

Guideline: Adherence to antiretroviral therapy in adolescents and young adults



A publication of the Southern African HIV Clinicians Society



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foreword

The South African Department of Health launched the *National Adherence Guidelines for Chronic Diseases (HIV, TB and NCDs)* in 2015.^[1] The guidelines provided welcome direction for healthcare professionals supporting patients on treatment regimens.

Subsequent to the introduction of the Guidelines, a number of stakeholders came together with the aim of exploring the treatment adherence difficulties of HIV-positive adolescents in particular. These stakeholders acknowledged that adherence during the adolescent years represents a significant challenge and poses a considerable threat to healthy outcomes.

Given the multiplicity of factors that influence adherence and the complexity of adolescence as a developmental stage, stakeholders who participated in the forum called for a set of adolescent-specific guidelines, aligned to the National Guidelines. These would offer a more in-depth look at adherence during the adolescent years, thereby meeting the needs of healthcare providers in a package comprising a concise set of guidelines, supported by a lengthier version for background and more in-depth reading.

Two documents have been developed. The first (***Guidelines for adherence to antiretroviral therapy in adolescents and young adults***) provides a quick reference and summary of the main aspects related to supporting antiretroviral therapy adherence for HIV-positive adolescents and young adults. The second, expanded version (***Guidelines for adherence to antiretroviral therapy in adolescents and young adults (expanded version): Recommendations, resources and references***) provides more detail for those requiring additional background information, resources and references.

Both documents are aligned to several related National Department of Health HIV guidelines, including: *National Adherence Guidelines for HIV, TB and NCDs* (2016); *National Consolidated Guidelines for the Prevention of Mother-To-Child Transmission of HIV (PMTCT) and the Management of HIV in Children, Adolescents and Adults* (April 2015); and *Disclosure Guidelines for Children and Adolescents in the Context of HIV, TB and Non-Communicable Diseases* (2016).

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1. Introduction and background

The guideline package reflects an appreciation that for most adolescents and young adults living with HIV (AYLHIV), understanding the commitment to the long-term nature of antiretroviral therapy (ART) is a challenging and complicated concept. This makes support one of the key aspects to helping youth become successful in maintaining ART adherence. The package provides direction on this and other aspects of adherence, such as helping AYLHIV who are not familiar with what it means to take chronic medication and those who are facing the challenge of dealing with their diagnosis.

1.1 Definition of an adolescent: Differentiating children from adolescents

Adolescence is defined as a time of both physiological and social transition to adulthood, during which individuals develop secondary sexual characteristics and take on increasing levels of independence and responsibility. The guidelines acknowledge that adolescence is a critical transition period characterised by tremendous and unique physical, biological, intellectual, behavioural and emotional growth and changes. For this reason, it is especially important that the adolescent stage of development and its potential impact on treatment adherence is distinguished from treatment support for adults and children. Adolescents are not children, nor are they adults.

Most national and international guidelines define adolescents as individuals aged 10 - 19 years,^[1,2] or 10 - 24 years;^[3] and this period may be divided into early (10 - 14 years), middle (15 - 16 years) and late (17 - 19 years) adolescence. Aligned with the WHO definition,^[3] these guidelines are intended to be applicable to AYLHIV aged 10 - 24 years.

1.2 Adherence and adolescents

Four overarching influences on adherence in adolescents are considered in the guidelines:

- *The individual themselves:* negotiating adolescence – a developmental stage during which normal striving for identity and independence from authority figures may lead to difficulties aligning decisions and behaviour with adherence guidance.

- *Family, community and cultural structures:* caregiver availability; level of trust and openness for disclosure; and general support available.
- *Health services:* accessibility; level of youth-friendliness; confidentiality; stock-outs; and service delivery models (including counselling and support group availability).
- *Medication:* formulations; adverse side-effects; timing of doses; and supplier changes.

1.3 Addressing the context

In 2015, adolescents represented the fastest-growing age group of people living with HIV (PLHIV), accounting for 5.9% of the burden of HIV.^[4] This underscores the need for greater understanding and suitable adaptation of HIV care and treatment services. Sustaining optimal ART adherence in AYLHIV has emerged as a major healthcare challenge, fundamentally due to regimen complexity and adherence efficacy.

Correlates exist between ART adherence among adolescents in low- and middle-income countries and: gender and knowledge of serostatus; influence of family structure; impact of onerous ART regimens; attitudes about medication; healthcare challenges; environmental factors, such as rural versus urban setting; and retention in care (RIC). Some studies cite being orphaned, loss of a caregiver, mental health challenges, changes in guardianship, and absence of parental and social support as adherence-related challenges. Others name lack of autonomy, reliance on caregivers to access care, compliance with clinic visits, collection of medication and adherence to dosing schedules.^[4]

These are confounded by issues concerning disclosure, autonomy and maturity. Non-disclosure is often associated with negative health outcomes and is compounded if the disclosure (from a vertical infection) reveals the HIV status of the parent on whom the adolescent may depend, or to whom the surviving caregiver is connected. Emerging maturity, developing autonomy and independence, and normal experimentation associated with this developmental stage, all factor into these complexities.^[4]

Great strides have been made in the field of paediatric HIV over the last 15 years, and improvements in ART have enabled many adolescents to reach adulthood and achieve their goals. However, many challenges with adolescent HIV treatment remain, and often place this age group at risk for failing their treatment. The treatment failure rate for adolescents with HIV is much higher than that of adults. Whereas the failure rate for adults ranges from 10% to 15% depending on location, failure rates for adolescents are reported to be as high as >50% in some studies.^[5]

Differentiated models of care for this vulnerable youth population are called for, with a 50% reported increase in AIDS-related mortality, relative to a 30% decline in the general population.^[6]

It is the purpose of these guidelines to provide practical guidance to support and improve adherence for adolescents and young adults.

2. Supporting adherence in adolescents and young adults

This section deals with four strategies to support adherence: firstly, the involvement of parents/caregivers; secondly, the management of disclosure; thirdly, the use of support groups; and fourthly, the provision of adolescent- and youth-friendly services.

2.1 Involvement of parents/caregivers

It is important to get the balance right in the fluctuating shift from dependence to independence.

- There is a misconception that because adolescents strive for independence, they no longer need their parents/caregivers. Young people need to know that they have the love and support of their parents/caregivers, and to be supported and guided as they move through different stages of adolescence into adulthood.
- The shift from dependence to independence and autonomy is a dynamic, complex and ever-changing process, with a movement back and forth along the continuum.
- Adherence for adolescents can be complicated and challenging. It is important for parents/caregivers to understand that the need for more independence is a normal part of adolescent development. It may be a source of conflict

between the young person and parent/caregiver, and requires flexibility, the courage to let go, open communication, a shared understanding of rules and boundaries, and the building of trust and confidence.

Key principle:

- Consent should be obtained from the young person for caregiver involvement.

Working with parents/caregivers to support adherence – key points

- Parents/caregivers of AYLHIV need to be equipped with the skills and knowledge to disclose their own and the adolescent's HIV status, incrementally in accordance with the adolescent's age, cognitive skills and emotional maturity. Adolescents who have been informed of their HIV status should be provided with ongoing support to prevent disclosure negatively affecting their psychological and social wellbeing. Furthermore, efforts should be made to explore the potential role of trusted family members in contributing to the disclosure process.
- Caregivers should be encouraged to involve adolescents in making the rules, and there must be agreement in terms of the consequences if they are broken.
- It must also be remembered that rules need to be adapted and changed as the young person grows up; the rules for a child aged 10 years will be different for a young person aged 16 years.
- Focus should be placed on developing a supportive home environment. Parents/caregivers and relevant family members should be oriented and involved in adherence support. Often they are more insightful in problem-solving the barriers to adherence. This is a dynamic process and needs to be re-visited, reinforced and adapted to the young person's changing living environment.
- Parent/caregivers require certain skills to be able to provide effective support and to learn how to manage AYLHIV. Certain skills apply to parenting adolescents generally, some relate to the management and parenting of adolescents with chronic illnesses, and some relate more specifically to their HIV status and living with HIV.

