Working with adolescents living with HIV

A handbook for healthcare providers
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<td>Abacavir</td>
</tr>
<tr>
<td>ADHD</td>
<td>Attention deficit hyperactivity disorder</td>
</tr>
<tr>
<td>AFASS</td>
<td>Accessible, Feasible, Affordable, Sustainable, Safe</td>
</tr>
<tr>
<td>AFB</td>
<td>Acid-fast bacilli</td>
</tr>
<tr>
<td>AIDS</td>
<td>Acquired immunodeficiency syndrome</td>
</tr>
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<td>AIN</td>
<td>Acute interstitial nephritis</td>
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<tr>
<td>ALHIV</td>
<td>Adolescents living with HIV</td>
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<td>ALT</td>
<td>Alanine transaminase</td>
</tr>
<tr>
<td>ANC</td>
<td>Antenatal care</td>
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<tr>
<td>ART</td>
<td>Antiretroviral treatment/therapy</td>
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<tr>
<td>ARV</td>
<td>Antiretroviral</td>
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<tr>
<td>ASCUS</td>
<td>Atypical squamous cells of undetermined significance</td>
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<tr>
<td>ATV/r</td>
<td>Atazanavir/ritonavir</td>
</tr>
<tr>
<td>AZT</td>
<td>Azidothymidine/sidovudine</td>
</tr>
<tr>
<td>BAL</td>
<td>Balanitis/balanoposthitis</td>
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<tr>
<td>BMD</td>
<td>Bone mineral density</td>
</tr>
<tr>
<td>BMI</td>
<td>Body mass index</td>
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<tr>
<td>cART</td>
<td>Combination antiretroviral therapy</td>
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<tr>
<td>CD4</td>
<td>Cluster of differentiation antigen 4</td>
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<tr>
<td>CET</td>
<td>Cervical excitation tenderness</td>
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<td>CICT</td>
<td>Client-initiated counselling and testing</td>
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<td>CLD</td>
<td>Chronic lung disease</td>
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<td>CMV</td>
<td>Cytomegalovirus</td>
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<td>CNS</td>
<td>Central nervous system</td>
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<td>COC</td>
<td>Combined oral contraceptive</td>
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<td>CPE</td>
<td>CNS penetration effectiveness</td>
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<tr>
<td>CPT</td>
<td>Cotrimoxazole prevention therapy/prophylaxis/axis</td>
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<td>CrAg</td>
<td>Cryptococcal antigen</td>
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<tr>
<td>CSG</td>
<td>Child Support Grant</td>
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<td>CT scan</td>
<td>Computerised tomography scan</td>
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<tr>
<td>CTOP</td>
<td>Choice on Termination of Pregnancy Act 92 of 1996</td>
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<tr>
<td>Cu IUD</td>
<td>Copper intrauterine device</td>
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<tr>
<td>CVD</td>
<td>Cardiovascular disease</td>
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<tr>
<td>d4T</td>
<td>Stavudine, Zerit</td>
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<tr>
<td>ddl</td>
<td>Didanosine (Videx EC, Videx)</td>
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<tr>
<td>DMPA</td>
<td>Depot medroxyprogesterone acetate (Depo-Provera)</td>
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<td>DNA</td>
<td>Deoxyribonucleic acid</td>
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<td>DOH</td>
<td>National Department of Health</td>
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<td>DOT</td>
<td>Directly observed therapy</td>
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<td>EBV</td>
<td>Epstein-Barr virus</td>
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<td>EFV</td>
<td>Efavirenz (Sustiva, Stocrin, Efavir)</td>
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<tr>
<td>ELISA</td>
<td>Enzyme-linked immunosorbent assay</td>
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<tr>
<td>EUA</td>
<td>Examination under anaesthesia</td>
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<tr>
<td>FBC</td>
<td>Full blood count</td>
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<tr>
<td>FDC</td>
<td>Fixed-dose combination</td>
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<tr>
<td>FTC</td>
<td>Emtricitabine (Emtriva)</td>
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<td>FNA</td>
<td>Fine needle aspiration</td>
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<tr>
<td>GAD</td>
<td>Generalised anxiety disorder</td>
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<tr>
<td>GBV</td>
<td>Gender-based violence</td>
</tr>
<tr>
<td>GFR</td>
<td>Glomerular filtration rate</td>
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<tr>
<td>GP</td>
<td>General practitioner</td>
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<td>GUS</td>
<td>Genital ulcer syndrome</td>
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<td>HAART</td>
<td>Highly active antiretroviral treatment/therapy</td>
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<td>HAD</td>
<td>HIV-associated dementia</td>
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<td>HAND</td>
<td>HIV-associated neurocognitive disorder</td>
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<tr>
<td>HB</td>
<td>Haemoglobin</td>
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<td>HBV</td>
<td>Hepatitis B virus</td>
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<td>HCT</td>
<td>HIV counselling and testing</td>
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<tr>
<td>HDL</td>
<td>High-density lipoprotein</td>
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<tr>
<td>HIV</td>
<td>Human immunodeficiency virus</td>
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<td>HIVAN</td>
<td>HIV-associated nephropathy</td>
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<tr>
<td>HIVE</td>
<td>HIV encephalopathy</td>
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<td>HIVICK</td>
<td>HIV immune complex kidney disease</td>
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<td>HPV</td>
<td>Human papillomavirus</td>
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<td>HSIL</td>
<td>High grade squamous intraepithelial lesion</td>
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<tr>
<td>HSRC</td>
<td>Human Sciences Research Council</td>
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<tr>
<td>HSV-2</td>
<td>Herpes simplex virus type 2</td>
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<tr>
<td>IEC</td>
<td>Information, education and communication</td>
</tr>
<tr>
<td>IMAI</td>
<td>Integrated Management of Adolescent and Adult Illness (WHO)</td>
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<tr>
<td>INH</td>
<td>Isoniazid</td>
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<td>IPT</td>
<td>Isoniazid preventive therapy</td>
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<td>IRIS</td>
<td>Immune reconstitution inflammatory syndrome</td>
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<td>IUCD</td>
<td>Intrauterine contraceptive device</td>
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<td>IUD</td>
<td>Intrauterine device</td>
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<td>IVIG</td>
<td>Intravenous immunoglobulin</td>
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<td>LA</td>
<td>Lipoatrophy</td>
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<td>LAP</td>
<td>Lower abdominal pain</td>
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<td>Long-acting reversible contraception</td>
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<td>Lymphoid interstitial pneumonitis</td>
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<td>LNG-IUS</td>
<td>Levonorgestrel intrauterine system</td>
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### Abbreviations and acronyms

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<td>LNMP</td>
<td>Last normal menstrual period</td>
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<td>LPV/r</td>
<td>Lopinavir/ritonavir</td>
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<tr>
<td>LSIL</td>
<td>Low grade squamous intraepithelial lesion</td>
</tr>
<tr>
<td>MAC</td>
<td>Mycobacterium avium complex</td>
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<tr>
<td>MDMA</td>
<td>3,4-methylenedioxy-N-methylamphetamine (ecstasy, 'E', 'X', 'XTC', 'Mandy', 'Molly')</td>
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<td>MDR/XDR-TB</td>
<td>Multidrug- or extensively drug-resistant tuberculosis</td>
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<td>MEC</td>
<td>Medical eligibility criteria</td>
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<td>MMC</td>
<td>Medical male circumcision</td>
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<td>MTCT</td>
<td>Mother-to-child transmission</td>
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<tr>
<td>MUAC</td>
<td>Mid-upper arm circumference</td>
</tr>
<tr>
<td>MUS</td>
<td>Male urethritis syndrome</td>
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<tr>
<td>NAFCI</td>
<td>South African National Adolescent-Friendly Clinic Initiative</td>
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<tr>
<td>NET-EN</td>
<td>Norethisterone enanthate</td>
</tr>
<tr>
<td>NGO</td>
<td>Non-governmental organisation</td>
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<tr>
<td>NIMART</td>
<td>Nurse-initiated management of antiretroviral therapy</td>
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<td>NNRTI</td>
<td>Non-nucleoside reverse-transcriptase inhibitor</td>
</tr>
<tr>
<td>NRTI</td>
<td>Nucleoside reverse-transcriptase inhibitor</td>
</tr>
<tr>
<td>NTM</td>
<td>Non-tuberculous mycobacteria</td>
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<tr>
<td>NVP</td>
<td>Nevirapine</td>
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<tr>
<td>OCD</td>
<td>Obsessive compulsive disorder</td>
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<tr>
<td>od</td>
<td>Once daily</td>
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<tr>
<td>OI</td>
<td>Opportunistic infection</td>
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<tr>
<td>OTC</td>
<td>Over-the-counter</td>
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<tr>
<td>PCOS</td>
<td>Polycystic ovary syndrome</td>
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<tr>
<td>PCP</td>
<td>Pneumocystis carinii pneumonia</td>
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<td>PCR</td>
<td>Polymerase chain reaction</td>
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<tr>
<td>PEP</td>
<td>Post-exposure prophylaxis</td>
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<tr>
<td>PEPFAR</td>
<td>U.S. President’s Emergency Plan for AIDS Relief</td>
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<td>PHC</td>
<td>Primary healthcare</td>
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<tr>
<td>PI</td>
<td>Protease inhibitor</td>
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<tr>
<td>PICT</td>
<td>Provider-initiated counselling and testing</td>
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<tr>
<td>PID</td>
<td>Pelvic inflammatory disease</td>
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<tr>
<td>PIh</td>
<td>Protease inhibitors</td>
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<td>PMTCT</td>
<td>Prevention of mother-to-child transmission</td>
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<td>PRC</td>
<td>Peer Review Committee</td>
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<td>PreP</td>
<td>Pre-exposure prophylaxis</td>
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<td>PTSD</td>
<td>Post-traumatic stress disorder</td>
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<td>Pyrazinamide</td>
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<td>Rifampicin</td>
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<td>RTV</td>
<td>Ritonavir</td>
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<tr>
<td>Rx</td>
<td>Treatment/prescription</td>
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<tr>
<td>SANCA</td>
<td>South African National Council on Alcoholism</td>
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<tr>
<td>SRH</td>
<td>Sexual and reproductive health</td>
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<tr>
<td>SSRI</td>
<td>Selective serotonin reuptake inhibitor</td>
</tr>
<tr>
<td>SSW</td>
<td>Scrotal swelling</td>
</tr>
<tr>
<td>STI</td>
<td>Sexually transmitted infection</td>
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<td>TB</td>
<td>Tuberculosis</td>
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<td>3TC</td>
<td>Lamivudine</td>
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<td>TCA</td>
<td>Tricyclic antidepressant</td>
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<td>TDF</td>
<td>Tenofovir disoproxil fumarate</td>
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<td>TG</td>
<td>Triglyceride</td>
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<td>TOP</td>
<td>Termination of pregnancy</td>
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<td>TST</td>
<td>Tuberculin skin test</td>
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<td>UNAIDS</td>
<td>Joint United Nations Programme on HIV/AIDS</td>
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<td>UTI</td>
<td>Urinary tract infection</td>
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<td>Voluntary counselling and testing</td>
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<td>Viral load</td>
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<td>Voluntary medical male circumcision</td>
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<td>World Health Organization</td>
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Introduction
Introduction

Globally, in 2012, UNAIDS estimated that 2.1 million adolescents between 15 and 19 years were HIV-positive, 56% of whom were female. Of these HIV-positive adolescents, 1.7 million (85%) reside in sub-Saharan Africa. AIDS-related deaths among 10–19 year olds in sub-Saharan Africa more than doubled during 2005–2012, in contrast to the overall decreases in all other age categories. Of these HIV-positive adolescents, 1.7 million (85%) reside in sub-Saharan Africa. AIDS-related deaths among 10–19 year olds in sub-Saharan Africa more than doubled during 2005–2012, in contrast to the overall decreases in all other age categories.

In South Africa an estimated 320,000 adolescents were living with HIV in 2014. Adolescents may be either perinatally infected with HIV through mother-to-child-transmission (MTCT) in pregnancy, delivery or through breastfeeding; or non-perinatally infected through sexual activity (consensual or non-consensual) or intravenous drug usage with shared needles.

Declining rates of MTCT since 2003 as a result of more effective prevention strategies and a plateau in HIV prevalence among pregnant women, has resulted in a decline of transmission rates from approximately 9.6% in 2008 to 2.8% in 2011.

The 2012 Human Sciences Research Council (HSRC) survey estimates that by 10 years of age, 6.2% of children born to HIV-positive women will be HIV-positive as a result of perinatal infection and breastfeeding. The National Department of Health (DOH) in its Strategic Plan on HIV, STIs and TB 2012–2016 (NSP) has set a goal to virtually eliminate new paediatric HIV infections in South Africa by 2015. In addition to ongoing political commitment, a concerted effort to address the gaps in PMTCT and HIV prevention and treatment is required from the health system overall. This is likely to result in few new HIV infections in children. As a result of the successful provision and scale-up of combination antiretroviral therapy (cART) a substantial number of HIV-positive children are ageing into adolescence.

In the recent HSRC survey, overall HIV prevalence in young people 15–19 years was 3.2%: 0.7% and 5.6% for males and females, respectively. This reflects an 8 times higher prevalence in females compared to males. By 20–25 years of age prevalence increases sharply to 5.1% for males and 17.4% for females 20–24 years of age, and by 25–28 years 28% of young women are HIV infected. Further, the incidence rate in the 15–24 year age group for 2012 was four times higher in females than their male counterparts.

Age-disparate relationships for the 15–24 year age group, regardless of gender, were associated with a higher prevalence of HIV, making age-disparate relationships in these age categories a risk factor for HIV. Age-disparate relationships are common, with about one fifth of the 15–19 year old respondents reporting that they had a sexual partner who was more than five years their senior. This finding was significantly different for females (33.7%) compared to their male counterparts (4.1%).

Increased focus on this high-risk period between 15–24 years is essential in reducing HIV incidence in this population and with it associated HIV transmission to children through MTCT and to sexual partners in discordant relationships. HIV positive youth (15–24 years) have had the lowest treatment exposure at 14.3% as a result of being newly diagnosed and not having reached the stage for ART eligibility and will require ART in future years either as part of PMTCT or for their own health.

The number of children perinatally infected with HIV, ageing into adolescence, along with the exceptionally high HIV incidence rate in young South African women, suggests that the number of HIV-positive adolescents (10–19 years) is estimated to exceed the number of HIV-positive children (0–10 years) in South Africa by 2016, ushering in a new era for HIV management in adolescents.

In this context, healthcare providers require a new set of skills to help HIV-positive adolescents to successfully navigate their care and treatment and transition into adulthood. Working with adolescents living with HIV: A handbook for healthcare providers aims to meet this need.
PURPOSE OF THE HANDBOOK

Adolescent HIV is a relatively new and important area in the HIV field. As the epidemic has evolved, programmes have focused on adult, paediatric and PMTCT services. With this new cohort of perinatally infected children moving into adolescence, as well as young people being infected with HIV during childhood and adolescence, there is a growing need for healthcare providers to develop the competencies and confidence in rendering care to this specific client group.

To this end, the handbook has been developed to assist healthcare providers to manage adolescents living with HIV in an integrated way, dealing with clinical, psychosocial and mental health issues.

TARGET USERS: FOR WHOM HAS THE HANDBOOK BEEN WRITTEN?

The handbook has been developed for frontline healthcare providers working with adolescents living with HIV, at primary healthcare facilities in South Africa.

Part A focuses on clinical management. This section has been written for HIV clinicians, including trained and experienced HIV doctors and NIMART-trained nurses. It can also be used as background information for all healthcare providers.

Part B focuses on psychosocial and mental health aspects of wellbeing and care, and is relevant for all healthcare providers working with adolescents living with HIV. Chapters 25 and 26 provide specific guidance for the screening and management of mental health in adolescents living with HIV.

STRUCTURE

The handbook consists of seven sections, grouped into two parts:

- **Part A** deals with the clinical management of adolescents living with HIV
- **Part B** deals with the management of the psychosocial and mental health aspects of adolescents living with HIV.

**Part A**

**Section 1**
An introduction to working with adolescents

**Section 2**
Consultation, screening and history-taking

**Section 3**
Continuum of care: HCT and ART

**Section 4**
Management of opportunistic infections and other HIV-related conditions

**Section 5**
Sexual and reproductive health

**Part B**

**Section 6**
Psychosocial wellbeing

**Section 7**
Mental health
KEY THEMES IN THE HANDBOOK – AN INTEGRATED APPROACH TO WORKING WITH ADOLESCENTS LIVING WITH HIV

The effective management of adolescents living with HIV requires a three-pronged approach taking into account the interplay between clinical, psychosocial and mental health factors. These are interwoven through the handbook.

Important themes that run through the handbook and that are fundamental to working effectively with adolescents living with HIV are:

- **Adolescent-friendly services**: Effective clinical, mental health and psychosocial services should be responsive and sensitive to the needs of adolescents. Adolescent-friendly services improve access and encourage constructive engagement between the health service and the adolescent client (chapter 1).

- **Specific clinical and psychosocial needs of adolescents living with HIV**: In addition to the medical management of HIV it is important to take into account specific considerations for adolescents living with HIV – these include the differences between perinatally and non-perinatally infected adolescents (chapter 2), developmental phases (chapter 3), the consultation, history-taking and examination (chapter 4) and psychosocial aspects (chapters 19–23).

- **Continuum of HIV care**: HIV care needs to include HIV counselling and testing (chapter 6), preparing for and initiation of ART (chapters 7, 8), follow-up and monitoring of ART (chapters 9–11) and the management of opportunistic infections (OIs) (chapters 12–15).

- **Quality of care**: All services need to be framed by quality healthcare. These include the six priorities identified by the DOH: waiting times, safety, drugs and supplies, infection control, staff attitude and cleanliness, and other cross-cutting standards for adolescent and HIV care.9,10

- **Psychosocial support**: This is intrinsic to working with adolescents living with HIV. Psychosocial support can assist in improving aspects of HIV care such as adherence, disclosure, transition of care, dealing with stigma, building self-esteem and learning to live with HIV into adulthood. The assessment of emotional, social and mental wellbeing needs to be integrated into all consultations (chapters 19–23).

- **Effective communication**: Open communication and rapport is at the heart of any constructive, positive interaction with adolescent clients and paves the way for an engagement that encourages mutual respect, trust, honesty, problem solving, responsibility and support (chapters 4, 19).

- **Mental health**: Adolescents living with HIV are more likely to experience mental health problems. These vary in terms of intensity and impact on young peoples’ lives, and can be acute, transient or chronic and may vary in severity. Neurocognitive effects of HIV should also be considered. All, if left unattended, are likely to result in problems with adherence, retention in care, self-esteem and coping with HIV. The ideal is referral to specialised services. In most settings in South Africa, however, there is a shortage of mental health resources in general, and even fewer for adolescents (chapters 24–26).

- **Sexual and reproductive health (SRH)**: It is vital that SRH services form part of a holistic approach to working with adolescents. Adolescence is a time of rapid development; it is a time of growth, awareness and maturation, including hormonal changes, burgeoning sexuality and the need for experimentation. Mostly it is a time of positive learning about life as the child moves into adulthood, but it is also a time of increased turbulence and risk, with life-changing consequences. The integration of SRH into routine HIV management of adolescents is crucial, as are prevention of HIV transmission, rape, gender-based violence (GBV), pregnancy and sexually transmitted infections (STIs) (chapters 16–18).
• **Support for parents and caregivers**: Parents/caregivers also require psychosocial support. They need to understand, adapt to and learn to deal with the changes that come with adolescence. This is especially so where their roles change in significant ways when dealing with transition in care (chapters 4.2, 21, 22).

### TERMINOLOGY: A NOTE ON TERMS USED IN THE HANDBOOK

<table>
<thead>
<tr>
<th>Adolescents, youth and young people</th>
<th>Adolescents are defined as persons between the ages of 10–19 and youth are defined as persons between the ages of 15–24. Young people refers to this broader age band of 10–24 years (UNAIDS 2013). The focus of this handbook is on adolescents between the ages of 10–19. The terms are used interchangeably as appropriate.</th>
</tr>
</thead>
<tbody>
<tr>
<td>cART, ART and ARV</td>
<td>cART (combination antiretroviral therapy), was previously referred to as HAART (highly active antiretroviral treatment). cART usually comprises three or more drugs from at least two different classes, either taken separately or in fixed-dose combinations. The use of the terms antiretroviral treatment/therapy (ART) and antiretroviral (ARV) are used as appropriate and refer to the generalised use of the drugs.</td>
</tr>
<tr>
<td>Perinatally infected and non-perinatally infected</td>
<td>The terms perinatally infected and non-perinatally infected are used. Perinatally infected defines mother-to-child transmission and is also known as vertical transmission of HIV. The term ‘non-perinatally’ infected has been used rather than ‘horizontally’ or ‘behaviourally’ infected as it is neutral and all encompassing, and includes infection via blood (blood transfusion and intravenous drug use), consensual sex, sexual abuse and rape.</td>
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## PART A:

Clinical management of adolescents living with HIV

### OVERVIEW

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SECTION 1

An introduction to working with adolescents
Working with adolescents living with HIV: A handbook for healthcare providers
1. Adolescent-friendly services

The period of adolescence is associated with significant sexual, reproductive, cognitive and psychosocial changes. It also coincides with the acquisition of behaviour patterns that potentially influence health-related risk in later adult life, including, for example, tobacco, drugs and alcohol misuse, unsafe sex and lack of physical activity. These important factors have resulted in increased global focus on meeting adolescent health needs over the last two decades. In particular, adolescents in sub-Saharan Africa have one of the worst health profiles of adolescents in the world, with high rates of unwanted teenage pregnancy, incidence and prevalence of HIV, and extensive risk factors for non-communicable diseases. This underscores the need for adolescent-friendly services within the region.

1.1 Barriers to adolescents using health services

There are several barriers to young people accessing healthcare. These can potentially impact on service utilisation, support, retention in care and adherence to treatment and can have a negative impact on health outcomes. As far as possible healthcare providers need to be aware of and address barriers to ensure that quality, youth-friendly services are rendered.

- **Clinic operating hours**: Many public sector healthcare providers in South Africa discourage clients from accessing routine clinical services in the afternoons. Mornings-only service delivery makes it particularly difficult for adolescents to access health services as this is when they should be at school.
- **Physical access**: Clinic location, distance from home or school and obtaining transport money.
- **Waiting areas and length of wait**: Confidentiality, being recognised, feelings of embarrassment, shyness and ‘imaginary audience’ (a perception that everyone is watching them – see additional information for this chapter).
- **Adult-centred environment**: Uncomfortable and unattractive physical environment, and educational material that speaks to adults rather than young people.
• **Confidentiality and privacy:** Fear of healthcare providers disclosing personal information to community and family members, having to tell clerical staff the purpose of their visit, being overheard, being seen should staff members open doors and interrupt consultations and having to walk through the waiting room carrying a urine sample. In a recent study several adolescent-simulated ‘mystery clients’ reported being overheard when requesting an HIV test, and additional breaches in confidentiality during the testing process were noted.²

• **Staff attitude:**
  - Lack of sensitivity and understanding of the physical, sexual and psychosocial development of adolescents and consequent poor rapport preventing open communication.
  - Poor communication skills including reprimanding, judgemental or impatient behaviour, and being patronising, e.g. talking down to young people as though they were stupid or as if they were children.
  - Embarrassment when discussing issues related to sex, sexuality, sexual identity and safer sex. Adolescents need to feel comfortable and be encouraged to discuss these issues with healthcare providers in an environment they regard with trust. When healthcare providers avoid broaching these topics adolescents may well leave the clinic without actually disclosing the real reason for their visit, thereby not accessing the services they needed.

• **Communication and language barriers:** Difficulty expressing oneself clearly and understanding verbal communication. Difficulty understanding information, education and communication (IEC) and behaviour change communication (BCC) materials and messages.
1.2 Key components of adolescent-friendly services

Since the mid-1990s different models of adolescent and youth-friendly services have evolved. These include dedicated stand-alone services, services functioning alongside other services within the same facility and the total integration of youth-friendly services within the mainstream healthcare service. Unfortunately, few of these models have been adequately evaluated and there is little evidence to demonstrate their impact on adolescent health or to support the implementation of any one specific model within a particular context. Despite these limitations, the decades of work to identify barriers and improve adolescent health-service utilisation provide sufficient evidence to support a shared understanding of the key components of youth-friendly health services as described below and summarised in Box 1.

- **Rights of adolescents**: Adolescents’ rights are underpinned by the constitution of South Africa as well as several other acts that protect and encourage optimal development of children and adolescents. The implementation and interpretation of these statutory rights are guided by the principle ‘in the best interest of the child’, as embodied by the Children’s Act 38 of 2005. Healthcare providers need to familiarise themselves with the appropriate legislation.

- **Importance of attitude in working with adolescents**: Healthcare providers need to be aware of their values, beliefs and attitudes toward adolescents, particularly related to issues such as lifestyle, SRH and HIV. Negative attitudes create significant barriers and impact on adolescents’ utilisation of healthcare, retention in care and health outcomes.

- **Importance of a multisectoral approach**: Working with adolescents effectively goes beyond rendering a health service. The healthcare provider alone cannot meet the diverse and cross-cutting needs of the young client: care should be complemented by multisectoral collaboration. Examples include education, social security agencies, institutions dealing with training and employment opportunities, police, faith-based organisations, organisations providing life skills and resources for psychosocial and mental health support.

- **Integration of adolescent-friendly services into the health facility**: Adolescent-friendly services do not require additional expenditure and resources. Simple, creative adaptations can ensure that services are accessible, acceptable and appropriate for adolescents. Some ideas are provided in Box 2.
Box 1: Key components of youth-friendly services

- Community mobilisation activities that raise awareness among adults of the health needs of adolescents and the importance and rights of adolescents to access health services that address those needs.
- Information available in the community about the services offered to adolescents.
- Clinic signage outlining information about the services provided for adolescents (the kind of services and the times available).
- Healthcare providers with the competencies and skills needed to identify and deliver services addressing the health of young people, including their sexual and reproductive health, HIV, psychosocial and mental health needs.
- Healthcare providers engaging in a non-judgemental manner and encouraging open communication.
- Protection of adolescent clients’ privacy and confidentiality.
- An expanded, integrated package of services addressing prevention, treatment, SRH, HIV and promotion of a healthy lifestyle, and utilising peer educators, discussion and support groups/clubs where appropriate.
- Participation of adolescents in the design and ongoing review and improvement of the services.
- Services underpinned by a rights-based approach, where the rights of adolescents are complemented by responsibilities, empowering them to take responsibility for their own health and the health of others.

The gold standard for youth-friendly services is that they are effective, safe and affordable and that they meet the individual needs of adolescents so that they will return when they should and recommend the services to their friends.

Remember: Adolescent services need to be accessible, acceptable and appropriate.
Special considerations for ALHIV

Do adolescents living with HIV have the same needs as other adolescents?

- Yes and no. Yes, because they share the same changes and challenges that all adolescents experience on their journey from childhood into adulthood and no because they face a whole range of additional issues arising from living with HIV.

- Critical to the success of public health interventions for young people living with HIV is the provision of quality, accessible health services that promote retention in care and support adolescents to achieve and maintain HIV viral load suppression. The quality of interactions with healthcare providers and other aspects of the health service have an impact on whether adolescents remain in care as well as on their viral load outcomes.

- As increasing numbers of HIV-positive children grow into adolescence, health services need to have the capacity to respond to the needs of both perinatally and non-perinatally infected adolescents who have different but overlapping clinical and psychosocial needs.

- Specific competencies required include an understanding of the psychosocial, mental and sexual components of adolescent developmental stages and the ability to identify and respond to an individual adolescent’s needs. These needs are based on their development trajectory across the complete continuum of care pathway. This extends from HIV testing (as an entry point for non-perinatally infected adolescents) to management of HIV and related conditions, initiation onto ART, retention in care, adherence, provision of, and/or referral to, other services (SRH, psychosocial), liaison with other agencies and to pave the way for transition into adult care.
Adolescent health-seeking behaviour: perspective on the situation in Africa

Recent research challenges the view that children and adolescents are merely passive recipients of adult care, with adolescents demonstrating significant responsibility for their own healthcare within developing countries such as Uganda, Kenya and Ghana. In Kenya, adolescents between 11–17 years (median age 13 years) dealt with more than two thirds of their episodes of minor illnesses without consulting adults, with a third of all treatments taken being obtained without adult involvement. In addition, few Kenyan adolescents consulted an adult if they were ill after around 16 years of age. In Uganda, while adults were consulted more frequently in the health-seeking process, partly as a result of the need in Uganda to obtain money from adults to access health services and buy medicines, adolescents were frequently left to administer the medicines themselves. Furthermore, in Uganda older children and adolescents frequently took responsibility for the medical treatment of younger children. In Ghana adolescents demonstrated fairly sophisticated health-seeking behaviour, with approximately a third having accessed a health service in the previous year, and just under a half of 15–17 year olds having accessed health services unaccompanied by an adult. Younger adolescents were, however, far less likely to attend a clinic unaccompanied.

André Tylee et al. noted that adolescents’ emerging capacity for abstract thinking, increasing autonomy, constructions of the imaginary audience (adolescents’ belief that everyone is watching them) and propensity to be embarrassed by their health issues require health services to be responsive to adolescent-specific needs in order to facilitate utilisation.

The South African National Adolescent-Friendly Clinic Initiative (NAFCI) appears to have made significant progress between 1999 and 2005 in addressing supply side barriers to adolescent healthcare delivery and utilisation. The programme was entrusted to provinces and districts to implement thereafter. A study conducted in 2005 to explore the impact of NAFCI accreditation on the quality of HIV testing services in Cape Town found improved access to HIV testing, but little effect on adolescents’ experience in terms of healthcare providers’ attitude, nor perceived breaches in confidentiality. The recent efforts by the National and Provincial Departments of Health, together with loveLife, to re-invigorate the provision of adolescent- and youth-friendly clinical services and the implementation of the Integrated Schools Health Programme in South Africa is welcomed. This handbook builds on these foundations for adolescent-friendly services, providing a specific focus on adolescents living with HIV.
Adolescents are not a homogenous group. There are variations in terms of their age, stage of development and a broad range of cultural, psychosocial and economic factors. In addition, there are important differences between those adolescents who acquired HIV perinatally and those who acquired HIV non-perinatally.

2. Adolescents living with HIV: who are they? 

2.1 Perinatally and non-perinatally infected adolescents: what are the differences?

These two groups of adolescents have needs that are both similar and different. Their life experience differs in significant ways and will shape their self-image, behaviour, needs and response to healthcare and treatment as HIV-positive young people. It is therefore important for healthcare providers to be aware of and sensitive to these differences. The mode of HIV acquisition (how and when they acquired HIV) will influence when they first come into contact with health services as well as their experience and perception of living with HIV.

- **Perinatally infected** adolescents will have had a longer duration of exposure to the virus and may have been on cART for many years. This has implications for development, maturation, treatment side effects and clinical conditions.
- **Non-perinatal** HIV acquisition could include consensual sex, rape, sexual abuse and infection via blood (e.g. blood transfusion, intravenous drug users).

Irrespective of their differences, both groups will share common experiences and challenges moving from adolescence into adulthood. Similarities and differences between these two groups are described in Table 1.

Table 1: Similarities and differences between perinatally and non-perinatally infected adolescents

<table>
<thead>
<tr>
<th>Important factors</th>
<th>Perinatally infected adolescents</th>
<th>Non-perinatally infected adolescents</th>
<th>Both share the following</th>
</tr>
</thead>
<tbody>
<tr>
<td><strong>Mode of transmission</strong></td>
<td>• Acquired HIV perinatally during pregnancy, labour and delivery, or postpartum through breastfeeding.</td>
<td>• Acquired HIV through unprotected sexual intercourse, or, less frequently, by exposure to blood (e.g. injecting drug use or nosocomial exposure).</td>
<td>• They are adolescents living with HIV.</td>
</tr>
<tr>
<td><strong>Awareness of their HIV status</strong></td>
<td>• Will depend on their support systems, health services and relationship with their parents/caregivers. May have known their HIV status for many years or may need to undergo disclosure when they become adolescents. • Acceptance, self-perception and attitude to HIV (e.g. self-image, levels of acceptance and denial) will be shaped by the above.</td>
<td>• Usually learn their status at time of testing and diagnosis. • Generally older at time of diagnosis. • Coming to terms with HIV begins with learning their status. • May learn of their HIV status through accessing other services (e.g. antenatal services) and require additional support and sensitivity.</td>
<td>• Challenges of disclosure: - by others (healthcare providers, parents/caregivers) and - to others (family members, friends, teachers, employers, romantic and sexual partners).</td>
</tr>
</tbody>
</table>
### Table 1: continued

<table>
<thead>
<tr>
<th>Important factors</th>
<th>Perinatally infected adolescents</th>
<th>Non-perinatally infected adolescents</th>
<th>Both share the following</th>
</tr>
</thead>
<tbody>
<tr>
<td><strong>Family structure and support</strong></td>
<td>• Mother HIV-positive.</td>
<td>• Mother or father may or may not be HIV-positive.</td>
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<tr>
<td></td>
<td>• Other family members (father, siblings, etc.) may also be HIV positive.</td>
<td>• Less likely to be a maternal or paternal orphan.</td>
<td></td>
</tr>
<tr>
<td></td>
<td>• Increased likelihood of being a maternal and/or paternal orphan.</td>
<td>• Parents/caregivers may not necessarily know of the adolescent’s HIV status.</td>
<td></td>
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<tr>
<td></td>
<td>• Increased likelihood of being in a child-headed household.</td>
<td>• Behavioural acquisition could be associated with increased stigma, discrimination and decreased support from family/caregivers.</td>
<td></td>
</tr>
<tr>
<td></td>
<td>• Parents/caregivers likely to know the HIV status of the adolescent.</td>
<td>• Support and guidance (material and emotional) required from family and reliable, trustworthy adults.</td>
<td></td>
</tr>
<tr>
<td><strong>HIV disease severity</strong></td>
<td>• More likely to have advanced disease with more co-morbidities as a result of lifelong HIV and/or cART exposure.</td>
<td>• Less likely to have advanced disease and may not yet meet criteria for initiation of cART.</td>
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<td></td>
<td>• Health status influenced by a number of factors including age at which cART was initiated, presence of co-morbidities, effective management of opportunistic infections, achievement and maintenance of viral suppression, CART regimens exposed to, and length of time on cART.</td>
<td>• May have been HIV positive for some time and then become symptomatic (symptoms reason for diagnosis).</td>
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<tr>
<td></td>
<td>• Likely to have fewer HIV-associated co-morbidities.</td>
<td>• Likely to have fewer HIV-associated co-morbidities.</td>
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<td></td>
<td>• Possibly more likely to use alcohol and tobacco (risk for sexual acquisition of HIV may cluster with behaviour such as alcohol and drug use).</td>
<td>• Possibly more likely to use alcohol and tobacco (risk for sexual acquisition of HIV may cluster with behaviour such as alcohol and drug use).</td>
<td></td>
</tr>
<tr>
<td><strong>Physical development</strong></td>
<td>• Increased likelihood of developmental delays such as shorter stature, and delayed sexual maturation.</td>
<td>• Less likely to have delayed development or changes in body composition and physical appearance as a result of HIV and/or cART.</td>
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<td></td>
<td>• Both HIV and cART can affect physical appearance and metabolism, including lean body mass, and amount and distribution of body fat.</td>
<td>• Puberty/bodily and hormonal changes, experienced by all adolescents.</td>
<td></td>
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<tr>
<td></td>
<td>• Appearance and metabolism can still be affected by long-term use of ART.</td>
<td>• Appearance and metabolism can still be affected by long-term use of ART.</td>
<td></td>
</tr>
<tr>
<td><strong>Sexual and reproductive health: sexuality/relationships</strong></td>
<td>• May not yet be sexually active.</td>
<td>• If horizontally transmitted, sexual debut already experienced, though may not have been consensual.</td>
<td></td>
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<td></td>
<td>• May be a time of sexual experimentation and sexual debut.</td>
<td>• If sexually active, more likely to require sexual and reproductive health services, including information, education, access to male/female condoms, hormonal contraception and screening for symptoms of STIs.</td>
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<td>• May be more inhibited, self-conscious and anxious about self-image and entering romantic/sexual relationships.</td>
<td>• Worry about the future: their reproductive capacity, ability to have children and having safe, intimate relationships.</td>
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<td></td>
<td>• Need to prevent unintended pregnancies.</td>
<td>• Issues related to risk, transmission and safe sex.</td>
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</tr>
<tr>
<td></td>
<td>• Need to prevent secondary HIV infection.</td>
<td>• Need to prevent secondary HIV infection.</td>
<td></td>
</tr>
<tr>
<td></td>
<td>• Sexual orientation: heterosexual, homosexual, bisexual, transsexual.</td>
<td>• Sexual orientation: heterosexual, homosexual, bisexual, transsexual.</td>
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</tbody>
</table>
### Table 1: continued

<table>
<thead>
<tr>
<th>Important factors</th>
<th>Perinatally infected adolescents</th>
<th>Non-perinatally infected adolescents</th>
<th>Both share the following</th>
</tr>
</thead>
</table>
| Disclosure (by other parties)          | • Disclosure by parents/caregivers may already have happened.  
  • If not yet aware, adolescence is when their status needs to be disclosed to them.  | • Disclosure by healthcare providers is usually when they receive results of HIV test. May be asymptomatic, which can reinforce denial.  | • Disclosure about status needs to be developmentally appropriate and support provided.  |
| Disclosure (to others)                 | –                                 | –                                    | • Will need to make carefully considered decisions as to whom to disclose as they move into adolescence and adulthood, and will need support.  |
| Antiretroviral treatment               | • Likely already on cART and may be on second line treatment. In younger adolescents treatment adherence may be overseen by carer but likely to be responsible for own treatment if older. Transition into adolescence may present adherence problems.  | • Probably not yet required, or only recently initiated.  
  • May be initiated as part of PMTCT.  | • Adherence may be problematic in adolescence, especially as responsibility shifts from parents/caregivers to self-administration.  
  • Need regular monitoring and management of drug side effects.  |
| Familiarity with health services       | • Most likely will have been attending paediatric services since infancy, and will be familiar with health services.  
  • May be transitioning from a paediatric service.  
  Note: A percentage of perinatally infected adolescents, the ‘slow progressors’, may only come to the attention of health services at this stage of their youth.  | • Most likely will have come to the health service for an HIV test or because of another problem, (e.g. illness, STI, contraception, pregnancy) and will have had less contact with the health service.  | • Require adolescent-friendly and responsive services.  |
| Stigma/blame                          | • Issues about the mode of transmission may need to be worked through (e.g. mother) and other members of the family who are HIV-positive.  
  • Level of acceptance dependent on factors such as when and how they learnt about their HIV status, levels of support and community attitude toward HIV.  | • Issues about the mode of transmission may need to be worked through (e.g. sexual partner and sexual experiences if sexually transmitted).  
  • Level of acceptance dependent on factors such as family’s response, levels of support and community attitude toward HIV.  | • Stigma, self-stigma and blame influenced by psychosocial factors.  
  • Issues around stigma and blame not static – will change as young people mature and grow older – need to be re-visited and worked through.  |
3. Development and maturation of adolescents living with HIV

The period of adolescence is characterised by physical, sexual, cognitive and emotional changes. HIV-positive adolescents have to deal with parallel processes: developmental changes, and living with HIV. The impact cuts two ways. On the one hand, HIV affects developmental processes, and on the other, the changes in adolescence affect the management of HIV.

3.1 Developmental phases and maturation of adolescents: an overview

Adolescent development can be grouped into three broad developmental phases (Table 2):

- Early adolescence (10–14 years)
- Middle adolescence (15–17 years)
- Late adolescence (18–19 years)

Although there is considerable variation between individuals in the timing and rate of development, the phases provide a useful practical grouping so long as they are not rigidly interpreted. There is also increasing recognition from longitudinal imaging studies that the brain continues to mature and change well into the 20s. In this regard, maturity is a societal rather than biological construct, and the age at which individuals are deemed adequately mature to do age-related activities (such as go out without parental supervision, drink alcohol, drive a car, have consensual sex, make independent health-related decisions, get married and vote) varies across legal systems, countries, cultures and societal norms.

(i) Physical development

Puberty usually begins from 8–14 years of age in females and 9–14 years of age in males. Although puberty proceeds in a predictable fashion, its onset and pace is influenced by several factors including body mass and height, nutrition and HIV-related factors.

The Tanner scale is a universally used tool to assess the sexual maturation of adolescents according to development of the secondary sexual characteristics, and identify abnormalities. This development proceeds in a predictable order. The onset of menstruation, for example, usually correlates with a Tanner stage 4, and as such other characteristics have to have developed to a certain extent before menarche occurs. The Tanner scale serves to monitor the progress of this sexual development and identify delays or the need for referral.
(ii) Emotional and psychological/cognitive development

In terms of cognitive development:

(a) Early adolescence is marked by concrete thinking in which the adolescent focuses on the present as compared to making long-term plans. Actions or non-action such as non-adherence can have consequences a few months or years down the line.

(b) Middle adolescence is characterised by the emerging development of abstract thinking, though the adolescent is still unable to think of and plan for the long-term future.

(c) Late adolescence sees a consolidation of abstract thinking. This means that most adolescents have a fairly good idea of their long-term plans and goals and have thought through how they can be achieved. Abstract thinking enables the adolescent to have a greater understanding that behaviour has consequences. By late adolescence moral reasoning is more evolved: knowing right from wrong, for example.

There are also similar patterns of adolescent behaviour which include:

- Shifts in social affiliation and toward peer-based interactions, with some withdrawal from parents/caregivers. This may be experienced as:
  - hostility, questioning, challenging and having a non-cooperative attitude toward parents/caregivers and authority figures
  - being self-centred and self-absorbed
  - preoccupation with body image and appearance
  - heightened sensitivity and feelings of being misunderstood, rejected or abandoned.

- Increased novelty-seeking and risk-taking behaviour, which may manifest as follows:
  - more adventurous – less fearful about trying new activities
  - less cautious – less fearful of consequences
  - less bound by rules – more rebellious
  - sexual exploration
  - experimentation with substances (smoking, drinking alcohol, taking drugs)
  - sense of naïve confidence and denial – the attitude that ‘nothing will happen to me’.

(iii) Sexuality and sexual development

Sexuality encompasses sex, culture, gender identities and roles, sexual orientation and reproduction. Sexuality also embraces a person’s emotions, self-image and needs. It is an intrinsic part of the development of adolescents. As physical changes occur, so we see an unfolding of the young person’s sexuality (Table 2).

A multitude of factors influence sexual development and sexuality, including social norms, environment, education, poverty, socioeconomic status, culture, peer pressure, alcohol/substance abuse, self-esteem and parents/guardians/caregivers.
### Table 2: Summary of adolescent development

<table>
<thead>
<tr>
<th>Category of change</th>
<th>EARLY 10–14 years</th>
<th>MIDDLE 15–17 years</th>
<th>LATE 18–19 years</th>
</tr>
</thead>
<tbody>
<tr>
<td><strong>Overview</strong></td>
<td>Preoccupation with the physical changes of puberty.</td>
<td>Increased sexual awareness and growing sense of sexual identity.</td>
<td>More definitive sexual identity.</td>
</tr>
<tr>
<td></td>
<td>Self-conscious regarding changes, often very concerned with whether or not their developmentab</td>
<td>More likely to engage in relationships, though these may be intense and short-lived.</td>
<td>More autonomy and increased experimentation.</td>
</tr>
<tr>
<td></td>
<td>progressed is normal.</td>
<td>Sex preoccupies thoughts and imagination (infatuation, fantasies and crushes).</td>
<td>Relationships and partnerships vary considerably, e.g. stable long-term, one partner one after another (serial monogamy) or more than one partner at the same time (multiple concurrent sexual relationships).</td>
</tr>
<tr>
<td></td>
<td>Increased sexual awareness – may begin to masturbate and male clients may experience nocturnal emissions.</td>
<td>Many adolescents have their sexual debut during this period.</td>
<td>Increased risk of pregnancy or desire to get pregnant.</td>
</tr>
<tr>
<td></td>
<td>Formation of sexual identity.</td>
<td></td>
<td></td>
</tr>
<tr>
<td></td>
<td>Rapid growth reaches a peak.</td>
<td>Growth slows down.</td>
<td>Refer to Tanner stages.</td>
</tr>
<tr>
<td></td>
<td>Refer to Tanner stages.</td>
<td>Reaches approximately 95% of adult growth.</td>
<td></td>
</tr>
<tr>
<td></td>
<td></td>
<td>Refer to Tanner stages.</td>
<td></td>
</tr>
<tr>
<td><strong>Growth of brain</strong></td>
<td></td>
<td></td>
<td></td>
</tr>
<tr>
<td>(prefrontal cortex)</td>
<td></td>
<td></td>
<td></td>
</tr>
<tr>
<td></td>
<td>Brain growth and change continues to occur throughout adolescence. This influences social and problem-solving skills (see cognitive development).</td>
<td></td>
<td></td>
</tr>
<tr>
<td><strong>Cognition</strong></td>
<td>Concrete thinking (‘here and now’) predominates.</td>
<td>Thinking becomes more abstract (theoretical) but goes back to concrete thinking when under stress.</td>
<td>Most thinking is now abstract.</td>
</tr>
<tr>
<td>(ability to acquire knowledge through different ways of thinking)</td>
<td>Does not understand that a present action has consequences in the future.</td>
<td>Better understands consequences/results of own actions.</td>
<td>Plans for the future.</td>
</tr>
<tr>
<td></td>
<td>Less problem-solving skills and looks to adults for answers.</td>
<td>Better able to engage in problem solving.</td>
<td>Understands how present choices and decisions can have an effect on the future.</td>
</tr>
<tr>
<td><strong>Psychological and social</strong></td>
<td></td>
<td></td>
<td></td>
</tr>
<tr>
<td></td>
<td>Spends time thinking about body image (how others see them).</td>
<td>Body image formed.</td>
<td>Plans and follows long-term goals.</td>
</tr>
<tr>
<td></td>
<td>Frequent changes in mood.</td>
<td>Thinks a lot about impractical or impossible dreams.</td>
<td>Usually comfortable with own body image.</td>
</tr>
<tr>
<td></td>
<td></td>
<td>Feels very powerful.</td>
<td>Understands right from wrong (morally and ethically).</td>
</tr>
<tr>
<td></td>
<td></td>
<td>Experiments with sex, drugs, friends, risks.</td>
<td></td>
</tr>
<tr>
<td><strong>Family</strong></td>
<td>Struggles with rules and issues about independence and dependence</td>
<td>Argues with rules and authority.</td>
<td>More able to reason about boundaries and rules.</td>
</tr>
<tr>
<td></td>
<td>Argues with rules and authority, argumentative and can be uncooperative.</td>
<td>Rebellious and can be uncooperative.</td>
<td>Moving from a child–parent/guardian relationship to a more equal adult–adult relationship.</td>
</tr>
<tr>
<td><strong>Peer group</strong></td>
<td>Intense friendships with same sex.</td>
<td>Peer group most important and determines behaviour.</td>
<td>Decisions/values less influenced by peers in favour of individual friendships.</td>
</tr>
<tr>
<td></td>
<td>Contact with opposite sex generally occurs in groups.</td>
<td></td>
<td>Selection of partner based on individual choice rather than what others think.</td>
</tr>
<tr>
<td><strong>Sexuality</strong></td>
<td>Self-exploration and evaluation.</td>
<td>Experimentation with sexual attraction, love and having romantic relationships.</td>
<td></td>
</tr>
<tr>
<td></td>
<td>Preoccupation with romantic fantasy.</td>
<td>Sex drive emerges; experimentation with sex.</td>
<td></td>
</tr>
<tr>
<td></td>
<td>Early beginnings of sexual attraction.</td>
<td></td>
<td></td>
</tr>
<tr>
<td></td>
<td>Sex drive emerges; experimentation with sex.</td>
<td></td>
<td></td>
</tr>
</tbody>
</table>

**Note:** The characteristics represent typical trends and may vary between individuals.
3.2 Effects of HIV on the development and maturation phases of adolescents

HIV has direct and indirect effects on adolescent development and maturation. The impact of HIV on development is affected by a range of factors including gender, nutritional and health status, socioeconomic circumstances, age of HIV infection, mode of transmission, World Health Organization (WHO) clinical stage of HIV, whether on ART or not, timing of ART initiation and psychosocial wellbeing.

Monitor growth and development is an integral part of care for all children and adolescents attending a healthcare facility for whatever reason. Adolescents living with HIV are at risk for delays in physical and/or neurocognitive development. Monitoring of all of these parameters will assist in early determination of problems, allowing for early intervention where required.

Special considerations for ALHIV

The importance of understanding and monitoring stages of development when working with adolescents living with HIV

Reviewing the stage of development is necessary in order to:

- identify delays in development
- inform the management of HIV, including approaches, consultations and treatment of adolescents to positively influence health outcomes
- provide appropriate sexual and reproductive health information, education and services, e.g. Menarche is an important event marking the need for education as well as the potential need for contraception
- identify adolescents ready to transition into adult care.

(i) Effect of HIV on physical development

HIV may affect physical development in adolescents in the following ways:

- **HIV may significantly affect growth**: Adolescents who were perinatally infected with HIV are frequently stunted as a result of the impact of HIV on growth in early childhood. In addition to affecting stature, HIV also affects the distribution and amount of both lean body mass and fat mass. The effect of HIV on growth may be influenced by other variables including length of time on ART, viral load/CD4 cell count, and health status. ART can minimise physical delays.

- **HIV can result in the delay of the development of secondary sexual characteristics**, e.g. onset of puberty and delayed or irregular menstrual cycles in girls. As a result of delayed sexual maturation and stunting, adolescents living with HIV may appear younger than their chronological age and their peers. This may lead to a negative self-image and may also affect how other people view and interact with them.

