

HIV AND ADOLESCENTS:
GUIDANCE FOR HIV TESTING
AND COUNSELLING AND
CARE FOR ADOLESCENTS
LIVING WITH HIV

RECOMMENDATIONS FOR A PUBLIC HEALTH
APPROACH AND CONSIDERATIONS FOR
POLICY-MAKERS AND MANAGERS

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Abbreviations and acronyms

AFHS	adolescent-friendly health services
AIDS	acquired immune deficiency syndrome
ALHIV	adolescent/s living with HIV
ANC	antenatal care
ART	antiretroviral therapy
ARV	antiretroviral drug
ASRH	adolescent sexual and reproductive health
CBO	community-based organization
CDC	U.S. Centers for Disease Control and Prevention
CQI	continuous quality improvement
CRC	Convention on the Rights of the Child
DAART	directly administered antiretroviral therapy
FGD	focus group discussion
FGM	female genital mutilation
FHI360	Family Health International
GNP+	Global Network of People Living with HIV
HIV	human immunodeficiency virus
HTC	HIV testing and counselling
IDU	injecting drug use
KP	key population
LMIC	low- and middle-income countries
LTFU	loss to follow-up
MCH	maternal and child health
MNCAH	maternal, newborn, child and adolescent health
MNCH	maternal, newborn and child health
M&E	monitoring and evaluation
MSM	men who have sex with men
OST	opioid substitution therapy
PEPFAR	President's Emergency Plan for AIDS Relief
PICO	Problem / Intervention / Comparison / Outcome
PITC	provider-initiated testing and counselling
PLHIV	person/people living with HIV
PMTCT	prevention of mother-to-child transmission of HIV
PWID	people who inject drugs
RCT	randomized controlled trial
SRH	sexual and reproductive health
STI	sexually transmitted infection
TB	tuberculosis
TG	transgender person
UNAIDS	Joint United Nations Programme on HIV/AIDS
UNESCO	United Nations Educational, Scientific and Cultural Organization
UNFPA	United Nations Population Fund
UNICEF	United Nations Children's Fund
USAID	United States Agency for International Development
VCT	voluntary counselling and testing
VMMC	voluntary medical male circumcision
WHO	World Health Organization
YFHS	youth-friendly health services

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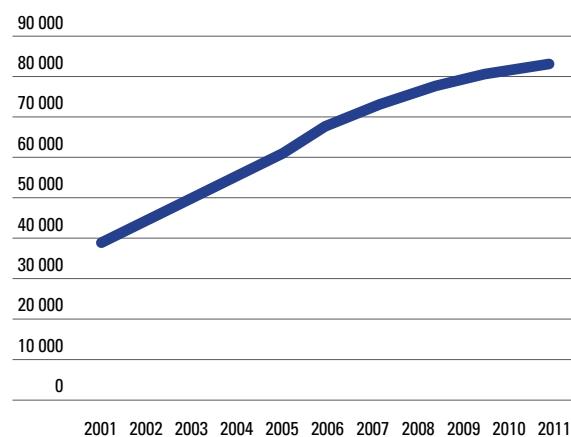
Executive summary

Adolescents (10–19 years) and young people (20–24 years) continue to be vulnerable,¹ both socially and economically, to HIV infection despite efforts to date (1). This is particularly true for adolescents—especially girls—who live in settings with a generalized HIV epidemic or who are members of key populations at higher risk for HIV acquisition or transmission through sexual transmission and injecting drug use. In 2012, there were approximately 2.1 million adolescents living with HIV (2). About one-seventh of all new HIV infections occur during adolescence (2).

Access to and uptake of HIV counselling and testing (HTC) by adolescents is significantly lower than for adults. Survey data collected from sub-Saharan Africa indicate that only 10% of young men and 15% of young women (15–24 years) were aware of their HIV status. However, access and coverage vary considerably across countries and regions.

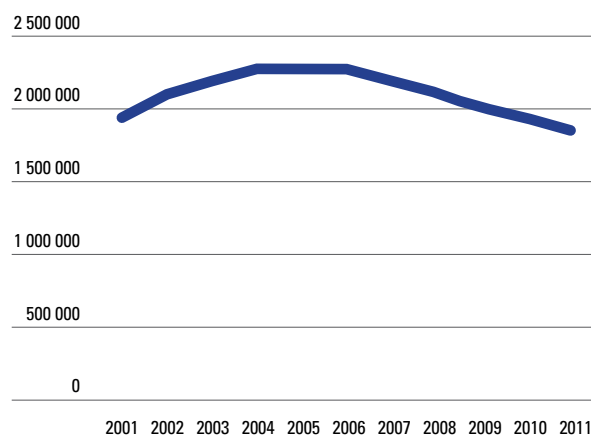
Between 2005 and 2012, HIV-related deaths among adolescents increased by 50%, while the global number of HIV-related deaths fell by 30% (2). This increase in adolescent HIV-related deaths is due primarily to poor prioritization of adolescents in national HIV plans, inadequate provision of accessible and acceptable HTC and treatment services and lack of support for adolescents to remain in care and adhere to antiretroviral therapy (ART).

Total adolescent AIDS-related deaths



Source: Kasedde S et al (3).

Total AIDS-related deaths



Source: UNAIDS (2).

¹ This document focuses on adolescents, ages 10–19 years. However, many programmes focus and report on youth, ages 15–24 years. Inconsistency in data collection often leads to overlapping age categories. This problem is compounded by different definitions of “child”, “adolescent”, “young person” and “young adult”. As a result data specific to adolescents often get lost, as the adolescent age group is subsumed in various different age ranges.

Purpose of the guidelines

Guidance for HTC and on care for adolescents living with HIV (ALHIV) is needed that explicitly considers the range of adolescents' needs and issues. The World Health Organization (WHO), in collaboration with the United Nations Children's Fund (UNICEF), the United Nations Population Fund (UNFPA), the United Nations Educational, Scientific and Cultural Organization (UNESCO) and the Global Network of People Living with HIV (GNP+), has developed these guidelines to provide specific recommendations and expert suggestions—for national policy-makers and programme managers and their partners and stakeholders—on prioritizing, planning and providing HIV testing, counselling, treatment and care services for adolescents.

Scope of the guidelines

HIV testing and counselling

Previous WHO guidance on HTC has concentrated on supporting provider-initiated HTC (PITC) for individuals, with recent guidance issued in 2011 focusing on HTC for couples and in 2013 on augmenting these approaches with community-based HTC. United Nations guidance specifically addressing the needs of adolescents and their health-care providers has not been developed at the global level, although some countries and organizations (e.g. FHI 360, U.S. Centers for Disease Control and Prevention (CDC) and amfAR) have developed guidance for testing young people ages 10–24 years. Access to and uptake of HTC by adolescents (especially those who are members of key populations) is lower than for many other groups, leaving them disadvantaged in terms of seeking and being linked to HIV prevention, treatment and care services. Late diagnosis of HIV infection, resulting in delayed initiation of antiretroviral therapy (ART), for perinatally infected adolescents is increasingly being recognized as a significant problem.

Care for adolescents living with HIV

Access to treatment and care for adolescents with HIV also remains inadequate. Following HTC, there are poor linkages to and retention in care for most populations, and ART coverage rates for adolescents are lower than for other age groups. Interventions and support for sustained treatment adherence and retention in care are challenges in many settings, the inability to address these issues has led to treatment failure and the high levels of HIV related morbidity and mortality increasingly being recognised in this group. Addressing these challenges and adapting systems to deliver good quality, effective health care and social support for adolescents are urgently needed. The WHO *Consolidated guidelines on the use of antiretroviral drugs for treating and preventing HIV infection (hereafter Consolidated ARV guidelines)* provides comprehensive clinical recommendations on the provision of ART for all populations (4), including adolescents, and these adolescent HIV guidelines provide complementary recommendations and operational guidance to support better provision of services to help adolescents remain in care and adhere to ART.

Ways to support better adherence to treatment and retention in care for ALHIV, including **community-based service delivery** and **training for health workers** and a range of other service delivery recommendations from the *Consolidated ARV guidelines* are also discussed, with specific consideration given to these for adolescent service provision.

Key populations

For these guidelines, **key populations** are defined as those populations at higher risk of HIV (those populations disproportionately affected in all regions and epidemic types, specifically sex workers, men who have sex with men, transgender people and people who inject drugs). These guidelines specifically address adolescent key populations, i.e. those aged 10 to 19 years. In addition to the groups mentioned above, other adolescents who are vulnerable to HIV include those who are sexually abused and/or exploited and those in prisons and other closed settings.

Principles guiding the development of the recommendations

- Compulsory or mandatory HIV testing of individuals on public health grounds or for any other purpose is a violation of human rights and counterproductive to accessing acceptable testing, treatment and care services as well as retention in care. Therefore, these guidelines do not support it.
- The heterogeneity of adolescents is recognized and requires flexibility and adaption of services and approaches, in addition to the context and local epidemiology.
- The meaningful involvement of adolescents, particularly ALHIV, as well as those at risk of HIV infection, is critical for developing and delivering effective and acceptable HTC and HIV treatment and care services for adolescents.
- All forms of HTC must adhere to the five Cs: Consent, Confidentiality, Counselling, Correct test results and Connections to treatment, care and prevention services.
- Issues that may be particular to male, female or transgender adolescents must be recognized and addressed when developing, providing, monitoring and evaluating services for adolescents.
- All services must be provided within a robust human rights framework.¹
- A supportive and conducive legal and policy environment is essential for effective and acceptable service provision.²
- For those under 18 years of age, testing and counselling services need to consider the best interests of the child as well as appropriate and safe referrals to child protection services when children have been abused and are at risk of abuse. Referral to legal/social services is also needed for adolescents aged 18–19 years.

This guidance highlights issues relating to adolescent **consent to HTC**. Policies related to age of consent to testing can pose barriers to adolescents' access to HTC and other health services. While policies on age of consent to HIV testing vary among countries, ministries of health are encouraged to revisit these policies in light of the need to uphold adolescents' rights to make choices about their own health and well-being (with consideration for different levels of maturity and understanding). The guidelines strongly encourage consideration of ways to strengthen **support for disclosure** by adolescents.

The guidelines consider **operational approaches** and options and provide a range of programme examples and guidelines principles for implementation. **Research gaps** identified in the course of the expert meeting and guideline development process are also documented.

¹ See CRC, General Comment 4 – <http://tb.ohchr.org/default.aspx?Symbol=CRC/GC/2003/4>; General Comment No. 15 (2013) – The right of the child to the enjoyment of the highest attainable standard of health (Article. 24).

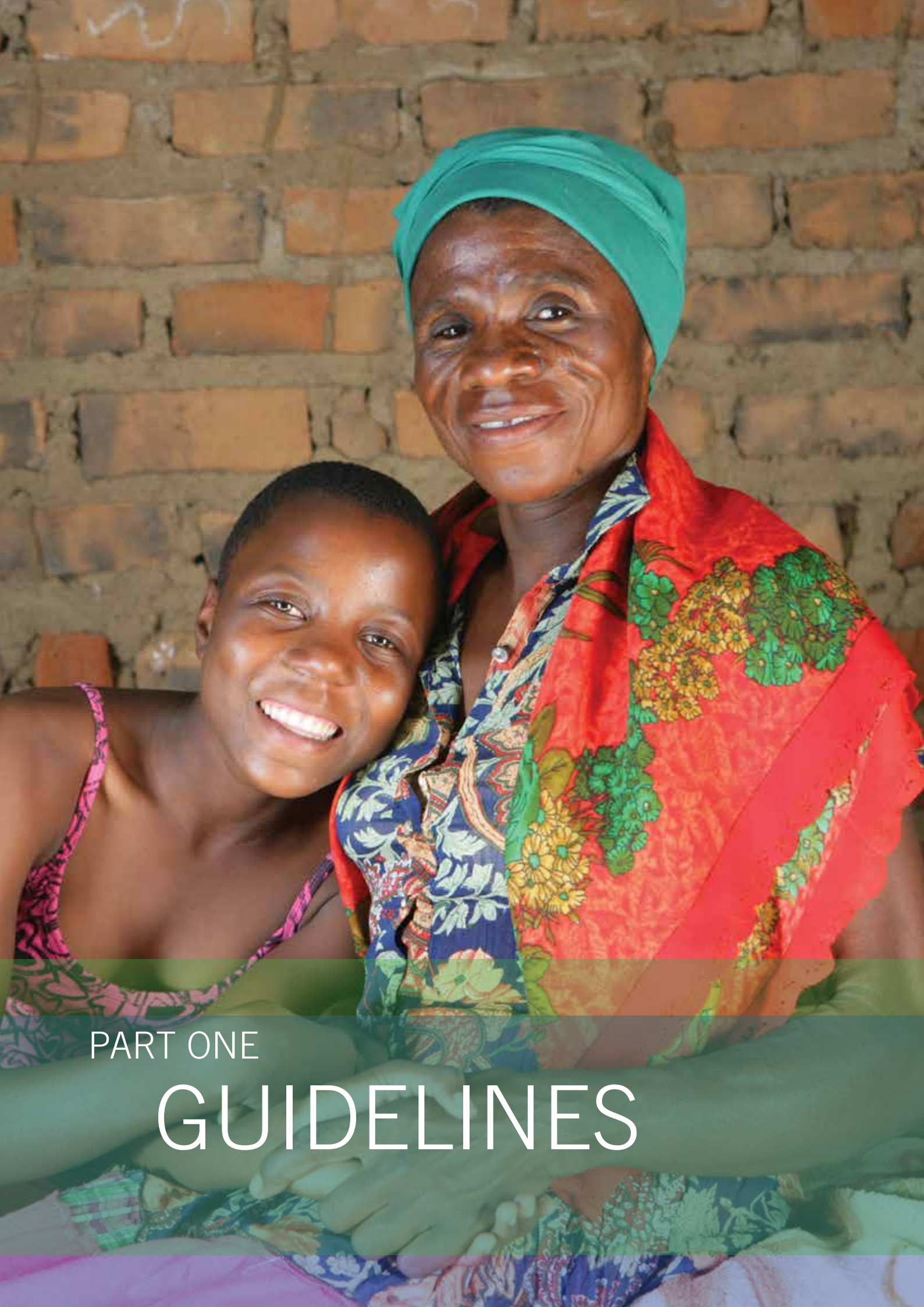
² A supportive and conducive legal and policy environment is critical for adolescents to access and benefit from HIV testing, counselling and linkage to appropriate treatment and care. The criminalization of HIV transmission, exposure and non-disclosure restricts an adolescent's ability to access and benefit from a range of essential HIV-related services.

RECOMMENDATIONS

1. HIV testing and counselling, with linkages to prevention, treatment and care, is recommended for adolescents from key populations in all settings (generalized, low and concentrated epidemics).
2. In generalized epidemics, HIV testing and counselling with linkage to prevention, treatment and care is recommended for all adolescents.
3. In low and concentrated epidemics, HIV testing and counselling with linkage to prevention, treatment and care is recommended to be made accessible to all adolescents.
4. Adolescents should be counselled about the potential benefits and risks of disclosure of their HIV status to others and empowered and supported to determine if, when, how and to whom to disclose.
5. Community-based approaches can improve treatment adherence and retention in care of adolescents living with HIV.
6. Training of health-care workers can contribute to treatment adherence and improvement in retention in care of adolescents living with HIV.

The recommendations regarding HTC for adolescents, disclosure, community-based approaches and training for health-care workers imply significant benefits for all socio-economic and epidemiological contexts and should be considered as global guidance. At the same time, it is recognized that health services in low-resource settings face the greatest challenges in providing services tailored for adolescents and may benefit most from the guidance presented here. Countries are encouraged to consider this guidance in light of the nature of the HIV epidemic in their setting and their national policies, programmes and resources.

This guidance is informed by human rights considerations, systematic reviews of the published and gray literature, community consultations with adolescents and health workers, field experience and expert opinion. Published evidence in adolescent populations is, however, limited or lacking and considerable weight is given to expert opinion, to the values and preferences of adolescents and their health-care providers and to the field experience of practitioners.



PART ONE

GUIDELINES

1.1 Background

More than 35.3 million people are currently living with HIV, and 2.1 million (5.9%) of these are adolescents ages 10–19 years (1, 2)¹. In 2012, there were more than 6300 new HIV infections each day worldwide (2). Around 2500 of these new cases were adolescents and youth ages 15–24 (2, 5).

While most of the approximately 712 new cases of HIV that are diagnosed each day in children under 15 years of age were due to vertical transmission, a small percentage were the result of horizontal transmission, including sexual transmission through sexual abuse or coercion, or early sex (5). Adolescents and young people remain extremely vulnerable to acquiring HIV infection, especially girls who live in settings with a generalized HIV epidemic or who are members of populations at high risk for HIV acquisition or transmission. (See Part 1, Section 2.1.2 for discussion of adolescent key populations.)

The last decade witnessed significant progress in scaling up access to HIV treatment and care. By the end of 2012, more than 9.7 million people from low- and middle-income countries (LMIC) were receiving antiretroviral therapy (ART) (1). Corresponding to this effort, HIV-related mortality has declined. However, global ART coverage is still inadequate at 61%², and most people living with HIV do not know their serostatus (2).

Early diagnosis and treatment can reduce HIV progression and prevent transmission, but adolescents are less likely than adults to be tested, access care, remain in care and achieve viral suppression (6, 7, 8, 9, 10). Although coverage data on adolescents receiving treatment is limited, adolescents' access to and uptake of treatment is often reported to be lower than for other age groups (11, 12). It is urgent that ALHIV are identified and enrolled in treatment interventions with clear and consistent linkages to care and support.

As of 2012, about 630 000 infants, children, and young adolescents below 15 years had been started on ART, representing a 28% coverage rate among children who need paediatric ART (1). This coverage follows increased emphasis on prevention of mother-to-child transmission (PMTCT) programmes that include early infant diagnosis and early initiation of treatment for infants.³ Over the next decade, these infants and young children with HIV on ART will become adolescents and face the challenges of adolescence as well as those associated with coping with living with a chronic infection, developing relationships and preventing transmission.

A substantial epidemic of HIV in perinatally infected adolescents is emerging in southern Africa. These adolescents include both those who were started on ART as infants as part of PMTCT programmes and perinatally infected children who were not started on ART either because their mothers were not reached by PMTCT programmes or they were lost to follow-up and have survived into adolescence without ART (often referred to as slow progressors). Data suggest that up to one-third of infants infected with HIV who are not started on ART are slow progressors with a median survival of greater than 10 years (13). The increasing cumulative number of slow progressors and infants and young children on ART (who must be supported to cope with the challenges of being on long-term treatment) highlights

¹ See Annex 1 for a glossary of key terms and definitions.

² Using the WHO 2010 ARV guidelines.

³ Some countries refer to this as prevention of parent-to-child transmission (PPTCT); the more common term, PMTCT, will be used in these guidelines.

the importance of urgently addressing the clinical needs of older children and adolescents with HIV (14). HIV is increasingly being recognized as a common cause of acute admission and in-hospital death among adolescents in high-prevalence, generalized epidemics (15, 16, 17).

Although rapid expansion of HIV treatment has significantly improved survival, life expectancy and quality of life for people living with HIV (PLHIV), delayed ART initiation remains a challenge in many settings, including high-income countries (18, 19). Previous WHO guidelines recommended ART initiation below 350 cells/mm³, and 42 LMIC had adopted this recommendation in their national ART guidelines (20). WHO now recommends (in the 2013 *Consolidated guidelines on the use of antiretroviral drugs for treating and preventing HIV infection*) initiation of ART for all PLHIV with a CD4 count of 500 cells/mm³ and below (4)¹. However, most patients are currently initiated on ART at CD4 counts far below national guideline recommendations. Low CD4 count has a direct adverse impact on HIV treatment outcome and health-care costs associated with management of advanced stages of HIV infection, including hospital admissions.

Multiple factors related to health-care delivery systems contribute to delays in ART initiation and poor adherence to ART and retention in care. These include diagnosis of HIV at an advanced stage, poor linkage to and retention in HIV care after testing positive (21, 22, 23) and loss to follow-up (LTFU), which is particularly high in the period between testing and initiation of ART. Additional patient-related factors for delayed initiation of ART include legal and/or familial constraints around disclosure, and lack of emotional and financial support.

All of these issues pose potentially greater challenges to adolescents, who experience more actual or perceived barriers to HIV testing and treatment services than the general population. ALHIV can also face challenges in the transition from paediatric services—where parents and guardians commonly have primary responsibility for their care—to adult ART services, where they will need to take much greater responsibility for their own care. In the case of decentralized services, where there may be only one ART service available, the greatest challenge is not a transition from one set of services to another, but rather a transitioning of health-care responsibilities from parent or guardian to the adolescent. This is generally a longer process during which the adolescent assumes autonomy for specific health-care activities and decisions, as related to their evolving capacity.

1.1.1 HIV testing and counselling for adolescents

HIV testing and counselling (HTC) is an essential component of efforts to achieve universal access to HIV prevention, treatment, care and support. Regardless of HIV acquisition route, underutilization of testing and counselling services results in late diagnosis; increasing uptake of HTC could lead to earlier diagnosis and more effective care.² Due to the increasing availability of ART and prevention interventions, early diagnosis can reduce transmission and improve health outcomes, thereby decreasing HIV incidence and HIV-related morbidity and mortality.

HTC for adolescents, as for adults, offers many important benefits. Adolescents who learn that they have been diagnosed with HIV are more likely to obtain emotional

¹ Also, to reduce HIV transmission to uninfected partners, WHO recommends that HIV-positive partners in serodiscordant couples should be offered ART, irrespective of their CD4 count.

² Although data is not available, there is thought to be a significant percentage of adolescents who have been tested and know their status and have not been effectively linked to care and treatment and therefore have not initiated treatment when they need it. (G. Hainsworth, Pathfinder, personal communication, 2013).

support and practice preventive behaviours to reduce the risk of transmitting HIV to others, and more likely to obtain HIV treatment and care, assuming these services are available to them. Early access to care can help them to feel better and to live longer, than if they present for care when their disease is already at an advanced stage. Access to HTC is also important for adolescents who do not have HIV to reinforce prevention messages and facilitate access to prevention services and commodities. Recent data from South Africa suggest that adolescents who had taken a test had a lower incidence of HIV over time compared with those who had not (24). HTC is also an essential component of the package of care included in voluntary medical male circumcision (VMMC) programmes for HIV prevention that are being scaled up in 14 priority countries in sub-Saharan Africa—in which adolescents are a key target group (25).

Access to and uptake of HTC by adolescents is significantly lower than for adults.¹ Survey data collected from 2005 to 2010 in sub-Saharan Africa indicate that only 10% of young men and 15% of young women (15–24 years) were aware of their HIV status (26). However, access and coverage vary considerably across countries and regions. For example, in Malawi and Zimbabwe data on the proportion of HTC clients who are 15–24 years of age show that they account for approximately 40% of all clients. Of these young clients, approximately 60% are females (R. Olson, UNICEF-South Africa, personal communication, 2013).

Because uptake of HTC by adolescents is currently low, and HTC services for adolescents have not been developed in many settings, these guidelines recommend expanding access to HTC for adolescents in different epidemic settings.² These guidelines also discuss service delivery approaches that have been acceptable and effective in increasing uptake of HTC among adolescents and highlight operational issues that must be addressed for effective implementation of the recommendations.

1.1.2 HIV treatment and care for adolescents living with HIV

Modes of transmission

Adolescents can acquire HIV infection in two ways—through vertical or horizontal transmission.