Need to know more? *Guidelines for adherence to antiretroviral therapy in adolescents and young adults (expanded version): Recommendations, resources and references (2017) – Chapter 3.2* – provides additional information about the *Children's Act*, the involvement of parents/caregivers and the relationship dynamics between the AYLHIV and parent/caregiver, and how this impacts on adherence.

2.2 Disclosure

In the context of AYLHIV, 'disclosure' describes the process whereby a person is informed about their HIV-positive status, usually at an appropriate time when they have reached a sufficient level of emotional and cognitive maturity. 'Onward disclosure' is the process whereby the HIV-positive person discloses their status to others. Disclosure assists the young person to come to terms with, and understand what it means to live with HIV.

Key principles

- Disclosure to vertically- and horizontally infected adolescents may require different approaches. This is influenced by the length of time they have lived with HIV, the mode of transmission, and experience related to living with HIV.
- Disclosure is not a one-off event; discussions need to continue and be adapted as the child grows into adolescence and early adulthood.
- Adolescence covers a range of physical and neuro-developmental stages. It is therefore critical to take into consideration both the physical age of the adolescent and their cognitive/developmental abilities. The level and content of disclosure information needs to be tailored to their needs and abilities.
- Disclosure to others is ultimately the choice of the adolescent, and cannot be forced or implemented without their consent. It is vital that the adolescent feels in control over the disclosure of their HIV status.
- Disclosure to others should be encouraged with sensitivity and understanding – it is important to engage with and address the barriers to disclosure in the context of the person's life.

Benefits of disclosure to support adherence

There are several benefits of informing adolescents of their HIV-positive status:

- Disclosure contributes to the understanding of the importance of taking medication regularly,

and encourages increased responsibility in taking medication without supervision. This motivates increased commitment to ART, which in turn improves the likelihood of achieving viral load (VL) suppression.

- Disclosure paves the way to developing a network of support. Building strong support systems among family, friends and partners is valuable for adolescents and young adults generally, but plays an especially important role in strengthening adherence. Some AYLHIV may not be mature enough to manage treatment and care commitments on their own, and they need guidance and support. Inadequate support can leave adolescents feeling isolated and excluded, and can impact negatively on their ability and desire to adhere to ART and to achieve life goals.
- Disclosure also opens up the possibility of joining support groups with other fully disclosed AYLHIV and consequently benefitting from the information, support and sense of belonging afforded by support groups.

Key role players in the disclosure process

The parent/caregiver, the AYLHIV and the healthcare provider based at the facility (counsellor, social worker, doctor or nurse) all play a role in disclosure. The healthcare provider plays an important role in supporting both the parent/caregiver and young person during the disclosure journey; but it is ultimately the responsibility of the parent/caregiver.

Vertically infected adolescents – key considerations

- It is generally recognised that the disclosure process should begin as early as possible with partial disclosure at around 4 years of age. This information can be adapted as the child matures.
- It is recommended that full disclosure has occurred by the time the young person reaches the age of 10 years.^[7]
- Starting the disclosure process early and in a way that takes into account the child's emotional and cognitive maturity, facilitates adjustment to news of an HIV-positive status; whereas late disclosure can have implications for psychological functioning and other behavioural outcomes. An important element is the potentially damaging effect on the trust in the adolescent-guardian relationship, at a time when support and guidance is most needed. Research also suggests that in addition to the stage of partial disclosure, there is often a stage of 'suspicion' when the young person suspects their status but is denied the opportunity to have this confirmed, impacting negatively on adherence.

- It is recommended that the parent/guardian is the most appropriate person to disclose to the young person.^[7]
- Healthcare providers have an important educational and supportive role to play. Healthcare providers need to assist in addressing the anxiety and barriers that parents/guardians may have in terms of telling their child that they have HIV.
- Parents/guardians need to understand that disclosure is in the best interests of the adolescent, and is a necessary step towards positive health outcomes.
- There are fears that disclosure may prompt or exacerbate mental health instability in young persons. The World Health Organization (WHO) suggests that psychological benefits outweigh any negative short-term effects. Despite the immediate reaction to learning their status, young people who are told earlier rather than later appear to have better emotional health than their non-disclosed counterparts, including higher self-esteem, fewer symptoms of depression, enhanced coping skills and better ability to obtain social support. Many of the benefits of disclosure are health-related, including better treatment adherence, good clinical outcomes and more responsible sexual behaviour.

Horizontally infected adolescents – key considerations

- Generally, disclosure takes place during the HIV testing and counselling process.
- When providing information, support and referrals, healthcare providers should be sensitive to the manner in which HIV was acquired. For example, there may be a difference in the nature of counselling and support when HIV is acquired from rape or coercion, as opposed to consensual sexual intercourse.
- The HIV testing and counselling process paves the way for engaging with the young person about what it means to be living with HIV, their level of knowledge, and myths and fears, and lays the foundations for discussing adherence. Informed consent allows the AYLHIV to feel in control of the process.
- The presence of another person – a parent/guardian, relative or friend – needs to be guided by and discussed with the young person. The rights of the AYLHIV should be explained tactfully to the parent/guardian, and their involvement reassured, especially where they may play an important role in future adherence.

- Ultimately, engaging horizontally infected adolescents in their HIV diagnosis and treatment from the outset enables linkages to adherence clubs and other support groups (where available) to be introduced early, and support around beneficial (onward) disclosure of diagnosis to be provided.

Onward disclosure (disclosure to others) – key considerations

- The healthcare provider should discuss the benefits of disclosure to relevant people in the young person's life. Benefits include, for example: not having to hide their status, visits to the clinic, and medication; being able to share their anxieties; and dealing with stigma – thereby reducing stress, anxiety, guilt and isolation.
- Disclosure can be frightening and emotional for the young person and is often avoided due to fear of the reactions of others, including rejection and stigma, enhanced by internalised stigma.
- Healthcare providers should explore the level of support, trust and understanding in the young person's primary relationships. This will assist in understanding how realistic fears of stigmatisation may be. It is important to bear in mind that adolescents may have very legitimate concerns about isolation, abandonment and even abuse.
- There are practical ways in which disclosure to others contributes to improved adherence, including: assisting the young person in remembering their appointments, to take medication and collect treatment; and assisting with arranging care and communicating with healthcare providers, where the young person feels unable to do so.

Post-disclosure support

Post-disclosure support is an important part of the disclosure process. Disclosure is not a one-off conversation, but an ongoing process to address changing needs as the young person develops and as their circumstances change.

Need to know more? *Guidelines for adherence to antiretroviral therapy in adolescents and young adults (expanded version): Recommendations, resources and references (2017) – Chapter 4* – provides additional information about: disclosure to vertically and horizontally infected adolescents; onward disclosure to others; and the legal aspects of disclosure.

2.3 Adolescent support groups

A crucial aspect for adherence support is the availability of peer support. Support groups provide a valuable opportunity for HIV-positive adolescents to share information, mitigate the effects of stigma, and to learn from and provide support to each other.