- **Drug-related side effects**: These may be experienced due to ART or other chronic medication. Effects may include changes in physical appearance, e.g. lipodystrophy (changes in fat distribution on the body).

(ii) Effect of HIV on cognitive development

Adolescents who acquired HIV perinatally may experience neurological consequences of prolonged HIV infection. The result may be developmental delays and learning problems, which in turn have the potential to lead to other challenges such as problems at school and low self-esteem.

The ability to understand adherence, and the benefits of ART and looking after one’s health, may be affected by cognitive problems.
(iii) Effect of HIV on psychosocial development

HIV has an enormous impact on the psychosocial and sexual development of adolescents. The challenges that are encountered by all adolescents during the process of acquiring autonomy are further complicated by the additional layers of complexity that HIV brings into their lives. The impact of HIV will be shaped by several factors including the adolescents’ history, mode of infection, health and life circumstances (especially home, family, economic and social security).

- **Education may be affected adversely:** Illness may prevent regular attendance at school, affect friendships and limit participation in extramural activities such as sports and hobbies.
- **Relationships with friends and peer groups may be affected by the sense of feeling different and of being embarrassed** about their status: Fear of stigma may have a major impact as adolescents are typically driven by the need to conform to their peers. This may result in fear of disclosure, denial and problems with adherence.
- **The impact of HIV on families, in particular orphanhood, exacerbates the impact on adolescents living with HIV:** The impact of child-headed households is well documented. Orphans living with extended family/foster care may not feel attached or fully accepted into their adopted home. This may be real or perceived and result in a sense of isolation, of not belonging and a fear of abandonment.
- **The impact on the sexuality of adolescents living with HIV is multilayered and complex:** Living with HIV may result in fears about the future, increased anxiety and insecurity.
  - Factors such as sexual history and mode of transmission impact on their sexuality, especially the circumstances for those non-perinatally infected (e.g. abuse, sexual coercion, the nature of the relationship with the partner who may have infected them).
  - Other factors include poverty, financial and social security and self-esteem where young people seek out sexual relationships for acceptance, affirmation or material and financial benefits. There are real and deep concerns about disclosure in relation to safer sex negotiation: these can drive adolescents living with HIV into denial rather than adopting responsible sexual behaviour.

(iv) Effect of developmental phases on the management of HIV

Adolescents with chronic conditions often find adherence to medication challenging.

- **Taking medication on a daily basis is a reminder of their condition and that they are somehow different:** Parents and carers of children and younger adolescents are able to oversee and monitor treatment, but as adolescents grow older, so they need to begin to take responsibility for their own adherence. This is often the stage for rebellion, refusal to take medication and resistance to being accountable. This may be attributable to the young person’s striving to be independent, not wanting to be different and denial about their HIV status.
- **Having less routine and structured lives than adults may impact on taking medication at the same time daily:** Reminders may need to be adapted accordingly.

It is important to work with the adolescent as an individual to find ways to explain the importance of adherence and consequences of non-adherence, reinforce positive behaviour and move toward responsibility for their own adherence.

Barriers to health services make it more difficult for adolescents to access care and may impact on retention in care. The importance of adolescent-friendly services is once again emphasised.
3.3 Adolescents living with HIV: specific developmental problems

Developmental problems common in adolescents living with HIV include delays in sexual development, menstrual abnormalities, gynaecomastia and pseudogynaecomastia/lipomastia. Although not unique to HIV-positive young people, information is also provided on sexual precociousness and contrasexual development. Considerations for the management of developmental problems are presented at the end of the chapter.

(i) Delays in sexual development

Delay in development of secondary sexual characteristics is common in clients with chronic health conditions. Perinatally infected HIV-positive adolescents have frequently been found to have delayed sexual development. Adolescents with delayed sexual development are often also stunted and may be underweight for their age.

• In female clients, delayed sexual development is defined as lack of any breast development by 14 years of age or when more than five years pass between initial growth of breast tissue and menarche. By the age of 16 most females should have started menstruating unless they are underweight or have been severely ill.

• In males, delayed sexual development is defined as no testicular enlargement by 14 years of age or the passing of five years between the initial and complete development of the genitalia.

Any delay beyond these ages requires referral to a secondary or tertiary level facility for review. Tanner staging, assessment of the height and weight (with relation to expected normal values) and a clinical history recording all medical conditions and medications should be included with the referral.

Recently there is evidence to suggest that earlier initiation of cART in childhood ameliorates the impact of HIV on sexual development.

(ii) Menstrual abnormalities

Menstrual abnormalities (or perceived abnormalities) are common during adolescence. Adolescents may have concerns regarding the frequency, duration or amount of menstrual bleeding. The healthcare provider should have an understanding of the normal menstrual cycle and menarche in order to identify problems.

Menarche should have started by age 16. The age of menarche is determined by many factors, including genetics, body mass index (BMI) and socioeconomic conditions. Usually, the adolescent will be at Tanner stage 4 when menarche occurs. It is unusual for it to occur at a Tanner stage lower than this.

After menarche, menstrual cycles may be irregular and unpredictable. This is normal as the ovulation cycle is not yet fully established. It may take up to three years post-menarche for cycles to regulate to a duration of 21 to 35 days, as is normal for adults. The use of long-acting contraceptives such as injectable contraception can interrupt the normal menstrual cycle and result in abnormal menstruation or amenorrhoea.

Red flags in association with menstrual abnormalities include:

• a positive pregnancy test result
• delay of sexual development (detailed above)
• features of hyperandrogenism, such as acne, deepening of the voice, increased muscle mass, development of male-pattern hair distribution (face, inner thighs, abdomen, lower back)
• excessive bleeding, with associated anaemia.
Absence of menarche by age 16 is primary amenorrhoea and warrants investigation. These clients should be referred for investigation to exclude hormonal causes and possible congenital malformations of the reproductive tract.

A client who has menstruated previously and who stops menstruating for 6 months or more has secondary amenorrhoea. Pregnancy is the most common cause of secondary amenorrhoea – a pregnancy test should be done as part of the initial evaluation. A clinical examination should also be done.

Possible causes of secondary amenorrhoea include:

- pregnancy
- contraceptives, particularly injectables
- serious systemic illnesses
- significant weight loss (or other forms of malnutrition)
- hormonal irregularities (including hyperthyroidism, pituitary tumours and hyperandrogenism associated with polycystic ovary syndrome (PCOS))
- medication (commonly used examples include phenytoin, valproate and high dose corticosteroids, although there are many others).

Many other menstrual abnormalities may be revealed during history-taking, including menorrhagia (excessive bleeding), dysmenorrhea (painful menstruation) and metrorrhagia (irregular menstrual bleeding). These menstrual problems may require referral for investigation and appropriate management, as per standard primary healthcare (PHC) management guidelines.

(iii) Gynaecomastia

Gynaecomastia is the development of female breast tissue in male clients. The healthcare provider should differentiate true gynaecomastia from pseudogynaecomastia (also called lipomastia), in which there is fat deposition in the breast region. Palpation will reveal whether the tissue is glandular (textured, irregular) or fat (smooth and soft).

Causes of gynaecomastia include:

- physiological changes (most common, particularly in middle and late adolescence)
- systemic illnesses (such as chronic liver or kidney disease)
- hormonal irregularities (including hormone-producing tumours)
- drugs (alcohol, phenytoin, haloperidol and recreational drugs such as marijuana).

A thorough history and examination are required. The testes should be examined and Tanner staging done. Gynaecomastia associated with abnormalities of the testes, including masses, absence or delays in growth, or progression after drug changes, necessitates referral.

The most common cause of gynaecomastia is related to the normal physiological changes associated with puberty. This usually resolves as the adolescent gets older, and no specific intervention is required. Reassurance and follow-up is recommended.

It should be noted that certain ARV agents have been associated with gynaecomastia. The most common agent implicated is Efavirenz (EFV). It is unclear whether the ARVs or the HIV infection are the primary cause of gynaecomastia. In cases of adolescents on EFV-containing regimens who present with gynaecomastia it is advisable to discuss the case with an expert. In certain instances drug switches may be warranted. The decision is best made on a case-by-case basis.

Drug-induced gynaecomastia usually resolves with time after stopping the drugs implicated. Improvement should be apparent shortly after the change, although resolution may take up to two years (after which the chance of spontaneous resolution is much reduced).
If gynaecomastia does not resolve spontaneously, surgery may be an option if the condition is causing significant psychological and/or emotional distress.

(iv) Pseudogynaecomastia/lipomastia
This is the result of fat deposition in the breast region and is a form of lipodystrophy. It may give the impression of breast tissue development, but palpation will reveal that no glandular tissue is present.

Lipomastia is associated with drugs commonly known to cause lipodystrophy, such as d4T, ddI and protease inhibitors (PIs). It has also been known to be associated with EFV, although the mechanisms for this are not entirely clear. Where possible it is best to take the client off the offending drugs, and replace with alternatives.

(v) Sexual precociousness

Note: These conditions have no specific association with HIV but may still occur as they would in an HIV-negative individual.

Normal puberty begins from around 8 years of age in females and around 9 years of age in males. Precocious sexual development is when secondary sexual characteristics develop earlier than this. Precocious puberty is an uncommon condition and needs referral for further investigation.

Factors influencing early puberty:
• physiological causes, more likely to occur in female clients than in males
• hormonal imbalances and hormone-secreting tumours
• exogenous hormones, such as anabolic steroid use in young males or oral contraceptives in young females.

(vi) Contrasexual development

Note: These conditions have no specific association with HIV but may still occur as they would in an HIV-negative individual.

In females:
Where there is excessive or early development of pubic hair or development of facial hair, hormonal abnormalities must be considered. However the cause of such changes may still be physiological.
• Clitoromegaly (>10mm) and increased muscle mass are concerning signs. This is especially true if loss of female contours and breast tissue is present. Hormonal abnormalities or hormone-secreting tumours may be underlying and referral is warranted.
• Polycystic ovary syndrome (PCOS) is a common hormonal disorder that occurs in women of child-bearing age. It should be considered in female adolescents with excess hair growth (especially facial hair), acne and infrequent menstrual periods where the cycle frequently exceeds 35 days. Adolescents with PCOS are also frequently overweight or obese. PCOS has been associated with insulin resistance and lipid abnormalities and these clients have an increased risk of heart disease. Referral is required for definitive diagnosis and management.16
In males:

- Certain rare tumours may cause feminisation of the male client. This is different from isolated gynaecomastia as the other secondary sexual characteristics will be affected. Referral is warranted.

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**Special considerations for ALHIV**

**Managing developmental problems in adolescents living with HIV: additional considerations for the healthcare provider**

- Adolescents are very body-conscious, especially in relation to their development and what they consider to be ‘normal’. Any deviation from this may have a significant impact on the adolescent’s self-esteem and body image. The healthcare provider should be sensitive to this fact when examining the adolescent, whether the perceived abnormality is clinically significant or not.

- Abnormalities or perceived problems may be attributed by the adolescent or caregiver to cART. This may affect the adherence to ART if not addressed speedily and with good communication between the healthcare provider and the adolescent.

- In adolescents presenting with gynaecomastia care should be taken to not over-emphasise ART as a cause as physiological gynaecomastia may be experienced by up to 70% of pubescent boys.

- Development is particularly affected in perinatally infected adolescents due to their long duration of exposure to the virus. These adolescents may be underweight, stunted and have delayed development of sexual characteristics. Adolescents who have been on ART for many years may also have physical abnormalities relating to treatment toxicity, such as lipodystrophy.

- These conditions may reinforce the stigma of being ‘different’ from peers, which may have implications for their psychological and emotional wellbeing. Extra care, sensitivity and motivation may be required.
Adolescent emotional and psychological development is characterised by the attainment of increasing autonomy. Understanding adolescent brain development is helpful in understanding the origins of adolescent behaviour.

Brain growth and changes continue until the mid-20s. There are notable changes in the structure of the brain during adolescence.

- Initial rapid brain growth occurs, which is then followed by a process called ‘pruning’ – in which less-used neural connections regress. This allows for the structure of the adolescent brain to be better able to respond to specific environmental demands. The ability of adolescents to adapt to and incorporate new technologies into their lives may well be a function of this over-production and subsequent pruning of neural connections.

- The grey matter grows rapidly, with volumes peaking at roughly 11 years in girls and 12 years in boys. This peak is then followed by a period of pruning (as covered above). The neural connections maintained after the pruning process become more efficient at transmitting information through a process of myelination.

- The frontal lobes, which are important in ‘executive functions’ such as planning and impulse control, appear to be among the last areas of the brain to complete myelination, occurring sometime in the mid-20s. This late maturation of the frontal lobes may in part explain some aspects of adolescent risk-taking behaviour. In particular, the ability to consistently exert impulse control seems to be related to the timing of completion of myelination. Since frontal lobes are also involved with working memory and planning, the late maturation may account for some of the difficulty that adolescents have in adhering to cART. It is likely that all adolescents will require additional adherence support and that this support possibly needs to be extended beyond 19 years of age.

- In addition to the above, there is evidence from animal studies that the neural connections between the frontal lobes and the structures involved with emotional processing, (especially those associated with fear and vigilance) become denser during adolescence. This integration between the emotional and cognitive processes continues well into adulthood. The time lapse between the development of the socio-emotional system and the cognitive control system of the brain could account for some adolescent risk-taking behaviour, with this being compared to ‘starting the engine of a car without the benefit of a skilled driver’.
SECTION 2

Consultation, screening and history-taking
4. The consultation

The healthcare provider should seek to understand each adolescent within the context of their specific life’s circumstances.

4.1 Guidelines for the consultation

To create a safe, trusting environment, the consultation should always include the following key elements:

- **A holistic perspective**: This includes understanding each client’s stage of physical and psychological and cognitive development and their home, educational and socioeconomic context and circumstances.

- **Sensitivity to the psychosocial dynamics of living with HIV**: Adolescents who are HIV-positive have a perception of being different. This can stem from knowing that they are living with a long-term condition, having to take medication for the rest of their life, having delayed sexual development, a different physical appearance to peers, such as having stunted growth, and academic challenges. In addition to the normal challenges of being a teenager, HIV-positive adolescents fear (or may have experienced) stigma, discrimination and rejection from their peers and romantic/sexual partners because of their status.

- **Gender sensitivity**: Some adolescents may feel more comfortable with a healthcare provider of the same sex, especially where a physical examination is involved. Where possible, this should be accommodated.

- **A focus on establishing rapport and opening up communication**: Engage with the adolescent in a caring, non-judgmental manner. Begin the consultation informally, finding a general topic that may be of relevance to the young person.

- **Different modes of transmission**: During a consultation healthcare workers need to be aware that while most adolescents living with HIV in South Africa acquired HIV perinatally or through consensual heterosexual contact, some have acquired HIV in other circumstances, for example – through sexual coercion, intravenous drugs or same-sex contact.

**Use the 5 “As” in consultations with adolescents**

Based on the WHO’s Integrated Management of Adolescent and Adult Illness (IMAI) for the management of chronic care, the guidelines for engaging with clients include the 5 “As”: **assess, advise, agree, assist and arrange**. This tool provides a useful framework to move through a process of identifying, exploring and problem-solving areas of concern, together with follow-up plans.
Box 3 outlines some tips when consulting with adolescent clients living with HIV.

**Box 3: Tips for consulting adolescents living with HIV**

**Establish a rapport**
- Create a comfortable, trusting environment.
- Speak to the client directly, even if also communicating with the parent/caregiver. Encourage the client to see that the responsibility is shifting from their parent/caregiver to themselves.
- Encourage interaction. Even if the client is shy and withdrawn, find a topic to chat about, like sport, music or hobbies.
- Ask the client about school and school progress.
- Ask about any problems or challenges experienced.
- Encourage the client to ask questions. Answer honestly with explanations they can understand.

**Ensure client’s rights are protected**
- Ensure confidentiality, and that the client knows information discussed in the consultation is confidential.
- Ensure privacy: close doors and discourage interruptions.
- Discuss results and findings with the client and explain the management plan in clear and easy-to-understand language.
- Obtain informed consent from the client for any and all procedures to be done.

**Be professional**
- Maintain a caring, respectful and warm manner.
- Maintain an atmosphere of mutual respect.
- Avoid judgemental communication. Do not allow personal ideas and values to influence your demeanour during the consultation.
- Have an understanding of adolescent development, sexuality, contraception and medical conditions. Where relevant, discuss these matters in an age-/developmentally-appropriate manner.
- Use correct medical terms when discussing the body and bodily functions, but explain them, and if necessary write them down.

... and avoid
- Medical jargon.
- Value judgements.
- Being critical.
- Showing anger or frustration.
- Shouting at the client or making accusations.
- Condescending behaviour or treating the client like a child.
- Speaking about the client in the third person with the client present, e.g. ‘Is he going to school?’ Rather address the client directly.
- Situations that compromise the client’s privacy, e.g. interruptions, speaking in a manner that could make others overhear the consultation.
4.2 Parents or caregivers and the consultation

Adolescents may attend the clinic alone or be accompanied by a parent or caregiver. Younger adolescents are more likely to be accompanied but this is not always the case. Parents/caregivers are an important part of the consultation with children and adolescents. They are an important source of information for the healthcare provider regarding past medical history, adherence and current issues and problems, and provide support for the adolescent (Figure 1).

Remember: The adolescent’s involvement in the consultation needs to be carefully managed to ensure that their emergent autonomy and rights are respected.

Figure 1: Participants in the care team

(i) Sensitivity to disclosure/non-disclosure

Some adolescent clients may not yet know their HIV status. Conversely, adolescents may be accompanied by a parent/caregiver who does not yet know that the adolescent has HIV: The very first step in the consultation is to identify: who is present; the relationship between the adolescent and any adult present; and whether the adolescent and/or any adults present know the adolescent’s HIV status.

(ii) Clients who do not yet know their HIV status

Clients to whom their HIV status has not yet been disclosed may have a limited capacity to participate in the consultation: Parents/caregivers should be allowed to join the consultation, but it is important that the healthcare provider avoids accidental disclosure. Where the healthcare provider is uncertain, request a private session to ascertain the situation with disclosure.

(iii) Parents or caregivers: in the consultation or not? 

Parents/caregivers are an important source of information for past medical history, current physical, emotional and psychosocial health, and adherence to cART. This is particularly important since adolescents are less likely to identify signs and symptoms than adults or may not volunteer information out of embarrassment. Parents/caregivers are also important allies in the management and support of HIV in children and adolescents.
When should parents or caregivers be included or excluded from the consultation? The following should be considered:

- **Will the presence of the parent/caregiver be in the client’s interest?** Healthcare providers need to use their discretion and professional judgment regarding the presence of the parent/caregiver during the consultation.

- **What role can the parent/caregiver play to support the client?** The role of the parent/caregiver may change over time, especially as the young client matures, develops increasing autonomy and prepares for transition into adult care.

- **What are the client’s feelings about their presence?** Recognising the potential value of having a parent/caregiver present in the consultation, the adolescent should be asked whether they wish for the parent/caregiver to be present during all or part of the consultation. The adolescent’s preference should be respected.

- **How can the healthcare provider ensure that the client’s privacy and autonomy is respected?** It is important to provide the opportunity for a one-on-one session with the client to ascertain if there is anything they would like to discuss without the parent/caregiver. In all consultations, the rights of the client and supporting the development of autonomy are of paramount importance.

(iv) **Clients who prefer to be seen alone**

The client’s right to privacy should be respected. There may be a reason for the client not wanting the parent/caregiver to be present.

- It should be explained to the parent/caregiver that it is necessary to have a private consultation with the client. They should be reassured that after the consultation a brief summary will be provided, including information that the client is happy to share and relevant information regarding the client’s care and treatment.

- The parent/caregiver should be politely requested to leave the consultation room. It may not be necessary to exclude the parent/caregiver for the entire consultation.

- At the end of the consultation the healthcare provider should ask the adolescent whether the parent/caregiver may be invited back into the consultation room and what information may or may not be shared.

(v) **Clients who prefer the parent or caregiver to be present**

The client may feel more comfortable with the parent/caregiver present but it is important to start building their confidence in gaining autonomy.

- Communicate directly with the client and involve them in all discussions.

- Do not talk about clients in the third person as if they are not there.

- It may be appropriate for the parent/caregiver to leave to allow for a private discussion and the physical examination. This provides the adolescent with privacy and the opportunity to have their queries and problems addressed confidentially.

- Some sensitive information (sexual development, sexual activity, STI symptoms, contraception needs, relationship with the caregiver and suspected abuse by parent/caregiver) can only be obtained directly from the client. The client’s rights to privacy and their right to participate in their own healthcare are vital.

- Get permission from the adolescent before asking the parent/caregiver to leave, e.g. ask the adolescent: ‘I am going to ask your parent/caregiver to wait outside for a few minutes. Is that okay?’

- At the end of the consultation the healthcare provider should ask the adolescent whether the parent/caregiver may be invited back into the consultation room and what information may or may not be shared.
(vi) The parent or caregiver as the client
Sometimes it may be necessary to have a session with the parent/caregiver alone. They may need information and guidance on how best to support and parent the adolescent and may wish to have a conversation with a healthcare provider without the adolescent present. Providing parents and caregivers information regarding adolescent development and behaviour can often improve their understanding and insight, which may decrease conflict between the caregiver and adolescent.

The arrangement for these sessions should be done sensitively, e.g. at a separate consultation or telephonically, without eroding the trust of the adolescent client.

(vii) Encouraging the involvement of parents or caregivers
At times it may be necessary to ask a client who usually attends the clinic alone to bring the primary caregiver to the clinic, particularly where mental health, social problems or adherence issues have been identified. It may be necessary to enlist the parent/caregiver’s help and support in order to adequately deal with such issues. Telephonic conversations with the parent/caregiver may be helpful. Permission to call the parent/caregiver should be obtained from the adolescent except in situations where the adolescent’s health is endangered, or where they lack adequate maturity or insight, e.g. in the case of severe depression.
5. Clinical management: history-taking, screening and examination

It is important that all aspects of the consultation, including history-taking, assessments and physical examinations, are conducted with sensitivity and in an adolescent-friendly manner. Since each consultation contributes to the client’s perception of the health service, each contact provides an opportunity to generate trust and confidence in the healthcare provider. This encourages open and honest communication between adolescents and healthcare providers, even when dealing with sensitive and potentially embarrassing issues.

The clinical history summary (Table 3), the HEADSSS screening tool (Box 4) and examination checklists (Table 4, Box 5) aim to provide tools for the comprehensive clinical management of the adolescent living with HIV. If any of the information is already known, omit the questions/examinations and update as necessary.

5.1 Key considerations in history-taking

A decision needs to be made about the presence of the parent/caregiver during history-taking. Parents/caregivers are an important source of information regarding the history of the client, especially for younger clients.

For the busy clinician, the questions (see Table 3 and Box 4) may seem time-consuming and daunting and it may not be easy to cover all the questions in a single session, but they are important if the HIV-positive adolescent is to be approached in a holistic way.

- **Adolescence is a dynamic time accompanied by many changes and as such these topics need to be re-visited and the care adapted as the adolescent moves through the different stages:**
  - In facilities where healthcare providers have long-term relationships with their clients, information can be elicited and updated in a less structured way.
  - In facilities where there is a high turnover of staff, information needs to be revisited every four months.

- **It is essential to have good record-keeping practices to facilitate follow-up and continuity of care:** This also reduces the duration of future consultations.

- **Obtaining an accurate history is highly dependent on the relationship developed with the client during both the current and previous consultations:** This is especially relevant for sensitive topics such as sexuality, substance use, stress, depression and feelings of suicide.

- **The healthcare provider should always remain aware of the fact that a sexual encounter (either reported or not) may not have been consensual:** No assumptions should be made. If the client does report an incident of abuse, it is the healthcare provider’s responsibility to ensure that the client does not return to an unsafe environment. Appropriate referrals for medical and psychological management should be made.

- **The healthcare provider should also remain aware of the fact that a sexual encounter may not have been heterosexual:** It is important not to make assumptions about sexual preferences or sexual orientation, and be aware that sex occurs between people of the opposite and of the same sex.
### Table 3: Guidelines for history-taking

<table>
<thead>
<tr>
<th>Key areas</th>
<th>Review and explore</th>
<th>Examples of questions</th>
</tr>
</thead>
<tbody>
<tr>
<td>(i) Disclosure of status? (documented on the file, ideally, for easy access)</td>
<td>• Does client know their HIV status? (This avoids accidental disclosure.)&lt;br&gt;• If they do, what is their level of insight and understanding?</td>
<td>‘Do you know why you are here today?’&lt;br&gt;‘Do you know what the medication is for?’&lt;br&gt;‘What have you been feeling/thinking about HIV the last few days?’&lt;br&gt;‘What worries you the most at the moment?’</td>
</tr>
<tr>
<td>(ii) Main complaint</td>
<td>• Client may be well and have come in for a routine check-up: this is a good opportunity to check in and see how things are going.&lt;br&gt;• Client may have come for a reason but may be shy or embarrassed and present with a problem that is not the real reason for their visit, or the main issue worrying them. Through active engagement and encouragement they will be willing to express the real reason at a later stage in the consultation.</td>
<td>‘How do you feel today?’&lt;br&gt;‘Any new problems today?’&lt;br&gt;‘Anything else you would like to talk about today?’&lt;br&gt;‘Anything else worrying you?’</td>
</tr>
<tr>
<td>(iii) Other medical conditions or previous problems</td>
<td>• Review the problems from the previous consultation where available. Follow up on all chronic conditions (e.g. for asthmatic and epileptic clients, are these conditions controlled?)</td>
<td></td>
</tr>
<tr>
<td>(v) Adherence</td>
<td>• Explore current adherence and barriers to adherence.&lt;br&gt;• Clients should be encouraged to be honest and reassured that the aim is to find solutions where possible. Blaming and judgemental comments should be avoided.&lt;br&gt;• Clients may not reveal adherence problems in front of parents/caregivers for fear of being reprimanded.&lt;br&gt;• May be of benefit to ask the parent/caregiver about adherence and ask the client once the parent/caregiver has left the room.</td>
<td>‘Any problems with taking your treatment?’&lt;br&gt;‘How many times did you forget your treatment?’&lt;br&gt;‘What worries you the most about taking your treatment?’&lt;br&gt;‘What are the things that make you skip a treatment dose?’</td>
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<tr>
<td>(vi) Sexual history</td>
<td>• A challenging topic to discuss with young people, further complicated by the additional layer of HIV. Important as it assists in assessing the sexual and reproductive health needs of the client.&lt;br&gt;• Provides an opportunity to discuss issues related to risk, transmission and sexuality within the context of HIV.&lt;br&gt;• A useful area to pick up on psychosocial issues for adolescents living with HIV, related to low self-esteem, fear of having relationships and disclosure.</td>
<td>‘Do you fancy anyone, in a romantic way?’&lt;br&gt;‘Do you have a girlfriend/boyfriend/are you dating anyone?’&lt;br&gt;‘Have you ever been forced to have sex?’&lt;br&gt;‘Has anyone ever touched you in a way that makes you feel bad or uncomfortable?’&lt;br&gt;‘If you are having sex, do you use any protection?’&lt;br&gt;‘Have you discussed HIV with your partner?’&lt;br&gt;‘Have you told them about your HIV status?’&lt;br&gt;‘Do you know why you need to protect yourself and your partner?’ (Discuss STIs, pregnancy, HIV transmission and disclosure.)&lt;br&gt;‘Do you/your partner need contraception?’&lt;br&gt;‘What are your worries/fears about becoming involved with someone romantically or sexually?’</td>
</tr>
<tr>
<td>(vii) Developmental issues</td>
<td>• For female clients it is important to include specific questions around the menstrual cycle.&lt;br&gt;• More specific questions may be required regarding the duration of the cycle and menstrual bleeding, as well as how heavy the bleeding is perceived to be.</td>
<td>For females:&lt;br&gt;‘Have you begun menstruating? If so, at what age?’&lt;br&gt;‘Are your menstrual cycles regular?’&lt;br&gt;‘What was the date of your last normal menstrual period (LNMP)?’&lt;br&gt;‘Do you have any concerns or problems regarding menstruation?’</td>
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</table>
Box 4: HEADSSS approach to adolescent screening

The HEADSSS screening tool is useful to identify any problems that have not been reported. Adolescents may not volunteer information on these issues out of embarrassment or fear of being judged. They need to be prompted. Many of these questions are better asked in private: escorts and parents/caregivers may need to leave the room.

<table>
<thead>
<tr>
<th></th>
<th>HOME: Ask about the home environment, parents/caregivers, support available.</th>
</tr>
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<tbody>
<tr>
<td>E</td>
<td>EDUCATION: Ask about school progress, grade, problems and suspensions. If out of school and not attending higher education, ask about employment.</td>
</tr>
<tr>
<td>E</td>
<td>EMPLOYMENT: Has the client found employment? Are they studying? Their future plans?</td>
</tr>
<tr>
<td>E</td>
<td>EATING: Ask about appetite and food security, e.g. ‘How many times in the past week have you been to bed hungry?’ Also ask about diets and trying to lose weight.</td>
</tr>
<tr>
<td>A</td>
<td>ACTIVITY: Ask what the client enjoys doing – with family and with friends. What sports and hobbies do they enjoy? Their answers will give an idea of how the adolescent interacts with their peers and family. Negative or self-deprecating comments may indicate underlying depression or social issues.</td>
</tr>
<tr>
<td>D</td>
<td>DRUGS: Ask about all substances, e.g. alcohol, cigarettes, over-the-counter (OTC) medication. Regular use or experimental?</td>
</tr>
<tr>
<td>S</td>
<td>SAFETY: Ask about the extent to which they feel safe in the home/school? Have they experienced any violence, abuse or bullying? Also ask about car safety.</td>
</tr>
<tr>
<td>S</td>
<td>SUICIDE/DEPRESSION: Ask about general mood. Any previous suicide attempts? Current plans? Sleep disturbance may also indicate underlying depression.</td>
</tr>
<tr>
<td>S</td>
<td>SEXUAL ACTIVITY: This is age- and developmentally related and questions should be age- and developmentally appropriate. Keep in mind the range of sexual identities and both hetero- and same-sex behaviours.</td>
</tr>
</tbody>
</table>

Remember: It is not the question that will get an honest answer, but the way in which it is asked.
5.2 The examination

In general, the principles for examining an adolescent living with HIV are similar to examining any other young client. The key difference is paying closer attention to HIV-related signs, symptoms and conditions.

(i) Guidelines for the examination of adolescents

Healthcare workers should follow these guidelines when examining adolescents:

- **Need for privacy and professionalism**: The adolescent should be made to feel comfortable. There should be no interruptions: a ‘do not disturb’ sign should be put on the consulting room door or the door should be locked. Due consideration should be given to whether parents/caregivers should be present during the examination or requested to leave.

- **Developmental assessment**: This refers to the physical and sexual development that begins with the onset of puberty. The Tanner scale is used for this purpose. Performing an assessment using Tanner staging requires inspection of breasts and genitalia. This should be done when there is suspicion of developmental problems and/or clinically indicated. Privacy is essential for conducting this aspect of the examination, and it should be explained to the client why this is necessary. It is within the client’s rights to refuse examination and this should be accepted and documented by the healthcare provider.

- **Explanation of findings**: Healthcare providers may be tempted to only explain findings to the parent/caregiver. It is important that the client also receives feedback from the examination in an understandable manner. This is important whether or not any abnormalities were found.

- **Know your ‘numbers’**: Feedback should be provided about blood results. Adolescents who have been disclosed to should be given their CD4 cell count and viral load results. The importance of these numbers should be explained. They should also be advised on what these results mean for their health and be encouraged to keep a note of them if they attend another clinic. The provision of information and education around their condition is part of empowering the adolescent to be able to actively participate in their own healthcare.

- **Use of a chaperone**: A chaperone should be present for more intimate examinations, with the client’s consent. A same-sex escort may fulfil this function if the client is comfortable with this.

- **Be sensitive and selective when doing examinations**: Many adolescents are very self-conscious physically, and will feel uncomfortable undressing or being touched by a healthcare provider. Past sexual abuse can increase the discomfort. This should be kept in mind and it is important for healthcare providers to be sensitive and considerate of the client’s needs and to maintain privacy, especially regarding pelvic examinations.

- **Gender sensitivity**: It is preferable, where possible, for a healthcare provider of the same gender to perform genital or gynaecological examinations. Clients’ rights are important: they have the right to refuse examination or to request a same-sex examiner where this is possible. Chaperones may be required at the client’s discretion.

- **Seek opportunities to promote healthy sexuality**: The routine consultation should be viewed as an opportunity to promote healthy sexuality in clients of both genders. Focus on issues such as prevention of pregnancy, STIs and HIV transmission, and on sexual development. Discuss relationships and issues such as disclosure and safer sex.

Key elements of the examination are summarised in Table 4 and an examination checklist is provided in Box 5.
### Table 4: Key elements of the examination

<table>
<thead>
<tr>
<th>Key elements of the examination</th>
<th>Check</th>
</tr>
</thead>
<tbody>
<tr>
<td><strong>Vital signs</strong></td>
<td>• Heart rate, respiratory rate and blood pressure. Temperature if indicated.</td>
</tr>
</tbody>
</table>
| **Growth parameters**           | • Height and weight should be measured and charted on appropriate growth charts.  
• Body mass index (BMI) can be calculated.  
\[ \text{BMI} = \frac{\text{weight (kg)}}{\text{height (m)}^2} \]  
• Updated international charts should be used to determine if growth is appropriate.  
For adolescent growth charts relating to height, weight and BMI.  
• Adolescents living with HIV, particularly those who have been perinatally infected, are often stunted, underweight or delayed in physical development. It is important to monitor growth and development.  
• Nutritional assessment and interventions may need to be performed where clients are not growing well. |
| **Urine dipstick**               | • Monitoring of urine is recommended for all clients, but is a necessity if the client is receiving tenofovir disoproxil fumarate (TDF). |
| **Examinations**                 | • A general examination should be done (Box 5). If any problems are identified on past or present history, a focused examination of the relevant system is also warranted. |
| **Developmental assessment**     | • Tanner staging should be done where clinical problems are suspected.  
• Mental/cognitive development should also be assessed as there is an increased risk of neurocognitive delay for adolescents living with HIV. |

See Appendix 1a

See Appendix 1b
### Box 5: Checklist for examinations 6,7

| General examination | | |
|---------------------|-----------------|
| Colour (normal, pallor, jaundice, cyanosis?) | | |
| Body habitus (wasting, underweight, stunted, well grown, lipodystrophy?) | | |
| Lymphadenopathy (size, location/generalised, characteristics. Change in size?) | | |
| Hydration status (especially for diarrhoea, vomiting, oedema) | | |
| Digital clubbing | | |
| Skin conditions | | |

| Respiratory system | | |
|-------------------|-----------------|
| Respiration rate and whether breathing is laboured | | |
| Chest abnormalities or deformities (especially with chronic chest conditions) | | |
| Auscultate (abnormal crackles, wheezing, adventitious sounds?) | | |

| Cardiovascular system | | |
|-----------------------|-----------------|
| Pulses, perfusion | | |
| Visible pulsations on the chest wall | | |
| Normal heart sounds (and additional sounds, murmurs, muffling of sounds?) | | |

| Abdomen | | |
|---------|-----------------|
| Appearance (distended, scaphoid, normal?) | | |
| Organomegaly (enlarged liver, spleen?) | | |
| Masses | | |
| Tenderness | | |
| Ascites | | |

| ENT and oral cavity | | |
|---------------------|-----------------|
| Dental caries | | |
| Parotidomegaly | | |
| Oral ulcers, gum disease, infections | | |
| Oral thrush (may extend posteriorly into the pharynx and into the oesophagus) | | |
| Discharge from ears (important to assess duration/recurrence and effect on hearing) | | |
| Damaged tympanic membrane (due to chronic ear discharge) | | |

| Neurological system | | |
|---------------------|-----------------|
| Fully oriented | | |
| Alert, interactive | | |
| Localising neurological signs (including cranial nerves) | | |
| Weakness or sensory disturbances (general/focal, peripheral/central?) | | |
| Meningism (present/absent?) | | |

| Developmentally appropriate or not? | | |
|-----------------------------------|-----------------|
| An overall impression of the neurocognitive development (from speech and interaction with the client) can provide clues as to the need for further evaluation. Stages of development are explained in chapter 3. | | |
| Neurocognitive delay and learning problems should be screened for at regular intervals. | | |
ii) **Gynaecological examination of adolescents**

This is not a routine examination and should only be done when indicated. Indications for a pelvic examination include:\(^8\):

- vaginal discharge (persistent/offensive)
- urinary tract symptoms if sexually active
- amenorrhoea
- severe dysmenorrhoea
- abnormal vaginal bleeding
- lower abdominal pain
- suspected/reported rape or sexual abuse
- intrauterine device insertion
- cervical cancer screening (visual, Pap smear)
- suspected pregnancy or pregnancy (antenatal care).

Guidelines for the gynaecological examination of the adolescent are provided in Box 6 and the gynaecological examination process is outlined in Table 5.

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**Box 6: Guidelines for gynaecological examination\(^8\)**

Be sensitive to the following with gynaecological examinations in adolescents:

- The healthcare provider should explain the reason for the required examination and obtain the client’s consent. The procedure, the process and the duration should be explained.
- Privacy must be ensured. The procedure should be carried out behind a screen, or in a consulting room with a door that locks.
- Clients have the right to refuse examination.
- The healthcare provider should be sensitive to the fact that the client may be afraid, embarrassed or uncomfortable at the thought of undergoing a pelvic examination. Reassurance is necessary.
- It should be explained that the procedure should not be painful but that there will be some mild discomfort. The client should be encouraged to report any pain or serious discomfort during the procedure.
- Clients, especially those with a previous history of sexual assault, may be very uneasy with a male examiner. It may be necessary to ask a female colleague to do the examination under such circumstances.
- A chaperone should be arranged, with the client’s permission. If a female escort has accompanied the client and the client requests that they stay, this should be accommodated.
- The client should be given an opportunity to ask questions.
- Reassure, chat and ensure the client is relaxed throughout the examination.

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*For very young clients, virginal clients or clients with physical or mental disabilities, it may not be possible to perform the pelvic examination in the PHC setting. These clients may require referral for an examination under anaesthesia (EUA).*
### Table 5: Gynaecological examination process in adolescents: what to do, what to look for

<table>
<thead>
<tr>
<th>Examination process</th>
<th>What to do, what to look for</th>
</tr>
</thead>
</table>
| **Procedure preparation**                         | - Clients should be counselled on the need for the procedure, the process and the duration. It should be explained that the procedure should not be painful but that there will be some mild discomfort. The client should be allowed to ask questions. Consent should be obtained.  
- Client should be asked to empty her bladder.  
- Equipment should be prepared.  
- Client should undress and be placed in lithotomy position, with drapes as appropriate. |
| **Examination of the external genitalia**          | - Anatomy should be inspected to look for any anomalies.  
- Pubic hair distribution should be checked for Tanner staging. Presence of pubic lice may be noted.  
- Skin abnormalities, ulcers or evidence of trauma may be present. Warts may also be present. The nature of any vaginal discharge or bleeding should be noted. |
| **Speculum examination**                          | - Vaginal wall should be observed for any abnormalities.  
- Normal cervix should be pink, but not hyperaemic or friable. There should be no discharge, ulcers or polyps.  
- Ectropion of the cervix may be visualised in certain clients. A visible demarcation or border will be seen where the squamo-columnar junction occurs. This is otherwise known as the transitional zone. In adults it should not be visible, however it is normal in adolescence and will resolve with age. Ectropion may be associated with a persistent non-offensive vaginal discharge. |
| **Bimanual examination**                          | - Performed to assess the uterus and adnexae, as well as to look for cervical excitation tenderness (CET). Clients who are nervous may give a false impression of excitation tenderness: it is important to try to ascertain whether they feel discomfort or true pain.  
- Normal ovaries should hardly be palpable and a normal non-pregnant uterus should be small and firm.  
- Any larger masses found should be a cause for further investigation or referral. |
| **Conditions warranting referral**                | - Adnexal mass.  
- Vulvar, vaginal or cervical lesion of undetermined aetiology.  
- Possible genital tract anomaly (abnormal hymen, duplicated upper tracts, absence of vagina or uterus).  
- Abnormal Pap test result requiring colposcopy.  
- Pregnancy. |
| **Indications for urgent referral**               | - Acute pelvic pain with possible ovarian torsion, ectopic pregnancy, adnexal mass.  
- Pelvic inflammatory disease. |
(iii) Genital examination of male adolescents
Examination of the male genitalia may be required to assess clinical problems. Tanner staging should be done concurrently.
Table 6 provides guidelines for the genital examination in adolescent males.

Table 6: Genital examination process in adolescent males: what to do, what to look for

<table>
<thead>
<tr>
<th>Examination process</th>
<th>What to do, what to look for</th>
</tr>
</thead>
</table>
| Examination of the male genitalia | • Examination consists primarily of inspection and palpation.  
• Clients should be counselled on the need for the procedure, the process and the duration. It should be explained that the procedure should not be painful. The client should be allowed to ask questions. Consent should be obtained. Clients have the right to refuse examination. |
| Signs and symptoms requiring male genital examination | • Testicular mass.  
• Testicular pain.  
• Testicular swelling.  
• Symptoms of STIs.  
• Skin conditions.  
• Swelling of the glans of the penis with inability to return the foreskin to its normal position (paraphimosis).  
• Inability to retract the foreskin (phimosis).  
• Post-circumcision problems. |
| Concerns for adolescents | • STIs.  
• Testicular torsion.  
• Varicocele.  
• Phimosis.  
• Paraphimosis.  
• Testicular cancer. |
| Inspection | • Anatomy should be inspected to look for any anomalies, skin lesions or evidence of STIs.  
• Pubic hair distribution should be checked for Tanner staging. Presence of pubic lice may be noted.  
• Scrotum should be symmetrical and without any swelling.  
• Urethra should open on the tip of the glans: if it appears above or below (epispadias or hypospadias) this may need correction to prevent fertility problems.  
• Client should be asked to milk the urethra if they report urethral discharge. |
| Palpation | • Testes should be easily palpable, smooth, non-tender, symmetrical and without irregularity. If there is an absent testis previous surgery should be excluded. |
| Conditions warranting referral | • Testicular mass.  
• Varicocele or hydrocele.  
• Inguinal hernia.  
• Absent testis with no history of surgical removal. |
| Indications for urgent referral | • Testicular mass.  
• Acute severe testicular pain. |
SECTION 3

Continuum of care: HCT and ART
6. HIV counselling, testing and linkages to care

Adolescents identified through HIV counselling and testing (HCT) may be either perinatally infected (and previously undiagnosed, with the possibility of having advanced complications of HIV) or non-perinatally infected.

HCT may be done as a result of provider-initiated counselling and testing (PICT) or as client-initiated counselling and testing (CICT), also known as voluntary counselling and testing (VCT).\(^1,2\)

- **PICT** refers to the healthcare provider offering HIV testing to all clients as part of routine medical care. PICT is especially important for clients attending antenatal and postnatal care, tuberculosis (TB) and STI management, contraception and fertility planning and medical male circumcision (MMC).\(^1\)
- **CICT** refers to the client requesting an HIV test from an HIV testing site.

### 6.1 HCT client’s rights

When working with adolescents, any HCT (whether PICT or CICT) should follow the five Cs: consent, counselling, confidentiality, correct results and connection to care (Box 7).\(^3,4\) Testing for HIV should be made available and accessible to all adolescents.

**Box 7: HCT and adolescents: the ‘five Cs’**

- **Informed consent** is required. No coercion should take place.
- **Pre- and post-test counselling** conducted by a suitably trained healthcare provider should be provided to all clients.
- **Confidentiality** must be ensured.
- **Correct results** refers to the provision of quality healthcare, including quality assurance of the testing process.
- **Connection to care** refers to the availability of well-established and easy-to-navigate referral mechanisms.
• **Post-test support (for both HIV-positive and HIV-negative clients) and linkages to adolescent-friendly care:** Post-testing support is a necessary and important consideration when providing HCT. This will assist in ensuring that adolescents are not lost after the initial diagnosis, and will facilitate retention in care.

• **Adolescents who are accompanied by others when requesting an HIV test:** Testing and disclosure of results is a sensitive and confidential process. This needs to be discussed with adolescents who come in with friends, escorts and parents/caregivers. It may be necessary to have a private discussion with the client, explaining that their escort will be privy to the results should they remain for the HCT process. If the client is not comfortable with this the escort may be requested to leave.

• **Clients brought in by parents/caregivers:** Clients, especially those who are younger, may be brought in by parents/caregivers. In cases where the parent/caregiver is the one requesting the test, it is important to remember the following:

  a. In order to conduct an HIV test informed consent should be obtained. Adolescents must give informed consent for HIV testing if they are:
     - 12 years and above
     - below 12 years but the healthcare provider is of the opinion that they have sufficient maturity to comprehend the implications around HIV testing.

  b. An adolescent meeting the above criteria cannot be tested without providing informed consent. This means that they should be aware of what the test is for, and implications of the results. The adolescent must receive appropriate pre- and post-test counselling in a language they can understand, plus in a manner appropriate to their age and level of understanding. Determining the adolescent’s level of maturity is explained in Box 8.

  c. The adolescent who is sufficiently mature may voluntarily include their parents or caregivers in the counselling and testing process.

  d. If an adolescent is not sufficiently mature or has no capacity to understand the implications of the HIV test (such as a client with mental illness or neurocognitive disorder), it is required that their parents/caregivers provide informed consent. These adolescents should be advised that they need their parents or caregivers to provide consent for them. In circumstances where this is impossible consent may have to be obtained through alternate means (e.g. the head or superintendent of the facility, the Children’s Court or the childcare organisation entrusted with the adolescent’s wellbeing).

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**Box 8: Assessing an adolescent’s maturity**

- The assessment of maturity should occur prior to any pre-test counselling.

- The adolescent may be considered sufficiently mature to independently consent to HIV testing after reviewing the adolescent’s:
  - age
  - knowledge of HIV and understanding of the implications of being either HIV-positive or HIV-negative
  - views on testing and on knowing their HIV status
  - reason for testing: motivation and social circumstances may act as indicators of their level of maturity.
6.2 The HCT process

The HCT process extends from pre-test counselling to client linkage to care, as presented in Figure 2.

![HCT Process Diagram]

**Figure 2: The HCT process**

(i) Pre-test counselling

Where feasible, it is recommended that group information sessions are conducted for clients who require HCT. Thereafter, targeted individualised counselling may be offered to address individual concerns. This is useful where large numbers of clients present for testing, such as at antenatal care. Group testing should be tailored to available resources and clinic function.

Adolescents presenting for HIV testing may have different levels of knowledge about HIV and the testing process. Some may have had an HIV test before. The counselling process should be tailored to the knowledge of the adolescent being tested, using clear and understandable language.

The checklist in Box 9 is designed to ensure that all necessary information is provided for informed consent.

**Box 9: Checklist for pre-test counselling**

- Emphasise that the HCT process, the results and everything discussed during counselling will remain confidential. Be honest and explain to the client that other staff in the facility may have access to the information on a need-to-know basis.
- Discuss the client’s reason for wanting an HIV test and any questions/issues that may arise.
- Explore the implications of testing and knowing one’s status, the benefits and possible people with whom they could share this information.
- Provide basic HIV information on modes of transmission, risks and risk reduction, and treatment options available.
- Provide SRH information including safer sex practices, contraception and dual protection with condoms, STI signs, symptoms and where to get treatment.
- Explain the test procedure and processes.
- Ask what a potential ‘HIV-negative’ and ‘HIV-positive’ test result would mean for the adolescent.
- Emphasise that if the test result is positive there are ways to support the adolescent to live a meaningful and fulfilling life.
- Explain the ‘window period’.
- Discuss the adolescent’s support system: at home, school and/or a trusted adult. If there is no one, direct the adolescent to support services in the facility or community.
- Ask if there are any questions and provide youth-friendly information to take away and read.
- Obtain informed consent (verbal or written) and note in patient’s file/record.
ii) HIV test

Perform the HIV test according to South Africa’s HCT guidelines (Figure 3). Keep waiting times to a minimum for each step of the testing, including receiving the result.3,4

![Figure 3: Testing algorithm for HCT](image-url)
(iii) Post-test counselling

If the HIV test result is negative:

- Avoid value-laden or congratulatory comments such as ‘Well done!’ in case the test result is within the window period.
- State that ‘the test result is negative’.
- Ask how the adolescent feels about the test result.
- Explain the window period, as well as the need for a follow-up HIV test in 3 months. If the follow-up test is negative, retesting is recommended every 6 – 12 months depending on the risk of HIV acquisition.
- Discuss SRH issues (condom use, other forms of contraception, STIs, negotiating safer sex practices, voluntary medical male circumcision (VMMC)) and refer where necessary. **There should be an emphasis on prevention and risk reduction.**
- Check if the adolescent wants to ask any questions.

If the HIV test result is positive:

**Note:** the client should be counselled on their positive status only after the second confirmatory test has shown a positive result.

- Most adolescents will be emotionally affected by a positive test result.
- Before proceeding to post-test counselling, allow the adolescent some time to register the test result. Then ask them if they have any questions.
- The news of being HIV-positive may have a major impact on the adolescent. They may not absorb large amounts of information. Information should be brief, regarding the need for CD4 testing and the availability of support and treatment.
- It is preferable to have a post-test follow-up counselling session where the client will be more able to engage with the issues. However, in the event that the adolescent may not return for a follow-up, proceed with the post-test counselling as if this was the only opportunity to talk to them.

