use, how to avoid sexually transmitted infections, and how to delay pregnancy through family planning. When asked about this, healthcare providers said that they do give this type of information to adolescents, but only to those who are already sexually active. Providers reported being able to identify sexually active adolescents by asking probing questions. According to providers, ART adherence and the importance of keeping clinic appointments are discussed with adolescent and adult clients equally.

“When it comes to sexual reproductive health, because we have adolescents who are students, we prefer to tell them to abstain until the right time comes, because they are still in school. For the adults we encourage them to use condoms.”

—FGD, healthcare provider

Almost all healthcare providers said that there is no difference in how they check for ART adherence among adolescent and adult clients; providers inquire in the same way and commonly count clients’ remaining pills. Providers added, however, that adults explain themselves more easily, making discussions with them straightforward in comparison with adolescents, who require more probing about challenges that affect their adherence to medication regimens.

Mostly, adolescents, their caregivers, and healthcare providers, reported that caregivers are significantly less involved in care after youth have transitioned to the adult clinic. Caregivers of younger children are required to accompany them to the facility and often remind them to take their medications on time and attend appointments. When adolescents are getting ready to transition to adult care, providers are encouraged to let their children take responsibility for remembering to take their medication and attend their appointments.
Adolescent HIV in Tanzania: Factors Affecting Viral Load Suppression and the Transition to Adult Care

“I was involved more when she was at the adolescent [clinic] because she was young. Now, they involve me less because she is more capable.”

—IDI, female caregiver

Some caregivers of adolescents who had already transitioned to adult care reported feeling relieved that they no longer need to attend clinics with their children. However, almost all said that they still assist their children with remembering to take medications and attending clinic appointments—and plan to continue doing so.

“The adult clinic is better than the adolescent one because she is the one who goes to take her medication. Previously, when she was in adolescent clinic, I was getting a bit disturbed as I was also having a young baby to nurse.”

—IDI, female caregiver

“As long as I live with her, I will just crosscheck in her card the date and remind her.”

—IDI, female caregiver

Adolescents highlighted interactions with other clients as an important difference between adolescent and adult care. When visiting facilities on adolescent days, they said, other youth are often friendly. This is unsurprising, especially in clinics where adolescents participate in teen clubs together. In contrast, adult clients do not talk freely and are not open about their HIV-positive status. As a result, adolescents feel more comfortable attending clinic with other adolescents.

“For the adults, it is as if there has been a fight such that everyone is always quiet; but, for the adolescents, we are always charming, happy, and interactive.”

—IDI, male adolescent, 17 years old

Adolescents expressed concern about lack of confidentiality in both adolescent and adult clinics. While healthcare providers do not disclose clients’ HIV status to others, adolescents said that they are sometimes careless when talking to clients in front of others (inadvertent disclosure).

“For both adults and adolescents, it many happen that another individual from the street, who is not a client, may intrude our sessions. After hearing what we may be discussing, they go to disclose to other people and this is too bad for both groups ... There are also the relatives who bring food for the patients, or they may need a doctor; such people may get into the session room and get to know about what we are taught. Then, one goes to disclose to other people.”

—IDI, male adolescent, 17 years old

Disclosure of HIV status

Adolescents must know that they are living with HIV before transitioning to adult care. Otherwise, they would be unable to independently access HIV services. All adolescents who participated in this study were aware of their positive HIV status, as this was a condition for participation. When asked about their disclosure experiences, many adolescents did not remember how old they were when they were told that they were living with HIV. Of the 52
adolescents who did remember, nearly half were told before they were 10 years old (24) and nearly all (47) were told before they were 15. When asked, many adolescents said that they would have preferred to learn of their HIV-positive status earlier. They recommended disclosure of HIV status to children before the age of 10 years—some suggested disclosure as early as three years of age. Adolescents argued that children would be more likely to adhere to their ART regimens if they knew why they were taking medication.

“When a child is told [their HIV status] when they are three or four years old, they will understand that when they take medicine they will get well, and if they don’t, they will die. If you leave it and not tell them their problem, then they will stop the medication and finally harm their bodies.”

—FGD, female adolescent

Most adolescents who grew up with HIV were kept unaware of their positive HIV status until their caregivers thought it necessary to inform them—usually when something happened to make disclosure necessary, such as the adolescent refusing to take their medication, experiencing prolonged illness, or graduating from school. Adolescents reported that they only learned their HIV-positive status several years after initiating ART. Even when they demanded explanations of why they needed to take medications, some were still not told the truth.

“I once asked my aunt, ‘Why I am taking the medicines without knowing the problem?’ Moreover, I was not feeling sick. My aunt told me that I have not finished the dose yet from that time when I got sick and said I should keep on taking the medicine. I remained patient while taking the medicines until I was in standard three. Around that time, I told my aunt that, ‘I cannot be taking medicines without being sick, then why should I continue taking medicine?’ I totally refused and that was when my aunt started telling me the whole story.”

—IDI, female adolescent, 17 years old

“At first, when she was younger, she was not aware [of her status], but she was taking medication. She asked me, ‘Mother, why are you not taking this medication? You just tell us to get this medication; what am I suffering from?’ I kept on telling her that she is suffering from chest problems, and they [providers] said, ‘you should continue taking your medication, is that okay?’ And she said, ‘Yes.’”

—IDI, female caregiver

“I asked her [caregiver] if the medication we were always taking was really for coughs. She said on that day she was going to tell me the truth—that the medication was for HIV/AIDS, and that she and I were suffering from HIV.”

—IDI, female adolescent, 15 years old

According to healthcare providers, it is sometimes difficult for them to keep track of the lies that caregivers tell children about why they need to take medication.