Key considerations

- *Group composition:* Support groups should take age into account and the young person's disclosure status, and members should be grouped accordingly.
- *Group facilitation:* In healthcare facilities, adolescent support groups can be facilitated by counsellors, nurses, health promoters, psychologists, social workers or peer educators.
- *Possible topics:* Common topics relevant to AYLHIV need to be covered according to the group's needs and should be age-appropriate. Health and development issues during the adolescent ages affect health later in adult life, hence the importance of equipping adolescents with life skills.
- *Adherence counselling as a focal point:* Support groups provide a platform for AYLHIV to support one another socially and emotionally, and an important opportunity for group adherence counselling. Most AYLHIV who attend are likely to see an improvement in their VLs and are encouraged knowing that they are not alone in the ART journey.

Need to know more? *Guidelines for adherence to antiretroviral therapy in adolescents and young adults (expanded version): Recommendations, resources and references (2017) – Chapter 3.1* – provides additional information about support groups and summarises relevant topics for discussion.

2.4 Adolescent- and youth-friendly services

- Effective adherence support needs to take place within the context of services sensitive and responsive to the needs of AYLHIV.
- Young people face several barriers in accessing healthcare, especially sexual and reproductive health (SRH) and HIV services, and these barriers are exacerbated by the additional complexities of being HIV-positive. Barriers affect service utilisation, support, RIC and adherence to treatment, and ultimately have a detrimental impact on health outcomes.
- Confidentiality, respectful treatment, integrated services and easy access are all widely recognised

as important components of adolescent-friendly services.

- Staff attitude is important. Healthcare providers need to assess whether their knowledge, personal views, attitudes and behaviours, as well the protocols and practices in use at their clinic, are potential barriers to their ability to be responsive to the needs of adolescent patients.
- Services need to be accessible, acceptable and appropriate to all adolescents across ages, and sensitive to the additional, nuanced needs of AYLHIV, including for: those who are pregnant or parenting; sex workers; sexual assault survivors; lesbian, gay, bi-sexual, transgender, intersex and questioning (BTIQ); disabled; homeless; displaced; and other special-needs individuals.

Key components of adolescent-friendly services

- Training/orientation needs to be provided to healthcare providers.
- Opening hours need to accommodate school-going youth.
- Youth-friendly sessions can be integrated into mainstream services. It is helpful to have dedicated sessions for adolescents, and if possible, separate youth-friendly areas in the clinic.
- Peer educators and peer counsellors can put young people at ease.
- It is important to engage with young people and provide opportunities for feedback about the services, and their potential for improvement.
- Services should be designed to provide integrated care, including HIV and SRH services.

Need to know more? *Guidelines for adherence to antiretroviral therapy in adolescents and young adults (expanded version): Recommendations, resources and references (2017) – Chapter 6* – provides additional information about: barriers to young people accessing health services, the key components of youth-friendly services, and encouraging youth participation in healthcare.

2.5 Simplification of regimens

- Given the difficulties experienced with adherence in some adolescents, regimen simplification can assist in improving adherence.
- Unfortunately this may be more difficult as an adolescent moves to second- and third-line regimens and develops further resistance mutations.

General principles

- Use fixed-dose combinations (FDCs) as far as possible; e.g. Atripla (efavirenz/emtricitabine/tenofovir – EFV/FTC/TDF) or equivalent when weight >40 kg and glomerular filtration rate (GFR) is normal
- Use abacavir/lamivudine (ABC/3TC), zidovudine/lamivudine (AZT/3TC), tenofovir/emtricitabine (TDF/FTC) combinations where possible instead of single drugs
- Aim for a once-daily regimen; e.g. Aluvia (lopinavir/ritonavir – LPV/r) and ABC/3TC can be given once or twice daily, but should be given once daily when possible
- Once-daily drugs include tenofovir (TDF), atazanavir (ATV) and some of the newer drugs, and these are good drugs to use to simplify regimens
- Atazanavir/ritonavir (ATV/r) is a good alternative to Aluvia if given with TDF/FTC
- Darunavir/ritonavir (DRV/r) can be given once daily as long as there are no associated DRV-resistance mutations
- FDCs are dependent on NDoH Tender and availability of drugs and formulations; therefore, these principles are subject to change as other drugs become available.

3. Mental health and adherence in adolescents and young adults

3.1 Overview

- Mental health disorders are defined as clinically significant behavioural or psychological impairment(s) of an individual's normal cognitive, emotional or behavioural functioning, associated with present distress and caused by physiological or psychological factors.
- Mental health disorders commonly start in adolescence between age 11 and 18 years, with depression and anxiety contributing the largest burden in this age group.
- Negative health and social outcomes include adolescent pregnancy, dropping out of school, and substance abuse.
- Despite recognition of the lifelong impact of mental health disorders, these receive relatively little attention in adolescents, and are frequently under-diagnosed and under-treated, *as routine screening is seldom conducted as a standard aspect of care*. Within families, under-reporting is common within families as mental health difficulties often attributed to normal adolescent behaviour.

3.2 Mental health and adherence

- From the perspective of adherence, the detection of mental health issues is of particular importance. While attention frequently focuses on promoting adherence to the treatment regimen, neurocognitive and mental health disorders *can* and *do* play a significant role in health outcomes. Vertically infected adolescents present with particularly high rates of emotional, behavioural and psychiatric disorders, exceeding rates in the general population and in other high-risk groups.
- Across the spectrum of chronic illnesses, adolescents find adherence to medication challenging; and this is often exacerbated by mental illness. In the context of HIV, the impact of mental health on treatment adherence is a serious concern: poor adherence increases the risk of HIV treatment failure and drug resistance, progressively limiting future ART options and increasing the likelihood of poor outcomes.
- Major depressive disorder is most commonly associated with HIV and has been widely linked to poor adherence and increased mortality. Even at subclinical levels, depressive symptoms have been found to disrupt adherence.
- Also relevant are: anxiety disorders, including generalised anxiety disorder, panic disorder and post-traumatic stress disorder; substance abuse disorder; attention deficit hyperactivity disorder; and impairments in cognitive function.
- Impairments in cognitive function – attention, memory, producing and understanding language, learning, reasoning, problem-solving and decision-making – also take a toll on health outcomes in AYLHIV. Milder forms of neurocognitive disturbance are recognised in HIV-positive children and adolescents, including milder forms of the HIV-associated neurocognitive disorders (HANDs) seen in adults. These are often overlooked, but can have implications for functioning at various levels including academic performance. Although initiation on ART improves cognitive functioning, particularly if treatment is started early, AYLHIV may present with deficits in specific areas, such as executive function, that may have implications for health literacy and adherence as they move towards taking more responsibility for their healthcare.

3.3 Co-morbid conditions with mental health

The presence of more than one mental health problem is also not unusual; for example, depression with co-morbid substance abuse. Substance abuse is the consumption and misuse of various dependence-forming substances such as alcohol, cannabis,

cocaine, heroin, methamphetamines and nyaope. It has serious, multifaceted and devastating impacts on the health of AYLHIV, including lower treatment adherence, increased sexual risk behaviour, anti-retroviral (ARV) regimen interference, incomplete viral suppression and disease progression.

3.4 Supporting adherence through early detection

- It is crucial to ensure adherence by linking key adolescent populations to programmes for early detection and management.
- *The National Mental Health Policy Framework and Strategic Plan (2013 - 2020)*^[8] states that mental health should be integrated into all aspects of healthcare, and must target certain vulnerable

groups including children and adolescents and PLHIV. In a similar vein, the *Child and Adolescent Mental Health Policy Guidelines (2013)*^[9] asserts that all front-line providers should be able to recognise and manage mental health issues in these populations. Early detection of mental health problems, appropriate referral and effective intervention can do much to improve the health outcomes of AYLHIV.

3.5 Referral

- Despite limited referral sites, some adolescents will require referral (see Table 1 for assessment) and it is important to collate information regarding referral and support resources within the catchment area of the relevant facility.