Vertical (mother-to-child) transmission

Adolescents living with HIV include long-term survivors of vertical transmission, some who are on treatment, as well as slow progressors (not on treatment). Some of these adolescents are receiving care having been followed through PMTCT programmes. However, a significant proportion has not been diagnosed due to loss to follow-up (LTFU) or poor coverage of PMTCT programmes.

Horizontal transmission

Horizontal transmission occurs in two ways:

Sexual transmission

Sexual activity begins during adolescence in most parts of the world, although age and conditions vary greatly. Risks for acquisition of HIV include sex without safe condom use, early coerced sex and sexual exploitation involving coercion and sometimes violence.

¹ In countries where adolescents ages 15–19 years are considered adults, they may only have access to HTC in ANC services, which would exclude male adolescents and therefore reduce access for this group.

² Expanded access includes making existing services more sensitive to the needs of adolescents.

Parenteral transmission

Non-sexual transmission among adolescents can involve injecting drug use (IDU), traditional practices (e.g. female genital mutilation (FGM), scarification with shared razor blades and traditional treatments requiring cutting of the skin) and certain medical procedures such as unsafe surgical procedures, injections and blood transfusions.

There are social and contextual factors that make adolescents vulnerable to HIV infection through horizontal transmission. These factors include: age and sex, gender, social and cultural norms and value systems about sexual activity, location (where the adolescent lives, learns and earns), economic and educational status and sexual orientation. Adolescents who are particularly vulnerable include those from key populations as well as orphans, migrants and refugees, prisoners and other groups that are socially marginalized and discriminated against, and adolescents affected by humanitarian crises. Conflict, displacement and food insecurity all can heighten risk. The HIV epidemic itself also increases vulnerability; for example, adolescents orphaned by AIDS can be more vulnerable to HIV if their circumstances lead them to engage in sex with older and/or concurrent partners for economic or emotional support.

Optimal HIV care for different groups of adolescents

There are several diverse groups of ALHIV who must be encouraged and able to access ART, care and support, and who will need support to adhere to treatment and remain in care. Optimal HIV care for different groups of ALHIV varies according to mode of transmission, age, sex, gender and social factors. Three broad groups, each with specific needs and challenges, need to be considered.

Adolescents infected vertically, diagnosed early and started on ART

In 2012, vertical transmission accounted for an estimated 260 000 new infections in children (2). Current efforts to optimize PMTCT programmes will not, on their own, eliminate HIV in newborns. Access to maternal and child health services will need to be dramatically improved, as will prevention measures, such as preventing and treating HIV before pregnancy.

Successful early infant diagnosis and links to treatment in some settings has resulted in more than 630 000 children in developing countries being started on ART (1). Intensive efforts will be needed over the next decade to support children with HIV on ART to remain engaged in care and to adhere to treatment as they become adolescents and need to transition to adult services. Health workers, even those experienced in caring for adults with HIV, are often ill-equipped to support the health-care needs of adolescents. In many countries, there is little experience with understanding and providing services for the particular needs of adolescents, and judgemental attitudes toward sexually active adolescents can hamper rapport and subsequent care.

A significant proportion of pregnant women are adolescents (approximately 16 million births per year are to adolescents) (27). Adolescent girls with HIV have less access to PMTCT interventions than adult women, and they need improved access to maternal and other types of health care.

Adolescents infected vertically, not diagnosed early and not started on ART

In generalized epidemics, an increasing proportion of children entering adolescence have acquired HIV infection perinatally and remain undiagnosed (28). These slow progressors have survived into adolescence without being diagnosed and started on ART. They may have chronic medical and developmental delay problems and would benefit from diagnosis and initiation on treatment, as well as long-term care and support.

Although there has been a significant increase in the provision of PMTCT interventions, many mothers still do not have access to antenatal services or PMTCT. In low- and middle-income countries, coverage of effective antiretroviral regimens for PMTCT reached only 57% in 2011 (2). In sub-Saharan Africa, where 92% of the world's pregnant women with HIV live, only 59% received ART or prophylaxis during pregnancy and delivery.

Even where PMTCT services are in place, they are not completely effective in preventing all vertical transmission of HIV. Furthermore, there is significant LTFU in many programmes, resulting in exposed infants not getting tested, and a significant proportion of perinatally infected children not linked to early care. Without ART, these children often will develop HIV-related symptoms early in their lives, requiring urgent HIV treatment and care.

Late diagnosis of HIV infection for perinatally infected adolescents is increasingly being recognized as a significant problem leading to delayed initiation of ART and poor linkages to and retention in care. This can be complicated by the reluctance of some parents to allow children to be diagnosed and/or started on ART for fear of the potential stigma related to implications of their own status or possible revelation of abuse as the cause of infection. In some areas, anecdotal evidence suggests that greater trust in traditional healers and fear of the side effects of ART can cause parents and caregivers to delay diagnosis and treatment for children.

Adolescents acquiring HIV horizontally

The main mode of HIV transmission among male and female adolescents in generalized epidemic settings is unprotected heterosexual sex (sometimes forced or coerced). A growing body of evidence shows that the experience of sexual coercion is fairly prevalent among young people and is associated with high-risk sexual behaviour thereafter (29). A review of nationally representative surveys in Burkina Faso, Ghana, Malawi and Uganda examined the prevalence of sexual coercion at sexual debut among adolescent females (12–19 years of age) (30). Thirty-eight per cent of girls in Malawi said that they were “not willing at all” at their first sexual experience; girls in Ghana (30%), Uganda (23%), and Burkina Faso (15%) responded similarly. In-depth interviews collected in 2003 with the same demographic found that there are four primary types of sexual coercion: forced sex; pressure through money or gifts; flattery, pestering and threatening to have sex with other girls; and passive acceptance.

In many settings, adolescents are also vulnerable to HIV infection through injecting drug use and sexual exploitation—which often involves unprotected heterosexual and homosexual sex (30)—as well as a small number of cases of nosocomial transmission due to unsafe medical practices and procedures, or traditional practices.

Diagnosis through expanded access to HTC, with good linkages to treatment and care, will often require different approaches for adolescents infected horizontally than for adolescents infected vertically. These approaches should take into consideration the needs of adolescents who have been infected through early sex or sexual abuse.

Additional Concerns

In many resource-constrained and high-HIV burden settings, limited capacity in health-care delivery systems poses a serious challenge to expansion of HTC, treatment and care services for adolescents. It is essential to minimize inefficiencies across the continuum of HIV care, explore innovative approaches to service delivery, and optimize treatment outcomes through linkages and integration with other services. Additionally, provision of chronic care requires reorganizing service delivery models, which in most settings are designed primarily to provide acute care.

These guidelines also address support for disclosure by ALHIV to others and, as means to improve adherence and retention, community-based service delivery and improved training for health workers. They recognize the urgency of the need to initiate ART when clinically indicated, to support adherence to ART for eligible ALHIV, and to strengthen the retention of these adolescents in care. Age of consent to testing is also discussed as an issue for consideration when planning and providing services for adolescents.

1.2 Objectives

WHO acknowledges the need to give high priority to increased access to HTC for adolescents and to support approaches to improving adherence to treatment and retention in care for ALHIV.

These guidelines are intended to:

- provide recommendations and suggestions for policy-makers and national programme managers, civil society organizations and technical and financial partners on prioritizing, planning and providing HIV testing, counselling, treatment and care services for adolescents in resource-limited settings;
- support the provision of a comprehensive, accessible, appropriate and acceptable range of services for adolescents along the continuum of care (including testing, counselling, treatment and care and referral to sexual and reproductive and mental health services and community support);
- complement and include relevant recommendations from the WHO *Consolidated guidelines on the use of antiretroviral drugs for treating and preventing HIV infection*. WHO, UN partners, ministries of health and a wide range of other implementers have recognized the need to highlight the importance of effective and accessible services for adolescents living with HIV, to support adherence to ART and retention in care, and to focus specifically on this neglected population;
- provide countries and programmes with evidence-based recommendations together with consideration of related implementation issues.

It is expected that the guidance will support countries and programmes to accomplish the following objectives:¹

1. **to provide universal access to HIV testing and counselling for adolescents** in generalized epidemics and for adolescents from key populations in all epidemics, with a full understanding of the particular nature, needs and challenges of adolescence;²
2. **to improve treatment and care for adolescents living with HIV.** It is essential to make it easier for adolescents to start treatment once they have been diagnosed and to help adolescents already on ART to make a safe and effective transition from paediatric to adult services. This objective also recognizes the need to reduce delayed initiation of ART for ALHIV and to support adherence to ART and retention in care.

It is anticipated that the accomplishment of these objectives will ensure that adolescents are managing their HIV infection effectively to ensure optimal health and survival, and that they are better equipped to take ownership of their health care and their lives as adults living with HIV.

¹ These objectives also relate to the service delivery recommendations from the WHO *Consolidated guidelines on the use of antiretroviral drugs for treating and preventing HIV infection* that are listed in Section 2.3.

² Achievement of Objective 1 will support ALHIV for ongoing treatment and care as well as support HIV-negative adolescents to remain HIV-negative.

1.3 Target audience

The primary target audiences for these comprehensive guidelines include policy-makers and programme managers. A more streamlined, electronic version of these guidelines will be produced for health workers providing HIV prevention and other health services for adolescents in all HIV epidemic settings, including lay counsellors and community health workers. These guidelines are also intended for governments, non-governmental and civil society organizations, donors, HIV advocacy organizations and patient-support groups that address HIV prevention, treatment and care for adolescents. Adaptation of the guidelines is recommended according to the HIV epidemic profile and country-specific cultural and socio-economic contexts.

1.4 Development of guidelines

The WHO Department of Maternal, Newborn, Child and Adolescent Health and the WHO Department of HIV/AIDS led the development of these guidelines in collaboration with UNICEF, UNFPA, UNESCO and GNP+. The evidence assessment for these guidelines included three complementary areas of work—systematic reviews, descriptive reports of community consultations and supplementary literature reviews of published and unpublished studies not included in the systematic review, and programmatic experience. This document presents a synthesis of the findings of that work as well as the expert opinion of the Guidelines Development Group and peer reviewers.

1.4.1 Systematic reviews of the evidence

Researchers developed search protocols and undertook systematic reviews of the available scientific evidence. Design of the search strategies employed in the systematic reviews, meta-analyses and GRADE profiles followed methodology described in the Cochrane Handbook for Systematic Reviews of Interventions (31).

The systematic searches for studies relevant to the PICO questions were conducted online using common electronic databases (see Annexes 3 and 4). The quality of evidence and the strength of recommendations were assessed using the GRADE methodology (32, 33). The GRADE process was used for all of the PICO questions, but it was not possible to develop relevant GRADE profiles for every question because there was a significant lack of GRADE-able research on the topic of adolescents and HTC, adherence to treatment and retention in care.

1.4.2 Values and preferences, literature reviews and programmatic experience

Commissioned qualitative work explored the values and preferences of adolescents with regard to HTC and of health-care providers who provide HTC services to adolescents. The full report (see Annex 10) documents findings gathered through workshops in two countries with generalized epidemics and one country with a low-level/concentrated epidemic, a multi-regional anonymous e-survey and interviews with selected service providers in the three countries where workshops were conducted. Similarly, a multi-regional anonymous e-survey of ALHIV explored their experiences with ART, disclosure and care and support services as well as their views on the health providers with whom they interact (see Annex 11 for full report).

Literature reviews of published and unpublished studies provided additional detail about HTC, adherence to HIV treatment and retention in HIV care.

Programmatic experience and observational studies have been used to illustrate the operational aspects of the recommendations, highlighting key inputs and processes for improving the access and effectiveness of HTC and treatment and care services for ALHIV. Case studies and programmatic data provide additional detail and value to the guidelines by documenting experiences in real programme and routine care settings, as contrasted with findings from research. They offer some insights into successful implementation of programmes designed specifically for adolescents, explaining why and how they worked and the types of challenges faced during implementation of activities.

1.4.3 Expert consultation and development of recommendations

WHO convened an expert consultation in October 2012 in Harare, Zimbabwe, to make recommendations regarding HTC, treatment adherence and retention in care for adolescents. Participants assessed the evidence for each PICO question, along with the risks and benefits associated with each possible recommendation, and reached consensus on recommendations. Disagreements were resolved through continued debate and revision of the recommendations to provide additional precision or qualifications not included in the original PICO questions.

The final recommendations and advice take into consideration the quality of the evidence, estimated costs, feasibility of implementing the recommendations and the values and preferences of adolescents who represent those whose lives will be affected by the guidelines and of their health-care providers.

Following the consultation, the full draft guidelines were prepared and circulated to the Guidelines Development Group and other international experts for comments that were incorporated into the final draft of the guidelines.

1.4.4 Scope of the guidelines

Health services in low-resource settings face the greatest challenges in providing services tailored for adolescents and may benefit most from the guidance presented here; however, as it is relevant for all HIV epidemic and economic settings, it should be considered global guidance. Regional and national meetings can be conducted to adapt these global recommendations to local needs, HIV epidemic context and existing services to facilitate implementation.

1.5 Evidence assessment

The development of a recommendation is guided by the quality of available evidence. Other factors affect whether recommendations are strong or conditional, especially when available evidence is of insufficient quantity or quality.

How to interpret the quality of evidence

In the GRADE assessment process, the quality of a body of evidence is defined as the extent to which one can be confident that the reported estimates of effect (desirable or undesirable) available from the evidence are close to the actual effects of interest. The usefulness of an estimate of the effect (of an intervention) depends on the level of confidence in that estimate. The higher the quality of evidence, the more likely a strong recommendation can be made. However, it is not always possible to prepare GRADE profiles for all research on interventions because of a lack of data and information to calculate the necessary risk ratios or because the evidence available to the GRADE methodologists is indirect.

The GRADE approach specifies four levels of quality of evidence (34), as shown in Table 1.

Table 1. Significance of the four GRADE levels of evidence

Quality level	Definition
High	We are very confident that the true effect lies close to that of the estimate of the effect.
Moderate	We are moderately confident in the effect estimate: The true effect is likely to be close to the estimate of the effect, but there is a possibility that it is substantially different.
Low	Our confidence in the effect estimate is limited: The true effect may be substantially different from the estimate of the effect.
Very low	We have very little confidence in the effect estimate: The true effect is likely to be substantially different from the estimate of the effect.

Values and preferences among the groups of interest for the guidance (adolescents) or views of the Guidelines Development Group based on technical expertise or programmatic experience may differ with regard to desired outcomes, or there may be uncertainty about whether the intervention represents a wise use of resources. Despite clear benefits, it may not be feasible to implement a proposed recommendation in a particular setting. A judgment must then be made regarding the strength of the recommendation.

1.6 Strength of recommendations

The strength of a recommendation reflects the degree of confidence of the Guidelines Development Group that the desirable effects of adherence to or implementation of the recommendation outweigh the undesirable effects. Desirable effects may include beneficial health outcomes (e.g. reduced incidence of HIV and reduced morbidity and mortality); benefits from service delivery (e.g. increased uptake of HIV prevention services, improved uptake of and retention in treatment and care services and increased adherence to treatment); less burden on the individual and/or health services; and potential cost savings for the individual, programme and/or health system. Undesirable effects can affect health services, individuals or families. Additional burdens include the costs of implementing the recommendations that programmes, care providers or patients have to bear, such as infrastructure modifications, increased training requirements for providers working with adolescents, relationship difficulties for adolescents receiving a positive diagnosis or legal complications where certain practices are criminalized.

A strong recommendation (for or against) is one for which there is confidence that the desirable effects of adherence to the recommendation clearly outweigh the undesirable effects, or clearly do not.

A conditional recommendation (for or against) is one for which the quality of evidence is low or may apply only to specific groups or settings; or the panel concludes that the desirable effects of adherence to the recommendation probably outweigh the undesirable effects or are closely balanced, but the panel is not confident about these trade-offs in all situations. Reasons for not being confident can include: absence of high quality evidence, presence of imprecise estimates of benefits or harms, uncertainty or variation regarding how different individuals value the outcomes, small benefits and benefits that may not be worth the

costs (including the cost of implementing the recommendation). ***A conditional recommendation is not a recommendation against doing something.*** Instead, interventions based on these recommendations should be monitored closely and evaluated rigorously. Further research is needed to address the uncertainties and is likely to provide new evidence that may change the calculation of the balance of trade-offs.

Table 2. Additional domains considered in assessing the strength of recommendations

Domain	Rationale
Benefits and risks	When a new recommendation is developed, desirable effects (benefits) need to be weighed against undesirable effects (risks), considering any previous recommendation or an alternative. The larger the gap or gradient in favour of the benefits compared with the risks, the more likely that a strong recommendation will be made.
Values and preferences (acceptability)	If the recommendation is likely to be widely accepted or valued highly, it is likely that a strong recommendation will be made. If there is a great deal of variability or strong reasons that the recommended course of action is unlikely to be accepted, it is more likely that a conditional recommendation will be made.
Costs/financial implications	Lower costs (monetary, infrastructure, equipment or human resources) or greater cost-effectiveness will more likely result in a strong recommendation.
Feasibility	If an intervention is achievable in a setting where the greatest impact is expected, a strong recommendation is called for.

2.1 HTC for adolescents

Two topics crosscut all issues addressed by these guidelines: the age of consent to testing and the recognition that adolescents from key populations must be a particular focus for increasing the accessibility and acceptability of HTC services for this age group.

The three recommendations on HTC and adolescents are then presented along with a summary of the evidence and a summary of the Guideline Development Group's discussion and other considerations. The evidence includes the systematic GRADE review of selected studies and the values and preferences obtained from community consultations and the e-surveys with adolescents and service providers. The summary of the discussion at the expert meeting in Harare is complemented by the findings of a review of published and unpublished studies and reports related to HTC and adolescents as well as contributions from peer reviewers.

2.1.1 Consent to HIV testing

Health-care decision-making requires individuals to exercise their right to independent decision-making. In most settings, however, adolescents' rights are limited, although the exact nature of this limitation varies considerably from country to country. In some settings, a regulatory framework on informed consent does not exist, while in other settings, the adolescent's rights are governed by a regulatory patchwork.

AGES OF CONSENT IN SOUTH AFRICA

In South Africa, different threshold ages of consent apply to HIV-related services such as treatment, surgery, voluntary medical male circumcision, provision of pharmaceutical drugs, contraception, and HIV testing. Consent for an HIV test on a child (defined in South Africa as an individual who is less than 18 years of age) may be given by (a) the child, if the child is either (i) 12 years of age or older or (ii) under the age of 12 years and of sufficient maturity to understand the benefits, risks and social implications of such a test; (b) the parent or caregiver, if the child is under the age of 12 years and is not of sufficient maturity to understand the benefits, risks and social implications of such a test. Thus, the child's legal capacity to consent to an HIV test depends upon the child satisfying particular biological (physical age) and cognitive ("sufficient maturity") criteria. Similarly, other countries consider both biological and cognitive criteria under "stage of development" assessments, and recognize the child's autonomy if the child demonstrates qualities implicit in a "mature minor" or "emancipated minor" (See Annex 15).

While stipulation of different ages of consent and qualifying criteria are intended to protect adolescents, policy-makers must carefully consider whether and how such pre-qualifying criteria could affect their access to health services. To this end, policy-makers should review their existing regulatory frameworks governing adolescent health care with a view to ensuring regulatory harmonization and facilitating linkage to care. For example, an adolescent who possesses the legal right to access HTC should have autonomous access to HIV prevention and treatment modalities as part of linkage to comprehensive care. Authorities should also consider especially how to facilitate access to HTC and linkage to care for orphans and vulnerable adolescents, including those living on the streets, adolescents in child-headed households, and particularly vulnerable adolescents from key populations, girls engaged in sex with older men and in multiple or concurrent sexual partnerships, and adolescent girls affected by sexual exploitation.

¹ Decision-making tables in Annex 8 summarize the basis upon which the recommendations and suggestions are made.

Authorities should also consider the role of surrogate decision-makers in HTC. In some settings only parents or guardians may consent to a child accessing HTC. In contrast, in settings such as South Africa (see box on previous page), a child may self-consent to HIV testing if he or she is 12 years of age and above, or, if under 12 years of age, the child is of sufficient maturity to understand the benefits, risks, and social implications of a HIV test. However, for children under the age of 12 with insufficient maturity to understand the benefits, risks, and social implications of a HIV test, a parent or caregiver must give consent for the test. The recognition of a caregiver as a surrogate decision-maker for children in relation to HIV testing recognizes that the absence of a parent or guardian should not serve as a barrier to a child accessing HTC, if the child has a caregiver (a caregiver is defined in South African law as any person other than a parent or guardian who factually cares for a child).

Authorities should also bear in mind their legally binding obligations in respect of children under international law. In particular, Article 3 of the 1989 Convention on the Rights of the Child (CRC) states:

In all actions concerning children, whether undertaken by public or private social welfare institutions, courts of law, administrative authorities or legislative bodies, the best interests of the child shall be a primary consideration.

Article 24 of CRC states:

1. States Parties recognize the right of the child to the enjoyment of the highest attainable standard of health and to facilities for the treatment of illness and rehabilitation of health. States Parties shall strive to ensure that no child is deprived of his or her right of access to such health-care services.

2. States Parties shall pursue full implementation of this right and, in particular, shall take appropriate measures:

... (b) To ensure the provision of necessary medical assistance and health care to all children with emphasis on the development of primary health care.

Respecting these obligations entails facilitating adolescent access to HTC and linkage to care.

2.1.2 Key populations

In the context of these guidelines, **key populations** are defined as those populations at higher risk of HIV (those populations disproportionately affected in all regions and epidemic types, including sex workers, men who have sex with men, transgender people and people who inject drugs).

These guidelines specifically address adolescent key populations, ages 10–19 years. In addition to the groups mentioned above, other adolescents who are vulnerable to HIV include adolescents who are sexually abused and/or exploited and those in prisons and other closed settings.

Sex work by definition involves only adults. The involvement of children and adolescents under 18 in sex work is classified as sexual exploitation by and engagement in commercial sex.

There has been little explicit focus on the particular needs of adolescents within the groups considered most at risk for HIV. Four groups of adolescents considered to be most at risk for HIV (referred to as adolescents from key populations) are adolescent males who have sex with men (MSM), adolescents who are sexually exploited (and those ages 18 years and over engaged in sex work), adolescents who inject drugs (PWID) and transgender (TG) adolescents (male and female). Other groups of adolescents, especially in generalized epidemics, are also at higher risk of infection. These include adolescents affected by AIDS (orphans and children of chronically ill caregivers) (35), clients of sex workers, the partners of these clients, HIV-negative partners in serodiscordant couples and, in high-prevalence settings, girls who are being sexually exploited by older men or having sex with adolescent MSM (36). Programmes need to find ways to reach out to sexually active adolescents (whose STIs and unintended pregnancies indicate unsafe sexual practices) through tighter integration of HIV screening with sexual and reproductive health (SRH) services. Programmes also need to take into consideration the differing age-related capacities of adolescent members of key populations to access services.

Often there are policy and legal barriers to providing services for young key populations. In some cases certain behaviours and sexual orientations are criminalized, and in other cases restrictive education policies or conditions such as requirements for schools to disclose the HIV status of learners or lack of educators with training to provide counselling or support need to be reviewed and amended.

Given their marginalized social position and their reluctance to attend diagnostic and treatment services due to fears of stigma including possible legal consequences, increased access to HTC for adolescents from key populations is a priority in all epidemic settings.