“… but the difficulty we face there is with those who don’t know why they are taking the medications. Others might stick to what their parents have told them, so, you have to talk very much to parents. If you talk to them [the child], it’s like they don’t understand...”
You, they say, ‘Viruses? What about viruses? My mother told me that I am taking this medication for my cough.’

—FGD, healthcare provider

Most adolescents learned about their HIV status from their caregivers, although some learned at the facility. A few decided to go for an HIV test on their own, because they did not believe what caregivers were telling them about why they were taking medication.

“I had gone to the hospital for circumcision; that’s when I learned that I was living with HIV.”

—IDI, male adolescent, 19 years old

“She started asking me when we reached home from the clinic. They had been given a seminar, so I had to tell her the truth—that whatever they told her was true. She asked, ‘So, am I infected?’ I told her, ‘Yes, you are.’ She asked, ‘Where did I get it from?’ I told her that she got it from her mother.”

—IDI, female caregiver

“They were all hiding it from me. I decided to be bold and willing to get tested. I went to Nkinga (healthcare facility) to get tested and the nurses asked me if I have a strong heart, so that I can receive my results, I said, ‘Yes—I am ready, whatever the case.’ So, they gave me my results.”

—IDI, female adolescent, 16 years old

Healthcare providers also encouraged disclosure at a much younger age. They recommended that children be told about their HIV status as soon as they can understand this information. Early disclosure, they added, usually has a positive impact on the care received by children living with HIV.

“A child must be told the truth as soon as they can talk. They have to know about the medicine that they are taking and its benefits, because children of this generation are living in the digital age. Children know things even when they are five years old … So, hiding it at that age, you are creating something that will cost you later on.”

—FGD, healthcare provider

“For me, I can say this, for the ones who don’t know that they are living with HIV infection, their adherence to medications isn’t good, because they don’t know why they are taking medications. But, for the ones who know, they mostly understand and adhere well to medications—differently from the ones who don’t understand, they can just stop taking them as they don’t know.”

—FGD, healthcare provider

Almost all adolescents described the person who told them about their HIV status (whether or not this was a family member) as being calm and supportive, having a positive attitude, and using encouraging language—all of which, they said, helped them not to lose hope. Adolescents all agreed that this is how disclosure should be handled.
“She just said, ‘You have to be patient my child, because I’m also infected with HIV. You have to be strong like me; you have to keep the secret between us, because me, you, and your younger sibling, we are all infected.’ I said, ‘Okay, and we understood each other well.’”

—IDI, female adolescent, 16 years old

“The nurses were supportive and comforting, [they said, it is] not like this is the end of the world. They told me I will live and have a family. I was comforted and my heart was at ease. I thank God, till now, I am using medication.”

—IDI, female adolescent, 16 years old

“The person telling the adolescent of their status should be calm. It shouldn’t be a person who is a drunk from the local alcohol clubs. Or a person who smokes, or one who likes to talk a lot. It should be a person who is calm, and who shows a hospitable face.”

—FGD, female adolescent

The transition experience

Of the eight facilities selected for this study, seven had adolescent clinics and one provided care to adolescents and adults together. The age of clients in adolescent clinics varied across facilities. Most adolescent clinics had opened within the past two years. As a result, few adolescents—in some facilities, none at all—had already transitioned to adult care. Table 8 shows transition criteria used in study facilities. Our data confirm that there are no standards for transitioning adolescents to adult care, even within the same district. Instead, each facility uses its own criteria for determining when adolescents should transition. All these criteria are age- or event-specific, with no guidelines for assessing readiness to transition.

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<thead>
<tr>
<th>Region</th>
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<th>Criteria</th>
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<td>Transition age: ≥24 years; younger adolescents transition if they marry or get pregnant</td>
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Adolescent HIV in Tanzania: Factors Affecting Viral Load Suppression and the Transition to Adult Care

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<td>Tabora</td>
<td>Nzega</td>
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<td>Transition age: ≥20 years; transition counseling provided for adolescents ages 18 years and above</td>
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Transition criteria

Age is the primary transition criterion used by facilities. Some facilities transition adolescents as early as 19 years of age, while others wait until they are at least 24 years old. Some facilities use events—such as marriage, becoming pregnant, or completing a certain grade at school—as transition criteria. Such criteria are also applied if adolescents are younger than the designated age for transition. Providers explained that they use pregnancy as a transition criterion to keep pregnant adolescents from influencing other teens to think that they should get pregnant young.

“…you cannot leave her at her fellow adolescent’s because her fellow adolescents will start learning, as to why our fellow has a child. They will think it is a good thing to have a child. Therefore, they might all be spoiled. Therefore, you must remove her from there and put her to the adults except that when you are serving her, you cannot serve her the same as other adults, you must serve her in a different way.”

—FGD, healthcare provider

Healthcare providers reported that existing transition criteria are insufficient; so, they use other measures to ensure readiness before transitioning adolescents to adult care. Indications of readiness most frequently cited by providers were the ability to adhere to ART regimen and attend facility appointments on their own, without supervision. Many providers do not transition adolescents to adult care until they have demonstrated these capabilities, even if they are older than the specified transition age.

“During transition, the first thing I look at is age, second is adherence to medications, third one is the person’s understanding.”

—FGD, healthcare provider
Adolescent HIV in Tanzania: Factors Affecting Viral Load Suppression and the Transition to Adult Care

“We know through her attendance/records on the card because performance can be seen, and medical adherence. So, it’s easy to know if they are ready for the move.”