Table 1: Mental health assessment tool for referral

These questions are not intended as a diagnostic tool, but can be asked by the healthcare provider to assess the need for referral to a mental health professional. Referral should be made if any of the 'often' boxes are ticked.

1. Do you worry a lot about things and find the worry just won't go away?

Never	Once or twice	Often
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2. Do you find that you have difficulty paying attention or concentrating on what people say to you at school or at home?

Never	Once or twice	Often
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3. Do you ever use alcohol to relax, feel better about yourself or fit in? (If yes, ask Q4)

Never	Once or twice	Often
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4. Has the use of alcohol or drugs meant that you haven't been able to do things that are expected of you at school or in the family?

Never	Once or twice	Often
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5. Do you ever feel worthless, hopeless, feel that you let people down all the time or are not a good person?

Never	Once or twice	Often
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6. Have you ever had thoughts, plans or actions about suicide or self-harm?

Never	Once or twice	Often
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7. Have you ever experienced or witnessed an event that caused you to feel intense fear, helplessness or horror? Do you think or dream about what happened and seem unable to put it out of your mind?

Yes	No
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8. Sometimes when they are alone, people hear voices, see things or smell things and they don't quite know where these things come from. Has this ever happened to you?

Never	Once or twice	Often
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- Referral systems and networks need to be established, ensuring that referral processes are youth-friendly. Interventions include making contact with the referral personnel, referring to a named provider where possible, and giving clear directions on how to access the service. It is preferable to accompany the adolescent to the referral point, wherever possible.
- Recommended mental healthcare referral sites where adolescents can be provided with psychotherapy and medication include community mental health clinics, hospital psychology departments, university psychology services for external patients or psychological assessment centres, and non-governmental (NGOs) and community-based (CBOs) organisations.

Need to know more? *Guidelines for adherence to antiretroviral therapy in adolescents and young adults (expanded version): Recommendations, resources and references (2017) – Chapter 5* – provides additional information about mental health and adherence in adolescents, mental health and substance abuse screening and assessment, counselling and referral.

4. Differentiated service delivery for all adolescents and young adults

- Differentiated service delivery (DSD) is a patient-centred approach to care that simplifies and adapts HIV services across the treatment cascade according to differing needs. The approach aims to offer less-intensive services to those who are stable on ART, thereby releasing resources to patients who require more intensive care and follow-up.
- To build a patient-centred DSD model, it is necessary to define and cluster: the core needs of the patient population (e.g. adult or adolescent), other defining population characteristics (e.g. MSM, sex worker), their clinical characteristics (e.g. stable or unstable), and their context (e.g. urban or rural).
- The WHO identified four clinical types of PLHIV to illustrate the diversity of clinical needs: patients presenting well, patients presenting with advanced disease, stable patients, and unstable patients – each requiring different care packages.
- Once the population has been defined, the following four questions need to be answered for clinical consultations and ART refill collection (Table 2): *Visit frequency*: When is care provided?; *Location*: Where is care provided?; *Provider*: Who is providing care?; *Service package*: What care or services are provided?

Table 2: Four questions regarding differentiated care

<i>When?</i>	<i>Depending on the situation:</i> Monthly; Every 2 months; Every 3 months; Every 6 months
<i>Where?</i>	HIV clinic; Hospital; Clinic; NGO; CBO; Home
<i>Who?</i>	Physician; Nurse; Pharmacist; Community health workers; Parent/guardian; Family; Adherence support counsellor; Treatment buddy
<i>What?</i>	ART initiation; Refills; Clinical monitoring; Adherence support; Laboratory tests; Opportunistic infections; Psychosocial support

ART – antiretroviral therapy; CBO – community-based organisation; NGO – non-governmental organisation.

Differentiated care – relevance for adolescents/young adults and adherence

Adolescents have a lifetime of ART management ahead. Sustained adherence, often from early childhood through adolescence into adulthood, is essential to reduce the risk of morbidity and mortality.

To date, focus has been placed on DSD models for adult patients who are stable on ART. Adolescent outcome studies report sub-optimal adherence and poorer outcomes than their adult counterparts. Access to DSD options that strive to support routine life-paths for AYLHIV should be considered as soon as feasible after treatment initiation, including: limited time in health facilities, uninterrupted school attendance, increased time with peers, etc.

Need to know more? See Annexure 1 for links to further information regarding differentiated care.

WHO guidance for differentiated ART delivery for adolescents

The WHO suggested the following:

- WHO eligibility criteria for DSD for stable adults also apply to adolescents.
- Adolescent DSD models should engage parents/caregivers to provide a support structure while fostering independence.
- DSD for adolescents requires consideration of building blocks (*when, where, who* and *what?*) for clinical review, ART refill, plus psychosocial support. The appropriate suggested building blocks for stable adolescents are described in Table 3.

Table 3: Key considerations for differentiated ART delivery for clinically stable adolescents

Eligibility for adolescents: Same as WHO recommendation for adults (at least one year on ART, no adverse drug reactions that require more frequent clinical monitoring, no current illnesses including mental health conditions, a good understanding of lifelong adherence and evidence of treatment success (two consecutive VL measurements of <1 000 copies/ml) and access to psychosocial support.

	ART refill	Clinical consultation	Psychosocial support
When?	3-6-monthly [§] [‡]	3-6 monthly [§] [‡]	1-6 monthly
Where?	Primary healthcare/out-of-facility	Primary healthcare/outreach from primary healthcare	Primary healthcare/out-of-facility/ virtual environment
Who?	Lay provider*	Nurse*	Lay provider/Peers
What?	ART refill Referral check Adherence check	<ul style="list-style-type: none"> • Adolescent clinical consultation • Mental health assessment • Laboratory testing: VL annually; or if not available, then CD4 count 6-monthly • Re-script: Cover period between clinical consultations 	<ul style="list-style-type: none"> • Peer group environment • Referral check • Onward disclosure support

ART – antiretroviral therapy; AYA – adolescent/young adult; AYLHIV – adolescents and youth living with HIV; MH – mental health; PHC – primary healthcare; SMS – short message service; SRH – sexual and reproductive health; VL – viral load; WHO – World Health Organization.

[§] If adolescents are away at school extending ART refills to accommodate school terms should be given priority.

[‡] In general do not need to be clinically reviewed more than twice a year.

[‡] If possible, adolescent friendly service hours (late afternoon and/or Saturdays) could be considered.

* Adolescent-friendly orientation should be considered.

Source: World Health Organization; 2017. Key considerations for differentiated antiretroviral therapy delivery for specific population: children, adolescents, pregnant and breastfeeding women and key populations.

5. ART service-delivery building blocks

5.1 ART maintenance – first year on ART (initiation to second viral load)

Below are key points for the initiation and first year of ART, together with a summary of service-delivery building blocks (Table 4):

Key points

- HIV care as close to home as possible.
- Treatment for all irrespective of CD4 count.
- Rapid ART initiation – defined for the purposes of these guidelines as within 7 days of diagnosis – with two ART preparation sessions from HIV diagnosis to the day of initiation (ideally aligned with these dates, not requiring additional clinic visits).
- Aligned ART refill and clinical review visits.
- Psychosocial support in the form of support group participation can also be aligned or provided separately at community level.
- Youth-orientated service provision to the extent that the context allows – i.e. AYLHIV-oriented staff, hours or allocated space within the clinic.

- Frequency of clinic visits kept to the minimum. Where AYLHIV are struggling with illness, adherence or social environment issues, clinician/counsellor/pharmacy consideration should be given to whether increasing visit frequency is desirable or whether intensified support can be provided without increasing visit frequency.

