

**PARTICIPANTS MANUAL**

# **IMAI One-day Orientation on Adolescents Living with HIV**



**World Health  
Organization**

WHO Library Cataloguing-in-Publication Data

Participant manual: IMAI one-day orientation on adolescents living with HIV.

1.HIV infections - prevention and control. 2.HIV infections - therapy. 3.HIV infections - transmission. 4.Adolescent health services. 5.Sexual behavior. 6.Education. 7.Adolescent. I.World Health Organization.

**ISBN 978 92 4 159897 2**

**(NLM classification: WC 503.6)**

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Printed in

Editing and design by Inis Communication – [www.iniscommunication.com](http://www.iniscommunication.com)

## Participant manual

# IMAI One-day Orientation on Adolescents Living with HIV

This course is part of a global commitment and recognition of the importance of addressing HIV and young people. The Political declaration on HIV/AIDS adopted at the United Nations General Assembly High-Level Meeting on AIDS (June 2006), states (we):

8. *Express grave concern that half of all new HIV infections occur among children and young people under the age of 25, and that there is a lack of information, skills and knowledge regarding HIV/AIDS among young people;*
23. *Reaffirm also that prevention, treatment, care and support for those infected and affected by HIV/AIDS are mutually reinforcing elements of an effective response and must be integrated in a comprehensive approach to combat the pandemic;*
26. *Commit ourselves to addressing the rising rates of HIV infection among young people to ensure an HIV-free future generation through the implementation of comprehensive, evidence-based prevention strategies, responsible sexual behaviour, including the use of condoms, evidence- and skills-based, youth-specific HIV education, mass media interventions and the provision of youth-friendly health services.*

[www.un.org/ga/aidsmeeting2006/declaration.htm](http://www.un.org/ga/aidsmeeting2006/declaration.htm)



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## **ACKNOWLEDGEMENTS**

This document has been prepared by Claudia Brann and Bruce Dick, with input from Akiiki Bitalabehe and Sandy Gove, HIV Department, WHO Geneva, and colleagues in the Department of Child and Adolescent Health and Development, WHO Geneva. Grateful thanks are due to a range of individuals and organizations in Guyana and Uganda who took part in the field testing of previous versions, and to participants in the WHO/UNICEF global consultation on Strengthening the Health Sector Response to Care, Support, Treatment and Prevention for Young People Living with HIV, Blantyre, Malawi, November 2006, who commented on and contributed to an initial draft.

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# 1

## Section 1:

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# **Introduction to the IMAI One-day Orientation on Adolescents Living with HIV**

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# 1.1 WHO trainings on adolescents and HIV

This one-day course has been developed as an additional optional training for the World Health Organization (WHO) Integrated Management of Adolescent and Adult Illness (IMAI) package, focusing on adolescents living with HIV. The target audience for this training are first-level facility health workers who have attended the WHO IMAI-IMCI [Integrated Management of Childhood Illness] Basic HIV Care with ART and Prevention training course and the WHO IMAI Acute Care training course, and are working with adolescent patients.

There are two WHO training modules to orient health workers to adolescents and young people living with HIV:

PARTICIPANTS COMPLETE THIS TRAINING . . .	. . . AND THEN ATTEND THIS TRAINING . . .	. . . THAT FOCUSES ON . . .
WHO IMAI-IMCI Basic HIV Care with ART and Prevention training course and WHO IMAI Acute Care training course	IMAI One-day Orientation on Adolescents Living with HIV	Issues for health workers who provide care to adolescents living with HIV
WHO Orientation Programme on Adolescent Health for Health-care Providers	Module N Young People and HIV	HIV prevention needs of young people in general

Also included, excerpts from the

## Adolescent job aid

A desk reference for primary level health workers, which includes 24 algorithms responding to common questions from adolescents and their accompanying adults, including “Could I have HIV?”



## 1.2 Course objectives

The objectives of this course are to orient a range of health workers, including medical officers and nurses, to the special characteristics of adolescence and to identify and practice appropriate ways of addressing important issues for adolescents living with HIV.

### **This course will:**

- inform participants of the stages of adolescent development;
- raise participants' awareness of the special needs and challenges facing adolescents living with HIV;
- strengthen participants' skills in providing appropriate prevention, care, treatment and support to adolescents living with HIV.

Section 1.4 below shows the schedule for the day.

During the course, participants will be asked to refer to their copies of the two IMAI guideline modules: *IMAI Acute care* (January 2009) and *IMAI-IMCI Basic HIV care with ART and prevention* (April 2007); and the *IMAI wall chart on the adolescent living with HIV* (hereafter referred to as *IMAI wall chart*).

## 1.3 Course methodology

### 1.3.1 Adolescent Development

The training methods used in this course include visualization in participatory programmes (VIPP), brainstorming and buzz groups, role plays, individual exercises, group work, plenary sessions and mini lectures. Participatory methods will allow everyone (participants and facilitators) to be resource people for this course.

#### **RULES FOR PARTICIPATORY LEARNING**

1. Treat everyone with respect at all times, irrespective of sex, age or experience.
2. Ensure confidentiality, so that facilitators and participants are able to discuss sensitive issues (such as those relating to sexual and reproductive health and HIV) without feeling concerned about negative consequences.
3. Keep track of time; begin and end all sessions on time.
4. Ensure that everyone gets an opportunity to be heard.
5. Accept and give critical feedback; take care not to hurt anyone's feelings.
6. Draw on the expertise of facilitators, adolescent expert patient trainers (EPTs) and participants in dealing with difficult situations if they arise.

Adherence to these rules will help to ensure an effective and enjoyable learning environment. Facilitators and participants may add other rules as appropriate.

The participatory methods used in this course are briefly described below.

### **Visualization in participatory programmes**

VIPP is a participatory process in which participants are asked to write their ideas and responses to an issue on cards of different sizes and colours. These cards are then displayed to enable participants to see (visualize) the ideas, identify the linkages between them, group similar cards/ideas and develop broad themes. For VIPP to be successful there are some basic rules for card writing.