—FGD, healthcare provider

However, several adolescents said that they transitioned to adult care earlier than the specified age, once they met these additional criteria. Providers agreed that this happens.

“I explained to the nurses, they accepted it and I shifted.”

—IDI, female adolescent, 16 years old

“...many times, my mother is travelling. That would mean that I would have to wait for her to return before we could go and get medication. Therefore, I simply decided that when the dates came while she was away, I will take the card and go to get the medication by myself ... It was a test to see if I could adhere to the medication whenever she would not be around, dead, or involved in accident. She wanted to know whether I could protect myself.”

—IDI, male adolescent, 16 years old

“First, there are trainings which are childish and, as a provider, you will see the adolescents saying that, ‘In this group, no; I am asking to go to the adults.’ They say that, ‘I have grown up now.’ Others even say that they have fiancés and they want to go there and learn adult things there.”

—FGD, healthcare provider

Adolescents, caregivers, and healthcare providers all felt that, in addition to these criteria, adolescents themselves should feel ready for transition. Adolescents who reached the transition age but did not yet feel ready to switch to adult care were allowed to remain at the adolescent clinic until they felt ready for transition.

“Others say, ‘No, I would like to keep on coming to the adolescents’ clinic.’ And, when they say that they want to keep on coming to the adolescents’ clinic, I leave them until they are ready.”

—FGD, healthcare provider

One adolescent who had already transitioned to adult care said that this transition happened after he missed his appointment at the adolescent clinic because he had school exams. He went to the adult clinic instead, because he needed to pick up his ART medication but did not want to miss his exams. He was surprised that his subsequent appointments were at the adult clinic and was not happy about the transition.

“They did not make me shift, but it’s me who initiated it. It was one day when we had an examination and the adolescents had gone for the services already, but I had not gone yet. After the exams, my guardian told me that I could go for the services on the other day. Then I came on the following Monday. Then I met with adult people here and since then, the doctors started giving me appointments on the adult clinic dates.”

—IDI, male adolescent, 17 years old
Preparing for the transition

Some facilities prepare adolescents for the transition to adult care before they become eligible to transition; others do not. Where it is offered, transition preparation takes different forms. Some facilities slowly introduce the concept of transition to the adolescent, allowing them to visit the adult clinic now and then to get used to how things are done there before transitioning fully. In other facilities, peer educators—usually adolescents who have already transitioned to adult care—prepare adolescents for transition, orienting soon-to-be-transitioned adolescents on how the adult clinics operate and why adolescents need to shift to adult care. Facilities start preparing adolescents between six months and two years before they are eligible to transition. However, if providers find that young people are not ready to transition when they reach designated age, the transition process can take much longer—as long as three years or more.

“Sometimes, you just need to tell them to visit you at the clinic on the day that the adults have their clinics. When they come, you show them the people and tell them that, ‘I need to move you to this group. What do you think?’ They will make their own decisions. We use this method to move them because, if you force them, they will start missing their appointments. It becomes hard and you lose follow-ups; then we will be doing nothing.”

—FGD, healthcare provider

“We involve [peer educators] because those are the people who teach the other adolescents most of the time; and most care providers would sit aside as they teach ... They are the people who moved from child clinic to adult clinic. They take the medicine on that day because they are their teachers. They must tell them why we are moving them.”

—FGD, healthcare provider

“We do this immediately we know that the adolescent has reached the age of 19 [years]. We start by telling the adolescent that they are now 19 years and, when they reach 20 years, we will move them. So, the counselling period is a year.”

—FGD, healthcare provider

“Three to four years; we just do it slowly. Every day, when they come at the clinic, we remind them whether they remember what we talked about the previous month.”

—FGD, healthcare provider

In facilities that do not prepare adolescents for the transition, when adolescents reach the specified transition age, healthcare providers inform them that they must transition to adult care. In some facilities, providers proceed with the transition immediately. In others, providers assess adolescents’ readiness—if adolescents can take their medications and keep their appointments independently, they are transitioned.

“... you might just find out that today, as this teenager is coming to the clinic, it’s the same day you realize that they have reached 24 years old. I will just let them know that, ‘From the next clinic, you will start attending the other side.’ No education and no nothing, and we don’t prepare them with anything, and so they will have to move to the
other side and do it according to the experience they used to have while they were in adolescent clinic.”

—FGD, healthcare provider

Adolescents and their caregivers confirmed that, in some facilities, there is no preparation for the transition from adolescent to adult care.

“I just came from school after I was through with the examination and, as I got here, I found that there were adult people. I used to find the adolescents, but I could not see one on that day. Then, I realized that it was the adult clinic. Then I went to the doctor, got the medication and left. Then the doctor gave the next appointment, upon which I also found that it was the adult clinic. Then I went on attending the adult clinic.”

—IDI, male adolescent, 17 years old

“In that changing process, they told me that, now that I have changed to a new place, it will be tough in the beginning, but I will get used to it and everything will be fine. ... No preparations.”

—IDI, male adolescent, 19 years old

Providers from facilities without a procedure for preparing adolescents to transition said that they were recently instructed to start offering such preparation, and many felt that this was an important development.

“In the past, for the adolescents who were growing up, we didn’t have special preparations for them; when they came and was above 19 years, we just told them, ‘Now you will shift from adolescent clinic and we will start scheduling you for the adults’ clinic.’ But there were instructions that we got that we are supposed to start preparing them earlier, and not surprising them that they have to shift.”

—FGD, healthcare provider

Some facilities involve caregivers in preparing for the transition more than others. Providers who involve caregivers do so by encouraging them to talk to their children about the need to start taking responsibility for managing their own illness and to begin making them responsible for taking their medication and keeping appointments—keeping an eye on them to make sure that they do so. Most caregivers said that they were not aware of the transition criteria.