**Key points to consider for post-test counselling when the test result is positive**

- **Emotional response:** The adolescent should be counselled on the possible emotional responses (including denial and anger) and that these are normal. They should be made aware that these emotional responses could affect their behaviour and ability to make healthy lifestyle choices. They should also be made aware of supportive services available at the facility or within their community.
- **Anger, disbelief:** It is not uncommon for the adolescent to not say anything after receiving the test result. It is also not uncommon for them to vent feelings of anger and disbelief toward the healthcare provider. These reactions should not be taken personally. Remain calm and reassure the adolescent of the facility’s support.
- **Confidentiality:** Reinforce that the test results are confidential. The healthcare provider needs to be honest and explain to the client that other healthcare staff may have access to the information on a need-to-know basis. Avoid the word ‘secret’ as it has negative connotations.
- **Disclosure:** Enquire if there is anybody to whom the adolescent can disclose their status. If the adolescent does have somebody, this should be gently encouraged (but not too aggressively at this stage).
- **HIV management:** Briefly explain the role of ART in HIV management. Also explain the need for ongoing monitoring and prevention services for all clients, including those who do not yet require ART. Not too much detail should be given at this stage.
- **SRH:** Discuss condom use, contraception, STIs, negotiating safer sex practices (both heterosexual and same sex), etc. and refer to services where necessary.
(iv) Concluding the consultation

This is a very important but difficult part of the HCT process. Check once again if there are any more questions. If available, give the adolescent youth-friendly information on HIV to take home.

_Inform the adolescent that they can return to the facility_ if need be for information, support or other services and provide information as to when it is best to attend, particularly if there are sessions especially for adolescents.

_When the client is ready to leave, check on their emotional state._ Enquire where they are going, and if they need any additional support. Provide details of contacts, e.g. local support groups and NGOs, if they require support.

> **Remember:** There should be an emphasis on prevention and risk reduction.

### 6.3 Screening and linkage to care after HIV diagnosis

In order to facilitate further care and management of the newly diagnosed HIV-positive adolescent there are some priority actions, screens and tests. Along with screening for pregnancy and other associated clinical conditions (Box 10) the need for support should be evaluated. Investigations and linkages to care should follow the testing process. Ideally a definite follow-up appointment should be provided with a named healthcare provider (if not the same as the one attending during HCT). It may be useful to ask for consent to contact the client so that there can be a follow-up if they do not attend their appointment.

> **Note:** An HIV-positive diagnosis may be overwhelming for the adolescent. They may not wish to engage in any further testing or counselling on the day the result is received. The adolescent has a right to refuse any further testing. In such an instance they should be given information and requested to come back at a later date, for staging and CD4 testing. This should preferably be within the following week, in order to reduce delays in accessing care.

**Box 10: Screening and tests post-HIV diagnosis**

- Check if the client is pregnant. If the adolescent is pregnant she must be started on PMTCT as a matter of urgency. Refer to antenatal clinic for further care and treatment.
- Screen for TB symptoms. If any positive symptoms are present, the client should be referred for TB investigations.
- Perform or refer for a CD4 cell count. Explain that this test will help to determine if they require ART.
- Book the client for follow-up within one week to follow up on their results. Clients who have not yet had a CD4 cell count can have follow-up counselling and have their blood taken at this stage.
- The healthcare provider could also advise the client to bring their parent/caregiver or possible future treatment supporter to the follow-up visit if they are not present. This would allow for counselling of the parent/caregiver/treatment supporter and to facilitate joint pre-ART counselling where required.
6.4 Facilitating fast tracking onto ART

Clients who are pregnant, breastfeeding, known to have multidrug- or extensively drug-resistant TB (MDR/XDR-TB) or WHO clinical stage IV conditions should be fast tracked onto cART. This means that treatment should be started within 7 days of the client being staged as eligible for cART. For women who are pregnant or breastfeeding, lifelong ART should be started on the same day as the HIV diagnosis as part of PMTCT.

For clients who qualify for cART based on these criteria, it is prudent to take blood tests in preparation for the future cART regimen as well as for the CD4 cell count at the time of diagnosis. In most cases, a full blood count (FBC) and serum creatinine is sufficient. If on TB treatment include an alanine transaminase (ALT). This will assist in speeding up the cART initiation process.

Special considerations for ALHIV

Further considerations for HCT in adolescents

Every effort should be made to establish respectful and adolescent-friendly relations with the client.

- HCT is often the entry point into healthcare for adolescents with HIV. Their experience of HCT will influence their relationship with healthcare services into the future (positively or negatively). A negative experience may drive them away from healthcare. Retention in care, encouraging adolescents to return for additional information and support, and referral for counselling and support where available are crucial.

- Getting clients who test negative to return after the window period can be challenging. Where possible, get their phone number and consent to call to remind and encourage them to return.

- Adolescents may feel particularly confused, lonely and vulnerable after learning about their diagnosis: their plans for when they leave the facility need to be explored. Some facilities have a follow-up telephone call service to ring/SMS to check that they are progressing well and coping.

- Disclosure is a process and the healthcare provider needs to go with the pace of the client. Where there are trusted adults in the young person’s life disclosure should be encouraged for additional support.

- All parts of the service need to be adolescent-friendly. This needs to be taken into account when referring the adolescent client to other services such as CD4 cell counts and other blood tests, antenatal care, STIs and contraception. It is useful to ensure they know where to go and to have a named person for them to see (e.g. an identified healthcare provider with whom you have an established arrangement to see adolescent referrals).
7. Preparing for ART: the initial assessment

The initial experience of the adolescent living with HIV is important as it influences their relationship with the health service and level of cooperation and retention in care for the future. A positive experience ensures that the client perceives the service as a source of care, support and hope. This applies whether the adolescent presenting for healthcare is newly diagnosed or if they have been transferred from elsewhere.

This initial visit requires a thorough assessment as it is the entry point for determining the young client’s state of health and care plan (Figure 4).

![Figure 4: Objectives of the initial visit](image)

**7.1 Processes and procedures for the initial visit**

The initial visit is an important part of the management of HIV. It provides an opportunity to engage with the client and identify physical, mental health and psychosocial issues that may influence the health and treatment plan for them specifically.

It is important to document all findings relating to the history, examinations and test results as this will facilitate follow-ups and speed up all future consultations. A checklist of the process required for this initial visit is provided in Box 11.
Box 11: Checklist for processes and procedures for the initial ART visit

- A thorough history.
- Screen for TB, STIs and contraceptive need.
- Check vitals, urine dipsticks, height and weight, and record appropriately.
- Clinical examination.
- Decide on the WHO clinical stage based on history and examination.\(^1\)
- Developmental status and examination.
- Check any and all available results.
- ART: decide on ART eligibility, or monitor ART if on treatment. If eligible, prepare the client and take blood tests as appropriate. If not yet eligible, ongoing monitoring is required to detect when ART becomes necessary.
- Include any other investigations as necessary (e.g. sputum to exclude TB, other investigations for OIs).
- Provide ongoing counselling and health education.
- Manage problems as raised by the client.
- Plan the follow-up visit: date when results are likely to be available (usually 1 week after the test) and counsel client as appropriate.

Remember: Keep a record of all findings on the history, examinations and test results.

Also note that ART initiation may take place at this visit if the client is eligible and all requirements for ART initiation have been met, particularly if there is a need to start treatment without delay. For pregnant or breastfeeding clients, treatment must be initiated on the same day as diagnosis.

7.2 Staging and eligibility for ART

The initiation of ART in adolescents is based on WHO clinical staging and CD4 cell count as described in Box 12.

Box 12: Eligibility criteria of ART for adolescents\(^2\)

Criteria for initiation of ART in adolescents living with HIV:
- WHO clinical stage III or IV irrespective of CD4 cell count, or
- CD4 cell count ≤500 cells/mm\(^3\) irrespective of WHO clinical stage
- Other criteria include:
  - known hepatitis B (HBV) co-infection*
  - active TB disease (includes all forms of TB including drug-resistant TB)*
  - pregnant or breastfeeding client*
  - HIV-positive partner in discordant couples, which includes counselling of the HIV-negative partner.*

Criteria for fast tracking (starting ART within 7 days of being eligible):
- CD4 cell count of ≤200 cells/mm\(^3\)
- WHO clinical stage IV disease, even if CD4 cell count not yet known
- pregnancy or breastfeeding (immediate ART initiation)
- MDR/XDR-TB is listed as criteria for fast-tracking ART in children and adolescents aged younger than 15 years in the national guidelines.

* This is currently the recommendation for older adolescents according to DOH guidelines.\(^2\)
7.3 Screening for other conditions

Further screening may be required to identify and manage any other existing conditions and concerns identified during the history-taking process.

Key elements of screening:\(^2,^3\)

- **TB symptoms:** If the TB screen is suggestive of TB, samples should be collected to send for testing. These results should be followed up at the next visit and a decision made on whether or not to treat for TB.

- **Pregnancy/the need for contraception:** All clients should be educated on the use of effective contraception.
  - Dual method use (condoms used with an additional contraceptive) should be advocated for clients who are already sexually active.
  - Pregnant clients should be referred for antenatal care. Follow current DOH guidelines for PMTCT.

- **STIs:** Symptoms of an STI should lead to management according to the standardised syndromic management of STIs as per the national protocol. The client will also benefit from education on the prevention of future STIs and their partner(s) should be requested to seek treatment. Condom use should be reinforced.

- **Problems reported by the client:** These may indicate an underlying opportunistic infection (OI) or other conditions. These will need to be reviewed and a decision made as to whether further investigation is required. If a minor ailment is reported it should be managed accordingly.

- **Mental and emotional health:** It is important to counsel the client, assess their psychosocial, emotional and mental wellbeing. Discuss issues such as how they are coping with their diagnosis, what support systems they have in place and how they feel about the possibility of starting lifelong ART. Social problems may be identified at this stage, some of which may require referral to a social worker or support organisation.

7.4 Management and development of a care plan

By now the following information should be available:

- client history, including any current illness and complaints
- information relating to the assessment of TB, STIs and contraceptive use/need
- information on the psychosocial status of the client and any problems
- findings from the clinical examination
- growth and development status
- CD4 cell count and WHO clinical stage, and whether or not the client is eligible for ART.

With this information, a management plan can be constructed.

- **The client who is not eligible for ART should enter into a wellness programme.** The client should be counselled on the fact that they do not require ART just yet, but that they will require regular monitoring. The rationale for this should be explained.

- **The client who is eligible should be prepared for ART initiation.**
7.5 Wellness programmes and HIV care

Adolescents living with HIV who are not yet eligible for ART still need comprehensive care and support to ensure they live healthy lives. It is important that they remain within the healthcare system so that their specific needs are addressed. Prevention services are of paramount importance. They also require regular monitoring so that once eligible, ART can be initiated without delay.

Regular follow-up of clients not yet eligible for ART ensures that:

- ongoing counselling, support and health education is given
- mental health, developmental and psychosocial issues can be addressed
- access to SRH services and TB screening and prevention is facilitated
- regular CD4 cell counts and clinical monitoring can take place
- OIs are picked up early and ART is initiated as soon as clients become eligible.

Key considerations to be addressed during wellness consultations:

- The information from the last visit should be reviewed: CD4 cell count, WHO clinical stage and previous problems. Problems should be reviewed and the client should be encouraged to report any new challenges.
- Appropriate monitoring (growth/development/CD4 cell count) should be done (see Table 7).
- Repeat screening for TB, SRH concerns and mental health issues should also be done at each follow-up.

Remember: TB screening should be done at each visit regardless of isoniazid (INH) preventive therapy (IPT) status.

- Clients should receive appropriate screening and preventive treatment/therapy for other health concerns, including:
  - IPT as required
  - cervical screening according to DOH guidelines
  - education and provision of appropriate contraception and fertility planning as necessary
  - information about MMC
  - vaccines, including annual influenza vaccine.
- Ongoing psychosocial support and health education should be provided. Where available, clients may be referred to support groups.
Table 7: Suggested monitoring for adolescents who do not yet qualify for ART

<table>
<thead>
<tr>
<th>Intervention</th>
<th>Purpose</th>
</tr>
</thead>
<tbody>
<tr>
<td>Document weight, height at each visit</td>
<td>• Monitor growth and to see if client has become eligible for ART.</td>
</tr>
<tr>
<td>Check that a CD4 cell count has been done in the last 6 months, repeat 6-monthly</td>
<td>• Determine if client has become eligible for ART.</td>
</tr>
<tr>
<td>WHO clinical staging at each visit</td>
<td>• Determine if client has become eligible for ART.</td>
</tr>
<tr>
<td>Screen for TB symptoms at each visit</td>
<td>• Identify TB/HIV co-infection.</td>
</tr>
<tr>
<td>If sexually active, offer sexual and reproductive health (SRH) services including contraception, STI screening and pregnancy testing if appropriate</td>
<td>• Determine risk, and provide sexual and reproductive health counselling, education, and services.</td>
</tr>
<tr>
<td>Assess mental health</td>
<td>• Assess for depression, suicidal ideation, non-consensual sex, sexual violence and substance abuse.</td>
</tr>
</tbody>
</table>

7.6 Preparing the client for ART

ART may be initiated once components such as clinical criteria and blood results (chapter 7.2) have been reviewed and where there is sufficient understanding of ART and its importance, by both adolescent and caregiver where appropriate.

Once it is established that the client is eligible for ART (Box 12) they will need to be prepared so that treatment can be started. Client preparation includes the following six elements:

(i) pre-treatment counselling
(ii) appropriate investigations and screening
(iii) selection of ART regimen and related investigations
(iv) provision of cotrimoxazole prophylaxis (CPT)
(v) review of test results, with initiation as soon as possible
(vi) provision of ongoing psychosocial support and health education.

(i) Pre-treatment counselling

Adherence counsellors who do pre-ART initiation counselling are available in many facilities. Where this service is not available, or the client needs to be fast tracked onto ART, the following points are important:

• Counselling for treatment initiation depends on whether or not the adolescent has been disclosed to, as well as the client’s age and developmental level.

• It is best that both the client and parent/caregiver (or an identified treatment supporter) are available. The treatment supporter should be someone who is willing to assist the client with taking their medication every day.

• Some clients will not require (or may not have available) a treatment supporter: this should not be a deterrent to initiating ART, provided that they are sufficiently independent, reliable and mature.
Continuum of care: HCT and ART

PART A. SECTION 3

Key counselling points:

- Include a treatment supporter during counselling sessions as deemed necessary.
- Ensure that the adolescent and treatment supporter have a good basic understanding of HIV.
- Explain adherence: what it is and the consequences of non-adherence.
- Emphasise confidentiality.
- Discuss disclosure and the importance of disclosure to sexual partners.
- Check what would be the best time for the client to take their medication.
- Mention the option of changing the times if the selected time does not work out and that there is some flexibility if the client needs to take the ART a few hours later than usual.
- Try as far as possible to simplify the regimen, e.g. once-daily dosing, fixed-dose combination (FDC).
- Check understanding: ask the client to demonstrate how the medication will be taken.
- Discuss side effects, as well as when and how to inform the healthcare provider should any side effects occur.
- Discuss the importance of the general management of HIV, such as regular scheduling and attendance of clinic visits.

Evidence suggests that treatment readiness prior to initiation of ART is associated with improved adherence.\(^5\)

(ii) Appropriate investigations and screening

- **TB management**: If the client has any positive symptoms on the TB screen, or if there is another reason to suspect TB (e.g. positive TB contact), sputum samples should be collected to exclude TB.

- **Other investigations**: Other necessary investigations will be dictated by the clinical picture, e.g. if the adolescent has pallor, further investigations for anaemia will need to be conducted.

Investigations required for ART initiation are addressed in Table 9.

(iii) Selection of ART regimen and ART-related investigations

Once it is decided that the client is eligible for ART the most suitable regimen needs to be selected. The investigations should be linked to the selected regimen (Table 8).

<table>
<thead>
<tr>
<th>Clinical requirements</th>
<th>Planned regimen</th>
</tr>
</thead>
<tbody>
<tr>
<td>Weight &lt;40 kg or age &lt;15 years</td>
<td>ABC + 3TC + EFV</td>
</tr>
<tr>
<td></td>
<td>(can be given once daily)</td>
</tr>
<tr>
<td>Weight ≥40 kg and age ≥15 years</td>
<td>TDF + 3TC/FTC + EFV</td>
</tr>
<tr>
<td></td>
<td>(FDC should preferably be used)</td>
</tr>
<tr>
<td>Pregnant adolescents: Age &gt;12 years and weight &gt;40 kg</td>
<td>TDF + 3TC/FTC + EFV</td>
</tr>
<tr>
<td></td>
<td>(FDC should preferably be used)</td>
</tr>
</tbody>
</table>

Table 8: First line regimens for adolescents
### Table 9: Suggested investigations for adolescents initiating ART

<table>
<thead>
<tr>
<th>Clinical requirements</th>
<th>Investigations required</th>
<th>Planned regimen</th>
</tr>
</thead>
<tbody>
<tr>
<td>All clients prior to initiation</td>
<td>CD4 cell count (if not done within previous 6 months).</td>
<td>All</td>
</tr>
<tr>
<td></td>
<td>FBC.</td>
<td></td>
</tr>
<tr>
<td></td>
<td>ALT if on TB Rx or if jaundiced.</td>
<td></td>
</tr>
<tr>
<td></td>
<td>Serum cryptococcal antigen (CrAg) if CD4 cell count &lt;100 cells/mm³.</td>
<td></td>
</tr>
<tr>
<td></td>
<td><strong>Clinical requirements</strong></td>
<td></td>
</tr>
<tr>
<td><strong>In addition, the following investigations should be done depending on the clinical assessment and planned regimen</strong></td>
<td><strong>Investigations required</strong></td>
<td><strong>Planned regimen</strong></td>
</tr>
<tr>
<td>Weight &gt;40 kg and age ≥15 years</td>
<td>Blood for creatinine (calculate GFR*).</td>
<td>TDF+3TC/FTC+EFV**</td>
</tr>
<tr>
<td></td>
<td>Urine dipstick.</td>
<td></td>
</tr>
<tr>
<td></td>
<td>Hepatitis B surface antigen only if TDF to be discontinued</td>
<td></td>
</tr>
<tr>
<td></td>
<td>(to screen for HBV).</td>
<td></td>
</tr>
<tr>
<td>Weight &lt;40 kg or age &lt;15 years (or any other contraindication to TDF use)</td>
<td>No additional investigations.</td>
<td>ABC+3TC+EFV</td>
</tr>
<tr>
<td>Pregnant adolescents: Age &gt;12 years and weight &gt;40 kg</td>
<td>Blood for creatinine (GFR not calculated for pregnant patients).</td>
<td>TDF+3TC/FTC+EFV**</td>
</tr>
<tr>
<td></td>
<td>Urine dipstick.</td>
<td></td>
</tr>
<tr>
<td></td>
<td>Hepatitis B surface antigen only if TDF to be discontinued</td>
<td></td>
</tr>
<tr>
<td></td>
<td>(to screen for HBV).</td>
<td></td>
</tr>
<tr>
<td>Contraindication to EFV</td>
<td>ALT.</td>
<td>Requires NVP (will replace EFV in above regimens)</td>
</tr>
<tr>
<td>Contraindication to EFV, and CD4 cell count ≥250 cells/mm³ in females and ≥400 cells/mm³ in males</td>
<td>Fasting cholesterol and triglycerides (TG).</td>
<td>Requires LPV/r, as NVP contraindicated (will replace EFV in above regimens)</td>
</tr>
</tbody>
</table>

* Formula for calculating the glomerular filtration rate (GFR) (modified Cockroft–Gaultt equation):

  GFR in females = \( \frac{(140 - \text{age}) \times \text{weight in kg} \times 1.04}{\text{ Plasma creatinine (in µmol/litre)}} \)

  GFR in males = \( \frac{(140 - \text{age}) \times \text{weight in kg} \times 1.23}{\text{ Plasma creatinine (in µmol/litre)}} \)

** Where available the FDC (fixed-dose combination) may be used.
Additional points about regimen selection

- **FDC should be selected where possible**: EFV-containing regimens are preferred as they can be given once daily as an evening dose. FDC tablets are ideal as the pill burden is lessened, which will improve adherence.

- **Contraindications to TDF**: Pre-existing renal disease, GFR less than 80 ml/min per 1.73 m². Additionally, TDF affects bone mineral density. The current recommendation from the Southern African HIV Clinicians Society is to avoid using TDF in younger clients with Tanner stage less than 3, until its safety is confirmed. This is because younger clients undergo rapid bone turnover. It should be noted that TDF can be used for younger clients or clients less than 40 kg in specific circumstances but these cases are best managed at tertiary level.

- **Contraindications to ABC**: Previous known hypersensitivity reaction. There is significant experience with its use in children and adolescents and it is considered safe (although not preferred as a first line in adults).

- **Contraindications to EFV**: Current severe neuropsychiatric illness or use of psychotropic medication. Nevirapine (NVP) is no longer the first line agent of choice in women of childbearing age. Recent studies have shown that EFV is safe to use throughout pregnancy, and that falling pregnant on EFV does not result in an increased risk of birth defects. However, NVP may be used where EFV is contraindicated: an ALT is required prior to NVP initiation.

- NVP is initiated as a daily dose, and the dose is increased to twice daily after a period of 2 weeks. This is termed a “lead-in dose”. This is not necessary for adolescents who are currently on EFV and are switching to NVP.

- Where both EFV and NVP are contraindicated, Lopinavir/Ritonavir (LPV/r) may be considered.

**Note:** There are no significant contraindications to initiating Lamivudine (3TC) or FTC in an ART-naïve client.

(iv) **Provision of CPT**

CPT serves to prevent many bacterial infections, pneumocystis carinii pneumonia (PCP), toxoplasmosis, malaria and diarrhoea caused by *Cyclospora* species or *Isospora belli*.

CPT should be given to adolescents living with HIV who have:  
- symptomatic HIV (WHO clinical stage III or IV) or  
- CD4 cell count <200 cells/mm³.

Prophylaxis should be continued until the CD4 cell count is above 200, the client is well and they have been on ART for at least 6 months. If the CD4 cell count ever falls below 200, prophylaxis should be restarted.
Adverse events:\textsuperscript{12}

- \textit{Adverse events are uncommon with CPT} and the benefits usually outweigh the risks.
- \textit{Contraindications to CPT} include allergy to sulphur-containing drugs, previous severe adverse reaction to CPT and severe renal or hepatic insufficiency.
- \textit{Possible adverse events associated with CPT} include rash, Stevens-Johnson syndrome, anaemia and pancytopenia.
- \textit{Management of adverse events}: If the client has an adverse reaction CPT should be discontinued. It may be replaced with: Dapsone 2 mg per kg per day orally as a daily dose (max. 100 mg per day). Clinical requirements for discontinuing Dapsone are the same as for CPT.

Dosing is based on weight. See CPT dosing for children and adolescents in Table 10.

\textbf{Table 10: CPT dosage for children and adolescents}^1

<table>
<thead>
<tr>
<th>Weight (kg)</th>
<th>3–4.5</th>
<th>5–9.9</th>
<th>10–13.9</th>
<th>14–29.9</th>
<th>≥30</th>
</tr>
</thead>
<tbody>
<tr>
<td>CPT dose</td>
<td>2.5 ml od</td>
<td>5 ml od</td>
<td>5 ml od</td>
<td>10 ml or 1 tab od</td>
<td>2 tabs od</td>
</tr>
</tbody>
</table>

\textbf{(v) Review of test results with initiation as soon as possible}

Review the client at an early date, when results from all investigations are likely to be available (within 1 to 2 weeks) in order to start treatment. Clients who require fast tracking should start treatment within a week of being found to be eligible for ART.

Note that pregnant clients are an exception and need to start ART immediately as per PMTCT guidelines.

\textbf{(vi) Provision of ongoing psychosocial support and health education}

Ongoing psychosocial support and health education should be provided.
8. ART initiation

ART initiation occurs after WHO clinical staging and once the client has been prepared. The consultation procedure for ART initiation involves adherence counselling, a clinical review, regimen selection and initiation, and post-initiation follow-up (Figure 5).

**Figure 5: Key elements of ART initiation**

### 8.1 Adherence counselling

Adherence counselling is vital and builds the foundation for future adherence. Counselling should be done concurrently with ART preparation and should be ongoing during the initiation process and subsequent follow-up.

**Key points to remember prior to initiation**

- Check what dosage time will suit the adolescent.
- Mention the option of changing dosage times if the current time does not suit the client.
- Teach the client how to take the medication. Check understanding: ask the client to demonstrate how the medication will be taken.
- If there is a parent/caregiver or treatment supporter available they should also be taught the correct way to take the treatment. This is so that they can support the client.
- Discuss side effects, as well as the need to inform the healthcare provider should they occur.
- Reinforce the importance of adherence and suggest the use of reminders and alarms where appropriate.
- Assist the adolescent to establish treatment reminders, e.g. cell phone alarms/calendar alerts, pillboxes.
- Encourage the adolescent to come in and chat to the healthcare provider if they have any concerns, need support or have any questions.
- Refer the adolescent to a support group where available.
8.2 Clinical review

Prior to initiation, do a clinical review of previous screening, tests and current health condition.

Key points to remember for clinical review are explained in Table 11.

Table 11: Clinical review checklist for initiation

<table>
<thead>
<tr>
<th>Check, review and follow up</th>
<th>Key areas</th>
</tr>
</thead>
<tbody>
<tr>
<td>Blood and screening results</td>
<td>Follow up all results for specimens obtained during the previous visit: includes blood results needed for ART initiation and results of screening for OIs, such as TB sputum results (chapters 12–15).</td>
</tr>
</tbody>
</table>
| Management of any conditions       | If client is diagnosed with TB or an OI at this stage, treating the infection should take precedence to ART initiation.  
• Clients with cryptococcal meningitis and those with TB meningitis should have ART deferred for 4–6 weeks.  
• Clients with any other form of TB should have treatment delayed by at least 2 weeks.2 |
| CPT                                | Review how client is tolerating CPT.                                      |
| Essential checks                   | Check weight, height and urine dipstick once again, and record.          |
| Serum creatinine and GFR calculation | The GFR must be calculated for clients who have had a serum creatinine test done (in preparation for starting TDF).  
Formula for calculating the GFR (modified Cockroft–Gaultt equation):  
GFR in females = (140-age) x weight in kg x 1.04  
Plasma creatinine (in µmol/litre)  
GFR in males = (140-age) x weight in kg x 1.23  
Plasma creatinine (in µmol/litre)  |
8.3 ART regimen selection and initiation

- Review of planned regimen: A preliminary decision will usually have been made and investigations will have been done with an appropriate regimen in mind. The previously chosen regimen should be reviewed in light of the results and current clinical condition to determine if it is still appropriate. Abnormal investigation results or new clinical problems may require that this decision is reviewed.

- Changes to planned regimen may be required under the following circumstances:
  - Urine dipstick is abnormal. These clients should not be started on TDF specifically, as it is nephrotoxic. Consider starting ABC and discuss with an experienced clinician.
  - Calculated GFR is less than 80 ml/min per 1.73 m². Clients found with a calculated GFR less than 80 ml/min per 1.73 m² should be referred for specialist evaluation. TDF should also be avoided – ABC is the preferred agent under these circumstances.
  - Abnormal ALT in client requiring NVP-based regimen. Consider starting on LPV/r based regimen.
  - Any new contraindication to one of the chosen drugs is present.

- Preferred first line regimens for adolescents: A list of preferred first line regimens in clients with no other contraindications is provided in Table 8.

- Dosing: Should be according to the client’s weight, referencing the ARV dosing table for children and adolescents. It may be necessary to adjust the dose in follow-up visits as clients grow and gain weight.

- NVP lead-in time: Where NVP has been chosen instead of EFV it is important to remember the 2-week lead-in dosage before changing the client onto the full NVP dose. If the client is receiving EFV at the time of switching, no lead-in dosage is necessary.

- Fast tracking ART:
  - Refers to initiating clients on treatment within 7 days of being diagnosed as eligible for ART. Circumstances warranting fast track initiation are outlined in Box 13.
  - Purpose for fast tracking is to prevent treatment delays in clients with very low CD4 cell counts or with life-threatening OIs.

Remember: Clients with a low CD4 cell count at initiation of ART have a higher risk of developing immune reconstitution inflammatory syndrome (IRIS). These clients should be closely monitored.

Box 13: Clients requiring fast-track ART initiation (as per DOH guidelines)

- HIV-positive women who are pregnant or breastfeeding.
- Clients with CD4 cell count <200 cells/mm³.
- Clients who are WHO clinical stage IV, irrespective of CD4 cell count.
- Clients with MDR/XDR-TB if under the age of 15 years.

Exceptions

- Clients with cryptococcal or TB meningitis: defer ART for 4–6 weeks.

The client should be reviewed within 2 weeks of starting ART. Post-initiation visits and follow-up are dealt with in more detail in chapter 9.
PART A. SECTION 3  Continuum of care: HCT and ART

special considerations for ALHIV

ART initiation in adolescents living with HIV: additional considerations for the healthcare provider

- Treatment literacy is essential: All adolescents, parents/caregivers and treatment supporters should be taught the names of the ARVs and the correct way to take their treatment. They should be made aware of the fact that the drugs are available under different trade names and formulations. They should be counselled not to identify drugs based on the trade name, box or appearance of individual tablets.

- Initiation is only the beginning of the process: It is important that the client is allowed to voice any concerns and difficulties that they have. They should be encouraged to report any problems to the clinician so that they can be addressed as appropriate. This will help to reduce discontinuation of treatment due to side effects and also improve early detection of adverse drug events and new clinical problems.
9. Follow-up and monitoring of clients on ART

Follow-up visits and monitoring are critical for effective ongoing treatment, improving health outcomes and minimising lost-to-follow-up adolescent clients.

9.1 Post-initiation visits

**Remember:** Follow-up visits are important and are best arranged by appointment.

**Frequency of post-initiation visits:**

Post-initiation: after 2 weeks
Thereafter: after 1 month, 3 months, then 3-monthly if stable

- The client should be reviewed within 2 weeks of starting ART.
  - This is done to review adherence and assess how the client is tolerating treatment. It is also to review the client for early side effects.
  - If the client is having difficulty tolerating the medication (e.g. unable to swallow the large EFV tablet) alternative formulations may be considered. This would be based on what is available in the pharmacy.
  - For mild side effects, they should be reassured and adherence reinforced. Symptomatic treatment can be given for side effects, but this should be balanced with the pill burden and potential for drug interactions.
  - For the management of more serious adverse events, see chapters 10–15 and 26.
- The frequency of visits may then be scheduled as recommended above.
- Adherence follow-up and counselling should be done concurrently with these scheduled visits.
- Clients with other clinical problems may necessitate closer monitoring. This should be done in consultation with the adolescent and at the healthcare provider’s discretion.
- Clients who are not virally suppressed also warrant more frequent clinic visits although structural difficulties with adherence, such as transport to the clinic, may impact this.

**Note:** It should be reinforced that information discussed between the client and the healthcare provider is confidential, and clients should be made to feel safe to reveal sensitive information without being judged or victimised. Clients who have been disclosed to should be given their blood results and should understand the effect of their adherence on these results.

9.2 Monitoring

Monitoring should be done as per Table 12 below, based on the national monitoring guidelines for adolescents on ART.
Table 12: Guidelines for monitoring adolescents on ART

<table>
<thead>
<tr>
<th>Aspects to monitor</th>
<th>Purpose</th>
</tr>
</thead>
<tbody>
<tr>
<td>Height, weight and assess development</td>
<td>• Monitor growth and development.</td>
</tr>
<tr>
<td></td>
<td>• Adjust medication doses where required.</td>
</tr>
<tr>
<td>Clinical assessment</td>
<td>• Monitor response to ART and exclude adverse effects.</td>
</tr>
<tr>
<td></td>
<td>• Identify new OIs or clinical concerns at follow-up.</td>
</tr>
<tr>
<td>Ask about treatment side effects at each visit</td>
<td>• Identify ARV-related toxicity and manage appropriately.</td>
</tr>
<tr>
<td>TB screening at each visit</td>
<td>• Identify TB/HIV co-infection and facilitate management.</td>
</tr>
<tr>
<td>CD4 cell count at 12 months into ART, then annually if below 15 years of age</td>
<td>• Monitor immune response to ART.</td>
</tr>
<tr>
<td>If above 15 years, only do the CD4 cell count at 1 year on treatment. Thereafter,</td>
<td>• Stop CPT as per national guidelines.</td>
</tr>
<tr>
<td>repeat CD4 cell count only if virological failure or clinical indication develops</td>
<td></td>
</tr>
<tr>
<td>VL at 6 months and 12 months into ART, then 12 monthly</td>
<td>• Monitor viral suppression in response to ART.</td>
</tr>
<tr>
<td></td>
<td>• Identify treatment failure and to identify problems with adherence.</td>
</tr>
<tr>
<td>If on TDF: creatinine + urine dipstick at 3 months, 6 months, 12 months into ART,</td>
<td>• Identify TDF-related renal toxicity.</td>
</tr>
<tr>
<td>then annually.</td>
<td></td>
</tr>
<tr>
<td>If on AZT: FBC at 3 months into ART, then 6 months and then annually if above the</td>
<td>• Identify AZT-related anaemia.</td>
</tr>
<tr>
<td>age of 15 years</td>
<td></td>
</tr>
<tr>
<td>If below 15 years, FBC at 1 month, 2 months and 3 months into ART and then annually</td>
<td></td>
</tr>
<tr>
<td>If on PI-based regimen: cholesterol + triglyceride at 3 months into ART if above</td>
<td>• Monitor for PI-related metabolic side effects.</td>
</tr>
<tr>
<td>the age of 15 years</td>
<td></td>
</tr>
<tr>
<td>If below 15 years, cholesterol + triglyceride at 12 months on treatment, then</td>
<td></td>
</tr>
<tr>
<td>annually</td>
<td></td>
</tr>
<tr>
<td>If on NVP: If client develops jaundice or rash do ALT and discuss with an expert</td>
<td>• Identify drug-related adverse events.</td>
</tr>
<tr>
<td>Sexual health</td>
<td>• Offer SRH services including contraception where appropriate, STI</td>
</tr>
<tr>
<td></td>
<td>screening and pregnancy testing if needed.</td>
</tr>
<tr>
<td>Mental health</td>
<td>• Assess for depression, suicidal ideation, non-consensual sexual</td>
</tr>
<tr>
<td></td>
<td>violence and substance abuse.</td>
</tr>
<tr>
<td>Also review:</td>
<td>• Follow-up on previous problems (e.g. side effect resolution, social</td>
</tr>
<tr>
<td></td>
<td>issues).</td>
</tr>
<tr>
<td></td>
<td>• Drug adherence and challenges.</td>
</tr>
<tr>
<td></td>
<td>• Any other issues that may arise during the course of the consultation</td>
</tr>
<tr>
<td></td>
<td>which might also require attention.</td>
</tr>
<tr>
<td></td>
<td>• If poor adherence is suspected the viral load may need to be monitored</td>
</tr>
<tr>
<td></td>
<td>more frequently.</td>
</tr>
</tbody>
</table>
9.3 Client management

(i) Managing the client who is virologically suppressed

A client is usually considered to be virologically suppressed when the viral load is measured and found to be less than 50 copies per ml.

- **Adherence should be reinforced:** The client should be commended for doing well on treatment. Adherence problems should be addressed to prevent future treatment failure.
- **The client should be invited to report any new problems or concerns** that might prompt further discussion or need for investigation.
- **Continued monitoring** should be done for growth, development and drug side effects.
- **Screening for other health concerns:**
  - TB screen should be conducted at each visit.
  - If the client is sexually active, the need for contraception should be addressed encouraging dual contraception. Responsible sexual behaviour should be encouraged but clients should not feel judged on their current practices.
  - Screen for symptoms of STIs.
  - Questions on how the client is coping in school and their future plans may reveal some information about their learning ability and state of mental wellbeing.
  - Mental health screening as appropriate.
- Clients who are well and virally suppressed can be reviewed at 3-monthly intervals and monitored as per Table 13.
- **Other important considerations:**
  - Cervical screening for sexually active females.
  - Voluntary medical male circumcision.
  - Vaccines, including annual influenza vaccine.

(ii) Managing the client who is not virologically suppressed

Table 13 details the appropriate monitoring of the viral load for first line regimens.

*Table 13: Guidelines for monitoring viral load for first line regimens*

<table>
<thead>
<tr>
<th>Viral load (VL)</th>
<th>Response</th>
</tr>
</thead>
</table>
| <400 copies/ml | • VL monitoring according to duration of ART and routine adherence support.  
• Continue routine VL monitoring as it may be 12 monthly depending on how long patient is on treatment. |
| 400–1000 copies/ml | • Assess and manage adherence carefully.  
• Repeat VL in 6 months and manage accordingly. |
| >1 000 copies/ml | • Adherence assessment and intense adherence support.  
• Repeat VL in 2 months and check HBV status and Hb, if not already done.  
• If <1000 copies/ml, repeat in 6 months and then reassess.  
• If >1000 copies/ml and adherence issues addressed, switch to second line therapy after checking HBV status and Hb. |

*NOTE: Always check for hepatitis B before stopping TDF. If client has chronic hepatitis B, stopping TDF may lead to a fatal hepatitis flare. If client is hepatitis B positive, TDF should be continued as a 4th drug in the second regimen.*
**Definition of virological failure**

Virological failure is generally defined as two elevated viral load levels greater than 1000 copies/ml on at least two consecutive occasions more than 1 month apart. If the viral load remains above 1000 copies/ml (on an NNRTI-based regimen) or above 10 000 copies/ml (on a PI-based regimen) after 3 months, the adolescent should be treated as having virological failure.

**Note:** Clients who are not virologically suppressed still need the same care, screening and interventions as the client who is virologically suppressed. This screening may also provide background information as to the cause of the increased viral load.

The most important differences in clinical management of these clients are in the adherence counselling, monitoring and follow-up.

- **Adherence counselling** in clients who are not virologically suppressed should focus on identifying barriers to adherence. This is not always easy as clients may not be forthcoming about all of the difficulties they face. Problems should be discussed with clients, (and parents/caregivers where appropriate,) with the intention of finding solutions. Clients should also be made aware of the fact that poor adherence promotes viral resistance, which can lead to reduced treatment options in future. Non-disclosure may influence adherence in the following ways:
  - Refusal to take treatment because the adolescent is not aware of why it is needed.
  - Inconsistency in treatment taking because the client is not aware of the implications of poor adherence.

- **Directly observed therapy (DOT)** by the parent/caregiver or treatment supporter may be necessary to ensure adherence. Younger clients, especially those who have not yet been disclosed to, may spit out tablets or hide them away. The advice to give to parents/caregivers would be to watch the client swallow all medication.

- **Closer monitoring of the viral load** is warranted in these clients to see if adherence interventions have improved the viral load. Depending on the subsequent viral load once the adherence issues are resolved, the client may need to change the treatment to second line therapy.
  - Clients who are not virologically suppressed need to be reviewed more frequently. This is in order to follow up on adherence problems as well as to monitor them for clinical deterioration.
  - Consider doing a VL earlier where there has been social upheaval, such as death of a family member, change of caregiver or relocation as these are common risks for poor adherence.
  - Usually these clients should be reviewed monthly, unless there is another reason to review them sooner. It should be kept in mind that travel expenses may affect the client’s ability to attend the clinic and this should be taken into account when booking follow-up appointments. It may be necessary to transfer the client to a facility closer to home under certain circumstances.

- **Approach the issue with sensitivity:** Dealing with adolescents with virological failure requires careful handling and diplomacy.
  - Clients should not feel as though they are being punished or policed by having supervised therapy.
  - Parents/caregivers should be advised that this role is a supportive one and should not promote conflict between the client and the parent/caregiver.

**Note:** for more information on the practical management of virological failure and on when to change treatment regimens, see chapter 11.
10. Adverse events and drug reactions to ARVs

Adverse drug events and drug reactions to ARVs, including acute and chronic complications, need to be identified and managed.

Acute adverse reactions to ARVs and an explanation of how to manage them is summarised in Appendix 4.

10.1 Chronic complications of ART/HIV

Chronic complications that may occur in treatment-experienced adolescents include fat redistribution syndrome, dyslipidaemia, gynaecomastia, renal and bone toxicity. It is difficult to separate the effects of the virus from those of ART as these are often interlinked. Chronic complications are more likely to affect perinatally infected adolescents who have been on cART for many years.

(i) Fat redistribution syndrome\(^1,2\)

Fat redistribution syndrome is often conceptualised as a single condition. Lipoatrophy (LA) and lipodystrophy (LD), however, while being the most common manifestations, are two distinct entities with different pathogenesis and require different management strategies. As adolescents are particularly sensitive to body image, fat redistribution syndrome is an important issue and may affect adherence.

Both LA and LD require a high degree of clinical suspicion as the diagnosis is often missed until the conditions are far advanced. While anthropometric measures provide somewhat objective methods to measure changes in body composition over time, and assist with diagnosis, they require considerable standardisation and experience in order to obtain valid and reliable measurements.

The more commonly used anthropometric measurements include:
- waist-to-hip ratio
- mid-upper arm circumference (MUAC)
- skin-fold thickness (triceps and subscapular).

The current recommendation, however, is that the diagnosis of LA and LD should be made on clinical suspicion rather than anthropometric measurements. This is because their interpretation in adolescents is somewhat complicated by changes as a result of normal growth, high rates of background malnutrition and limited data on normal reference ranges for our population.

Lipoatrophy

LA is the loss of sub-cutaneous fat in all areas of the body, though is most notable in the face, limbs and buttocks. It is the result of mitochondrial toxicity in combination with inflammatory changes that leads to decreased fat formation and increased apoptosis. LA is most strongly associated with the NRTIs that are most toxic to mitochondria (d4T, ddI, AZT). It is important to note that EFV and NVP have been associated with higher rates of limb LA in adults compared to LPV/r.\(^3\) Children who were switched to NVP in the Neverest 2 study\(^4\) similarly displayed greater evidence of lipoatrophy than children who remained on LPV/r. In addition to drugs there is a well-described genetic component.
**Management of LA:** Substitution of drugs associated with mitochondrial toxicity (e.g. substituting ABC or TDF for d4T or AZT) once viral load suppression has been confirmed, i.e. the viral load has been measured and is less than 50, within the past 3 months:
- if <15 years and <40 kg switch to ABC
- if >15 years and >40 kg switch to TDF.

While drug substitution should halt progression, improvement may be minimal and not noticeable by the client. EFV/NVP should not be substituted for PIs to manage LA.

In severe cases plastic surgery may be required.

**Lipodystrophy**

There is increasing evidence from research on HIV-positive adults that fat accumulation, or lipodystrophy (LD), is the consequence of a combination of ageing and treating the infection, and not associated with individual drugs or classes of ARVs.

Studies that have explored the role of non-nucleoside reverse-transcriptase inhibitors (NNRTIs) and PIs and switching from PIs to NNRTIs to decrease LD have generally concluded that there is no evidence to support switching ARV agents to manage fat accumulation.⁵

**Management of LD:**⁶ There is no evidence to support drug switches for LD. Lifestyle changes, including aerobic exercise and healthy diet may assist and should be encouraged.

**(ii) Dyslipidaemia**⁷,⁸,⁹,¹⁰

Initiation of cART has been associated with a rise in total cholesterol, low-density lipoprotein (LDL) and high-density lipoprotein (HDL) in both adults and children. The effects appear more marked for clients receiving PI-based therapy. d4T has also been associated with dyslipidaemia.

These metabolic disturbances are a concern for future cardiovascular health, especially as adolescents grow into adulthood. They may contribute to accelerated atherosclerosis, which is a risk for cerebrovascular and coronary artery disease.

A fasting serum cholesterol is the basic monitoring investigation. The American Academy of Pediatrics criteria for intervention of hyperlipidemia for children and adolescents suggests using the following reference ranges:¹¹
- LDL >4.9 mmol/litre for children with no known cardiovascular disease (CVD) risk factors
- LDL >4.1 mmol/litre for children with 2 or more CVD risk factors as cut-offs for intervention.

HIV infection has not been specifically identified as a risk factor, but as HIV is a state of chronic inflammation, many clinicians would consider it a risk factor.

Lifestyle modifications may assist with an abnormal lipid profile. This should be the first step. A diet low in lipids and regular exercise should be prescribed, with referral to a dietician where available. Adolescents receiving d4T therapy should be switched to an alternative. The LDL should be repeated at 6 months after the intervention to assess for improvement.

Adolescents on PI therapy may warrant a change in their treatment if there is an inadequate response to lifestyle interventions. Atazanavir has been reported to have a more favourable lipid profile than LPV/r and a simple switch may be considered where this is feasible. In situations where NNRTIs can still be used, these may be substituted. The switch may need discussion with an expert.
The use of statins and other medications for controlling the cholesterol should be done with caution, considering drug interactions and possible adverse drug reactions. Simvastatin, the most freely available statin in the South African government sector, is contraindicated with the use of RTV, as RTV may increase concentrations of simvastatin in the blood to dangerously toxic levels.

(iii) Gynaecomastia

Gynaecomastia has many possible causes but in adolescents is most frequently physiological. It has been associated with long-term ART use. This has been dealt with in detail in chapter 3.2 and 3.3.

(iv) Renal toxicity\textsuperscript{12,13,14,15,16,17}

- \textit{TDF has been associated with renal toxicity:} It is recommended that TDF be avoided in clients known to have renal disease.
- \textit{Regularly monitoring the urine dipstick is essential} for all adolescents receiving TDF. The serum creatinine should also be checked regularly. The GFR should be calculated.
- \textit{TDF may cause proximal renal tubular toxicity,} and also has an effect on glomerular filtration. This may present acutely (as acute kidney injury, with a reduced glomerular filtration rate or GFR). It may also present chronically, where there is a proteinuria and glycosuria on dipstick testing, with GFR changes only appearing much later. Laboratory testing of the urine may show phosphaturia and uricosuria. Abnormal urine dipstick tests or a GFR below 80 ml/min per 1.73 m\textsuperscript{2} may warrant a switch from TDF. These adolescents should be referred for expert review.
- \textit{The use of TDF and PIs together may have a greater effect on renal function.}
- \textit{Indinavir is a PI that has been associated with nephrotoxicity:} The primary manifestation of toxicity is urolithiasis, or kidney stones. More commonly used PIs such as LPV/r and Atazanavir are much less toxic, although a few cases have been previously reported.
- \textit{Renal disease not related to ART may progress while on ART:} These adolescents should be managed by an experienced HIV clinician, in discussion with the renal physician attending to them. Specialised dosing of ART may be required.

(v) Bone toxicity\textsuperscript{14,18,19,20}

- \textit{HIV infection has been associated with lower overall bone mineral density (BMD):} This may have a particular effect for perinatally infected adolescents due to prolonged exposure to the virus.
- \textit{ART in general has been found to have an association with lower BMD} after starting treatment. This may place adolescents on ART at a risk for osteoporosis later in life. There is also a theoretical increased risk for pathological fractures.
- \textit{TDF has been associated with a reduction in BMD exceeding that of other agents:} This is particularly in combination with PIs such as LPV. PIs have been found to have a negative impact on bone health, particularly LPV/r, full dose RTV, and indinavir (which is no longer in broad use, and is not part of South African guidelines).
- \textit{Adolescence is a time of high bone turnover} (due to rapid growth) and it is therefore not recommended that TDF be used early in adolescence. It is advised that TDF only be used in older adolescents who have completed their pubertal growth spurt (and thus already reached their peak bone mass). Currently the evidence for using TDF in younger clients is limited, so it cannot be recommended.

Also see Tables 11 and 12
• **Ideally, the Tanner staging is used to determine developmental progress of the adolescent**, and thus determine if it is safe to use TDF. It has been suggested that TDF may safely be used at a Tanner stage 3 and above. Tanner staging is not used routinely in clinical practice in South Africa. For this reason, the surrogate markers for TDF use are:¹³
  - age above or equal to 15 years, and
  - weight above or equal to 40 kg.

Adolescents who do not meet these criteria should be initiated on an alternative regimen (ABC/3TC/EFV) unless there are contraindications to these agents. Once they are older and meet the criteria for TDF use, they can be switched to TDF.

• **General measures that should be taken to ensure bone health** in all adolescents living with HIV include:¹⁸
  - education and advice to avoid alcohol and cigarette use
  - weight reduction for adolescents who are overweight
  - regular exercise (preferably high impact, if a well client)
  - nutrition optimisation and ensuring adequate calcium and vitamin D intake
  - bone ‘unfriendly’ medication avoidance (e.g. non-steroidal anti-inflammatory drugs and systemic corticosteroids) where possible.
11. Managing virological failure and changing treatment regimens

For a definition of virological failure see chapter 9.3 (ii).

11.1 Management of the adolescent client who is not virologically suppressed

Management of a client with an elevated viral load

- Intensify adherence counselling and identify barriers to adherence.
- Review the client monthly, with ongoing adherence monitoring and interventions.
- After 3 months of good adherence, repeat the viral load.
- If the viral load remains elevated above 1000 copies/ml, the client has virological failure. The drug regimen may need to be changed.

The further clinical management of the client with an elevated viral load is dependent on the regimen they are currently receiving:

- **EFV/NVP-based regimens (>1000 copies/ml consecutively)**
  Will most likely require a change in regimen if the client’s viral load fails to suppress after adherence interventions.

- **PI-based regimens (>10 000 copies/ml consecutively)**
  The client will need referral if viral load fails to suppress after adherence interventions. These clients may require resistance testing.

**Special considerations for ALHIV**

Key considerations when managing virological failure in adolescents

- **Barriers to adherence**: The relationship between the client and the healthcare providers is vital. A trusting relationship and rapport will facilitate honest discussion around problems the client may be experiencing with adhering to treatment.