2.1.3 Recommendations—HTC for adolescents

- ① HIV testing and counselling *with linkage to prevention, treatment and care* is recommended for adolescents from key populations in all settings (generalized, low and concentrated epidemics). *Strong recommendation, very low quality evidence*
- ② In generalized epidemics, HIV testing and counselling *with linkage to prevention, treatment, and care* is recommended for all adolescents. *Strong recommendation, very low quality evidence*
- ③ In low and concentrated epidemics, HIV testing and counselling *with linkage to prevention, treatment and care* is recommended to be made accessible to all adolescents. *Conditional recommendation, very low quality evidence*

All three recommendations pointedly emphasize *linkage to prevention, treatment and care*. Health workers will likely face greater challenges ensuring adolescents are appropriately linked to services following HIV testing, than they face working with children who are accompanied by caregivers or when working with adult patients—who usually have more ability, experience and maturity to seek out and take responsibility for their care.

Any intervention related to counselling, care and support for adolescents must include elements of sexuality education. Furthermore, adolescent sexuality should be treated in a positive, non-judgmental way with all adolescents, regardless of their HIV status (37, 38, 39).

Expansion of HTC for adolescents will identify greater numbers of horizontally infected individuals; even if many of them do not immediately require treatment, health services will be challenged to make sure that this group consistently accesses prevention, care and support services over the long term. For all ALHIV who are enrolled in treatment, linkage to services for adherence support and for retention in prevention, care and support will be essential.

Summary of the evidence

The particular characteristics and needs of adolescents often cannot be addressed by applying guidelines based on evidence and recommendations relating to paediatric or adult populations. Furthermore, adolescents themselves are not a homogeneous group. Physical and psychological (cognitive and emotional) development varies among adolescents, and differing social and cultural factors as well as their evolving capacities can affect both their ability to make important personal decisions and their access to services. For these reasons guidance should take into consideration the range of adolescents' needs and issues. As little research has been conducted related to HTC among adolescents and adolescents living with HIV to date, these guidelines have given considerable weight to expert opinion, the values and preferences of adolescents and health-care providers, and the field experience of practitioners.

Systematic review: summary of main results

See Annex 3 for the full report of the systematic review related to HTC for preventing HIV transmission and improving uptake of HIV treatment and care in adolescents.

Few randomized controlled trials (RCT) were found examining the impact of HIV testing on outcomes important to adolescents and young adults in either generalized epidemic settings or high-risk populations in low-level epidemics.

Generalized epidemic settings

In generalized epidemic settings there are no randomized trials conducted specifically among adolescent populations. However, indirect evidence, from RCTs conducted among adults, found that HTC is effective at reducing unprotected sexual intercourse with non-primary partners and reducing STI incidence among those at risk for HIV infection. Additionally, enhanced post-test counselling that includes community support agents is effective at improving uptake of pre-ART care among patients with HIV.

With new evidence to support treatment as prevention and the potential of potent antiretroviral regimens to reduce HIV-related morbidity and mortality, more data are needed on the impact of different HTC strategies on HIV incidence and linkage to HIV care for adolescents with HIV. Most data on the effectiveness of HTC are based on a voluntary counselling and testing (VCT) model that includes personalized risk assessment and development of a personalized risk reduction plan for each client. Interventions using brief discussions instead of such personalized counselling need further evaluation. Furthermore, data are needed on the most cost-effective strategies for testing adolescent populations, whether in facilities or in the community. Data are needed also on effective strategies to link adolescents who test positive to HIV treatment and care, and those who test negative to prevention services and commodities.

Low-level or concentrated epidemic settings

HTC has demonstrated efficacy in generalized settings among adults. In low-level epidemic settings among high-risk youth, sub-analysis of one RCT found that HTC reduced the incidence of STIs among heterosexual adolescents attending STI clinics. This interactive risk reduction counselling includes personalized risk assessment and risk reduction plans. This intervention has not been studied, however, in several important high-risk populations, including young MSM and

homeless and substance-abusing youth. The applicability of these data to such key populations of adolescents in low-level epidemic settings is unclear; there may be a need for specialized counselling and community outreach due to higher risk behaviours and lack of HIV knowledge. Data from another RCT among youth in community-based substance abuse services support the effectiveness of rapid, oral, point-of-care testing technologies in improving the uptake of HIV, HBV, and HCV testing. This may prove a model for high-risk populations. No studies evaluated the impact of HIV testing among adolescent populations in low-level epidemics on HIV incidence, morbidity and mortality. More data are needed from and about young MSM and other adolescent key populations on the efficacy of HTC interventions on outcomes important to patients and on linkage to care.

Quality of evidence

In this analysis the quality of evidence from RCTs varied from very low to moderate in generalized epidemic settings and from low to very low in low-level epidemics. The quality of evidence was moderate for the outcome of STI incidence, based on one RCT (40), which was downgraded only for indirectness due to a largely adult population. However, for all other outcomes in both generalized and low-level epidemics, evidence from RCTs was either of low or very low quality, downgraded for imprecision (few participants and events) and indirectness (evidence from largely adult populations, or self-reported behavioural outcomes). Additionally, one study was also downgraded for indirectness, as the population was sick, hospitalized inpatients (41).

In this analysis the quality of evidence from the observational studies was very low, downgraded for serious study design limitations (no comparator), imprecision (few participants and events), and indirectness (self-reported behavioural outcomes, or evidence from largely adult populations).

Values and preferences: HTC

A study of the values and preferences of adolescents and service providers facilitated the participation of those who will be most affected by improved access to HTC and to ensure that their perspectives were included in the guidelines development process (see full report in Annex 10). A series of 10 workshops, involving 98 participants (ages 15–24 years) was conducted in the Philippines, South Africa and Zimbabwe. An online survey was also conducted in four languages to ensure a broader geographical representation of the values and preferences of adolescents regarding HTC; 655 respondents from 92 countries completed the survey. Interviews with 16 service providers from various health-care settings in three countries were also conducted.

Motivations for and deterrents to testing

In community consultations in the Philippines, South Africa and Zimbabwe, young people (15–29 years) reported that, in spite of various barriers to testing, they recognize the benefits of testing and knowing their HIV status, including the autonomy it demonstrates in taking decisions about their own health and survival. They talked about taking control of their lives, the importance of looking after their own health, the need to “take the right steps” when receiving a positive diagnosis and, if the result is negative, being able to get the support and advice that they need to remain negative. Many participants mentioned a sense of responsibility to themselves, their partners, their families and society as a motivation for testing. Starting a new relationship was mentioned as a motivation by 15% of respondents of the survey, and 40% found that being offered HTC while seeking other health services was a useful motivator to testing. One of every six survey respondents indicated that encouragement from others was an important motivation for seeking a test.

At the same time, a number of participants talked about feeling pressured or required to test by parents or partners, while one participant made a stronger statement about pressure from health providers: *“They don’t treat you if you don’t get tested when you are sick.”*

The greatest barrier to testing for all participants is fear—of the process, of the result, of their parents’ reactions, of disruption to their educations, of death. Almost 9% of young MSM and who had taken a test reported that they live with considerable fear that their parents will be informed; this was twice the rate of other male respondents. In contrast to findings from other countries, South African participants were very specific about the burden of living with HIV in terms of the changes to one’s lifestyle: having to use condoms, adhere to ART, eat healthy foods and regularly attend clinic. Filipino participants observed, *“HTC seems so burdened with negatives”*, which can be a considerable deterrent to testing.

One of the main deterrents to testing is the potential to experience stigma and discrimination. Workshop participants repeatedly mentioned the expected consequence of being rejected, if the result is positive, by friends, family and the community as a reason for reluctance to seek a test. Concerns about stigma and its consequences were also evident in e-survey responses: 16% of tested respondents listed being afraid of what others may think as a concern when deciding to test. This concern was more evident (27%) for those who identified as MSM.

All workshop participants agreed that the lack of testing facilities is a barrier to access. Specific issues included location, costs, long waiting times and limited hours of operation. Some felt that there were not enough health staff and other resources to tend to all those who needed assistance. Regarding access, 27% of online respondents reported that they would like to get tested but did not know where to get tested or had not had the opportunity to test (34%). Only 17% of the 351 online respondents who had taken an HIV test reported referral and linkage to care following the test (regardless of test result), while 70% received no onward referrals and 13% did not answer the question.

Adolescents and young adults: improving access to and uptake of HTC for adolescents

Workshop participants and survey respondents offered suggestions for improving access to and uptake of HTC by adolescents. They proposed options for consideration at four different levels:

- **Engaging the community.** It is important to *“captivate young people”* in their own environment and to *“make testing less scary”*. Awareness-raising events and activities can be designed specifically for adolescents in places that are comfortable for them, such as schools, nightclubs, sporting venues and churches. Other suggestions for engaging the community included the involvement of celebrities and peers living with HIV as public role models and advocates for testing. This strategy depends significantly on the availability and accessibility of accurate and complete information and optimal use of social media, libraries and mass communication channels. “Normalization” was often mentioned as an essential step toward increasing understanding and decreasing stigma related to HIV and HTC.
- **The role of health service providers.** Adolescents consider it very important to be able to relate to the person providing HTC. In ideal situations this might mean engaging adolescent and ALHIV peers as health educators and HTC providers, thus bridging the gap between adolescents and health services. Above all, there is a need for respectful, accepting, friendly, understanding and supportive providers to encourage adolescents to test.
- **HTC service delivery.** Participants in the workshops consider the service environment as very important for adolescents seeking HTC. This includes several components: a youth-friendly atmosphere, flexible hours, separate waiting areas for adolescents, alternative service delivery settings (e.g. schools,

social centres and mobile services) and the assurance of confidentiality, which might include the option for self-testing.

- **Improvements to the health system.** These included increasing the number of testing sites (addressing capacity as well as issues of proximity/rural access), reducing fees and other costs of testing and strengthening referrals from community organizations and rural health clinics.

Service providers: improving access to and uptake of HTC for adolescents

Service providers recognize that adolescents in many settings can be at high risk of HIV infection, and they consider effective and accessible services for adolescents a high priority. At the same time providers note that policies and services concerning HTC often are not geared specifically towards adolescents, and the needs of this group are underserved.

Providers acknowledge that interactions with adolescents are challenging and emotionally draining. They attribute some of this to cultural norms or societal views concerning HIV and sex, the influence of religious restrictions and widespread stigma and discrimination. Many providers also note a lack of appropriate training in specific skills needed for working with adolescents. Additionally, understaffing is considered a problem in many places, preventing providers from spending the time required to address adolescents' particular needs and often resulting in long queues and waiting times that could discourage adolescents from testing. Expanding access to HTC through decentralization and greater involvement of community-based organizations could help to alleviate the pressure of workforce shortages in formal health facilities. Adolescent-friendly approaches that are centred on adolescents' own particular communities could increase the acceptability of services for adolescents, (especially for key populations). This might be easier to deliver through community-based organization than in larger or more formal facilities.

Many service providers raised the issue of age of consent. Inconsistencies in the practical application of consent laws emerged as significant concerns, even in South Africa where adolescents can get tested at age 12. Some providers noted that age of consent in their facilities was higher than that of the national law, while others admitted acting in defiance of the law *“to do what is best for the adolescent”*. There are concerns about having to choose between complying with the law and testing an underage adolescent, and facing the possible consequences of either choice. Some adolescents have no parent or guardian, while some seek services with an adult claiming to be their parent. Laws must be clarified and providers must be trained to adhere to laws or official guidelines while acting in the best interest of their adolescent clients.

Service providers suggested some strategies for improving access to and uptake of HTC for adolescents, including:

- **education** of adolescents to increase awareness and reduce the fear surrounding testing
- **adolescent-friendly testing environments**
- **involving adolescents** in the design and delivery of services
- **clarification of legal issues**, especially with regard to consent.

Summary of the expert panel discussion and other considerations

This section documents the key points raised during the discussion on HTC at the expert meeting in Harare as well as feedback and inputs provided as part of the review process.

Adolescence

Adolescents are less likely than adults to be tested and less likely to be linked to services if they test positive. Also, HIV-negative adolescents who have been tested

are frequently not actively linked to prevention services supporting them to remain HIV-negative.

People responsible for HIV programming need to understand that the changes that take place during adolescence affect:

- how adolescents understand information;
- what information and which channels of information influence their behaviour;
- how they think about the future and make decisions in the present;
- how they perceive risk in a period of experimentation and first-time experiences;
- how they perceive sex, which is common during late adolescence;
- how they form relationships, respond to the social values and norms that surround them, and are influenced by the attitudes (or perceived attitudes) of their peers and others.

It will be important for programme managers to ensure that interventions are modified as necessary to reflect the particular range of characteristics of adolescence and different sub-populations within the adolescent population, e.g. younger/older, male/female, and adolescents from key populations.

The “ecology” of the adolescent is, for most adolescents, the family and the community. Schools are especially important as educators have an important role to play in promoting HTC. Parents and guardians must be educated and be willing to support their child being tested (and accompanying the adolescent for testing if she or he chooses). The broader community needs a better understanding of the importance of testing as well as the importance of respecting the rights of adolescents, including the right to confidentiality. However, while efforts to enlist the support of parents are important, parents’ involvement is not always beneficial and some adolescents will need additional support. This is especially true for adolescents from key populations who may be estranged from their families and who define their family and community very differently from other adolescents.

HIV testing

Testing should not be viewed as an end in itself. There need to be clearly defined linkages to post-test support services for both adolescents with and without HIV. Tracking and monitoring of service provision are also important.

Lack of linkages between testing and subsequent care discourages adolescents from seeking HIV testing in the first place. Post-test support is particularly important for adolescents, and standards for quality post-test counselling are needed. The potential adverse outcomes of inadequate or poor quality post-test counselling must be avoided. More guidance is needed on effective approaches to counselling (pre- and post-test), testing, links and pathways to prevention, treatment, care and protection.

Cost-effectiveness is important to deciding how to implement these guidelines. Expanding access to HTC is the overarching goal, but this does not imply that all adolescents should be tested regularly. Programmes should be informed by context-specific epidemiology to facilitate optimal use of resources. In all settings, HTC should be available to any adolescent who wishes to test. In settings with generalized epidemics, efforts should be made to increase access to HTC for all adolescents, and in all settings priority should go to providing services for adolescents from key populations. In settings with low-level or concentrated epidemics, it is important to understand groups that are disproportionately affected by or more vulnerable to HIV and encourage them to create demand for the uptake of HTC amongst their communities. “Test-for-the-test” risk assessments

and other screening tools are available to identify adolescents who may be at risk (42). However, some adolescents, particularly those who are homeless or orphans, may have been sexually abused; they may not consider this abuse to be “sex”, or they may be unable or reluctant to talk about it. This can make effective and predictive risk screening difficult. For all who test, consistent follow-up is necessary, including systems to track those lost to follow-up. It is also important to promote better integration of HTC with SRH services, especially for adolescents whose STIs and unintended pregnancies indicate their high-risk sexual behaviour. A better understanding of the extent of forced sexual activity among adolescents is needed, and better linkages between HTC and protection services are needed to refer those who have been the victims of violence and sexual abuse. When HTC uncovers issues of sexual abuse, there must be mechanisms to alert protective services to ensure that adolescents do not return to abusive settings.

Offering routine testing in clinical settings in generalized epidemics—that is, provider-initiated testing and counselling (PITC)—is particularly important for 10–14 year old adolescents so as to identify both slow progressors and symptomatic adolescents who have not yet been diagnosed despite clinical contacts. Both groups urgently need to be diagnosed so that they can be linked to treatment and care. However, providers must take care to avoid the misinterpretation of PITC as mandatory testing and to facilitate adolescents’ ability to opt out of testing.

Ministries of health need to develop standards, guidance, models, monitoring and supervision protocols and accountability and recourse mechanisms.

Consent to testing

Studies have shown that requiring parental consent to HTC services might reduce adolescent access because of perceived negative reactions from parents/guardians or health-care providers and the fear of HIV-related stigma (43, 44). Adolescents may opt not to seek care because they want to avoid telling their parents about their health problems and sexual activity (45).

Some caution is advised: if the legal age of consent to HTC is too definitive and prescriptive, it may be more difficult for health workers to use their judgment when dealing with individual cases, as many currently do. Furthermore, the advantages of parental involvement and parental consent to facilitate psychological support—that is helpful for treatment adherence and retention in care—must be balanced with the negative aspects of required parental consent when parents/guardians are not supportive or when adolescents fear abuse or other adverse outcomes with regard to parents/guardians.

Current consent policies are a key barrier to uptake of services by adolescents.¹ Countries should consider how best to address these issues within their own legal and social context and how, in general, to lower the age of consent for HTC. A range of issues need to be considered, including options for which persons can provide consent on behalf of a minor, e.g. an older sibling or relative.² Where countries have lowered the age of consent to 12 years (e.g. Lesotho and South Africa), access to and uptake of HTC by adolescents has increased without adverse consequences (South African Ministry of Health, personal communication, 2013).

Countries are encouraged to examine their current consent policies and consider revising them to reduce age-related barriers to access and uptake of HTC and to linkages to prevention, treatment and care following testing.

¹ See Annex 15 for a review of the current situation with regard to consent in sub-Saharan Africa.

² In the case of parental death, guardianship is often not legally conferred, but tends to be the head of the household with whom the adolescent is living at that time.

Directness of evidence

Some experience with adults regarding expansion of access to HTC could be applicable to adolescents, with appropriate modifications made to adult-oriented services. However, certain issues, especially concerning age of consent, will require careful consideration and policy review to ensure that the needs of adolescents are being met and that their rights are being protected.

Benefits of HTC

Adolescents are underserved, and changes in the systems that deliver HTC, treatment and care services are needed to prioritize appropriate and acceptable care for adolescents. It is expected that increased uptake of improved services—including linkages to prevention, treatment and care—by adolescents will have benefits for the individual as well as for public health.

Increasing uptake of HTC by adolescents

Routine PITC, home-based HTC and rapid testing may help to increase uptake of HTC services among adolescents, especially for slow progressors and pregnant adolescents. In low-prevalence settings, where infection is often acquired sexually and is concentrated in key populations, outreach or special venue-based HTC services may better serve these adolescents who may be socially marginalized and have limited access to conventional clinic services as well as potentially facing considerable risk of discrimination and legal consequences.

Many adolescent women, who make up a high percentage of the pregnant population, are already being tested in PMTCT programmes.¹ Lessons from the successful scale-up of HTC in antenatal care (ANC) programmes can be applied to the development of routine testing programmes for adolescents, particularly in sub-Saharan Africa (in the Asian context, low coverage of PMTCT and ANC limit these opportunities). Some data suggests that adolescents are more likely to drop out of care after delivery than adult women. This should be addressed through youth-friendly linkages and retention-in-care programmes. PMTCT services often find it a challenge to provide referral and adequate preventive services to adolescents testing negative (G. Hainsworth, Pathfinder, personal communication, 2013).

Adolescents consistently indicate preferences for compassionate, friendly, and competent staff; counselling linked with testing and other services along the continuum of HIV care; and rapid testing free of charge.

The main barriers to testing include stigma and discrimination, perception of low HIV risk, fear of knowing one's HIV status and of living with HIV.

Approaches to increasing uptake of HTC that require further research include pre-test risk reduction education, social networking, computerized testing prompts, adolescent-friendly services, and outreach HTC services accompanied by motivational interviewing. Self-testing kits also may expand options for adolescents who are reluctant to seek any type of HTC services; research will also be needed to determine the effectiveness of this approach with this population.

¹ About 16 million women 15–19 years of age give birth each year—about 11% of all births worldwide. See http://www.who.int/maternal_child_adolescent/topics/maternal/adolescent_pregnancy/en/index.html

Key populations

In all epidemic settings, accessible and acceptable HTC services must be available for adolescent key populations, and provided to them in ways that do not put them at risk.

Although the emphasis in low- and concentrated epidemics should be on providing acceptable HTC for adolescents from key populations, HTC services should be available to any adolescent who wishes to test. In low-level and concentrated epidemics, key populations are the most at risk, but it is important to ensure that they do not feel set apart or vulnerable to marginalization. Among the different epidemic settings, the delivery of testing and other services should take into consideration the social and legal environment of key populations, other socio-cultural factors for adolescents in general, and cost-effectiveness in different settings. Interventions to adapt delivery of services include outreach to places where adolescents from key populations congregate, social networking, and snowballing techniques to contact these adolescents in safe and acceptable ways.

Some countries have heterogeneous or mixed epidemics—where in some regions of a country the HIV epidemic is generalized, while in others it is concentrated. In many countries with generalized epidemics, there are also significant, more acute epidemics among adolescents from key populations. In resource-constrained countries it will be especially important to distinguish among sub-national epidemics to avoid misallocation of scarce resources. At the same time, targeting key populations can be extremely stigmatizing. For this reason it is essential that everyone has access to testing. In concentrated epidemics, testing should be available to any adolescent who requests a test; however, it is usually not cost-effective in these settings to conduct campaigns promoting testing to the general public.

Adolescents from key populations are frequently among the most underserved groups in society. Few health workers, or policy-makers in particular, address the needs of these groups—and most fail to acknowledge these adolescents at all—thus limiting services and policies to people 18 years of age and above.

Although key populations commonly refers to MSM, transgender people, sexually exploited adolescents, MSM and PWID, in many settings, particularly in generalized epidemics, other population groups such as adolescent girls and orphans should be prioritized and included in programme planning because of their increased vulnerability to HIV.¹

It is essential for each country to understand the epidemiology of its own epidemic, i.e. which groups are most likely to be infected or at risk of infection and face the greatest barriers to accessing health services. These groups will require prioritization for accessible and acceptable testing and additional support.

Operational guidance in this area is urgently needed.

Agreement on the recommendations

Many countries have accreditation processes that require HTC services to provide good referrals/linkages to follow-up prevention, treatment and care, yet most referral systems are inconsistently implemented and rely on passive referrals from HTC sites, and adolescents in particular are not benefiting from appropriate referrals. All recommendations addressing HTC, therefore, include specific mention of

¹ Orphans may face particular barriers when caregivers are unaware of the HIV status of a child they have taken responsibility for, or may be reluctant to disclose the status of the child if they do know.

linkages to prevention, treatment and care as an essential component of effective HTC services for adolescents.

For the first two recommendations, the WHO Guidelines Development Group considered the benefits and cost-effectiveness of HTC for all age groups and the urgent need to identify adolescents who require initiation of ART or more effective support for prevention. For that reason, there are strong recommendations regarding expanded access for key populations in all settings and for all adolescents in generalized epidemic settings.

For the third recommendation, there is uncertainty about resource availability and use for HTC interventions in concentrated epidemic settings. Still, the recommendation is considered important to enable adolescents who want to know their HIV status to receive support to do so.

2.2 Adolescents living with HIV: disclosure, adherence and retention

This section covers recommendations regarding support for disclosure by adolescents to others and approaches to strengthen support for adherence to treatment and retention in care, specifically through community-based interventions and training of health workers.

In these guidelines, disclosure refers to disclosure by adolescents to others to facilitate support for managing with a positive diagnosis, retention in care and adherence to treatment, and to reduce the likelihood of new infections.

The issue of disclosure of HIV status to children and adolescents by providers and parents is addressed in the WHO guidelines on HIV disclosure to children. These recommend that children of school age should be told their HIV status and that of their parent/s or caregiver/s; younger children should be told their status incrementally to accommodate their cognitive skills and emotional maturity, in preparation for full disclosure (46). These WHO recommendations therefore apply to adolescents, as full disclosure is recommended for all primary school age children. However, in many settings, adolescents are often not aware of their own HIV status, and this non-disclosure is associated with significantly lower retention in HIV care (47).