“When we want to switch them [the adolescents], we inform their parents through the phone.”

—FGD, healthcare provider

“Mostly, for us, since they are more like an adult as they are more than 18 years, most of the time we talk with the adolescent alone; we don’t involve the parents. You may find that they make their own decisions.”

—FGD, healthcare provider

Overall, HP+ found notable differences in the transition process between higher and lower performing districts; these are summarized in Table 9.
Table 9. Preparing for the Transition to Adult Care

<table>
<thead>
<tr>
<th>Transition Criteria (See Table 8)</th>
<th>Higher Performing District</th>
<th>Lower Performing District</th>
</tr>
</thead>
<tbody>
<tr>
<td>Preparation Offered</td>
<td>At least six to 12 months prior to transition</td>
<td>Commonly, no preparation</td>
</tr>
<tr>
<td>Parental Involvement</td>
<td>More involvement</td>
<td>Less involvement</td>
</tr>
<tr>
<td>Peer Educator Involvement</td>
<td>Involved; peer educators usually older and already in adult care</td>
<td>Not involved; peer educators usually younger and still in adolescent care</td>
</tr>
</tbody>
</table>

Adolescents’ transition experience

Adolescents usually transition to adult care alone unless more than one adolescent attending the facility meets the transition criteria and is ready to transition to adult care. Seven adolescents in our study had already transitioned. These adolescents said that the most important element of their transition experience was being well received and treated at the adult clinic. Some had attended their first adult clinic visit alone, others went with a relative. Four of the already transitioned adolescents said that they had felt ready for the transition—they either felt old enough or had themselves requested to transition. The remaining three said they had not felt quite ready for the transition—one said that the adolescent clinic offered education that was more relevant for him than what was offered in the adult clinic; the remaining two did not specify why they had not felt ready to transition.

“I found that I miss some important things when I go for adult HIV services … To be knowledgeable on the issues regarding the medications … To know on how I was to take the medication daily and if there is possibility that I would stop taking them. I wanted to know about that.”

IDI, male adolescent, 17 years old

Not surprisingly, the four adolescents who felt ready for transition said that all their questions about the transition were answered. Those who did not feel ready for transition reported either that their questions were not answered or that they were not given the opportunity to ask questions. Arriving at the adult clinic for their first visit, only two of the seven adolescents found that their arrival was expected and their files were present; regardless, all seven felt that they were well attended.

Healthcare providers from higher performing districts said that transitioning adolescents generally accept the transition well, while providers from lower performing districts said the opposite. The first of the following two quotes is from a high-performing district, the second from a district that is not performing as well.

“They usually receive it well because we have already started talking to them since the beginning, even before they shifted. So, when they go there it is just a matter of repetition because it is a continuous education.”

—FGD, healthcare provider
“Honestly, they don’t receive them well, because there are things they miss from their adolescents’ clinic when they go to the adult clinic.”

—FGD, healthcare provider

When asked what their greatest fear is regarding transitioning adolescents to adult care, many healthcare providers reported worrying about adolescents being lost to follow-up or not adhering to their ART regimens.

“Our greatest fear is that there is a very huge possibility of losing this client because they were transitioned abruptly without preparation.”

—FGD, healthcare provider

“The greatest fear ... is transitioning of the adolescents suddenly, they might feel bad and their attendance to the clinic may not be good because they weren’t prepared, so, they can miss some of the clinic visits because maybe of the fear of meeting the adults.”

—FGD, healthcare provider

Despite these fears, providers reported that most transitioning adolescents remain in care and very few are lost to follow-up during the transition process. They described some adolescents who had skipped their adult clinic appointments for a few months, but started attending again after providers followed up with them.

Adolescents who had already transitioned to adult care said that their biggest challenge is having clinic appointments on weekdays instead of Saturdays, as attending clinic appointments requires missing school. Healthcare providers confirmed that this is indeed a challenge adolescents face as they transition.

“I miss many school sessions, as I come on Mondays. It would be better if I were coming on Saturdays ... On Saturdays, I will not miss the session.”

—IDI, male adolescent, 17 years old

“Some of these adolescents are still in school, and adult clinics are on weekdays. Therefore, it can hinder them to come from school and, if they are far from the facility, it would mean missing school the whole day.”

—FGD, healthcare provider

To cope with this challenge, adolescents who had transitioned said they try to go to the clinic when there are fewer adult clients (late afternoon or early morning); alternatively, they go on days other than their scheduled day, thinking the facility may not be as crowded; or they ask to switch to a less crowded facility. Healthcare providers said that they help adolescents deal with the challenge of weekday clinics by scheduling adolescents’ appointments at whatever time adolescents say would work best, or by allowing their caregivers to pick up medications for them.

“They aren’t lost to follow-up; they keep on coming, but their attendance is that, they can come at the very end or they can come very early. There is one I met with and he came at 3 a.m., he was already there, and I was in night shift and I had to serve him so
that he could go, and that time was also very dangerous, and I don’t know why he did so.”

—FGD, healthcare provider

“We ... let them share their ideas on how they think it can be done because they will no longer be coming to adolescents. Therefore, they will share their ideas on at what times they think they can come, although it’s still the same adult services. If I agree with the time, then they will be coming at that particular time. Most times they like to come at around noon because most adults have gone already.”

—FGD, healthcare provider

“We normally get their caregivers mostly, and you might meet with them [the adolescent] after three months.”