5.2 ART maintenance – from second year on ART onwards (after second viral load)

Below are key points for ART maintenance from the second year on ART, together with a summary of service-delivery building blocks (Table 5):

Key points

- Simplify ongoing access to HIV care as far as possible to support long-term adherence.
- Prioritise a reduced frequency of HIV-care-related visits, with longer periods between ART refills, quick pick-up and psychosocial support services as close to home as possible.
- Clinical reviews do not need to take place at every ART refill visit. Consider de-linking ART refill collection and psychosocial support from clinical review visits.

Table 4: Service-delivery building blocks: ART maintenance for first year on ART (initiation to second viral load)

	Stable at initiation <i>Defined as: clinically well, CD4 >200 cells/μl, no high-risk psychosocial concerns</i>		Unstable at initiation <i>Defined as: clinically unwell, CD4 <200 cells/μl, high-risk psychosocial concerns</i>	
	Clinical review + ART refill	Psychosocial support	Clinical review + ART refill	Psychosocial support [§]
When? (visit frequency)	m0, m1, m3, m6, m7, m9, m12, m13*	1 - 3-monthly	Monthly [†]	1 - 3-monthly
Where? (visit location)	PHC facility	PHC facility or in community	PHC facility/specialised paediatric service (if available) [‡]	PHC facility or in community
Who? (service provider)	<ul style="list-style-type: none"> Nurse Lay HCW 	<ul style="list-style-type: none"> Lay HCW CBO worker 	<ul style="list-style-type: none"> Nurse (with access to expert clinical support if needed) Lay HCW 	<ul style="list-style-type: none"> Lay HCW CBO worker Social worker Community psychologist
What? (service package)	<ul style="list-style-type: none"> Clinical examination: 1m, 3m, 7m and 13m, specifically checking for IRIS or any side-effects VL: 6m, 12m[¶] VL results: 7m, 13m CD4 count: 12m TB screen: at each visit SRH screening e.g. FP, STIs: at each clinical examination visit MH screening (see Table 1): 1m, 7m, 13m Risk factors (substance abuse/IPV etc.): at each visit Requires any additional support (e.g. CCG for child): as needed <p>Notes:</p> <ul style="list-style-type: none"> If any concerns, then move to unstable group. Include three ART preparation sessions (pre-start, at ART start and m1) and MH screening. If necessary, include nurse assessment at ART start, m6/7 and m12/13; m13 includes stability assessment. 	<ul style="list-style-type: none"> Stability assessment Post-ART-initiation one-on-one adherence support session: 1m Peer-support-group environment 	<ul style="list-style-type: none"> Include all in 'stable' package plus: If OI or clinically unstable: monthly clinical examinations until clinically stable (resolved TB, etc.) VL: same as stable patients, but if VL >1 000 copies/ml, then step-up adherence and repeat VL after 3 months Additional blood test monitoring: as indicated, e.g. ALT if on TB treatment Track appointments and pharmacy refill, if possible Psychologist/psychiatrist assessment: as applicable 	<ul style="list-style-type: none"> Peer-support environment One-on-one adherence and other support counselling including: 1m for post-ART-initiation session Every month until m6 if there are psychosocial concerns requiring additional support Three enhanced adherence sessions if VL >1 000 copies/ml Social services support
Appropriate service-delivery model examples	<ul style="list-style-type: none"> Youth clubs (see section 7.1) Facility care plus attendance at community/facility support group 		<ul style="list-style-type: none"> Facility care plus attendance at community/facility support group 	

ALT – alanine transaminase; ART – antiretroviral therapy; AYLHIV – adolescents and young adults living with HIV; CBO – community-based organisation; CCG – child care grant; DSD – differentiated service delivery; FP – family planning; HCW – healthcare worker; IPV – intimate partner violence; IRIS – immune reconstitution inflammatory syndrome; m – month(s); MH – mental health; OI – opportunistic infection; PHC – primary healthcare; SRH – sexual and reproductive health; STIs – sexually transmitted infections; TB – tuberculosis.

* Where a facility has the capacity to recall AYLHIV with high VLs effectively, it is possible to schedule visit frequency as follows: ART start, m3 and 3-monthly thereafter, recalling any AYLHIV patient with a high VL immediately for repeat consultation.

† Consider the reason(s) for instability and whether visit frequency can be reduced throughout the first year. Provided that AYLHIV consent has been obtained, prioritise caregiver involvement.

‡ Specialised paediatric services must be utilised for complicated clinical cases, e.g.: TB, psychiatric complications or multi-treatment.

§ Prioritise access to a support-group environment. If this is not available in the community, then consider starting a group within the facility (refer to Chapter 3.1 in the extended guidelines in this regard).

¶ For VL visits, give the patient the laboratory form at the previous visit. This is a quick visit for blood tests only, unless any concerns are raised. A full visit is conducted at the next visit when the VL results are available.

Table 5: Service-delivery building blocks: ART maintenance from second year on ART (after second viral load)

	Stable on ART <i>Defined as: on ART for 12 months; two consecutive VLs <1 000 copies/ml, no acute illness, side-effects or psychosocial issues requiring more regular clinical follow-up</i>			Unstable on ART <i>Defined as: not stable</i>	
	Clinical review	ART refill	Psychosocial support	Clinical review + ART refill	Psychosocial support[†]
When? (visit frequency)	6-monthly	3-monthly	1 - 3-monthly	1 - 3-monthly*	1 - 3-monthly
Where? (visit location)	PHC or mobile outreach from PHC	PHC or in community	PHC or in community	PHC/specialised paediatric service (if available) [‡]	PHC or in community
Who? (service provider)	<ul style="list-style-type: none"> Nurse 	<ul style="list-style-type: none"> Lay HCW CBO worker Private provider 	<ul style="list-style-type: none"> Lay HCW CBO worker 	<ul style="list-style-type: none"> Nurse (with access to expert clinical support if needed) Lay HCW 	<ul style="list-style-type: none"> Lay HCW CBO worker Social worker Community psychologist
What? (service package)	<ul style="list-style-type: none"> Clinical examination: annually TB screen: each visit SRH screening: each visit MH screening for risk factors (substance abuse/IPV etc.): each visit VL and CD4: annually[§] VL and CD4 results and annual check-up to coincide Any additional support (e.g. CCG for child): as needed 	<ul style="list-style-type: none"> ART refill Adherence check Referral check 	<ul style="list-style-type: none"> Peer-support-group environment Adherence check Referral check 	<ul style="list-style-type: none"> Include all in 'stable' package plus: If OI or clinically unstable: monthly clinical examinations until clinically stable (resolved TB, etc.) If clinically stable: 6-monthly examinations VL as opposite, but if VL >1 000 copies/ml, then step-up adherence and repeat VL after 3 months Additional blood test monitoring as indicated, e.g. ALT if on TB treatment Track appointments and pharmacy refill, if possible Psychologist/psychiatrist assessment: as applicable Assess whether possible to move to stable management: every visit 	<ul style="list-style-type: none"> Peer-support environment[†] One-on-one adherence and other support counselling including: Every month if there are psychosocial concerns requiring additional support Three enhanced adherence sessions if VL >1 000 copies/ml Social services support
Appropriate service-delivery model examples	<ul style="list-style-type: none"> Youth clubs Saturday or after-school-hours clinic for AYLHIV Community-/clinic-provided fast ART pick-up and support groups (see section 7.3) 			<ul style="list-style-type: none"> Adolescent treatment failure intervention (see section 9) Youth clubs plus intensified clinical/adherence support 	

ALT – alanine transaminase; ART – antiretroviral therapy; CBO – community-based organisation; CCG – child care grant; DSD – differentiated service delivery; FP – family planning; HCW – healthcare worker; IPV – intimate partner violence; IRIS – immune reconstitution inflammatory syndrome; MH – mental health; OI – opportunistic infection; PHC – primary healthcare; SRH – sexual and reproductive health; STIs – sexually transmitted infections; TB – tuberculosis.