For ART to be effective in the long term, it is important that adolescents are supported to adhere to treatment and remain in care. These guidelines examine whether training of care providers can support better adherence and retention. They also review a wide range of community-based approaches and highlight operational issues, which are recommended in the WHO *Consolidated guidelines on the use of antiretroviral drugs for treating and preventing HIV infection* (4). The recommendation concerning disclosure by adolescents and the two recommendations for improving adherence and retention are presented along with summaries of the evidence and summaries of the Guidelines Development Group discussions. The evidence includes the systematic GRADE review of selected studies and the values and preferences derived from an e-survey of adolescents living with HIV. The summaries of the Guidelines Development Group discussions are accompanied by complementary findings of a literature review of published and unpublished studies and reports related to ARV service delivery for adolescents as well as contributions from peer reviewers. The 13 service delivery recommendations presented in the WHO *Consolidated guidelines on the use of antiretroviral drugs for treating and preventing HIV infection* are also included (4).

2.2.1 Recommendation—Disclosure

4 Adolescents should be counselled about the potential health benefits and risks of disclosure of their HIV status to others and empowered and supported to determine if, when, how and to whom to disclose. *Conditional recommendation, very low quality evidence*

Summary of the evidence

Systematic review: summary of main results

See Annex 4 for a full report of the systematic review related to disclosure of HIV status by adolescents to others.

Overall, studies of adolescents have found that disclosure was associated with improved clinical outcomes as measured by increased CD4 cell counts (48), decreased number of partners (but not with decreases in unprotected sex) (49) and increased distress when disclosure was to acquaintances, but with no statistically significant association with mental health symptoms with disclosure to family or close friends (50).

Seven studies of adults showed disclosure was associated with better linkage to care and ART adherence (51, 52, 53, 54, 55, 56, 57), only one found no association (58). Other studies showed disclosure was associated with higher CD4 counts (59), and nondisclosure was associated with virologic failure at 48 weeks (60). Disclosure was associated with better HIV testing and nevirapine adherence in the infants of mothers who disclosed their positive HIV status to their partners (61, 62), while nondisclosure was associated with suboptimal PMTCT outcomes (63).

Other studies of adults reported on additional outcomes. Disclosure to sexual partners was associated with increased frequency of condom use and reduced number of sexual partners; those who disclosed to HIV-negative partners were significantly less likely to engage in unprotected anal sex compared with those who did not disclose their HIV status (64, 65, 66, 67, 68, 69, 70). One study of adult women of three ethnic groups in the United States of America found no association between disclosure and depressed mood or health-related psychological distress except among Latinas, in whom a modest association was found (71). In four studies of adults, disclosure was associated with higher levels of HIV stigma; women who disclosed to sexual partners reported negative experiences such as anger and blame, including one study where women reported that partners reacted with violence and terminated the relationship (66, 72, 73, 74).

Small group discussions or group counselling supporting disclosure was shown in a trial of adolescents with HIV in the USA to significantly decrease the adolescents' report of unprotected sex, but there was no statistically significant difference in disclosure of HIV status to sexual partners (75). In other studies in the USA, when small group discussions were used to support disclosure by parents with HIV (75), there was no significant increase in disclosure to their adolescent children, and the parents had significantly higher mean depression scores at three months (but no significant difference at 15 or 24 months). Adult MSM living with HIV were no more likely to disclose to a higher number of family members (statistically non-significant) than was the control group (76).

Structured support groups or workshops in Africa were shown to significantly increase disclosure by pregnant women with HIV at two and eight months of follow-up; there was no statistically significant difference in reported depression (77). Another study (78) found no significant difference one week after women with HIV participated in empowerment workshops to help them deal with the emotional consequences of keeping their HIV status a secret.

One-on-one counselling significantly increased disclosure by mothers with HIV to their young children in one study (79), but the quality of the evidence is very low.

Peer-led behavioural interventions were shown to significantly increase adult MSM's self-reported motivation to inform sexual partners (80).

Nine additional studies were included, but were not amenable to GRADE analysis because of inadequate data. One study was a disclosure-only intervention (81); the remaining were more comprehensive interventions designed to address multiple issues relating to HIV infection, but included disclosure as part of the intervention.

Small group discussions (adolescents). There was limited evidence from the one adolescent study (82) that professionally led small group sessions had a positive effect on the adolescents' mental health.

Small group discussions (adults). A cluster randomized controlled trial of pregnant women with HIV found small group teaching by peer mentors resulted in increased preventive behaviours, decreased maternal depression, and better infant outcomes; no significant effects of the intervention were observed with respect to disclosure of the women's HIV status to their children (83). A randomized controlled trial found professional and peer-led support groups for low-income women with HIV increased condom use but not disclosure of HIV status to sexual partners (84).

Community-based interventions with disclosure component. One study found less loss to follow-up, improved retention in care and improved community-wide promotion of disclosure among adults with HIV who received community-level support from case managers, adherence counsellors and community volunteers, as measured against facility baseline data (85). Another study found that adults with HIV, with support from community health workers, were significantly more likely to disclose their serostatus to family members (86).

Individual counselling-based interventions. One study found that adults with newly diagnosed HIV infection had a significant decrease in depression scores four weeks after assessment and a significant increase in their intention to disclose their status (87). Another study found that adults with HIV who reported unprotected sex with a partner of negative or unknown serostatus all reduced unprotected sex, regardless of their randomized assignment to intervention or control group (88).

Online, computer-based interventions. One study found no difference in the rate of HIV disclosure among MSM (both with and without HIV) after viewing an online intervention designed to promote critical thinking about HIV risk, but were less likely to report a new or casual sexual partner or unprotected anal intercourse than before the intervention (89). Another study found that disclosure behaviours improved in terms of intentions and attitudes among MSM living with HIV after facilitated administration of an intervention tailored for disclosure to casual sexual partners (81).

Values and preferences: disclosure

A study of the values and preferences of young people living with HIV (10–24 years of age) was conducted to obtain the views of those who will be most affected by HIV treatment and care services for ALHIV and to ensure the inclusion of their voices in the guidelines development process (see Part 1, Section 2.2.2 for summary and Annex 11 for full report).

A scoping review indicated that disclosure of HIV status was correlated with increased social support, social self-confidence and decreased problem behaviour. In some studies reviewed it was observed that disclosure of one's positive status to others is a skill that takes time to develop and can be improved through support and instruction by health workers.

The online, anonymous survey did not explore the issue of disclosure specifically, but some of the respondents' comments suggest that support for disclosure may be needed and beneficial for adolescents.

“Privacy is an issue . . . Not all of us are ready to disclose . . . When we queue at a window [labelled with a sign] ‘ARVs’ . . . everyone can see that we are HIV-positive and that makes the stigma to be worse. . . My family doesn’t know yet . . . Teach us how to discuss [our HIV status] with family.”

During the workshops in South Africa and Zimbabwe (part of the values and preferences work related to HTC, see Part 1, Section 2.1.3), participants agreed that disclosing one's HIV status is the decision or right of an individual. Opinions were divided, however, regarding whether one should share one's status and with whom. Some participants felt that *“you should share your status with those you can trust”*, as this provided a *“necessary means of support”*, especially for accepting a positive diagnosis. Other participants, notably those in the Philippines and South Africa, felt that *“it was better to keep it [HIV status] to yourself”*. This view reflected concerns that *“someone could use your status against you in the future”* or *“spread it around to others without your permission”*, or that disclosure could result in rejection and loss of relationships.

Service providers interviewed during the community consultations on HTC expressed a more complex perspective than the adolescents. Many admitted that disclosure is very challenging to discuss and is often not adequately addressed with adolescents in pre- or post-test counselling. In the Philippines, some providers felt that guidance or policy on how to address disclosure was unclear or non-existent. While most providers asserted that disclosure was the adolescent's decision, a number of providers advocated disclosure to parents by providers. This was seen as essential for the practical support that most ALHIV will need. Others highlighted the need to take into account the willingness and readiness of each adolescent to disclose.

Summary of the expert panel discussion and other considerations

This section documents the key points raised during the discussion on disclosure among the participants at the expert meeting in Harare as well as feedback and inputs provided as part of the peer review process.

Benefits and risks of disclosure

Support from family and close friends can be particularly important for adolescents who may lack the maturity, experience or resources to cope with a positive diagnosis by themselves. They will be able to access this support only if trusted family members and close friends know their HIV status. From a public health perspective, disclosure is important for prevention of onward transmission.

However, adolescents who disclose their positive status face the potential of stigma, violence and abandonment, often at the hands of the people closest to them. Young married women and adolescent members of key populations may experience this more often and/or intensely than others.

It is important to emphasize that disclosure also comes with different degrees of risk, depending on who is disclosing to whom. Implications of disclosure by an adolescent to others, can include the risk of violence from sexual partners and risk of legal repercussions due to laws that criminalise HIV non-disclosure, exposure and transmission. For members of key populations in particular, disclosure may entail risk of persecution or other legal consequences if it suggests illegal behaviour or practices.

Disclosure to different people

Disclosure to sexual partners and disclosure to parents, friends, peers and others are very different processes, carried out for different reasons with very different implications. The possible support that can be gained from disclosing to a friend or family member can be a critical component of an adolescent's care and is a principle reason that an adolescent may choose to disclose. Disclosure to a sexual partner (either past or future) could provide support, but it could instead have significant negative implications for self-esteem and confidence in one's sexuality and for sexual and reproductive rights, and it is often done from a sense of responsibility.

Prevention of onward transmission

The primary benefits of disclosure should be to maximize support for the adolescent. Disclosure to sexual partners for the sake of their own health should be seen as only one of the ways that an adolescent could choose to prevent onward transmission and, therefore, is not explicitly part of the recommendation. The creation of safe environments for disclosure is the paramount for this recommendation. At the same time and to the extent possible, WHO recognizes that honesty in terms of disclosure to partners is a good stance and part of an adolescent's ethical development. Adolescents should be encouraged to take responsibility for onward transmission in some way, e.g. always using condoms, and partners should have access to post-exposure prophylaxis and emergency contraception if a condom breaks.

Operational guidance is needed for disclosure by adolescents specifically to their sexual partners. This should be considered within a "prevention package" including condom use, PMTCT and attention to legal frameworks and implications.

In general, disclosure to sexual partners is different for adolescents than for adults. Adolescents are often not in long-term stable relationships, and they may not have the knowledge and emotional skills to deal with the difficult issues raised by disclosure to partners, including dissolution of the relationship. Unequal power dynamics that are common among adolescents (e.g. between adolescent women and older partners) may also come into play, leaving the adolescent partner more vulnerable to isolation or abuse following disclosure. Moreover, there are major challenges with ensuring that ALHIV protect themselves and their partners from HIV transmission; e.g. poor or inconsistent condom use is a common problem. Alcohol, drug use, and other high-risk behaviours that often begin during adolescence also may constrain effective disclosure and safe sexual behaviour. Providers need to understand all the issues and dynamics involved with disclosure by adolescents in order to focus on the safety of the individual who is disclosing.

Support for disclosure from health-care providers

Disclosure of one's positive serostatus may involve disclosure about many other aspects of life (particularly for members of key populations). Health workers and peer counsellors need operational guidance on how to support adolescents to make decisions about disclosure, including their right to disclose and *not* to disclose. For adolescents, it is especially important to ensure that anonymous reporting systems are in place to ensure confidentiality and protection. Obligatory disclosure by health workers to authorities can be a powerful deterrent to HTC for members of key populations and other ALHIV. Also, it can lead to loss to follow-up among individuals who have not yet enrolled in treatment and care services, and it can also undermine retention in care for individuals who have already been enrolled in treatment and care. As part of HTC, service providers can discuss the issue of shared responsibility for prevention as well as disclosure of a positive diagnosis if an adolescent with HIV chooses to do this.

Disclosure by adolescents to others requires that they are aware of their own HIV status (see Part 1, Section 2.1.3 for discussion on the importance of HTC). In some cases adolescents may not know that they are living with HIV, even though they may have been diagnosed and may even be on treatment. When parents or other caregivers have not informed a vertically infected adolescent that he or she has HIV, it is possible that the parents may be more concerned about disclosure of their own HIV status than about their adolescent's health and well-being. All adolescents should be informed of their own HIV status, as this has significant benefits. Countries need to ensure that good policies, tools, training and programme support are in place to help health workers inform adolescents of their status when they have not already been told.

In situations where health workers are uncomfortable providing disclosure advice and support, or where there are health workforce shortages or other constraints on health staff, peer educators and community-based organizations could provide valuable support about disclosure.

Legal considerations

The Guidelines Development Group expressed considerable concern regarding the adoption and application of criminal law in relation to HIV and the potential implications of these laws for adolescents living with HIV. Safe and supportive disclosure is possible only in a legal and policy environment where adolescents do not risk harassment or arrest by police due to decisions to disclose or not to disclose their HIV status.

Adolescents are less knowledgeable about the law than their older counterparts. They may have a poor understanding of the legal environment in which they live and lack capacity to obtain legal support. The growing trend to introduce new laws that criminalize HIV transmission and exposure, and the use of existing laws to prosecute people living with HIV, could significantly deter adolescents from disclosing or from accessing services in the first place. An adolescent living with HIV can be much less inclined to disclose if they fear accusation by previous “disgruntled” sexual partners, followed by criminal prosecution. To avoid legal repercussions, individuals can elect not to disclose, denying themselves access to sources of support and links to vital treatment and care services. In such contexts the law continues to hinder access to essential HTC services and, in particular, to deter young people whose understanding of the law is limited. Where non-disclosure of HIV status is criminalized, the safest legal defence is ignorance of one's own serostatus, which is ultimately counterproductive to public health interventions and an individual's right to health and survival.

Other issues

Failure to disclose can be a particular problem among adolescents who are pregnant or delivering. If her partner or supportive family members do not know that a young woman has HIV, she will not have their support for safe infant feeding and uptake of PMTCT interventions and HIV care.

A scoping literature review (Annex 11) emphasized the notion of “skills” for disclosure. Developing these skills requires instruction and support from health-care providers and others. Some of the studies and reports reviewed suggest that disclosure may result in increased social support, self-confidence, and decreased risk-taking behaviour.

Some field practitioners and adolescents have noted that the notion “HIV stops with me” is gaining more importance and acceptability among people living with HIV, where individuals with HIV assume the responsibility to avoid putting someone else

at risk.¹ However, adolescents need to feel safe and protected from discrimination and other adverse consequences following disclosure. Legal, ethical and social issues therefore need to be considered in the context of this recommendation. Where relevant and acceptable, partners/couples counselling and mutual disclosure of serostatus should be considered (including in ANC) (90).

Agreement on the recommendation

Although there was limited evidence on which to base a recommendation, the Guidelines Development Group felt that counselling and support for disclosure are extremely important and are represented in the guidance as a recommendation based on the best judgment of practitioners and advocates working in the field. The recommendation serves as the basis to support further operational research to evaluate approaches to implementation.

2.2.2 Recommendations—Adherence to treatment and retention in care

- 5 Community-based approaches can improve treatment adherence and retention in care of adolescents living with HIV. *Conditional recommendation, very low quality evidence*
- 6 Training of health-care workers can contribute to treatment adherence and improvement in retention in care of adolescents living with HIV. *Conditional recommendation, very low quality evidence*

Two key types of interventions that could support adherence to ART and retention in care—training of health workers and a range of community-based approaches—were specifically reviewed by the Guidelines Development Group for these guidelines in addition to the interventions recommended in the WHO *Consolidated guidelines on the use of antiretroviral drugs for treating and preventing HIV infection* (i.e. service integration, decentralization, task shifting and mobile text messages) as they related to adolescents.

Summary of evidence

Systematic review: summary of main results

See Annex 4 for full report of systematic reviews related to community-based approaches and training for improved adherence to treatment and retention in care for ALHIV.

Community-based approaches

Overall, findings were a mixture of positive effects and no effects attributable to a range of community-based approaches in different populations and contexts.

Sixteen of the 17 studies amenable to GRADE analysis included adult populations, and one involved only children less than 16 years old. Therefore, the findings of this review may not be generalizable to populations of adolescents. Other concerns are the financial costs of community-based strategies for improving health outcomes of populations with HIV, as well as how to optimize adherence to programme protocols and quality of care provided by community health workers. Also, there may be significant challenges to scaling up community-based programmes for supporting adherence where there is limited infrastructure for monitoring or supporting community health workers.

¹ Adolescents in the focus group discussions (FGD) in Zimbabwe expressed this attitude, mentioning a sense of responsibility to themselves, their partners, their families and society (see Section 2.1.3, regarding motivations and deterrents to testing).

The 10 RCTs analysed provided low- to very low-quality evidence for the benefits of community-based interventions and very low-quality evidence for most outcomes due to the observational nature of the studies, the small number of events reported, and indirectness of the populations studied (i.e. adults or children less than 10 years old).

Home-based health assessment, education and support by community health workers. Community-based interventions that included home-based health assessment, education and support by community health workers were associated with better levels of ART adherence in one of three studies (91), with viral suppression in one of three studies (92) and reduced mortality rates in two of four studies (92, 93).

mHealth support intervention used by peer health workers at home visits. All studies involved adult populations. Exposure to an intervention delivered by peers and supported by mHealth was associated with greater viral suppression at 96 weeks after initiation of treatment in one study (94). However, no significant association between exposure to an mHealth intervention and virologic suppression was observed at earlier time points (94, 95, 96). None of four studies of mHealth-supported interventions showed an association with ART adherence (94, 95, 96, 97). None of three mHealth studies that examined mortality showed differences in mortality rates between intervention and control groups (94, 95, 96). Although the available evidence suggests that mHealth interventions for peer health workers may have a role in supporting patient adherence and retention in some settings, there is insufficient consistent evidence to give clear guidance on when and how these should be used to best effect. Further research on the impact of mHealth/peer health workers is needed.

With regard to mHealth interventions provided to patients, the WHO *Consolidated guidelines on the use of antiretroviral drugs for treating and preventing HIV infection* provides a strong recommendation to consider mobile phone text messages to adult patients reminding them to take their ART medications. This intervention holds considerable promise for adolescents, too, as mobile phone use is often widespread in low- and middle-income settings. However, careful monitoring and evaluation of this approach for adolescents is needed to ascertain acceptable and effective implementation.

Peer-support interventions. One of three peer-support interventions showed an association with better adherence (98). One study of a peer-support intervention that examined the effect of the intervention on mortality showed no effect (98). One study that examined the effect of an intervention on keeping follow-up appointments found no effect (99).

Socioeconomic support. The one study of a socioeconomic support intervention showed a reduction in mortality (100).

Community-based Directly Administered Antiretroviral Therapy (DAART). Neither of two studies of community-based DAART showed an association with better adherence (101, 102). A study of community-based DAART that examined mortality did not show an intervention effect on mortality (102). However, one of two studies showed an association between receipt of DAART and reduced mean viral load (103). One study that examined community-based DAART showed no effect on retention on the first-line ART regimen (103).

Ten studies were identified for inclusion in this review but presented insufficient information for GRADE analysis; they lacked regression parameters (104), had no comparator or the comparator was not the comparator of interest (i.e. standard care) (104, 105, 106, 107, 108, 109, 110, 111, 112) or reported only odds ratios without numerators (113). Therefore, associations are described only briefly below.

Mortality

One observational prospective cohort study of adolescents and adults with HIV (>15 years) at a community-based ART clinic in South Africa reported the probability of death in the first year of ART (7.9%, 95% CI 7.0%-8.9%) and the cumulative probability of death after six years (15.2%, 95% CI 13.1%-17.6%) (110). Male sex, lower baseline CD4 cell count, and WHO stage III and IV were associated with higher mortality risk.

One observational study comparing adolescents with HIV (9–19 years) and young adults with HIV (20–28 years) at a public sector community-based ART programme in South Africa reported similar overall mortality rates—1.2 (95% CI 0.3–4.8) deaths per 100 person-years among adolescents and 3.1 (95% CI 2.4–3.9) deaths per 100 person-years among young adults (111).

One observational retrospective cohort study conducted in Rwanda reported a low mortality rate (5%) at two years following ART initiation among adults with HIV in care at a community-based ART programme (112).

One non-randomized prospective cohort study conducted in Uganda compared treatment outcomes and mortality in a rural community-based ART programme with those in a hospital-based programme in the same district (108). In this study mortality at six months was not significantly different between the cohorts (11.9% versus 9.0%).

Viral failure or viral suppression

One observational study that evaluated outcomes of patients enrolled to a community-based, comprehensive ARV programme in Uganda staffed by peer health workers and nurses reported 86% of active patients (211 of 246 tested) to have a viral load of <400 copies/mL (107). Virologic failure was significantly associated with lack of CD4 response and any history of prior ARV use. No external comparator was included in the study.

One observational retrospective cohort study of patients with HIV in government HIV treatment sites in South Africa found that a significantly higher proportion of patients with a community-based adherence supporter maintained a suppressed viral load of <400 copies/mL at six months of treatment compared with patients without a treatment supporter (104). Also, a significantly greater proportion of patients in care at sites with a community-based adherence supporter services maintained a suppressed viral load and for a longer period compared with patients in care at clinics without a community-based adherence supporter service.

One observational prospective cohort study of adolescents and adults with HIV (i.e. >15 years) at a community-based ART clinic in South Africa reported high rates of virological suppression by 16 weeks after ART initiation and no significant variation between successive years of recruitment (110). Lack of virological suppression was associated with younger age (<25 years) and high baseline viral load (>5 log₁₀ copies/mL).

One observational study comparing adolescents with HIV (9–19 years) and young adults with HIV (20–28 years) at a public sector community-based ART programme in South Africa reported adolescents to have significantly lower rates of virological suppression at 48 weeks than did young adults (111). In addition, adolescents had significantly higher risk of virological failure than young adults, although the association was not significant when the comparison was limited to those perinatally infected.

One observational retrospective cohort study conducted in Rwanda reported a high rate of virologic suppression at two years after ART initiation (97.5% with <500 copies/mL) among adults with HIV in a community-based ART programme (112).

One observational prospective cohort study conducted in South Africa reported high and sustained rates of virologic suppression (<400 copies/mL) over a 3-year period (100%, 92% and 98% for 2002, 2003 and 2004 cohorts) among adults with HIV in care at a public sector community-based ART clinic (106).

One observational retrospective cohort study conducted in Kenya reported that time to treatment failure was significantly longer in patients who participated in peer support groups and/or received home visits than in those who did not (105). Further, risk of treatment failure was significantly lower among patients who participated in support groups than among those who did not.

One non-randomized prospective cohort study conducted in Uganda reported that virologic suppression at six months was not significantly different between patients enrolled in a rural community-based ART programme and patients in care at a hospital-based programme in the same district (90.1% versus 89.3%) (108). However, in a later report (109) the authors reported that patients enrolled in the rural community-based ART programme were more likely to achieve viral suppression at two years of follow-up compared with patients in care at the hospital-based programme.

ART adherence

One observational retrospective cohort study of patients with HIV receiving care in government HIV treatment sites in South Africa showed that a significantly higher proportion of patients with a community-based adherence supporter attained a treatment pickup rate of over 95% than patients without a treatment supporter (104).

One observational retrospective cohort study conducted in Mozambique reported that patients who had a treatment partner had significantly higher levels of adherence than patients who had no treatment partner (113). No differences in adherence were observed between patients with community-based treatment partners and patients with self-selected treatment partners.