#### **RULES FOR VIPP CARD WRITING**

- 1. Write only one idea per card.**
- 2. Write a maximum of three lines on each card.**
- 3. Use keywords; write legibly.**
- 4. Follow the colour code established by the facilitator for the different categories of ideas.**

It is important to follow these rules so that all participants can read the cards, and hence their ideas, from a distance.

An advantage of this method is that it allows all participants the opportunity to express themselves, so that the quieter members in the group are also able to participate.

### **Brainstorming/buzz groups/group work**

Brainstorming (in plenary discussions or in groups), or working in buzz groups (small groups of 3–4 participants), helps quickly generate ideas, which can be used as a basis for later discussions. They also help the group to cooperate on a task and focus on an issue or problem.

Brainstorming is often used at the beginning of a session. It involves posing a clear question and inviting participants to share their ideas. During brainstorming, all the participants' ideas are listed and neither the facilitator nor the other participants should comment on any ideas raised. The responses are written on a flipchart or on VIPP cards, which can be organized to show the main issues

that emerged from the exercise. Once this has been done, the issues can be examined and discussed.

## **Role play**

Role play can be a valuable method both for teaching and learning. It provides an opportunity for the expression of emotions, which cannot be achieved through discussions alone. Role play has the potential to raise many issues in a much shorter time than would be possible using other teaching–learning methods.

## **Spot checks**

Spot checks are short questions focusing on adolescents living with HIV. They are for self-evaluation and the participants individually write responses in their Manual at the beginning of the course. They will not be required to share their answers. In the concluding session, the facilitator will review the spot checks and discuss the responses with the participants. At this time, the participants will be able to evaluate their own knowledge gains and attitude changes.

## **Adolescent expert patient trainers**

This course should include as participants, young people who are trained as EPTs, particularly adolescents living with HIV. Their involvement will provide other participants with a unique insight into adolescents' views on living with HIV. The EPTs can assist throughout the day and can be asked to give participants a “true” representation of what it is like to be a young person living with HIV.

## ***IMAI wall chart on the adolescent living with HIV***

The *IMAI wall chart* will be displayed on the wall throughout the day. Initially, it will be covered with blank flipcharts. During the day the facilitator will lower or remove the flipcharts to uncover each box of information as it is presented to the participants.

## **“Come Back to Later” board**

The “Come Back to Later” board is a blank flipchart that is put up at the beginning of the day with the title “Come Back to Later” written on the top. Participants are encouraged to “park” on the board those questions, comments and issues that come up during the day but that they feel are not dealt with adequately at the time they arise. This ensures that participants' questions do not get forgotten or dismissed if they arise when there is no time for discussion or when it is not appropriate to deal with them. Anyone is free to write a comment or question on the board throughout the day. The board will be

reviewed at the end of the day during the concluding session, to ensure that all the issues raised have been covered.

### 1.3.2 Language

Consider carefully the language you use when working with people living with HIV. Health workers should use appropriate, non-judgemental and non-discriminatory language. General guidance on words and terms to be used in talking about issues around HIV can be found in the *UNAIDS terminology guidelines*<sup>1</sup>.

**Here are some general language issues to bear in mind:**

- When working with adolescents living with HIV, remember to talk of parents, guardians or caregivers, not just parents, as many adolescents living with HIV are orphans.
- When referring to adolescents who acquired HIV around birth, use the term “adolescents with perinatally acquired HIV” or “adolescents who were infected perinatally”.
- When referring to adolescents who acquired HIV as adolescents, use the term “infected with HIV during adolescence” or “having acquired HIV as adolescents”.

<sup>1</sup> [http://data.unaids.org/pub/Manual/2008/jc1336\\_unaids\\_terminology\\_guide\\_en.pdf](http://data.unaids.org/pub/Manual/2008/jc1336_unaids_terminology_guide_en.pdf)

## 1.4 Schedule for the One-Day Orientation on Adolescents Living with HIV

Sessions	Activity	Page	Time (mins)
<b>Session 1:</b> <b>Introduction to IMAI Orientation on Adolescents Living with HIV</b> <ul style="list-style-type: none"> <li>&gt; Spot checks</li> <li>&gt; Introductions</li> <li>&gt; Course objectives</li> <li>&gt; Participatory methods</li> </ul>	<ul style="list-style-type: none"> <li>&gt; Individual exercise</li> <li>&gt; Group work</li> <li>&gt; Mini lecture</li> <li>&gt; Mini lecture</li> </ul>	5	20
<b>Session 2:</b> <b>Adolescent development</b> <ul style="list-style-type: none"> <li>&gt; Introduction to adolescent development</li> <li>&gt; Participants' experiences of adolescence</li> <li>&gt; Adolescents today</li> </ul>	<ul style="list-style-type: none"> <li>&gt; Mini lecture and plenary discussion</li> <li>&gt; Individual exercise and plenary discussion</li> <li>&gt; Brainstorming</li> </ul>	13	50
<b>Session 3:</b> <b>Adolescence – a unique stage in life</b> <ul style="list-style-type: none"> <li>&gt; How adolescents differ from children and adults</li> <li>&gt; How adolescents differ from each other</li> <li>&gt; Difficult situations for health workers in providing services to adolescent patients living with HIV</li> </ul>	<ul style="list-style-type: none"> <li>&gt; Brainstorming and buzz groups</li> <li>&gt; Mini lecture</li> <li>&gt; Buzz groups and plenary discussion</li> </ul>	19	50
<b>BREAK</b>			<b>30</b>
<b>Session 4:</b> <b>Adolescents living with HIV and health services</b> <ul style="list-style-type: none"> <li>&gt; HIV transmission periods for adolescents: Perinatal or adolescence</li> <li>&gt; Adolescents living with HIV seeking health services</li> <li>&gt; Identifying changes to improve services for adolescents living with HIV</li> </ul>	<ul style="list-style-type: none"> <li>&gt; Mini lecture</li> <li>&gt; Plenary discussion and brainstorming</li> <li>&gt; Individual exercise</li> </ul>	24	45
<b>Session 5:</b> <b>Introduction to using the <i>Adolescent job aid</i></b> <ul style="list-style-type: none"> <li>&gt; Overview of the Adolescent job aid and its use in providing services to adolescents living with HIV</li> </ul>	<ul style="list-style-type: none"> <li>&gt; Plenary presentation and discussion</li> </ul>	38	30
<b>Session 6:</b> <b>Communicating with adolescents</b> <ul style="list-style-type: none"> <li>&gt; Communicating successfully with adolescents</li> </ul>	<ul style="list-style-type: none"> <li>&gt; Group work and plenary discussion</li> </ul>	40	45
<b>LUNCH</b>			<b>60</b>

