Globally, HIV-related deaths are declining among all age groups except for adolescents (10–19 year-olds). The majority of adolescents living with HIV do not know their status. Those who do know it rarely receive the treatment or care they need to stay in good health and prevent transmission. Many more are at risk of acquiring HIV because they do not have the knowledge or means to protect themselves.

In 2013, over 2 million adolescents were living with HIV. Adolescent girls are the most vulnerable, particularly in sub-Saharan Africa. Two-thirds of all new HIV infections in 2012 were among adolescent girls. Clearly adolescents are not benefitting from progress being made to end the AIDS epidemic.

Adolescence is different to any other time in life: the young person is changing physically, emotionally and mentally. It can be both a challenging and exciting period, when adolescents form aspirations for their lives, develop relationships and explore their sexuality. It is also important that they build good health for the future during this time. Adolescents’ experiences are all different, dependent on factors that include their age, gender, sexual orientation, and the support they receive from their family and community.

<table>
<thead>
<tr>
<th>Barriers facing adolescents</th>
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</thead>
<tbody>
<tr>
<td>Fear of disclosing HIV positive status</td>
</tr>
<tr>
<td>Lack of training of service providers in adolescent development, health and rights</td>
</tr>
<tr>
<td>Lack of community-led initiatives and networks, particularly for key populations</td>
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<tr>
<td>Discriminatory laws, policies and practices, including age restrictions on services and the need for parental consent</td>
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<tr>
<td>Insufficient information about sexual and reproductive health and rights</td>
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<tr>
<td>Lack of high-quality, affordable antiretrovirals suitable for children of different ages</td>
</tr>
<tr>
<td>High intensity of support often required for adolescents to take up services</td>
</tr>
<tr>
<td>Lack of adolescent age-specific health services</td>
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</tbody>
</table>

AIDS is the second largest cause of death among adolescents worldwide.

**WHAT DO THE 2013 GUIDELINES SAY FOR ADOLESCENTS?**

**WHAT DOES THIS MEAN FOR MY COUNTRY?**

**WHO 2013 HIV and adolescents: guidance for HIV testing and counselling and care for adolescents living with HIV.** Available at: www.who.int/hiv/pub/guidelines/adolescents/en/
What do the 2013 Guidelines say about adolescents?

HIV and adolescents: guidance for HIV testing and counselling and care for adolescents living with HIV, issued by the World Health Organization (WHO) in November 2013, is the first-ever set of HIV guidelines addressing the specific needs of adolescents. It complements the clinical and operational guidance in the 2013 WHO Consolidated guidelines on the use of antiretroviral drugs for treating and preventing HIV infection, and the specific recommendations for adolescent key populations in WHO’s 2014 Consolidated guidelines on HIV prevention, diagnosis, treatment and care for key populations. Between them, these three documents provide specific, evidence-based recommendations for adolescents across the continuum of HIV care. The new recommendations from WHO’s 2013 Adolescent Guidelines are highlighted below.

What does this mean for my country?

Breaking down barriers and promoting rights

Reflecting diversity WHO emphasises services needs to reflect the heterogeneity of adolescents including, variations in modes of transmission, age, gender, sexual orientation and levels of poverty. These all need to be taken into consideration when constructing HIV programmes for adolescents, as does the role they have in their family, such as whether they are the main wage earner. The continuum of care needs to reflect the differing needs of adolescents of various ages. It should also respond to their evolving capacity. As children become more capable, they require different forms of protection and should be given greater responsibility for decision-making.

Better research and data Data needs to be systematically disaggregated by age, gender and location. For example, data is particularly scarce for children aged 10–14, as work with this age group often requires parental consent and greater safeguards. In addition, more research is needed into adolescent-specific and adolescent-friendly health and social sector interventions to better understand what works well and the costs involved.