One observational retrospective cohort study conducted in Kenya reported that a significantly greater proportion of patients who participated in support groups achieved higher mean adherence than patients who did not participate in support groups (105).

Retention in care

One observational retrospective cohort study of patients with HIV receiving care in government HIV treatment sites in South Africa showed that the median retention in care was significantly longer for patients in care at sites with community-based adherence supporter services than for patients at clinics without a community-based adherence supporter service (104).

One observational retrospective cohort study conducted in Rwanda reported a high rate of retention in care two years after ART initiation (92.3%) among adults with HIV in care at a community-based ART programme (112). In multivariate analysis attrition was associated with older age (>50 years). An interaction existed between WHO clinical stage at baseline and sex. Men, but not women, with WHO stage 3 or 4 disease at baseline were more likely to drop out of care than those with WHO stage 1 or 2 disease at baseline.

One observational prospective cohort study conducted in South Africa reported low rates of loss to follow-up over a 3-year period (2.9%) among adults with HIV in care at a public sector community-based ART clinic (106).

Training of health workers

No studies were found evaluating the training of health workers who provide treatment and care to adolescents living with HIV and the effect of this training on adolescent adherence to treatment and retention in care. However, one study using a quasi-experimental design was identified. It evaluated the use of a set of tools to build the capacity of health workers to respond to their adolescent clients effectively and with sensitivity. As there was such limited available published literature in this field, the reviewers also considered studies relating to health workers providing other chronic care to adolescents. Two randomized control trials were found that evaluated the training of health workers providing care to adolescents with other chronic conditions and the effect of this training on quality of care and adolescent health outcomes.

The overall goal of an evaluation in Gujarat, India, (114) was to determine whether, for selected reproductive health services in primary health centres, the WHO *Orientation programme on adolescent health for health-care providers* and the WHO *Adolescent job aid* tools would improve the quality of service provision and experiences of care for young female clients, ages 15–25 years. The findings indicated a number of positive outcomes of training including:

- improving health-care providers' understanding of the need to ensure privacy for young female clients;
- improvements in the attitudes of health-care providers at the intervention site towards young female clients;
- increased adherence to recommended procedures for assessment, pre-examination explanations, examination and treatment;
- improved client perceptions of the quality of consultations and satisfaction with services.

The RCT results of the intervention “Talking Diabetes” was published in two papers (115, 116). The intervention involved training providers in agenda-setting, communication style and a flexible menu of consultation strategies to support patient-led behaviour change. It found that training diabetes care teams had no effect on HbA1c levels (a marker for diabetes control) or on self-reported adherence to diabetic medications. The authors reported that improving glycaemic control in children attending specialist diabetes clinics might not be possible through brief, team-wide training in consultation skills.

The RCT results of a second intervention, in this case involving children with asthma, were published in one paper (117). The study randomized children and adolescents, ages 3–17 years, living with asthma in the US to a “planned care” intervention arm (n=213), a “peer leader” intervention arm (n=226) or a control arm of standard care (n=199). The peer leader intervention consisted of training one physician per practice in asthma guidelines and peer teaching methods. The planned care arm combined the peer leader intervention supported by a nurse, planned visits with assessments, care planning and self-management support in collaboration with physicians. The planned care intervention had a significant effect on the number of asthma symptom days compared with the control arm and a non-significant trend favouring the peer leader intervention compared with the control arm. Both intervention arms had lower oral use than the control arm. The authors concluded that planned care is an effective model for improving asthma care in the primary care setting, and, while peer leader education on its own may also work, it is much less comprehensive than planned care.

Values and preferences: treatment and care

A survey and a comprehensive literature review of qualitative research on the treatment and care of ALHIV were conducted to better understand the significant facilitators of and barriers to accessing services and remaining in care and treatment services and to gain an adolescent perspective of HIV care and treatment services (Annex 11).

Survey

The survey consisted of two phases:

- **A scoping review of published and gray literature** identified key issues to include in the development of the anonymous global survey.
- **A survey of ALHIV** (in both electronic and paper form) was conducted to understand the range and depth of perspectives of respondents regarding the care they receive to treat and manage HIV as well as other health needs. The final survey comprised 36 questions, 33 close-ended and three open-ended, and it was translated into five languages in addition to English.

The survey of ALHIV was completed by 447 young people (10–24 years old)—215 female, 213 male, and 19 transgender, other, or undisclosed—from 57 countries. Adolescents already actively engaged in HIV care and treatment provided the highest number of responses. For this reason, the survey results were limited and not representative of all adolescents living with HIV who may not be linked to networks or receiving care.

Ease of access. For most of the adolescents and young people who took the survey, access to care and attending health-care appointments were either very easy or not a significant challenge. Twenty-six per cent of those who responded to the open-ended question asking what they liked the most about the care they receive, stated that it was access to treatment – from availability and cost of regular health check-ups and drug treatment (ART) services to proximity of services, short lines/queues, and specialized health workers. Several mentioned the importance of NGOs in supporting the provision of life-saving drugs and services.

Those who found access somewhat or very difficult identified barriers to access to services such as cost, ARV stock outs, lack of doctors or adequately trained health-care professionals, lack of HIV services in many (especially rural) areas, lack of youth-friendly services, and poor treatment and stigma by health-care providers.

Transition to adult services. The survey revealed that a majority of adolescents and young people either do not receive paediatric or adolescent services, or, if they do, have never discussed transitioning to adult services. Of the respondents who said they are currently receiving paediatric or adolescent services (n=282), 38% had discussed a transition to adult care with their provider on at least one occasion, 40% had discussed it two to three times with their provider, and 22% had discussed it more than three times with their provider.

Interactions with providers. Most survey respondents indicated they had good experiences interacting with health-care providers. Eighty-five per cent of respondents reported moderately good (51%) to very good (34%) interactions with their providers in terms of comfort in asking general health-related questions, while 15% reported less favourable interactions with their providers. Eighty-eight per cent of respondents reported moderately good (51%) to very good (38%) interactions with their providers in terms of comfort in asking HIV-related questions. Thirty-five per cent reported that a provider contacts them if they miss an appointment.

Autonomy. Responses regarding the extent to which respondents took responsibility for their health care suggest a high level of autonomy among the group surveyed. Autonomy was gauged by respondents' indications that they took responsibility for

a range of activities around seeking care and making appointments, interacting with providers and treatment adherence.

The most positive aspects of care reported by respondents included sensitive and caring treatment by health-care providers; home visits; opportunities for meeting other ALHIV to share experiences and to feel empathy with others; and interactions with providers who preserve a sense of optimism and hope. Twenty-three per cent of respondents to an open-ended question asking what they liked most about the care they receive, valued the support they received from peer groups, teen clubs, and peer mentors.

Suggestions for improvements in services for ALHIV included age-appropriate support,¹ material support (clothing, food, support for orphans), more protection from the damaging effects of stigma and discrimination, more comprehensive information about all the ways that HIV is transmitted, dedicated spaces and activities for ALHIV where they can be with peers who understand what it is like to live with HIV, and with educational opportunities for those who do not attend school.

Literature review

A comprehensive review of published literature examined the findings of a wide range of studies including randomized controlled trials, quasi-experimental, and descriptive research in order to gain insight into the values, preferences, perceptions, and attitudes of adolescents and young people regarding HIV treatment and care.

Confidentiality and disclosure. For ALHIV, privacy and confidentiality are major concerns in the provision of care. Those adolescents studied indicated that they are particularly sensitive to the stigma associated with HIV, and felt it is important for health-care providers to offer a safe environment that ensures the privacy of young patients or clients and confidentiality of their discussions, decisions, test results, and treatment. Disclosure best practice was articulated as a gradual process that should be based on the adolescent's development and readiness to reveal their HIV status to others, and that this process requires a wide range of support – from health-care providers, caregivers, peers, and the community – and skills development to increase self-confidence, self-efficacy, and empowerment. The major barriers to disclosure were fear of unintended or unwanted disclosure by teachers, parents, or friends, or because of inadequate privacy in clinics or pharmacies; and fear of negative reactions from family, friends, and the community.

Accessing care. Access to care is broadly defined to include physical access to treatment and care, as well as financial and social support. Those adolescents studied wanted universal access to care, as well as care designed specifically for their needs and provided in a youth-friendly atmosphere. Trusting relationships with and between parents or guardians and health-care providers, and the availability of counselling and support were the primary facilitators for adolescents accessing care. Provider and community stigma, and inadequate or incorrect information about HIV were considered major barriers to utilization of available services.

Adherence to ART. High adherence to ART by ALHIV was linked to psychological adjustment, effective coping mechanisms and adoption of explicit medication routines. ALHIV identified both positive and negative factors as facilitators for adherence to ART: positive – e.g. free or low-cost medications, electronic reminders, family and peer support, self-esteem and empowerment skills building and support; and negative – e.g. taking medication regularly so 'people won't know I'm sick', fear of consequences, and fear of re-infection or superinfection. Depression, regimen

¹ E.g. the separation of adolescent and adult services by location, day, or time, to the provision of peer support in the forms of groups, mentoring, teen clubs, or camps.

fatigue, weak health-care systems, lack of youth-friendly services or privacy, and misinformation were articulated as the primary barriers to adherence to ART for ALHIV.

All health-care facilities or delivery sites should be safe spaces where adolescents can freely express their emotions and concerns, and where providers demonstrate patience, understanding, acceptance and knowledge about the choices and services available to the adolescent.

Retention in care. Also important was the strength of the relationship between the health-care provider and adolescent (and parent or guardian depending on the age and readiness of the adolescent). Like the other key findings, an ALHIV's level of self-esteem and feeling of empowerment to make decisions improved retention, as did supportive family or family-like environments and peer support. Similarly, barriers to retention in care included the lack of youth-focused services and privacy, poor communication with health-care providers, misinformation, and anxiety or depression.

Successful transition to adult services. It is vital that an adolescent has a clearly defined pathway into adult care and that the transition is carefully managed. Abrupt changes can be destabilizing and confusing; continuity of care and the transition to adult services should be a joint effort involving the adolescent, their parent or guardian, and the health-care provider, the balance of which should be determined by rights, readiness, and willingness of the adolescent to assume responsibility for various health-seeking and maintenance activities—e.g. taking medication, making appointments, asking questions of health-care providers, and helping to choose their own treatment plans. Facilitators for ALHIV taking responsibility for these types of activities included family-centred and peer support and counselling; self-esteem, empowerment, and coping skills-building activities and support; and a gradual developmental approach that takes into consideration the individual's particular needs. The greatest barriers to successful transition for ALHIV included the poor evaluation of adolescents' abilities to receive and process information, and the lack of or poor communication with health-care providers. The loss of a good relationship with a paediatric provider was also a major barrier to ALHIV successfully moving to adult services when developmentally appropriate.

Summary of the expert panel discussion and other considerations

This section documents the key points raised during the discussion on community-based approaches and training among the participants at the consultation in Harare as well as feedback and inputs provided as part of the draft review process. It also presents the main findings of a literature review exploring the facilitators and barriers to retention in care and adherence to treatment.

Literature review: retention and adherence considerations

A separate literature review of published and unpublished studies and reports was conducted to look specifically at facilitators and barriers to adolescents' adherence to treatment and retention in care (Annex 13).

Several of the studies and reports included in this review suggested that continuity of care in the transition from childhood to adulthood should be a focus for policy-makers and programme managers. Continuity of care and the transitions between different stages should be joint efforts involving the adolescent, service providers, families/caregivers, health facilities, schools and the broader community.¹

¹ The challenge of transition to adult care is common to the management of many chronic illnesses in adolescents; providers of services for ALHIV can learn from health care workers treating adolescents for other chronic illnesses.

Attitudes of health-care providers are an important consideration in services for ALHIV. All service provision settings should be safe spaces, where patients can express anger, frustration, fear and confusion. Providers need to take time to answer questions, validate feelings, explain choices, identify and organize support and express unconditional acceptance.

Some aspects of clinic structure and the availability of tools and resources may help adolescents to access care, support, prevention and treatment when and as they wish. There are ways to make services more accessible and acceptable for adolescent clients. These include adolescent-only days or evening hours with flexible appointments or walk-in options as well as linkage to other supportive services and activities off-site.

Community-based interventions

Community-based service delivery is important for adolescents; it can minimize logistical and financial constraints and offer services in familiar and easily accessible settings. Community-based settings can refer to proximity to where adolescents live as well as services that are delivered in a specific community of adolescents with common characteristics or challenges, such as a key population. Nearby, accessible services can support adherence to treatment and retention in care for ALHIV and minimize risk behaviours and, when an individual tests negative, facilitate timely and low-cost referrals to further prevention support.

As with management of other chronic illnesses during adolescence, ALHIV have serious problems with adherence. Most research shows that this is a greater challenge for adolescents than for adults.

Community-based services can mitigate some of the burden faced by adolescents who need accessible and free/low-cost services to support adherence. Greater accessibility, acceptability and affordability also can help increase retention in care and reduce loss to follow-up.

However, in some cases, the “familiarity” of community-based services may be a disincentive for adolescents due to concerns about confidentiality. More research will be needed to determine how to address this issue.

Depending on the setting, one of the key challenges with decentralization and reliance on community-based services will be developing some degree of capacity at peripheral facilities to handle the array of HIV-related services required by adolescents. In some cases, particularly with vertically infected adolescents, complex health issues are likely to be harder to address in community-based settings, e.g. cardiac, lung, cognitive and pubertal delay issues. Additionally, adolescents on ART need to be monitored annually for long-term toxicity and co-morbidities; there may be limitations to the scope of services that community-based providers can offer.

Given the diversity of community-based approaches, it is important to note that there are aspects of some current programmes that may have no benefit, may increase stigma and discrimination or are considered to be harmful (e.g. in which patients are advised to suspend their medication). These concerns and lack of consensus resulted in a conditional recommendation.

Common elements or conditions needed for effective community-based interventions:

1. Adolescents should be involved in the design and implementation of community-based interventions so that these programmes reflect their knowledge, motivation and skills.
2. Community-based services should be considered an integral part of the continuum of care, with formal linkage to facility-based services.
3. Flexibility should be designed into community-based services for adolescents to accommodate the needs of diverse groups, especially young members of key populations and adolescents of various ages who were vertically infected and have been living with HIV for many years.¹
4. There should be clearly defined selection criteria for community-based workers/agents as well as routine supervision and monitoring.
5. Careful monitoring and evaluation of community-based approaches as they are implemented remains a priority to assess acceptability, cost-effectiveness and efficacy.

Topics that are well-suited to collaboration between the community and health sectors include addressing myths about HIV and adherence, feelings associated with coping with HIV and seeking support for disclosure.

Training health workers

Although no studies were found evaluating the training of health workers providing services to ALHIV and the effect of this training on adherence to treatment and retention in care, there was consensus among the Guidelines Development Group that training is required for providing health services for adolescents. In the same way that health workers need training to deal with the range of issues faced and presented by adolescents, they also need training to support adherence to care and to retain patients in care.

Adolescents often find it difficult to think about the future consequences of today's actions. With emerging abilities to think about themselves and their social environment, they challenge authority, and seek new experiences, some involving risks. This behaviour has implications for the information and support that adolescents require and how they respond to advice. Adolescents are receptive to peer influence and to concerns about body image. They often have less structured lives than adults, which may make treatment adherence more difficult. Unemployment and poverty make it more likely that they have to rely on parents for financial and other support. These factors limit their ability to make independent decisions about using health care and other services.

Because of the ways that adolescents think and react—the ways in which they are influenced; their changing capacity and autonomy; their relative lack of information, skills and resources; and the values and norms that surround them (which influence how communities and health workers react to them)—there is a need to mobilize and train service providers at many levels if adolescents are to access and be retained by services.

Some adolescents who were vertically infected and diagnosed early may have already been on treatment for 10 or more years. They may have been started on sub-optimal HIV regimens or faced treatment interruptions. They may have complex HIV disease with various drug-resistance mutations, and they may face a variety of chronic illnesses and developmental delays as well as depression. Special skills are required for management of the complex health profiles of these adolescents.

¹ Community-based interventions are essential for identifying and reaching adolescents in key populations, who may not seek facility-based services due to fears of stigma and/or legal consequences.

Health workers need training to help them understand and address the barriers to adherence that many adolescents with HIV on treatment have.

Assessment of these adolescent adherence barriers include consideration of the adolescent's cognitive skills, their buy-in to medication regimes, their home and family support situation, the adolescent's routines and when they are most likely to miss doses and ways to simplify regimens, including reducing the number of times a day medications must be taken.

Patients' transition from childhood to adolescence can be challenging for health workers. They often do not feel prepared to deal with the new issues this transition presents—sex and sexuality, a range of developmental issues. It is important that health workers are sensitized to how adolescents differ from adults and from small children and to know what resources in their communities are available to support adolescents. Health workers need to be able to link with a wide range of other practitioners and organizations that can help (e.g. community health workers, NGOs, community-based organizations (CBOs), ALHIV peer support groups).

At the same time, it is not necessary—and usually not feasible—to create a separate cadre of health workers specializing in the needs of ALHIV. While it would be ideal if there were more specialists and centres of excellence, it is of primary importance that health workers providing services to PLHIV in general are able to respond adequately to the needs of ALHIV in a decentralized and integrated way. For example, a retrospective cohort study in Zimbabwe found that involving adolescents in the planning and introduction of additional medical and social services for adolescents in a public sector ART clinic resulted in significant increases in initiation of ART and retention in care as well as lower mortality compared with data on other adolescent patient populations in the country (118).

As summarized by one member of the Guidelines Development Group:

Training by itself rarely results in large changes in the quality of services or in provider attitudes. Rather, training needs to be part of a continuous quality improvement (CQI) process that includes a range of elements at the provider level such as job aids, supportive supervision, training follow-up and mentorship. At the facility level, CQI might include a range of actions including small infrastructure changes, modified admittance procedures or signage for increased privacy and confidentiality for adolescent clients. Informational materials and visual aids can help providers to be better able to communicate with ALHIV around their treatment and care needs; having the necessary equipment and commodities on hand facilitates appropriate and timely delivery of services. The involvement of peer educators and lay health workers can alleviate the workload of health workers and provide additional support.

Negative attitudes of health workers affect adolescents more than adults, and they affect young people in key populations more than other adolescents. In this regard health-care providers must have the skills to listen attentively, speak clearly and be aware of adolescents reticence and uneasiness in communicating with providers. Training may be needed for health-care providers to better understand how to provide such care.

Health worker training on HIV-related services for adolescents needs urgent attention, especially regarding how to link it with and build on existing training. For example, adolescent-specific content can be integrated into existing HIV training on adults, or HIV-related content can be integrated into existing training on adolescent

health or adolescent-friendly health services. Attention is also needed to pre-service training (adolescent health, ALHIV, adolescent sexual and reproductive health, young key populations). Further, other professionals, e.g. social workers, play key roles in the support of ALHIV; their involvement needs to be taken into consideration when planning the strengthening of human resources.

Training of health workers should focus particularly on:

- **Primary care:** Chronic illnesses in ALHIV, psychological and emotional illness, contraception and sexual and reproductive health issues, nutrition;
- **Prevention:** Condoms, prevention of high-risk behaviours (e.g. alcohol and substance use), harm-reduction (for PWID) and communication skills;
- **HIV treatment and care:** Adherence, retention, self-management;
- **Mental health:** Positive and negative coping styles, depression and mental health issues, dealing with a history of abuse, dealing with history of parental death;
- **Disclosure:** Supporting adolescents to disclose (a) to others in order to obtain the support they need and (b) to sexual partners in order to contribute to safer sex/HIV prevention (although the priority for individuals should be adherence to treatment and correct, consistent condom use).

Other topics of particular importance to adolescents include:

- Learning about and coping with their feelings;
- Finding support;
- Learning about the impact of HIV on their bodies, how to live a healthy life and when and why ART and adherence are important;
- Learning about safer sex, relationships and fertility choices (i.e. whether or not to have children and being supported in either choice) and making plans for the future, including education and employment.

To some extent training health workers is about attitude and behaviour change, which is not likely to occur due to a single training event. However, the recommendation for training is a starting point and one component of working toward increased adherence to treatment and retention in care. Ongoing supervision and professional support are essential as part of the change process.

Agreement on the recommendations

With regard to support for treatment adherence and retention in care through community-based interventions and training of health workers, there was insufficient evidence in the systematic reviews or the review of the published descriptive and gray literature upon which to base recommendations. However, the interventions in question are important enough that they are represented in this guidance as the best judgment of practitioners and advocates and as the impetus for further research focused on implementation.

Both of the recommendations have weak evidence bases, but meet the criteria for conditional recommendations.

2.3 General service delivery recommendations

The WHO *Consolidated guidelines on the use of antiretroviral drugs for treating and preventing HIV infection* present a number of service delivery recommendations, as shown in Table 3.¹ When GRADE reviews for the consolidated ARV guidelines—that led to these service delivery recommendations—were commissioned, the researchers were expressly tasked with identifying studies that were specific to

¹ For background to these recommendations, please see the report on the Operational and Service Delivery Guideline Development Group Meeting, Geneva, Switzerland, 6–8 November 2012.

adolescents or had adolescent participants. However, they identified no studies of adolescent populations. These recommendations were also discussed at the adolescent expert meeting and specific considerations for adolescents were raised for each area, as follows.

Table 3. Service delivery recommendations from the WHO Consolidated guidelines on the use of antiretroviral drugs for treating and preventing HIV infection

Community-based HIV testing and counselling	In generalized HIV epidemic settings, WHO recommends community-based HIV testing and counselling with linkage to prevention, care, and treatment services in addition to provider-initiated testing and counselling. (Strong recommendation, low quality evidence)
Service integration and linkage	<p>In all HIV epidemic settings, WHO recommends community-based HIV testing and counselling with linkage to prevention, care, and treatment services for key populations in addition to provider-initiated testing and counselling. (Strong recommendation, low quality evidence)</p> <p>In generalized epidemic settings, ART should be initiated and maintained in eligible pregnant and postpartum women and in infants at maternal, newborn and child health-care settings, with linkage/referral to ongoing HIV care and ART, where appropriate. (Strong recommendation, very low quality evidence)</p> <p>In settings with a high HIV prevalence ($\geq 5\%$) among TB patients, ART should be initiated for HIV-positive individuals with TB in TB treatment settings, with linkage to ongoing HIV care and ART. (Strong recommendation, very low quality evidence)</p> <p>In settings with a high burden of HIV and TB, TB treatment should be provided for individuals with HIV in HIV care settings where TB diagnosis has also been made. (Strong recommendation, very low quality evidence)</p> <p>In settings in which opioid substitution therapy is provided, ART should be initiated and maintained in people with HIV who are eligible for ART. (Strong recommendation, very low quality evidence)</p>
Decentralization of treatment and care	<p>The following options should be considered for decentralization of ART initiation and maintenance:</p> <ul style="list-style-type: none"> • Initiation of ART in hospitals, with maintenance of ART in peripheral health facilities. (Strong recommendation, low quality evidence) • Initiation of ART with maintenance of ART in peripheral health facilities. (Strong recommendation, low quality evidence) • Initiation of ART at peripheral health facilities, with maintenance at the community level between regular clinical visits (i.e. outside of health facilities in settings such as outreach sites, health posts, home-based services or community-based organizations). (Strong recommendation, low quality evidence)
Task-shifting	<p>Trained non-physician clinicians, midwives and nurses can initiate first-line ART. (Strong recommendation, moderate quality evidence)</p> <p>Trained non-physician clinicians, midwives and nurses can maintain ART. (Strong recommendation, moderate quality evidence)</p> <p>Trained and supervised community health workers can dispense ART between regular clinical visits. (Strong recommendation, moderate quality evidence)</p>
Interventions to optimize ART adherence	Mobile phone text messages could be considered as a reminder tool for promoting adherence to ART. (Strong recommendation, moderate quality of evidence)

2.3.1 Community-based HTC¹

The provision of HTC is very important for all adolescents, and all affordable, feasible and acceptable approaches for increasing the likelihood of adolescents being tested should be explored. It is particularly important for horizontally infected older adolescents, as this group is very inadequately tested in generalized epidemics.² However, while increasing HIV testing of adolescents is important, it is essential to also give adequate attention to:

- post-test counselling, links to services (prevention, treatment and care) and consent/confidentiality are major concerns for adolescents;
- understanding that adolescents testing positive for HIV may not yet require treatment, but do need care and retention by the health system;
- special issues for adolescents from key populations accessing testing and adequate counselling.