Sessions	Activity	Page	Time (mins)
<b>Session 7:</b> <b>Prevention and support for adolescents living with HIV</b> > Important questions asked by adolescents living with HIV > Responding to adolescents' questions > Beneficial disclosure > Positive prevention  > Consent and confidentiality > Developmental delays	> Brainstorming  > Group work > Plenary discussion > Mini lecture and plenary discussion > Plenary discussion > Mini lecture and plenary discussion	44	45
<b>Session 8:</b> <b>Treatment and care for adolescents living with HIV</b> > Clinical status when entering care > Transition of care > Antiretroviral therapy > Challenges in adherence to ART for adolescents > Living with a chronic condition	> Mini lecture > Mini lecture > Plenary discussion > Brainstorming  > Mini Lecture	61	45
<b>BREAK</b>			30
<b>Session 9:</b> <b>The 5 "A"s and the adolescent patient</b> > Using the 5 "A"s with an adolescent patient  > Feedback	> Group work and plenary presentation (or role play) > Plenary presentation (or role play)	72	60
<b>Session 10:</b> <b>Concluding session</b> > Spot checks > Difficult situations for health workers, "Come Back to Later" board and course objectives > Individual action plan > Key messages and conclusion	> Review > Review  > Individual exercise > Review	—	60

# 2

## Section 2:

# Adolescent Development

### LEARNING OBJECTIVES

- to discuss the stages of adolescence;
- to help participants reflect on positive and negative experiences from their own adolescence, with a focus on sexual and reproductive health;
- to discuss how experiences of today's adolescents compare with those of adolescents 10–20 years ago.

Today's generation of young people is the largest in history. Nearly half of the global population is less than 25 years old, with about 30% in the 10–24 years age group.

Adolescence is a period in which an individual undergoes major physical, psychological and emotional changes.

According to the World Health Organization (WHO)

- “**adolescents**” are individuals in the 10–19 years age group
- “**youth**” are individuals in the 15–24 years age group
- “**young people**” combine both adolescence and youth and include the 10–24 years age group.

Adolescence has physical, psychological, emotional and socio-cultural dimensions. It is a phase in an individual's life, rather than a fixed age band, and is perceived differently in different societies.

- Adolescence is characterized by exceptionally **rapid growth and development**. During this stage, the body develops in size, strength and reproductive capabilities, and the mind becomes capable of more abstract thinking. There is also an increase in emotional control.
- The rate of growth and development during adolescence is exceeded only by the rate during fetal life and early infancy. However, in comparison with infancy (when the milestones occur at a similar time for most infants), there is much greater **individual variation** both in the timing of developmental milestones and in the timing and degree of changes in the rates of growth during adolescence. This means that there can be great variations in development among adolescents of the same age, and there are often significant differences between girls and boys.
- The individual's capacity for **abstract and critical thinking** also develops, along with a sense of self-awareness. The prefrontal cortex of the brain grows during adolescence, which affects social and problem solving skills.

- During adolescence, social relationships move from a family base to a wider network in which peers, other respected adults in the community, and also adults in the media (such as pop music and film stars) come to play more significant roles. The adolescent experiences **changes in social expectations** and perceptions, which require an increased level of emotional maturity.
- Physical growth and development are accompanied by **sexual maturation**, often leading to intimate relationships. Adolescence is usually the time when sexual activity is initiated, as adolescents with little experience explore relationships and look for emotional and physical intimacy.
- Globally, **puberty is occurring earlier** and in many countries adolescents are having sex for the first time at a younger age than the previous generations. Worldwide, people are having sex for the first time at an average age of 17.7 years.

## 2.1 Developmental stages of adolescence

Adolescents are often grouped into three overlapping developmental age groups: 10–15, 14–17 and 16–19 years. The overlap of ages is important because the changes are not fixed and happen at different ages for different adolescents.