Meaningful involvement of adolescents Adolescents lack systematic ways to participate in the HIV response. It is important to acknowledge their ability to lead and to build on their competencies and capacities, especially to articulate the kind of services they need. Many adolescents have skills that can be particularly useful including, technological knowledge, the ability to write software packages, create apps for mobile phones etc. They should be involved in policy-making, service delivery and monitoring programmes, and be empowered and trained as peer educators, counsellors, trainers and advocates. Adolescents from key populations have the right to be meaningfully engaged and have their views taken into account.

Addressing the needs of key populations In the 2013 Adolescent Guidelines, WHO recognises that: “Fearing discrimination and/or possible legal consequences, many adolescents from key populations are reluctant to attend diagnostic and treatment services. Consequently, they remain hidden from many essential health interventions, further perpetuating their exclusion.”

Adolescents from key populations* often face overlapping challenges and circumstances that make them particularly vulnerable. All their varying needs must be met and their rights guaranteed whether they are an adolescent in a detention centre, a displaced person in a refugee camp, a drug user etc. Approaches to tailoring services to adolescents from key populations include:

- integrated health services, such as providing antiretrovirals (ARVs) at drug treatment centres
- scheduling service hours that are regular, dependable and suit clients
- locating services strategically where key populations congregate or transit, offering transportation or house visits

* WHO defines key populations as groups, who due to specific higher-risk behaviours, are at increased risk of HIV infection for example: men who have sex with men, people who inject drugs, people in prisons and other closed settings, sex workers and transgender people.
- involving the peer community in service development, promotion, delivery, and monitoring and evaluation
- training staff to work with different key populations
- taking steps to ensure that law enforcement activities do not interfere with clients’ access to HIV services.

See more in Module I: HIV and key populations of this Community Guide.

**Reviewing laws and policies** Many adolescents say that they avoid getting tested for HIV because they would need their parents’ or caregivers’ consent. WHO encourages countries to change their consent laws and policies in order to reduce age-related barriers to access and uptake of HIV services. It also recommends that sexual and reproductive health services, including contraceptive information and services, be provided for adolescents without them needing parental or caregiver consent.

Adolescents from key populations often face additional legal and policy barriers, including stigma related to their behaviours, and prosecution if these activities are illegal. Fear of disclosing such behaviours can significantly discourage adolescents from accessing HIV testing and counselling (HTC) services, as well as treatment and other forms of support. Every effort should be made to keep adolescents out of criminal justice systems. Where adolescents are incarcerated they should be empowered to choose a sentence plan that supports the management of their HIV treatment while in custody and prepares them for resettlement into the community.

**Respecting human rights** Most countries have committed to international conventions that recognise adolescents’ right to the highest attainable standard of health. They must now use these to inform the development of human rights-based national policies and laws. Systems must be in place and organisations (including civil society groups) equipped to respond to and report violations of the human rights of adolescents. There must be avenues of redress for adolescents whose rights are violated.

Communities must also ensure that the HIV response for adolescents links to social protection laws, policies and programmes. Such programmes should include: increased access to education and basic necessities (food, housing, shelter, etc.); and economic and social support for HIV-affected adolescents.

**Promoting sexual and reproductive health and rights** All adolescents have the right to a healthy, enjoyable and safer sex life, which should be supported in an age-appropriate way. Adolescents require counselling, information and services tailored to their needs and evolving capacities. It is particularly important that programmes for adolescents from key populations address social norms and stigma concerning sexuality, gender identities and sexual orientation. They should do this through comprehensive sexuality education in schools, supportive information for families and training of educators and healthcare providers.

**Encouraging HIV testing and counselling, and linking to care**

HIV testing and counselling (HTC), with linkages to prevention, treatment and care, is recommended for adolescents from key populations in all settings, and for all adolescents in generalised epidemics. In low and concentrated epidemics, the recommendation is that HTC should be “made accessible” to all adolescents.

While testing should be routinely offered and widely available, it should not be mandatory. Confidentiality is of paramount importance to adolescents. Pre- and post-test counselling sessions with adolescents should use clear language, with information adapted to adolescents’ literacy levels and developmental stages. This should be provided in a non-judgmental and inclusive way by respectful, accepting and understanding healthcare providers. Adolescents must be
supported to adopt health-seeking behaviour whatever the result: treatment and care if HIV positive, and prevention to remain negative.