2.3.2 Integration of HIV treatment with TB, ANC/MNCH and IDU services

Integration of HIV services into other clinical settings may also be considered for adolescents, but these services will need to:

- have ways to encourage adolescents to enrol early for PMTCT/ANC (currently, late enrolment in ANC is a significant problem for adolescent pregnant women) and to support them through their pregnancy, including: access to ART and adherence counselling for PMTCT and ART for their own health; and support for making safe infant feeding choices, making post-delivery contraception choices, and involving the father of the child/partner(s) and supportive family members;
- consider linking to efforts to make all health services more responsive to the needs of adolescents (not just maternal, newborn and child health (MNCH), but MNCAH);
- understand that, for all aspects of programmes and policy, adolescents in key populations need specific consideration. For example, most young injecting drug users are less likely to use routine health services, so HIV treatment needs to be integrated into services that are provided for injecting drug users;
- ensure that national plans/strategies explicitly cover adolescents.

2.3.3 Decentralization of HIV treatment and care

Providing services near home can be important for adolescents, as this is likely to make their access to services easier. At the same time it is important to ensure that:

- service providers have at least minimal training to: respond to the specific needs of adolescents; support disclosure and adherence by adolescents; provide prevention education and support to adolescents (e.g. safe condom use); and link with others (e.g. community groups and community workers) who may be better able to support the particular needs and complex challenges that adolescents face;
- support groups for ALHIV are also decentralized, where appropriate (depending on the type of epidemic and context);
- special considerations are made for adolescents in key populations;
- there is adequate age (and sex) disaggregation of routinely collected data for monitoring and planning;
- there are effective systems of referral for other health issues (e.g. chronic illnesses, depression, sexual and reproductive health).

¹ “Community-based” in this context refers to services (including HTC services provided by NGOs and CBOs) available within communities where adolescents live, with links to the formal health system.

² Slow progressors are more likely to be diagnosed through PITC.

2.3.4 Task-shifting for HIV care and treatment

This could be considered for adolescents, but:

- The people to whom the tasks are shifted need to be trained to respond to the needs of adolescents.
- There must be strong linkages to NGOs and community groups working with adolescents/ALHIV that can support disclosure, adherence, etc.

2.3.5 Use of mobile technologies for adherence support and social support for PLHIV

Mobile technologies have been used successfully for other chronic illnesses among adolescents, and this is a technology that they are familiar with. Its use potentially can improve adherence and support, but it is essential that ALHIV are involved in the development of the programmes.



PART TWO

OPERATIONAL CONSIDERATIONS

The following guiding principles should underpin the design, development, implementation, monitoring and evaluation of HTC and treatment and care services for adolescents.

1.1 Voluntary testing

While testing should be routinely offered and available, it should not be mandatory. National HTC policies and practices should be reviewed to eliminate all non-voluntary forms of testing. There should be no compulsory or mandatory testing of members of key populations at higher risk of HIV infection and other vulnerable populations, including pregnant women, people who inject drugs and their sexual partners, men who have sex with men, sex workers, prisoners, migrants, refugees and internally displaced persons, and transgender people.¹

1.2 Heterogeneity of adolescents

Adolescents are not all the same. The heterogeneity of adolescents needs to be recognized, from the modes of their infection (vertical/horizontal) to their age, sex, sexual orientation, and from their roles and responsibilities in the family and community to the variability of their transitions to adulthood. Service delivery responses need to reflect this heterogeneity of adolescents as well as context-specific aspects of their lives.

1.3 Meaningful involvement of adolescents

Adolescents, including adolescents living with HIV and those from key populations, must be involved in the development and implementation of acceptable and appropriate programmes and in supporting country processes for development of policy.

1.4 HTC minimum standards: The 5 Cs

The following are key principles of HTC and apply to services for adolescents in all circumstances:

- Adolescents receiving HTC must give informed **consent** to be tested and counselled (see discussion in Part 1, Section 2.1.1 and guidance on consent as an operational issue in Part 2, Section 2.1). Adolescents should be informed of the process and understand the implications of learning their HIV status.
- Adolescent services must be **confidential**, meaning that what the HTC provider and the individual discuss will not be disclosed to anyone else without the express consent of the adolescent being tested. Decisions concerning to whom to disclose test results should be made with the support of the provider or counsellor and a family member or friend if possible. While confidentiality must be respected, it should not be allowed to reinforce secrecy, stigma or shame. Counsellors should raise the issue of whether the adolescent may wish to disclose to others, how she or he would like this to be done, etc.

¹ See "Statement on HIV testing and counselling: WHO, UNAIDS re-affirm opposition to mandatory HIV testing." http://www.who.int/hiv/events/2012/world_aids_day/hiv_testing_counselling/en/index.html

- Adolescent HTC services must be accompanied by appropriate and high-quality pre-test information and post-test **counselling** (ensured by quality assurance mechanisms and supportive supervision systems).
- Programmes for adolescents should strive to assure the high quality of testing services, and quality assurance mechanisms should be in place to ensure the provision of **correct test results**. Quality assurance may include both internal and external measures and should include support from the National Reference Laboratory as needed.
- HTC services for adolescents must provide effective referrals for **connections/linkage to appropriate care** and follow-up services as indicated, including long-term prevention and treatment support.

1.5 Gender issues

Gender issues must be considered in the implementation of all the recommendations, considering the specific needs of adolescent men, adolescent women and transgender adolescents.

1.6 Human rights perspective

A human rights perspective will ensure that all actions taken with respect to delivery of HTC, treatment and care services will be in the best interest of the adolescent. As specified in the Convention on the Rights of the Child, adolescents have:

- the right to non-discrimination;
- the right to privacy and confidentiality, including with respect to advice and counselling on health matters;
- the right to express views freely and to have them duly taken into account;
- the right to participate in decision-making processes that are relevant in adolescents' lives and to influence decisions taken on their behalf;
- the right to health and development, including the right to choose to have an HIV test and to use an array of HIV-related services;
- the right to a safe environment;
- the right to access to appropriate information, with particular regard to numerous health-related situations;
- the right to be free from disease and ill health;
- the right to be free from harm, and that children must have protection from all forms of sexual exploitation and sexual abuse;
- the best interests of the child should guide all actions concerning children.

These principles apply to all children, irrespective of their circumstances and the behaviours they practice (sell sex or use injectable drug), and entitle them to the protections and services (including harm-reduction), they need in order to avoid acquiring HIV and other infections, and to protect and improve their health and wellbeing.

1.7 Developmental appropriateness

Services must reflect developmentally appropriate considerations for a range of stages of cognitive and physical development. A continuum of care will respond to the evolving capacity of adolescents. While these guidelines focus on adolescence, service providers will need to consider the various transitions into appropriate types of care before and beyond adolescence and the importance of preparing adolescents to manage their lives and health needs as adults.

1.8 Supportive and conducive legal and policy environment

A supportive and conducive legal and policy environment is critical for adolescents to access and benefit from HIV testing, counselling and linkage to appropriate treatment and care. The criminalization of HIV transmission, exposure, non-disclosure and specific behaviours such as same sex relations, injecting drug use and involvement in commercial sexual exploitation significantly restricts an adolescent's ability to access and benefit from a range of essential HIV-related services.

1.9 Legal protection

In cases of sexual exploitation and violence, adolescents need referral to appropriate child protection services. Such services may be specialized legal and protection services that have experience with counselling adolescents—for example, police services and/or specialized child protection services and post-rape care services dealing with sexual abuse.

There is strong consensus on the need to expand access to and uptake of HTC by adolescents in all settings, to improve the quality of health services for adolescents living with HIV, to scale them up and to increase adolescents' access to and use of available services. However, answers are needed to operational questions on:

- how best to deliver HTC services for adolescents and to increase uptake and linkages to appropriate care?
- how best to deliver interventions and services for adolescents living with HIV?
- how to integrate lessons learnt and best practices into existing systems, given limited resources and capacity?
- how to increase the quality, coverage and equity of services for adolescents living with HIV in a resource-constrained operating environment?
- how to increase cost-effectiveness and sustainability?

To shed light on these questions and to highlight relevant work being done in resource-poor settings, UNICEF has initiated the UNICEF ALHIV Lessons Learned project, developing a living document—with an emphasis on “how it was done”—that is intended as a repository for experiences that will stimulate and guide accelerated action to meet the needs of ALHIV (see Annex 14). In emerging areas of programming, while there is not always a substantive base of research evidence to develop programme guidelines, the experiences of pioneers can provide examples for others. The preliminary report on this project presents summaries of successful or promising programmes that are being or have the potential to be taken to scale. These programmes focus on testing, entry to and retention in treatment and care, adherence, prevention for ALHIV (e.g. avoidance of high-risk behaviours) and primary care for ALHIV (e.g. care for chronic illnesses and sexual and reproductive health).

This section examines the conditions and approaches that will facilitate effective expansion of HTC for adolescents and support adherence to treatment and retention in care. It draws on many of the examples and discussion points included in the UNICEF Lessons Learned report, as well as other programmatic experiences contributed by members of the Guidelines Development Group and other contributors.

Operational issues are often context-specific. WHO, UNESCO, UNICEF, UNFPA and GNP+ recognize the heterogeneity of adolescent populations, differences in epidemiology and social context and the diversity of health-care delivery systems across and within countries. Additional considerations are resource levels, disease burden and local health sector priorities. Policies regarding consent to test, disclosure and confidentiality also vary widely across countries and influence the implementation of a range of interventions. Adaptation of these operational options must take into consideration all of the context-specific realities.

2.1 HTC

2.1.1 Consent to HIV testing

A specific challenge that has implications for many aspects of programming, and for research, is the issue of consent. Obtaining the necessary informed consent can take significant time; it needs to be built into the planning of the programme. Informed consent needs to be based on human rights principles (e.g. the best interests of the child, the evolving capacity of the child) and involve ALHIV, parents, caregivers and health-care providers.

LOWERING THE AGE OF CONSENT FOR TESTING (SOUTH AFRICA)

Since July 2007, adolescents aged 12 years and older in South Africa have had the right to consent for an HIV test, if it is considered to be in his/her best interest—so long as s/he is of sufficient maturity to understand the benefits, risks and social implications of the test. According to South African HIV counselling and testing guidelines, an HIV test is in the best interests of a child if the test will result in access to the continuum of care and support for their physical and emotional welfare.

The age of consent for HIV testing was determined as part of a larger process. South Africa commenced a period of intense legislative review and reform shortly after the end of Apartheid. In 1997 the South African Law Commission was mandated to review the old Child Care Act (which allowed children above the age of 14 to consent to medical treatment and children above the age of 18 to consent to surgical procedures). The commission elicited comments and held public consultations between 1998 and 2002. As a result of the review and public consultations coinciding with the height of the Mbeki AIDS denialism era, the constitutional protection of children's rights in the face of the HIV/AIDS epidemic was prioritized. Notably, the Commission actively sought input from children themselves.

The outcome of the process was a progressive new Children's Act that removes age-related barriers to children's access to health care. The age of consent for medical interventions, including HTC, was at least partly informed by the age of sexual debut, rates of STI in adolescents and the realisation that the age threshold needed to be lowered to allow children younger than 14 years to access sexual and reproductive health services. In addition, however, the decision was informed by the desire to recognise and support the growing autonomy of adolescents.

The impact of the age of consent for HTC is difficult to quantify. Firstly, the change was relatively minor, having previously been set at 14 years of age. Secondly, routine health information data, including HTC data, are aggregated in a manner that precludes the assessment of adolescent health-care utilisation. Anecdotal reports from health-care providers indicate that 12–14 year old adolescents do request and receive HTC at health facilities, usually after having undergone schools-based HIV education. There are no documented instances of serious adverse consequences in those who test positive, with health workers indicating that adolescents undergo CD4 testing and commence ART if indicated.

✉ For more information contact Henry John Moultrie: hmoultrie@wrhi.ac.za

2.1.2 Linking testing with prevention, treatment and care

The recommendations of these guidelines related to HTC explicitly note the importance of linkages to prevention, treatment and care. All adolescents should have access to testing, but it is essential to ensure that those who are most vulnerable and those with high-risk behaviours are supported to access testing that is linked with adequate post-test counselling (something that is particularly important for adolescents) and prevention and/or treatment and care, depending on

the results of the test. Another important consideration is the role of counselling prior to HIV testing and how it encourages or discourages access among adolescents.

While specific programmes may be developed to test adolescents (e.g. through schools), all strategies directed to adults, such as community-based counselling/testing, PMTCT and PITC, need to take into equal consideration the particular needs of adolescents.

GROUP PROGRAMME FOR NEWLY DIAGNOSED ALHIV USING LAY COUNSELLORS (SOUTH AFRICA)

Hlanganani is an interactive modular (3–6 modules) group programme that equips newly diagnosed adolescents to link to care. Lay counsellors facilitate the group session, and a training module for them has been designed. Adolescents who took part really enjoyed the experience, and it seems from preliminary data that the adolescents who participated in the programme were more likely to commence ART if eligible than adolescents who did not participate.

While the group approach to counselling is not for everyone, for those who did join the group sessions the programme has been a great support. Longer follow-up will tell whether the adolescents who took part will have better outcomes and retention than those who do not. The plan is to adapt the programme for adolescents infected perinatally when transitioning into adolescent care, and subsequently into adult care.

With support from the Desmond Tutu HIV/AIDS Foundation (DTHF) and the Adolescent AIDS Programme in the Bronx, NY with funding from PEPFAR/CDC (SA).

✉ For more information contact Linda-Gail Bekker: linda-gail.bekker@hiv-research.org.za or Donna Futterman: dfutterman@adolescentaids.org

2.1.3 Increasing uptake of services by adolescents

STRENGTHENING HTC AND REFERRAL FOR ADOLESCENTS (SUB-SAHARAN AFRICA)

UNICEF is supporting a multi-country initiative in sub-Saharan Africa aimed at strengthening HTC uptake and referral for adolescents. The work takes innovative approaches to communication and engagement with adolescents—through TV, radio, mobile phones, social media and a graphic novel (online, print and serial newspaper insert)—to provide adolescents with critical information and link them to services. This work is engaging with adolescents and young people in six sub-Saharan African countries with an extremely high burden of HIV to improve HIV knowledge and attitudes, to build demand for HTC, to help improve planning, coordination and referral systems for adolescents and young people and to monitor delivery of HIV services and referrals for this age group.

Preliminary data show good levels of knowledge regarding the benefits of condoms, but there is a persistence of attitudes among adolescents and young people that may constrain efforts to increase uptake of HTC. There is reluctance to request partners to test due to fear of raising suspicions and accusations of infidelity or negative past behaviour. It also seems that adolescent males with HIV have less favourable views of HTC and related services, and they are less likely to disclose, report experiences or seek help following rape or sexual violence.

There are a number of legal, logistical and administrative issues that need to be addressed in order to expand access and improve uptake of HTC among adolescents. Age of consent in many countries remains a significant barrier to uptake of HTC, as adolescents are often reluctant or afraid to seek services that require the consent of a parent or guardian. There are numerous system bottlenecks and inefficiencies such as supply chain challenges,

human resources capacity related to working with adolescents, and loopholes in patient management and follow-up, reflected in incomplete or parallel data records. Referrals for those testing positive are too reliant on self-motivation; for those testing negative, follow-up and referrals are weak to non-existent.

✉ For more information contact Susan Kasedde: skasedde@unicef.org

2.2 Disclosure

Adolescent sexual and reproductive health (ASRH) services for ALHIV need to have a strong focus on disclosure and building self-esteem. Many young people living with HIV are sexually active and make the choice to have children, and ASRH programmes need to stress their responsibilities for their own (and their partners') sexual health. Balancing positive living against sexual needs is a real challenge for this age group, particularly in terms of disclosure, due to fear that a potential partner may be put off by their HIV-positive status. Like other adolescents, ALHIV have rights to a pleasurable and healthy sexual and reproductive life and to programmes that respond to their different needs and challenges (e.g. can an HIV serodiscordant couple get access to post-exposure prophylaxis if a condom breaks?).

2.2.1 Support for disclosure and adherence to treatment

ADHERENCE AND DISCLOSURE FOR ADOLESCENT MOTHERS: THE “EVE FOR LIFE” EXPERIENCE (JAMAICA)

“Eve for Life”, a local NGO, has been working with the Ministry of Health to provide a comprehensive approach to support and care for adolescent mothers who are living with HIV. Currently, the NGO is working to deliver services in support of adherence and disclosure in the three parishes with the highest rates of HIV infection.

Recruitment: Adolescents are recruited into the programme through antenatal or HIV treatment programmes. Adherence counsellors or social workers refer clients deemed especially vulnerable and in need of additional support. In this way, the Eve for Life Programme has grown increasingly collaborative with the public health sector.

Assessment: Upon recruitment, a needs assessment identifies issues that must be addressed to improve outcomes for the adolescents and their children. Additional data collected include demographic information, knowledge and attitudes around HIV primary and secondary prevention and treatment literacy, as well as emotional wellness, sexual health and history in terms of forced sex and other gender-based violence. Clients are then referred to other relevant educational, psychosocial and social security programmes to address their needs.

Engendering trust: The overall approach that the public sector has employed to encourage support for adherence among PLHIV is applied in this programme. This is done through the engagement of older women with HIV called “life coaches”, and programme “graduates” called “mentor moms.” These women form a key part of the care and support team. In the event of a breach of confidentiality, a reporting and redress system is in place, and the adolescents involved are informed when action is taken.

Support groups: Clients are able to discuss their challenges and successes in a safe environment, free of stigma, discrimination and judgment. Life skills are also reinforced in the support groups.

Adherence support: A team approach is taken to adherence. With the consent of clients, mentor moms liaise with adherence counsellors and social workers to monitor adherence and

assist in addressing the relevant barriers. Attention to psychosocial issues has led to good adherence, and less than 1% of the girls in the programme have repeat teen pregnancies.

Support for disclosure to parents/guardians and partners: Disclosure is viewed as a critical component of successful adherence, as it opens up an environment of trust and support. Disclosure to a loved one is an indicator used to measure success in the programme. It is encouraged throughout the programme, and as such, disclosure is treated as a life skill. Girls are walked through a process of disclosure and role-play discussions with their loved ones. The discussions address selection of the partner(s), family member(s) or friend(s) to whom the clients will disclose, how and whether they require the assistance of a life coach, mentor mom or trained counsellor. Each coach must have disclosed to their partner or a family member so they can be of optimal assistance to the girls in this area.

Strategy for scale-up: Increased cooperation with the MOH includes capacity building of health workers to improve their skills in service delivery for ALHIV. Additionally,

adolescents who have completed the programme are engaged as peer support links for adolescent mothers attending antenatal or HIV treatment programmes in the public health sector.

Factors contributing to the success of this work

- Close collaboration with government
- A team approach to adherence
- Peer-to-peer approaches to support
- Engagement of older women living with HIV as lay counsellors/mentors
- Disclosure of HIV status as a key component of the programme.

Challenges facing the programme

- Limited scope of the programme (it is present in only three parishes and targeted towards ALHIV who are mothers)
- Limited funding threatens sustainability.

✉ For more information contact Novia Condell: ncondell@unicef.org

2.3 Community-based approaches

When an adolescent tests negative, community-based service delivery can help to minimize risky behaviours and facilitate timely and low-cost referrals to further prevention support. The following are examples of approaches to assist those adolescents who test positive.

2.3.1 Support for adherence

As for treatment of other chronic diseases, ensuring adherence to ART is a challenge; support is needed from a variety of people to help adolescents adhere to their medications and care regimens. Various approaches involve home visits by health workers, lay counsellors and ALHIV peers to support the ALHIV and their families, and working to ensure that there are ongoing long-term relationships with health staff, establishing partnerships with the patients' guardians and the adolescents themselves and developing support groups for ALHIV.

COMMUNITY-BASED ADHERENCE SUPPORT THROUGH LAY COUNSELLORS (SOUTH AFRICA)

In this intervention, lay community-based adherence support (CBAS) workers provide regular adherence and psychosocial support for patients and undertake home visits to address household challenges affecting adherence. Family and household members are assessed

together with patients, and issues are discussed at clinic multidisciplinary team meetings.

The project was evaluated through a multicentre cohort study using routinely collected clinical data at public ART sites supported by Kheth'Impilo, a local NGO. ART-naïve adolescents and youth (ages 10–25 years) starting ART between 2004 and 2010 were included. All the parameters that were assessed were improved in the adolescents who received the CBAS intervention: patient retention, mortality, loss to follow-up and viral suppression.

Factors that contribute to the success of this work

- Relationships that are developed between adherence workers and adolescents, reinforcing positive adherence behaviours
- Long-term follow-up to encourage long-term treatment success
- Cost-efficiency for resource-poor settings.

Challenges facing the project

- Long-term funding in the face of the global economic downturn
- A database specific for community workers is still under development
- Serving patients who live far from clinics.

✉ For more information contact Nontuthuzelo Manjezi: Nontuthuzelo.Manjezi@khethimpilo.org

2.3.2 Strengthening the continuum of care for children and adolescents with HIV and improving retention in care

IN GENERALIZED EPIDEMICS: THE BOTSWANA-BAYLOR CHILDREN'S CLINICAL CENTRE OF EXCELLENCE (BOTSWANA)

The entry point into the Centre of Excellence (COE) is the HTC or Screening Clinic. For those testing positive for HIV, the goal is optimisation of treatment and adherence, retention in care, avoidance of high-risk behaviours and deliberate and seamless transition to adult care. Opened in 2003, the main clinic in Gaborone, with over 2300 child and adolescent patients, is able to reach an additional 4000 patients through its decentralized countrywide outreach and mentoring services. Thus, the COE is impacting over two-thirds of all paediatric patients who are receiving ART in the country.

Each patient is provided various multi-faceted but linked interventions that include: a simplified and sequential disclosure process; adherence classes for the primary caregiver and at least one other member of the household; nutritional support and counselling; home visits; morning play group; remedial classes for students having difficulty with schoolwork; a week-long annual camp; adolescent support; services centred around teen clubs (recreation, life skills and SRH); and a structured transitioning programme to usher adolescents into adult care. For pregnant adolescents there is a support group that teaches parenting skills and encourages them to return to school; for those who are unable or unwilling to return to school, there are income-generating activities available.

Key factors that have contributed to the success of this project

- HIV is the main focus of the COE
- Innovative and responsive staff
- The COE is an NGO working in partnership with the government.