## 2.1.1 Stages of adolescence

	EARLY 10–15 years	MIDDLE 14–17 years	LATE 16–19 years
Category of change			
<b>GROWTH OF BODY</b>	<ul style="list-style-type: none"> <li>■ Secondary sexual characteristics appear</li> <li>■ Rapid growth reaches a peak</li> </ul>	<ul style="list-style-type: none"> <li>■ Secondary sexual characteristics advance</li> <li>■ Growth slows down</li> <li>■ Has reached approximately 95% of adult growth</li> </ul>	<ul style="list-style-type: none"> <li>■ Physically mature</li> </ul>
<b>GROWTH OF BRAIN</b> (Prefrontal cortex)		<ul style="list-style-type: none"> <li>■ Brain growth occurs</li> <li>■ Influence on social and problem solving skills</li> </ul>	
<b>COGNITION</b> (ability to get knowledge through different ways of thinking)	<ul style="list-style-type: none"> <li>■ Uses concrete thinking ("here and now")</li> <li>■ Does not understand how a present action has results in the future</li> </ul>	<ul style="list-style-type: none"> <li>■ Thinking can be more abstract (theoretical) but goes back to concrete thinking under stress</li> <li>■ Better understands results of own actions</li> <li>■ Very self-absorbed</li> </ul>	<ul style="list-style-type: none"> <li>■ Most thinking is now abstract</li> <li>■ Plans for the future.</li> <li>■ Understands how choices and decisions now have an affect on the future</li> </ul>
<b>PSYCHOLOGICAL AND SOCIAL</b>	<ul style="list-style-type: none"> <li>■ Spends time thinking about rapid physical growth and body image (how others see them)</li> <li>■ Frequent changes in mood</li> </ul>	<ul style="list-style-type: none"> <li>■ Creates their body image</li> <li>■ Thinks a lot about impractical or impossible dreams</li> <li>■ Feels very powerful</li> <li>■ Experiments with sex, drugs, friends, risks</li> </ul>	<ul style="list-style-type: none"> <li>■ Plans and follows long-term goals</li> <li>■ Usually comfortable with own body image</li> <li>■ Understands right from wrong (morally and ethically)</li> </ul>
<b>FAMILY</b>	<ul style="list-style-type: none"> <li>■ Struggles with rules about independence/dependence</li> <li>■ Argues and is disobedient</li> </ul>	<ul style="list-style-type: none"> <li>■ Argues with people in authority</li> </ul>	<ul style="list-style-type: none"> <li>■ Moving from a child-parent/guardian relationship to a more equal adult-adult relationship</li> </ul>
<b>PEER GROUP</b>	<ul style="list-style-type: none"> <li>■ Important for their development</li> <li>■ Intense friendships with same sex</li> <li>■ Contact with opposite sex in groups</li> </ul>	<ul style="list-style-type: none"> <li>■ Strong peer friendships</li> <li>■ Peer group most important and determines behaviour</li> </ul>	<ul style="list-style-type: none"> <li>■ Decisions/values less influenced by peers in favour of individual friendships</li> <li>■ Selection of partner based on individual choice rather than what others think</li> </ul>
<b>SEXUALITY</b>	<ul style="list-style-type: none"> <li>■ Self-exploration and evaluation</li> <li>■ Preoccupation with romantic fantasy</li> </ul>	<ul style="list-style-type: none"> <li>■ Forms stable relationships</li> <li>■ Tests how he/she can attract opposite sex</li> <li>■ Sexual drives emerging</li> </ul>	<ul style="list-style-type: none"> <li>■ Mutual and balanced sexual relations</li> <li>■ Plans for the future</li> <li>■ More able to manage close and long-term sexual relationships</li> </ul>

Adapted from the Orientation Programme on Adolescent Health for Health-care Providers, WHO, 2003 (Handout for Module B, the Meaning of Adolescence)

These age groups roughly correspond with stages in physical, social and psychological development in the transition from childhood to adulthood. The stages provide a basic framework to understand adolescent development.

The first stage, early adolescence, is characterized by separation from family and identification with a peer group. Patterns of healthy behaviour are best established at this time, before health-risk behaviours develop.

The second and third (middle and late) stages of adolescence involve moving towards social and economic independence, including exploring livelihood options and secondary education. Staying in school past the primary years involves challenges for those adolescents who must pay fees or help support a family.

### **2.1.2 Brain development during adolescence**

Brain development continues in the prefrontal cortex during adolescence and well into early adulthood. This area of the brain contributes to developing social and problem solving skills, regulating emotions and moderating moods.

This is why adolescence is an important time to learn life skills. Life skills complement this phase of brain development, and can help adolescents to deal with the emotional changes and other challenges that they are experiencing and help in the transition to adulthood.

### **2.1.3 Tanner scale (see Annex 2)**

The Tanner scale is another method of assessing an adolescent's phase of development. This scale uses physical measurements of development based on external primary and secondary sexual characteristics.

The Tanner scale should not be confused with WHO Clinical Staging, which is used to determine if a person needs to receive antiretroviral therapy (ART).

## KEY POINTS OF SECTION 2

- 1. WHO defines adolescents as individuals who are 10–19 years old.**
- 2. Adolescence is a period in which an individual undergoes tremendous physical, psychological and emotional changes. There is rapid growth and development of the body and brain, causing physical changes and changes in thinking, problem solving and social skills and relationships.**
- 3. It is important for health workers to understand these changes because they influence how adolescents behave and respond to information that they are given.**
- 4. By remembering our own experiences of adolescence, we may be able to understand better the challenges facing adolescents.**
- 5. The experiences of adolescents today are different from those faced by adolescents 10–20 years ago.**

## Notes

[illegible]

# 3

## Section 3:

# Adolescence – a unique stage in life

### LEARNING OBJECTIVES

- to examine ways in which adolescents differ from children and adults, and explore the implications of these differences for providing adolescents with HIV prevention, care, treatment and support;
- to recognize how adolescents differ from each other;
- to identify difficult situations that health workers can encounter when providing services to adolescents living with HIV.

## 3.1 Characteristics of adolescence and implications for HIV prevention, care, treatment and support

There are characteristics of adolescence that distinguish this stage of life from both childhood and adulthood. These characteristics can have an affect, both positive and negative, on prevention, care, treatment and support for an adolescent living with HIV. The following are some examples of such characteristics; however, they are generalizations and may not be applicable to all adolescents.

- **Energetic, open or inquisitive**

Implications: interested in information on HIV, open to changes to reduce risks, however also inquisitive about having sex and other new experiences (e.g. substance use).

- **Unruly, inattentive or disobedient**

Implications: misses appointments, problems with adherence to care and ART, not attentive to their general health.

- **Desiring independence**

Implications: takes responsibility, challenges authority, participates in care agreement, active in self-care, will not listen to health worker.

- **Influenced by friends more than family**

Implications: peer group can be an important source of HIV care and support (importance and advantages of a well informed peer group).