Adolescents need to know their status in order to improve their own health and prevent new infections. Addressing stigma is critically important. Approaches to improve access to and uptake of HTC for adolescents include:

- Basing activities and services in places where adolescents are comfortable; separate waiting areas for adolescents; alternative service delivery settings.
- Increasing the number of testing sites; flexible hours; reducing costs of testing; and strengthening referrals from community organisations and rural health clinics.
- Peers living with HIV can act as public role models and help to reduce stigma. A good relationship with the person providing HTC is very important for adolescents. Any adolescents, not just young people living with HIV, can play their part, and champion and support peer-based interventions.
- Community-based testing may help to improve uptake of services, but must include support to address the possible negative impacts of a positive test within the family, such as rejection or violence.

Programme managers must consult adolescents on the barriers they face in accessing HTC services, and work with them to design services that respond to their needs.

Supporting disclosure

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.

Adolescents may not have the knowledge or emotional skills to cope with the difficulties of disclosing their status. Unequal power dynamics (such as between adolescent women and older sexual partners) may also come into play, leaving the adolescent more vulnerable to isolation or abuse following disclosure. Alcohol, drug use and other high-risk practices that often begin during adolescence may also constrain effective disclosure and safer sex. In some countries, non-disclosure is criminalised, adding a further dimension for adolescents to contend with. Providers need to understand all the questions surrounding disclosure by adolescents (if, when, how and to whom) in order to focus on the safety of the individual who is disclosing. Further operational guidance is needed to support disclosure by adolescents to their sexual partners.

It is also critical to support healthcare providers and parents to tell children and adolescents about their HIV status. Countries should share experiences and explore different ways to support this disclosure, including through community-based interventions.

Improving treatment, adherence and retention

Community-based approaches can improve treatment adherence and retention in care of adolescents living with HIV.

Training of healthcare workers can contribute to treatment adherence and improvement in retention in care of adolescents living with HIV.

By 2012, around 630,000 infants, children and young adolescents in developing countries had been started on antiretroviral therapy (ART). Over the next decade, these children will face the challenges of adolescence in addition to those associated with living with HIV. Adolescents living with HIV also include “slow progressors”: those whose CD4 count remains low over a period of time without treatment and who may not be aware of their HIV status. Some adolescents are receiving care, having been followed through prevention of vertical transmission programmes. However, a significant proportion have fallen out of healthcare systems due to a lack of effective follow-up programmes.
Evidence shows that adolescents have lower adherence to ART than other age groups. This may be due to factors relating to medication (pill burden, treatment fatigue, side effects), social factors (fear of disclosure, poverty) or health service factors (access to services, distrust of authorities). Tailored approaches to retention in care are needed to support the diversity of adolescents living with HIV.

Evidence shows that community-based services can provide a critical link with clinical services for adolescents. Community-based interventions, including home-based health assessment, education and support by community health workers, have the potential to improve adherence and viral suppression, reduce mortality rates and help adolescents cope with psychological impacts. However, in some cases, the “familiarity” of community-based services may be a disincentive for adolescents due to concerns about confidentiality.

Well-trained healthcare providers who understand the needs of adolescents can support adherence among adolescents by:

- assisting them in exploring factors influencing their adherence
- improving their understanding of HIV and ART, including physical and psychological side effects
- recognising developmental needs while supporting their emerging independence
- offering simplified ART regimes and helping them to integrate ART into daily life
- encouraging participation in peer support groups and community-based interventions.

Mobile technologies have been used successfully among adolescents for other chronic illnesses, and can potentially improve adherence and support. However, adolescents living with HIV must be involved in developing such programmes.

Guidance and counselling should be provided to parents and caregivers of adolescents living with HIV so they are better able to support their adolescents. Evidence shows that adolescents living with HIV have stronger health outcomes when they have higher levels of parental and caregiver involvement. Therefore, programmes based on a family-centred model of care are most promising. But it is important to ensure that the best interests of the adolescent have priority over the opinions of parents and caregivers. Adolescents who do not have parents, or who have unsupportive or abusive parents, require specific support to access services, including treatment. This is often an issue for adolescents from key populations, and has important implications for their ability and their right to provide informed consent for themselves.