—FGD, healthcare provider

Some adolescents who had transitioned were sad because they were separated from their friends at the adolescent clinic. Adolescents also identified long wait times and high client volumes as a challenge they face when attending adult clinics. They reported missing the meals and the sport and group activities offered in adolescent clinics. Healthcare providers confirmed that these are challenges faced by adolescents.

“The first challenge is that in the adult’s clinic, the people are very many. Honestly, it has many people, so, if it has many people and they are staying for all that time, like 5 or 6 hours, just sitting there waiting for medications without anything else, differently from the adolescents’ clinic where there are things which encourage them to play.”

—FGD, healthcare providers

One adolescent told researchers that at the adult clinic he was still asked to attend with his caregiver. However, this adolescent had transitioned at his own request and was several years younger than the usual age of transition. Caregivers of adolescents who had already transitioned said they did not face any challenges related to the transition process.

One challenge reported by healthcare providers is adolescents’ resistance to transitioning. According to providers, adolescents are afraid of all the strangers they will encounter in the adult clinic and concerned about other clients finding out about their HIV-positive status; they may also resist transitioning because the adult clinic does not offer the same incentives (entertainment, food, drink, etc.) as the adolescent clinic.

“When you tell them, ‘We have been with you till this time and now you must switch to adult care,’ they would tell you, ‘I am not used to the other clinic.’ ... When they come, they find many adults; and they don’t want them to find out and so they go away.”

—FGD, healthcare provider

“The adolescent is used to getting enough food when at the adolescent clinic and he is going back home when he is full. Some resist when they think of stopping doing that.”

—FGD, healthcare provider
Participant suggestions for improving the transition process

Adolescents, caregivers, and healthcare providers gave specific recommendations about how to improve the transition process and ensure that more adolescents continue adhering to treatment regimens and attending facility appointments after transitioning to adult care.

1. Most providers, caregivers, and adolescents recommended that the transition to adult care take place between 18 and 25 years of age—although responses ranged from 15 to 30 years. By 18–25 years of age, respondents felt that young people would be mature enough to transition and/or would have learned all they can from adolescent care.

   “I would like an adolescent to change to adult care when they are 25 years old. They will have already been given the education to know themselves at adolescent care. At that point, they will know everything and will move to adult care. All the other things they will get from there will be like an addition, so they can remember.”

   —FGD, healthcare provider

2. In addition to age, participants of all types recommended that adolescents' readiness be assessed before they are transitioned to adult care. Adolescents regarded their peers as mature if they are stable, follow provider instructions, are pregnant, or have a child. Caregivers, on the other hand, regarded girls as mature at menarche and boys at puberty and recommended transitioning them to adult care at that time.

   “When the person starts her menstrual cycle, and if a boy reaches puberty, I think this is the right time for the transition.”

   —IDI, female caregiver

3. Participants said that adolescents must have certain skills before transitioning to adult care, including being able to take care of their own health, adhere to their ART regimen, and attend their clinic appointments.

   “They must possess the understanding of taking own medicines and must be able to follow medical instructions.”

   —FGD, female adolescent

4. Before transitioning, adolescents, caregivers, and healthcare providers agreed that adolescents need to understand why the transition to adult care is necessary. Procedures in the adult clinic must be clearly understood in advance of the transition. Well before transitioning, adolescents should begin familiarizing themselves with the adult clinic to reduce feelings of sadness and loneliness after the transition. Some healthcare providers suggested that these topics should be included in routine counseling for children and adolescents, so they realize early on that they will eventually need to transfer to adult care and understand the implications of this transition.

5. Adolescents requested that facilities make sure that their files transition to the adult clinic with them and are available before their first adult appointment.

6. Adolescents said that they should be informed and involved in the transition process and must feel ready before they transition.
“They should involve us adolescents in the transition, so that we know and not just moving us. They move people without the rest of us knowing. We just suddenly see the person at the adult clinic.”

—FGD, female adolescent

7. Caregivers requested guidelines and procedures about how to prepare themselves and adolescents for the transition to adult care. Caregivers said they did not receive any counseling to help them through the transition process; instead, they just did what they felt was right—but this did not always work out. Specifically, they asked to be trained in identifying adolescents’ readiness to transition.

8. Some healthcare providers suggested that group educational activities, like vocational training, be added to adult care as an additional incentive to attend the facility. They also recommended that providers should continue to follow up with their adolescent clients after the transition, at least for a while.

9. Finally, healthcare providers asked to be trained on transitioning adolescents to adult care.

“As care providers, we should be given training so that we can cope with adolescent transition to adults because most of us don’t have the training and we just do it anyhow and that’s the reason adolescents get lost and stop getting the services.”

—FGD, healthcare provider
Discussion

The Government of Tanzania is in the process of improving programs and approaches to better address the needs of children and adolescents living with HIV and ensure that they receive the care they need to live full and productive lives. This study was designed to enable the Government of Tanzania to prepare appropriate infrastructure and guidelines to improve quality of care and clinical outcomes for adolescents living with HIV. To do so, the study explored factors influencing viral load testing, viral suppression, and the transition to adult HIV care among adolescents living with HIV and estimated the number of people living with HIV who will be eligible for and actually transitioning from adolescent to adult HIV care each year between 2018 and 2025.

The study consisted of both quantitative and qualitative elements. Quantitative components sought to establish baseline estimates and trends for viral load testing and viral suppression in children, adolescents, and young adults living with HIV, and to project the numbers of people living with HIV eligible for and actually transitioning to adult HIV care. The study's qualitative elements sought to identify enablers and barriers affecting viral load testing, viral suppression, and the transition from adolescent to adult HIV care. Our findings have direct policy implications and offer important insights that can be used to strengthen programs and guidelines in support of adolescent HIV care.