- **Embarrassed to talk with an adult about personal issues and sexuality**

Implications: adolescent may appear inattentive or rude; health workers need training to understand how best to approach and communicate with adolescents.

## 3.2 Adolescents differ from each other

It is important to remember that not all adolescents are same, i.e. they are not a homogeneous group. In providing care, health workers need to understand the situation of each individual adolescent. Their situations will vary depending on factors such as their age, sex, stage of development, life circumstances and socioeconomic conditions.

Adolescents may have social and sexual interactions with a range of subgroups, and adolescent girls in particular may be linked with older partners of unknown HIV status. Adolescence is also a period of experimentation, for example drug use. Health workers can provide better care when they are able

to complete a full history with the adolescent, including a psychosocial assessment (see for example HEADS in the *Adolescent job aid*)

The following examples of differences between adolescents highlight some of the implications for health workers in terms of providing support and care.

### **Differences among adolescents and some implications for health workers**

- **Age:** minor (e.g. parental/guardian consent may be needed to provide treatment, issues of confidentiality), younger or older adolescent (sexually active or not, the need for age-appropriate prevention information)
- **Stage of development and maturity:** physical and cognitive growth (e.g. whether sexually active, in need of psychosocial and family support, importance of peer group, ability to understand information, understanding consequences of actions, adherence to medication)
- **Gender differences:** different social and cultural influences on boys and girls that affect how they view themselves and relate to others (e.g. sexuality, contraception, condom use, social acceptance of /tolerance for being sexually active, attitudes to same sex preference)
- **Married/unmarried:** (e.g. potential for couple counselling, fertility regulation, consent of partner, other sexual partners)
- **Home situation:** living alone, living with parents/guardians, living on the street, orphan, in school or out of school (e.g. availability of support and care networks, quality and availability of peer support, access to information and services)
- **Education level:** (e.g. literacy level, how to explain health issues, future prospects).
- **Level of information and understanding of risk factors:** for sexually transmitted infections (STIs), HIV, injecting drug use (e.g. able to understand risks of behaviour, knowledge and attitudes of peers)
- **Disposable income:** (e.g. whether the adolescent has money for health care, basic needs and transport costs for accessing health services)
- **HIV transmission pattern:** acquired HIV perinatally or as an adolescent (e.g. how long they have known (or suspected) that they are HIV-positive, implications for mother, clinical status, timing for entering care, new diagnosis, health-risk behaviours)
- **Who else knows they are HIV-positive:** can they control issues of disclosure and confidentiality (e.g. support network, prevention, coping with stigma)
- **Health and stage of HIV disease:** (e.g. asymptomatic or symptomatic, opportunistic infections, needing treatment)
- **Personal and family experience of stigma and discrimination:** (disclosure, support, fear)

Although all people are different, adolescents particularly differ from each other because this is a time of rapid change, and the factors that give rise to this change or the manifestations of the change differ among adolescents. The differences may be physical, psychological (cognitive and emotional) or social.

Health workers need to understand these differences and take them into consideration when caring for adolescents.

### **3.3 Adolescents and sexual behaviour**

Health workers should not presume that adolescents are or are not sexually active. However, they need to recognize that adolescents may already be sexually active. Statistics on adolescent pregnancy and STI rates confirm that many adolescents are sexually active.

For the vast majority of adolescents, sexual activity begins during adolescence. Adolescence includes a wide age range (10–19 years) and during this time many significant developmental and behavioural changes occur. These changes happen at different ages for different adolescents. The particular age at which an adolescent becomes sexually active depends on many individual, social and cultural factors. This means that discussions on sexual behaviour that are appropriate for older adolescents may well be inappropriate for younger adolescents. The implications of this are that the health worker may need to counsel adolescents aged 10–14 years on abstinence and counsel 17-year-olds on safer sex, for example.

Adolescents need to know that abstinence is the safest way to avoid acquiring or transmitting HIV. They need encouragement and support to delay sexual activity until they are physically and emotionally ready. When they are sexually active, they need appropriate information on safer sex (i.e. condom use) so they can protect themselves and their partners. The Joint United Nations Programme on HIV/AIDS (UNAIDS) has reported that when adolescents are provided with correct information on sex, the information does not encourage them to become sexually active, but instead it may help them make better choices about how and when to become sexually active.

Abstinence may not be possible or acceptable to all adolescents. Adolescents may be forced or coerced into being sexually active, or may be curious about sex and choose to become sexually active earlier than their peers. Some adolescents may change their sexual partners frequently while others may remain with one partner for a long time. As with all people, patterns of sexual activity vary among adolescents, even adolescents within the same peer group. This course encourages health workers to be aware of this and to remain

non-judgemental about the sexual choices or preferences that adolescents make.

During this course, the different issues concerning sexuality for two groups of adolescents living with HIV (those who acquired HIV perinatally and those who acquired HIV during adolescence) will be discussed. Adolescents who acquired HIV perinatally are likely to be younger and may never have been sexually active, while those who acquired HIV during adolescence are probably already sexually active. Each group will have their own concerns and questions.

During discussions with adolescents before or during this course it may be possible to identify culturally acceptable ways for adolescents to find sexual pleasure without the risk of acquiring or transmitting HIV. Health workers could use this information to counsel adolescents and inform adolescent peer counsellors.

### **KEY POINTS OF SECTION 3**

- 1. Adolescents living with HIV differ from adults and children living with HIV because of the rapid changes that occur during this stage of development.**
- 2. Adolescents also differ from each other. Adolescents of the same age may differ in their physical, psychological (thinking patterns and emotions) or social development.**
- 3. There are many developmental differences between a younger adolescent of 10 years and an older adolescent of 18 years, which have implications for their needs and capacities.**
- 4. Health workers need to understand these differences and take them into consideration in the prevention, care, treatment and support of an adolescent living with HIV.**
- 5. Adolescents may behave in ways that health workers can find challenging. Knowing the changes that occur during adolescence can help health workers deal with difficult situations and understand adolescent behaviour in the context of the individual's phase of development.**

# 4

## Section 4:

# Adolescents living with HIV and health services

### LEARNING OBJECTIVES

- to discuss the different needs of the two groups of adolescents living with HIV;
- to discuss how adolescents living with HIV first come to health services and what may prevent or encourage their return.