### Case management

Coordination of care across services, including through case management, can support adolescents to: obtain information needed to make informed decisions; access focused education and employment opportunities; manage a crisis if needed; and meet basic needs of housing, food, clean water sanitation and transportation. Case managers can also help to link to health facilities, peer support groups, legal assistance, social protection services, etc.

Community health or social workers can take on the role of case manager. Initiatives such training in pill swallowing for younger patients, and taking ARVs under supervision, have shown to improve short-term treatment outcomes among adolescents and children living with HIV.

### Designing and delivering adolescent-friendly services

WHO calls for services to be “safe spaces that increase protection from the effects of stigma and discrimination, where adolescents can freely express their concerns, and where providers demonstrate patience, understanding, acceptance and knowledge about the choices and services available to the adolescent.”
It is important to understand the kind of services that adolescents themselves prefer using. The most innovative programming focuses on new ideas for creating and disseminating messages intended for adolescents. Multimedia models that successfully combine traditional media (TV and radio) with new media like websites, social media and mobile apps, allow content to be accessed at any time and shared with other users. Social networking (online and in person) can also help to increase adolescents’ sense of engagement and active citizenship. Access to social infrastructure and a safe physical space can be especially important to the most vulnerable adolescents, particularly girls and those from marginalised groups.

**Transition**

Programmes need to consider the transitioning of healthcare responsibilities from a parent or caregiver to the adolescent and from paediatric to adult services. Good transition approaches should support adolescents to:

- acquire knowledge and build life skills
- reduce any risk-taking behaviour that can interfere with treatment adherence and retention in care
- take on the psychological responsibility for when and if to disclose
- manage their own treatment and nutrition.

Transition programmes should also link to effective mental health and psychosocial support to improve the quality of life and well-being of adolescents living with HIV.

There are also a number of interventions designed primarily for adults that should be prioritised and included in all HIV programming for adolescents, including voluntary medical male circumcision, HTC, ART for treatment and prevention, condom use, opioid substitution therapy, hormone replacement therapy and provision of sterile injecting equipment to people who use drugs. Their age is often a barrier to adolescents accessing services, for example they may be denied access to sterile injecting equipment or they may be scared to access services at all through fear of reporting to law enforcement agencies, their parents or guardians.

It is also important to recognise that many pregnant women are adolescents (approximately 16 million births each year are to adolescents). Adolescent girls with HIV have less access to prevention of mother-to-child transmission interventions than adult women. They also need improved access to maternal and other types of healthcare including abortion services and counselling.

**Decentralisation and community-based approaches**

Limited capacity in healthcare delivery systems poses a serious challenge to expansion of HIV testing, treatment and care for adolescents.

WHO recognises that community-based service delivery is important for adolescents. This can minimise logistical and financial constraints, and offer services in familiar and accessible settings. Community-based settings can refer to proximity to where adolescents live, as well as services that are delivered in a community of adolescents with common characteristics or challenges, such as a key population.

Community-based organisations, particularly those serving key populations, should seek opportunities to strengthen their capacities to serve adolescents and ensure that their programmes are non-judgemental and respectful. Monitoring the coverage, quality and costs of community-based and -led programmes is essential to improve services and ensure accountability to adolescents themselves.

Well-coordinated partnerships between state and communities are essential to expanding access to services and assuring quality of services for adolescents. 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 vice versa.
Take stock! Take action!

- Is national HIV and health data disaggregated by age, gender and geography? Do data collection systems in your country identify the needs of adolescents? How can civil society contribute to strengthening the evidence base?

- Are adolescents and their needs and rights adequately reflected in your national HIV plan? Has an essential HIV service package for adolescents (including those from key populations) been agreed? Were adolescents involved in their development?

- Are adolescents themselves meaningfully involved in national discussions and HIV-related programme design? Are adolescents involved in monitoring and ensuring the accountability of programmes?