* At the discretion of the clinician, dependent on the reason for instability, with a continued focus on reducing frequency to support adherence as soon as possible.

† Prioritise access to a support-group environment. If this not available in the community, then consider starting a group within the facility (refer to Chapter 3.1 in the extended guidelines in this regard).

‡ Specialised paediatric services are only to be utilised for complicated clinical/psych cases. Where these require infrequent clinical follow-up, ART refills should be de-linked and provided at PHC level in between specialised facility visits.

§ For VL visits, give the patient the laboratory form at the previous visit. This is a quick visit for blood tests only, unless any concerns are raised. A full visit is conducted at the next visit when the VL results are available.

6. Moving between stable and unstable classifications

AYLHIV patients are on ART for life. During the period of adolescence and young adulthood there are likely to be periods of instability, possibly requiring multiple transfers between stable and unstable categorisations. This needs to be managed smoothly with the participation of the AYLHIV, and with as little disruption to their life as possible. The points below summarise the management of moving between stable and unstable classifications.

6.1 Stable to unstable

- Criteria include: high VL, acutely unwell, pregnant, high-risk psychosocial issue(s) requiring attention, or missed appointment for more than 30 days with missed doses.
- The patient does not necessarily have to be taken out of their existing service-delivery model, but could have additional/intensified clinical or psychosocial visits added. This is especially relevant where removing AYLHIV from a strong peer-support environment may prove harmful.

6.2 Unstable to stable

- Requires a VL <1 000 copies/ml and management of clinical or psychosocial issues
- Requires continual assessment to ensure the patient does not remain in the unstable category unnecessarily with increased visit frequency and longer visits. This can be demotivating and lead to a break down of trust in the healthcare system.

7. Service -delivery models to support adherence in adolescents

In order to meet the needs of AYLHIV and provide effective adherence support, flexible, responsive and adaptive service-delivery models are required. Examples of different service-delivery models are described –including the youth club model, Saturday morning and after-hours clinics, mechanisms to fast-track ART refill pick-up, clinic- and community-based support groups, and treatment failure interventions. Adherence support can be reinforced further through the use of social media and youth-focused material.

7.1 Youth club care model

- The youth club care (YCC) model is included in the National ART Adherence Guidelines as an additional recommended intervention.^[4] The model, summarised in the expanded version of these guidelines, has proven to be an effective group-management approach to providing integrated clinical, ART refill and psychosocial care that supports adherence and RIC.

- The YCC model supports effective transition from adolescence to early adulthood, as youth clubs can evolve into adult clubs, ensuring continuity of care.
- The YCC model aims to improve ART initiation and adherence among newly initiated and ART-stable AYLHIV aged 12 - 24 years.
- YCC members are grouped into closed clubs of 15 - 20 members according to age and can be differentiated further by mode of transmission (perinatal or horizontal).
- Where CBOs are already running functioning peer-support environments such as support groups, consideration could be given to supporting the integration of ART refill distribution to the stable AYLHIV members taking part in the group.

7.2 Saturday or after-hours (after school) clinics

- In South Africa and the broader region, examples exist of models that integrate clinical review, ART refill collection and peer psychosocial support outside of routine clinic hours specifically for AYLHIV. For example, Saturday morning Teen clinics, provide age-segmented group adherence, psychosocial support and youth activities while AYLHIV individually collect pre-packed ART refills and are seen clinically.

7.3 Community-/facility-provided fast ART refills and support groups

- Where stable AYLHIV only need to see a clinician every 6 - 12 months for clinical review, they can also be provided with access to fast ART refill collection options.
- Similarly to adults, AYLHIV can attend the pharmacy directly to pick up their ART refill (ideally after school hours) without having to queue at the reception or see a clinician.
- They could also have the option to collect their ART refills outside of the facility at community pick-up points such as those provided by mobile outreach services or supplied by the Central Chronic Medicine Dispensing and Distribution (CCMDD) programme.

7.4 Additional tools to support adherence

Additional adherence support that can be added to service-delivery models include:

- Mobile technology interventions:
 - B-wise app
 - 'Whatsapp' groups for virtual peer support
 - SMS appointment and adherence reminders.
- Treatment literacy materials aimed at, or adapted for AYLHIV.

8. Mapping of community services

- For most adolescents receiving ART, the frequency of clinic visits is monthly to quarterly. Between these times, adolescents should have access to community-based support. This provides a stabilising influence, especially when youth are struggling with adherence and other challenges.
- It is important to identify and map available resources.

The value of community mapping

- It is important for facilities to do mapping of community services to determine the support that could be leveraged. Healthcare providers need to recognise the important role that community systems can play, e.g.:
 - Providing structured psychosocial support groups encompassing prevention education and SRH
 - Providing direct support to youth on ART with referral links to clinical services.
- Community resources can be utilised more formally as part of the service-delivery model, e.g.:
 - Existing CBO-run support groups could facilitate distribution of ART refills (i.e. AYLHIV referred from clinics to this service for both ART refills and psychosocial support)
 - ART refill could be managed through a fast pick-up system either at a community point or clinic, and the AYLHIV attends a CBO-provided support group.
- Establishment of a functional, bi-directional referral system between CBOs and the facility is recommended. The introduction of a referral form, for example, is helpful to encourage community partners to refer AYLHIV patients back to the facility for their next clinical review. Accompaniment of AYLHIV patients should be encouraged.
- Some AYLHIV may be referred to community services from the local or regional hospital services. These referrals will need to be linked to community structures and the necessary referral systems need to be established to address this level of referral.

Need to know more? *Guidelines for adherence to antiretroviral therapy in adolescents and young adults (expanded version): Recommendations, resources and references (2017) – Chapter 9* – provides additional information about the benefits of working with community structures, the importance of partnerships, patient mapping and referrals, and linking youth to services.

9. Treatment failure intervention

9.1 What is paediatric HIV treatment failure?

Treatment failure in AYLHIV can be categorised as *virological failure* (high VL), *immunological failure* (low CD4 count), *clinical failure* (development of opportunistic infections and other illnesses), or a combination of the three.^[2]

Virological failure: In South Africa, virological failure in AYLHIV is defined as two VLs >1 000 HIV RNA copies/ml on two consecutive occasions 2 months apart.

9.2 Causes and consequences of HIV treatment failure in adolescents and young adults

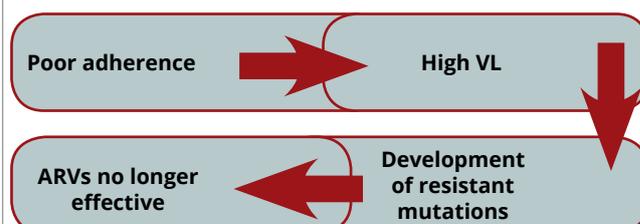
For most patients with treatment failure, the cause is *secondary* ARV failure due to **poor adherence**. ART must be taken >95% of the time to achieve virological suppression, which **equates to missing only two or three doses of ARVs per month**. This is difficult to achieve and is the major reason for the high treatment failure rate among adolescents.

Causes and consequences of poor adherence are summarised in Table 6.