- **Investigating other causes**: It is important to note that an elevated viral load does not automatically mean that the client is poorly adherent. Other causes of an elevated viral load need to be investigated, and could include:
  - incorrect dosing
  - drug interactions
  - poor absorption
  - drug resistance.
Tips for improving adherence in clients failing their treatment

- **Review the treatment time**: Is this still the optimal time for the adolescent to take their treatment? Has something changed? Advise on selecting the most suitable time.

- **Adolescents may skip doses if the treatment time has been missed**: Ask about this specifically. Advise them that it is better to take treatment late than not at all.

- **Review the use of treatment reminders**: Pillboxes, alarms and other reminders may help if forgetfulness is an issue. Pillboxes may be especially useful if clients are away from home at treatment times (e.g. sport or activities in the evenings).

- **Simplify treatment regimens**: If possible, change treatment to once-daily dosing and use combination tablets (such as the FDC) if available.

**Note**: Individual drugs should not be substituted without the availability of drug-resistance testing. For example, a change from d4T/3TC/EFV to ABC/3TC/EFV in order to allow for once-daily dosing constitutes a single drug substitution. This should **not** be done in cases of virological failure unless in consultation with an expert.

- **Ask if the client is able to tolerate the current drug formulations**: Adolescents may report being unable to swallow larger tablets. Changing to paediatric tablets (at the appropriate dose) may be considered in such circumstances. Provide advice on improving the palatability of treatment (e.g. follow with something to take away the taste), as this may also affect adherence.

- **Ask specifically about treatment side effects**: Clients may not mention these on their own. The side effects may be of such concern that the client stops treatment on their own. Regimen changes may be indicated, depending on the clinical circumstances.

- **Ask the clients if they are tired of taking ART**: Pill fatigue is common but adolescents often do not report this. At present there is insufficient evidence to recommend drug holidays or structured treatment interruptions. Increased support, counselling, education and encouragement may be needed for these clients. There may also be underlying psychosocial issues requiring attention.

- **Ask questions around disclosure issues**:
  - Clients who are aware of their HIV status may have issues around taking treatment when other members of the household have not been disclosed to.
  - Clients who have been disclosed to long after diagnosis (perhaps in childhood) may not have been properly educated on why adherence to treatment is important.
  - Clients who have not yet been disclosed to by parents/caregivers may refuse treatment because they are not aware what the treatment is for.

- **It may be necessary to request the parent/caregiver (or another treatment supporter) to attend the clinic with the adolescent**: This should be done in discussion with the adolescent. The relationship between the adolescent and the treatment supporter should be considered, as treatment adherence may be a source of conflict between the parent/caregiver and adolescent. Parents/caregivers should be counselled that the adolescent needs extra support, and that the reason for calling them in is not to institute punitive measures but to enlist their help. Treatment supporters may be requested to remind clients to take treatment or to perform directly observed therapy (DOT).

**Remember**: Never switch a single drug in a failing regimen in order to use an FDC or simplify treatment: If the client has already developed resistance to their current regimen the viral load will not improve, and there is a risk of their developing resistance to the new drug that has been introduced.
11.2 Changing treatment regimens

(i) Second line ART regimens

It is essential to address any barriers to adherence prior to initiating the second line therapy. This is to preserve the integrity of the second line regimen and ensure that the client maintains maximal adherence to avoid failing the second line.

Guidelines for changing regimens

- Switch only once adherence issues resolved.
- Never switch a single drug in a failing regimen.
- Do not continue therapy with a failing NNRTI regimen for prolonged periods.

The choice of second line regimen depends on which drugs the client was receiving previously. Table 14 describes second line regimen options.

Table 14: Options for second line regimens

<table>
<thead>
<tr>
<th>Second line regimens for adolescents aged 10–15 years</th>
<th>Proposed second line regimen</th>
</tr>
</thead>
<tbody>
<tr>
<td>ABC/TDF + 3TC/FTC + EFV</td>
<td>AZT + 3TC + LPV/r</td>
</tr>
<tr>
<td>d4T + 3TC + EFV</td>
<td>AZT + ABC + LPV/r</td>
</tr>
</tbody>
</table>

<table>
<thead>
<tr>
<th>Second line regimens for adolescents aged &gt;15 years</th>
</tr>
</thead>
<tbody>
<tr>
<td>Failing on a TDF-based first line regimen</td>
</tr>
<tr>
<td>AZT + 3TC + LPV/r</td>
</tr>
<tr>
<td>AZT + TDF + 3TC + LPV/r (If HBV co-infected)</td>
</tr>
</tbody>
</table>

| Failing on a d4T-based first line regimen            |
| TDF + 3TC (or FTC) + LPV/r                          |

| Dyslipidaemia (total cholesterol >6 mmol/litre) or diarrhoea associated with LPV/r |
| Switch LPV/r to ATV/r                              |

| Anaemia and renal failure                          |
| Switch to ABC                                      |

Note: Always deal with adherence issues before changing regimens.

In terms of second line regimens, the following should be noted:

- An FBC or haemoglobin (Hb) result should be available prior to initiating AZT.
- Thereafter, monitoring should proceed as follows: Hb or FBC at month 1, 2, 3 and 6 into ART and then annually if on AZT.
- The triglycerides (TG) and cholesterol levels should be checked at baseline. Thereafter, they should be checked after one year on LPV/r if <15 years. If ≥15 years they should be repeated 3 months after the regimen change. Annual monitoring should be instituted thereafter.
- The client should be seen monthly until month 3, when the viral load may be repeated. If the client’s viral load has suppressed on treatment, they may be seen 3-monthly.
- If the viral load is still not suppressed, intense adherence measures should be re instituted, with close monitoring and follow-up.

The management of treatment failure on second line ART is as per Figure 6.
(ii) Third line regimens

- These are regimens used for clients who have failed second line ART therapy with extensive drug resistance, which may include resistance to PIs such as LPV.
- The drugs used in third line regimens are not available at primary healthcare level. Clients with extensive resistance who require these drugs should be referred for specialist opinion and genotyping.
- The third line drugs may be accessed through the DOH Third Line ARV Peer Review Committee (PRC), once each case has been considered individually. Examples of third line drugs accessible in this way are Darunavir (PI), Raltegravir (integrase inhibitor) and Etravirine (NNRTI).

The information required to adequately manage the client in need of a third line regimen is summarised in Box 14.
Box 14: Managing the client in need of a third line regimen.

Referral to an expert clinician is required. Information necessary to include in the referral is listed below.

- Initial regimen and start date.
- All drug switches (with reasons).
- Second line regimen and start date.
- Use of 3TC monotherapy or any other holding regimens, and treatment dates.
- Previous adverse drug reactions.
- PMTCT history where applicable.
- Most recent blood results, as well as the results before these (to assess the trends).
- All available resistance test results (if done).
- Past medical history and concomitant medical conditions.
- Current clinical and psychosocial problems.

Third line drugs may be accessed after a review of each individual case by the Third line Committee. For the necessary application forms and to submit applications for third line drugs, contact the Secretariat of the Department of Health Third Line ARV Peer Review Committee (PRC) at jamalk@health.gov.za

3TC monotherapy

This section includes information on the use of 3TC monotherapy as a holding regimen and has been included for information purposes: it is not intended to promote the use of 3TC monotherapy as a routine course of management. There is a paucity of clinical evidence regarding its use and it cannot be recommended for routine use, or for inclusion in guidelines. It may, however, be used or recommended by experienced clinicians under specific circumstances. The following information is intended to provide guidance on the safe use of this strategy where it has been deemed necessary.

Note: 3TC monotherapy may be used or recommended by experienced clinicians under specific circumstances. Clients should not be placed on 3TC monotherapy without first discussing with an expert.

Why use 3TC?

3TC monotherapy is not included in any local guidelines on ARV management. It may, however be used by experienced clinicians as a holding regimen in cases where:

- definitive treatment is not available (e.g. due to extensive resistance or where the necessary drugs are not immediately available)
- adherence is difficult or impossible and there is a real risk that the client may jeopardise future treatment options if left on their current regimen.

3TC monotherapy is intended only for use temporarily while resolving the problems as identified above. This should only be done in cases where the client has already failed a 3TC-containing regimen and 3TC resistance with the M184V mutation has been documented on a resistance test. The rationale behind 3TC monotherapy is that the 3TC-resistant virus has been found to replicate more slowly than the wild type virus.6 This means that the mutation that causes resistance to 3TC (known as the M184V mutation) may effectively weaken the virus.
3TC monotherapy continued

- It has been suggested that clients who are on 3TC monotherapy have a slower rate of disease progression than clients in whom ART is stopped. The client’s CD4 cell count may drop slower than if they received no treatment. Thus, the intended role of 3TC monotherapy is for immune preservation where the alternative would be to stop treatment. It cannot replace definitive ART.
- 3TC monotherapy does not cause viral suppression. There is no guarantee that it will maintain the client’s immune status or CD4 cell count. Its use warrants very close clinical and CD4 cell count monitoring.

Note: 3TC monotherapy is used as an alternative to stopping treatment. It is not an alternative to ARV treatment.

What are the prerequisites for 3TC monotherapy?
Essential prerequisites before starting a client on 3TC monotherapy:
- The client should be clinically well, with no current OIs.
- The client should have a CD4 cell count above 200/mm³, checked within the previous 3 months. The client will require 3-monthly CD4 cell count measurements on 3TC monotherapy.
- The client must have failed a regimen containing 3TC with proven resistance.
- The reason and expected duration for the use of monotherapy must be clearly defined and understood by those who will be providing clinical care.
- The client must understand the rationale for monotherapy and must find this acceptable.
- The healthcare provider must be comfortable managing clients on 3TC monotherapy. Each case should be discussed with an expert.

What about dosage, monitoring and length of treatment?
Note the following regarding 3TC monotherapy:
- 3TC monotherapy is given as a once-daily dose as appropriate for the client weight.
- Clients on monotherapy should have their CD4 cell count checked every 3 months.
- Clients should be seen at the clinic regularly and reviewed for any new OIs at each visit.
- Viral load monitoring is not necessary as the client is not expected to reach viral suppression.
- There is no evidence as to a time limitation with regards to 3TC monotherapy use. It should be used only as long as necessary to resolve the initial problem that was identified. Clinical or marked CD4 cell count deterioration is an indication to initiate definitive treatment urgently.

When should 3TC be discontinued?
3TC monotherapy is a temporary strategy. As such, once the clinical issues that necessitated its initiation have been resolved, it should be discontinued and definitive treatment started. It may be necessary to discontinue 3TC monotherapy despite not having resolved all challenges.
3TC monotherapy should be discontinued if:
- CD4 cell count drops below 200 cells/mm³.
- The client develops a new WHO clinical stage III or IV condition.
- The client starts losing weight or develops failure to thrive.

In these cases a definitive ART regimen should be started as soon as possible.
3TC monotherapy issues to consider for adolescents

Before any treatment change is made it is always advisable to explain and give reasons for the change. This encourages discussion, and facilitates full understanding and acceptance of the change in regimen.

- It is essential that clients be properly counselled before starting on 3TC monotherapy. Counselling should include:
  - an explanation to ensure that the client understands the reason behind changing their treatment
  - the client’s approval of the regimen change
  - reassurance if the client feels that they are being punished for poor adherence or that they have run out of treatment options
  - education and information about the client not being virally suppressed, and that for this reason they have an increased risk of transmitting HIV to sexual partners.

- Adolescents with severe adherence difficulties may in fact prefer this option as the pill burden is reduced. They should be advised that it is a temporary solution and must be made aware that future treatment may not be as simple.

(iii) Other holding regimens

In clients with extensive drug resistance it is possible to create holding regimens that consist of multiple NRTIs or other unusual drug combinations. This is something that can only be done with the availability of HIV drug-resistance testing as the regimen is constructed based on these results. These clients are best managed at a tertiary referral centre, by an expert healthcare provider.
SECTION 4

Management of opportunistic infections and other HIV-related conditions
INTRODUCTION TO SECTION 4

This section deals with two of the most common opportunistic infections, TB and cryptococcal disease (with a focus on meningitis). Other opportunistic infections are also discussed, including Mycobacterium avium complex (MAC), pneumocystis carinii pneumonia (PCP), extensive candidiasis and cytomegalovirus (CMV). Other non-infectious disorders which occur in adolescents living with HIV are outlined, namely lymphoid interstitial pneumonitis (LIP), bronchiectasis, HIV-associated nephropathy (HIVAN)/HIV immune complex kidney disease (HIVICK), HIV encephalopathy (HIVE)/HIV-associated neurocognitive disorders (HANDs) and malignancies.

12. Tuberculosis

73% of people with TB are co-infected with HIV. The problem is compounded by the increasing prevalence of various strains of drug-resistant TB. The management of TB in people living with HIV is a priority. This includes the screening, diagnosis and treatment of TB, management of ART and TB co-therapy, management of potential drug interactions, plus the active promotion of TB prevention strategies.

12.1 Screening for TB

It is advisable to screen clients for TB at every visit. The TB screen consists of a few simple questions (Box 15).

<table>
<thead>
<tr>
<th>Box 15: Screening for TB</th>
</tr>
</thead>
<tbody>
<tr>
<td>Ask about the following symptoms</td>
</tr>
<tr>
<td>Current cough (any duration)</td>
</tr>
<tr>
<td>Persistent fever of more than 2 weeks</td>
</tr>
<tr>
<td>Unexplained weight loss of &gt;1.5 kg in a month</td>
</tr>
<tr>
<td>Drenching night sweats</td>
</tr>
</tbody>
</table>

Any HIV-positive client with one or more symptoms present should be considered a TB suspect.

Other suggestive symptoms include:
- new palpable lymphadenopathy
- sputum production, which may or may not be bloodstained
- shortness of breath, chest pains
- loss of appetite, malaise, tiredness.

In certain cases, adolescents may not report symptoms of TB even though these are present. They may consider the symptoms to be unimportant or attribute them to minor ailments. It is therefore important to take into account the clinical presentation of the client as well. Loss of weight is an important clinical sign and should necessitate further enquiry and investigation. The history of a positive TB contact should always be sought.
12.2 Diagnosis of TB

TB is sometimes difficult to diagnose. This is especially true in clients who are HIV-positive as the tests may yield a negative result even in the presence of disease. The introduction of the GeneXpert probe has significantly improved the identification of TB in clients in which the AFB smear (used previously) would be negative.\(^4\)

**What is GeneXpert?**

GeneXpert is a DNA-based test that detects the presence of DNA of organisms within the group *Mycobacterium tuberculosis*. It is also able to detect specific DNA sequences that would cause the mycobacterium to have rifampicin resistance, which is one of the hallmarks of MDR-TB.

The new algorithm for the diagnosis of TB incorporates the use of the GeneXpert probe (Figure 7). GeneXpert has been extensively rolled out for use in primary care facilities.

The client should be encouraged to produce at least two good quality sputum samples for diagnostic tests. Early morning samples are recommended but not essential.

The tuberculin skin test (TST) has limited utility for the diagnosis of TB. Its use for diagnostic purposes is restricted to children under the age of 5 years for the detection of TB infection, not necessarily disease, and it should not be used for the diagnosis of TB in HIV-positive adolescents.\(^5\)

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**Figure 7: Diagnostic algorithm, TB Xpert** (from the national tuberculosis management guidelines, DOH, 2014)
12.3 Treatment of TB

TB should be managed according to the national DOH guidelines. Duration of treatment and the regimen used depend on the case definition and whether the patient has been treated for TB previously. For the purposes of TB management, the children’s guidelines are applied to children aged 0–14 years, and adult guidelines are applied from the age of 15 years.

Included here are some considerations for the management of TB in adolescents living with HIV:

- **Weight and dosage adjustment:** The weight is more important than the age when prescribing treatment, in order to avoid overdose and adverse drug reactions. It should be noted that severely underweight clients need to receive smaller doses in order to avoid overdosing. Paediatric dosing tablets may need to be used in order to get adequate doses. Doses should be adjusted as the client gains weight. For TB regimens and dosages, see Appendix 5.

- **Side effects/adverse events (for INH, RIF, PZA and Ethambutol):**
  - Minor drug reactions may include nausea, vomiting and discoloured body fluids (orange tears or urine). Clients with these symptoms should be reassured and encouraged not to stop their TB treatment. Symptomatic management may be used to alleviate some of the symptoms.
  - Peripheral neuropathy may be caused by INH: this is managed by administering high dose pyridoxine.
  - More severe drug reactions for clients on TB therapy include drug-induced hepatitis, skin rashes (including Stevens-Johnson syndrome) and loss of colour vision. Clients who present with symptoms suggestive of a severe reaction should be referred urgently. Clinical signs that should trigger referral are: jaundice, confusion, skin rash, decreased urine output, shock and visual disturbances.

12.4 Managing ART and TB therapy

(i) Client with TB newly diagnosed with HIV

All HIV-positive clients who have been diagnosed with TB should be initiated on ART. This is irrespective of the CD4 cell count.

- The timing of ART initiation depends on the client’s CD4 cell count and the site of TB.
  - Clients with TB meningitis should be initiated after receiving 4–6 weeks of TB therapy. This is because these clients have a higher risk of IRIS if treatment is started sooner.
  - Clients with a CD4 cell count of less than 50 cells/mm$^3$ should be initiated within 2 weeks of starting their anti-TB therapy (note that this excludes those clients with TB meningitis). These clients need close monitoring for the features of IRIS (see Box 16).
  - Other clients may be initiated within 2–8 weeks of TB therapy.
- ART initiation is as per National Guidelines.
- Sometimes when ART is initiated the client experiences a transient worsening of their TB symptoms. Such a reaction is termed an IRIS, and is due to an improvement in the functioning of the immune system. This may occur especially in clients with a CD4 cell count $<$100 cells/mm$^3$.
- It is important to reassure such clients that they should not stop either their TB treatment or their ART. They should be monitored closely. In some cases, they may benefit from the use of steroids. If unsure, or the client continues to deteriorate, it is best to refer.
- Drug-resistant TB should also be considered and investigated in a client on TB therapy who has worsening symptoms.
(ii) Clients on ART who develop TB

Clients on ART who develop TB should be continued on ART throughout their TB treatment.

- If the client is on LPV/r the dose should be doubled. This is because of drug interactions between rifampicin and ritonavir-boosted protease inhibitors. This elevated dose should be continued up until 2 weeks after the client has completed their TB treatment.

- Giving additional RTV is preferred to double-dosing the LPV/r where this is available. The short shelf-life of this drug has made it difficult to keep in stock in many pharmacies and clinics. If available, RTV should be added to the regimen as per the ARV drug dosing chart for children.

- NVP is best avoided for clients on anti-TB therapy. This is due to an increased risk of hepatitis. The reason for using NVP should be reviewed and it should be substituted if required. It may be necessary to consult with an expert under complicated circumstances.

- Other classes of ARVs can be continued at the usual doses.

- Be aware of the possibility of IRIS.

Box 16: Management of immune reconstitution inflammatory reaction (IRIS) for clients with TB

If the features of TB disease appear within the first 6 months of ART initiation, this could be due to an IRIS. As the client’s immune system improves, it may unmask infections that were previously present but not causing any symptoms.

- TB treatment should be started as usual, but these clients may warrant more careful monitoring by the clinician.

- If symptoms continue to worsen on ART and TB treatment, a referral may be warranted.

12.5 Drug interactions

Note: It is not advisable for clients to use combined oral contraceptives while on TB therapy as the contraceptive effect may be reduced. Another contraceptive method should be used.

- Serum levels of ritonavir-boosted PIs such as LPV/r are reduced by the presence of rifampicin, as described above. Boosting of the dosage is required to ensure adequate drug levels.

- Other drugs may require dose adjustment, such as anticonvulsants or Warfarin.
12.6 Prevention of TB

(i) Infection control

Infection control within the clinical environment is of utmost importance. This is in order to protect the healthcare provider, support staff, as well as other clients attending the facility.

Basic infection control measures include:7

- **Administrative controls** such as development of an infection control plan within the facility, education of clients and healthcare providers in cough hygiene, designated areas for sputum collection and triaging of coughing patients.
- **Environmental controls** such as adequate ventilation (windows open, ensure air exchange) and light in waiting areas and consultation area. Extractor fans or ultraviolet (UV) lights also form part of environmental infection control.
- **Personal control measures** such as masks for use by healthcare providers and suspected infectious clients.

For further information on TB prevention measures, see Appendix 6.

(ii) Isoniazid preventive therapy (IPT)

- All HIV-positive clients should be screened for TB symptoms at each visit.
  - All HIV-positive clients above the age of 15 years with a negative TB screen are candidates for TB preventive therapy with INH.3
  - Current guidelines do not advise IPT in HIV-positive clients under the age of 15 years unless they have had a recent TB contact.8
- Those with a positive TB screen warrant investigation to exclude TB disease. If these investigations are negative, they should not be initiated on IPT but rescreened for eligibility for IPT after 3 months.3

**Note:** If there is any suspicion of TB, IPT should **not** be initiated. Further investigations may be required to satisfactorily exclude TB. These may include X-ray, fine needle aspiration (FNA) of suspicious lymph nodes and referral where necessary.

- IPT can be given to clients who have had TB previously to prevent recurrence.
- IPT is safe in pregnancy.
- A single course of IPT is sufficient, unless the client has had subsequent exposure to TB. In this case, the course of IPT may be repeated.

**Box 17: Dosage of INH prophylaxis**

<table>
<thead>
<tr>
<th>INH 5 mg per kg orally as a daily dose (max. = 300 mg daily)</th>
</tr>
</thead>
<tbody>
<tr>
<td>+ Pyridoxine 25 mg orally as a daily dose</td>
</tr>
</tbody>
</table>

- Where available a TST should be done: the result of this test will determine the duration of IPT. The current recommendations from the National ART guidelines are listed in Table 15.3
Table 15: TST recommendations for adolescents ≥15 years of age

<table>
<thead>
<tr>
<th>TST status</th>
<th>Pre-ART (irrespective of CD4 cell count)</th>
<th>On ART</th>
</tr>
</thead>
<tbody>
<tr>
<td>TST not done</td>
<td>IPT for 6 months</td>
<td>IPT for 6 months</td>
</tr>
<tr>
<td>TST negative</td>
<td>No IPT</td>
<td>IPT for 12 months</td>
</tr>
<tr>
<td>TST positive</td>
<td>IPT for 36 months</td>
<td>IPT for 36 months</td>
</tr>
</tbody>
</table>

(iii) Clients with a known TB contact

- An HIV-positive client who has been in contact with a known TB case should be screened for TB symptoms. If negative, this client should receive IPT for a period of at least 6 months. This is regardless of previous IPT exposure. Positive TB screens warrant further investigation.
- If a clinician diagnoses TB in a client they should advise them that all HIV-positive people in the same household, as well as any HIV-negative or untested children under the age of 5, should be screened for TB and should access preventive therapy where appropriate.

Special considerations for ALHIV

Management of TB in adolescents living with HIV: additional considerations for the healthcare provider^a^

- Adherence to TB therapy is essential to achieving a cure. Adolescents need DOT as do all clients receiving TB treatment. Where feasible it may be more convenient to have the client receive DOT at their nearest clinic, with the healthcare provider administering the treatment and observing the client swallowing all tablets. Where this is not practical it may be necessary to enlist another member of the household to perform this function. The ideal is to have a community health worker regularly follow up on clients at home.1,4
- There may be a high pill burden due to TB treatment, CPT and ART. There is also the possibility of drug interactions. This should be discussed with the adolescent and they should be encouraged to present as soon as they experience any side effects or problems. These should be managed promptly and with reassurance to the client. In certain instances reassurance may be all that is required, but it is still important that the adolescent feels that their concerns are being taken seriously.
13. Cryptococcal disease\textsuperscript{1,2}

Cryptococcal disease occurs as an AIDS-defining illness in clients with very low CD4 cell counts: usually below 100 cells/mm\textsuperscript{3}. It may also be the first presentation of a client with HIV, leading to the client being tested and diagnosed with HIV.

The most common form of cryptococcal disease in clients with advanced immune suppression is cryptococcal meningitis. This is a life threatening infection, and may also cause serious complications such as blindness. It is a common cause of meningitis in South Africa for people living with HIV.

13.1 Symptoms of cryptococcal meningitis

Cryptococcal disease may present with insidious symptoms, such as fever and headache. These symptoms are relatively non-specific and a high index of suspicion must be maintained in an adolescent with known or suspected advanced immune suppression.

Consider cryptococcal meningitis in clients who present with:\textsuperscript{3}

\begin{itemize}
  \item headaches
  \item confusion
  \item seizures
  \item new-onset psychiatric symptoms
  \item altered level of consciousness
  \item focal neurological signs
  \item visual abnormalities or loss of vision
  \item neck stiffness – may or may not be present
  \item fever – may or may not be present.
\end{itemize}

13.2 Managing cryptococcal meningitis

\textit{Note}: Care should be taken when referring adolescents.

\begin{itemize}
  \item \textit{Clients need urgent referral to hospital} with a letter explaining that there is suspicion for cryptococcal meningitis. A lumbar puncture is necessary to confirm the diagnosis.
  \item \textit{Cryptococcus may also cause disease in other systems}: It may present with a rash or may involve the lungs. In HIV-positive clients the presence of any cryptococcal disease usually indicates a disseminated infection.
  \item \textit{Clients with disseminated cryptococcal disease (including meningitis) need hospital admission} for intravenous antifungal medication (which includes Amphotericin B and fluconazole) for at least 2 weeks. They will then be put onto consolidation therapy with fluconazole, which lasts for 8 weeks. Thereafter they should be maintained on fluconazole prophylaxis until fully immune reconstituted.
  \item \textit{A history of previous cryptococcal meningitis should be documented} in the client record.
  \item \textit{It should be explained to the client that adherence to prophylaxis is essential} to prevent recurrence of the disease.
\end{itemize}
13.3 Starting ART after an episode of cryptococcal meningitis
Disseminated cryptococcal disease and cryptococcal meningitis are AIDS-defining conditions (WHO clinical stage IV) and indicate the necessity to start ART.

- The current recommendation is that the client should receive treatment for their cryptococcal disease for a minimum of 4 weeks before the initiation of ART. Clients who start ART before 4–6 weeks of treatment are at greater risk of developing IRIS.

- The IRIS which results from cryptococcal disease is often severe, and in some cases may be fatal. Clients with cryptococcal disease who have recurrence or worsening of their meningitis symptoms, or any new neurological symptoms after initiating ART, should be referred urgently to hospital for further management. This may indicate either an IRIS or a recurrence of disease.

13.4 Clients already on ART who develop cryptococcal disease

- ART should be continued. No dose adjustments are required.

- If the client was previously well with a high CD4 cell count, the development of cryptococcal disease, or any other OI, represents clinical failure of treatment. Blood should be taken for CD4 cell count and viral load to look for concomitant virological and immunological failure, and where found these should be addressed.

13.5 Drug interactions

- Fluconazole may increase the risk of ART side effects in clients who receive AZT or NVP.

- Clients on TB therapy who are prescribed fluconazole have a greater chance of developing drug-induced hepatitis. In addition, rifampicin decreases the concentration of fluconazole and may increase the risk of recurrence of cryptococcal meningitis. Careful monitoring is essential. Early referral is warranted where hepatitis is suspected.

13.6 Preventing cryptococcal disease

- Early initiation of ART is the best method for primary prevention of cryptococcal disease. The earlier that clients initiate ART, before they develop severe immunocompromise, the less likely they are to develop cryptococcal disease.

- Routine screening for cryptococcal disease with a serum cryptococcal antigen test for adolescents with a CD4 cell count ≤100 cells/mm³ is recommended. Adolescents with a positive result warrant a lumbar puncture to determine if there is meningitis, which requires inpatient treatment with Amphotericin B. Those who have no evidence of meningitis will require treatment with high dose fluconazole.

- If the client has been on ART for more than one year and the CD4 cell count has improved to above 200 cells/mm³ on two separate measurements, 6 months apart, the healthcare provider may consider stopping the fluconazole prophylaxis. However, should the CD4 cell count drop below 200 cells/mm³ again, the client will need to restart fluconazole prophylaxis. For recommended dosage see Box 18.

See Figure 8 for an outline of the process for cryptococcal screening and prophylaxis.
Box 18: Recommended dosage of fluconazole prophylaxis

Fluconazole as prophylaxis after previous cryptococcal disease:
200 mg orally as a daily dose (6 mg/kg up to max. 200 mg).

*Note*
Fluconazole dosing should not exceed 12 mg/kg for adolescents who are underweight for their age.

---

Figure 8: Algorithm for cryptococcal screening and prophylaxis
(from the national consolidated guidelines for PMTCT and the management of HIV in children, adolescents and adults, DOH, December 2014)
14. Other opportunistic infections

The following opportunistic infections may occur in adolescents living with HIV who are immunosuppressed. Many of these conditions are diagnosed and managed at hospital level, but may initially present at all levels of care.

14.1 Mycobacterium avium complex (MAC)  
WHO clinical stage IV

MAC consists of a group of non-tuberculous mycobacteria (NTMs) found commonly in the environment. Usually these organisms do not cause disease. However, they can cause disseminated disease in clients who are severely immunocompromised.

- **Disease caused by MAC usually occurs with a CD4 cell count less than 50 cells/mm$^3$:** MAC may also occur as an IRIS after ART initiation.
- **Clients with MAC often present with non-specific symptoms which may include fever, loss of weight and failure to thrive:** They may also have recurrent abdominal pain and persistent or recurrent diarrhoea. There may be lymphadenopathy, hepatomegaly or splenomegaly. Respiratory symptoms are uncommon.
- **Clients may have symptoms of anaemia:** The full blood count may show unexplained low blood counts (most often a pancytopenia with white cells, red cells and platelets affected). The diagnosis is based on blood culture, or culture of an affected sterile site (such as a lymph node FNA or biopsy). Occasionally MAC may be identified on the sputum culture when testing for TB. It should only be treated if found on two separate sputum samples in a client who is clinically unwell.
- **Clients with MAC require long-term antibiotic therapy (more than one year):** First line treatment is with a macrolide (clarithromycin or azithromycin) and ethambutol. Drug interactions should be taken into consideration. While clarithromycin is the drug of choice for MAC treatment, it interacts with EFV and is best avoided in clients on/about to start EFV.
- **Clients with MAC are best managed by an experienced clinician at a referral centre.**

14.2 Pneumocystis carinii pneumonia (PCP)  
WHO clinical stage IV

- **Clients with PCP present with tachypnoea, severe dyspnoea, cough and fever:** Oxygen saturations are usually low and they may have cyanosis.
- **This condition usually occurs at a CD4 cell count below 200 cells/mm$^3$:** PCP may be the presenting problem in clients who have not yet been diagnosed with HIV.
- **PCP requires oxygen and an urgent referral to hospital for admission.**
- **Treatment consists of high dose IV cotrimoxazole therapy, usually given together with IV corticosteroids:** This treatment is given for a duration of 14–21 days and thereafter cotrimoxazole should be continued as prophylaxis at the appropriate dose.
- **CPT is used to prevent this infection in clients with a CD4 cell count below 200 cells/mm$^3$.**

14.3 Extensive candidiasis  
WHO clinical stage III/IV

Extensive candidiasis is a common problem and may present at the primary healthcare facility. The management differs according to the site of infection.

- **Vaginal candidiasis:** This is usually treated with topical preparations if it is mild. More extensive infections may warrant oral therapy with fluconazole. Poor response to fluconazole requires referral.
- **Oropharyngeal candidiasis:** Milder infections may be treated with topical antifungals, which may consist of suspensions, gels or lozenges. Severe oropharyngeal candidiasis should be treated with fluconazole as it may extend into the oesophagus and interfere with eating or taking medication. The client may benefit from an additional topical agent.
• **Oesophageal candidiasis**: This should be suspected when the client complains of odynophagia (pain on swallowing). The client may also report retrosternal chest pain or difficulty swallowing. On examination, one may be able to see evidence of candidiasis on the posterior pharynx. It may be associated with severe oral thrush. Oral fluconazole may be started empirically under these circumstances. Intravenous fluconazole might be required if the client is unable to swallow. Clients who do not respond to fluconazole therapy should be referred for endoscopy and biopsy. Other causes of the symptoms may include CMV ulceration, fluconazole-resistant candida species and aphthous ulcers of the oesophagus.

### 14.4 Parvovirus infection

Parvovirus B19 is a virus acquired through respiratory spread: It has many manifestations, and may cause illness in immune-competent children (commonly, ‘fifth disease’ or ‘slapped cheek disease’) and adults (flu-like illness associated with arthralgia). Usually the effects are self-limiting.

• **It acts as an OI in those with advanced immune suppression**: Clients with a CD4 cell count of less than 100 cells/mm$^3$ may have chronic infection involving the bone marrow. These clients present with severe anaemia without a history of bleeding. They are afebrile and usually otherwise well.

• **Usually the white cell and platelet counts remain normal**: This is termed a pure red cell aplasia.

• **Clients suspected of having parvovirus infection should be referred** to the appropriate level of care for investigation, diagnosis and ongoing management: Diagnosis is based on bone marrow aspirate and trephine. The peripheral blood may also be tested with a PCR test to identify the presence of the virus.

• **Management requires intravenous immunoglobulin (IVIG) infusion and ongoing monitoring** as the anaemia is likely to recur: Once the CD4 cell count has improved, the infection will be controlled by the client’s recovering immune system. Transfusion may be required for severe anaemia.

### 14.5 Chronic gastroenteritis

Chronic gastroenteritis is defined as gastroenteritis that lasts for a period of longer than 4 weeks: There are many possible causes of chronic diarrhoea, including drugs, malabsorption syndromes and infections. The management will depend on the cause identified.

• **Clients with severe immunocompromise may have copious amounts of watery diarrhoea** caused by coccidian parasites. These are parasites infecting the small bowel, for many of which there is no specific treatment. ART and immune reconstitution will assist in clearing the infection.

• **Replacement of fluid losses and electrolytes with an appropriate rehydration solution is essential**: Clients with severe dehydration may need IV fluid and electrolyte replacement.

• **Malabsorption may occur as a result of damage to the intestinal mucosa** as part of HIV infection or other OIs. Clients may benefit from referral to a dietician to optimise diet and aid recovery of the bowel.
14.6 Cytomegalovirus (CMV)  

- **CMV** is a virus usually acquired in early childhood: It may cause disease in severe immune suppression. It can cause disease in various sites. It may also occur as an IRIS.
- **CMV disease may occur if the CD4 cell count is below 100 cells/mm$^3$.**
- **CMV pneumonitis** may occur and present similar to PCP as above: co-infection is common.
- **CMV colitis** may cause ulcers and bleeding per rectum.
- **CMV retinitis** affects visual acuity and can eventually lead to blindness: Clients who report deterioration in vision after ART initiation may have CMV retinitis as part of an IRIS. They should be referred urgently to an ophthalmologist.
- **CMV hepatitis** is uncommon and occurs more frequently in newborns: It should, however, be considered in cases of hepatitis where the aetiology is unclear.
- **CMV infection is treated with IV ganciclovir** for a period of 14 to 21 days: Intraocular ganciclovir for retinitis may also be used.
15. HIV-associated conditions (non-infectious)\textsuperscript{1,2}

These conditions are not caused by opportunistic infections. Some may be caused by the HIV virus itself. It is important to be aware of these conditions, to facilitate referral where required.

15.1 Chronic lung disease (CLD)

Perinatally infected HIV-positive children who are diagnosed with HIV when they are older or as adolescents often have severe immunosuppression and chronic complications of HIV. CLD, along with growth failure and cardiac disease, is frequently present in these clients, with more than 80% of adolescents meeting diagnostic criteria for CLD in one report.\textsuperscript{3}

For a detailed review of CLD in HIV-positive children and adolescents see Weber et al. in the JIAS 2013 special issue on perinatally HIV-positive adolescents.\textsuperscript{4}

(i) Identifying CLD

CLD is most commonly the result of recurrent lower respiratory tract infections. CLD is a clinical picture rather than a specific diagnosis. While there are no agreed definitions of CLD in HIV-positive adolescents, CLD should be suspected in adolescents presenting with two or more of the following:\textsuperscript{3}

- chronic cough (defined as a cough present for most days for 3 months of the year in the past 2 years)
- recurrent respiratory tract infections (>2 antibiotic courses in the last year)
- breathlessness resulting in moderate to severe limitation in physical activity
- diagnosis of cor pulmonale (right parasternal heave, raised jugular venous pressure)
- hypoxia ($O_2$ saturation <92% at rest).

The most common factors and conditions associated with CLD are shown in Figure 9. In this handbook we address the following: TB (see chapter 12), lymphoid interstitial pneumonitis (LIP) and bronchiectasis.

All children and adolescents with suspected CLD should be referred to the nearest-level hospital for diagnosis and initial management. While initiating cART is important to reduce further damage, cART will not improve lung function in the short-term. Investigations conducted may include chest X-rays, computer tomography scans (CT scans), lung function tests, sputum microscopy, culture and sensitivity, and echocardiography for evidence of pulmonary hypertension.
Figure 9: Factors associated with CLD in HIV-infected children and adolescents
(from Weber et al, JIAS 2013)

(ii) Management of children and adolescents with CLD

All children and adolescents with suspected CLD should receive annual influenza vaccines and a pneumococcal vaccine every 5 years. Training caregivers to perform home-based chest physiotherapy and airway clearance techniques may assist. Bronchodilators may be prescribed for adolescents with evidence of reversible airway obstruction. Acute exacerbations as a result of bacterial infections should be treated with oral antibiotics for 14 days. The choice of antibiotics will be guided by the sputum cultures.

Tuberculosis

Note: TB is dealt with in chapter 12.

Lymphoid interstitial pneumonitis

LIP is caused by lymphocyte infiltration of the lungs. This results in inflammation that leads to lung damage. The cause is not fully understood, though it appears to be a lymphoproliferative response to HIV and/or Epstein-Barr virus (EBV).

- Clients with LIP present with a persistent cough (usually not productive), generalised lymphadenopathy and enlarged parotid glands. They may also have digital clubbing and hepatosplenomegaly.
- They will have an abnormal chest X-ray due to lymphatic infiltrates into the lungs. This X-ray appearance may be mistaken for TB.
- The treatment for LIP is ART. Severe cases may need corticosteroid therapy which helps to improve hypoxia for clients with this complication. Prednisone may be started at higher doses and weaned over time. This is best managed in consultation with a specialist. CPT should be continued for clients who are on steroid treatment.
• It is important to recognise this entity. Correct diagnosis will facilitate management and avoid repeated TB testing and treatment.
• Without ART, LIP can eventually lead to bronchiectasis and respiratory failure.

**Bronchiectasis**

Although bronchiectasis can complicate many conditions it is common in HIV and frequently under-diagnosed. It results from repeated lung infections, particularly recurrent TB, and other conditions, such as LIP. In bronchiectasis the normal architecture of the lung is destroyed.

• Clients usually have a chronic and productive cough, often with purulent sputum. They have digital clubbing and may have halitosis. The chest X-ray will show evidence of bronchiectasis.
• Clients with bronchiectasis usually need chest physiotherapy to help them clear their extensive secretions. They also need monitoring and regular follow-up. Severe bronchiectasis may necessitate the use of home oxygen.
• These clients are best managed at a referral centre.

**15.2 Renal conditions**

Perinatally infected HIV-positive children who are diagnosed with HIV when they are older or as adolescents often have severe immunosuppression and chronic complications of HIV. CLD, along with growth failure and cardiac disease, is frequently present in these clients, with more than 80% of adolescents meeting diagnostic criteria for CLD in one report.³

For a detailed review of kidney disease in HIV-positive children and adolescents see Bhimma et al. (2013)⁵

(i) **HIV-associated nephropathy (HIVAN) and HIV immune complex kidney disease (HIVICK)**

High viral load and severe immunocompromise are well-described risk factors for HIVAN. HIV directly infects and affects various kidney cell types. cART has an important role in the prevention and management of HIVAN.

HIVICK (HIV immune complex kidney disease) is the result of deposition or formation of immune complexes in the renal tissue. It has a similar presentation to HIVAN, but generally with less severe proteinuria.

• In adults, HIVAN progresses rapidly to end-stage renal failure and death. Progression in children and adolescents is slower, with reasonable outcomes with appropriate management.
• A urine dipstick should be performed at every visit in order to identify HIVAN/HIVICK as early as possible.
• HIVAN should be suspected in a client with any of the following in the absence of a urinary tract infection:
  o >1+ proteinuria for >1 month
  o urinary protein creatinine clearance >0.1 for more than 2 months, though creatinine may not be affected until late in the disease
  o abnormalities on microscopic examination of urine sediment, e.g. microcysts
  o microscopic haematuria >1 month.
Management of suspected HIVAN/HIVCK

- Children with suspected HIVAN or HIVICK should be referred to hospital where additional investigations, including serum urea and electrolytes, urine analysis, urine protein creatinine ratio, urine microscopy, renal ultrasound and possibly a renal biopsy, will be conducted to confirm the diagnosis.
- Tuberculosis should be excluded.
- The mainstay of the management of HIVAN and HIVICK is the rapid commencement of cART if not already on cART, or the optimisation of cART, and adherence to achieve viral suppression.

**Note:** It is important to remember that these clients should not be started on tenofovir.

- Clients with severely decreased renal function may need adjusted doses of NRTIs. This should be managed by an expert.
- Dose adjustment may be required for other chronic medications as well. This should be done in consultation with a renal physician, preferably at a referral centre.

(ii) Acute interstitial nephritis (AIN)

AIN occurs as a result of renal toxicity of some drugs commonly used to treat HIV and HIV-associated co-morbidities. These include non-steroidal anti-inflammatory agents, cotrimoxazole, rifampicin and ritonavir.

Presentation is usually with non-specific signs and symptoms such as fatigue, weight loss, anorexia, nausea, vomiting and decreased urine output. Most clients do not have proteinuria.

Management of AIN

- Children and adolescents with suspected AIN should be referred for diagnosis.
- Management includes the discontinuation of the causative drug, and supportive therapy as required.

15.3 Neurodevelopmental issues in adolescents

(i) Encephalopathy and HIV-associated neurocognitive disorder (HAND)

Perinatally infected adolescents who have developed HIVE early in life may have developmental delay as well as problems with behaviour and cognition. Motor problems such as increased tone and weakness also occur. This is symmetrical, affecting either both legs (diparesis) or all four limbs (quadriparesis).

Other clients who develop neurocognitive disorders much later may present with the features of HAND, which in advanced cases progresses to HIV-associated dementia (HAD).

- Clients with HAND have problems with memory and cognitive function. Cognitive slowing may occur. Behavioural changes may also occur. Motor problems such as deterioration in coordination and fine motor function may be present.
- Acute neurological changes are best referred to hospital, as it is necessary to first rule out any other causes that can be treated, such as cryptococcal meningitis.
- Treatment for encephalopathy consists of ART, as well as specific management for any associated problems.
- Physiotherapy, speech therapy and occupational therapy all have vital roles to play in maximising function and quality of life.
15.4 Cardiac complications of HIV⁹,¹⁰,¹¹

HIV is associated with significant cardiac morbidity. This may arise from the effects of the virus itself, associated OIs or as a result of chronic respiratory disease. Protease inhibitors pose a risk for the metabolic syndrome, which increases the risk of cardiovascular disease. Adolescents with perinatally acquired HIV may have multiple risk factors for cardiac disease, and require routine, systematic cardiac evaluation.

For a detailed review of the cardiac complications associated with HIV see the paper by Lipshultz et al. 2013⁹

(i) Dilated cardiomyopathy

• Cardiomyopathy in association with HIV may be attributed to myocarditis and subsequent cell damage. Viruses have been implicated in the cause of myocarditis: they include HIV-1, EBV and coxsackie viruses. Inflammation associated with HIV infection may also cause release of toxic inflammatory cytokines, which can be damaging to cardiac cells.
• Dilated cardiomyopathy can cause left ventricular dysfunction, which may eventually lead to congestive cardiac failure.
• Symptoms suggestive of heart failure in an adolescent require referral for specialist review. These may include cough, dyspnoea (particularly on lying flat), palpitations, decreased effort tolerance and peripheral oedema. The diagnosis is made on echocardiography, and treatment consists of ART and anti-failure therapy.

(ii) Pulmonary hypertension and cor pulmonale

• Pulmonary hypertension is most often a result of chronic or recurrent respiratory disease. Increased vascular resistance results, and the pressures in the pulmonary circulation rise as a consequence. In addition, there appears to be an increased incidence of primary pulmonary hypertension in HIV-positive patients,¹² where no predisposing respiratory abnormality exists.
• Unchecked, pulmonary hypertension eventually gives rise to right ventricular dysfunction. Right-sided heart failure and cor pulmonale may eventually develop.
• Right-sided heart failure presents with marked peripheral oedema, distended neck veins and decreased effort tolerance. There may also be abdominal distension and tenderness in the right upper quadrant caused by fluid congestion within the liver.
• Referral for diagnosis and treatment is recommended. Echocardiography is required to diagnose pulmonary hypertension. The causes should be addressed where possible.

(iii) Accelerated atherosclerosis

Atherosclerosis has become a growing concern as perinatally infected adolescents have begun to age into adulthood. Metabolic effects associated with certain ARV drugs and the fact that HIV infection is considered to be a state of chronic inflammation (similar to some autoimmune disorders) contribute to concern that these adolescents will be at increased risk of diseases associated with atherosclerosis.¹³ This includes cerebrovascular disease and coronary artery disease.

There is some evidence suggesting that atherosclerosis may occur in children with HIV, independent of other risk factors.⁹
• Risk factors should be appropriately managed.
• Adolescents with the metabolic syndrome should be counselled about aerobic exercise and heart-healthy diet, and dyslipidaemias appropriately managed.
• Smoking cessation/avoidance is necessary in reducing cardiac risk.
15.5 Metabolic complications of HIV

HIV and/or cART has been associated with development of the metabolic syndrome, which features:

- reduction in subcutaneous fat, most notably in the face, limbs and buttocks (lipoatrophy)
- accumulation of fat in the abdomen, breasts and/or the dorsocervical area (lipodystrophy)
- insulin resistance and abnormal glucose metabolism
- dyslipidaemia.

These aspects of metabolic syndrome on long-term complications of HIV and ART are covered in chapter 10.

**Note:** It is important to note that HIV can cause accelerated atherosclerosis independently of cART and that it is not always possible to determine the individual contributions by HIV and ART.

15.6 Malignancies

- HIV is associated with a number of malignancies, including Kaposi’s sarcoma and non-Hodgkin’s lymphomas such as Burkitt’s lymphoma. It is important to have a high index of suspicion when clients present with abnormal swellings, skin or oral lesions or any abnormalities in the blood counts. Biopsy of suspicious lesions, or referral for biopsy, will help to identify early malignancies in order to facilitate early treatment for the best possible outcome.

- It should also be remembered that female HIV-positive clients who are sexually active should receive regular cervical screening due to the increased risk of cervical cancer, according to DOH guidelines.
16. Sexual and reproductive health (SRH)

In addition to the physical, psychological, social and emotional changes, adolescence is also characterised by a dynamic phase of sexual development and maturation. It is a time of increased sexual awareness, sexual exploration and risk taking.

16.1 Importance of sexual and reproductive healthcare for adolescents

About half of all adolescents have had sex by the age of 18 years and they have the highest incidence of STIs, including new HIV infections. Adolescent girls are at high risk for unintended pregnancy, unsafe termination of pregnancy (TOP) and sexual violence. Pregnancy and childbirth are a leading cause of death for adolescent girls aged 15–19, and infants born to females under 18 years old have a 50% increased risk of death. Teenage pregnancy also results in a range of other problems including obstetric complications and leaving school at an early age.

All adolescents require education, support and access to services for safer sexual activity; STI, HIV and pregnancy prevention; STI diagnosis and treatment; contraception and sexual and reproductive rights, including their legal rights. This should be offered within the context of youth-friendly services, as outlined in chapter 1.

In addition to the above, adolescents living with HIV face additional challenges in expressing their sexuality and forming their sexual identity. HIV is spread through sexual contact and this immediately adds a layer of complexity for young people forming sexual relationships, where issues of disclosure, fear of stigma and rejection are raised. These adolescents require support and guidance to navigate complex issues such as deciding whether or not to disclose their HIV status to their sexual partners and peers, their hopes and aspirations for the future, their rights and responsibilities in sexual relationships (including prevention) and issues related to pregnancy and transmission.

16.2 Adolescents and laws related to SRH in South Africa

(i) Contraception

Adolescents have the right to access contraception services. The Children’s Act states in section 134:

- All children over the age of 12 years have the right to access condoms.
- Contraception other than condoms (such as the pill or injection) should be provided to a child at their request and without the consent of the parent or caregiver of the child if:
  - the child is at least 12 years of age
  - proper medical advice is given to the child
  - a medical history is taken and an appropriate examination is carried out to determine whether there are any medical reasons why a specific contraceptive option should not be provided to the child.
(ii) Termination of pregnancy

All children and adolescents, regardless of age, can consent for TOP without the consent of their parents. These rights are delineated in the Choice on Termination of Pregnancy Act (CTOP).\textsuperscript{10}

(iii) HIV counselling and testing

According to the \textit{National HIV Counselling and Testing Policy Guidelines} (DOH 2010)\textsuperscript{11} and Section 130 of the Children’s Act,\textsuperscript{9} a child may consent independently to HIV testing if he or she is:

- 12 years old or older or
- under the age of 12 years and of sufficient maturity (as outlined below) to understand the benefits, risks and social implications of such a test.