Adolescents are at the centre of the HIV pandemic in terms of transmission, impact, and the potential for changing the attitudes and behaviours that underlie the disease.

## Young people in the 15–24 years age group living with HIV

(data for 10–14 year olds are not available)

	FEMALE	MALE	TOTAL
REGION			
EAST ASIA AND PACIFIC	110,000	450,000	570,000
EASTERN EUROPE AND CENTRAL ASIA	100,000	240,000	340,000
NORTH AFRICA MIDDLE EAST (inc. SUDAN)	47,000	35,000	81,000
SUB-SAHARAN AFRICA	2,500,000	780,000	3,200,000
LATIN AMERICA AND CARIBBEAN	140,000	280,000	420,000
SOUTH ASIA	270,000	440,000	710,000
TOTALS	3,100,000	2,200,000	5,400,000

Source: UNAIDS, AIDS Epidemic Update, 2007

Sub-Saharan Africa has 3.2 million young people infected with HIV. Most of these young people have been infected through heterosexual transmission.

Adolescents are vulnerable to HIV for many reasons, including a lack of access to HIV information and prevention services. Differences in infection levels between men and women are most obvious among young people – young women in some countries are more than three times as likely to be infected as young men of the same age.

Many adolescents do not believe that HIV is a threat to them, and many do not know how to protect themselves from HIV, or are unable to protect themselves due to forced sex.

It is estimated that only 16% of young people living with HIV know their serostatus, which means that the vast majority of young people who are HIV-positive do not know that they are infected. Few young people who are engaging in sex know the HIV status of their partners.

Asymptomatic adolescents living with HIV are indistinguishable from their peers. They behave similarly and are affected by the same social and cultural forces as their HIV-negative peers. They may engage in safer-sex behaviours or high-risk behaviours, as do HIV-negative adolescents.

Adolescents living with HIV are found in all sectors of society – they may live with their families or on the streets, go to work or school, be sex workers or inject drugs. They may have been tested and know their status, they may suspect that they are HIV-positive and not yet have confirmed their fears with a test, or they may be living with HIV and be completely unaware that they have acquired the virus.

To support individuals living with HIV and prevent further transmission, HIV programmes must focus on offering HIV testing to adolescents; identify adolescents who are already HIV-positive, help them access the services that will keep them healthy, and teach them the skills that will protect them and their partners. Testing can also identify adolescents who are HIV-negative and link them with prevention programmes in order to help them stay negative.

## **4.1 Adolescents and vulnerability to HIV**

Vulnerability to HIV is a measure of an individual's or a community's ability to control their risk of HIV infection. The concept of vulnerability recognizes that there are many factors other than individual choices that influence whether or not someone engages in behaviours that put them at risk of acquiring HIV.

Vulnerability increases the likelihood of negative health outcomes. There are social and contextual factors that make young people more vulnerable to HIV infection. These factors include: age and sex, social and cultural norms and value systems about sex, location (where the adolescent lives, learns and earns), economic and educational status, and sexual orientation.

Adolescents who are particularly vulnerable include those who are migrants and refugees, prisoners, in war situations, or who are socially marginalized and discriminated against. HIV itself also increases vulnerability, for example children orphaned by AIDS (many of whom are adolescents) are particularly vulnerable to HIV if they have to resort to sex work to survive.

The following issues affect an adolescent's vulnerability to HIV.

### **4.1.1 Lack of information about HIV**

Many adolescents do not know the seriousness of HIV, and do not know how it is acquired or what they can do to protect themselves. Many adolescents do not go to school, and do not have access either to information about HIV, or to opportunities to develop the life skills necessary to turn information into action. Frequently they also do not have access to information materials or services that take their specific needs into consideration.

### **4.1.2 Sex work**

UNAIDS estimates that approximately one million youth worldwide become sex workers each year. In many countries, there are out-of-school youth who are often socially marginalized and exist on the fringes of society, and who are more likely to use psychoactive substances or be forced into commercial sex.

### **4.1.3 Gender**

Gender differences in society have a big impact on adolescents' patterns of behaviour. Gender refers to the socially constructed roles, behaviours, activities and attributes that a society considers appropriate for men and women. Gender norms reflect the society's idea about "being" male or female. These are established early in life and depend on cultural and social attitudes, expectations and behaviours. How a society encourages or accepts certain attitudes and behaviours from men/boys and women/girls, may put them at risk of HIV.

### **4.1.4 Orphans**

There are many adolescents living with HIV who have the added burden of being orphans. Adolescent orphans require different kinds of assistance than

orphans who are still small children; in some ways their needs are more complex than the needs of younger orphans because of the physical and psychological development that takes place during puberty, and the steps that they need to take to move towards independence and adulthood. They also often have more demands placed on them to become household caretakers or income earners.

### **4.1.5 Homelessness**

It is generally not known how many adolescents who are living on the street are also living with HIV. Studies show that a high proportion are at risk of acquiring HIV, because of injecting drug use or unsafe sex, and that adolescents who have acquired HIV perinatally are at increased risk of becoming homeless. The United Nations estimates that there are more than 150 million street children worldwide. Approximately 40% are homeless, either orphaned or abandoned by their families. These young people are at risk for early and unsafe sex, violence and gang activities. Studies show that young people who are homeless are more likely to report a history of sexual abuse.