Viral Load Testing and Viral Suppression

Viral suppression is the ultimate goal of ART and viral load testing is the preferred method for monitoring treatment and identifying viral suppression (WHO, 2016). Tanzania's current HIV management guidelines prescribe the use of routine viral load testing for all those on ART, regardless of age or disease stage (MOHCDGEC, 2017).

Findings of this analysis show that, in the Dar es Salaam region, only about two-thirds of children, adolescents, and young adults who are eligible for viral load testing are actually tested, and only about two-thirds of those tested are virally suppressed. HP+ found several demographic and clinical characteristics to be associated with viral load testing and viral suppression. Males were more likely than females to have a documented viral load test (65.7% of males, compared to 63.0% of females). This difference, although statistically significant, was slight (2.7%). It may reflect unconscious bias toward testing males, or males may tend to present for testing more often than females. Among those with viral load tests, however, females were significantly more likely than males to be virally suppressed. These findings are consistent with data from the 2016/17 Tanzania HIV Impact Survey (TACAIDS and ZAC, 2018).

Tanzania's HIV management guidelines stipulate the same viral load testing strategies for all those on ART, regardless of age. Yet, HP+ found that rates of viral load testing and viral suppression differed by age. HP+ found older age at last clinical encounter (used as a proxy for current age) to be positively associated with having a documented viral load test, and with being virally suppressed. The older the individual, the more likely they were to have a viral load test and, among those tested, the more likely they were to be virally suppressed. This finding is likely related to emotional maturity and the ability to understand the importance of treatment adherence. On the other hand, younger age at ART initiation was positively associated with viral load testing. Children and adolescents who initiated ART before 10 years of age were more than
Adolescent HIV in Tanzania: Factors Affecting Viral Load Suppression and the Transition to Adult Care

twice as likely, and those who started treatment between ages 10 and 14 years were 1.4 times as likely, to have a documented viral load test than those who started treatment between 15 and 19 years of age. This is to be expected, given that those who started treatment when they were younger, most of whom presumably were born with HIV, are well known by health facility staff, as they have long been enrolled in care and attending facilities with their caregivers.

Not surprisingly, HP+ found initiating ART earlier in disease progression to be positively associated with viral suppression. Children and adolescents who started ART when they were in WHO clinical stage one or two were more likely to be virally suppressed than those who started treatment in WHO clinical stage three or four. However, interestingly, those who started treatment at an earlier clinical stage were less likely to have a documented viral load test—although Tanzania’s HIV management guidelines dictate that all ART patients, regardless of clinical stage, should receive a viral load test (MOHCDGEC, 2017). This difference could be due to a potential testing bias toward those whose condition is considered more urgent. Similarly, children and adolescents who reported poor adherence were significantly more likely to have received a viral load test and less likely to be virally suppressed. Those who had been on ART longer were more likely to have received a viral load test. However, children and adolescents who had been on ART for less than 12 months, were 1.5 times more likely to be virally suppressed than those who had been on ART for five years or more. This finding is consistent with known trends in retention, which show a negative relationship between length of treatment and adherence.

The statistical relationships between ARV regimen at ART initiation and viral load testing and viral suppression are also of interest. Children and adolescents were less likely to have received a viral load test if they were on older ART regimens or those that are being phased out, such as d4T (see Table 3).

**Barriers to viral load testing and viral suppression**

The literature suggests that lack of understanding of viral load testing and the benefits of viral suppression—by adolescents and their caregivers—is a significant barrier to uptake of viral load testing (Lowenthal, 2015). This does not appear to be a problem in Tanzania, as most study participants understood viral load suppression and the need for viral load testing. Similarly, according to Roberts et al. (2016), some healthcare providers are not comfortable with, or have insufficient knowledge of, viral load testing due to large workloads and limited training. This was not confirmed by our study. Most of the healthcare providers interviewed understand the importance of viral load testing and are committed to testing their clients. Based on our study findings, provider attitudes and quality of care also do not appear to be a problem in adolescent HIV care in Tanzania. Stockouts of medication, a common barrier in many settings, were evident in our study but only in a limited way—some respondents mentioned having to change ART regimens because of stockouts. In Tanzania, ARV stockouts are uncommon, and therefore unexpected; when stockouts do happen, most clients learn of the stockout when they arrive at the clinic.

Our qualitative findings identified several additional barriers to improving implementation of viral load testing and increasing viral suppression. Fear of test results, and fear of injections or finger pricks, were commonly cited as a barrier to viral load testing, which can be easily overcome with proper counseling. Such counseling could also overcome the barrier posed by the
common misconception, among adolescents and caregivers, that only sick individuals should be tested and as long as they feel fine, there is no need to get a viral load test.

An additional barrier identified in this study was low treatment literacy and understanding of the concept of “viral load.” Although half the adolescents interviewed indicated they had heard the term viral load testing, some wrongly referred to it as a CD4 test. CD4 is well-known in Tanzania, while viral load is not as common. Also, the Kiswahili term for viral load test is complicated and can be difficult to remember.

One clear barrier is the long wait time for receiving viral load test results. So long, in fact, that some adolescents are due for their next test before they have received results of their earlier test. This finding confirms the literature about prolonged delays in returning results (Robert et al., 2016). Having to wait in long lines to get a viral load test was another commonly mentioned barrier.