Table 6: Causes and consequences of poor adherence in adolescents and young adults

Patient-related causes	Health-system-related causes
<ul style="list-style-type: none"> • Treatment fatigue • Influence of peers • Unwell/unstable/varying caregiver • No treatment supporter • Food insecurity • Disclosure issues • Stigma • Alcohol abuse • Mental illness (patient or caregiver) • Unstable home life • Multiple barriers 	<ul style="list-style-type: none"> • Complicated treatment regimens • Poor palatability of drugs • Poor HIV education • Lack of treatment drugs available • Stock-outs of ARVs • Poor patient support and tracing

Development of resistance due to poor adherence:



ARVs – antiretrovirals; RIC – retention in care; VL – viral load.

- Once resistance has developed to a specific ARV, it will no longer be effective and the adolescent will need to switch to an alternative ARV regimen – either second- or third-line depending on the current failing regimen – adherence to which can be even more difficult and may cause additional side-effects.
- *Cross-resistance* may develop to other drugs within the same ARV class, particularly the non-nucleoside reverse transcriptase inhibitors (NNRTIs).

in Table 7. Some are essential for a successful programme, and others are recommended, depending on available resources.

Need to know more? *Guidelines for adherence to antiretroviral therapy in adolescents and young adults (expanded version): Recommendations, resources and references (2017) – Chapter 2.6* – provides additional information about monthly data-collection indicators.

9.3 Adolescent HIV treatment failure programme

The components needed to start an adolescent HIV treatment failure programme are described

Table 7: Adolescent HIV treatment failure programme

Component	Required or Recommended?	Description
DoH and clinic support	Required	Before establishing a treatment failure programme, it is important to gather support and buy-in from key DoH representatives and clinic personnel. Discussions with DoH officials, facility managers and others will be necessary to gain consent. Once obtained, it can be helpful to inform the full staff complement about the programme.
Dedicated, youth-friendly space for the programme	Recommended	While a space to see patients is obviously a necessary component, having a <i>dedicated space</i> to provide adolescent treatment failure services can be beneficial – with adolescent-oriented medical equipment, materials and supplies, and the provision of ‘youth-friendly’ posters, pamphlets and books. This space can also be used to hold support groups. It is recognised, however, that many clinics are extremely short of space and it may not be practical to have a room allocated solely to adolescents; consultations and adherence counselling can be performed adequately within the existing clinic set-up.
Flagging system for high VLs	Required	It is imperative to establish a system to flag high VLs – without this it will be difficult to know which adolescents are failing treatment and require enrolment into the programme. The following is required to implement a flagging system: <ul style="list-style-type: none"> • A designated person (clerk, nurse, doctor, etc.) to follow up VL results for returning patients (ideally, on a weekly basis). • A notification system to alert the clinician if the VL is high (e.g. marking the patient folder with a visible identifier, such as a star or circle). • A referral system to schedule high VL patients to attend the programme.
Adolescent adherence tools	Required	As poor adherence is the main cause of treatment failure, good adherence counselling is the most important intervention in an adolescent treatment failure programme. Comprehensive adherence documents are available that provide step-by-step guidance for counselling adolescents about adherence to ARVs.
Adolescent ‘champions’ and a passionate healthcare team	Recommended	An adolescent programme will be much more successful if the people involved have a genuine interest in caring for adolescents. Such ‘adolescent champions’ take the lead in scheduling adolescent patients and overseeing the day-to-day organisation of the programme. Responsibilities include: <ul style="list-style-type: none"> • Doctor: oversee organisation of programme activities (daily clinic, support clubs); provide clinical care to patients; teach adherence modules to patients; send, follow up and interpret laboratory results including genotypes; complete programme patient data forms; provide guidance and mentorship to programme nurses and counsellors; oversee scheduling of patients and follow up patients LTFU. • Nurse: provide clinical care to patients and refer to the programme doctor (if available) with any questions; teach the programme adherence modules to patients; draw blood samples for laboratory testing; schedule patients for clinic and follow-up if patients are LTFU; complete programme patient data forms. • Counsellor: facilitate programme support group meetings; assist doctor and nurse with scheduling of patients; assist with overall patient flow in the clinic; assist doctor and nurse with translation (if needed).
Support groups	Recommended	<ul style="list-style-type: none"> • Support groups can be a powerful way for people to learn about HIV and troubleshoot problems related to ART administration. Led by a facilitator, these 30 - 40-minute structured sessions enable adolescents to share their ART experiences and learn from one another. Specific discussion topics include alcohol and drug use, dating, contraception, ARVs and school attendance, among others. During a productive support group, the participants do most of the talking among themselves, with the facilitator speaking only infrequently to clarify misconceptions. If possible, these sessions should be held before the individual follow-up appointments.

ART – antiretroviral therapy; ARVs – antiretrovirals; DoH – Department of Health; LTFU – lost to follow-up; VL – viral load.

10. Adherence support for more vulnerable groups of adolescents and young adults

10.1 Pregnant and/or breastfeeding adolescents and young adults

- An overwhelming majority of the estimated 1.4 million women living with HIV who give birth every year reside in sub-Saharan Africa. Although ART adherence is necessary to ensure good health for all PLHIV, it is particularly critical for pregnant and breastfeeding women in order to prevent maternal disease progression and reduce mother-to-child transmission of HIV (MTCT). Compared with their older counterparts, pregnant AYLHIV have poorer outcomes at a number of steps along the HIV care continuum, including an increased risk of MTCT and poorer maternal and infant health outcomes.
- ART adherence presents a significant challenge for pregnant AYLHIV.
 - Studies examining age as a variable in ART adherence in pregnancy have consistently found a negative association with younger age (<25 years old).^[5-9]
 - There is increased stigma associated with teenage pregnancy, in addition to high losses to care especially after delivery. Frequently, pregnant teens are no longer regarded as adolescents eligible for adolescent services.
- Pregnant AYLHIV require specific considerations and services in order to support ART adherence and good health through pregnancy and the post-partum period.

Interventions to support adherence for pregnant adolescents and young adults

- Differentiated care: It is important to gain or retain access to stable differentiated care models during this challenging time for pregnant or new young mothers with increased healthcare visits for infants.
 - If already in the stable model, then consider not removing the patient only due to pregnancy, but ensure that she attends antenatal mother-and-child (infant follow-up) care.
 - If diagnosed during pregnancy, fast-track the patient into stable models post delivery once two VLs are <1 000 copies/ml.
- Identify community-based parenting support groups.

It is not advisable to transition AYLHIV to adult services early due to pregnancy, as often this can make the young pregnant woman more vulnerable.

10.2 Key populations

- There is increasing focus on the needs of key adolescent populations including young sex workers, MSM, LGBTIQ and people who inject drugs. This extends to adolescents with increased vulnerabilities, such as those who are disabled, orphaned, part of child-headed households, homeless, sexually abused or exploited, or in correctional institutions or care homes.
- HIV prevalence is higher in key populations than in the general population because of engagement in higher risk behaviours. Legal and social issues also render these populations more vulnerable due to discriminatory laws and policies, stigma and prejudice, with associated barriers to health services.
- PLHIV from key populations face stigma, exclusion, harassment and violence on two fronts: because of their HIV status and because they are from a key population.
- Despite the number of new HIV infections occurring in these populations, they often have the least access to prevention, treatment and care.

The provision of health services that are available, accessible and acceptable to adolescent key populations requires additional effort, outreach and sensitivity, as recommended below.

Interventions to support adherence in key populations

- Differentiated care: It is important to consider which models of care can work with support services for specific key populations in order to support adherence.
 - It may be appropriate not to include a patient from a key population in the general AYLHIV group model of care (unless desired by the patient).
 - Key populations are not homogenous; the needs of the sub-group must be assessed.
 - Individualised models of care should be considered: quick community/facility ART refill pick-up plus support from specific key-population-sensitised services or access to mobile services for specific key populations such as sex workers or MSM AYLHIV. Alternatively, the patient may prefer to collect ART refills from pick-up points and attend support groups specifically tailored to their needs.
- Training and capacitation of healthcare providers can improve treatment adherence and RIC.