A child is considered to be sufficiently mature if they can demonstrate that they understand information on HIV testing and can act in accordance with that knowledge. In deciding whether a child is sufficiently mature, factors that should be taken into account include:

- \textit{Age}: The older the child the more likely it is that they will be sufficiently mature.
- \textit{Knowledge}: A child with knowledge of HIV and its implications is more likely to understand its consequences.
- \textit{Views}: A child who is able to articulate their views on HIV testing and whether or not it is in their best interest is likely to meet the maturity requirements.
- \textit{Personal circumstances}: An assessment of the child’s personal situation and their motivations for HIV testing may help in assessing their maturity.
16.3 Guidelines for SRH-related issues in adolescence

(i) Tips for working with adolescents on SRH-related issues

Adolescents need accurate, understandable and age-appropriate information to make informed decisions about SRH-related issues.

- **Avoid making assumptions about the adolescent’s sexual orientation, behaviour and knowledge**: Information needs to be obtained through conversation and asking questions.

- **Take special care to provide equal and fair medical services to gay, lesbian, bisexual and transgender youth**: Ensure that they have access to SRH services in an unbiased, professional and non-judgemental manner.

- **Engage adolescents in conversation about sexuality and sexual health**: One-way lectures where information is provided close off discussion and do not allow engagement about the young person’s lifestyle, reality and challenges. The more open the communication, the more likely that the healthcare provider can respond to the individual needs of the client.

- **Communicate potential positive outcomes of actions and not just the down-side risks**: Adolescents tend to respond better to rewards and hopeful positive outcomes than risks and punishments.

- **Routinely ask about SRH, even in adolescents who deny sexual activity**, in order to assess their current or future plans regarding sexual behaviour.

- **Communicate in an age-appropriate manner and provide clear accurate information**: A natural and comfortable manner will assist the client in feeling less embarrassed. Use the right terms, such as penis and vagina (instead of ‘down there’ or pointing).

- **Use each visit as an opportunity to offer brief, practical, appropriate information on SRH** (Box 19).

- **Ensure that all healthcare providers inform adolescent clients of their right to confidentiality**: Explain that information may be shared with other healthcare providers on a need-to-know basis and that disclosure to others will be agreed between the client and healthcare provider.²

- **Provide opportunities for the adolescent to have sessions without the parent/caregiver**: It may be embarrassing or difficult for the adolescent to discuss issues related to sexuality and sexual health with their parent/caregiver present. Explain tactfully to the parent/caregiver that from time to time, one-to-one sessions are required for clinical and psychosocial assessments.
Box 19: Issues to discuss in relation to SRH wellbeing

- Adolescents’ rights.
- Puberty, focusing content toward current and next Tanner stage (Appendix 1a).
- Menarche and menstruation.
- Sexual debut.
- Sexual risk and associated HIV/STI transmission risk (oral, anal, vaginal, masturbation) and the impact of ART and viral suppression on HIV transmission risk.
- Signs and symptoms of STIs and the importance of seeking treatment.
- Fertility, pregnancy and available contraception methods, including information on low risk of transmission of HIV to the baby if virally suppressed on current ART regimen or enrolled early into PMTCT programme.
- Correct condom use demonstration, contraception and condom access, condom use negotiation skills and water-based lubrication.
- Potential strategies to maintain good SRH including reducing partner numbers, adhering to ART, and good oral health hygiene.
- Sexual rights, information on staying safe from rape or unwanted sexual solicitation and what to do in the case of sexual assault.

(ii) Suggestions for talking about sex and sexuality

Clients who are not yet sexually active

The healthcare provider will never know whether the client is sexually active or not. Clients may be too embarrassed or worried about the healthcare provider’s response to be open about sexual activity.

- Don’t make assumptions: Some adolescents are in a relationship that they do not feel free to disclose, e.g. sex with an older partner, transactional sex (sex in exchange for money or goods), or a same sex relationship.
- Reinforce and support abstinence: Those who have chosen to abstain should be supported and encouraged. Reinforce the idea that if it is their choice, they should feel positive and proud of this decision. If they are currently, or plan to be, sexually active, emphasise the importance of protecting themselves and their partners. Reassure the importance of rights, choice and not succumbing to peer pressure.
- Sex and sexual activity are a healthy part of growing up: Healthcare providers should be wary of creating a negative impression of sexual activity. Adolescents should be supported in developing a healthy attitude toward sex in which sex is seen to be an important part of normal life.
- Open up and encourage discussion about sex and sexuality: HIV-positive adolescents may delay or avoid sexual activity. There may be issues of impaired body image, e.g. lipodystrophy, delayed puberty and fear of sexual intimacy because of transmission or disclosure issues. These issues need to be identified and sensitively resolved through appropriate counselling and education.
- Choices change over time: The topic of sex and sexuality needs to be re-visited as the adolescent develops.
- Education and information is important: Even if they are not currently in a sexual relationship, information is essential to allow them to make informed decisions in future. Provide education regarding contraception and condom use, STIs and HIV transmission and life skills related to positive prevention for adolescents living with HIV.
Clients who are sexually active

Explore issues related to disclosure. Encourage the adolescent to consider ‘beneficial disclosure’ of their HIV status to their sexual partner. Suggestions for inclusion in an SRH questionnaire are presented in Box 20.

Remember: Legally, people living with HIV are not obligated to disclose their HIV status to their partner. However, from an ethical perspective (including rights and responsibilities), it is important to respect and protect oneself and one’s sexual partner. Protecting one’s partner from HIV transmission, STIs and pregnancy needs to be emphasised.

Box 20: Sexual health issues to explore

- Is the client currently sexually active?
- Are they making regular use of barrier contraception? Do they understand the risks of HIV and STI transmission?
- Do they know how to use condoms consistently and correctly?
- Are the client and their partner making use of any other contraceptive method (in addition to condoms)? Dual methods are advised for optimal fertility planning, as well as preventing HIV and STI transmission.
- Have they disclosed their HIV status to their current sexual partner? Previous sexual partners?
- Does the client have more than one sexual partner?
- Has the client previously been treated for an STI?
- Do they currently have any symptoms of an STI?
- For the female client, has she ever been pregnant? What was the outcome of the pregnancy? Does she have plans to get pregnant now or in the near future?

For all clients:

- Provide basic information about sex and protection, including prevention of HIV, STIs and unintended pregnancy.
- Most importantly, encourage clients to feel free to discuss concerns and questions about sex and relationships for themselves at this point in their life, plus in relation to living with HIV.
- Provide reassurance that healthcare providers are there to provide information and support to keep them safe and in good health, and not to judge.
The key issues for managing SRH in adolescents living with HIV are summarised in Box 21.

**Box 21: Key issues to consider when managing SRH issues in adolescents living with HIV**

- Contraception and planning for healthy pregnancies
- Pregnancy
- Prevention of HIV transmission: to sexual partners, as well as PMTCT for pregnant clients
- Prevention and management of STIs
- Disclosure
- Body image, fears and hopes
- HPV vaccination
- Cervical cancer screening according to DOH guidelines
- Promotion of healthy lifestyle including nutrition, exercise and positive sexuality

### 16.4 Contraception and dual protection

**Guidelines for contraception provision for adolescents living with HIV**

Discuss available contraceptive methods with the adolescent, as per the national contraception policy and service delivery guidelines.

- **Clients should be advised on the availability of emergency contraception within 120 hours after unprotected intercourse**, namely copper intrauterine device (Cu IUD) insertion and emergency contraception pills within 120 hours after unprotected sex: the sooner, the more effective.

- **Long-acting reversible contraception (LARC) methods are the most effective to prevent pregnancy**: LARC includes methods which require administration less than once per cycle or month (injectables, Cu IUDs and implants).

- **LARC plus condom use** provides maximum protection for pregnancy, HIV and STIs. This provides protection for both the client and their partner. LARCs are highly effective and should be encouraged among adolescents living with HIV.
  - LARCs are reversible if pregnancy is desired.
  - They do not rely on compliance or correct use (as with barrier methods and the pill). LARCs assist in avoiding teen pregnancy, MTCT and associated problems.

- **Condom use requires education**: Clients should be advised on consistent and correct use plus the availability of emergency contraception, in cases where the condom breaks, slips or is not used.

- **Provide or refer for contraception if required**: When referring, have clear referral systems that are accessible for the adolescent client.

- **Screen for pregnancy** and facilitate early access to TOP counselling and services if requested, or antenatal booking and PMTCT care.

- **All referrals should be youth-friendly and accessible**: Assist the client in navigating the health system.

The contraceptive methods of choice for adolescents and youth according to the National Contraception Clinical Guidelines from the DOH (2012) are summarised in Box 22.
Box 22: Recommended contraceptive methods for adolescents

- Abstinence (including secondary abstinence).
- Delay sexual debut.
- Barrier method (strong reinforcement of condom use) with highly effective contraception:
  - combined hormonal contraception
  - progestogen-only injection
  - Cu IUD
  - LNG-IUS (levonorgestrel intrauterine system)
  - progestogen-only implant.
- Emergency contraception, to be promoted and accessible in the event of unprotected intercourse, method misuse or failure.

(ii) Considerations for contraceptive choice for adolescents living with HIV

- Adolescents who are sexually active should be advised to always make use of condoms: For both male and female clients, negotiating for the use of condoms can be difficult. Negotiation skills should be addressed during counselling: this is something to be reviewed on an ongoing basis. Disclosure to one’s sexual partner is a complicated issue and also needs to be explored during the session.
- LARC and condom use provide maximum protection to prevent pregnancy and transmission of HIV and STIs: However, individual circumstances and informed choice need to guide decision-making. The client’s lifestyle and specific needs also need to be taken into account. It is important that the client finds the method acceptable, to ensure continuation. They should be educated on use, benefits, side effects and the option of switching methods should there be problems.
- Take into consideration potential drug interactions when prescribing hormonal contraception: This applies to ART, TB therapy and many other chronic medications that clients may be on, such as anticonvulsants.
- Take into consideration other medical conditions: Always review WHO medical eligibility criteria (WHO MEC) for clients who have concomitant medical conditions, see Table 16.

<table>
<thead>
<tr>
<th>Classification</th>
<th>With clinical judgement</th>
<th>With limited clinical judgement</th>
</tr>
</thead>
<tbody>
<tr>
<td>Category 1</td>
<td>A condition for which there is no restriction for the use of the contraceptive method.</td>
<td>Use the method in any circumstances.</td>
</tr>
<tr>
<td>Category 2</td>
<td>A condition for which the advantages of using the method generally outweigh the theoretical or proven risks.</td>
<td>Generally use the method.</td>
</tr>
<tr>
<td>Category 3</td>
<td>A condition for which the theoretical or proven risks usually outweigh the advantages of using the method.</td>
<td>Use of the method not usually recommended unless more appropriate methods are not available or not acceptable.</td>
</tr>
<tr>
<td>Category 4</td>
<td>A condition that represents an unacceptable health risk if the contraceptive method is used.</td>
<td>Method not to be used.</td>
</tr>
</tbody>
</table>
(iii) Male involvement in contraception and fertility planning

- **Males need to be encouraged to take responsibility for the prevention of unintended pregnancies and encourage and support condom use and contraception.**
- **The consistent and correct use of condoms needs to be discussed,** together with water-based lubricants (such as K-Y jelly) when required. Adolescent males may be embarrassed to use condoms for fear of incorrect use or losing their erection. Clients may benefit from practising condom use when they are alone, in order to build confidence.

(iv) Abstinence as an option\(^9\)

Abstinence is the only method of contraception that is 100% effective. It also prevents exposure to STIs and the risk of HIV transmission. Primary abstinence (delaying sexual debut) and secondary abstinence (abstaining even though previously sexually active) should be discussed with clients as an option. **However, abstinence should never be the only method that is promoted.** Clients should be provided with information on all available contraceptive methods, allowing them to make an informed choice on the most appropriate contraceptive option for their circumstances.

Abstinence should be discussed with clients as an option in a non-biased manner as part of promoting responsible sexual behaviour and choice. The reality is, however, that many young people are sexually active, and an ‘abstinence-only’ approach will inhibit discussion about alternative safer sex approaches.

Table 17 provides a summary of contraception and important considerations for contraceptive methods available to adolescents living with HIV.\(^{14,18,20}\)

**Note:** This table records some of the more common contraindications present in adolescents living with HIV. Before the prescription of any contraceptive method, the client should be reviewed as regards the WHO MEC for contraceptive use, to ensure that there are no contraindications to the chosen method of contraception.
### Table 17: Considerations for contraception for adolescents living with HIV (ALHIV)

<table>
<thead>
<tr>
<th>Method</th>
<th>Common side effects</th>
<th>Common contraindications</th>
<th>Drug interactions – TB Rx</th>
<th>Drug interactions – ART</th>
<th>STI prevention</th>
<th>HIV prevention</th>
<th>Comments/recommendations</th>
</tr>
</thead>
<tbody>
<tr>
<td>Male condom</td>
<td>None</td>
<td>None</td>
<td>None</td>
<td>None</td>
<td>☑</td>
<td>☑</td>
<td>Promote condom use in all ALHIV: consistency, correct use and with confidence</td>
</tr>
<tr>
<td>Female condom</td>
<td>None</td>
<td>None</td>
<td>None</td>
<td>None</td>
<td>☑</td>
<td>☑</td>
<td>Promote condom use in all ALHIV: consistency, correct use and with confidence</td>
</tr>
<tr>
<td>Combined oral contraceptives (COCs)</td>
<td>Nausea, inter-menstrual bleeding, mild headaches, breast tenderness</td>
<td>History of thrombosis, hypertension</td>
<td>Rifampicin – do not use together (WHO MEC 3)</td>
<td>RTV-boosted PIs – do not use together (WHO MEC 3)</td>
<td>NNRTIs – generally can use. To add condom (WHO MEC 2)</td>
<td>☒</td>
<td>Client dependant: adherence essential. Can be used where adherence ensured. Combine with condom use</td>
</tr>
<tr>
<td>Injectable (DMPA/NET-EN)</td>
<td>Changes in menstruation (irregular, prolonged, heavy, amenorrhoea), weight gain</td>
<td>Undiagnosed vaginal bleeding</td>
<td>DMPA: none. (WHO MEC 1) NET-EN: mild interaction with rifampicin. To add condom (WHO MEC 2)</td>
<td></td>
<td></td>
<td></td>
<td>Recent studies have shown that DMPA may increase HIV transmission risk. WHO has reviewed the available evidence and recommends continued use (WHO MEC 1), with an emphasis that use of condoms should be strongly reinforced.20</td>
</tr>
<tr>
<td>Cu IUD</td>
<td>Menstrual changes (bleeding may be heavier, longer, more cramps)</td>
<td>Current AIDS and unwell, current cervicitis/PID</td>
<td>None</td>
<td>None</td>
<td>☒</td>
<td>☒</td>
<td>Good, client-independent contraception. May be used as emergency contraception. Combine with condom use. Can be inserted if well (WHO MEC 2) Note: unwell HIV-positive – WHO MEC 3</td>
</tr>
<tr>
<td>LNG IUD</td>
<td>Irregular and infrequent bleeding initially, development of amenorrhoea later</td>
<td>Current AIDS and unwell, current cervicitis/PID</td>
<td>None</td>
<td>None</td>
<td>☒</td>
<td>☒</td>
<td>Not currently available in the PHC setting. Good client-independent contraception. Cannot be used for emergency contraception. Can be inserted if well (WHO MEC 2) Note: Unwell HIV-positive – WHO MEC 3</td>
</tr>
<tr>
<td>Progestogen-only implants</td>
<td>Irregular bleeding and amenorrhoea, but less pronounced than with injectables</td>
<td>Undiagnosed vaginal bleeding</td>
<td>Interaction with rifampicin. Avoid concurrent use (see comments)</td>
<td>Interaction with PIs and NNRTIs. Avoid concurrent use (see comments)</td>
<td></td>
<td></td>
<td>Recent evidence has shown that EFV, rifampicin and certain anticonvulsants should not be used with the implants due to reduced contraceptive efficacy. Use with PIs is not recommended due to drug interactions. If already inserted, it may be removed and an alternative method used, or an additional non-hormonal method should be added (such as IUCD or condom use).21</td>
</tr>
<tr>
<td>Emergency contraceptive pills</td>
<td>Nausea, vomiting, headaches, fatigue, cycle irregularities</td>
<td>Incident occurred more than 120 hours ago</td>
<td>With rifampicin, No dose adjustment recommended</td>
<td>With PIs, No dose adjustment recommended</td>
<td></td>
<td></td>
<td>All clients should be aware of the availability of this method. Consider emergency IUCD use where pill use is inappropriate</td>
</tr>
</tbody>
</table>
16.5 Managing STIs

Some clients may have symptoms of an STI but not want to report them. Others may not think the symptoms need any specific treatment, or may not have recognised or noticed them. For these reasons it is good practice to screen sexually active clients for the symptoms of an STI even if these are not volunteered.

(i) Symptoms of STIs

The signs and symptoms of STIs are summarised in Box 23.

Box 23: Signs and symptoms of STIs

Symptoms for male clients
- Urethral discharge or dysuria – male urethritis syndrome (MUS).
- Genital sore or ulcer with/without pain – genital ulcer syndrome (GUS).
- Scrotal swelling (SSW) or pain.
- Soreness or itchiness of the glans, inability to retract foreskin or malodour – balanitis/balanoposthitis (BAL).
- Hot and tender inguinal swelling (bubo).
- Warts in the anogenital region, meatus or urethra (genital warts).
- Intense itching of the pubic/perianal area with nits or pubic lice present. These may also infect the eyelashes.

Symptoms for female clients
- Abnormal vaginal discharge or vulval itching/burning – vaginal discharge syndrome (VDS). Note: candidiasis or bacterial vaginosis (which are not sexually transmitted and quite common) should be considered in these clients, especially those who report no sexual activity in the last 3 months.
- Lower abdominal pain (LAP) with or without vaginal discharge. Note: urinary tract infection (UTI) should be screened for as well as it may cause the same symptom.
- Genital sore or ulcer with/without pain – genital ulcer syndrome or (GUS).
- Hot and tender inguinal swelling (bubo).
- Warts in the anogenital region, vagina or cervix (genital warts).
- Intense itching of the pubic/perianal area with nits or pubic lice present. NB: these may also infect the eyelashes.

(ii) Managing STIs in adolescents

Adolescent clients may be particularly sensitive about discussing symptoms of an STI. Some of them may find it difficult due to embarrassment, or fear of being reprimanded or judged by the healthcare provider. It is important to handle such clients with sensitivity and tact.

The management of STIs is outlined in the national guidelines and should address the following:
- Education on the condition and the prevention of future recurrences. Condoms should be offered.
- STIs imply unprotected intercourse.
  - It should be explained to the client that there is a risk of HIV transmission to their partners, as well as the ongoing risk of acquiring new STIs.
  - Contraception methods should also be discussed.
  - Clients should be counselled on the benefits of dual contraception.
- The need to treat their current sexual partners should be discussed. Untreated infection in their partners carries a risk of progression (especially for females) as well as the risk for reinfection of the treated partner.
16.6 HPV, HPV vaccine and cervical screening for adolescents living with HIV

Cervical cancer is the most common cause of cancer in women of reproductive age in South Africa, and is caused by a common sexually transmitted infection, human papillomavirus (HPV). HPV is also the cause of genital warts, other anogenital cancers and head and neck cancers in men and women. People who are infected with HIV are more likely to have higher rates of HPV infection and to be infected with multiple HPV types, particularly high-risk types that cause cancers. 24,25

HPV vaccination trials have demonstrated more than 90% effectiveness in preventing HPV 16/18 which cause 70% of cervical cancer cases worldwide. 26 In 2006, two HPV vaccines were approved for use in women from 9–26 years of age and WHO has recommended the inclusion of the HPV vaccine into national immunisation programmes. 27

Given the increased risk that HIV-positive individuals have for HPV infection and HPV-related cancers it is recommend that all HIV-positive adolescent girls between 9–14 years of age are vaccinated for HPV. In South Africa, the schools-based programme, which targets Grade 4 learners, also includes HIV-positive girls.

It is recommended that all HIV-positive women over the age of 25 years need cervical cancer screening on diagnosis and, if normal, every 3 years thereafter*, irrespective of their CD4 count and whether or not they are on ART. Any suspicious cervical lesions or suspected abnormalities identified in younger women should be referred to a specialised service. (Low grade lesions in younger women often resolve spontaneously). 28 An abnormal Pap smear should be managed according to the result.

* At the time of going to print, the cervical screening guidelines were still in their draft form, and healthcare providers should get guidance from respective provincial DOH cervical screening guidelines until the national guidelines are finalised.
16.7 Gender-based violence, sexual assault and sexual abuse

South Africa has one of the highest prevalence rates of gender-based violence in the world. Women are particularly vulnerable to sexual abuse and violence, with far reaching consequences but males are also frequently affected. Research indicates that this is endemic in South Africa, though it is largely unreported. In a national school-based survey, two out of five males of school-going age reported being raped.

The effects of sexual violence are both physically and psychologically damaging: consequences include injuries, gynaecological disorders, anal tearing and injury for males, sexual dysfunction, adverse pregnancy outcomes, STIs, HIV and serious mental health problems, such as depression, anxiety, post-traumatic stress disorder and risk of suicide.

(i) Gender-based violence

There is a close association between violence and HIV infection. Imbalances in power and intimate partner violence contribute to this trend. Evidence has shown that dealing with the social and economic drivers of HIV risk and vulnerability can impact on the course of HIV and decrease the risk of gender-based violence. This includes encouraging economic independence (e.g. through the provision of micro-financing for women), keeping young girls in school, participation in school-based activities, improving educational qualifications of young women and strategies to decrease age disparate/intergenerational sex.

Adolescent girls and gender-based violence: increased risk

Adolescent girls are often victims of sexual coercion and abuse, often closely linked to economic exploitation; rape; trafficking and forced prostitution. This exposes them to sexually transmitted diseases, teenage pregnancy, unsafe abortion and maternal morbidity and mortality. Severe complications such as obstructed labour and obstetric fistulae occur most commonly among young women. Every year an estimated 1–4 million young women between the ages of 15–19 undergo unsafe abortions: 11 000 of these take place in Africa. Of the 17 million adolescent girls marrying before the age of 20, sub-Saharan Africa has the highest: over 30% of girls are married before the age of 20.

(ii) Gender-based violence and sexual assault: special considerations for adolescents living with HIV

While the overarching issue of gender-based violence and sexual assault affects all children and adolescents in South Africa, there are certain issues that pertain to adolescents living with HIV.

- Particular sensitivity needs to be paid to non-perinatally infected adolescents. They may have acquired HIV through this route.
- Orphans and young adolescents living with HIV may be particularly vulnerable to sexual abuse due to their circumstances. The need for food and money, for example, may drive them to sex work or transactional sex, where they are open to abuse and sexual exploitation.
- Women living with HIV have shown a higher predisposition to experiencing intimate partner violence. Low self-esteem and poor body image may present challenges for an adolescent living with HIV. Issues around sexuality and sexual desirability may be a contributing factor to exploitative and abusive sexual relationships.
- The identification of sexual abuse in young people requires awareness and fine-tuning to possible signs of the abuse. These are not always physical, but may manifest as a discernable change in mood and behaviour. This may be noticed by the parent/caregiver, a teacher who reports a decline in school work, or by the healthcare provider.
(iii) Dealing with sexual abuse and sexual assault

The most reliable and common indicator of sexual abuse is the client’s disclosure that it has occurred and this always needs to be investigated further. Many young people find it difficult to speak about, and may remain silent about, sexual abuse and assault. An awareness of the possibility that it may have occurred needs to form an integral part of a general psychosocial assessment.

The Sexual Offences and Related Matters Amendment Act 32 of 2007 provides protection for children and adolescents against rape and sexual abuse. It is mandatory to report the case to the police.

Possible signs and symptoms of abuse, how to interview an adolescent who may have been abused, and follow-up are discussed further in Appendices 8 and 9. Interventions to manage sexual assault are presented in Box 24.

Box 24: Interventions to manage sexual assault

Any episode of sexual assault should be followed up by the following interventions:

- HIV testing and post-exposure prophylaxis (PEP), following national guidelines (note that if the adolescent is already known to be HIV-positive and on ART, this is not necessary).
- Medical examination that includes the collection of forensic evidence.
- Prophylaxis for STIs including HIV if the adolescent is HIV-negative.
- Pregnancy testing and the provision of emergency contraception (for females).
- Provision of other medical treatment as necessary.
- Counselling and support.
- Temporary place to stay, if needed for safety.
- Link to the police for an investigation of the assault.

Many young people find it difficult to speak about, and may remain silent about, sexual abuse and assault.
Special considerations for ALHIV

Sexual and reproductive health in the context of adolescents living with HIV: additional notes for the healthcare provider

- Adolescents who present to healthcare facilities for SRH services are at risk of being discriminated against on the grounds of their age. It is vital that healthcare providers separate their own personal values and opinions from their professional directive of providing quality service to all clients.

- Adolescents living with HIV face several challenges in terms of sexual relationships.
  - They need to decide when and to whom they disclose.
  - They need to take extra care in terms of safer sex, and may find this difficult: they may be embarrassed that they are sexually active (with HIV) and not be honest.
  - They may be fearful of sex and romantic involvement.
  - Their quest to be like their peers may result in their using sex to be available/popular/attractive.

This means that any discussion about SRH issues needs to have an overlay of sensitivity and counselling.

- There are many myths and misconceptions around contraception, STIs and pregnancy. These should be corrected by healthcare providers as this may be the only opportunity that the adolescent has to discuss sexuality with an adult in a non-judgemental environment.

- Adolescents living with HIV who are aware of their HIV-positive status may not engage in sexual intercourse but in other sexual behaviour that they believe to carry a ‘lower risk’ of HIV transmission. This may include unprotected oral or anal sex. A thorough sexual history should obtain information regarding this, so that myths can be dispelled and accurate good health education provided, with advice on safer sexual practice.
17. Pregnancy and adolescents living with HIV

Adolescent pregnancy provides many challenges to the client, their family and those responsible for their care.

17.1 Key considerations for pregnancy in adolescents living with HIV

- There are social implications regarding finances, childcare and the interruption of the client’s schooling. There are psychological implications with regard to the maturity of the adolescent and whether or not they will be able to cope with parenthood. It is also well known that adolescent clients have a higher rate of medical complications during pregnancy and delivery.
- Adolescents with HIV who get pregnant also need education on infant feeding practices and PMTCT. Preventing HIV infection of the infant should be regarded as a priority.
- Social problems may present at any stage through the pregnancy or may present post-delivery. Stressors, such as financial constraints, can place significant strain on the client and their support system. If the pregnancy resulted from a sexual assault there are numerous additional psychological and clinical factors to take into consideration and clients may require referral.

**Note:** Pregnant adolescents living with HIV should attend antenatal care as soon as possible.

17.2 Issues to explore with the client when pregnancy is confirmed

The following are some issues to check with adolescents when they find out they are pregnant:

- Is the pregnancy intended/unintended? Wanted/unwanted?
- Does the client need counselling about options in terms of proceeding/not proceeding with the pregnancy?
- PMTCT and breast feeding: explain why this is important.
- Are there significant concerns that require social work referral? These include gender-based violence and abuse, financial and food insecurity, and lack of support.
- Are there any medical reasons for referral?

(i) Options for unwanted pregnancies

There are several alternatives if the client decides she cannot proceed with the pregnancy. Careful counselling is recommended: each decision has implications for her future. Thorough counselling goes a long way to ensure that whatever her decision, she knows she considered the options carefully.

- **Adoption:** Requires referral to a social worker – a long-term, permanent option.
- **Fostering:** Warrants referral to a social worker – the baby is placed in temporary care until the mother is able to care for the baby.
- **Family support:** The child is looked after by a family member, this is generally an informal arrangement and the mother can still be involved.
- **Termination of pregnancy:** See chapter 17.3.
17.3 Termination of pregnancy

According to South African law¹ a female client of any age may request TOP without parental consent. This is designed to protect clients and their right to make reproductive decisions, as well as to protect their confidentiality.

- **Clients who present within the first 12 weeks of pregnancy and request TOP should be referred to an appropriate centre**: The healthcare provider does not have the right to refuse this referral.
- **Clients who present between 12–20 weeks of pregnancy may be allowed TOP under specific circumstances**: This will require motivation from two healthcare providers, at least one of whom must be a medical practitioner.
- **Above 20 weeks of pregnancy, termination may only be done for specific medical reasons**.
- **TOP requires that the client provide informed consent**.
- **All clients requesting TOP require counselling**: They should be advised on all of the options available and on the procedure involved in TOP. They should also be advised of possible complications.
- **Post-procedure, the client needs to be counselled and offered appropriate contraception**: They should also be informed about warning signs that they need to return to the clinic.

**Note**: The consequences of pregnancy for adolescents living with HIV are far reaching and may impact on their reproductive health, education and socioeconomic status. Therefore prevention (contraception or abstinence) is the priority, but where this fails, the choice to terminate, with proper counselling, should be made available. The healthcare provider needs to pay specific attention to early referral and assistance accessing the designated TOP service in the area.
17.4 Antenatal care and PMTCT

Clients who plan on continuing their pregnancy should be referred to antenatal care as early as possible.

- Clients not yet on cART should enter the PMTCT programme as per national PMTCT guidelines. They are a high priority initiating antiretroviral therapy on the same day they present for antenatal care services.\(^3\)
- Clients already on ART should continue their treatment with optimal adherence. It is no longer recommended to switch from EFV to NVP during the first trimester of pregnancy.
- All ARVs can safely be given during pregnancy according to the standard dosing appropriate for client weight.
- It is essential that clients maintain good adherence during pregnancy. Clients with a high viral load during pregnancy have a higher risk of transmitting HIV to the unborn child, even on ART. This is especially concerning where the mother is on a second line regimen as there is a risk that she may transmit HIV with pre-existing ARV drug resistance to the child.
- For very young adolescents, ill clients and clients with concomitant medical conditions it is advisable to refer to the appropriate level of care for antenatal services as per standard antenatal care procedures.
- Feeding practices should be discussed early so that the young mother has time to make a considered decision. Exclusive feeding is desirable to reduce transmission to the newborn infant.
- Exclusive breastfeeding is recommended: there are markedly reduced chances of HIV transmission via breastfeeding if the mother is receiving appropriate PMTCT with cART. The benefits associated with breastfeeding are well documented and result in lower infant morbidity and mortality. Mothers who elect to formula feed should be advised of the WHO AFASS criteria (accessible, feasible, affordable, sustainable, safe).
- Formula feeding may also be prescribed by the clinician under certain circumstances as part of PMTCT, for example if the mother is not virally suppressed on second line ART.
- If the WHO AFASS criteria are not met, formula-feeding may pose a risk to the infant in terms of contracting infectious diseases or not receiving adequate nutrition.

17.5 Postnatal care

- Post-delivery, clients are encouraged to attend their routine postnatal checks. Clients should be advised to use a reliable method of contraception to prevent unintended pregnancy. They should also be encouraged to present early should they experience any problems or have any concerns, and to continue with their ARVs and prescribed PMTCT regimen.
- Exclusive feeding should be reinforced, as well as follow-up for routine well-baby visits.
- Young mothers following up at the clinic should be encouraged to ensure their children get tested appropriately for HIV and access care where necessary. Early diagnosis and initiation of ART for the infant is a priority to prevent early illness, progression of HIV and death.\(^5\)
- Adolescents who are newly diagnosed with HIV on postnatal follow-up need to access ART on the same day if they are breastfeeding, as part of PMTCT.\(^2\)
- The mother’s psychological status should be monitored and she should be encouraged to seek help and support where she feels it is necessary. Where required, she could be referred to a social worker to access a Child Support Grant (CSG) or to assist with other issues that may need to be addressed, such as adoption.
18. Prevention for adolescents

One of the main goals of the National Strategic Plan 2012–2016 is to reduce the incidence of HIV by 50%.\textsuperscript{1} For this to be realised the dynamics of HIV transmission and factors that place adolescents at risk need to be off-set by the strategies that improve prevention, increase early identification and linkage into care and treatment.

Based on this goal, and prevalence data across the country and neighbouring regions, it is imperative to deliver a comprehensive package of services to youth. This package needs to address the risk and protective factors for acquiring or preventing HIV.

18.1 Tackling the drivers of HIV in young people

Research conducted by the Human Sciences Research Council (HSRC) in South Africa has shown that the main drivers of the HIV epidemic in young people between 15–24 years of age can primarily be attributed to risk factors related to sexual behaviour, such as early sexual debut, intergenerational sex and multiple concurrent partners.\textsuperscript{2} These and other factors, such as poverty and food insecurity which are associated with increasing rates of transactional sex,\textsuperscript{1} are summarised below.

(i) Sexual debut

According to the South African national HIV prevalence, incidence and behaviour survey (2014), 5% of the young women surveyed between the ages of 15–24 years, reported having had sex before the age of 15, compared to 17% of their male counterparts.\textsuperscript{3} Earlier sexual debut is significantly associated with increased risk of HIV infection, a higher likelihood of having multiple partners, a lower likelihood of condom use at first sexual encounter, higher overall number of sexual partners, as well as high biological susceptibility to infection of adolescent and young girls.\textsuperscript{4,5,6,7,8}

(ii) Intergenerational sex

Intergenerational sex, or age mixing, is an important social determinant of HIV infection.\textsuperscript{9} Shisana et al. found a higher HIV prevalence among teenage males and females who reported having sexual partners who were 5 or more years older than them.\textsuperscript{3,10} According to further HSRC reports there was a substantial increase in the percentage of teenagers who had an older sex partner, from 9.6% in 2005 to 14.5% in 2008 and 19.8% in 2012. When disaggregated by gender the same pattern was found among females where the rates increased from 18.5% in 2005 to 27.6% in 2008 to 33.6% in 2012.\textsuperscript{3,9} Due to unequal power dynamics in relationships, vulnerability to HIV may be exacerbated for young females who do not have the skills or power to negotiate condom use.\textsuperscript{11}
(iii) Multiple concurrent sexual partnerships

Multiple concurrent partnerships increase the chances of HIV transmission as they contribute to sexual networks that create a vehicle for the spread of HIV transmission. Sexual partners linked to a sexual network increases the rapid spread of HIV especially due to the high viral load in the early phase of infection, where transmission is up to 10 times more likely to occur than during the latent phase of infection.\(^\text{12}\)

The percentage of youth aged 15–24 years who reported multiple sexual partnerships (two or more partners in the last 12 months) increased to 22% in 2012.\(^\text{3}\) As with age at sexual debut, young males were more likely to be engaged in this behaviour, with reported multiple partnerships increasing from 23% in 2002 to 37% in 2012. This is not surprising as multiple concurrent partnerships are often more acceptable in patriarchal societies and cultures where patriarchy is condoned.\(^\text{13}\) Factors driving multiple concurrent partnerships are financial exchange, sexual exploration, peer pressure, acquisition of status as a result of being sexually desirable, seeking sexual pleasure and a de-emphasis on long-term relationships.\(^\text{14}\) Among young women, the percentage reporting multiple partnerships remained lower than young males (8%) and had not changed significantly since 2002.\(^\text{3}\)

(iv) Gender issues

In sub-Saharan Africa, HIV prevalence has fallen by 42% from 2001 to 2012 amongst young people 15–24 years old. Despite this favourable achievement, the prevalence rates for young women in sub-Saharan Africa continue to be more than two times higher than that of men.\(^\text{15}\) Sexual violence against women and girls continues to be reported as one of the barriers to effective HIV prevention.\(^\text{15}\) This is due to several contributing reasons such as biological factors that make women more susceptible to HIV infection, gender-based violence and women not being able to negotiate for condom use due to imbalances in power (gender, age and economic-related factors).\(^\text{16}\)

(v) Other factors

Other factors contributing to HIV in young people include peer pressure, transactional sex, lack of hope, pessimism for the future, low self-esteem and, particularly for females, sexual coercion, biomedical factors, gender-based violence, poverty, lack of education and leaving school at an early age.\(^\text{17,18}\)

Overall the prevalence of HIV from 2008 to 2012 had increased from 10.6% to 12.2%. However, for the age group 15–24 years HIV prevalence had decreased from 8.7% in 2008 to 7.1% in 2012. This age group (71.6%) was also more likely to consent to an HIV test.\(^\text{3}\)

Although condom use had increased steadily in the period 2002 to 2008, a decline in condom use was reported among young men and women in 2012, with 67% of males and 50% of females aged 15–24 reported condom use at last sex.\(^\text{3}\) This was a decline from 87% of males and 73% of females reporting condom use at last sex in 2008.\(^\text{9}\)

Given this evidence, it is important to ensure that programmes address the drivers of the epidemic and deal with gender disparities. Youth programmes must be cross-cutting, embracing prevention, education, life skills and economic and psychosocial empowerment. It is also important that young people have access to appropriate health services. It is within this context that the provision of youth-friendly services has been developed.
18.2 Prevention strategies

(i) Combination HIV prevention

The aims of HIV prevention programmes are to off-set the threat of new infections and promote the gains in HIV care and treatment. To date gaps have been identified in the development of interventions that focussed on reducing individual risk in the absence of other contextual factors like the sociocultural, economic, political and legal factors that increase ones’ vulnerability to HIV. A call for a more systematic approach is needed that coordinates all efforts and clearly defines and outlines programme objectives that are linked to other existing interventions. An approach known as “combination prevention” includes biomedical, behavioural and structural strategies to reduce HIV infections. These mutually reinforcing interventions are described in Box 25.

Box 25: Combination HIV prevention

**Biomedical interventions** are those that directly influence the biological systems through which the virus infects a new host, such as blocking infection (e.g. male and female condoms), decreasing infectiousness (e.g. ART as prevention), pre-exposure prophylaxis (PrEP) or reducing acquisition/infection risk (e.g. voluntary medical male circumcision).

**Behavioural interventions** include a range of sexual behaviour change communication programmes that use various communication channels (e.g. mass media, community-level, and interpersonal) to disseminate behavioural messages designed to encourage people to reduce behaviours that increase risk of HIV and increase protective behaviours (e.g. risks of having multiple partners and benefits of using a condom correctly and consistently). Behavioural interventions also are aimed to increase the acceptability and demand for biomedical interventions.

**Structural interventions** address the critical social, legal, political, and environmental enablers that contribute to the spread of HIV. PEPFAR uses five categories to describe structural interventions: legal and policy reform; reducing stigma and discrimination against people living with HIV and marginalised groups; gender inequality and gender-based violence; economic empowerment and other multi-sectoral approaches; and education.

Source: PEPFAR

Evidence that combination HIV prevention efforts are effective are shown in various studies. In Namibia, for example, improvements across key knowledge and behaviour indicators – including comprehensive knowledge, age of sexual debut, engagement in higher-risk sex and condom use among both males and females aged 15–24 years – were associated with declines in HIV prevalence among young people, from slightly more than 10% in 2007 to about 5% in 2009.

(ii) Medical male circumcision (MMC)

Studies have shown that MMC may reduce transmission from HIV-positive females to HIV-negative males by as much as 60%.
(iii) Gender-based violence

There is a close association between violence and HIV infection. Imbalances in power and intimate partner violence contribute to this trend. Evidence has shown that dealing with the social and economic drivers of HIV risk and vulnerability can influence the course of the epidemic. Interventions shown to positively impact on prevention include: improved condom use, a decrease in intimate partner violence, a reduction in transactional sex, a decrease in teenage pregnancy and early marriage, improved negotiation skills in relation to having sex, and practising safe sex.

Interventions specific to gender include:
- economic independence, food security and micro-financing for women
- keeping young girls in school (with incentives such as cash transfers), participation in school-based activities, and improving educational qualifications of young women

The net result of these interventions is a decrease in HIV.

18.3 Prevention strategies for HIV-positive adolescents

In order to prevent the spread of HIV, HIV-prevention activities have increasingly been targeting people living with HIV and not just those who are HIV-negative. Research shows that this is an effective strategy to reduce HIV infection and transmission. This approach is known as positive prevention or prevention for, by or with HIV-positive people. More recently positive prevention has become known as positive health, dignity and prevention.

Generally, positive prevention embraces the following four objectives:
- keeping HIV-positive persons physically healthy
- keeping HIV-positive persons mentally healthy
- preventing further transmission of HIV
- involving people living with HIV in prevention activities, leadership and advocacy.

These include biomedical and behavioural interventions. Prevention needs to be integrated into all aspects of the healthcare of adolescents living with HIV.

Prevention for HIV-positive adolescents includes the prevention of the further spread of HIV through:
- HIV testing and knowing one’s status
- partner disclosure, if there is no risk of violence
- protecting oneself (from reinfection) and one’s partner from HIV transmission through risk reduction and safe sex
- PMTCT
- adherence to ART
- transmission via blood-borne HIV
- transmission through shared injection use or sharing sharp instruments
- post-exposure prophylaxis (PEP)
- pre-exposure prophylaxis. (PrEP)

Note: PrEP has been shown to be effective with men who have sex with men (MSM), evidence for its effectiveness with adolescents is still being researched.
Positive prevention also includes:
- prevention and treatment of STIs, including among partners
- prevention and treatment of TB
- prevention of unintended pregnancy
- protecting oneself against sexual assault
- cervical screening
- positive living, including adherence, attending the health service when necessary and keeping appointments, lifestyle, nutrition and avoidance of alcohol and drug abuse
- reduction of gender-based violence
- MMC
- dealing with factors that are associated with increased risk of HIV infection and teenage pregnancy:
  - age of sexual debut
  - multiple sexual partners
  - intergenerational sex
  - poverty
  - level of education
- combination HIV prevention efforts: a combination of prevention strategies can further reduce HIV transmission. This includes increased condom use, delaying sex before age 15 years (early sexual debut), avoiding intergenerational sex, and not having multiple partnerships.\(^{20}\)

18.4 Medical male circumcision (MMC)

MMC is freely available at a number of healthcare facilities in South Africa. Current evidence suggests the following health benefits in association with MMC: \(^{26,27,28}\)
- reduced chance of acquiring HIV (for HIV-negative male clients)
- reduced chance of acquiring HPV infection, and so also a reduced chance of transmitting HPV to partners or developing HPV-associated diseases
- reduced chance of acquiring certain STIs.

Circumcision may help to reduce HIV infection in HIV-negative males by up to 60%. It also provides protection against STIs and HPV, which is associated with cancers of the anogenital region.\(^{29}\)

There is no substantial evidence that male circumcision protects females from HIV transmission, although studies show that male circumcision reduces the risk of HPV and genital herpes (HSV-2) in women.\(^{28,30}\). The protective effects attributed to circumcision are no substitute for the correct and consistent use of condoms. Responsible, safer sex should be reinforced.

Clients requesting circumcision should be referred to an appropriate facility. Medical circumcision can provide benefits for clients who are already HIV-positive, with regards to HPV and other STIs. It should be noted that the procedure should not be undertaken in clients with a low CD4 cell count as they have a higher risk of infection, the procedure is best performed in well clients.
PART B:

Management of the psychosocial wellbeing and mental health of adolescents living with HIV

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Psychosocial support and communicating effectively with adolescents living with HIV is vital for successful health outcomes. The clinical management of HIV is only one aspect of care and needs to be complemented by services sensitive and responsive to the specific psychosocial and mental health needs of adolescents. As well as the usual physical, emotional, mood and social changes that characterise adolescence, young people living with HIV face additional challenges and stressors. They are also more prone to mental health problems.\(^1,2,3,4,5,6\)

Healthcare providers need to be attuned to these factors when rendering services to adolescents living with HIV. The package of physiological, behavioural and emotional changes combined with HIV makes diagnosis and management challenging. There is a spectrum of presentation – from commonly occurring, transient adolescent problems on the one end, to more severe conditions warranting treatment and therapeutic interventions on the other.

Although this may be difficult terrain for healthcare providers to navigate it is absolutely essential. **Successful health outcomes with adolescents depend on a holistic approach, taking into account their clinical, psychosocial and mental health needs.**

**Note:** Adolescence is not solely a phase dominated by problems and difficulties – it can also be a positive and formative time of self-discovery, personal growth and opportunities unfolding for the future. It is a time when a person’s status moves from being a child to becoming an adult, often accompanied with pride, enjoyment, hope and excitement. These are the strengths that need to be harnessed and built on to deal with life’s challenges.

**Common mental health problems and mental illness: what is the difference?**

It is important to differentiate between common mental health problems and mental illness in order not to pathologise large portions of the population. Mental health lies on a spectrum with mental illness (most severe) at one end of the scale, moving to common mental health problems (less severe) and with stress and diminished coping (mostly benign) at the other end.

Severe mental illness (e.g. schizophrenia, bipolar mood disorder) is relatively easy to recognise but can be difficult to treat and symptoms tend to be long term.

Common mental health problems (e.g. depression, anxiety, post-traumatic stress disorder, substance/alcohol abuse) are more difficult to recognise due to their pervasive occurrence. They are, however, easier to treat than severe conditions.

Stress and diminished coping from day-to-day situations are common. Sometimes these are more extreme – for example, when we are presented with shocking or unexpected news, or experience a crisis. This affects our mental health but is not a ‘disorder’. When support is in place or the context altered, most people can manage life well again. Evidence points to more HIV-positive adolescents suffering from increased stress and common mental health problems than from mental illness.
SECTION 6
Psychosocial wellbeing
19. Psychosocial support and communication

Adolescents living with HIV have similar and additional needs to other adolescents. They face the same physiological, developmental and psychosocial changes as all adolescents. In addition, living with HIV introduces additional complexities which require different interventions, specialised knowledge and sensitivity on behalf of healthcare providers.

19.1 Adolescence: a time of change

Adolescents have a range of needs that are different from adults and children. Although adolescents are not a homogenous group, they do share a cluster of common changes and needs that are defined by this unique phase of life. Closely linked to physical and developmental maturation, there are a range of changes which characterise adolescence, including:

- Increased risk-taking and experimentation.
- Moving from dependence to independence, with an increased need for autonomy – often manifested as pulling away from parents/caregivers – and a greater need for peers.
- Emotional changes, including anxiety, moodiness, reactive emotions, rebelliousness and defiance against authority, at times insecure and at other times overly confident.
- More self-conscious with an increased awareness of physical appearance and body image.

The intensity and manifestation of these changes differ between individuals but all adolescents share the need for affirmation, reassurance, counseling, guidance and boundaries to varying degrees, as well as support and the opportunity to learn necessary and useful life skills.

19.2 Support required for adolescents living with HIV

Adolescents living with HIV have further vulnerabilities, stressors and challenges that are specifically HIV-related. They will need additional support with the following:1,2,3

- Understanding and coming to terms with living with HIV.
- Dealing with anger and unresolved emotions in relation to the way HIV was acquired.
- Understanding and coming to terms with other family members’ HIV status and possible associated health problems.
- Grieving the illness or loss of parents and/or siblings.
- Coping with added responsibilities at home, especially in child-headed households.
- Dealing with problems related to identity, a sense of belonging and acceptance – particularly in orphans and where the adolescent is adopted, fostered, taken in by other family members or placed in a care home.
- Coping with cycles of wellness and poor health, and with repetitive visits to health services.
- Dealing with long-term adherence to medicines.
- Coping with disclosure.
- Learning to live with HIV in relation to sexuality and sexual and reproductive health (SRH) issues, including: fear of intimacy; fear of transmission; denial of status; disclosure to partners; practising safer sex; the prevention of pregnancy or choices about pregnancy and having children.
• Dealing with self-image and self-esteem, including lack of confidence, and anxiety about physical appearance and body image, especially where physical changes are as a result of ART side effects and delayed growth and maturation.
• Dealing with stigma (Box 26), discrimination and social isolation.
• Worry and anxiety about education (and disruptions due to illness), work opportunities and planning for the future.
• Managing mental health issues such as anxiety, depression and substance abuse.

The support needs of adolescents living with HIV are also influenced by factors such as:
• whether they were perinatally or non-perinatally infected
• whether they are members of key populations, including male adolescents who have sex with men; adolescents who use drugs; and adolescents engaged in sex work or involved in sexual exploitation
• when and how they learnt about their HIV status
• continuity and quality of healthcare
• the length of time they have been on ART
• whether they have access to support.

Box 26: Notes on stigma

There are different kinds of stigma:
(i) Stigma towards others: Refers to negative views, stereotypes and discrimination shown towards others who are in some way different.
(ii) Self-stigma: Refers to the process whereby recipients of perceived stigma from others begin to internalise and adopt the stigma. They take on the stigmatised attitudes towards themselves.
(iii) Secondary stigma: Refers to a person becoming stigmatised by way of association, for example, being friends with a person who is HIV-positive.

The impact of stigma and discrimination can be far reaching
It can:
• cause barriers for adolescents living with HIV to access care and treatment
• be a deterrent to adherence, retention in care and disclosure
• be the cause of isolation, anxiety and depression, denial, and involvement in risky behaviour.

Dealing with stigma
It is important for healthcare providers to identify measures that mitigate against stigma. These include:
• getting to know the community context and attitudes where clients live
• discussing ways in which the healthcare setting and personnel contribute to or reduce stigma
• facilitating community engagement and outreach to address stigma
• ensuring respect for clients’ rights in terms of confidentiality and privacy
• creating opportunities that encourage open discussion about stigma and ways to deal with it, including discussions as to how clients experience stigma during consultations
• providing group forums/support groups for the sharing of challenges and strategies to deal with stigma.

Dealing with stigma needs to form part of the broader range of life skills which adolescents living with HIV need to acquire as they move into adulthood.
19.3 Useful tools for providing psychosocial support

There are two useful tools to assist with the integration of psychosocial assessment and support in the consultation with adolescents living with HIV.

(i) The *psychosocial assessment tool* (Appendix 9): This tool has been developed to support healthcare providers with assessing and responding to the client’s psychosocial needs. Key aspects of their life are explored, including moods, activities, alcohol/substance abuse, sexual health, disclosure, stigma, friends and support, living situation, adherence and retention in care. The format encourages the adolescent to ask questions as well as to identify areas of concern.