Adherence to medication regimens is essential to achieve viral suppression. Our findings show evidence of several barriers to ART adherence at the individual, family, community, and facility levels. At the individual level, disruption to routine was the most commonly cited reason for skipping medication. Adolescents, caregivers, and healthcare providers all suggested coping mechanisms and reminder efforts that can help combat this challenge.

HIV-related stigma remains an important barrier to adherence in many settings—in health facilities, the community, and sometimes even in the family. Adolescents sometimes skip their medication (or do not come to the facility to pick up their prescription) because they are afraid of being recognized as HIV positive. Stigma also results in feelings of loneliness and the perception of adolescents living with HIV that they are not taken care of.

**Recommendations:** *viral load testing and viral suppression*

Based on our quantitative and qualitative study results, HP+ offers the following recommendations to improve viral load testing and viral suppression in Tanzania:

1. Strengthen viral load testing implementation in accordance with national guidelines to:
   - Increase viral load testing rates to 100%. HP+ found that only 64.2% of the study population in Dar es Salaam had at least one documented viral load test.
   - Close the gap in testing uptake between males and females. HP+ found that male children and adolescents were more likely to have a viral load test than their female counterparts.
   - Improve testing of those who initiate ART between 15 and 19 years of age.
   - Ensure that clients who are nonadherent or on ART for a shorter period receive viral load testing.

2. Scale up capacity and access to viral load testing, including reducing turnaround time for results return.

3. Identify and apply training strategies to increase providers’ understanding of the benefits of viral load testing and suppression.
4. Offer training to improve providers’ ability to communicate the benefits of viral load testing and viral suppression to adolescents and caregivers to further encourage adherence and retention.

5. Expedite introduction of an age- and developmentally appropriate treatment and viral load literacy strategy for children and adolescents living with HIV and their caregivers.

6. Standardize and expand HIV-specific and general peer support interventions for adolescents—in both clinic and community settings. Interventions could include opportunities for buddy systems for those who are new to the groups or who may be struggling with particular issues.

7. Continue moving to decentralized models of care, coupled with treatment and viral load literacy for adolescents.

**Transition to Adult HIV Care**

The application of the transition model to Tanzania revealed that a large and increasing number of adolescents will become eligible to transition to adult care and treatment in the coming years. As many as 13,500 18-year-olds could be on ART and eligible to transition by 2025. These adolescents will need to be prepared for the transition, then helped through the transition process.

There is a need to provide adequate support to young people as they transition from adolescent to adult care. Regions with the largest numbers estimated to become eligible to transition (Dar es Salaam, Mbeya, and Mwanza) may face the largest challenges in providing continuity of care to transitioning adolescents. The qualitative data presented in this study helps identify enablers of and barriers to successful transition from adolescent to adult care. Procedures and guidelines must be put in place to enable health facilities and communities to overcome these barriers. Policymakers interviewed indicated that, at the time of their interview, Tanzania had no national guidance dedicated to adolescent care.

The literature generally defines successful transition from adolescent to adult HIV care as the continuation of care post transition. Adolescents, caregivers, and healthcare providers who participated in this study offered a more specific definition. For a transition to be considered successful, they all saw two elements as essential post transition: (1) attending facility appointments as scheduled, and (2) adhering to medication regimens.

The challenge, then, is to provide adolescents the support they need to continue attending appointments and adhering to treatment after they have transitioned to adult care. There seemed to be universal agreement among participants at all levels that adolescents should be made “ready” for the transition, and that transition readiness is not necessarily age dependent.

Readiness is most often defined in terms of agency, knowledge, and skills—the adolescent is considered ready if they can manage appointments and medication independently. Readiness requires that adolescents feel a sense of responsibility and maturity (Masese et al., 2017) and that they have the skills needed for self-management (Sharer and Fullem, 2012). These aspects of readiness were confirmed by our study participants—providers, caregivers, and adolescents alike. In addition, study participants associated various social constructs with intellectual maturity and readiness to transition. For example, pregnant adolescents and those going
through the physiological processes of menarche and puberty were deemed mature by caregivers and healthcare providers. The association of puberty and menarche with maturity is a common cultural concept and a key social determinant of health in Tanzania.

**Barriers to transition**

The literature identifies several barriers faced by adolescents and their families in the process of transitioning to adult care. Katusiime et al. (2013) and Kung et al. (2016) posit that adolescents are often unwilling to leave healthcare providers with whom they are comfortable. Further, healthcare providers are sometimes reluctant to transition adolescents—whom they may have cared for most or all of their lives—out of their care. Overall, HP+ found that these concerns are not problems in our study settings, as the same providers usually continue to care for adolescents after they transition to adult care. Adult care may be happening on different days of the week and involve different education and group support services, but—for the most part—the providers remain the same.

The literature also identifies decreased client support in adult care, compared to adolescent care, as a barrier to successful transition (Inzaule et al., 2016; Masese et al., 2017). Our findings confirm this assertion to some degree. According to respondents, it is not really support that is reduced, but rather education, group activities, and meals. In adolescent clinics, clients meet in groups and receive information and education to a far greater extent than clients in adult clinics. Also, adolescents are fed when they visit the facility and adults are not.

One barrier to transition noted in the literature that our findings clearly support is adolescents’ fear of encountering greater stigma in adult HIV clinics (Kung et al., 2015; Masese et al., 2017). The adolescents interviewed were wary that, in adult care, more people would recognize them and discover their positive HIV status.

Our findings suggest several additional barriers that must be overcome to successfully transition from adolescent to adult care. First and foremost, the issue of costs. In our study areas, adolescents receive meals and reimbursements for the cost of transportation to the facility for appointments, while adults do not. Respondents suggested that this change makes facility visits prohibitively expensive for young adults who are just starting off in life and often have limited resources. Weekday scheduling in adult clinics can also be problematic, as appointments may conflict with school schedules for those who are still in school.