### **4.1.6 Not in school and school drop-outs**

Adolescents not in school and those who drop out prematurely miss crucial educational opportunities. Literacy is one of the keys to making healthy choices. If young people do not have the skills necessary to read an HIV information booklet, they are at a significant disadvantage.

### **4.1.7 Adolescent girls and older sexual partners**

A significant age difference between an adolescent girl and her sexual partner is strongly associated with unprotected sexual activity. Older partners bring a sense of importance to young women, particularly those whose self-esteem may be low because of poor school performance or lack of family support. Older partners can provide monetary resources that same-age partners cannot match, which may be considered to be important in a “consumer society”. Older partners also introduce a power imbalance in the relationship that may ultimately slow down the young woman’s psychosocial development, introduce her to alcohol and drug-use networks, or expose her to unwanted pregnancy and STIs.

### **4.1.8 Men who have sex with men**

In many places, young men who are having sex with men or boys will not want to be known to the health (or any other) services. The discrimination and

homophobia, which exists in many societies, can produce a disabling fear of disclosure about same sex relationships. This fear may result in sexual encounters at venues for anonymous social and sexual networking, which can remove the sense of personal responsibility. Young boys may have older sexual partners who bring a sense of importance to young men whose self-esteem may be low and who may be lacking family and peer support, similar to the relationship dynamics in young women noted above, and with similar consequences.

### **4.1.9 Adolescents and sexual abuse**

Childhood sexual abuse has been strongly associated with numerous disturbing behavioural and psychological outcomes in adolescents and adults. These include domestic violence, adolescent pregnancy, child abuse, drug and alcohol abuse, bulimia, STIs, depression, prostitution, self-mutilation, running away from home and dropping out of school. A history of sexual abuse, physical abuse or domestic abuse is associated with engaging in risk behaviours for HIV. Childhood sexual abuse is significantly associated with injecting drugs use; exchange of sex for drugs, money or shelter; higher number of sexual partners; and having had a sexual relationship with a person at high risk for HIV.

### **4.1.10 Stigma**

The stigma associated with HIV is particularly hard for adolescents, as they are unlikely to have the maturity or experience of adults to cope with the day-to-day challenges of dealing with discrimination. In addition, during adolescence, acceptance by the peer group is very important. HIV can set individuals apart, and the stigma of HIV can therefore affect the social and emotional development of adolescents. Peer support from other young people living with HIV, through groups and informal connections, can provide a vital source of information and support for the normal and healthy psychosocial development of adolescents living with HIV.

### **4.1.11 Adolescents and human rights**

The right to health and development for adolescents needs to be fulfilled and protected for them to take the risks that are important and normal for their development but avoid those that will do them irreparable harm. This includes their rights to information and life skills, to access health services, to a safe and supportive environment, and to participate in decisions that affect their lives. Frequently, these human rights are not fulfilled. HIV flourishes where human rights are not protected.

## 4.2 HIV transmission periods: Perinatal or adolescence

Essentially, there are two specific groups of adolescents living with HIV:

- **adolescents who acquired HIV perinatally**, during pregnancy, labour and delivery, or postpartum through breastfeeding;
- **adolescents who acquired HIV during adolescence**, usually through unprotected sexual intercourse or injecting drug use, or less frequently through blood transfusion or sharing instruments used for tattooing or skin piercing.

### 4.2.1 Adolescents who acquired HIV perinatally

According to estimates by UNAIDS and WHO, more than four million children under the age of 15 years have acquired HIV since the epidemic began. More than 90% of them were infants born to HIV-positive mothers, who acquired the virus before or during birth, or through breastfeeding. Without treatment, HIV infection in children usually quickly progresses to AIDS. Before treatment was available, most HIV-positive children did not survive into adolescence.

However, there are now a growing number of adolescents living with HIV, particularly in countries where a paediatric service infrastructure exists and ART has been provided. Many of these adolescents will be living with extended families, but some will have to survive without support, living on the streets surrounded by added risks and challenges. These adolescents are often marginalized and discriminated against, and are especially vulnerable to many health and social problems. In addition, their HIV infection may have caused delayed growth and development, resulting in them looking different from their peers (at a time in their lives when they want and need peer acceptance).

### 4.2.2 Adolescents who acquired HIV during adolescence

Worldwide, sexual transmission (penetrative sex without a condom) is the predominant transmission route for young people acquiring HIV infection. In some regions, injecting drug use is also a major transmission route for young people, because sharing injecting equipment carries a high risk of transmitting HIV.

Some young people are particularly vulnerable to HIV, as discussed in Section 4.1. But young people who have unprotected sexual intercourse (vaginal or anal), particularly those who have multiple concurrent partners, and those who inject drugs using shared needles and syringes, are most at risk of HIV.

In countries where the predominant mode of transmission is by heterosexual sex, girls are more likely to be infected than boys, for both biological and social reasons. Conversely, in countries where the predominant transmission route is men having sex with men or injecting drug use, boys are more likely to be infected with HIV.

### 4.2.3 Differences between two groups of adolescents living with HIV based on the transmission period (perinatal or adolescence)