(ii) The “5 A’s” for consultations with adolescents (Appendix 2): This tool provides an overview of coping strategies based on the WHO’s Integrated Management of Adolescent and Adult Illness (IMAI) for the management of chronic care. The guidelines use the “5 A’s” when engaging with clients: *assess, advise, agree, assist and arrange.* The tool is a useful framework for moving through the process of identifying, exploring and problem-solving areas of concern, as well as for follow-up plans.

**Note:** Support groups are also an important means of providing psychosocial support.

19.4 The keys to effective support: communication and the relationship between the adolescent client and the healthcare provider

As with any consultation, *communication and the relationship between the adolescent client and the healthcare provider* form the foundation of all successful interventions. Establishing rapport and building trust are underpinned by positive encounters. This is reinforced by:

- **Seeing the adolescent as an individual:** Each adolescent is different, with their own personal experiences and needs. Use their name, especially the name they like being called by. Ask questions and find ways to make the client feel that they are acknowledged.
- **Respecting confidentiality:** Be reassuring but honest: explain that within the context of the health service, confidential information may be shared with other healthcare providers on a need-to-know basis to ensure that the client receives good care.
- **Respecting privacy:** Ensure doors are closed and others cannot hear the conversation. This minimises interruptions and affords privacy when examining the client.
- **Involving the client in the care process:** Encourage the client to be involved in decisions and options. Explain what is being done in a manner that they understand and include the parent/caregiver where appropriate.
- **Showing respect:** Avoid patronising or speaking to clients as if they are young children. Encourage mutual respect: between the healthcare provider, the client and the parent/caregiver.
- **Being encouraging and positive:** Praise punctuality, adherence, good ideas and strategies proposed by the client.
- **Displaying patience and encouraging clients to speak for themselves:** Avoid judgemental attitudes. Be honest and firm without making the client feel humiliated or embarrassed as this can close communication channels.
- **Involving parents/caregivers where appropriate:** Get the balance right between the autonomy and privacy of the client and the involvement of parents/caregivers. Their involvement is important, however it may be necessary to arrange sessions without them. Check with the client whether they are comfortable with information being shared with the parent/caregiver and seek their permission to do so.
• Providing quality, adolescent-friendly services: This includes service operating hours and waiting times, privacy, efficient systems of record keeping (including psychosocial management), mechanisms for client feedback, and referral systems.

• Linking with other services and support networks: The healthcare provider and health service cannot provide for every need. It is important to also identify and refer clients to community support groups and other agencies and services that cater for young people living with HIV.

Remember the Children’s Act: be guided by the best interests and safety of the child.

In addition, it is important that referral systems are developed to ensure that referral points are accessible to adolescents. A mechanism should be in place to notify the referring healthcare provider that their client has received the service to which they were referred.

Tips on referring adolescents

- Make prior arrangements with the referral point concerned.
- Make an appointment for the client at a time that is convenient for them.
- Link the adolescent with a named healthcare provider.
- Give clear directions to the referral point.
- Arrange for someone to accompany the adolescent where possible.
- Provide the client with a referral letter.
- Receive confirmation that the referral was successful.
20. Adherence

HIV-positive adolescents on ART generally have lower viral suppression rates than either adults or younger children. This is attributed to relatively lower adherence to ART. As with other chronic conditions (e.g. asthma, epilepsy, diabetes) normal developmental changes experienced during adolescence, may impact on the management of the condition. Besides retention in care, lifestyle and nutrition, factors impacting on adherence during adolescence include denial, the fear of stigma and the striving for independence and autonomy, which may cause oppositional, defiant behaviour.

Note: Adherence includes adherence to treatment (routine, correct dosage, correct manner) and adherence to care (e.g. keeping appointments).

Adherence reinforces retention in care; retention in care reinforces adherence.

20.1 Importance of adherence support

There is evidence that treatment readiness prior to the initiation of cART is associated with improved adherence. Both adolescents and parents/caregivers require support to ensure adherence.

Tips for adherence to be effective

😊 Adapt and revisit support as the young client moves from childhood and adulthood: Take into account the different needs specific to younger, middle and older adolescence.

😊 Carefully manage the gradual shift in responsibility from the parent/caregiver to the young client for adherence to treatment and care - this is an intrinsic part of transition of care.

😊 A strength-based approach to counselling and support for adolescents on ART is best: For example, good adherence should be praised and used as an opportunity for positive reinforcement.

😊 A non-judgemental and supportive attitude encourages both the adolescent and the parent/caregiver to be honest regarding adherence and any problems: Honesty is essential to identifying problems and facilitating practical solutions.

20.2 Factors impacting on adherence

(i) Factors that can potentially impact on adherence

- Adherence counselling and support: Quality of counselling and how well the client understands the treatment, ability to maintain a routine, having a ‘treatment buddy’, access to reliable and youth-friendly healthcare, and ability to keep clinic appointments.
- The adolescent’s relationship with HIV: Issues related to disclosure and support, ability to accept HIV diagnosis, ability to cope with stigma and discrimination, and level of stigma and discrimination in their community.
- Availability of support: Social, financial and emotional support, adolescent–healthcare provider relationship, adolescent–parent/caregiver relationship, lack of support, and inconsistent care or absence of parents/caregivers in overseeing adherence.
- Lifestyle issues that disrupt routine: High mobility due to homelessness, frequent moves to different caregivers, transport (especially around holiday periods) and child-headed household where the adolescent has the burden of caregiving responsibilities (e.g. taking care of sick family members, parenting younger children).
• *Changes in routine:* For example, increases in extramural activities, such as sport, may also affect adherence.

• *Psychosocial and mental health factors:* Mental health challenges (e.g. depression), alcohol/substance abuse and behavioural problems that disrupt routine (e.g. crime, dropping out of school, leaving home).

• *Health system-related issues* such as:
  - multiple healthcare providers, high turnover of staff
  - access to care such as distance and cost to get to clinic, opening hours if at school or work, waiting times, language and terminology understanding
  - quality of care such as drug stock-outs, repeated visits for test results, healthcare provider’s attitude, lack of privacy and confidentiality

• *Medical factors and disease progression:* Side effects (support for/ability to deal with these), pill burden (especially when the client needs to take other medication as well), comorbid conditions and advanced HIV status.

### 20.3 Tips for improving adherence

• Build on strengths and praise good adherence.

• Discuss treatment and logistics of getting to the clinic – with client, and parent/caregiver where appropriate.

• Provide adolescent-friendly services, including accessible, acceptable and appropriate services, so that young clients feel welcome at the clinic.

• Create an environment for both parents/caregivers and adolescents to be honest about adherence, by being non-judgemental and building a relationship based on trust, respect and openeness.

• Check in with clients frequently after they start or change medicines – if not during clinic visits then by phone or outreach workers going to their homes, but beware of breaching confidentiality.

• Ensure that systems are in place, with consent granted, so that clients can be contacted (by SMS, phone or outreach) if they miss clinic appointments or need prescription refills.

• Where possible, use fixed-dose combinations (FDCs) and simplify treatment and dosing.

• Always explore the underlying reasons for poor adherence. Encourage the young client to weigh up the pros and cons, benefits and possible consequences of good and poor adherence. This needs to be revisited as they grow older.

There is evidence that treatment readiness prior to the initiation of cART impacts on good adherence. Fernández et al. emphasise its importance in adolescents and identify five components for assessing treatment readiness:

(i) disclosure
(ii) psychosocial issues
(iii) connection with care
(iv) HIV medication beliefs
(v) alcohol and drug use.

Generally, planned treatment breaks, or ‘treatment holidays’ are not recommended.
21. Disclosure

Disclosure to the child or adolescent living with HIV is a process that involves age-appropriate information which will enable them to understand their HIV diagnosis, how it was acquired and to come to terms with living with HIV. It is an ongoing process of learning and is not a one-off event. Disclosure may also be by the adolescent to others. Disclosure of HIV infection to and by adolescents requires due consideration: where, when, who and how? It requires nuanced planning, sensitivity and understanding.

Perinatally infected adolescents may already be disclosed to and aware of their HIV status but as they grow from childhood into adolescence they may have new questions that they have not previously raised. Others may never have been told directly about their HIV status and will need to be taken through the disclosure process. Similarly, non-perinatally infected adolescents may or may not be aware of their status. They may have requested HIV testing for themselves or may have been tested with the caregiver’s consent, in which case they may not be aware of their HIV status.

There are two routes for disclosure:
(i) someone informing the adolescent about their HIV status
(ii) the adolescent voluntarily informing others about their HIV status.

21.1 Potential benefits of disclosure

(i) Disclosure to the adolescent living with HIV

Disclosure to adolescents living with HIV:

• enables adolescents to gain more knowledge and understanding of HIV
• encourages adolescents to take more responsibility for their own care
• builds a relationship of honesty, trust and support between the client, parent/caregiver and healthcare workers
• potentially assists in improving:
  o adherence
  o access to support services
  o family communication
  o emotional wellbeing
  o retention in care.

(ii) The adolescent disclosing to others

Adolescents disclosing to others contributes to:

• treatment adherence through no pill hiding and an opportunity to recruit a treatment supporter or attend peer support groups
• support from others
• the supporters’ understanding of the adolescent’s diagnosis
• open communication about their status
• protection of sexual partners and adherence to practising safer sex
• less worry and stress through a reduction in isolation and secrecy
• retention in care.
21.2 Rights related to disclosure\textsuperscript{11}

(i) Disclosure to the adolescent living with HIV

It is the adolescent’s right to know their HIV status, as supported by the Children’s Act, which recognises the rights of children to participate in decisions affecting their healthcare and their right to privacy of their disclosure of HIV status.

According to the National HIV Counselling and Testing Policy Guidelines (DOH 2010)\textsuperscript{12} and the Children’s Act No. 38 of 2005 (section 130)\textsuperscript{13} a child may consent independently to HIV testing if they are:

- 12 years of age or older
- younger than 12 years and of ‘sufficient maturity’ to understand the benefits, risks and social implications of such a test.

(ii) The adolescent disclosing to others

It is the adolescent’s right to choose who else knows their status. Section 133 of the Children’s Act (No. 38 of 2005) provides that information regarding a child’s HIV status must be kept confidential. Healthcare providers can encourage adolescents living with HIV to seek out someone they trust to support them but the adolescent’s wishes must be ultimately respected.

The following factors are important regarding the adolescent disclosing to others:

- The adolescent must feel in control over their HIV status and who is privy to this information.
- Healthcare providers need to be sensitive to the complexity of adolescents disclosing to their romantic or sexual partners. Although there is no legal obligation to disclose their HIV status to a sexual partner, it is important to encourage clients to practise safer sex at all times and to share their status as a basis for honest, trusting relationships.

The likely consequences of disclosure will need to be explored and decisions made based on the client’s personal circumstances. Peer support can also be helpful in this respect. There are many factors that may discourage disclosure to friends and partners. Other than the fact that many relationships at this age are short-term and transient, there is the fear of stigma (Box 26), rejection and others learning about their status. Some young people may also worry about violence related to disclosure to others.\textsuperscript{5}
21.3 When is the best time to disclose?

There is not a definite age when disclosure is appropriate; it depends on the individual circumstances. Guidelines advise commencing the process of disclosing HIV status to children from as early an age as possible. Many children are ready for full disclosure from between 8–11 years of age and it is recommended that the process should be complete by the time they turn 12 years old.

- **The decision to disclose needs to be age- and developmental stage-appropriate.** Older adolescents are different to early adolescents (Table 19). It is important to assess the client’s cognitive ability and emotional maturity to establish whether they are ready to be able to deal with their HIV status and all that it implies. An indication could be, for example, if the young person begins to ask questions about health, medication and the reason why they have regular visits to the clinic.

- **The disclosure discussion needs to be shaped by their level of understanding, physical and psychosocial wellbeing, and available support.**

- **It is better to disclose HIV status when the child or adolescent is physically well,** to enable them to cope better with their diagnosis.

(i) Considerations for disclosure to adolescents

Disclosure is an ongoing process: as the information is processed, further questions may be asked. It is important to provide opportunities for further discussion and questions, and to answer these accurately and honestly.

- **The relationship with the parent/caregiver needs to be gauged by the healthcare provider:** In some cases the young person will seek reassurance from their parent/caregiver before speaking freely to the healthcare provider. In other cases, the presence of the parent/caregiver may inhibit openness with regards to discussions or questions around HIV.

- **Assess their developmental level:** This includes cognitive and psychosocial levels. The ability to learn, process and act upon new knowledge is broadly related to chronological age but levels of maturity differ and are not age related.

- **It is important to find out how much the young client knows:** They may be aware of HIV and related issues from exposure through the media, community and their visits to the healthcare services. They may even know their own HIV status before disclosure. Their knowledge and attitude toward HIV provides an important foundation from which to work.

If the adolescent already knows their status:

- **Build on their existing knowledge**

- **Provide positive feedback** to the adolescent and family, using affirming comments like:
  - ‘It is good that you already know about your HIV status.’
  - ‘You are right to have told us, it will help us to look after you better.’

(ii) Preparation for disclosure

Disclosure should not only focus on giving adolescents the diagnosis of HIV. It is also about ensuring understanding of the condition and creating a positive outlook on their future, their healthcare and living a healthy life with a chronic medical condition.

Preparation for disclosure involves health education as the foundation. It is necessary for the young person to have a basic understanding of:

- good health and ways that health is maintained, e.g. healthy eating, hygiene, hand-washing, seeking healthcare, and medication

- the concept of an immune system, where white blood cells act as ‘soldiers’ or ‘defenders’ which protect against illness

- the concept of a virus or ‘germ’ (something small and not visible which can cause illness).
Caregivers and healthcare providers can use these concepts to discuss aspects of the child’s healthcare and treatment, to answer questions in an age-appropriate manner and to prepare the child for full disclosure. Table 19 provides a guide to what most children and young people are able to understand at different ages, but may need to be adapted to the individual’s specific needs.

Ideally, disclosure should be done in partnership with parents/caregivers, who also require preparation for the disclosure process. When children learn about their status directly from their caregivers, it can provide comfort and reassurance, and may improve their relationships with their caregivers.

**Table 19: Age- and development-specific disclosure**

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<th>Age group</th>
<th>Developmental stage related to disclosure</th>
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| Younger adolescents | • Developing the ability to hold onto ideas and apply them to new situations.  
                   | • Developing the ability to understand past, present and future.  
                   | • Acquiring social and moral awareness about right and wrong behaviour.  
                   | • Beginning to be more curious and take some control over their lives.  
                   | **Explaining or confirming their diagnosis and assessing their knowledge of HIV**  
                   | • Ask the young person if they know why they attend clinic and take medication regularly.  
                   | • Explain that the treatment is for a type of ‘germ’ known as a virus.  
                   | • Explain that viruses are ‘clever germs’ that can damage the white blood cells which are the body’s defence against infection.  
                   | • Explain that if medicines are not taken correctly the virus can get stronger and stop the medicines from working, and that this is what ‘resistance to medicine’ means.  
                   | • Refer to the HIV virus by name if the caregiver and client are emotionally ready and if the client is mature enough to understand.  
                   | • Explain that the information about their health is private and should only be shared with those agreed with their parent/caregiver. Help the child to identify who they can talk to about their health or HIV.  
                   |
| Older adolescents   | • Developing the ability to think in a more abstract manner. Increased ability to understand future consequences of actions.  
                   | • Striving for more independence, e.g. in developing their own identity, in decision-making and in decreased dependence on caregivers.  
                   | • Increase in importance of relationships with friends.  
                   | • Puberty and sexual development are particularly marked at this age.  
                   | **Understanding their diagnosis and preparing for the future**  
                   | • Check the adolescent’s understanding of health, medicines, sexual development and HIV infection.  
                   | • Directly address the client during clinic consultations.  
                   | • The importance of CD4 cell counts and viral load testing should be explained. Results should be shared with and explained to the adolescent in language that they can understand.  
                   | • The client needs to understand the responsibility for not transmitting HIV (e.g. safer sex) and their rights (e.g. family planning, confidentiality).  
                   | • Encourage the young person’s direct involvement in discussions and decisions, and encourage them to ask questions if they need additional information.  
                   | • Promote the benefits of attending adolescent support groups.  
                   |
21.4 Role of the parent or caregiver in disclosure

Disclosure takes place over time and requires ongoing communication between the adolescent and key individuals involved in their care and support. These include parents/caregivers, healthcare providers and those forming part of the care team.

(i) Preparing the parent or caregiver for disclosure

Disclosure should be done in partnership with parents/caregivers. They should be made familiar with the benefits of disclosure. The parent/caregiver disclosing to the adolescent has the advantage of paving the way for openness, acceptance and support. In this respect parents/caregivers also:

- require counselling and support, and information to be able to answer questions accurately and sensitively
- need to work through their own barriers to disclosure and come to terms with their child’s medical condition and the implications thereof
- may also first need to work through their feelings and acceptance of their own HIV status if living with HIV.

These factors will help to reduce conflict between the parents/caregivers and the adolescent.

(ii) Factors impacting on disclosure by the parent or caregiver

Caregivers may be concerned that the adolescent is ‘too young’ to be disclosed to. They may want to delay or avoid disclosure or may want to put sole responsibility on the healthcare provider. Underlying factors that need to be considered include the possibility of:

- feelings of guilt (especially concerning perinatally infected adolescents)
- denial of the adolescent’s HIV status
- fear of the adolescent’s response.

(iii) Support for the parent or caregiver

Late or non-disclosure may have adverse effects on the relationship between child and parent/caregiver and may affect the adolescent’s ability to deal with their HIV positive status. The healthcare provider should re-emphasise the benefits of timely disclosure and of the parent/caregiver’s involvement. Parent/caregivers may benefit from:

- specific counselling to facilitate the disclosure process
- support groups to offer advice and support, dispel misconceptions and allow sharing of experiences

Note: If the parent/caregiver is not ready to disclose, the process cannot be forced but follow-up counselling should be ensured to work toward disclosure. The healthcare provider should emphasise the rights of the child, which includes the right to know their HIV status as stipulated in the Children’s Act.
21.5 Providing post-disclosure support

The first clinic visit after disclosure is very important in building a relationship of trust and openness between the healthcare provider and the client.

- Establish if the adolescent has shared their diagnosis with anyone else, and if not, explore their reasons.
- Initiate a discussion to reflect on their experiences with disclosure to others.
- Ask if knowing and understanding their status has been an advantage and what challenges they are facing.
- Always talk to the client about:
  - HIV and ART
  - myths and misconceptions
  - their emotions and feelings about their status
  - their SRH rights, concerns and responsibilities.
- Check their ability to understand and process information by asking them to reflect back some of what has been shared with them.
- Encourage them to ask questions. Discuss who they can talk to or go to for advice and support (e.g. at home, school) and emphasise those in the health facility who can give advice and support.
- Reassure the client that HIV is nothing to be ashamed of. Explain that people can sometimes treat those with HIV badly but this is usually done out of fear based on their lack of knowledge.
- Reinforce the fact that information such as HIV status is private and that the client’s confidentiality will be respected.
- Facilitate contact with peer and other support groups.

**Remember:** Disclosure is not a one-off event but an ongoing process as the young person matures and faces different challenges.
21.6 Supporting adolescents in disclosing to others

Support, inform, guide, assist and equip the adolescent to prepare for and manage disclosure.

Key aspects to explore together with the adolescent when they are ready to disclose:

- **Who and why**
  - *Who do they want to tell and for what reasons?* Are these appropriate? What does the adolescent hope to gain by telling them?
  - *Identify people to whom it would be beneficial to disclose,* e.g. family, close friends, teachers and healthcare providers.
  - *When, where and how best to disclose.*

- **Advantages of disclosure**
  - *Disclosure has the potential to strengthen relationships, make people feel closer, reduce isolation, and increase support.* Disclosure removes the feeling that they have something to hide, such as information, clinic visits and medication.
  - *Explore the potential advantages linked to specific people,* such as family members, friends, romantic or sexual partners, teachers and work colleagues. Talk through the implications of disclosing their status.

- **Challenges of disclosure**
  - *Fears and perceived risks in telling someone else:* Risks include fear of abandonment, isolation, anger and even physical harm. Assist the adolescent to explore issues related to trust and the possible implications of sharing their HIV status: remind them that once shared, it cannot be taken back.
  - *Privacy and confidentiality:* Benefits and consequences of disclosure in romantic and intimate relationships need to be discussed. Importance of protection and prevention (HIV transmission, STIs, pregnancy) must be emphasised.
  - *Implications and consequences:* Advantages and disadvantages should be weighed up for disclosing their status to the different parties, such as family, friends and teachers.

- **Response to disclosure**
  - *How is the recipient of the information likely to respond?* What kinds of questions could they ask?
  - *Their own response:* level of knowledge regarding HIV and confidence to respond to the person to whom they have disclosed in a satisfactory manner.
  - *Equip the adolescent with the information and knowledge* they need to ensure they can answer HIV-related questions.
  - *Prepare them to anticipate and deal with responses:* Role-play is helpful for practising possible questions, reactions and responses.

- **Support**
  - *Is there someone with whom they can share the experience,* practise what they are going to say and who will support them after the disclosure (particularly if it does not go well)?
  - *Where can they get additional support* and learn from others’ experiences?
  - *Attending support groups:* Explore the advantages and options in their area.
  - *Having a treatment buddy* where possible: Discuss how this may be helpful. Facilitate peer support if required.

- **Follow-up**
  - *Debriefing* provides an opportunity to express their feelings, seek guidance and support and build relationships with healthcare staff.
  - *Offer the adolescent a follow-up session after they have disclosed* to reflect on the successes and challenges they faced.
  - *Arrange the follow-up session* or initiate discussions around disclosure at the next clinic visit.
  - *Results of their disclosing:* Explore positive and negative consequences and managing these.
  - *Facilitate counselling and HIV testing for sexual partners* who have been disclosed to.
Due to the success of early diagnosis and ART, HIV-positive children now have a longer life expectancy. This section focuses on the move from paediatric or adolescent care into adult care, a common but complex form of transition.

This transitory period can be disruptive and challenging for all concerned, including the adolescent, healthcare providers and parents/caregivers. Transition can result in a range of problems with retention in care and adherence, and interruptions in keeping appointments if adolescents and their families are not sufficiently supported.

**Note:** The goal of transition is to ensure the provision of comprehensive, uninterrupted, coordinated, developmentally and age-appropriate care before, during and after the transition.¹

Transition may be from:

- paediatric or child-orientated services into adult care
- paediatric into dedicated adolescent care
- adolescent services into adult care.

Alternatively, if the adolescent is not in a child/adolescent-specific service, the transition may be the transfer of responsibility from the caregiver to the adolescent – rather than changing a clinic or physical space.

Whatever the nature of transition, the process needs to be actively managed to ensure that the medical, psychological and social needs of the young person are addressed. Clients need to be made to feel acknowledged, comfortable, reassured and accepted as they move to new and different levels of care.

The transition of care from paediatric to adult services, with the accompanying challenges and dynamics, is not unique to HIV and is a feature of other chronic conditions, such as epilepsy and diabetes.²,³

The aim of a managed approach to transition in young people includes:

- increasing resilience
- reducing risk-taking behaviour, including non-adherence, substance abuse and risky sexual behaviour
- offering an opportunity to increase autonomy, knowledge and life skills
- promoting adherence and retention in treatment and care.
22.1 Key considerations for adolescents making the transition into adult care

Transition should not be a single discussion or a sudden event. It needs to be a process that takes the following into account:

- **The process of transition involves more than the young client**: Many perinatally infected children have attended the same health setting since birth and will have developed strong attachments to both health personnel and the familiar environment. The parent/caregiver will likewise have developed a strong relationship with the staff, and understand and feel comfortable with the system. Similarly, healthcare providers need to work through their own feelings of loss and let go of their clients who have ‘grown up’ and often thrived under their care. Therefore transition needs a team approach: current healthcare providers, future healthcare providers, parents/caregivers and the adolescent client.

- **The transition generally takes place alongside many other developmental physical, emotional and sexual changes**: These changes, combined with the additional complexities of living with HIV, will have an effect on the level of preparedness and ability of the client to assume more responsibility, to move toward independence and to cope with the changes involved in moving into adult care.

- **The involvement of the parent/caregiver varies and will depend on their level of insight and relationship with the client**: For some adolescents living with HIV, parents/caregivers play a minimal role. For others, they are important, positive sources of support. Transitioning into adult care does not mean a severing of relationships with adult supporters, but rather a redefining of their role, with the underlying objective of encouraging the young person to take responsibility for their health and management of HIV.

Given the correct support and education, parents/caregivers can play a constructive role before, during and after transition, but it is important for this to be underpinned by the objective of building a sense of responsibility, autonomy and independence in the transitioning adolescent. This often means letting go as the primary caregiver and enabling the adolescent to develop their own confidential independent relationships with healthcare providers. The level of involvement of parents/caregivers will also be guided by the developmental level and maturity of the client, which may have been adversely affected by HIV.

22.2 Tips to support transition

- **Discuss the future transition of care early during childhood and as the young person grows up**: Revisit the discussion over time with both the adolescent and the parent/caregiver, focusing on an exploration of fears, hopes, risks and opportunities, and planning together. Adolescents are at an exciting yet vulnerable stage and need support from healthcare workers who acknowledge and believe in their opportunities and potential for success rather than their potential for failure.

- **Ensure that the adolescent is ready for the transition**: There are real risks that if young clients are given responsibility for their own ART before they are adequately skilled and prepared, their adherence will deteriorate. Adherence in adolescents living with HIV has been shown to worsen over time. Contributing factors include being given increased responsibility for managing their ART and HIV without proper support or when they are not developmentally ready to take such responsibility. Transition should therefore be based on the maturity, developmental readiness and responsibility of the young person rather than on chronological age.
Transitioning requires a range of life skills which need to be built incrementally over time, including:

- taking responsibility for adherence to all medication – correct time, correct dose, correct method; identifying when prescription refills are required and the process to follow for this
- making and keeping appointments; rescheduling missed appointments; days and times for the different services
- understanding HIV and related health issues: the monitoring that may be required; the importance of getting and understanding test results; when, how and who to ask for help with health problems
- understanding when they are ill and need to access health care urgently before the next appointment
- understanding other psychosocial-related issues – such as stress, risk, SRH and rights, alcohol and substance abuse; where to get advice and support (including support groups).

Build the bridge between the paediatric and adult facility: Organise for healthcare providers from the adult service to visit the paediatric service for an introduction or take the clients to the adult facility to meet staff there and to familiarise themselves with finding the location, the personnel, the systems and the services. Where possible, identify a healthcare provider who will supervise the transfer and provide continuity of care. Identify other adolescents and peer educators already in the new clinic who can provide support. For those transitioning within the same facility, maintaining informal relationships with providers in a familiar environment may make transition easier.

Transitioning needs a supportive health system: For example, this includes copies of clients’ files/records/test results and medical history, the convening of case conferences for handover and referral procedures, and identifying most at-risk or complex cases where additional care may be required (clinical and/or psychosocial).
23. Support groups for adolescents

Support groups provide a structured group environment for people to share, discuss and learn from others with similar problems, challenges or experiences. Support groups have the additional benefit of providing support to people who may feel marginalised, stigmatised or alone in the challenges they face due to their circumstances. They can be self-run or facilitated, often by a person who brings relevant experience or expertise to the group.

Support groups for adolescents living with HIV provide a useful forum to provide mutual support and share information with other young people who are non-judgemental and understand the challenges of living with HIV.\(^1,2\)

23.1 Role of the facilitator in support groups

Although some support groups are self-run, it is more common to have support groups for adolescents living with HIV supported by a facilitator. It is the role of the facilitator to:\(^3\)

- assist with ground rules, especially in relation to attendance, confidentiality and mutual respect
- ensure accurate information is shared and provide information that is age-specific
- ensure age and developmental needs are met and that the age mix is appropriate, e.g. very young adolescents may have different needs to their older counterparts
- manage group dynamics (especially to ensure participation of all), deal with issues such as gender, diversity, discrimination
- maximise on the opportunities, skills and experience brought to the group by its members
- guide the group but allow it to develop a life of its own: the facilitator is ‘in control’ of the group, but the adolescents are ‘in charge’ of it.

23.2 Key considerations for adolescent support groups\(^4\)

The support group may provide the only opportunity for the adolescents to express themselves. Key considerations are as follows:

- **Support and trust:** To feel safe and comfortable they need to trust the facilitator and be confident in the facilitator’s ability to control the group.
- **Safety from judgement, blame, stigma and discrimination:** Facilitators must be aware of their own values, ensure that these are not imposed on the group and moderate judgemental and discriminatory attitudes between group members.
- **Time allowed for unstructured discussions and for people to talk about their situations:** Externalising, or talking about HIV, allows the adolescent to share and unload the burden of living with HIV. It also allows them to deal with stigma, both external and internal, and self-stigma. Sharing the ‘secret’ of living with HIV enables the adolescent not to be defined by HIV but to accept that it is an aspect of their life that they have to deal with.
- **Confidentiality:** This is an important ground rule and needs to be constantly reinforced, particularly when personal information is shared.
- **Relevant information:** This should be based on the needs of the group, including their ages and interests. The methodology for sharing information should be varied, e.g. debates, role plays, dramas, videos.
- **Social base:** The support group provides an opportunity for adolescents to form friendships with others who share similar experiences and can offer support in various forms. It provides a healthy environment to fulfil the need for a sense of belonging and feeling like a valuable, contributing individual. It also provides an opportunity to establish emotional connections with others, which is not always possible in the home environment.
SECTION 7

Mental Health
24. Mental health and HIV in adolescence

Common mental health disorders in adolescents include depression, anxiety, trauma and substance abuse. Suicide and attention deficit hyperactivity disorder (ADHD) are particularly relevant in adolescents (see chapter 25), together with a broad spectrum of HIV-associated neurocognitive disorders (see chapter 26). This section makes practical suggestions for the management of these conditions.1,2,3,4,5

24.1 Defining mental health

*Mental health* refers to a state of psychosocial wellbeing whereby people are able to realise their potential, cope with normal day-to-day stress and function productively in their different spheres of life, such as school, work, family and community.

*Mental illness* or mental disorders comprise a broad range of problems with different symptoms. Mental illness generally refers to alterations in thought, emotions, mood or behaviour (or a combination of these) associated with distress and/or impaired functioning.

Mental illness covers a broad spectrum of conditions and may be difficult to diagnose – this is even more so during adolescence, which is a period of enormous biological, psychosocial and emotional changes.

Mental illness or mental disorders are characterised by the presence of one or both of the following over time:6

- persistent and severe subjective distress (or discomfort)
- moderate or severe impairment in functioning (not being able to ‘get through’ day-to-day activities).

**Note:** Temporary states of stress, distress and reduced functioning are not considered mental illness. These are often caused by life’s events and need to be dealt with through ongoing counselling and psychosocial support.

24.2 Mental health and HIV

There is a close association between HIV and mental health problems. HIV-positive clients are twice as likely to have mental disorders as the general population.7,8,9,10,11 In South Africa, 56% of patients with a recent diagnosis of HIV met criteria for a mental disorder, the most common being depression (25–37.6%) and post-traumatic stress disorder (15%).12,13,14

Poor mental health can be both a cause and effect of living with HIV, as described in Figure 10.
Adolescents living with HIV are more likely to develop mental health problems

Adolescents with mental health problems are more likely to acquire HIV

Possible causes:
- Social stressors such as stigma, financial difficulties and relationship difficulties.
- Lack of adequate support structures.
- May also be associated with certain medications or with the direct effect of the virus on the brain.

Possible causes:
- Vulnerable and are more likely to engage in risky behaviour such as unprotected sex and substance abuse.
- Also at risk of being sexually abused.

Figure 10: Mental health problems: cause and effect of HIV (adapted from Stoloff and Joska15)

24.3 HIV and adolescents: increased vulnerability to mental health problems16,17

HIV-positive children and adolescents display a higher rate of behavioural, social, cognitive and emotional problems in comparison to their uninfected peers. Causes are complex and varied and include:
- pre-morbid mental conditions
- effects of the virus on the central nervous system (CNS)
- psychological impact of living with HIV
- breakdown of family structure as a result of multiple losses
- side effects of medication
- consequences of social stigma and discrimination.
24.4 Importance of addressing mental health issues in adolescents living with HIV\textsuperscript{1,18,19,20}

Addressing the mental health issues for adolescents living with HIV is central to a comprehensive approach to HIV management. Poor management of mental health can result in a range of social and health problems and ultimately compromise HIV health outcomes, as identified below.

- **Delayed initiation onto ART**: Attention is diverted to the person’s mental condition and behavioural problems.
- **Poor adherence**: Adolescents with mental health and substance use problems are more likely to forget or decide not to take their medication.
- **Increased progression of HIV**: Mental health influences the course of HIV, e.g., research shows that depression may lead to HIV disease progression over time.\textsuperscript{21}
- **Increase in risky behaviour**: Mental health problems may result in diminished responsibility and increased risk behaviour, such as drug and alcohol abuse, and the lack of ability or willingness to practice safer sex (with resultant unintended pregnancies, HIV and STI transmission).
- **Co-morbidity of mental problems**: The presence of one mental illness predisposes a person to the onset of other mental disorders, e.g. it is not unusual to see a depressed adolescent who also abuses alcohol or drugs, which can result in psychosis. Similarly, people who experience mental health problems, e.g. depression, are more likely to abuse drugs or alcohol and to engage in risky sexual behaviour.
- **Social problems**: The consequences of untreated mental illness may be far reaching and may interfere with ability to attend school, work and to form social relationships.
- **Increased risk of suicidality**: Untreated mental illness can result in suicide.

24.5 Factors influencing mental health in adolescents living with HIV\textsuperscript{22}

The mental health of adolescents living with HIV is affected by several factors, including levels of stigma and self-stigma, timing and mode of transmission.

(i) **Stigma and self-stigma**

People living with HIV are exposed to stigma and discrimination (Box 26). ‘Self-stigma’, or ‘internalised stigma’, is particularly common in adolescents. If adolescents internalise stigma regarding their diagnosis they are more likely to become depressed, deny their condition, be non-adherent and potentially engage in risk-taking behaviour. Self-stigma also impacts on disclosure, where adolescents fear disclosing their status to others and feel shame regarding their condition.

(ii) **Timing and mode of transmission: perinatally and non-perinatally infected adolescents**

The timing and mode of transmission influence the way adolescents respond to living with HIV, with implications for their mental health. There is a difference in the experiences and challenges between those infected perinatally and those infected non-perinatally.
Adolescents infected perinatally have lived with HIV for a significantly longer period than those recently infected. Many adolescents who contracted the virus from their mothers are orphaned by the time they reach adolescence and have had to deal with death and grief early in their lives. These adolescents may experience complex and unresolved feelings about loss, family disruption and anger at their HIV status which may never have been adequately dealt with. They will generally have been on ART for many years and have a relationship with the health service. These adolescents have been exposed to the virus since birth, which has the potential to cause a direct effect on the CNS.

- There is a subset of adolescents who are perinatally infected but may only be diagnosed with HIV in adolescence: they may have been chronically ill for years, without a cause being identified. These adolescents will also have to deal with the news of their diagnosis and cope with learning to navigate the health system. Encouragement and support are needed to build trusting relationships with healthcare providers.

Adolescents infected non-perinatally need to deal with discovering and learning to live with their HIV status and the issues related to how they contracted HIV, which could be from exposure to infected blood, unprotected consensual sex, sexual abuse or rape. They need to learn the importance of keeping appointments and adherence, and healthcare providers will need to understand the moods, vulnerabilities and patterns of behavior particular to adolescents, including adolescents from key or marginalised populations.

(iii) Developmental factors

*Understanding the interplay between adolescent developmental phases and a young person living with HIV is key to successful mental health outcomes.* As an example, one of the primary developmental tasks of adolescence is the establishment of one’s identity. This results in an increasing need for independence and may result in the adolescent being in denial about their HIV infection, and possible related conditions, rebellion against authority figures and questioning of issues related to the management and treatment of HIV. This may affect the adolescent client’s relationship with healthcare providers, and other issues such as adherence to treatment. Developmental factors that influence mental health are summarised in Figure 11.

*The age of the client may also influence presentation of mental health problems:* For example, younger clients may act out or complain of physical symptoms, such as stomach ache, to flag an underlying problem, while older adolescent clients may present issues through behaviour-related problems such as running away from home, disruption in the classroom, truancy, job loss, violence or substance abuse.

*Adolescents living with HIV may have an associated neurocognitive disorder:* This will have an impact on their normal cognitive and psychological development. School-related and behavioural difficulties may negatively affect self-esteem and social relationships. This will have an impact on their mental wellbeing.
Figure 11: Interaction between psychosocial, physical development and mental health

- Interruption in schooling due to illness, high mobility
- Delays in growth, e.g. under weight, smaller, stunted; delays in puberty
- ART-related physical changes e.g. lipodystrophy
- Neurological consequences of prolonged unsuppressed HIV (perinatally infected)
- Striving for independence and identity: impacts on adherence
- Complexity of adherence with adolescents with chronic conditions
- Fear about disclosure, future
- Effect of stigma and self-stigma
- Self-image, self-esteem affected by physical differences and delays

Adolescent living with HIV
Working with mental health and adolescents: risk and protective factors

A useful process for understanding and working with adolescents living with HIV is to identify potential risk and protective factors (Table 20). Risk factors refer to dynamics that increase the probability of mental health difficulties, while protective factors refer to aspects that mitigate the effects of risk exposure.

When working with adolescents attention needs to be paid to the:

- reduction of risk factors
- building and promotion of protective factors.

This shifts the focus from a problem-centred to a strength-based approach that is empowering and positive.

Table 20: Selected risk and protective factors for mental health of adolescents

<table>
<thead>
<tr>
<th>Domain</th>
<th>Risk factors</th>
<th>Protective factors</th>
</tr>
</thead>
<tbody>
<tr>
<td>Biological</td>
<td>• HIV infection.</td>
<td>• Age-appropriate physical development.</td>
</tr>
<tr>
<td></td>
<td>• Congenital malformations.</td>
<td>• Good physical health.</td>
</tr>
<tr>
<td></td>
<td>• Genetic tendency to psychiatric disorder.</td>
<td></td>
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<tr>
<td></td>
<td>• Malnutrition.</td>
<td></td>
</tr>
<tr>
<td></td>
<td>• Other illness.</td>
<td></td>
</tr>
<tr>
<td>Psychological</td>
<td>• Psychiatric disorder.</td>
<td>• Ability to learn from experiences (resilience).</td>
</tr>
<tr>
<td></td>
<td>• Maladaptive personality traits.</td>
<td>• Good self-esteem.</td>
</tr>
<tr>
<td></td>
<td>• Effects of emotional and sexual abuse, and neglect.</td>
<td>• High level of problem-solving ability.</td>
</tr>
<tr>
<td></td>
<td>• Self-stigma.</td>
<td>• Effective social skills.</td>
</tr>
<tr>
<td></td>
<td>• Orphanhood.</td>
<td>• Supportive peer group.</td>
</tr>
<tr>
<td></td>
<td>• Ability to learn from experiences (resilience).</td>
<td>• Supportive parent/caregiver.</td>
</tr>
<tr>
<td>Social: Family</td>
<td>• No family.</td>
<td></td>
</tr>
<tr>
<td></td>
<td>• Deceased parents.</td>
<td></td>
</tr>
<tr>
<td></td>
<td>• Divorced parents.</td>
<td></td>
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<tr>
<td></td>
<td>• Family conflict and domestic violence.</td>
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<tr>
<td></td>
<td>• Poor family management.</td>
<td></td>
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<tr>
<td></td>
<td>• Poor family discipline.</td>
<td></td>
</tr>
<tr>
<td>Social: School</td>
<td>• Academic failure.</td>
<td>• Opportunities for involvement in school activities.</td>
</tr>
<tr>
<td></td>
<td>• Learning disability.</td>
<td>• Supportive and safe school environment.</td>
</tr>
<tr>
<td></td>
<td>• Poor commitment to schooling.</td>
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</tr>
<tr>
<td></td>
<td>• Inadequate/inappropriate educational provision.</td>
<td></td>
</tr>
<tr>
<td>Social: Community</td>
<td>• Community disorganisation.</td>
<td>• Connectedness to community.</td>
</tr>
<tr>
<td></td>
<td>• Exposure to violence.</td>
<td>• Opportunities for constructive use of leisure.</td>
</tr>
<tr>
<td></td>
<td>• Effects of discrimination.</td>
<td>• Safe environment.</td>
</tr>
<tr>
<td></td>
<td>• Poverty.</td>
<td>• Positive role models.</td>
</tr>
<tr>
<td></td>
<td>• Mobility/access/transport.</td>
<td>• Legislation that is favourable to development.</td>
</tr>
<tr>
<td></td>
<td>• Transition/urbanisation.</td>
<td>• Appropriate gender equity norms.</td>
</tr>
<tr>
<td></td>
<td>• Transactional or intergenerational sex.</td>
<td></td>
</tr>
</tbody>
</table>
24.7 Screening for mental health

Although the identification and diagnosis of mental illness requires specialised training and experience, healthcare providers can identify signs of mental health problems in many ways. Comprehensive HIV care should include screening for possible mental health problems during routine visits (including the client’s recent and past history), basic observations and routine psychosocial assessments. A framework for screening is provided in Appendix 10.

**Basic mental health screening**

Questions to explore when integrating mental health screening into consultations:

- How are things in your life at present?
- How have things been since you were last at the clinic/during the last month?
- Are there any problems?
- How do you feel about and respond to the problems?
- What support do you have?
- How are you coping?
- What support do you need to cope with what’s happening in your life?
The main mental health conditions manifesting in adolescents living with HIV are discussed in this chapter. This includes a brief description, suggestions for screening and useful interventions.

- **A broad spectrum**: There is a broad spectrum of conditions when dealing with mental health, spanning everyday challenges and upheavals, psychosocial problems, mental health challenges and acute mental illness. The very nature of adolescence with accompanying behaviour changes and mood swings makes diagnosis difficult. Some conditions are easily managed through support and counselling, while others which result in impaired functioning or harm to themselves and/or others will need more specialised interventions.

- **Referrals**: In South Africa there are minimal referral points for the management of mental health problems and therefore healthcare providers, including doctors, nurses, social and auxiliary workers, community health workers and counsellors, frequently need to render counselling and support themselves. Some adolescents will require referral and it is important to collate information regarding referral and support resources within the catchment area of the relevant clinic. Referral systems and networks need to be established, ensuring that referral processes are youth-friendly. This includes: making contact with the referral personnel, referring to a named provider where possible, and giving clear directions for how to access the service. It is always preferable to accompany the adolescent to the referral point if possible.

- **Assessment**: The healthcare provider needs to gauge the severity of the condition. Psychosocial support and counselling will assist the adolescent but certain conditions require clinical interventions, and high risk conditions require specialised observation and management.

- **Psychosocial support can go a long way**: Often the manifestation of mental health problems provides an opportunity to work through a range of feelings and issues that the adolescent needs to deal with in moving from childhood into adulthood. Working through feelings and issues can, in the longer term, have positive, constructive outcomes in the personal journey of the adolescent as they come to terms with living with HIV.

- **Importance of communication**: This underpins any screening, diagnosis and management cycle. Rapport with adolescents is vital for a successful intervention, from screening and diagnosis to treatment.

### 25.1 Depression

Depression is one of the most common mental illnesses found in adolescents living with HIV. Depression is a continuum, ranging from sadness to an extreme inability to function. Clinical depression is a mood disorder in which feelings of sadness, loss and anger, lack of motivation and impaired functioning last for weeks or longer.

#### (i) Signs and symptoms

Possible signs of depression are summarised in Box 27.
Working with adolescents living with HIV: A handbook for healthcare providers

Mental Health

PART B. SECTION 7

Box 27: Possible signs and symptoms of depression

| General features of clinical depression                                                                 |
| Five (or more) of the following symptoms have been present during the same 2-week period and represent a change from previous functioning: |
| • Depressed mood for most of the day.                                                                     |
| • Loss of interest or pleasure in all or most activities.                                                |
| • Significant unintentional weight loss or gain.                                                         |
| • Insomnia or sleeping too much.                                                                         |
| • Agitation or psychomotor retardation noticed by others (irritability in children and adolescents).     |
| • Fatigue or loss of energy.                                                                             |
| • Feelings of worthlessness or excessive guilt.                                                          |
| • Diminished ability to think or concentrate, or indecisiveness.                                         |
| • Recurrent suicidal thoughts (this is particularly the case with adolescents).                          |

At least one of the symptoms is either depressed mood, or loss of interest or pleasure.

| Features to look out for in adolescents                                                                |
| • Negative thinking, hopelessness, low energy, lack of motivation, deterioration in schoolwork, dropping out of activities that were previously enjoyed (e.g. sport, extramural activities), headaches, sleeping a lot or inability to sleep, social withdrawal, isolating themselves, talk of suicide. |
| • Weight loss or weight gain, runs away or talks of it, low self-esteem, self-injury.                    |
| • Interruption in adherence to ART or other medication. Explore issues such as anger or denial about living with HIV. |
| • Depression can be the cause of or the result of alcohol and other substance abuse.                    |
| • Uncharacteristic behaviour, such as being confrontational, becoming reckless or developing school-related problems. |
| • Irritability and angry behaviour, instead of appearing sad or tearful. This should be kept in mind during the interview process. |

(ii) Screening

Screening questions for adolescents are suggested in Box 28.

Box 28: Screening questions for depression

Questions to explore when screening the adolescent for depression

• Do you feel tearful, sad or down most of the time? How long have you felt this way?
• Do you have feelings of worthlessness, or guilty feelings?
• Do you have difficulty taking pleasure in the things you used to enjoy?
• Do you have problems with sleep, eating or your sexual desire?
• Have you ever been diagnosed as having depression, or taken antidepressant medication?
• Important – suicidal screening can include:5,10,11
  ○ In the past month did you wish you were dead?
  ○ Did you want to hurt yourself?
  ○ Did you think of killing yourself?
  ○ Did you think of a way to kill yourself? Did you try to kill yourself?

(iii) Depression: interventions by the healthcare worker

✔ Counselling.
✔ Check for alcohol and substance abuse.
✔ Review HIV history, ART (adherence, changes in regimen).
✔ Always screen for suicidal ideation and assess the risk (Appendix 11).
✔ Referral to a psychologist for therapy as required.
✔ Consider medical management (antidepressants). Refer if necessary.
✔ Consider referral for admission if showing signs of self-harm, suicide, or violence towards others.
A note on bereavement and grief

Many adolescents living with HIV have lost significant loved ones. For some, multiple losses may have been endured over time. These losses could have led to significant grief that has not been addressed.

Grief is not a mental disorder, as it is an expectable and culturally accepted response to the event of loss or death of a loved one. However, the manner in which some individuals react to grief may present with symptoms characteristic of depression.

The difference between grief or bereavement and depression is described in Box 29.

<table>
<thead>
<tr>
<th>Grief/bereavement</th>
<th>Depression</th>
</tr>
</thead>
<tbody>
<tr>
<td>Guilt is focused on aspect of loss.</td>
<td>Guilt is preoccupied with a negative self-image.</td>
</tr>
<tr>
<td>Have moments of pleasure or happiness.</td>
<td>Feelings of emptiness and despair are constant.</td>
</tr>
<tr>
<td>Preoccupation with deceased.</td>
<td>Preoccupation with self.</td>
</tr>
<tr>
<td>Not demoralising or humiliating.</td>
<td>Demoralising and humiliating.</td>
</tr>
<tr>
<td>Overt expression of anger.</td>
<td>Anger not as pronounced.</td>
</tr>
<tr>
<td>Diminishes in intensity over time.</td>
<td>Consistent sense of depletion.</td>
</tr>
<tr>
<td>Suicidal gestures are rare.</td>
<td>Suicidal gestures are not unusual.</td>
</tr>
<tr>
<td>Responsive to support.</td>
<td>Unresponsive to support.</td>
</tr>
<tr>
<td>Elicits sympathy, concern and desire to embrace.</td>
<td>Elicits irritation, frustration and a desire to avoid.</td>
</tr>
<tr>
<td>Usually functions at work, home and/or school.</td>
<td>Inability to function at work, home, and/or school.</td>
</tr>
</tbody>
</table>

25.2 Anxiety

Anxiety disorders refer to prolonged and intense anxiety and worry. There is a broad continuum of an anxious state, ranging from everyday worries and concerns preoccupying many adolescents, to more excessive anxiety, manifested by physical and behavioural symptoms, such as panic attacks. While many people cope with anxiety, for others it can be incapacitating.