- What adolescent-specific interventions and services are in place in your country to meet the needs of the diverse range of adolescents? What is missing? What is the role of civil society in service provision, particularly for key populations?

- What services and modes of service delivery are most effective for the varying needs of adolescents, their parents and caregivers? Which services should be decentralised and/or integrated to improve service coverage?

- Are there connections and referral systems along the continuum of care, and in both directions between the community and formal health systems?

- How important are social networks and community systems and structures for adolescents in your country, and how do they affect their health-seeking behaviour? How can civil society groups improve the ways in which adolescents meet and communicate to create environments that foster mutual support and reduce stigma?

- What are the potential risks of working with adolescents who are still minors in your country? What strategies can civil society follow to mitigate risk?

- What legislation, policies and practices hamper adolescent-specific programming and service delivery in your country, particularly for adolescents from key populations and those not supported by parents? What actions are being taken to change the situation?

- Is civil society working with adolescents adequately equipped to respond to, monitor and report human rights violations and punitive laws, policies and practices?

- Has civil society established links with child protection and the juvenile justice system (where it exists) to support the progressive realisation of the rights of adolescents affected by HIV?

- Who supports the transition from paediatric to adult health services, and of healthcare responsibilities from parent or caregiver to adolescent in your country? How can civil society contribute?

- What financial, human and other resources and infrastructure are required to implement an adequate response to HIV for adolescents in your country? What resources are currently available, what additional funds are required, and how might those be obtained?
Resources

1. The Y+ Leadership Initiative is a virtual platform for young people living with HIV, and organisations that support emerging young HIV-positive leaders, available at: www.yplusleadership.org

2. The Coalition for Children Affected by AIDS has a resource on ethical decision-making guidance for caregivers, particularly focused on children from key populations. Available at: www.ccaba.org/our-projects/policy/care-worker-guidance/

3. The Committee on the Rights of the Child has a wealth of information on its website, available at: www.ohchr.org/en/HRBodies/CRC/Pages/CRCIndex.aspx

4. FHI 360 provides guidance for people leading support groups for adolescents living with HIV. Positive connections: leading information and support groups for adolescents living with HIV, is available at: www.fhi360.org/resource/positive-connections-leading-information-and-support-groups-adolescents-living-hiv
Young people most at risk of HIV, is available at: www.fhi360.org/resource/young-people-most-risk-hiv-0

5. The Inter-Agency Task Team for HIV Prevention and Young People has an online resource and networking portal dedicated to HIV and young people, available at: www.youngpeopleandhiv.org


7. The International Planned Parenthood Federation outlines keys to youth friendly services for “unlocking” access to sexual and reproductive health services for young people, available at: www.ippf.org/resources/publications/Keys-youth-friendly-services


10. UNICEF has a website dedicated to children and AIDS, available at: www.childrenandaidsonline.org


12. From the World Health Organization (WHO):
   - an accessible and interactive tool to help service providers reach adolescents http://apps.who.int/adolescent/hiv-testing-treatment/
   - Health for the world’s adolescents: a second chance in the second decade www.who.int/adolescent/second-decade
   - Guidelines on HIV disclosure counselling for children up to 12 years of age www.who.int/hiv/pub/hiv_disclosure/en/
   - a guide for health workers in their relations with adolescents www.searo.who.int/bangladesh/publications/adolesc_job aid.pdf

Adolescents from key populations

13. An AIDS Data Hub selection of publications relating to young people from key populations can be found at: www.aidsdatahub.org/Thematic-Areas/Young-Key-Affected-Populations


The full set of modules that make up Driving the HIV response: a community guide to the WHO 2013 Consolidated guidelines on the use of antiretroviral drugs for treating and preventing HIV infection is available at:

www.gnpplus.net/community-guide
www.aidsalliance.org/communityguide
www.stopaidsnow.org/community-guide

Researched and written by Aditi Sharma, Anja Teltschik and Laura Davies. For further information contact Aditi Sharma at aditi.campaigns@gmail.com

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