Key challenges that have been met

- Reaching out to as many children as possible through outreach mentoring and the establishment of outreach teen clubs in partnership with local community service organizations and ART clinics (Airborne Lifeline, an international NGO has provided free flights to remote parts of the country for COE staff)
- Achieving excellent levels of retention in care through home visits and caregiver training.

✉ For more information on programme support tools, visit <http://botswanateenclub.wordpress.com/>

✉ For more general information contact the COE: ganabwani@baylorbotswana.org.bw

WORKING WITH ALHIV: THE EXPERIENCE OF UZBEKISTAN

The overall aim of the work with ALHIV is to improve their quality of life through the provision of information (about HIV/AIDS, modes of HIV transmission, ART, adherence to treatment, CD4 count, viral load, prevention and treatment of opportunistic infections, nutrition, hygiene, reproductive health, mental health); education (prevention for positives, life skills development, leadership/volunteering, the development of skills relating to specific interests); and comprehensive psychosocial support for disclosure of HIV-positive status.

Services for ALHIV have been integrated into the existing system of services for children with HIV and their families through the day-care centres (DCC) for children and families affected by HIV in Uzbekistan. More than 100 ALHIV are now attending the DCC, although only about 40 of them have received full disclosure about their HIV status.

Objectives of the services

- Provide psychosocial support for ALHIV and their families at all stages of disclosure of HIV-positive status;
- Create an enabling environment for the transition of adolescents into medical and non-medical services for adult PLHIV and coordination of the various types of care for ALHIV;
- Strengthen the connection between ALHIV in different regions of Uzbekistan to exchange experiences and provide mutual support.

Core strategies/activities include

- Psychological/social counselling, especially to support disclosure
- Regular self-support groups for adolescents who know their HIV status, activity groups for adolescents who know their HIV status, including knitting, beading, computer, and languages (Russian, English)
- Information materials for ALHIV (personal diary entries, art calendars, HIV/AIDS booklets), education activities for parents of ALHIV
- Development of an online platform to enhance the relationship between ALHIV from different regions of the country.

An additional activity that has only partially been carried out is camps/schools for ALHIV to build their capacity, leadership and ability to independently defend their rights at various levels. This involves training ALHIV on a number of themes, including:

- Promoting a healthy lifestyle
- Development of a broad range of life skills including combating stigma and discrimination
- Skills for responsible health maintenance
- Prevention for positives support trainings (training of trainers).

Planned activities include

- Implementation of the system for transitioning of ALHIV from paediatric AIDS services to adult AIDS services (using services of AIDS Centres, Maternal and Child Department of the MOH)
- Regulatory support of HIV disclosure for ALHIV
- Adaptation and adoption of WHO guidelines/protocols on disclosure of HIV status for children.

Reasons the programme is considered to be a success

- On a regular basis, support groups have been developed for ALHIV who know their HIV status in the DCCs in Tashkent and Andijan
- All parents report changes for the better among ALHIV who worked with DCC staff, including taking responsibility for their health and treatment adherence, greater interest in life, less conflict with parents and better communication skills with peers
- Partnerships for work with ALHIV (AIDS Centres, UNDP, GFATM Project, UNAIDS, UNFPA).

Factors that contributed to success

- Availability of a team of qualified professionals—social workers, psychologists, paediatricians and infectious disease specialists
- Financial support for support groups, trainings, office supplies, office equipment
- Mobilization of ALHIV, who have become leaders and volunteers to work with new adolescents whose status has not yet been disclosed.

Challenges facing the programme

- Lack of an enabling environment for ALHIV (misunderstanding in the public sector of the importance of working with adolescents, regulatory constraints or lack of regulatory framework for adolescents with HIV)
- Growth in the number of HIV cases among adolescents, poor health of the adolescent and delayed entry into care due to lack of disclosure to adolescent and denial among parents, and the related family stresses
- Lack of a support system for ALHIV after HIV diagnosis.

✉ For more information contact the Day-care Centre for Children and Families Affected by HIV - “Qaldirgoch” Tashkent, Uzbekistan: qaldirgoch@gmail.com or Kamila Fatikhova: kfatikhova@unicef.org

2.3.3 Involvement of adolescents and integration of services

THE ZVANDIRI MODEL OF INTEGRATED, ADOLESCENT-LED PREVENTION, TREATMENT, CARE AND SUPPORT (ZIMBABWE)

Africaid, a Zimbabwean NGO, is committed to helping children, adolescents and young people living with HIV from 5–24 years to develop the knowledge, skills and confidence to cope with their HIV status and to live happy, healthy, fulfilled lives. It is achieving this through the innovative “Zvandiri” programme that provides community-based treatment, care, support and prevention services that are integrated with government and private-sector clinical care services. This integration creates a robust continuum of care for children and young people with HIV and their families and aims to promote good health and psychosocial outcomes.

Zvandiri (meaning “as I am”) is led by adolescents with HIV who are trained and mentored as service providers. Through community support groups, community outreach and clinic-based Zvandiri Centres, ALHIV identify children for HIV testing, link children living with HIV to treatment and care, provide sustained counselling for children, adolescents and their families and life skills training for their peers. Community Adolescent Treatment Supporters (CATS) are adolescents with HIV who provide adherence monitoring and support in clinics and homes, trace treatment defaulters and assist in identifying adolescents at risk of treatment failure. Zvandiri’s SRH programme ensures young people living with HIV have the

knowledge, skills and confidence to make informed prevention decisions and that they are linked to care including STI, family planning services, PMTCT and Zvandiri's young parents support groups. Adolescents with HIV also provide training and counselling as caregivers and training of health workers, teachers, social welfare officers, church leaders and community members.

Zvandiri is being scaled up across Zimbabwe under the Government of Zimbabwe's National Action Plan for OVC. Zvandiri has been recognized as a highly effective, innovative model for the provision of sustainable treatment, care, support and prevention services for children and adolescents with HIV. It was documented by SADC [Southern African Development Community] in 2012 as a regional best practice and a national best practice by Zimbabwe's National Action Plan for OVC in 2009.

Key challenges that have been met

- Improving access through decentralization to the community level
- Meeting demand for scale-up of services by making it a national programme through the Government of Zimbabwe's National Action Plan for OVC
- Ensuring quality through robust coordination systems and standardized materials (e.g. weekly meetings with youth service providers for planning and supportive supervision, and training manuals and standard operating procedures in line with national and international guidelines for consistent delivery of quality services).

✉ For more information contact info@africaid-zvandiri.org or Nicola Willis: nicola@maruva.org

2.4 Training

2.4.1 Support for adherence to treatment and retention in care

An important aspect of counselling once ART has been initiated is support for adherence. In many places where the formal health workforce is insufficient to meet local needs, lay counsellors provide adherence counselling. Thus, one approach to supporting adherence to treatment involves ongoing training and supervision for lay adherence counsellors.

TRAINING AND SUPERVISION FOR BEHAVIOUR CHANGE COUNSELLING (SOUTH AFRICA)

An evaluation of standard-care ARV adherence in Western Cape, South Africa, found that the lay counsellors were not following international standards of client-centred, problem-management counselling that results in personalized plans for behaviour change (119). Instead, they were mainly employing directive and health-advising techniques, assuming the role of "expert" in their sessions with clients. The study concluded that, at a minimum, counsellors should be provided with regular supervision focusing on micro-counselling skills and the avoidance of inappropriate strategies such as moralising, warning and confrontation. Supervision should also include case management, where the accepted counselling model, and problem-management techniques in particular, are revised and applied. The extent to which lay counsellors could adopt and implement more evidence-based models of adherence counselling was unclear.

Options for Health is a behaviour change intervention based on an approach called Motivational Interviewing (MI) (120). Thirty-nine ARV adherence lay counsellors in the Western Cape were trained to deliver "Options" to their patients to help them optimize ART adherence. An assessment of counsellors' ability to deliver the intervention effectively after 35 hours of training revealed that counsellors failed to achieve proficiency in MI (121). A follow-up study examined the impact of refresher training and supervision on the counsellors' proficiency in the intervention; it found that the recommendations of the assessment had been applied with promising results (122). Over a 12-month period, with

18 hours of refresher training and supervision, lay counsellors were able to improve on basic counselling communication skills and therapeutic approaches. When compared to a group of control counsellors, their counselling was more collaborative, supportive, empathetic, and it featured more problem-solving... (123). This study demonstrates the importance of ongoing training and supervision in achieving and maintaining the delivery of good quality service by lay health workers.

As large-scale lay health worker interventions involve considerable financial investment (124), more research is needed—especially in contexts where lay health workers are a necessary and integral part of service delivery—to understand how the most benefit from such a significant investment can be achieved.

✉ For more information contact Cathy Mathews: cathy.mathews@mrc.ac.za

The establishment of peer support groups can reinforce and extend the efforts of lay counsellors to ensure that adolescents adhere to treatment.

TRAINING AND SUPPORT GROUPS TO IMPROVE ADHERENCE (MOZAMBIQUE)

Fundação Ariel Glaser supports the Ministry of Health to provide clinical care in all districts in Maputo and Cabo Delgado provinces, where HIV shows the characteristics of a generalized epidemic. In order to improve adherence to ART by the adolescents and improve retention of this group in care and treatment services, the Ariel Glaser Foundation staff, in collaboration with staff from the provincial health directorate, have conducted specific training on paediatric and adolescent psychosocial support for lay counsellors, psychologists and psychiatry medical officers, including an explicit focus on adherence reinforcement and HIV disclosure (to the adolescents). At the same time, staff received training and improved skills in creating and supporting child and adolescent support groups. The groups are now fully active in seven out of eight districts, with each group consisting of about 20 adolescents (10–19 years). To support the training, the participants were provided with a range of materials, including job aids, an adherence flip chart and a manual on support groups.

There are differences in adherence among adolescents attending the support groups, and the reasons for non-attendance need further exploration (sometimes related to distance, family and/or psychosocial issues). The support groups seem to positively influence not just adherence but also self-esteem and coping with HIV more generally.

From 2013, F. Ariel Glaser will be supporting youth- and adolescent-friendly services, known as SAAJ, now in the process of revitalization by the Ministry of Health, and there are plans to build on and link with the experiences of working with ALHIV.

✉ For more information contact Paula Vaz: pvaz@arielglaser.org.mz

2.5 Other important considerations

2.5.1 Key populations

The most vulnerable adolescents, especially those in key populations living with HIV, must be reached and their needs must be met. This section highlights issues that may affect all adolescents but may be particularly important to adolescent members of key populations.

Young MSM

Research has found that among young MSM factors such as stigma, discrimination (125), less condom use, more alcohol and drug use, and having sex with older partners (126) contribute to even higher risk than older MSM for HIV acquisition.

This analysis found that young MSM were significantly less likely to use condoms during last sexual intercourse, more likely to drink alcohol or use drugs before last sexual intercourse, and more likely to have had four or more partners during their lifetimes than young men who had sexual intercourse only with females. These behaviours are associated with substantial risk for infection. In one study among MSM the attributable risk for new HIV infection was 29% for using alcohol or drugs before sex and 32% for having had four to nine sex partners (127). Further, in a study of primarily young MSM, 75% of those with acute HIV infection reported sex under the influence of drugs or alcohol, compared with 31% of HIV-negative MSM. The risk for HIV infection doubled for MSM with a sex partner five years older and quadrupled with a sex partner ten years older (3, 126).

Role of peers

The role of peer support or peer counselling is important for all adolescents living with HIV but particularly for young people in key populations.

Disclosure and confidentiality

There is a risk for adolescents in key populations of being “revealed” by undertaking certain necessary activities (e.g. collecting medications at primary health-care clinics). Similarly, some activities at the community level can pose significant personal safety and legal risks to these adolescents. Forced disclosure of HIV status or disclosure without the consent of the individual often drives those in key populations, and ALHIV in general, away from HTC services and discourages retention in care.

In settings where counsellors are uneasy about providing support for disclosure, peer educators and CBOs can provide valuable support to offset some of the risks, and anonymous reporting can be established as a routine practice. All services must establish a system of unique identifier codes, as name-based reporting for national requirements and donor reporting risks violating confidentiality.

Laws and legal environments

Laws governing access to opiate substitution treatment (OST) for young drug users and access to ART need to be harmonized with other policies, e.g. needle and syringe programmes. Eligibility requirements for these programmes also need to be clarified.

Policy and legal barriers to providing services need to be reviewed and amended. In some cases certain behaviours and sexual orientations are criminalized. In other cases, educational institutions require applicants to disclose their HIV status as a pre-condition for admission. Until such laws and practices are changed, many adolescents with HIV in key populations may need legal support following HTC.

2.5.2 Education sector response

Access to education must in no way be linked to health status. The education sector has an important role to play in the continuing development of ALHIV in their school environments and potentially in the actual delivery of HTC.¹ There are five essential components of a comprehensive education sector response to HIV and AIDS (128):

1. **quality education:** Access to educational opportunities is widely recognized as an effective means for reducing the vulnerability of children and young people to HIV;
2. **content, curriculum and learning materials** that are evidence-based, that build knowledge and skills for protective behaviour, and that start early and are sequenced and appropriate for the age and development stage of the learner;

¹ The potential involvement of the education sector in the delivery of HTC needs to be explored although currently there is not significant evidence for this.

3. **educator training and support** that includes pre- and in-service training on HIV knowledge, confidence and communication skills and supervision and that addresses educators' own vulnerabilities to HIV, especially those living with HIV themselves;
4. **policy, management and systems** that include workplace policies to ensure zero tolerance of violence, abuse and discrimination, and strategic plans that are funded to implement, enforce and monitor these policies;
5. **approaches and entry points** including school health programmes, peer education, communication and media interventions, and life skills education.

Practical recommendations for the education sector to address the needs and aspirations of ALHIV include (129):

- **Know your epidemic** in order to recognize trends and appreciate the nature and implications of its impact on the education system and upon learners in relation to access, retention and achievement in school.
- **Recognize the presence of students living with HIV.** Some may know their status and others may not. Some will want to disclose and others may not. ALHIV have the same needs as other learners as well as needs that are HIV-specific.¹
- **Establish and reinforce links with other sectors** to help ensure the education sector's participation in HIV response planning and resource allocation.
- **Review, adapt and reinvigorate existing policies and practices** in order that they benefit ALHIV. In particular, policies related to privacy and confidentiality in education contexts need to be reinforced.
- **Develop and set up monitoring and evaluation systems.**
- **Continue to improve knowledge about HIV** among teaching, management and administration staff.
- **Encourage and support the provision of non-formal education.**
- **Recognize the value of teachers, staff, parents and community members living with HIV** as part of the response and contact trade unions, support groups and PLHIV networks.

Treatment education is a sectoral initiative with a broader reach than school-based activities. It is a critical component of efforts to ensure universal access to prevention, treatment and care (130). Treatment education engages communities and individuals to learn about ART in order to:

- encourage increased uptake of HTC
- improve understanding of ART and drug regimens
- understand and be prepared for treatment-related costs
- advocate greater and more equitable access to treatment (including gender equity)
- support adherence to treatment
- encourage protective behaviours and healthy living
- reduce stigma and discrimination against PLHIV
- link testing, prevention, care and treatment initiatives for a comprehensive response to HIV.

2.5.3 Involvement of adolescents

Involving ALHIV is important for programmes: Nobody understands their problems better than they do. Involvement also contributes to their personal development. Empowering young people living with HIV to serve as peer educators and play a key role in the programme, as counsellors, trainers and advocates, not only improves programmes, thanks to their enthusiasm and creativity, but also provides ALHIV with new skills, power, and knowledge. Furthermore, providing adolescents with a physical space that belongs to them helps to build a supportive long-term

¹ Orientation for staff (e.g. at residential facilities particularly) is important for sensitivity to the needs of students who are on ART and who may be subjected to harassment (about medical supplies, personal behaviour, etc.), which can discourage adherence.

relationship, and demonstrates that the community is interested in addressing their health needs. Ministries of health need to ensure that adolescents' contributions to service delivery are formally included and recognized in national plans.

Meaningful and proactive involvement of adolescents in the programmes that provide services as well as in their own health care requires sustained patient education designed specifically for adolescents, accompanied by acceptable and effective support.

Adolescents must also be empowered and supported to make decisions about their own health care, with the ultimate goal of self-management, as part of the transition to adulthood.

2.5.4 Increasing acceptability and uptake of services

To increase the acceptability and uptake of services among adolescents while reducing direct and indirect costs to patients, there are a number of approaches to consider:

- minimizing the number of required facility visits;
- providing services at times when adolescents can attend without interfering with their education;
- reducing waiting times for all visits;
- providing separate waiting areas for adolescents that offer separation from adult waiting areas and of peer supporters and adolescent-friendly materials and activities.

Coordination of facility visits across services—e.g. clinical care, laboratory services, and pharmacy pickup—or across different points of care, when care is provided at different locations, are important to reduce the burden of care to patients and their care providers.

2.5.5 Living positively

BAYLOR TEEN CLUB (SWAZILAND)

Swaziland has the highest rate of HIV in the world. The Teen Club was born out of a desire to help adolescents living with HIV become powerful agents of change. Since starting in 2006, Teen Club has grown to include one monthly meeting in each of the four regions of Swaziland. There are currently four teen club centres—Mbabane, Manzini, Hlathikulu and Siphofaneni.

The mission of Teen Clubs is to empower adolescents with HIV in Swaziland to live positively and successfully transition into adulthood. Services offered at the clubs include emotional and educational support through structured activities designed to teach life skills, foster relationships, and build confidence. The clubs provide a forum for adolescents to constructively express themselves and discuss issues regarding their condition without the threat of stigma.

Each month more than 350 ALHIV attend the support groups on Saturday mornings. Every meeting begins with games and icebreakers that help new members quickly feel comfortable while making new friends. Teen Club members then participate in educational and empowering activities from the Baylor life skills curriculum. During their meetings the teens are split into different age groups, allowing the younger adolescents to participate in activity-based lessons, while the older teens engage in in-depth conversations with a more mature focus. With the help of adult Teen Club coordinators, the lessons are conducted by Teen Leaders, older members of Teen Club who have successfully completed the Teen Leadership Training programme. Topics include advocacy, body changes, disclosure, peer

pressure, self-expression, safer sex practices, grief and bereavement, self-expression and realizing your dreams. To help ease the financial burden on our members, each teen is provided a snack and travel reimbursement for public transportation.

Strong leadership, partnerships and ongoing training of adult volunteers and Teen Leaders ensure the sustainability of the Teen Club activities. With the expansion of support groups and the addition of a Teen Club office and a dedicated staff, Baylor has been able to increase participation of teens while decreasing average costs. Despite the accomplishments made over the past six years, there are still several challenges facing implementation of teen clubs.

Is it a success?

When adolescents living with HIV are given a voice and supported to overcome obstacles to good health, their strength, creativity and passion can engender hope, even in the most desperate situations. Teen Club helps build the capacity of Swaziland's civil society to support Swaziland's adolescents in the battle against HIV. A recent evaluation of the Teen Clubs has shown that adolescents with HIV appreciate the services provided through the clubs, and they provide a forum in which adolescents with HIV can come together to share their personal experiences and provide one another the much-needed psychological and emotional support. The teen club members benefit from being able to speak openly and freely without fear, stigma and discrimination. Restricting Teen Club membership to teens with HIV is believed to be one of the main reasons for the success of the clubs.

While there are many benefits of attending Teen Club, ... what is accomplished is best described by the Teen Club members themselves: "I am not alone and I can help other teens living with HIV". "I want to learn life skills and how to improve my health". "I am going to be a leader".

Challenges facing the programme

- How best to provide nutritious food within a constrained budget?
- How best to decentralize Teen Club so that more adolescents living with HIV are able to get the vital support they need?
- How to empower the adolescents to successfully transition to adult health care and services?

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2.5.6 Importance of parents and caregivers

It is important to give adequate attention to supporting the parents and caregivers of ALHIV, so that they in turn are better able to support their adolescents. A sense of partnership between health-care providers and the parents and caregivers of ALHIV can facilitate adherence to treatment and retention in care. It is also important for providers to recognize and resolve conflicts that may exist between parent/caregivers and ALHIV (and even with peer educators and counsellors) on issues such as how and when adolescents disclose their status to others, and what to do if an ALHIV becomes sexually active, is not adhering to treatment or care regimens, or becomes pregnant. Continuous support counselling and education for the caregivers of ALHIV is critical to the success of programmes. At the same time it is important to acknowledge the tension between autonomy and protection; the best interests of the adolescent and the adolescent's needs and rights may have to take precedence over the opinions of parents and caregivers.

Programmes will serve the interests of adolescents when they consider the challenges facing caregivers—especially in the case of those caring for orphans or other vulnerable children—who often are not compensated and who are caring for other family members as well.

Some adolescents do not have parents or have unsupportive or abusive parents. This may be a particular issue for adolescents in key populations and has important implications for the ability and the right of adolescents to provide informed consent for themselves. If a parent is unavailable, it is important to encourage the adolescent to identify another supportive adult.

THE IMPORTANCE OF RELATIONSHIPS BETWEEN HEALTH-CARE PROVIDERS AND FAMILIES—INSTITUTO DE INFECTOLOGIA EMILIO RIBAS (BRAZIL)

The HIV clinical group was created in 1985, the beginning of the HIV epidemic in Brazil, when the first child with HIV was referred to the hospital. The team is composed of infectious diseases specialists, paediatricians, nurses, social workers and psychologists.

Expertise was initially developed through research of medical literature, exchanging experiences with other groups worldwide and day-to-day learning through success and frustrations with patients. This learning approach helped staff respond to issues such as disclosure of the diagnosis, HIV testing, treatment adherence and social inclusion. Solutions were sought as the problems arose; as the first team in the country to deal with HIV infection in the paediatric population, creativity, innovation and patience were important.

The team now meets on a daily basis and all the emerging problems are fully discussed within the team. Furthermore, the same team works together on clinical research and on training young professionals, so everyone is always in contact with the most recent publications and experts from all over the world.

Key factor for success

The team has changed very little since 1985, and it has therefore been possible to establish good partnerships with the patients' guardians and the children and adolescents themselves.

✉ For more information contact Marinella Della Negra: aacphiv@uol.com.br

2.5.7 Integration of services

HIV prevention, diagnosis, treatment and care interventions for adolescents should, as far as possible, be integrated with those for adults and for children.¹ At the same time, the health sector must be able to respond effectively to the specific needs of adolescents in general (e.g. adolescent-friendly health services) by utilizing non-judgemental staff who like and understand adolescents and by addressing issues such as accessibility of care and confidentiality.

Integration also needs to take place between community-based health, education and social welfare services and government services, staff and other local stakeholders. Partnerships and collaborations between state and civil society/communities are essential to expanding access to services and assuring the quality of services and a continuum of care at every level. State health systems must be closely linked to community-based services and providers. There must be established connections and referral systems along the continuum of care and in both directions—from the community to the formal health system and from the formal health system back to the community.

¹ Some ALHIV need particular sensitivity with respect to physical appearance. The physical immaturity of many vertically infected adolescents may make them stand out more in adult clinics, and providers should be prepared to make accommodations that will put these individuals at ease if necessary.

SERVICES AND SUPPORT FOR ALHIV (NAMIBIA)

The programme focuses on adolescents aged 10–19 years in the Caprivi and Khomas regions of Namibia, including ALHIV, with the aim of strengthening the design, development and implementation of service delivery mechanisms for increased uptake and quality of HTC for adolescents and young people, including Post Test Support Services (PTSS), and improving service provision for ALHIV.