Adolescence is a time of introspection and worry – about school, friendships, love, family and living with HIV – which makes anxiety disorders difficult to diagnose. These are different from day-to-day worrying in that the symptoms are prolonged, more intense (fear, panic) and the person has difficulty in controlling the anxiety and worry (Box 30).
### Mental Health

#### PART B. SECTION 7

(i) Signs and symptoms

<table>
<thead>
<tr>
<th>Box 30: Possible signs and symptoms of anxiety</th>
</tr>
</thead>
<tbody>
<tr>
<td><strong>General features of anxiety</strong></td>
</tr>
<tr>
<td>The presence for most days over the previous 6 months of three or more (only one for children) of the following symptoms:</td>
</tr>
<tr>
<td>• <strong>Physical</strong>: increased pulse and heartbeat, dizziness, nausea, tension, dry mouth, tingling or numbness in hands or feet, insomnia.</td>
</tr>
<tr>
<td>• <strong>Cognitive</strong>: difficulty in concentration, repetitive thoughts, feelings of fear (mostly irrational), panic, dread.</td>
</tr>
<tr>
<td>• <strong>Behavioural</strong>: irritability, tearful, avoidance of situations, tiredness, poor concentration, restlessness, repetitive actions.</td>
</tr>
<tr>
<td><strong>Manifestations include:</strong></td>
</tr>
<tr>
<td>• <strong>Generalised anxiety disorder (GAD)</strong>: excessive, persistent and unrealistic worry about everyday problems, lasting for a period of 6 months or longer.</td>
</tr>
<tr>
<td>• <strong>Panic attacks</strong>: recurrent attacks of overwhelming anxiety, for no apparent reason.</td>
</tr>
<tr>
<td>• <strong>Phobias</strong>: excessive fears of specific objects, e.g. spiders, or situations, e.g. flying.</td>
</tr>
<tr>
<td>• <strong>Obsessive compulsive disorder (OCD)</strong>: repetitive thoughts or images that are disturbing and that the client is unable to control. They sometimes also have rituals or other repetitive actions they are unable to stop themselves from doing.</td>
</tr>
<tr>
<td><strong>Features to look out for in adolescents</strong></td>
</tr>
<tr>
<td>• Self-reported feelings, such as a feeling of being overwhelmed, stressed out, distressed, fearful.</td>
</tr>
<tr>
<td>• Daily functioning impaired, e.g. deterioration of schoolwork or work performance.</td>
</tr>
<tr>
<td>• Fearfulness and insecurity: nightmares, fear of the dark, fear of being alone.</td>
</tr>
<tr>
<td>• Physical manifestations such as panic attacks, shortness of breath, increase in skin conditions (e.g. eczema, acne), medical problems presenting as a call for help (e.g. headaches).</td>
</tr>
<tr>
<td>• Behavioural manifestations such as a change in sleeping patterns, repetitive behaviour not previously shown, refusal to eat, withdrawal from school/social activities.</td>
</tr>
<tr>
<td>• Anxiety may be the cause or result of alcohol and other substance abuse.</td>
</tr>
</tbody>
</table>
(ii) Screening

The symptoms cause ‘clinically significant distress’ or problems functioning in daily life. Some people can have many of the aforementioned symptoms and cope with them well enough to maintain a reasonable level of functioning. Screening questions for anxiety are suggested in Box 31.

Box 31: Screening questions for anxiety

<table>
<thead>
<tr>
<th>Questions to ask when screening the adolescent for anxiety:</th>
<th>If the client answers ‘yes’, continue by asking:</th>
</tr>
</thead>
<tbody>
<tr>
<td>• Do you often feel worried or stressed? What causes these feelings?</td>
<td>• How long have you been feeling this way?</td>
</tr>
<tr>
<td>• Do you feel that you can cope with your current stress levels?</td>
<td>• Does your worrying affect your ability to concentrate on schoolwork and other activities?</td>
</tr>
<tr>
<td>• How is your eating? Sleeping? Schoolwork? How are things with your friends?</td>
<td>• Does worrying affect your ability to sleep, or eat?</td>
</tr>
</tbody>
</table>

Note: Remember to observe the client’s appearance and behaviour as well.

(iii) Anxiety: interventions by the healthcare provider

- Symptoms may be managed through psychosocial counselling and support strategies (relaxation, coping mechanisms to deal with anxiety, reassurance, and communication with school or employers).
- Check for alcohol and other substance abuse.
- Review the client’s HIV history, ART (adherence, dosing changes in regimen, new medication).
- Referral to psychologist for therapy if necessary and where available.
- Consider medical management, e.g. antidepressants, may need tranquilisers.
- Referral to specialist care if unresponsive to interventions and if functioning impaired.

25.3 Trauma

Trauma is a life-threatening event which a person has experienced or witnessed, either in the present or in the past. Examples include rape (in both male and female adolescents), abuse, violence, accidents or being exposed to information that causes trauma.

As with other mental health problems, not everyone will need counselling immediately after a traumatic event or in the longer term. For others, however, the impact of trauma which has not been dealt with can be far-reaching and can affect both mental health and behaviour in the short and long term.

Post-traumatic stress disorder (PTSD) is a form of trauma common to adolescents living with HIV. PTSD refers to a person who has experienced, witnessed, or been confronted with an event that involves actual or threatened death, harm or injury to themselves or to others, with resultant shock, fear, helplessness or horror.
### Box 32: Possible signs and symptoms of trauma\textsuperscript{17,18}

<table>
<thead>
<tr>
<th>General features of trauma</th>
<th>Features to look out for in adolescents</th>
</tr>
</thead>
<tbody>
<tr>
<td>Shock, fear, irritability, and insecurity (especially toward circumstances similar to where and how the trauma occurred), nightmares, flashbacks, poor concentration, heightened anxiety.</td>
<td>- Daily functioning impaired, e.g. deterioration of schoolwork or work performance, disorganised, agitated behaviour.</td>
</tr>
<tr>
<td><strong>PTSD</strong> – in addition to the above, the following may be manifested:</td>
<td>- Fearfulness and insecurity: nightmares, fear of the dark, fear of being alone.</td>
</tr>
<tr>
<td>- The traumatic event may be re-experienced through recurrent or intrusive recollections of the event, recurrent dreams, or cues that resemble the event, and trigger a distressed response.</td>
<td>- Internalised behaviour where feelings are repressed, e.g. depressed, sad, fearful, shame.</td>
</tr>
<tr>
<td>- Avoidance of situations, places or people associated with the event, avoidance of emotions, avoidance of discussing the event or associated feelings.</td>
<td>- Externalised behaviours, 'acting out', e.g. disruptive, dishonest, aggressive, violent.</td>
</tr>
<tr>
<td>- Heightened arousal, hypervigilance or being easily startled. Sleep disturbances may occur. There may be associated aggressive or reckless behaviour (‘fight or flight’).</td>
<td>- Alcohol and substance abuse.</td>
</tr>
<tr>
<td>- Negative mood and thoughts, which may include a distorted sense of blame toward self or others, or social withdrawal.</td>
<td>- Self-harm.</td>
</tr>
</tbody>
</table>

#### Mental Health

#### PART B. SECTION 7

(i) **Signs and symptoms**

Possible signs and symptoms of trauma are outlined in Box 32.

![TRAUMA diagram](image)
(ii) **Screening**

Screening questions for trauma are suggested in Box 33.

**Box 33: Screening questions for trauma**

<table>
<thead>
<tr>
<th>Questions to ask when screening the adolescent for trauma:</th>
<th>If the client answers ‘yes’, continue by asking:</th>
</tr>
</thead>
<tbody>
<tr>
<td>• Have you ever had a traumatic or upsetting experience that distressed you deeply? or</td>
<td>• Do you think about it?</td>
</tr>
<tr>
<td>• I know you experienced X last year/month (whenever it occurred), would you like to discuss it?</td>
<td>• Would you like to share what happened after xxx?</td>
</tr>
</tbody>
</table>

(iii) **Trauma: interventions by the healthcare provider**

- Psychosocial counselling and support strategies (it is important to discuss the event and its effect in a safe environment) e.g. relaxation, coping mechanisms to deal with triggers, reassurance, asking the client to write about or draw their experience.
- Check for alcohol and other substance abuse.
- Referral to psychologist for therapy if necessary and where available.
- Consider medical management (e.g. tranquilisers, antidepressants) based on the clinical picture.
- Referral to specialist care if unresponsive to interventions and if functioning impaired.
25.4 Alcohol and substance abuse\textsuperscript{19,20,21,22}

Experimentation is a normal part of adolescence. However, when alcohol or substance use impacts negatively on the life of the adolescent and those around them, it warrants attention.

In South Africa, some commonly used drugs are dagga (cannabis/marijuana/ganja/‘weed’/‘dope’), mandrax (buttons/white pipe), cocaine, crack (rocks/street base), crystal methamphetamine (tik/speed/rocks/ice), heroine and ecstasy.\textsuperscript{23} A recent South African survey found alcohol to be the most commonly used substance among adolescents, followed by tobacco/cigarettes and dagga (cannabis/marijuana/ganja/‘weed’/‘dope’).\textsuperscript{24} Drug interactions between ARV, alcohol and substances (narcotics) are summarised in Table 21.

Harmful drinking among young people is an increasing concern in many countries. It reduces self-control and increases risky behaviour. Harmful drinking is a primary cause of injuries (including those due to road traffic accidents), violence (domestic violence in particular) and premature death.

- **Adolescents who abuse alcohol are more likely than their non-drinking counterparts to be suicidal and to attempt suicide.**
- **Binge drinking is most common among 15–24 year olds.**
- **Adolescents living with HIV are vulnerable to alcohol and other substance abuse:** Reasons are varied and include the need to boost confidence, the need to mask feelings, peer pressure and conformity. Alcohol and substance abuse may be the cause of other mental health problems, or mental health problems may be the reason the young person turns to alcohol and substances to self-medicate.
- **Substance abuse can have a negative effect on health outcomes in people living with HIV, and can result in poor adherence to treatment, HIV disease progression, lower CD4 cell counts and opportunistic infections.\textsuperscript{25}

(i) Signs and symptoms

Possible signs and symptoms of substance abuse are summarised in Box 34.
Box 34: Possible signs and symptoms of alcohol and other substance abuse

### General features of alcohol and substance abuse
Experimentation and occasional use is different to addiction or a disorder, when one or more of the following occur within a 12-month period.26

- As a result of substance use the following are noted: poor performance at school or work, failure to fulfil obligations at home, absenteeism, expulsion, neglect in personal appearance.
- Recurrent substance use in situations that are potentially dangerous (e.g. driving or use of machinery when impaired by substance use).
- As a result of use of substances: trouble with the law, such as shoplifting, disorderly conduct, violence.
- Continued substance use in spite of the problems it causes and in spite of negative consequences, including punishment.

### Features to look out for in adolescents
- Daily functioning impaired, e.g. deterioration of schoolwork or work performance, forgetful.
- Changes in eating habits, especially reduced eating and associated weight loss.
- Red eyes, dilated pupils, shaking.
- Changes in sleeping patterns (significantly more or less), disorganised, and agitated behaviour.
- Theft from home, money or goods disappearing.
- Change in personality, evasive, secretive behaviour, nervousness, withdrawal.
- Changes in patterns of socialising, becomes more isolated, change in friends.
- Aggression, violence, defiance.
- Changes in relationship with healthcare: poor adherence to treatment, missing of appointments, defensiveness.
- Comorbidity: depression, anxiety, trauma, PTSD, other psychiatric problems.

(ii) Screening

Box 35 provides examples of issues to explore when screening an adolescent for substance abuse disorders. See Appendix 12 for an example of a screening tool.

Box 35: Screening questions for alcohol and other substance abuse

- Do you/your friends ever drink alcohol? How often do you/they drink alcohol?
- When you drink, how many alcohol units* do you consume?
- Do you/your friends ever smoke dagga/cannabis/marijuana/ganja/‘weed’/‘dope’? How often do you/they do this?
- Do you/your friends use any other substances (including over-the-counter and prescription medicines) to get high?

Definitions of units:28

1 standard drink = 1 can ordinary beer (e.g. 330 ml at 5% ABV*) or
  1 single shot of spirits (whiskey, gin, vodka) (40 ml at 40% ABV) or
  1 glass of wine (140 ml at 12% ABV) or
  1 small glass of sherry (90 ml at 18% ABV) or
  1 small glass of liqueur or aperitif (70 ml at 25% ABV)

*Alcohol by volume
(iii) Substance abuse: interventions by the healthcare provider

- Provide general education and counselling on risk reduction, behaviour change and the potential negative effects of substance abuse on their health.
- Work together with family, schools, employers, where possible: set goals and boundaries and agree on consequences if the client fails to keep the terms of agreement (work these out in a mutually agreed ‘contract’ with the adolescent).
- Refer to more specialised assistance, where possible (e.g. websites and help lines for SANCA (South African National Council on Alcoholism), Alcoholics Anonymous, Narcotics Anonymous), as substance addiction in adolescents is challenging.
- Provide ongoing support and follow-up at every visit.

Table 21: Summary of substance use, potential harm/side effects and impact in relation to HIV and ART

<table>
<thead>
<tr>
<th>Substance</th>
<th>Clinical problems</th>
<th>Drug interactions</th>
<th>Effect on adherence</th>
<th>Metabolism (potential for drug interactions)</th>
</tr>
</thead>
<tbody>
<tr>
<td>Alcohol</td>
<td>Causes physical and psychological dependence. May also cause hepatotoxicity.</td>
<td>May increase ABC levels (unclear whether clinically significant).</td>
<td>Present.</td>
<td>Metabolised by alcohol dehydrogenase (same as ABC).</td>
</tr>
<tr>
<td>Benzodiazepines e.g. “Valium” (diazepam)</td>
<td>Sedation. May cause physical and psychological dependance.</td>
<td>Certain benzodiazepines may lead to excessive sedation when used with PIs or EFV.</td>
<td>Present.</td>
<td>Metabolised by P450 (CYP3A4) and drugs which affect this system may have interactions.</td>
</tr>
<tr>
<td>Amphetamines e.g. “Ecstasy” (MDMA), “Tik”</td>
<td>Stimulant. Causes psychological dependance.</td>
<td>RTV may increase amphetamine levels and precipitate toxicity (limited data). RTV may increase levels of MDMA to near fatal levels (case reports) even in low doses used for boosting.</td>
<td>Present.</td>
<td>Metabolised via CYP2D6, which may be inhibited by PIs (especially RTV).</td>
</tr>
<tr>
<td>Heroin</td>
<td>Sedative. Causes physical and psychological dependance.</td>
<td>None documented.</td>
<td>Present.</td>
<td>Metabolised to morphine then to active metabolites via glucuronidation.</td>
</tr>
<tr>
<td>Barbiturates e.g. phenobarbitone</td>
<td>Sedative. May cause physical and psychological dependance.</td>
<td>EFV and NVP are also potent inducers of CYP3A4 (this may lead to increased clearance).</td>
<td>Present.</td>
<td>Potent inducer of CYP3A4, part of the P450 system.</td>
</tr>
</tbody>
</table>

25.5 Attention deficit hyperactivity disorder (ADHD)

ADHD is one of the most commonly occurring neurodevelopmental disorders in children and adolescents. There appears to be an increased prevalence of ADHD in children and adolescents who are HIV-positive. This is not necessarily reflected in WHO clinical staging for HIV, and behavioural problems may be present in children who are clinically well and stable. Diagnostic criteria for ADHD are provided in Box 36.
(i) Signs and symptoms

ADHD is considered where symptoms have been present before the age of 12 years and have lasted for more than 6 months. ADHD can only be diagnosed where the symptoms could not be better accounted for by another mental disorder. Other conditions, including the use or abuse of substances, depression or anxiety, may produce symptoms that mimic ADHD. For this reason, referral for diagnosis by an experienced healthcare provider is recommended.

**Box 36: Diagnostic criteria for ADHD**

People with ADHD show a persistent pattern of inattention and/or hyperactivity-impulsivity that interferes with functioning or development.

- **Inattention:** Six or more symptoms of inattention for children up to age 16, or five or more symptoms for adolescents 17 years and older and adults; symptoms of inattention have been present for at least 6 months, and are inappropriate for developmental level.
  - Often fails to give close attention to details or makes careless mistakes in schoolwork, at work, or with other activities.
  - Often has trouble holding attention on tasks or play activities.
  - Often does not seem to listen when spoken to directly.
  - Often does not follow through on instructions and fails to finish schoolwork, chores, or duties in the workplace (e.g. loses focus, gets side-tracked).
  - Often has trouble organising tasks and activities.
  - Often avoids, dislikes, or is reluctant to do tasks that require mental effort over a long period of time (such as schoolwork or homework).
  - Often loses things necessary for tasks and activities (e.g. school materials, pencils, books, tools, wallets, keys, paperwork, eyeglasses, mobile telephones/cellphones).
  - Often distracted.
  - Often forgetful in daily activities.

- **Hyperactivity and impulsivity:** Six or more symptoms of hyperactivity-impulsivity for children up to age 16, or five or more symptoms for adolescents 17 and older and adults; symptoms of hyperactivity-impulsivity have been present for at least 6 months to an extent that is disruptive and inappropriate for the person’s developmental level.
  - Often fidgets with or taps hands or feet, or squirms in seat.
  - Often leaves seat in situations when remaining seated is expected.
  - Often runs about or climbs in situations where it is not appropriate (adolescents or adults may be limited to feeling restless).
  - Often unable to play or take part in leisure activities quietly.
  - Is often ‘on the go’ acting as if ‘driven by a motor’.
  - Often talks excessively.
  - Often blurs out an answer before a question has been completed.
  - Often has trouble waiting their turn.
  - Often interrupts or intrudes on others (e.g. butts into conversations or games).

*In addition, the following conditions must be met:*

- Several inattentive or hyperactive-impulsive symptoms were present before age 12 years.
- Several symptoms are present in two or more settings (e.g. at home, school or work; with friends or relatives; in other activities).
- There is clear evidence that the symptoms interfere with, or reduce the quality of, social, school, or work functioning.
- The symptoms do not happen as part of those associated with schizophrenia or another psychotic disorder. The symptoms are not better explained by another mental disorder (e.g. mood disorder, anxiety disorder, dissociative disorder, or a personality disorder).
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(ii) **ADHD: interventions by the healthcare provider**

- Psychosocial counselling and support, focusing on self-awareness and self-regulation.
- Counsel the parent/caregiver, focusing on improving parenting skills and giving advice on how to create a structured home environment.
- Consider medication, e.g. methylphenidate or similar, to control symptoms of the disorder.
- Referrals may be required: management of ADHD is based on a multidisciplinary approach (this may involve occupational therapy and consulting a clinician experienced in the management of neurodevelopmental conditions).
- Screen for associated substance use and other mental health problems as these may co-exist.

25.6 **Behavioural disorders**\(^{29,36,37,38}\)

Behavioural disorders are marked by socially unacceptable behaviour that interferes with an adolescent’s ability to carry out daily activities, and negatively affects their social relationships and effective functioning at school or at home. This generally includes argumentative behaviour, defiance of authority, temper tantrums, threatening or aggressive behaviour, stealing, bullying, lying and violations of rules.

The healthcare worker should take a careful history, preferably from the adolescent as well as from the parent/caregiver or other collateral source. Specific behaviour may not constitute a disorder and may be related to psychosocial issues or another underlying mental health issue, such as substance use or abuse, or depression.

(i) **Suspected behavioural disorders: interventions by the healthcare provider**

- Psychosocial counselling and support, focusing on self-awareness and self-regulation.
- Counsel the parent/caregiver, focusing on improving parenting skills and giving advice on how to create a structured home environment.
- Work with the carer, family and school, where possible.
- Review the client’s HIV history, recent changes in disease status, ART regimen (adherence, any dosing changes or new medication).
- Screen for HIV encephalopathy (HIVE), which may present with behavioural issues.
- Screen for underlying mental health problems.
- Referral to a psychiatrist may be necessary.
- Provide referrals to local support services as required.

25.7 **Psychotropic drugs and HIV**\(^{39,40,41,42}\)

As far as possible, the use of psychotropic drugs in adolescents should be discussed with a clinician experienced in the management of neurological and psychiatric disorders in this particular population.

- For clients on ART it is essential to minimise possible drug interactions. Where these drugs are prescribed by different providers, good communication will assist in avoiding clinical errors.
- Specific dosing and initiation criteria have not been included here: it is recommended that the lowest effective dose be given as HIV-positive individuals may be more prone to drug side effects. A low dose should be initiated and titrated to effect: the client’s age, weight and physical development should be taken into account.
(i) ARVs and interactions

Efavirenz (EFV) and interactions:
- EFV has psychotropic effects.
- EFV is best avoided in clients with current severe neuropsychiatric illness.\(^{43}\)
- EFV has been associated with insomnia and nightmares, and has been reported to cause mood change.\(^{44}\)

Due to the above, it is advisable to prescribe an alternative drug in patients with active neuropsychiatric illness.

(ii) Psychotropic drugs and interactions

(a) Anticonvulsants: for management of seizures and mood stabilisation.

Recommended:
- Sodium valproate is the preferred anticonvulsant for use in HIV-positive clients. Levels should be monitored as clinically indicated.
- Lamotrigine may also be used, but the client may eventually require higher doses if on an RTV-containing ART regimen. Lamotrigine should be initiated by a psychiatrist or neurologist.

To be avoided:
- Many of the other anticonvulsants affect blood levels of NNRTIs and PIs and should not be used. Carbamazepine in particular decreases the blood levels of both NNRTIs and PIs.

(b) Antipsychotics: for management of psychosis or psychotic features.
- HIV-positive clients have a higher risk of extrapyramidal side effects, especially with older ‘typical’ antipsychotics such as haloperidol.
- These drugs may be used but the healthcare provider should remain alert for possible side effects. Low doses should be initiated and increased slowly.

Recommended:
- Low dose atypical antipsychotics such as risperidone are preferred. However, these drugs should be initiated by a psychiatrist and are not available at all levels of care.
- Depot (injectable) antipsychotics may be used where clients have no other contraindications and are agreeable to this administration.

To be avoided:
- Clozapine should be avoided, unless in consultation with a specialist. Levels may increase with concomitant use of a ritonavir-boosted PI, which could precipitate seizures and other adverse effects. Neutropenia may also occur as a side effect.

(c) Antidepressants: include the selective serotonin reuptake inhibitors (SSRIs) (usually used for depression and anxiety-related disorders) and the tricyclic antidepressants (TCAs) (usually used to manage neuropathic pain or refractory depression).
- Fluoxetine and paroxetine (both SSRIs) should be used with caution in conjunction with ART: both may interact with PIs and NNRTIs and there is a risk of serotonin syndrome when they are used with RTV.
- Fluoxetine can be started at low doses if the client is on first line ART (i.e. no exposure to RTV). If a dose increase is required this should be done slowly.
- Citalopram or sertraline should preferably be used (these are psychiatrist initiated). Citalopram is preferred as an initial agent in clients on second line ART. However, this drug is not available at all levels of care. Referral may be required.
- Amitryptalline is the most frequently used TCA. For clients with HIV it is usually used in low doses to manage neuropathic pain but it may be used to treat depression. Side effect monitoring is essential. Levels may be increased when used together with a PI, which should be considered when using a higher dose.
- St John’s Wort (*Hypericum perforatum*), an herbal OTC preparation with antidepressant properties, should not be used as it may reduce the levels of NNRTIs and PIs in the blood.

(d) *Benzodiazepines*: may be required for the initial treatment of anxiety disorders. They may also be used acutely to sedate aggressive or agitated clients.
- Certain drugs should be avoided due to interactions with ART that may lead to excessive sedation. Of note, diazepam, midazolam and alprazolam should be avoided.
- Preferred drugs include lorazepam and oxazepam.
- There is always a risk of dependence when using benzodiazepines and they should generally not be prescribed for more than 2 weeks, unless in consultation with a specialist for specific indications.

(e) *Methylphenidate* (*Ritalin*): may be used for clients with ADHD to improve concentration and attention.
- Known for its effects on appetite and for a negative effect on weight gain: these should be monitored.
- No clinically significant interactions with ART.

(f) *Lithium*: used as a mood stabiliser in clients with bipolar mood disorder.
- Usually initiated by a psychiatrist and requires careful monitoring. Management is best continued by a psychiatrist.
- Should not be used in clients with renal dysfunction as there is an increased risk of toxicity in these clients. It has been advised that it not be used together with TDF.
Further to the common mental health disorders that are particularly relevant in adolescents, there is also a broad spectrum of HIV-associated neurocognitive disorders.

HIV can manifest neurologically at any age.

- **HIV encephalopathy (HIVE)** refers to the disease, damage or malfunction of the brain caused by HIV-1. With perinatal HIV infection, early invasion of the CNS by the virus, affecting the developing foetal and infant brain, is believed to result in the most common primary HIV-related CNS complication, HIVE. This complication can be present before significant immunosuppression, however its presence in a child infected with HIV constitutes an AIDS-defining illness, reflecting the severity of the disease.

- **HIV-associated neurocognitive disorders (HAND)** may develop later in older children and adolescents as part of the progression of HIV disease, in a way similar to that in adults. This may occur in perinatally and non-perinatally infected adolescents. This complication is more likely if they are not yet on ART or if they have treatment failure, with evidence of advanced HIV. There is a broad spectrum of presentations, from mild neurocognitive deficit to HIV-associated dementia.

### 26.1 Neurodevelopmental delays associated with HIV

- Neurodevelopmental delays associated with HIV include specific cognitive deficits, impaired motor skills and decreased language ability.
  - The effects may be seen in concentration, attention, memory, learning and higher level functioning such as planning, judgement and organisation.
  - Clients may also be slower at processing information, and there may be abnormal motor skills or sensory perception.

- HIV viral integration into the frontal cortex and connecting structures of the CNS are suggested as possible mechanisms for these manifestations.

While a considerable reduction in disease progression and deaths has occurred in children treated with ART, behavioural and scholastic difficulties continue to negatively impact on overall functioning and quality of life of children and adolescents living with HIV. Early initiation of ART may reduce the risk of severe forms of neurological and neurocognitive disease.

Clinicians need to screen for, assess and manage the minor neurocognitive and behavioural problems that can adversely affect the cohort of children now surviving into adolescence and young adulthood.³

### Note

While HIV is a risk factor for neurocognitive delay, many adolescents living with HIV have the capacity to perform well academically and continue on to higher education. This includes perinatally infected adolescents. The healthcare worker should not foster assumptions that problems at school are to be expected. Where identified, learning difficulties should be addressed just as they would for an adolescent who is HIV negative. Each adolescent should be assessed and managed as an individual and encouraged to reach their maximum potential.
26.2 Screening for neurocognitive disorders

Screening should occur in the context of general HIV clinics across all levels of healthcare. It has been recommended that screening be done 6–12 monthly, especially for perinatally infected adolescents.4 This will assist early identification of problems. Currently there are no locally validated screening tools for adolescents. As such it is recommended to screen in the following manner:

- Obtain input from school teachers and parents/caregivers.
- Assess school reports.
- Assess the client’s deep tendon reflexes and motor function (tone, power, fine motor function – adolescents who have problems with fine motor function may have difficulty with tasks like writing, which require fine control).

Note: Neurocognitive screening tools should not be used in isolation from clinical information and risk profiles. Tools available for screening adults, such as the International HIV Dementia Scale, have not been validated for use in adolescents and may not pick up milder neurocognitive impairment.

Some considerations for screening are outlined in Box 37.

<table>
<thead>
<tr>
<th>Considerations for the healthcare practitioner when screening for neurocognitive disorders</th>
<th>Questions for/about the adolescent</th>
</tr>
</thead>
<tbody>
<tr>
<td>• Screening is not easily done: many of the more subtle impairments may not be picked up.</td>
<td>• How is the client coping in school?</td>
</tr>
<tr>
<td>• Regular enquires about school progress and difficulties are advisable. The clinician should also ask about new onset behavioural problems.</td>
<td>• If there are problems, are these related to all subjects or specific subjects?</td>
</tr>
<tr>
<td></td>
<td>• Are problems related to difficulty in learning, poor attention, or to poor effort?</td>
</tr>
<tr>
<td></td>
<td>• How long has the client been experiencing school-related difficulty?</td>
</tr>
<tr>
<td></td>
<td>• Has the client repeated any grades previously? How many times?</td>
</tr>
</tbody>
</table>

26.3 Diagnosis of HIV and HAND2,5

The diagnosis of HAND is based on the exclusion of other possible causes of disease, so investigations are needed to exclude such causes. It is advisable to refer adolescents with suspected neurocognitive disorders for further evaluation, which may include imaging studies, blood tests and cerebrospinal fluid investigation.

HAND is characterised by a cognitive deficit in association with a change in behaviour (e.g. aggression, isolation) or motor skills (e.g. tremor, clumsiness) after other possible causes have been excluded.
The WHO presumptive and definitive criteria for recognising HIV-related clinical events among adults (15 years or older) and among children (younger than 15 years) with confirmed HIV infection outline the following:

- **The clinical diagnosis of HIV for children under the age of 15 years** must include at least one of the following for at least 2 months in the absence of a concurrent illness:
  - failure to attain or loss of developmental milestones, or loss of intellectual ability, verified by a standard developmental scale or neuropsychological tests
  - impaired brain growth or acquired microcephaly, evident by head circumference measurements or brain atrophy demonstrated by computerised tomography or magnetic resonance imaging (serial imaging is required for children <2 years of age)
  - acquired symmetric motor deficit manifested by two or more of the following: paresis, pathologic reflexes, ataxia, gait disturbance.

- **The clinical diagnosis of HAND for adults and adolescents over the age of 15 years** is based on disabling cognitive and/or motor dysfunction interfering with activities of daily living, progressing over weeks or months in the absence of a concurrent illness or condition, other than HIV infection, that might explain the finding.

### 26.4 Management of HIVE/HAND

Management of HIVE/HAND requires accurate diagnosis, excluding or addressing secondary causes.

**Note:** It is always essential to rule out other treatable medical causes, which may include opportunistic infections (OIs), and other neurological and general medical conditions.

#### (i) The client develops cognitive impairment on cART

This is likely to be associated with virological failure as cART is protective against the development of neurocognitive disorders caused by HIV.

- **Rule out other medical factors** (e.g. OIs, chronic illnesses, neurological disorders, problems with ARVs) that may be causing the problem.
- Check treatment compliance.
- Check viral load.
- Consider neurotoxicity (especially EFV).
- Take measures to correct the virological failure.

#### (ii) The client develops cognitive impairment and is not yet on ARVs

- Fast track onto ART – HIVE/HAND are listed as WHO clinical stage IV conditions.
- Ensure good adherence to treatment.

**Remember:** Performance decline at school may also be due to mental health, social or behaviour problems (e.g. depression, substance abuse) both in the parents/caregivers and in the adolescents themselves. Poor school performance is not necessarily related to neurocognitive decline.
ART is the treatment of choice for both treatment and prevention of HAND. Achieving viral suppression may prevent progression of the features of HAND. In general, ART regimens that suppress HIV RNA in the serum also suppress HIV in the CNS. ARVs vary in their ability to penetrate the blood–brain barrier. Current standard regimens are recommended nonetheless, without any specific modifications.

**26.5  HIVE/HAND: further interventions by the healthcare worker**

- Referral for pure neurocognitive decline should in the first instance be to a paediatrician/physician/family physician according to the client’s age. However, concern about contributing mental health/behavioural issues may require psychiatric review.
- Occupational therapy at community level for schoolchildren should be arranged.
- Manage issues within the family and social context as appropriate.
- Communicate with the school where there is a need to arrange remedial schooling or review with an educational psychologist.

**Remember:** Disclosure should not be made without the client’s consent, and is usually not necessary in order to request assistance.

**Box 38: ARVs and CNS penetration effectiveness (CPE)**

- ARVs with the best CNS penetration include the NRTIs abacavir (ABC), emtricitabine (FTC), and zidovudine (AZT, ZDV); the NNRTI nevirapine (NVP); the protease inhibitors indinavir/ritonavir and lopinavir/ritonavir.
- Current guidelines recommend the use of standard ART regimens and there is no need to adjust treatment based on the above, unless in consultation with a specialist under specific circumstances.
References: Part A

Part A: Clinical management of adolescents living with HIV
Working with adolescents living with HIV: A handbook for healthcare providers
Part A: Clinical management of adolescents living with HIV

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7. Personal communication with Dr H Moultrie, Technical Head, Adolescent team on 24 May 2013.

SECTION 1: AN INTRODUCTION TO WORKING WITH ADOLESCENTS

Chapter 1: Adolescent-friendly services
Chapter 2: Adolescents living with HIV: who are they?


Chapter 3: Development and maturation of adolescents living with HIV

SECTION 2: CONSULTATION, SCREENING AND HISTORY-TAKING

Chapter 4: The consultation


Chapter 5: Clinical management: history-taking, screening and examination


SECTION 3: CONTINUUM OF CARE: HCT AND ART

Chapter 6: HIV counselling, testing and linkages to care

Chapter 7: Preparing for ART – the initial assessment


3. DOH. Psychosocial support (PSS) for children and adolescents infected and affected by HIV. Pretoria: Department of Health, 2012.


Chapter 8: ART initiation


Chapter 9: Follow-up and monitoring of clients on ART


Chapter 10: Adverse events and drug reactions to ARVs


Chapter 11: Managing virological failure and changing treatment regimens


SECTION 4: MANAGEMENT OF OPPORTUNISTIC INFECTIONS AND OTHER HIV-RELATED CONDITIONS

Chapter 12: Tuberculosis


Chapter 13: Cryptococcal disease


**Chapter 14: Other opportunistic infections**


**Chapter 15: HIV-associated conditions (non-infectious)**


**SECTION 5 SEXUAL AND REPRODUCTIVE HEALTH**

**Chapter 16: Sexual and reproductive health**


Clinical management of adolescents living with HIV

PART A. REFERENCES


25. Lowry DR. HPV vaccines: progress to date and future worldwide directions. Presentation at the Conference on Retrovirals and Opportunistic Infections (CROI) 2013, Boston.


28. DOH. Draft DOH Cervical Screening Guidelines (Nov 2013) Please note: At the time of going to print, the cervical screening guidelines were still in their draft form, and healthcare providers should get guidance from respective provincial DOH cervical screening guidelines until the national guidelines are finalised.


Chapter 17: Pregnancy and adolescents living with HIV


Chapter 18: Prevention of HIV infection for adolescents


18. UNAIDS. Addressing the vulnerability of young women & girls to stop the HIV epidemic in South Africa. UNAIDS, 2008.


References: Part B

Part B: Management of the psychosocial wellbeing and mental health of adolescents living with HIV
Working with adolescents living with HIV: A handbook for healthcare providers
Part B: Management of the psychosocial wellbeing and mental health of adolescents living with HIV

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SECTION 6: PSYCHOSOCIAL WELLBEING

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Chapter 20: Adherence and adolescents


Chapter 21: Disclosure

Chapter 22: Transition

Chapter 23: Support groups for adolescents
SECTION 7: MENTAL HEALTH

Chapter 24: Mental health and HIV in adolescence


8. Palmer A. HIV-infected adolescents have multiple risk factors for mental illness. *HIV Clinician,* 2011, 23(3):1-4


Chapter 25: Management of common mental health conditions in adolescents living with HIV

Management of the psychosocial wellbeing and mental health of adolescents living with HIV

PART B. REFERENCES


Chapter 26: Neurocognitive effects of HIV
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Appendix 1: Tanner staging and growth charts

Appendix 1(a): Tanner staging


The Tanner scale (or Tanner staging) provides a measure of physical development in adolescents. The scale defines physical measurements of development based on external primary and secondary sex characteristics. The scale is based on observing the development of the breasts in girls, the development of the genitalia in boys, and the growth of pubic hair in both sexes.

Due to natural variations, individuals pass through the Tanner stages at different rates. The Tanner scale cannot measure the entire course of puberty because the changes in internal reproductive organs begin much earlier and finish much later than the changes in visible external characteristics.

In ART, the Tanner scale is used to determine which treatment regimen to follow (paediatric or adult). Adolescents at Tanner scale 1, 2 or 3 should be started on a paediatric regimen, while adolescents at scale 4 or 5 should be put on the adult regimen.

<table>
<thead>
<tr>
<th>Scale</th>
<th>Description</th>
</tr>
</thead>
<tbody>
<tr>
<td>1</td>
<td>no breast tissue with flat areola</td>
</tr>
<tr>
<td>2</td>
<td>breast budding with widening of the areola</td>
</tr>
<tr>
<td>3</td>
<td>larger and more elevated breast extending beyond the areola</td>
</tr>
<tr>
<td>4</td>
<td>larger and even more elevated breast. Areola and nipple projecting from the breast contours</td>
</tr>
<tr>
<td>5</td>
<td>Adult size with nipple projecting above areola</td>
</tr>
</tbody>
</table>
### Annex 2: The Tanner scale

#### Annex 2: The Tanner scale

**Tanner scale: Male and female pubic hair**

<table>
<thead>
<tr>
<th>Scale</th>
<th>Description</th>
</tr>
</thead>
<tbody>
<tr>
<td>Scale 1</td>
<td>none</td>
</tr>
<tr>
<td>Scale 2</td>
<td>small amount of long hair at base of male scrotum or female labia majora</td>
</tr>
<tr>
<td>Scale 3</td>
<td>moderate amount of curly and coarser hair extending outwards</td>
</tr>
<tr>
<td>Scale 4</td>
<td>resembles adult hair but does not extend to inner surface of thigh</td>
</tr>
<tr>
<td>Scale 5</td>
<td>adult type and quantity extending to the medial thigh surface</td>
</tr>
</tbody>
</table>

**Tanner scale: Male genitalia**

<table>
<thead>
<tr>
<th>Scale</th>
<th>Description</th>
</tr>
</thead>
<tbody>
<tr>
<td>Scale 1</td>
<td>testes small in size with childlike penis</td>
</tr>
<tr>
<td>Scale 2</td>
<td>testes reddened, thinner and larger (1.6–6.0 cc) with childlike penis</td>
</tr>
<tr>
<td>Scale 3</td>
<td>testes larger (6–12 cc), scrotum enlarging, increase in penile length</td>
</tr>
<tr>
<td>Scale 4</td>
<td>testes larger (12–20 cc) with greater enlargement and darkening of the scrotum; increase in length and circumference of penis</td>
</tr>
<tr>
<td>Scale 5</td>
<td>testes over 20cc with adult scrotum and penis</td>
</tr>
</tbody>
</table>

Appendix 1b: Growth charts

Appendix 1(b)

Appendix 1b: Growth charts  continued
Appendix 1b: Growth charts  continued

Height-for-age BOYS
5 to 19 years (z-scores)
Appendix 1b: Growth charts  continued

Height-for-age GIRLS
5 to 19 years (z-scores)
### Appendix 2: “5 A’s” for consultations with adolescents


#### Overview of Coping Strategies

Health workers should use the “5 A’s” when conducing psychosocial assessment with clients: **ASSESS**, **ADVISE**, **AGREE**, **ASSIST**, and **ARRANGE**. Note that the “5 A’s” were also covered in Module 3; these are part of the WHO IMAI guidelines on working with clients with chronic conditions, including HIV. See Table 5.1 for a review of the “5 A’s.”

**Table 5.1: Using the “5 A’s” during clinical visits with adolescents, including psychosocial and counselling sessions**

<table>
<thead>
<tr>
<th>The 5 “A’s”</th>
<th>More Information</th>
<th>Health Worker Might Say</th>
</tr>
</thead>
</table>
| **ASSESS**  | • Assess the client’s goals for the visit  
• Assess the client’s clinical status, classify/identify relevant treatment, and/or advise and counsel  
• Assess risk factors  
• Assess the client’s (caregiver’s) knowledge, beliefs, concerns, and behaviours  
• Assess the client’s understanding of the care and treatment plan  
• Assess adherence to care and treatment (see Module 8)  
• Acknowledge and praise the client’s efforts | • What would you like to address today?  
• Can you tell me about_____?  
• Tell me about a typical day and how you deal with_____?  
• Have you ever tried to_____? What was that like for you?  
• To make sure we have the same understanding, can you tell me about your care and treatment plan, in your own words?  
• Many people have challenges taking their medicines regularly. How has this been for you?  
• I have some information about ____ that I’d like to share with you  
• Let’s talk about your risk related to _____. What do you think about reducing the risk by _____.  
• What can I explain better?  
• What questions do you have about _____? |
| **ADVISE**  | • Use neutral and non–judgemental language  
• Correct any inaccurate knowledge and gaps in the client’s understanding  
• Counsel on risk reduction  
• Repeat any key information that is needed  
• Reinforce what the client needs to know to manage his or her care and treatment (for example, recognizing side effects, adherence tips, problem–solving skills, when to come to the clinic, how to monitor one’s own care, where to get support in the community, etc.) | • We have talked about a lot today, but I think we’re agreed that _____ is this correct?  
• Let’s talk about when you will return to the clinic for _____.  
• Can you tell me more about any obstacles you’re faced with_____ (for example, taking your medicines regularly, seeking support, practicing safer sex)?  
• How do you think you can overcome this ARRANGE obstacle?  
• What questions can I answer about _____?  
• I want to make sure I explained things well—can you tell me in your own words about _____? |
| **AGREE**   | • Negotiate WITH the client about the care and treatment plan, including and changes  
• Plan when the client will return | • I would like to see you again in ____ for _____.  
• It’s important that you come for this visit or let us know if you need to reschedule.  
• What day/time would work for you?  
• What do you think about reducing the risk by _____. |
| **ASSIST**  | • Provide take –away information on the plan, including any changes  
• Provide psychosocial support, as needed  
• Provide referrals, as needed (to support groups, peer education, etc.)  
• Address obstacles  
• Help the client come up with solutions and strategies that work for him or her | • |
### Appendix 3: ARV Drug Dosing Chart for Children

**Compiled by the Child and Adolescent Committee of the SA HIV Clinicians Society in collaboration with the Department of Health**

#### Available Formulations
- **Lamivudine (3TC)**
  - Available: 4mg/kg TWICE daily by weight band OR once daily when <8 weeks of age.
  - By weight band:
    - Target BOC: 4mg/kg TWICE daily OR 300mg/300mg.
    - Target BOL: 4mg/kg daily.
- **Abacavir (ABC)**
  - Available: 8mg/kg TWICE daily by weight band OR once daily when <8 weeks of age.
  - By weight band:
    - Target BOC: 8mg/kg TWICE daily OR 300mg/300mg.
    - Target BOL: 8mg/kg daily.
- **Nevirapine (NVP)**
  - Available: 160-200mg/m2 dose by weight band.
  - By weight band:
    - Target BOC: 160-200mg/m2 dose OR twice daily after once daily lead-in x 2 weeks.
    - Target BOL: 160-200mg/m2 dose OR TWICE daily.
  - OR: when on Rifampicin:
    - 1 cap tab bd OR 1x250mg tab bd.
- **Zidovudine (AZT)**
  - Available: 10mg/m2 Tab 600mg/m2 (not scored) ABC/3TC 600/300mg.
  - By weight band:
    - Target BOC: 10mg/m2 Tab 600mg/m2 (not scored) ABC/3TC 600/300mg.
    - Target BOL: 10mg/m2 Tab 600mg/m2 (not scored) ABC/3TC 600/300mg.

#### Available Formulations

#### Available Formulations

### ARV Drug Dosing Chart for Children

<table>
<thead>
<tr>
<th>Weight (kg)</th>
<th>0-4.9</th>
<th>5-6.9</th>
<th>6-7.9</th>
<th>7-8.9</th>
<th>8-9.9</th>
<th>9-10.9</th>
<th>10-13.9</th>
<th>13-21.9</th>
<th>21-23.9</th>
<th>≥24</th>
</tr>
</thead>
<tbody>
<tr>
<td>Available Formulations</td>
<td></td>
<td></td>
<td></td>
<td></td>
<td></td>
<td></td>
<td></td>
<td></td>
<td></td>
<td></td>
</tr>
<tr>
<td>Lamivudine (3TC)</td>
<td>2ml bd</td>
<td>2ml bd</td>
<td>2ml bd</td>
<td>3ml bd</td>
<td>4ml bd</td>
<td>4ml bd</td>
<td>5ml bd</td>
<td>10ml bd</td>
<td>10ml bd</td>
<td>10ml bd</td>
</tr>
<tr>
<td>Abacavir (ABC)</td>
<td>2ml bd</td>
<td>2ml bd</td>
<td>2ml bd</td>
<td>3ml bd</td>
<td>4ml bd</td>
<td>4ml bd</td>
<td>5ml bd</td>
<td>10ml bd</td>
<td>10ml bd</td>
<td>10ml bd</td>
</tr>
<tr>
<td>Nevirapine (NVP)</td>
<td>1.5ml bd</td>
<td>2ml bd</td>
<td>2ml bd</td>
<td>3ml bd</td>
<td>4ml bd</td>
<td>4ml bd</td>
<td>5ml bd</td>
<td>10ml bd</td>
<td>10ml bd</td>
<td>10ml bd</td>
</tr>
<tr>
<td>Zidovudine (AZT)</td>
<td>1.5ml bd</td>
<td>2ml bd</td>
<td>2ml bd</td>
<td>3ml bd</td>
<td>4ml bd</td>
<td>4ml bd</td>
<td>5ml bd</td>
<td>10ml bd</td>
<td>10ml bd</td>
<td>10ml bd</td>
</tr>
</tbody>
</table>

*Consult a clinician with experience in paediatric ARV prescribing for neonates (<28 days of age) and infants weighing <3kg.*

**Available Formulations**

**Lamivudine (3TC)**
- Available: 4mg/kg TWICE daily by weight band OR once daily when <8 weeks of age.
- By weight band:
  - Target BOC: 4mg/kg TWICE daily OR 300mg/300mg.
  - Target BOL: 4mg/kg daily.

**Abacavir (ABC)**
- Available: 8mg/kg TWICE daily by weight band OR once daily when <8 weeks of age.
- By weight band:
  - Target BOC: 8mg/kg TWICE daily OR 300mg/300mg.
  - Target BOL: 8mg/kg daily.

**Nevirapine (NVP)**
- Available: 160-200mg/m2 dose by weight band.
- By weight band:
  - Target BOC: 160-200mg/m2 dose OR twice daily after once daily lead-in x 2 weeks.
  - Target BOL: 160-200mg/m2 dose OR TWICE daily.
  - OR: when on Rifampicin:
    - 1 cap tab bd OR 1x250mg tab bd.

**Zidovudine (AZT)**
- Available: 10mg/m2 Tab 600mg/m2 (not scored) ABC/3TC 600/300mg.
- By weight band:
  - Target BOC: 10mg/m2 Tab 600mg/m2 (not scored) ABC/3TC 600/300mg.
  - Target BOL: 10mg/m2 Tab 600mg/m2 (not scored) ABC/3TC 600/300mg.

*Available Formulations*
### PRACTICAL ADVICE ON ADMINISTRATION OF ARV DRUGS

#### Abacavir (ABC)
Caregivers must be warned about potential severe progressive hypersensitivity reaction which may include fever, rash, gastrointestinal & respiratory symptoms. If hypersensitivity occurs it is usually during first six weeks of therapy; symptoms tend to worsen in the hours immediately after the dose and worsen with each subsequent dose. Caregivers or patients should discuss symptoms early with the clinician rather than terminating therapy without consultation. ABC should be stopped permanently if hypersensitivity reaction occurs. Avoid combining ABC and NVP in a regimen and avoid concurrent initiation of ABC and co-trimoxazole. Tablets (except 60mg) must not be chewed, divided or crushed; swallow whole with or without food.

#### Lamivudine (3TC)
Well tolerated; no food restrictions, oral solution may be stored at room temperature. Tablets are scored and can be easily divided; may be crushed and mixed with a small amount of water or food and immediately ingested.

#### Stavudine (d4T)
Well tolerated & palatable but oral solution requires refrigeration after reconstitution. Discard after 30 days. Capsules may be opened and powder contents dispersed in water or mixed with a small amount of food (e.g. yoghurt). See dosing chart for further details. Consider early drug substitution if toxicity e.g. lipoatrophy develops.

#### Lopinavir/Ritonavir (Kaletra* solution; Aluvia* tablets)
Dose is calculated on lopinavir component. Solution should be taken with food as increases absorption. Solution should be refrigerated however can be stored at room temperature up to 25°C for 6 weeks. May need techniques to increase tolerance & palatability; coat mouth with peanut butter, dull taste buds with ice, follow dose with 1 wheat foods. Tablets must not be chewed, divided or crushed; swallow whole with or without food. Many drug interactions due to RTV inhibition of cytochrome p450.

#### Efavirenz (EFV)
EFV is not approved for children <3 years/ <10kg. Tablets must not be chewed, divided or crushed; swallow whole with or without food. Many drug interactions due to RTV inhibition of cytochrome p450.

#### Didanosine (ddI)
At least 2 tablets of appropriate strength must be used at any one time for adequate buffering. Tablets may be chewed or crushed and dispersed in 30ml water and immediately ingested. Enteric coated (EC) capsules (250mg) are available for once daily use in children >2.5kg. It is recommended to administer ddI on an empty stomach at least 30 minutes before or 2 hours after meals.

#### Ritonavir (RTV)
Only recommended use at present is as booster for lopinavir/ritonavir when co-administered with rifampicin-containing TB treatment. Ritonavir boosting dose is not less than 0.75 x lopinavir/ritonavir dose. Should be taken with food. May be stored at room temperature, limited shelf life of 6 months. May need to use techniques described for Kaletra* to improve tolerance of bitter taste.

#### Nevirapine (NVP)
Once-daily dosing during the first 2 weeks of treatment reduces frequency of rash. If a mild rash occurs during the induction period, continue once daily dosing and mixed with a small amount of water or food and only escalate dose to twice daily once the rash has subsided and the dose is well tolerated.