- Skills-based, values-clarification workshops can serve to counteract the stigma and discrimination that deter young people from accessing health services; encompassing skills in non-judgemental communication, and an understanding of the challenges young key populations face related to HIV disclosure, violence, discrimination and judgment.
- Be aware of the range of needs faced by adolescents from key populations in addition to healthcare needs. Referral to other service providers to address these needs may indirectly support adherence by promoting self-efficacy.
- Develop interventions to enhance community involvement among key populations – peer support is particularly important to sustain adherence; e.g. adherence support groups.

10.3 Adolescents and young adults with disability

AYLHIV with disability face ongoing challenges with disclosure and in accessing HIV counselling and treatment services. Reasons for this include:

- Disabled persons are stigmatised and may not seek medical assistance.
- Healthcare providers are not trained to work with persons with disabilities, may lack knowledge about disability issues, or have misinformed attitudes towards such persons. Healthcare providers often feel overwhelmed and unsettled when confronted by a person with a disability.
- Services offered at clinics, hospitals and other locations may be physically inaccessible, lack South African Sign Language (SASL) interpreters, or fail to provide information in alternative formats such as Braille, audio or easy-to-understand language.
- Confidentiality for persons with disabilities during HIV testing and counselling may be compromised, for example, by the need for a personal assistant or SASL interpreter to be present.
- In settings with limited ART and post-exposure prophylaxis (PEP), persons with disabilities may be considered low priority for treatment.
- Health professionals may not pay enough attention to the potential for negative drug interactions between ART and the medications that persons with disabilities are taking. Some medications may actually worsen the health status of persons with co-morbid health conditions such as depression.

Interventions to support adherence for disabled adolescents and young adults

- Differentiated care: It is important to consider how to reduce the frequency of health facility

visits and provide access to supportive group environments.

- Engaging CBOs or ward-based outreach teams (WBOTs) for home delivery of ART refills would support reduced trips to the clinic.
- Identifying and facilitating access to support groups: AYLHIV with disabilities are often already isolated. It is therefore important to identify support groups for people with disability or after-school programmes.
- Assessing the needs of disabled AYLHIV: explore whether they are comfortable with being included in general AYLHIV group models of care, or whether there is a preference for separate services adapted to their needs.
- Adapted treatment literacy tools, where possible.
- Include training for professionals working in the area of disability and HIV, including rights and sensitisation to the respective needs of different sub-groups.
- Provide adequate HIV training and support for personal assistants, SASL interpreters and other people who support persons with disabilities, with a particular focus on rights and confidentiality.

11. Transitioning care

11.1 Overview

- AYLHIV transition from paediatric to adolescent care, and from adolescent to adult healthcare.
- The shift not only has implications for the medical care required, but necessitates an adaptation on the part of the young patient, especially related to the associated comfort and familiarity with respective services.

Transitioning is a **purposeful, planned process** to facilitate and support the movement of young people with special health needs into different levels of care – from child- to adult-centred healthcare.

11.2 Common barriers to transitioning

- Common barriers have been identified regarding transitioning adolescents with chronic diseases into adult care. Many young patients experience worry and anxiety about transitioning and have a difficult time adjusting to new staff, different systems, and the increased responsibility and expectations in an adult care setting.
- The complexities of living with HIV compound the issues, and can make the transition more difficult for this population than for adolescents with other chronic illnesses.^[7]

11.3 Prerequisites for a smooth transition

The essential requirements for a smooth transition include: preparation, disclosure, a transition plan, familiarisation visits, a multi-disciplinary approach, and referral to age-appropriate services.

11.4 Transitioning and adherence

The key considerations for transitioning and adherence for AYLHIV are summarised in Table 8.

Table 8: Key considerations for transitioning and adherence in adolescents and young adults	
Transitioning from paediatric to adolescent/young adult services	<ul style="list-style-type: none"> Clinical: ensure simplification of regimens to support lifelong adherence and retention in adult services Puberty/SRH assessment Service-delivery model or location transition: prioritise orientation of AYLHIV (and, if possible, caregiver) at a new service-delivery facility or to a new service-delivery model. This is relevant even if the transition is within the same facility, e.g. from paediatric to AYLHIV clinic hours or to a youth club.
Transitioning from adolescent/young adult to adult services	<ul style="list-style-type: none"> Service-delivery model or location: prioritise orientation of AYLHIV (and, if possible, caregiver) at a new service-delivery facility or to a new service-delivery model. This is relevant even if the transition is within the same facility, e.g. from adolescent/young adult clinic hours or to an adult adherence club.
Important considerations	<ul style="list-style-type: none"> Where AYLHIV are in a group service-delivery model, consider transitioning the entire group/some of the peer group to adult services; e.g. a youth club can transition into an adult club managed by adult services. Where an AYLHIV is in an individual service-delivery model, ensure that the adult service-delivery model is not more onerous; e.g. if the patient had after-hours access for ART refill pick-up, do not require daytime collection at the clinic.
AYLHIV – adolescent(s) and/or young adult(s) living with HIV; SRH – sexual and reproductive health.	

Need to know more? *Guidelines for adherence to antiretroviral therapy in adolescents and young adults (expanded version): Recommendations, resources and references (2017) – Chapter 11* – contains detailed information about transition, including: transition from paediatric, to adolescent- and youth-friendly, to adult healthcare; common barriers to transition; challenges to successful transitioning of AYLHIV; models of transition; practical approaches for transitioning; and the prerequisites for a smooth transition.

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Annexure 1: Tools and resources for ART adherence in adolescents and young adults

Note: This is not a comprehensive list of all resources, but represents tools and resources utilised and referred to in these guidelines.

Resource	Link/Contact
Caregiver support groups	https://tulane.box.com/s/v91fqs9hmzrk0kzroifb9423pbw60bkl .
Talk Tool (Zoe-Life – Kidz Alive Resources, 2015)	http://zoe-life.co.za/kidzalive/#resources
Support Clubs (Right to Care, 2014)	Tel.: +27 (0)71 372 3550 for more info
Flipster Support Club Tool (Right to Care, 2015)	
Mini Disclosure Flipster Tool (Right to Care, 2016)	
Working with Adolescents Living with HIV: Handbook and Toolkit for Healthcare Providers ^[10]	http://www.wrhi.ac.za/uploads/files/ALHIV_12August2015-1.pdf
I-ACT documents (<i>nationally mandated, so these are made available by the training partner in the specific province, e.g. by the HPCSA in Gauteng</i>)	B-wise (http://www.bwisehealth.com)
Differentiated care	http://www.differentiatedcare.org/Portals/0/adam/Content/yS6M-GKB5EWs_uTBHk1C1Q/File/Decision%20Framework%20REPRINT%20web.pdf
	http://www.who.int/hiv/pub/meetingreports/hiv-differentiated-service-delivery-report/en/
National Adherence Guidelines for HIV, TB and NCDs, 2016 ^[11]	http://www.hst.org.za/publications/adherence-guidelines-hiv-tb-and-ncds
National Mental Health Policy Framework and Strategic Plan, 2013 - 2020 ^[8]	https://www.health-e.org.za/wp-content/uploads/2014/10/National-Mental-Health-Policy-Framework-and-Strategic-Plan-2013-2020.pdf
Child and Adolescent Mental Health Policy Guidelines, 2013 ^[9]	http://www.gov.za/sites/www.gov.za/files/childmentalhealth_0.pdf