Disclosure is another possible barrier to transition. While all adolescents in our study knew their HIV status (a study requirement), not all adolescents do, and young people cannot transition to adult care until they know that they are living with HIV. Most of our respondents recommended early disclosure to children living with HIV, as soon as a child is able to comprehend what this means.

Healthcare providers identified the lack of transitioning guidelines, as well as insufficient training, as barriers that restrict their ability to help adolescents prepare for and successfully achieve the transition to adult care.
**Recommendations: transition to adult HIV care**

Based on our quantitative and qualitative study results, HP+ offers the following recommendations to improve the transition from adolescent to adult HIV care in Tanzania:

1. Ensure that adult care facilities are equipped to provide support to transitioning adolescents, including, but not limited to, infrastructure development and improvement, systems, and human resources to accommodate the increasing number of clients expected in the coming years (see quantitative results section on the transition to adult care).

2. Finalize NACP guidance on transitioning and disseminate the new guidance to healthcare providers; this is vital, given the anticipated increase in the number of adolescents and young adults eligible for and actually transitioning to adult care over the next eight years.

3. Incorporate peer support groups for adolescents into adult models of care to ensure that adolescents continue receiving peer support after they have transitioned to adult care—all those interviewed mentioned the importance of peer support for adolescents.

**Study Limitations**

There are several limitations to the study. First, the quantitative analysis of viral load testing and viral suppression was limited to one region, Dar es Salaam. Results, therefore, cannot be generalized to the rest of the country. Still, the data provide important indications of demographic and clinical characteristics that are associated with viral load testing and viral suppression—indications that should be considered everywhere in Tanzania.

Second, the transition model application is based, not only on current trends, but also on several sets of assumptions. Therefore, the estimates generated may not be realistic. Moreover, current trends used are based on data from Baylor facilities, which may not necessarily be representative of the rest of the country. However, the use of different assumptions to calculate parallel estimates in different ways provides a realistic range of figures. The model scenarios and assumptions were validated by a wide range of in-country stakeholders, who also deemed the model results accurate based on their service delivery experience.

The qualitative work also has some limitations. First, it is limited to adolescents who know their HIV status and regularly attend care. They may be in a very different place in their treatment and their ability to manage their treatment than those whose status has not been disclosed to them. Another limitation, due to resource constraints, was the inability to include adolescents who were lost to follow-up, or their caregivers. Further, healthcare providers helped the team identify respondents, likely introducing selection bias, as providers may have been more likely to identify participants who are known to them, possibly those who are more adherent and visit the facility more regularly. Finally, in all study sites, very few adolescents had already transitioned to adult care. As a result, few adolescents and caregivers could express their opinions based on post-transition perceptions. However, HP+ reached saturation within the study population.

Despite these limitations, our findings open the door to a better understanding of crucial elements of adolescent HIV care. To the best of our knowledge, this is the first study to explicitly
examine all the combined quantitative and qualitative components with all those involved in the care of this important population—adolescents living with HIV.

**Policy Recommendations**

The study was undertaken to provide the Tanzanian government with information that can help improve HIV care for children and adolescents. The rich data and informative results of this study have direct policy implications, leading HP+ to offer the following recommendations:

1. Peer support groups for adolescents and optional group activities should be incorporated into adult models of HIV care to ensure that adolescents who have transitioned receive ongoing support and continue to benefit from activities similar to those available in adolescent care.

2. Treatment and viral load literacy training and guidance for adolescents, caregivers, and healthcare providers should be developed and rapidly brought to scale—with adolescents living with HIV involved in the development process.

3. Scale-up of routine viral load testing should be continued and implementation strengthened by:
   - Improving turnaround times for delivering test results
   - Ensuring the availability of equipment and supplies
   - Using training and other strategies to enhance providers’ understanding of the benefits of viral load testing and viral suppression and their ability to communicate these benefits to adolescents living with HIV and their caregivers
   - Further developing differentiated models of care for clinically stable and advanced adolescents living with HIV, including expanding outreach activities in communities where health facilities are less accessible, to enable adolescents and adults to access ARVs and lab tests closer to home

4. Expedite introduction of an age-and developmentally appropriate treatment and viral load literacy strategy for children and adolescents living with HIV and their caregivers.

5. National guidance on disclosure should be crafted and made available to healthcare providers, caregivers, and adolescents, with adolescents living with HIV involved in the development process.

6. Guidelines on the transition from adolescent to adult HIV care should be rapidly finalized and implemented, including ensuring that:
   - All providers are trained on the guidelines and on assessing transition readiness
   - Adolescents living with HIV are involved in guideline formulation and implementation
   - The guidelines:
     - Are written in simple, easily understood language
     - Are available in English and Kiswahili
     - Specify that adolescents should be prepared for and engaged in the transition process well in advance of transition
o Use readiness, rather than age, as the primary transition criterion—i.e., before transitioning, adolescents must show that they are able to take responsibility for independently managing their condition, including attending appointments as scheduled and taking medications on time; 18-year-olds should remain in adolescent care until they are ready to transition; likewise, younger adolescents who wish to transition should have this option, if they are ready

o Include guidance for providers on preparing adolescents for transition, discussing test results with adolescents, and assessing transition readiness

o Emphasize the importance of involving caregivers in the transition process

7. Conduct a rapid policy and guideline scan to determine the status of priority guidelines from conception to implementation. Results can be used as an advocacy tool to prioritize recommendations that need expedited implementation.
References