Activities include baseline data collection, collation and analysis; the development of training materials; training of adolescent facilitators who are living with HIV and their parents, caregivers and health-care providers; the establishment of peer support groups and spaces for them to meet; and the use of a disclosure tool with all adolescents with HIV attending the paediatric ART target site.

In addition, HTC is emphasized as an entry point to prevention as well as care, treatment and support services through: PTSS to support all adolescents and young people (with HIV or not); strengthened referral linkages between HTC, PTSS and other prevention, care and treatment, and support services; and community-based mobilization mechanisms, including interpersonal and mass media communication to reach out to adolescents and young people.

Reasons for success

- Initiated in one of the hospitals where there was already a functional teen club
- Establishment of a project steering committee to oversee the project implementation
- Technical assistance and funding for capacity building of ALHIV, parent/caregivers, and health-care providers
- Incorporating the teen club from the beginning
- “Ownership” of the project by ART site and hospital management
- Wider stakeholder involvement in the development of the national guidelines
- Adoption of the Adolescent-Friendly Health Services (AFHS)-ALHIV curriculum by the national health training centre within the MOH
- Engagement of NGOs working with children and adolescents on HIV and SRH matters in the projects.

Factors that contributed to the success of the project:

- Exposure of staff and ALHIV to a global consultation on programming for ALHIV
- Committed and dedicated staff
- Availability of space and incentives for participation (e.g. the provision of refreshments by the implementing site for teen club activities).

Challenges facing the programme

- Confidentiality: consent from parents and caregivers to health-care providers to allow them to introduce the paediatric disclosure tool to the children and adolescents; consent from parents and caregivers to allow health-care providers to engage an NGO to provide training to ALHIV and their caregivers; and consent for ALHIV to voluntarily enrol in the teen club. This took a long time, and delayed project implementation.
- Funding: the funding came to an end at a time when the need for resources was greater than when the project started (for training and for electronic devices for defaulter tracing);
- Unfriendly space: the space provided for the teen club corner in the implementing facility needs refurbishment, painting and extra equipment.

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LINKS WITH ADOLESCENT-FRIENDLY SEXUAL AND REPRODUCTIVE HEALTH SERVICES (MOZAMBIQUE)

In 2004, the World Bank launched a pilot HIV/AIDS Treatment Acceleration Project (TAP) in Mozambique, Burkina Faso, and Ghana aimed at slowing the epidemic by increasing access to voluntary testing and counselling (VCT) and adherence to care and treatment. In Mozambique the four-year US\$1.25 million Treatment Acceleration Project (TAP) was implemented by Pathfinder International in collaboration with the Government of Mozambique and with additional technical and financial support from UNFPA. TAP built and expanded on the successes of the national Geração Biz Programme. TAP was implemented in two provincial hospitals that offered youth-friendly SRH services (YFS) in Maputo and Xai-Xai in Gaza Province.

Through TAP, HIV counselling and testing, ART, and PMTCT were integrated into the YFS service delivery package for the first time. Young people testing positive were provided immediate support and counselling, given a CD4 test, and linked to treatment if needed. Pregnant adolescents who tested positive were linked to PMTCT services. In addition, a trained psychologist spent several hours a day at the YFS offering counselling and support for disclosure as well as positive and healthy living. Young people testing positive were immediately linked with a peer educator with HIV who had been trained to provide care and support and “sheltering”.¹ Finally, all youth clients testing positive for HIV were urged to join a weekly support group at the YFS facility led by peer educators with support from providers and the psychologist. Over the course of the project, about 12,000 young people were tested for HIV, with about 25% testing positive, and 656 young people began ART. The programme had high levels of retention for ART clients, with only 11% and 16% of ART clients dropping out over the course of the project in Maputo and Xai-Xai, respectively.

The programme was considered to be highly successful by the MOH and other partners in the country. It was a catalyst for the scale-up of HIV counselling and testing within all YFS sites in Mozambique. HIV counselling and testing is now offered at 335 Geração Biz YFS sites nationwide, and approximately 153,000 young people were tested in 2011. In addition, peer educators living with HIV remain active in the Geração Biz Programme, and in 2011 the Ministry of Health issued guidelines that all YFS facilities should have support groups for young people living with HIV. This is a big step in scaling up some of the key elements of TAP, but it has yet to be fully operationalized in the country.

Factors that contributed to the success of TAP

- Building on an existing national programme with well-known and successful youth-friendly services allowed young people to be aware of the services and increased participation of young people in the programme.
- Empowering young people living with HIV to serve as peer educators and play a key role in the programme not only improved the programme, but also equipped young people living with HIV with skills, power, and knowledge to improve their health and that of their peers.
- Support groups and “sheltering”, including home visits, were crucial to adherence to treatment and maintaining follow-up care with young people living with HIV.

Challenges facing the programme

Psychologists play a key role in the programme, but there are few in Mozambique, especially in remote areas. Peer educators can be trained to fulfil some of these duties, but supervision is required to ensure quality.

✉ For more information contact Rita Badiani: rbadiani@pathfinder.org or Gwyn Hainsworth: ghainsworth@pathfinder.org

¹ In this project “sheltering” refers to the role of the peer educator in providing support to newly diagnosed young people by accompanying him/her through counselling and medical appointments, providing insight and support related to treatment (including adherence), and offering social support inside and outside of the clinic walls. Sheltering also includes the role that the peer educator served in providing home visits to young clients and their families once the young person chooses to disclose.

IN CONCENTRATED EPIDEMICS: INTEGRATION OF SERVICES—SERVIÇO DE IMUNOLOGIA CLÍNICA E HOSPITAL-DIA DO IMIP, INSTITUTO DE MEDICINA INTEGRAL PROF. FERNANDO FIGUEIRA (BRAZIL)

The programme started in 1987, when the first paediatric AIDS case was diagnosed in the Northeast region of Brazil. In 1988, the service became a national reference centre for HIV infection among children and had started to train health professionals locally and from other regions of Brazil, expanding to incorporate the testing of all pregnant women for HIV, becoming Mother-Child HIV clinics. In 1998, treatment for other adults was added, and in 2003 the move to new facilities made it possible to put together a multi-professional team to offer comprehensive care and day-care services for adolescents and children.

Currently, IMIP's complex provides an HIV reference service, with paediatricians, immunologists, infectious disease specialists, gynaecologists, rheumatologists, psychologists, dentists, nursing staff and social health assistance. Approximately 450 children and adolescents living with HIV have been registered with the service, of which 300 are alive and in follow-up. In addition, the clinic is following up 10 children born to mothers with HIV who themselves were perinatally infected; only one of these children has HIV.

Lessons learned

- Improving the skills of health workers is essential so that they can better understand and treat adolescents, who need strict adherence to antiretroviral drugs
- Flexible approaches to transitioning to adult services are important (at the same clinic)
- Since the beginning of the programme, the “AIDS clinic” was called the Immunodeficiency Outpatient Department and later the Clinical Immunological Service for HIV and Non-HIV Patients (including primary immunodeficiency, allergy and rheumatology). It is important to call the services something that helps to decrease stigma and discrimination (the day-care hospital is used mostly by non-HIV patients).

✉ For more information contact Edvaldo Souza: edvaldo.es@gmail.com or visit www.imip.org.br

2.5.8 Scaling up interventions

If programmes are to be scaled up in a sustainable way, it is important to work with and through the existing systems and structures, including the development of training materials and guidelines. Government health systems provide facilities through which services can be delivered, and integration helps to ensure that those with other chronic illnesses and vulnerable groups can benefit from the efforts to strengthen services for ALHIV. One of the challenges that have been mentioned in several programmes is the absence of relevant policies—for example, the lack of a formal policy for adolescents living with HIV, or more specifically the lack of a policy on disclosure of HIV status to children and adolescents who have HIV. Furthermore, there is a lack of specific standards and guidelines relating to adolescents—e.g. for adherence and psychosocial support. It is important to note that while many countries now have such guidance for small children, these documents are often not relevant to adolescents, especially older adolescents.

Programmes for/with ALHIV should link and integrate with programmes that provide health services to young people more generally, including services for other chronic illnesses, programmes for ASRH, and prevention interventions for young people. Building on existing and successful national programmes helps young people to be aware of, have confidence in, and increase the uptake of services. It can also engage NGOs that are focusing on adolescents to contribute to efforts to improve services for ALHIV as well. Providing services for ALHIV within general adolescent-friendly services (including HIV services) may help to decrease stigma that may be attached to going to an “HIV clinic”.

In Asia, services for key populations are provided largely by NGOs and CBOs. These services need to be scaled up to include adolescent members of key populations (which involves issues of consent). By providing clear guidance, governments will support and legitimize NGOs in this work. In concentrated epidemic settings this approach may be more effective than services provided by public institutions.

Decentralization is also important to scaling up interventions for adolescents, as it takes services closer to the client, an important aspect in reducing barriers to adolescents' use of services. Successful decentralization of services for adolescents will require health worker training, decentralization of support groups to community venues or local health centres, monitoring systems that include data disaggregated by age, and robust referral systems for a range of problems affecting adolescents. Young people in key populations will require special attention.

Quality control

Although decentralization and scaling up improve ALHIV's access to support, it is also essential to ensure quality. Coordinated rollout of services has been achieved through robust coordination systems and standardized materials—e.g. weekly meetings with youth service providers for planning and supportive supervision; training manuals and standard operating procedures in line with national and international guidelines for consistent delivery of quality services. Continuous monitoring and evaluation allows the programme to evolve over time, continually adapting to meet the changing needs of the target population. At the same time it is essential to have mechanisms in place to check that the established standards are actually being observed (quality assurance).

Sustainability

CBOs and community-based service delivery are vulnerable to inconsistent funding and reliance on volunteers. Compensation and sustainability issues must be considered when expanding access to HTC and other services at the community level.

2.5.9 Messaging

Public health communication should address specific adolescent populations using non-traditional approaches that identify particular locations and activities for dissemination of information and key messages, e.g. sports clubs, bars, youth centres, vocational centres, markets, schools. Ideally, messages should be formulated by or with the involvement of adolescents themselves, ensuring that their perspectives are reflected; this is particularly true for adolescent members of key populations.

Other approaches for effective communication with adolescents involve social marketing of key products and services and peer role models, especially those living openly and positively with HIV. The role of new technology may be especially powerful for communication initiatives addressing adolescents. Online social networks, mobile technologies and related innovations can contribute to the increased connectedness of adolescents around the world and facilitate rapid and effective dissemination of life-saving information. Private–public partnerships can facilitate messaging and promotion of services for adolescents; these partnerships will have different purposes and channels of communication in different settings.

2.5.10 National-level issues

HIV as an opportunity to move the adolescent health agenda

As health systems dedicate new energy and resources to the needs of adolescents, every effort should be made to maximize the opportunities that treating ALHIV

provides to focus more generally on strengthening national efforts on behalf of adolescents with chronic illness and provision of services for adolescents more generally (e.g. SRH). National data collection and analysis by health management information systems (HMIS) will need improvement to gather and assess information specific to adolescents.

Disaggregation of data

There are gaps in the collection and analysis of strategic information regarding ALHIV and adolescent members of key populations.

Disaggregation of data remains a challenge (or in many cases avoiding the aggregation of data as it moves up the reporting chain). There is still minimal knowledge about ALHIV because of the way in which data are aggregated: More generally, data are aggregated in broader groups (15–49 years or just greater than 15 years), or more specifically, younger adolescents are grouped with infants and children (0–14 years) and middle and late adolescents are grouped with young adults (15–24).

To strengthen services for adolescents, national health management systems will need to stratify data more appropriately into clear adolescent age groups (10–19 years) or sub-groups (10–14, 15–19 years), as well as by sex. This will advance a better understanding of the needs and practices of adolescents, allow for more effective monitoring and evaluation (M&E) for this age group (e.g. programme performance in relation to better serving ALHIV as well as exposing gaps in the continuum of care) and facilitate refinements to overall supply, procurement and distribution planning. Key indicators specific to adolescents include uptake of testing, linkages with treatment and care, and trends in LTFU.

To assess how well the needs of adolescents in key populations are addressed, several questions need answers:

- How do existing national data collection systems support addressing and monitoring those who need HIV services most?
- What are the characteristics of marginalized individuals who do not fit into key populations as currently understood?
- How best can M&E identify and document successful models and best practice of community-based delivery of services for key populations?

Policies and legislation addressing adolescent-specific issues

There are a number of policies that require attention—in particular, policies and legislation relating to informed consent by adolescents (without parental consent) and laws that criminalize the behaviours of adolescents in key populations.

2.5.11 Advocacy

EAST EUROPEAN AND CENTRAL ASIAN UNION OF PEOPLE LIVING WITH HIV (ECUO): MOBILIZATION OF ADOLESCENTS AFFECTED BY HIV/AIDS IN THE EECA REGION

The goal of the ECUO project was to ensure that the needs and concerns of adolescents living with HIV (ALHIV) would be better articulated and heard by adult PLWH, community leaders, local authorities, service providers, governments and other stakeholders. Project objectives included strengthening advocacy skills, increasing knowledge about issues relevant to ALHIV (including adherence, rights to health, education and other social services), and building networks to empower adolescents to advocate their rights in Ukraine, Russia, Kazakhstan, Uzbekistan, Kyrgyzstan and Belarus. The project included the development and monitoring of social networking platforms, advocacy events where adolescents promoted the rights of ALHIV among national and regional leaders, and strengthening psychosocial and other services. The project also included “mapping” of organizations that provide health and social services available to ALHIV in and beyond the project countries.

Lessons learned from the project

- Despite numerous trainings on advocacy skills, participation in local and regional events, support groups, etc., many adolescents still have not accepted their HIV diagnosis. Not all adolescents are ready to talk about their feelings related to HIV, let alone speak about their lives openly. Most of them still operate only with basic information about HIV/AIDS, ARV medications and adherence.
- HIV issues are often not a priority in the lives of adolescents affected by HIV since they are too busy coping with numerous other difficult life situations, including poverty, not attending school and not having a stable place to live due to termination of parental rights—many parents are drug users and they often do not care for their children.
- Adolescents are constantly living in stress and experiencing stigma and discrimination, all of which often lead them to stop taking their ARV medication.
- Weak government support reduces access to critical social services, such as placing ALHIV in foster families or boarding schools. Coordinators of projects and other initiatives end up dealing with the kinds of social issues that the government should be handling.
- By providing social assistance (either from community-based projects or sometimes from state social services), adolescents affected by HIV/AIDS receive help in solving issues that are not directly connected to HIV/AIDS, but their quality of life still improves.

✉ For more information visit http://old.ecuo.org/for_about/About_mission_goal/Listovka_A4_eng_final_150.pdf

2.5.12 Research

There is no single solution that responds to the needs of all ALHIV. Several of the programmes highlighted in this guidance emphasize being innovative and flexible and thinking outside the box. This is often easier for NGOs than for government health systems—which has implications for subsequent integration, decentralization and scaling up. NGOs can be testing grounds on behalf of government, and governments can be supported to implement demonstration projects with the intention from the beginning of scaling them up.

RESEARCH TO SUPPORT SERVICE PROVIDERS (ZIMBABWE) (131)

Objective: To develop an algorithm for primary-care health workers for identifying adolescents with HIV in populations at high risk through mother-to-child transmission.

Methods: Five hundred and six adolescent (10–18 years) attendees at two primary care clinics in Harare, Zimbabwe, were recruited. A randomly extracted “training” data set (n = 251) was used to generate an algorithm using variables identified as being associated with HIV through multivariable logistic regression. Performance characteristics of the algorithm were evaluated in the remaining (“test”) records (n = 255) at different HIV prevalence rates.

Results: HIV prevalence was 17%, and infection was independently associated with client-reported orphanhood, past hospitalization, skin problems, presenting with sexually transmitted infection and poor functional ability. Classifying adolescents as requiring HIV testing if they reported >1 of these five criteria had 74% sensitivity and 80% specificity for HIV, with the algorithm correctly predicting the HIV status of 79% of participants. Even in low HIV prevalence settings (<2%), the algorithm would have a high negative predictive value (≥99.5%) and result in an estimated 60% decrease in the number of people needing to test to identify one individual with HIV, compared with universal testing.

Conclusions: The simple algorithm that was developed can identify which individuals are likely to be exposed to or infected with HIV with sufficient accuracy to provide a screening tool for use in settings not already implementing universal testing policies among this age group, for example, immigrants to low HIV prevalence countries.

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Countries will have to adapt these guidelines for their particular contexts, taking into account explicit considerations of:

- the **heterogeneity of adolescents** (age, sex, marital status, different responsibilities in the family and community);
- the **rapid physical, cognitive and social development** that are features of this stage of life;
- the particular vulnerabilities of **adolescents in key populations**;
- the ways in which adolescent members of key populations **self-identify, form communities, and follow community norms and where they can be found**;
- the particular country-specific (national or sub-national) **characteristics of the epidemic** as well as the general characteristics of adolescents in the country in terms of age of sexual debut, how many are out of school, not in training, out of work, etc.

WHO normative guidelines are developed for a global audience; it is expected that each country will adapt the recommendations to suit its own circumstances. The implementation of some recommendations may be challenging in some settings in view of the differing prevalence of HIV and of limited available and promised resources. The new recommendations have the potential to increase substantially the number of people seeking HTC, treatment and care services and thus to increase the total cost of delivering services. Immediate and full implementation of these recommendations may not be practicable, feasible or affordable. However, country-level strategic planning should be directed towards eventually implementing these recommendations and achieving national universal access to HIV testing, treatment and care for adolescents.

Research concerning interventions specifically addressing adolescents has not yet been prioritized. Urgent attention should be given to the increasing numbers of perinatally exposed infants and children on ART who are surviving into adolescence and adulthood—with evolving needs for care—and adolescent slow progressors who need diagnosis, treatment and care. Table 4 highlights areas identified by the Guidelines Development Group and other contributors as priorities for the research agenda on adolescents and ALHIV.

Table 4. Needs for research on HTC for adolescents and treatment and care for adolescents living with HIV

Theme	Research areas
General	<ul style="list-style-type: none"> • Implement programmes in a way that maximizes the evidence output; should include comparative effectiveness studies • Programmes need to strengthen M&E systems and disseminate data generated by these systems • Development of culturally specific and valid measures of mental health, stigma and adherence outcomes for adolescents • Research on the magnitude of the issues under consideration in these guidelines • Pragmatic RCTs • Consider applications for interventions for adolescents within paediatric as well as adult research.
HTC	<ul style="list-style-type: none"> • Cost-effectiveness of routine HTC in generalized epidemics • Innovative strategies for adolescent in key populations • In generalized epidemics understanding how HCT affects girls' and young women's behaviour • Pre-HIV testing "Screening questions/ tests" (risk screens) • Comparative effectiveness and cost-effectiveness of interventions to improve access to HTC and linkage to care in different settings • Feasibility, acceptability, ethics, effectiveness of self-testing • Feasibility, acceptability, ethics of school-based testing • HTC and effectiveness, e.g. one outcome would be individual-level impacts and behaviour change following testing for all adolescents (with HIV or not) • Investigation of interventions that successfully promote HTC for adolescent members of key populations • Research is needed in countries where the age of consent has been lowered to determine that this has not led to riskier behaviour among young people; there is already a framework to build upon with the work that has been done demonstrating that sex education does not lead to increases in risky behaviour. <p>Outcomes</p> <ol style="list-style-type: none"> a. Number needed to test and <ul style="list-style-type: none"> — linked to care/ANC — linked to prevention interventions (circumcision, contraception, preventive behavioural interventions) b. Cost-effectiveness data c. Cost per person with HIV identified and linked to prevention and care using different approaches.

Theme	Research areas
Access and linkage to care	<ul style="list-style-type: none"> • Magnitude of attrition and reasons for attrition at each step along the treatment cascade • Interventions (rigorously evaluated) to link adolescents to and retain them in HIV care • Interventions to link and retain young people in key populations in care • Gender-related barriers to retention in care • Integration of care into school-based settings • Feasibility/cost-effectiveness/outcomes of decentralization • Optimal pre-ART retention strategies (systematic review of models of pre-ART care for adolescents) • Integration with SRH services for youth with STI or other indicators of unsafe sex. <p>Outcomes</p> <ol style="list-style-type: none"> a. Access to care b. Linkage to care c. Retention in care
Disclosure	<ul style="list-style-type: none"> • Interventions to help parents/guardians support disclosure • Supportive interventions to help adolescents' decision-making about beneficial disclosure • Training of providers. <p>Outcomes</p> <ol style="list-style-type: none"> a. Short- and long-term psychosocial outcomes
Adherence	<ul style="list-style-type: none"> • Effective interventions for sustained adherence • Training of providers.
Community-based Interventions	<ul style="list-style-type: none"> • Identify effective components and combinations of community-based interventions that improve adherence, linkage and retention in care as well as proximal outcomes • Identify what aspects of community-based approaches work (e.g. psychosocial, economic, treatment literacy); not all community-based initiatives are effective.
Decentralization	<ul style="list-style-type: none"> • Clinical outcomes and patient preferences, especially in the age group considered. (There are data that suggests that retention in care might be better.)



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UNICEF, with its partners, works to advocate for and support effective HIV prevention, treatment and care in adolescents. This involves efforts to overcome stigma and discrimination against people affected by the HIV and AIDS pandemic as well as efforts to strengthen national responses so that they respond comprehensively in order to fulfil the rights of the most vulnerable adolescents. We recognize, however, that stigma persists, and we take active steps to ensure that our communications work safeguards the identities of subjects in accordance with their wishes and with global standards of child rights and protection. We obtain written consent from people living with the virus before identifying them as such in photographs and other media. Unless otherwise noted, those depicted in images provided by UNICEF should not be assumed to be living with HIV. Any adolescents and young people shown have been reached through HIV prevention and adolescent development programmes, or are living in situations significant to an effective global HIV response.

Front cover

Boy holding puppy, Philippines, 2011

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Amsani, 12, is selling puppies in the streets of Manila, Philippines. In June 2011 in the Philippines, an estimated 250,000 children lived and worked on the streets, at increased risk of being trafficked, enduring abuse and sexual exploitation, forming dependence on illegal drugs and other harmful substances or coming into conflict with the law.

Top back cover and page 69

Girl in black, smiling, Chad, 2011

© UNICEF/Patricia Esteve

A girl laughs during a skit on the prevention of HIV, at a youth centre in Moundou, Chad. The centre teaches adolescents how to prevent the transmission of HIV and offers free HIV testing. The centre also has a small library and game centre and hosts a drama club and other extracurricular activities.

Centre left back cover and page 43

Boy from Ukraine sitting on a wall

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Artem, 14, sits on a wall outside 'Way Home', the shelter where he lives in the city of Odessa, Ukraine. The UNICEF-assisted shelter provides food, accommodation, literacy training and HIV/AIDS-awareness and prevention outreach programmes for children who live or work on the streets. Because of unsafe sex and injecting drug use, street adolescents are one of the groups most at risk of contracting HIV in Ukraine.

Centre right back

Indian girls

© UNICEF/Prashanth Vishwanathan

In Youth Information Centers located in Gujarat, India, engaged adolescents are trained to disseminate information on HIV/AIDS and other health issues.

Bottom back cover and page 1

Grandmother and Granddaughter, Zimbabwe, 2011

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HIV positive Monica and her granddaughter, Sympathy, 14, sitting at home on a bed in the village of Makuzeze, Zimbabwe.



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