NVP should be permanently discontinued and not re-started in children who develop severe rash especially if accompanied by fever, blistering or mucosal ulceration. No food restrictions. Tablets can be crushed and mixed with a small amount of water or food and immediately ingested. Avoid NVP if rifampicin is being co-administered. Consider drug-drug interactions.
<table>
<thead>
<tr>
<th>SIDE EFFECT</th>
<th>ARVs RESPONSIBLE</th>
<th>SIGNS AND SYMPTOMS</th>
<th>INCIDENCE AND TIME OF ONSET AFTER INITIATION THERAPY</th>
<th>DIAGNOSIS</th>
<th>TREATMENT AND MANAGEMENT TIPS</th>
</tr>
</thead>
<tbody>
<tr>
<td>LACTIC ACIDOSIS</td>
<td>NRTIs</td>
<td>Onset: 4-6 weeks</td>
<td>Asymptomatic hyperlactataemia:</td>
<td>• Observation of clinical signs and symptoms • Increased lipase or amylase (&gt;3x ULN)</td>
<td>Consider switching ARV therapy—usually to abacavir in children or tenofovir in adults</td>
</tr>
<tr>
<td>LIPODYSTROPHY</td>
<td>NRTIs</td>
<td>Onset: 4-6 weeks</td>
<td>Systemic symptoms and abnormalities of the skin, fat accumulation, impaired concentration, amnesia, euphoria, psychosis</td>
<td></td>
<td></td>
</tr>
<tr>
<td>HEPATIC STEATOSIS</td>
<td>NRTIs</td>
<td>Onset: 4-6 months</td>
<td>Elevated liver enzymes, nausea, vomiting, abdominal pain, anorexia, diarrhoea, fatigue, jaundice</td>
<td>Increased risk if initiating therapy with a CD4 count &gt;250 in females or &gt;400 in males (adult data)</td>
<td></td>
</tr>
<tr>
<td>PANCREATITIS</td>
<td>NRTIs</td>
<td>Onset: 4-6 weeks</td>
<td>Signs of hypersensitivity, nausea, vomiting, abdominal pain, anorexia, diarrhoea, fatigue, jaundice</td>
<td></td>
<td></td>
</tr>
<tr>
<td>LACTIC ACIDOSIS</td>
<td>NRTIs</td>
<td>Onset: 4-6 weeks</td>
<td>Asymptomatic hyperlactataemia;</td>
<td>• Observation of clinical signs and symptoms • Increased lipase or amylase (&gt;3x ULN)</td>
<td>Consider switching ARV therapy—usually to abacavir in children or tenofovir in adults</td>
</tr>
<tr>
<td>HEPATIC STEATOSIS</td>
<td>NRTIs</td>
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<td></td>
</tr>
<tr>
<td>PANCREATITIS</td>
<td>NRTIs</td>
<td>Onset: 4-6 weeks</td>
<td>Signs of hypersensitivity, nausea, vomiting, abdominal pain, anorexia, diarrhoea, fatigue, jaundice</td>
<td></td>
<td></td>
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<td>NRTIs</td>
<td>Onset: 4-6 weeks</td>
<td>Asymptomatic hyperlactataemia;</td>
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<td>Onset: 4-6 months</td>
<td>Elevated liver enzymes, nausea, vomiting, abdominal pain, anorexia, diarrhoea, fatigue, jaundice</td>
<td>Increased risk if initiating therapy with a CD4 count &gt;250 in females or &gt;400 in males (adult data)</td>
<td></td>
</tr>
<tr>
<td>PANCREATITIS</td>
<td>NRTIs</td>
<td>Onset: 4-6 weeks</td>
<td>Signs of hypersensitivity, nausea, vomiting, abdominal pain, anorexia, diarrhoea, fatigue, jaundice</td>
<td></td>
<td></td>
</tr>
</tbody>
</table>

**APPENDIX 4: Managing acute adverse ARV reactions and grading toxicity**

**DIAGNOSIS**

- **Stop immediately,** if toxicity is severe. If toxicity is not severe, then consult a specialist.
- **Refer to a specialist,** if the management is not clear.
- **Consider switching ARV therapy,** if the toxicity is severe or persistent.
- **Initiate supportive treatment,** if the toxicity is severe or persistent.
- **Monitor the patient,** if the toxicity is mild or moderate.

**TREATMENT AND MANAGEMENT TIPS**

- **Stop the causative drug,** if toxicity is severe. If toxicity is not severe, then consult a specialist.
- **Switch the ARV therapy,** if the toxicity is severe or persistent.
- **Initiate supportive treatment,** if the toxicity is severe or persistent.
- **Monitor the patient,** if the toxicity is mild or moderate.

**SIDE-EFFECTS OF ANTIRETROVIRAL DRUGS**

- **Lactic acidosis**
  - Symptoms: Nausea, vomiting, abdominal pain, anorexia, diarrhoea, fatigue, jaundice
  - Incidence: 0.2%-2.5% (uncommon in children)
  - Treatment: Supportive treatment, do not continue ART.

- **Hepatic steatosis**
  - Symptoms: Elevated liver enzymes, nausea, vomiting, abdominal pain, anorexia, diarrhoea, fatigue, jaundice
  - Incidence: Increased risk if initiating therapy with a CD4 count >250 in females or >400 in males (adult data)
  - Treatment: Supportive treatment, do not continue ART.

- **Pancreatitis**
  - Symptoms: Signs of hypersensitivity, nausea, vomiting, abdominal pain, anorexia, diarrhoea, fatigue, jaundice
  - Incidence: |NRTIs|
  - Treatment: Supportive treatment, do not continue ART.

**REFERENCES**

MANAGING ARV TOXICITY

Consider other medications and diseases, including opportunistic infections, immune reconstitution inflammatory syndrome (IRIS), or other illnesses.

CHILD ON ART (OR THEIR CAREGIVER) REPORT POSSIBLE ADVERSE REACTION

HISTORY OR CLINICAL FINDING SUGGEST ADVERSE REACTION

LAB TESTS INDICATE POSSIBLE PROBLEM RELATED TO ART

Evaluate concurrent medications and any concurrent new or pre-existing condition. Establish whether adverse reaction is due to:
• other drugs or drug-drug interaction
• other medical conditions

Determine seriousness of adverse reaction

IS IT A LIFE-THREATENING EVENT?

NO

GRADE 1: MILD

Is it ARV-related? Bothersome? Reassure. No Change in ART required

GRADE 2: MODERATE

Is it ARV-related? Continue ART as long as feasible. If patient does not improve, consider single drug substitution

GRADE 3: SEVERE

Is it ARV-related? Substitute the offending drug without discontinuing ART

Stress importance of adherence to ART despite toxicity in the case of mild and moderate reactions

YES

GRADE 4: SEVERE LIFE-THREATENING (e.g. Stevens-Johnson syndrome, lactic acidosis, etc.)

Immediately discontinue ALL drugs including ARVs and manage the medical event. When the patient is stabilized, reintroduce ARVs using a modified regimen (substitute the offending drug).

* For grading of severity see (pg 69-71)
### Appendix 4: Managing acute adverse ARV reactions and grading toxicity continued


#### 21.6. Grading of selected clinical and laboratory toxicities

<table>
<thead>
<tr>
<th>Estimating severity grade</th>
<th>Mild</th>
<th>Moderate</th>
<th>Severe</th>
<th>Potentially life-threatening</th>
</tr>
</thead>
<tbody>
<tr>
<td>Clinical adverse event NOT identified elsewhere in the table</td>
<td>Symptoms causing no or minimal interference with usual social and functional activities</td>
<td>Symptoms causing greater than minimal interference with usual social and functional activities</td>
<td>Symptoms causing inability to perform usual social and functional activities</td>
<td>Symptoms causing inability to perform basic self-care OR medical or operative intervention indicated to prevent permanent impairment, persistent disability or death</td>
</tr>
<tr>
<td>Haemoglobin</td>
<td>8.0−9.4 g/dl OR 80−94 g/l OR 4.93−5.83 mmol/l</td>
<td>7.0−7.9 g/dl OR 70−79 g/l OR 4.31−4.92 mmol/l</td>
<td>6.5−6.9 g/dl OR 65−69 g/l OR 4.03−4.30 mmol/l</td>
<td>&lt;6.5 g/dl OR &lt;65 g/l OR &lt;4.03 mmol/l</td>
</tr>
<tr>
<td>Absolute neutrophil count</td>
<td>1000−1500/mm³ OR 1.0−1.5/G/l*</td>
<td>750−999/mm³ OR 0.75−0.99/G/l*</td>
<td>500−749/mm³ OR 0.5−0.749/G/l*</td>
<td>&lt;500/mm³ OR &lt;0.5/G/l*</td>
</tr>
<tr>
<td>Platelets</td>
<td>75000−99000/mm³ OR 75−99/G/l*</td>
<td>50000−74999/mm³ OR 50−74.9/G/l*</td>
<td>20000−49999/mm³ OR 20−49.9/G/l*</td>
<td>&lt;20000/mm³ OR &lt;20/G/l*</td>
</tr>
<tr>
<td>Chemistry</td>
<td>Mild</td>
<td>Moderate</td>
<td>Severe</td>
<td>Potentially life-threatening</td>
</tr>
<tr>
<td>----------------------------------</td>
<td>------</td>
<td>----------</td>
<td>--------</td>
<td>----------------------------</td>
</tr>
<tr>
<td>Hyperbilirubinaemia</td>
<td>&gt;1.0−1.5 x ULN</td>
<td>&gt;1.5−2.5 x ULN</td>
<td>&gt;2.5−5 x ULN</td>
<td>&gt;5 x ULN</td>
</tr>
<tr>
<td>Glucose (fasting)</td>
<td>110−125 mg/dl</td>
<td>126−250 mg/dl</td>
<td>251−500 mg/dl</td>
<td>&gt;500 mg/dl</td>
</tr>
<tr>
<td>Hypoglycaemia</td>
<td>55−64 mg/dl OR 3.01−3.56 mmol/l</td>
<td>40−54 mg/dl OR 2.19−3.00 mmol/l</td>
<td>30−39 mg/dl OR 1.67−2.18 mmol/l</td>
<td>&lt;30 mg/dl OR &lt;1.67 mmol/l</td>
</tr>
<tr>
<td>Hyperglycaemia (nonfasting and no prior diabetes)</td>
<td>116−160 mg/dl OR 6.44−8.90 mmol/l</td>
<td>161−250 mg/dl OR 8.91−13.88 mmol/l</td>
<td>251−500 mg/dl OR 13.89−27.76 mmol/l</td>
<td>&gt;500 mg/dl OR &gt;27.76 mmol/l</td>
</tr>
<tr>
<td>Triglycerides</td>
<td>–</td>
<td>400−750 mg/dl OR 4.52−8.47 mmol/l</td>
<td>751−1200 mg/dl OR 8.48−13.55 mmol/l</td>
<td>&gt;1200 mg/dl OR &gt;13.55 mmol/l</td>
</tr>
<tr>
<td>Creatinine</td>
<td>&gt;1.0−1.5 x ULN</td>
<td>&gt;1.5−3.0 x ULN</td>
<td>&gt;3.0−6.0 x ULN</td>
<td>&gt;6.0 x ULN</td>
</tr>
<tr>
<td>AST (SGOT)</td>
<td>1.25−2.5 x ULN</td>
<td>&gt;2.5−5.0 x ULN</td>
<td>&gt;5.0−10.0 x ULN</td>
<td>&gt;10.0 x ULN</td>
</tr>
<tr>
<td>ALT (SGPT)</td>
<td>1.25−2.5 x ULN</td>
<td>&gt;2.5−5.0 x ULN</td>
<td>&gt;5.0−10.0 x ULN</td>
<td>&gt;10.0 x ULN</td>
</tr>
<tr>
<td>GGT</td>
<td>1.25−2.5 x ULN</td>
<td>&gt;2.5−5.0 x ULN</td>
<td>&gt;5.0−10.0 x ULN</td>
<td>&gt;10.0 x ULN</td>
</tr>
<tr>
<td>Alkaline phosphatase</td>
<td>1.25−2.5 x ULN</td>
<td>&gt;2.5−5.0 x ULN</td>
<td>&gt;5.0−10.0 x ULN</td>
<td>&gt;10.0 x ULN</td>
</tr>
<tr>
<td>Bilirubin</td>
<td>1.1−1.5 X ULN</td>
<td>1.6−2.5 X ULN</td>
<td>2.6−5.0 X ULN</td>
<td>&gt;5 X ULN</td>
</tr>
<tr>
<td>Amylase</td>
<td>&gt;1.0−1.5 X ULN</td>
<td>&gt;1.5−2.0 X ULN</td>
<td>&gt;2.0−5.0 X ULN</td>
<td>&gt;5.0 X ULN</td>
</tr>
<tr>
<td>Pancreatic amylase</td>
<td>&gt;1.0−1.5 X ULN</td>
<td>&gt;1.5−2.0 X ULN</td>
<td>&gt;2.0−5.0 X ULN</td>
<td>&gt;5.0 X ULN</td>
</tr>
</tbody>
</table>
### Appendix 4: Managing acute adverse ARV reactions and grading toxicity

<table>
<thead>
<tr>
<th></th>
<th>Mild</th>
<th>Moderate</th>
<th>Severe</th>
<th>Potentially life-threatening</th>
</tr>
</thead>
<tbody>
<tr>
<td>Lipase</td>
<td></td>
<td></td>
<td></td>
<td></td>
</tr>
<tr>
<td>&lt;1.0−1.5 x ULN</td>
<td>&gt;1.5−2.0 x ULN</td>
<td>&gt;2.0−5.0 x ULN</td>
<td>&gt;5.0 x ULN</td>
<td></td>
</tr>
<tr>
<td>Lactate</td>
<td>&lt;2.0 x ULN without acidosis</td>
<td>&gt;2.0 x ULN without acidosis</td>
<td>Increased lactate with pH &lt;7.3 without life-threatening consequences</td>
<td>Increased lactate with pH &lt;7.3 with life-threatening consequences</td>
</tr>
<tr>
<td>Gastrointestinal</td>
<td>Mild Grade 1</td>
<td>Moderate Grade 2</td>
<td>Severe Grade 3</td>
<td>Potentially life-threatening Grade 4</td>
</tr>
<tr>
<td>Nausea</td>
<td>Mild OR transient; reasonable intake maintained</td>
<td>Moderate OR discomfort OR intake decreased for ≤3 days</td>
<td>Severe discomfort OR minimal intake for &gt;3 days</td>
<td>Hospitalization required</td>
</tr>
<tr>
<td>Vomiting</td>
<td>Mild OR transient; 2−3 episodes per day OR mild vomiting lasting &lt;1 week</td>
<td>Moderate OR persistent; 4−5 episodes per day OR vomiting lasting &gt;1 week</td>
<td>Severe vomiting of all foods/fluids in 24 hours OR orthostatic hypotension OR intravenous Rx required</td>
<td>Hypotensive shock OR hospitalization for intravenous Rx required</td>
</tr>
<tr>
<td>Diarrhoea</td>
<td>Mild OR transient; 3−4 loose stools per day OR mild diarrhoea lasting ≤1 week</td>
<td>Moderate OR persistent; 5−7 loose stools per day OR diarrhoea lasting &gt;1 week</td>
<td>Bloody diarrhoea OR orthostatic hypotension OR &gt;7 loose stools/day OR intravenous Rx required</td>
<td>Hypotensive shock OR hospitalization required</td>
</tr>
<tr>
<td>Respiratory</td>
<td>Mild Grade 1</td>
<td>Moderate Grade 2</td>
<td>Severe Grade 3</td>
<td>Potentially life-threatening Grade 4</td>
</tr>
<tr>
<td>Dyspnoea</td>
<td>Dyspnoea on exertion</td>
<td>Dyspnoea with normal activity</td>
<td>Dyspnoea at rest</td>
<td>Dyspnoea requiring O2 therapy</td>
</tr>
<tr>
<td>Urinalysis</td>
<td>Mild Grade 1</td>
<td>Moderate Grade 2</td>
<td>Severe Grade 3</td>
<td>Potentially life-threatening Grade 4</td>
</tr>
<tr>
<td>Proteinuria</td>
<td>Spot urine 1+ 2+ or 3+ 4+</td>
<td>2+ or 3+</td>
<td>4+</td>
<td>Nephrotic syndrome</td>
</tr>
<tr>
<td>24-hour urine</td>
<td>200 mg to 1 g loss/day OR &lt;0.3% OR &lt;3 g/l</td>
<td>1 g to 2 g loss/day OR 0.3% to 1.0% OR 3 g to 10 g/l</td>
<td>2 g to 3.5 g loss/day OR &gt;1.0% OR &gt;10 g/l</td>
<td>Nephrotic syndrome OR &gt;3.5 g loss/day</td>
</tr>
<tr>
<td>Gross haematuria</td>
<td>Microscopic only</td>
<td>Gross, no clots</td>
<td>Gross plus clots</td>
<td>Obstructive</td>
</tr>
<tr>
<td>Miscellaneous</td>
<td>Mild Grade 1</td>
<td>Moderate Grade 2</td>
<td>Severe Grade 3</td>
<td>Potentially life-threatening Grade 4</td>
</tr>
<tr>
<td>Fever (oral, &gt;12 hours)</td>
<td>37.7−38.5 °C OR 100.0−101.5 °F</td>
<td>38.6−39.5 °C OR 101.6−102.9 °F</td>
<td>39.6−40.5 °C OR 103−105 °F</td>
<td>&gt;40.5 °C OR &gt;105 °F for ≥12 continuous hours</td>
</tr>
</tbody>
</table>
### Appendix 4: Managing acute adverse ARV reactions and grading toxicity  
*continued*

<table>
<thead>
<tr>
<th>Condition</th>
<th>Mild; no Rx required</th>
<th>Moderate OR non-narcotic analgesia Rx</th>
<th>Severe OR responds to initial narcotic Rx</th>
<th>Intractable</th>
</tr>
</thead>
<tbody>
<tr>
<td>Headache</td>
<td></td>
<td></td>
<td></td>
<td></td>
</tr>
<tr>
<td>Allergic reaction</td>
<td>Pruritus without rash</td>
<td>Localized urticaria</td>
<td>Generalized urticaria, angioedema</td>
<td>Anaphylaxis</td>
</tr>
<tr>
<td>Rash hypertesnsitvity</td>
<td>Erythema, pruritus</td>
<td>Diffuse maculopapular rash OR dry desquamation</td>
<td>Vesication OR moist desquamation OR ulceration</td>
<td>ANY ONE OF: mucous membrane involvement, suspected Stevens-Johnson (TEN), erythema multiforme, exfoliative dermatitis</td>
</tr>
<tr>
<td>Fatigue</td>
<td>Normal activity reduced by &lt;25%</td>
<td>Normal activity reduced by 25−50%</td>
<td>Normal activity reduced by &gt;50%; cannot work</td>
<td>Unable to care for self</td>
</tr>
</tbody>
</table>

Source: Division of AIDS, National Institute of Allergy and Infectious Diseases, version 1.0 December 2004, clarification August 2009.

*NOTE:* This clarification includes the addition of Grade 5 toxicity, which is death.

For abnormalities not found elsewhere in the toxicity table, use the information on Estimating severity grade in the first column.
Appendix 5: TB regimens in adolescents with TB Disease


<table>
<thead>
<tr>
<th>Body Weight kg</th>
<th>Initial phase</th>
<th>Continuation phase</th>
<th></th>
</tr>
</thead>
<tbody>
<tr>
<td></td>
<td>Rifampicin/Isoniazid 60/60</td>
<td>Pyrazinamide 500mg</td>
<td>Ethambutol 400mg</td>
</tr>
<tr>
<td>15-19.9</td>
<td>3 ½ tablets</td>
<td>1 tablet</td>
<td>1 tablet</td>
</tr>
<tr>
<td>20-24.9</td>
<td>4 ½ tablets</td>
<td>1 ½ tablets</td>
<td>1 tablet</td>
</tr>
<tr>
<td>25-29.9</td>
<td>5 tablets</td>
<td>2 tablets</td>
<td>1 ½ tablets</td>
</tr>
<tr>
<td>30-37</td>
<td>2 tablets</td>
<td>2 tablets</td>
<td>2 tablets</td>
</tr>
<tr>
<td>38-54</td>
<td>3 tablets</td>
<td>3 tablets</td>
<td>2 tablets</td>
</tr>
<tr>
<td>55-70</td>
<td>4 tablets</td>
<td>2 tablets</td>
<td>2 tablets</td>
</tr>
<tr>
<td>&gt;71</td>
<td>5 tablets</td>
<td>2 tablets</td>
<td>2 tablets</td>
</tr>
</tbody>
</table>

Malnourished or HIV positive adolescents should receive pyridoxine 25 mg daily with TB treatment

**Note:** All previously treated adolescents must be assessed and investigated for drug resistant TB. If drug susceptible TB, treat and monitor closely for clinical response and adverse events.
Appendix 6: TB prevention


### Summary: TB infection control interventions

**Supportive interventions to implement TB infection control:**
- Formation of an Infection Control and Prevention Committee
- Training of staff in TB infection control interventions
- Education of the community in TB/HIV awareness and prevention
- TB/HIV collaborative activities

**Administrative controls reduce the production of infectious TB particles in health care facilities:**
- Screening of clients for cough as they enter the facility
- Education of clients in cough hygiene
- Provision of masks/tissues to coughing clients as they enter the facility
- Separation of clients who cough from those who don’t
- Reduction of waiting times for clients who cough
- Early referral and investigation of clients who are coughing for TB
- Provision of a safe environment for collection of sputum

**Environmental controls eliminate infectious TB particles in health care facilities:**
- Well ventilated waiting areas for clients
- Maintenance of good air circulation by opening windows and use of fans in waiting areas and consultation rooms
- Use of ultraviolet germicidal radiation

**Personal risk reduction to reduce the inhalation of infectious TB particles by staff and clients, and reduce risk for TB disease:**
- Use of N95 respirator/masks to prevent inhalation of TB
- Encouraging clients and staff to know their HIV status, and to take INH prophylaxis if appropriate
- Training in infection control strategies

### References:

APPENDICES

Appendix 6: TB prevention  continued

Fact Sheet: Ventilation and TB Infection Control

Why is ventilation important in the implementation of infection control?

Tuberculosis is spread by airborne route. Infectious particles (droplet nuclei) are suspended in the air and infection with TB is acquired by inhalation of infectious particles. Breathing clean air (air free of TB particles) will not lead to TB infection; therefore keeping air clean is critically important. This can be achieved by ensuring good ventilation.

How can I measure ventilation rates?

Ventilation rates are measured by ‘air changes per hour’ (ACH). This is calculated by dividing room ventilation rate (m³/hr) by the room volume (size, in m³). Ventilation rate for naturally ventilated spaces are difficult to calculate (refer National TB Infection Control Guidelines). However one can ‘feel’ if air is moving within the environment, and confirm this using the smoke test (refer to Section 4). Air-conditioners usually have fixed or variable settings which can be read on the unit. An air-conditioning technical specialist can assist.

How does natural ventilation compare with mechanical ventilation (air conditioning)?

Natural ventilation is almost always more effective than mechanical ventilation. A study in Peru showed that natural ventilation achieved more than 17-40 air change per hour (ACH), while well functioning air conditioning in isolation rooms achieved 12 ACH.

What are recommended ventilation rates for health care facilities?

The CDC recommends 12 air change per hour (ACH) for respiratory isolation rooms and areas where suspected TB patients are managed. In South Africa, we do not have resources for isolation rooms. When considering TB infection control issues, all persons attending health care facilities should be managed as TB suspects.

If I cannot open windows, or if mechanical ventilation is used in my facility, how can I ensure that ventilation rates are adequate?

Consult an air conditioning technical expert and present the problem and the requirements.

Maintain air conditioning units regularly, according to a schedule

Ensure that air mixing is taking place in the facility and in high risk consulting rooms

Keep the direction of air flow correct to minimize risk to health care workers, especially in the consulting rooms.

What is ‘ventilation’?

Ventilation refers to the removal of old, stale or ‘diseased’ air, and replacing it with new, fresh or ‘clean’ air. This has the effect of removing infectious particles, and diluting those that remain, so that the chances of inhaling infectious particles are kept to a minimum. Ventilation can also control the direction of air flow so that air flows from less contaminated areas.

What is ‘air mixing’?

Air mixing refers to the mixing of existing air within an environment so that infectious particles are evenly mixed within an environment and pockets of air with high concentrations of infectious particles are evenly distributed. This will mean that all infectious particles have an equal chance of being removed or diluted by ventilation. Air mixing is essential if ventilation is to be effective. If air is not mixed properly, ventilation may not remove enough infectious particles.

How can I mix the air?

Air can be mixed by using fans (standing fans or extraction fans) or by opening windows and taking advantage of wind or natural flow patterns of air within an environment.

What is ‘directional air flow’ and how can I use this to keep health care workers safe?

Air should flow from low concentration of infectious particles, towards a high concentration. The HCW should always be ‘upwind’ of the patient – ie clean air should flow from behind the HCW towards the patient.

References:

2. RSA NDOH National TB Infection Control Guidelines. June 2007
Fact Sheet: N95 Respirator/Masks

What is an N95 respirator/mask and how does it work to prevent transmission of TB?
Masks placed in front of and around the mouth and nose can act as filters, to capture infectious particles and prevent them from being inhaled. In this way, infection with TB can be prevented. Masks in this context can be called ‘particulate filter respirators.’ Droplet nuclei that have potential to transmit TB infection are 1-5μm in diameter. Masks that are able to prevent TB infection must capture particles this size and larger.

N95 respirator/masks meet specifications required by the United States National Institute for Occupational Safety and Health (NIOSH) which include:

- Filter size of 1μm in size
- Filter efficiency = 95%
- Tight facial seal.

The letter ‘N’ in N95 refers to the fact that the mask/filter is ‘Not resistant to oil’.

How well do the N95 respirator/masks prevent TB infection?
No-one has been able to measure this! Some guidelines don’t even recommend the use of these masks! But one thing is for certain – they will NOT work if:
- They are not properly fitted
- If the wearer has facial hair (beard) preventing a proper fit
- They are damaged or crushed
- They are saturated (reused until the filter capacity has been exceeded)
- They get wet (even if they dry again).

Can I re-use N95 respirator/masks?
N95 respirator/masks are expensive. It is helpful to re-use them. New masks can be issued after 2 weeks of use. General guidelines to facilitate reuse include:
- Each staff member should re-use their own mask (it is helpful to write the staff member’s name on the mask)
- Keep the mask dry and clean.
- Replace masks if they are damaged, or get wet
- Never use the mask ‘inside out’ or reversed.

Who should use ordinary surgical masks?
Surgical masks are very different from N95 respirator/masks. They have only 50% filter efficiency and lack a tight facial seal. Infectious patients should use ordinary surgical masks because these reduce the numbers of infectious particles in the air. Surgical masks are useful to catch larger respiratory droplets and prevent droplet nuclei from forming.

Who should use N95 respirator/masks, and when?
HCW (and visitors) should use N95 respirator/masks in specific high-risk areas only¹. These could include:
- Areas where administrative and environmental controls probably will not protect persons from inhaling infectious airborne droplet nuclei. This would include the clinic rooms where TB suspects are seen, hospital casualty facilities, MDR TB treatment facilities.
- When dealing with patients with suspected or confirmed infectious TB (i.e. pulmonary TB, not TB meningitis)
- When cough-inducing procedures are performed on patients with suspected or confirmed TB disease;
- XDR or MDR treatment points or facilities.

Masks are NOT a substitute for administrative and environmental controls. Masks will improve personal protection when administrative and environmental controls are functioning optimally.

Which TB patients are most infectious?
TB suspects with the following symptoms or conditions are more likely to be infectious:
- Cough
- Cavitation on chest x-ray;
- Positive AFB sputum smear result;
- Respiratory tract disease with involvement of the lung or airways, including larynx;
- Failure to cover the mouth and nose when coughing;
- On TB treatment for less than 2 weeks.

References:

Fitting an N95 respirator/mask
A mask will provide no protection if it is not properly fitted, as air will flow through ‘gaps’ between the mask and the wearer’s skin. Fit-tests should be done when selecting the type of mask that your facility uses as variability in facial structure can mean that different types of masks fit better. Any facial hair, such as beards or long sideburns, may prevent the respirator from fitting properly. An informal way to test the fit of your mask is as follows:
- Fit the mask according to manufacturer’s instructions.
- Once the mask is in place, inhale sharply. The mask should be drawn in towards your face, indicating that a negative pressure has been generated.
- If the mask does not draw in towards your face, or you feel leakage at the edges, adjust straps by pulling back along the sides and/or reposition respirator.
- Repeat until mask is sealed properly.

Figure 1. (A). N95 respirator/mask (B) Air leaks on an incorrectly fitted N95 respirator/mask.
Appendix 7: Distress protocol for managing adolescent rape victims

Distress protocol for managing adolescent rape victims

*Important: know where your community/clinic/hospital/police station referral options are. This ensures effective and safe referral of adolescent victims.*

*Legal definition of rape:* ‘Any person (‘A’) who unlawfully and intentionally commits an act of sexual penetration with a complainant (‘B’), without the consent of B, is guilty of the offence of rape.’ (Criminal Law (Sexual Offences and Related Matters) Amendment Act 32 of 2007, ss3.)

*Rape:* a crime reliant on physical evidence; a crime where the testimony of the victim can be viewed with mistrust by the legal system (health professionals, courts, prosecutors, police); each case is unique but what needs to be proven is **penetration and no consent.**

Although many may think that it is ‘traumatising to victims’ to be asked about interpersonal violence, research indicates quite the opposite (De Prince et al, 2004 & Griffin et al, 2003); victims are relieved that somebody has asked and is concerned. You will need to be prepared for the victim’s reply and response.

There is much we can do: firstly, respond appropriately (empathically and respectfully); ask what you can do to assist (surprisingly, victims sometimes don’t want intervention other than having someone to listen to them); if appropriate, refer to Thuthuzela Care Centres (TCCs) and medico-legal clinics (http://www.info.gov.za/events/2009/TCC_2009.pdf). Let the police and Department of Social Development, Child Welfare/ChildLine know, especially if adolescents are involved (health professionals are mandated reporters).

Sexual assault victims have the right to proper post-exposure prophylaxis (PEP) and this MUST be obtained within 72hrs of the assault for it to be effective. Find out which facilities in your area are mandated to administer PEP so that if victims come to your facility, you know where to send them fast.

**Guidelines for dealing with the victim:**

- Manage your own response to the events of your client.
- The client will probably present with feelings of guilt and shame, heightened confusion, heightened emotion (ranging from dysregulated affect to a numbed responsiveness), a keen sense of feeling unsafe and having little control.
- Make sure the victim feels safe. Remember most perpetrators are known to their victims: it could be that the perpetrator brings the victim to your care. Ask the victim what would make them feel safer and ensure conversations are held in private.
- It is important that the rape victim feels acceptance and support, regardless of her/his emotional response.
- Do not evaluate or pass judgement on the credibility of the circumstances of the assault, especially if there was alcohol consumption or drug use.
- Providing help to victims of sexual assault requires significant sensitivity. Social, cultural, and religious practices may cause victims additional stress, especially if they are concerned about discriminatory treatment while seeking support and accessing services.
- Privacy is important and should be respected, but don’t leave the victim alone.
- Know the medical and legal procedures for victims.
Appendix 7: Distress protocol for managing adolescent rape victims  

A. History: obtain and document the following:
1. Time, date, and place of the attack.
2. Ascertain all body areas violated in the attack.
3. If the victim is still wearing the clothing worn during the assault, suggest she/he take other clothing with her/him to be worn home.
4. If the client changed clothes after the attack, the clothing must be brought along to the hospital in a paper bag.
5. All marks or evidence of trauma and other significant physical findings.
6. Medical history, including possibility of pregnancy.

B. Physical exam: unless a life-threatening condition occurs:
1. Carefully explain all procedures to be performed prior to undertaking them.
2. Obtain consent for the examination. Do not assume that your presence automatically implies consent to treatment on part of the client.
3. Where possible, limit the physical examination to any evidence you can visually obtain without causing any further emotional distress to the client.

Prepare the victim for the examination
- The victim has experienced trauma and may be in an agitated, depressed or numbed state of mind. The health workers must prepare the victim for the examination and undertake this care in the most respectful, compassionate, systematic, and complete fashion.
- Explain what is going to happen during each step of the examination: why it is important, what it will tell you, and how it will influence the care you are going to give.
- Explain that she/he is in control of the pace, timing and components of the examination.
- Ask the victim if she/he has any questions.
- Ask the victim if she/he wants to have a specific support person present.
- Limit the number of people allowed in the room during the examination.
- Undertake the examination as soon as possible.
- Do not force the victim to do anything against her/his will.
- The client will have an HIV test and will be given PEP. If the HIV test results are negative, the client must take the full 28-day course of PEP for it to be effective. Giving complicated medical information to a traumatised person increases confusion: make sure you write down what their medical instructions are and give your number so they can call if they need clarity.
  - The client will need to take another HIV test after six weeks, three months, six months and a year. This is very important, as the initial 6 week test may produce a false negative (although this is uncommon).
  - All clients should also be treated for the following:
    - antibiotics for sexually transmitted infection (STI) prevention
    - the ‘morning after’ pill to prevent pregnancy
    - medication/vaccination to prevent Hepatitis B.
Appendix 7: Distress protocol for managing adolescent rape victims  continued

If the victim would like to lay charges they need to go to the police station (this is not a mandate but up to the victim). At the police station, the victim has the right to:

- make her/his statement in a private room
- make her/his statement to an officer they feel comfortable with (e.g. for a female victim, she can request a female officer, if available)
- make her/his statement in their own language
- have a friend/family member with her/him for support.

Guidance to the support person/caregiver

- Don’t criticise or blame victims
- Listen
- Don’t over-simplify
- Reassure victim that you are there
- Don’t take control of the situation
- Help victim feel safe
- Don’t do unexpected things
- Don’t blame yourself
- Don’t be afraid to talk to victim
- Don’t be afraid to ask victims how they are doing, if they would like a hug or if they would like to be left alone.
Appendix 8: Medical and legal protocol for adolescent rape victims

Algorithm for rape protocol

Person allegedly sexually assaulted

Medical response

Open a folder. Take a history

Prepare and complete a physical examination

Give relevant medication for prevention of STIs, pregnancy, hepatitis B

Within 72 hours

Counselling and testing

If negative

Give PEP

Re-test at 6 weeks, 12 weeks, 6 months, 1 year

If positive

Counselling and client declines testing

Give PEP for 3 days and ask to come back within 3 days. Repeat counselling if client still declines testing

Patient referred for HAART and continued HIV management

Legal response

Rape: a crime reliant on physical evidence, where penetration and no consent must be proved

Report of rape can be made to the police at any time: before or after medical examination

Patients Rights

• Make her/his statement in a private room
• Make her/his statement to an officer they feel comfortable with (e.g. if a female victim, she can request a female officer)
• Make her/his statement in spoken/written language of choice
• Have a friend/family member with them for support

Working with adolescents living with HIV: A handbook for healthcare providers
Appendix 9: Psychosocial assessment tool


How to Use This Tool

This Psychosocial Assessment Tool was developed to support a range of providers (trained counsellors, lay counsellors, doctors, nurses, and others) who work with ALHIV and their families. Conduction a psychosocial assessment with each client (and caregiver, if applicable) helps providers learn more about the client’s specific situation helps them prioritise needs, and helps give direction to ongoing counselling and psychosocial support. This includes referrals for needed community- and home –based services.

A psychosocial assessment should be conducted with each adolescent client both after enrolment in HIV care and treatment services and annually after that. Health workers may want to conduct another psychosocial assessment or revisit specific psychosocial issues when a client’s situation changes in a significant way, such as when a client reaches a new developmental stage or starts to show signs that he or she is facing new challenges or problems. Always respect client confidentiality and conduct sessions in a space that offers visual and auditory privacy. Key information from the psychosocial assessment should be recorded on the form and the form should be kept in the client’s file for reference during follow-up visits.

Basic information: Write down the client’s name and file number. Be sure to sign and date the form at the end of each session.

Questions to ask the client/ caregiver: These questions allow the health worker to discuss and assess the client’s psychosocial issues and needs. It is important to allow time for the client to respond to each question. Clients should always be made to feel comfortable expressing psychosocial challenges and should never be judged or punished. Write down any important information from the client’s responses in the right-hand column, as this will help you to decide on effective next steps, to decide on important areas for follow-up, and in supporting client’s psychosocial well-being over the long term. Also make sure that the client has time to ask questions and that you have time to summarize the session and agree upon next steps. Record key next steps in the space provided.

Additional notes: Write any additional notes about the session or the client’s psychosocial needs in the space provided.

REMEMBER:
• Do not talk down to an adolescent.
• Allow the adolescent to speak for him or herself. Respect his or her opinions.
• Be patient! Allow the adolescent to express his or her views and to describe his or her experiences.

Referrals made: Linkages and referrals to psychosocial support services are an important element of HIV care and treatment programs and the ongoing support of adolescent clients and their families. Each clinic should have an up-to-date list of community support services (such as Adolescent Peer Educators, adherence supporters, ALHIV associations, food support, education and job training programs, gender-based violence services, legal support, etc.) and formal two-way referral systems to these organizations and services. Clients with severe psychosocial and psychological issues (such as depression, alcohol or other substance use disorders, suicidal feelings) will require careful follow-up and immediate referrals to ongoing professional counselling and other services. Record any referrals made to the client in the space provided. At the next session, follow up to determine if the client accessed these services.

Date of next counselling session/ clinic appointment: Schedule a follow-up counselling appointment with the client and record this date, as well as any other clinic appointments, in the space provided.
## ALHIV Psychosocial Assessment Guide and Recording Form

| 1. | Smile, introduce yourself, and give a short explanation of your role. Explain that this discussion will be confidential |
| 2. | Can you tell me how things have been going since you learned your HIV-status (or since we last met)? How are you coping? *Explore and discuss client’s coping strategies* |
| 3. | Tell me about your mood now. Do you feel sad or stressed? What changes have you noticed in your mood? What about in your eating and sleeping habits? *Assess risk of depression and need for referral* |
| 4. | How often in the last week have you used cigarettes, alcohol, or other drugs? *Assess for harmful coping strategies, such as drug/alcohol use, provide counselling and referrals* |
| 5. | To whom have you disclosed your HIV-status? What was their reaction? Do you want to disclose to anyone else? What concerns do you have about disclosure? *Counsel on disclosure* |
| 6. | Who do you feel close to? Who can you go to for emotional support? *Counsel on importance of social support* |
| 7. | Do you belong to a community/religious organization or support group? Would you be willing to join a support group to meet other ALHIV? *Make referrals as needed* |
| 8. | Tell me about any negative attitudes or treatment you’ve experienced. Has anyone caused you harm (e.g., been violent, made unwanted sexual advances)? *Counsel and discuss support services; consider gender-based violence services, if appropriate* |
| 9. | Some adolescents have sex with their partners. It’s important for you and your partner to do this safely. Are you having sex? If so, what are you doing to prevent pregnancy and the spread of STIs and HIV? *Screen for sexual risk-taking and counsel on safer sex, dual protection, etc.; give condoms* |
| 10. | Let’s talk about your living situation. Who are you living with? How long have you lived with them? How well do you get along? *Assess living situation* |

If not living with parents, ask: Where are your parents? When did this happen? How did this affect you?
### Appendix 9: Psychosocial assessment tool  
*continued*

<table>
<thead>
<tr>
<th>11. Tell me what you do most days. Do you, for example, go to school or work outside the home? Where do you go to school/work? How is this going for you?</th>
<th></th>
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<tbody>
<tr>
<td><strong>Assess school/work situation</strong></td>
<td></td>
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<tr>
<td>12. Do you have financial support from you family or partner, a regular source of income, or do you receive help, such as social grants or food? <strong>Refer to social worker and community-level support</strong></td>
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<tr>
<td>13. Other than coming to this clinic, where else do you go for health services (for example, other clinics, traditional healers, etc.)?</td>
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<tr>
<td>14. How do you/will you remember to come to this clinic for your appointments and refills? How do you/will you manage it with your school or work? Who can help you? <strong>Counsel on adherence to care</strong></td>
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<tr>
<td>15. How do you/will you remember to take your medications every day? How do you/will you remember when to come back to the clinic? Who can help you? <strong>Counsel on adherence and briefly discuss:</strong> • <strong>WHO</strong> will give or manage your medicines? • <strong>WHEN</strong> will you take them? • <strong>WHERE</strong> will you store them? • <strong>HOW</strong> will you remember to take them (revise use of reminders, like calendars, pill boxes, etc.)</td>
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<tr>
<td>16. What other question or concerns do you want to discuss today? Would you like to bring someone else into our conversation – today or at another visit (e.g. family member, partner)?</td>
<td></td>
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<tr>
<td>17. Summarize the session and review immediate plans and next steps, including the next clinic visit date.</td>
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**Notes:**

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Appendix 9: Psychosocial assessment tool  

<table>
<thead>
<tr>
<th>Referrals made:</th>
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Date of next counselling session / clinic appointment: ________________________________

Health worker signature: ________________________________  Date: ____________________
### Appendix 10: Tips for health workers on identifying possible mental illness


<table>
<thead>
<tr>
<th>Categories</th>
<th>Sign of a possible metal illness that require follow-up</th>
</tr>
</thead>
<tbody>
<tr>
<td><strong>1. Ask the client and caregiver about:</strong></td>
<td></td>
</tr>
</tbody>
</table>
| Present history (reported by client or caregiver) | • Reports symptoms of mental illness or mental distress  
• Reports new problems functioning at home, school, work or new problems with friends and family  
• Reports a dramatic change in behaviour and/or a major decrease in psychosocial functioning (e.g., used to be very calm, now violent, used to do well in school, now failing behind; used to be friendly, is now withdrawn, etc.)  
**Note:** Review the client’s HIV history, recent changes in disease status, and ART regimen (including dosing or medicine changes) |
| Past history (reported by adolescent client or caregiver) | • Reports a past history of mental distress; problems functioning at home, school, work; or problems with friends and family  
• History of psychiatric hospitalization, treatment, or psychotropic medication use  
• History of school failure  
• History of severe behavioural disturbances  
• History of mental illness in the family |
| **2. Observe and ask for the caregivers observations of the client’s:** | |
| Appearance and presentation | • Hygiene and grooming are poor  
• Comes across as frightening or frightened  
• Has alcohol on his or her breath or appears intoxicated  
• Does not make eye contact  
• Crying, shouting, or laughing uncontrollably |
| Attitude and behaviour | • Restless, belligerent, or uncooperative  
• Making threats  
• Unwilling to unable to speak  
• Behaving in odd and unusual ways |
| Mood and emotions | • Seems frightened, sad or angry  
• Unusually happy for no apparent reason |
| Speech, thinking, and perception | • Speaking very rapidly or overly loud  
• Whispering or speaking very softly  
• Saying things that make no sense  
• Saying things that are unlikely to be true  
• Claiming to hear voices or to see visions of people/things that are not there |
| Level of alertness and orientation | • Having trouble staying alert and attentive  
• Drowsy  
• Confused about things such as where he or she is or the time of day |
| Social and intellectual skills | • Lacks verbal, behavioural, and/or social skills that would be expected of someone his or her age  
• Behaving like a much younger child/adolescent |
| **3. Conduct regular psychosocial assessments and document major findings (see Module 5)** | |
| Conduct a psychosocial assessment (at enrolment, annually, and when the client’s situation changes significantly) | • Major changes in mood  
• Experiencing chronic sadness or anxiety  
• Changes/problems in sleeping, eating, or other routines  
• Harmful coping strategies, including use of alcohol or drugs  
• Problems in school, with friends, or with family members |
Appendix 11: Distress protocol and screening tools for managing suicide ideation in adolescents

If a client says that they are very depressed or indicates that they are feeling suicidal (things are too tough to keep on living), the recommended action plan is as follows:

**Note**: Let the adolescent know that you will need to break confidentiality to ensure their safety as you are mandated by law to report when adolescents are in danger of harming themselves or others (this conversation is helpful at the beginning of the session).

Be kind, empathetic and non-judgemental when assessing the risk for suicide (whether the patient reports just thinking about it or whether they are actively planning an attempt or have attempted to commit suicide in the past). Manage your own reaction to this disclosure and adopt a collaborative position. Understand risk and protective factors and assess the risk factors present for the patient. Engage in an assessment of suicide risk by asking direct questions; assess mental status and formulate a safety plan.

It’s essential that you take suicidal behaviour or previous attempts seriously; and get assistance quickly. Aside from professional treatment, a suicidal adolescent needs to know that there are people able to support them, and who are available to talk to. A person should be reassured that there are always solutions to problems or ways other than suicide for coping with them. **Don’t hesitate to bring up the subject of suicide, and to ask direct questions.** Somebody who hasn’t considered ending their life isn’t going to adopt the idea simply because the possibility has been raised. On the other hand, for individuals who are thinking about suicide, your concern will only be reassuring; people can take the opportunity to open up about their distress. **Restricting access to firearms and ammunition is also an important preventive measure.** Weapons kept in the home increase the risk that suicide attempts will be successful, by giving a suicidal adolescent the means to take their own life.

**Step 1: Explore the adolescent’s comments to see what they mean**

Ask:
- *How are you feeling about things that have happened to you?*
- *Sounds like you might be feeling hopeless [helpless, alone] right now. Is that correct?*

**Step 2: Ask about suicide**

Don’t be afraid to ask directly. If we ask indirectly, we may get mixed signals and then the real risk is not understood. It is OK to talk about suicide.

Ask:
- *Sometimes when people feel bad, they have thoughts of harming or killing themselves.*
- *Have you had such thoughts?*
- *Are you thinking about suicide?*
- *Are you planning to kill yourself?*
- *Do you ever wish you could go to sleep and never wake up?*
- *Are you so overwhelmed you can’t seem to see the solutions to some of your problems?*
Appendix 11: Distress protocol and screening tools for managing suicide ideation in adolescents  

Step 3: Review the risk

Ask about current suicide plan:
*Have you thought about how and when you would do it? What have you done about carrying out your plan?*

Ask about their means:
*How would you do it? Do you have easy means to facilitate your plan (i.e. access to firearm or excessive drugs etc.)*

Ask about resources:
*Do you feel you have few, if any resources?*

Ask about prior suicidal behavior:
*Have you attempted suicide before?*

Ask about their history of mental health:
*Are you receiving or have you received mental healthcare?*

*Note:* Adolescents who have attempted suicide in the past and are actively planning a current attempt may need to be hospitalised immediately as they are very high risk.

<table>
<thead>
<tr>
<th>RISK LEVEL</th>
<th>RISK/PROTECTIVE FACTOR</th>
<th>SUICIDALITY</th>
<th>POSSIBLE INTERVENTIONS</th>
</tr>
</thead>
<tbody>
<tr>
<td>High</td>
<td>Psychiatric diagnoses with severe symptoms or acute precipitating event; protective factors not relevant</td>
<td>Potentially lethal suicide attempt or persistent ideation with strong intent or suicide rehearsal</td>
<td>Admission generally indicated unless a significant change reduces risk. Suicide precautions</td>
</tr>
<tr>
<td>Moderate</td>
<td>Multiple risk factors, few protective factors</td>
<td>Suicidal ideation with plan, but no intent or behaviour</td>
<td>Admission may be necessary depending on risk factors. Develop crisis plan. Give emergency/crisis numbers</td>
</tr>
<tr>
<td>Low</td>
<td>Modifiable risk factors, strong protective factors</td>
<td>Thoughts of death, no plan, intent or behaviour</td>
<td>Outpatient referral, symptom reduction. Give emergency/crisis numbers</td>
</tr>
</tbody>
</table>

Step 4: Listen to their reasons for dying and living

It encourages the person to think of other options in life and can shift their focus and thinking. Be gentle:

- *What is happening to make you feel this way?*
- *What would make you change your mind, do you think?*
- *What is it you still want to achieve in your life?*  
  *(Examples of internal: feelings, hope, beliefs, value, faith, attitudes, skills. Examples of external: family, future, work, relationship, pets, hobbies.)*
Step 5: Contract a ‘safety plan’ with the adolescent

- Explore the adolescent’s resources that they can make use of when they start to feel very depressed or have thoughts of suicide:
  - informal resources: family and friends (accessed immediately if needed); advisers (these could be friends, peers, community groups); personal connections (include hobbies, internal resources)
  - formal resources: emergency (hospitals; GP; social worker); health workers (counsellors, youth workers, teachers, social workers); community (support groups, clergy, GP, youth groups).
- Link the safe plan to the risk alert.

Step 6: Make referral

If the adolescent is high risk, you may need to refer or have them admitted into hospital. This can be done by referral from a doctor, nurse, social worker, psychologist or psychiatrist. It is important to make the legal guardians and caregivers of the adolescent aware of the risk and contract them in safety planning. Remind the adolescent that you are a mandated reporter and need to break confidentiality and let other significant people know the current risk of harm. If the adolescent is low risk, refer them for counselling services at the clinic or a local NGO who can help them further.

Useful contact numbers:

<table>
<thead>
<tr>
<th>Service</th>
<th>Number</th>
</tr>
</thead>
<tbody>
<tr>
<td>ChildLine Hotline</td>
<td>0800 055 555</td>
</tr>
<tr>
<td>LifeLine Hotline</td>
<td>0861 322 322</td>
</tr>
<tr>
<td>Suicide Hotline</td>
<td>0800 567 567 3</td>
</tr>
</tbody>
</table>
Appendix 12: Distress protocol and screening tools for managing substance and alcohol abuse in adolescents

Substance abuse is the overindulgence in or dependence on an addictive substance, especially alcohol or drugs.

Binge drinking is drinking large quantities of alcohol in a short period of time; or drinking to get drunk or feel the effects of alcohol.

Assessing the problem
- Substance use should be evaluated as part of an age-appropriate comprehensive history. Reviewing the adolescent’s environment can identify risk and protective factors for the development of alcohol or drug abuse.
- Use informal methods.
- Recognise the importance and complexity of confidentiality issues, so provide a place where the adolescent can speak confidentially.
- Begin with open-ended questions about substance use at home and school and by peers before progressing to open-ended questions about personal use/abuse.

1) Ask about:
   - the type of substance being used or that they are addicted to
   - the frequency of use
   - the environment of use
   - their history of use
   - their family history with substances/alcohol
   - a history of mental illness
   - previous attempts to seek treatment or stop.

2) Identify the needs of the adolescent and the type(s) of intervention required.

3) Refer the adolescent to:
   - a clinic counsellor, social worker, psychologist or psychiatrist
   - an NGO or community organisation dealing with substance abuse and alcohol abuse
   - an inpatient treatment centres (such as detoxification, rehabilitation or long-term residential treatment)
   - Narcotics Anonymous or Alcoholics Anonymous, or SANCA

USEFUL CONTACT NUMBERS

Alateen General Service Number: 021 595 4508
Alcoholics Anonymous SA National Helpline: 0861 435 722
LifeLine: 0861 322 322
LoveLife: 0800 121 900
Narconon South Africa: 011 622 3998
SANCA: 011 892 3475/011 892 3139