PERIOD WHEN ACQUIRED HIV		
Differences relating to:	PERINATAL	ADOLESCENCE
AGE	■ Younger: early adolescence	■ Older: usually over 15 years
PHYSICAL DEVELOPMENT	■ Delayed: shorter stature	■ Normal development
SEXUAL AND REPRODUCTIVE HEALTH	<ul style="list-style-type: none"> <li>■ Not yet sexually active</li> <li>■ Thinking about sex</li> <li>■ Sexual debut</li> </ul>	<ul style="list-style-type: none"> <li>■ Sexually active</li> <li>■ Need to change risk behaviour(s)</li> <li>■ Wanting children</li> </ul>
RELATIONSHIPS/MARRIED	<ul style="list-style-type: none"> <li>■ No/maybe</li> <li>■ Wanting intimate relationship</li> </ul>	<ul style="list-style-type: none"> <li>■ Probably in sexual relationship</li> <li>■ May want marriage</li> </ul>
DISCLOSURE	<ul style="list-style-type: none"> <li>■ To adolescent, if he/she does not yet know the diagnosis</li> <li>■ Peers</li> </ul>	<ul style="list-style-type: none"> <li>■ New diagnosis</li> <li>■ Disclosure to partner, family, peers</li> <li>■ Asymptomatic, which can reinforce denial</li> </ul>
FAMILY SUPPORT	<ul style="list-style-type: none"> <li>■ Orphan</li> <li>■ Living with caregivers</li> </ul>	<ul style="list-style-type: none"> <li>■ Support depends on disclosure</li> <li>■ Few resources (such as money, information, experience)</li> </ul>
ANTIRETROVIRAL THERAPY	<ul style="list-style-type: none"> <li>■ Yes</li> <li>■ Adherence may be a problem as an adolescent, not as a child</li> </ul>	<ul style="list-style-type: none"> <li>■ Probably not yet needed</li> <li>■ When taking ART: adherence may be a problem</li> </ul>
STIGMA/“BLAME” FOR HIV	■ Less likely	■ More likely

**Note:** The purpose of this table is to highlight some of the most common differences between the two transmission groups. These are generalizations and may not refer to all adolescents.

## 4.3 Adolescents living with HIV seeking health services

It is anticipated that in the future there will be an increase in the number of adolescents living with HIV attending health centres. It is important to plan for this.

**This can be attributed to four factors:**

1. With successful ART and care, more children with perinatally acquired HIV are surviving into adolescence.
2. More adolescents are being tested for HIV, as a result of factors such as: provider initiated testing, increased awareness, more testing being available, and increasing availability of antiretrovirals (ARVs) providing a reason to be tested.
3. More adolescents who are pregnant are being tested, as services for preventing mother to child transmission (PMTCT) become more widely available.
4. As the stigma of living with HIV lessens and the understanding of HIV increases, more adolescents will come for testing, treatment and care.

In general, people make contact with health services because they feel unwell. Many adolescents living with HIV are in WHO Clinical Stage 1 or 2 and may not yet feel unwell or need treatment, and therefore have no reason to visit the health centre. However, it is important that asymptomatic adolescents living with HIV attend health services, so that they can receive care and support, as well as prevention and treatment education.

The HIV transmission pattern can determine how and when an adolescent comes into contact with health services, and is likely to influence their feelings when they visit health services. Adolescents who acquired HIV perinatally may have been referred from paediatric or adolescent services to adult services. In this case, they may be familiar with health services and have known their diagnosis for many years. Alternatively, they may not have come into contact with any health services since childhood as they had remained asymptomatic and only recently learnt of their HIV diagnosis. For those who acquired HIV during adolescence, there are likely to be differences between those who acquired the virus through sexual transmission compared with those who acquired it through injecting drug use.

There are factors specific to the adolescent, the health worker and the health services that influence whether an adolescent living with HIV visits health services. There are also factors that relate specifically to the stigma associated with HIV.

When health workers are aware of the circumstances of adolescents, they can offer care and support that is appropriate to their needs. Health workers should encourage adolescents to include their family members, guardians and friends in their care and support.

Health workers can identify barriers in the existing health services that prevent or discourage adolescents living with HIV from making contact with the services. They can then work towards making the services more available and accessible to adolescents, so that adolescents will want to return once the initial contact is made.

Adolescents living with HIV need support from their peers to help them cope with their diagnosis and to offer practical and appropriate help about living with HIV. Health workers can assist in the training and supervision of peer support workers, and in providing professional backup for peer support workers and peer support groups in the event of situations arising beyond their competency. Peer support workers must be understood to be an extension of the health team and never viewed as a substitute for it.

School-based peer support can offer additional support for adolescents still enrolled in schools, and community groups interacting with young people can provide support for young people living on the streets. Youth drop-in centres, often organized by young people themselves, are an excellent support network for both HIV-positive young people and those most-at-risk of HIV.

## **4.4 Adolescents newly diagnosed with HIV**

When faced with a new HIV diagnosis, young people, like adults, frequently enter into a period of denial, made easier by the asymptomatic nature of early HIV infection. Denial stops them from seeking health services, thus preventing them from obtaining the care and support they need. It may also allow them to continue behaviours that put them and others at risk. Helping adolescents living with HIV to understand their individual situation, and their role in accepting personal responsibility for stopping continued transmission, is critical to stop the cycle of infection.

Because of their stage of development, young people need support to process the meaning of HIV infection in their lives. Ensuring that this support is available immediately after they receive an HIV-positive diagnosis is a critically important part of providing adolescent HIV services. This support can be provided through individual or group support involving peers, although in many places peer support may not exist. Health workers should actively encourage and support young people, schools and communities to develop local peer support groups for adolescents living with HIV.

## 4.5 Adolescent-friendly health services

Adolescent-friendly health services (AFHS) aim to ensure that existing health services are able to respond effectively to the specific needs of adolescents, given the reality of the available health resources and infrastructure. AFHS aim to be accessible, acceptable and appropriate for adolescents. They need to be in the right place at the right time at the right price (free where necessary) and delivered in a style acceptable to adolescents.

They should be equitable by ensuring that they are inclusive and do not discriminate against any group of adolescents living with HIV in terms of sex, ethnicity, religion, disability, social status or for any other reason. They should reach out to those who are most vulnerable and those who lack services. The services need to be comprehensive, delivering an essential package including, where appropriate, prevention, care, treatment and support for adolescents living with HIV.

AFHS are more likely to be effective if they are delivered by trained and motivated health workers who are technically competent and who know how to communicate with adolescents without being patronizing or judgemental. These providers need to be backed up by adolescent-friendly support staff and have access to the necessary equipment and supplies. They should also maintain a system of quality improvement so that staff are supported and motivated to maintain defined standards of care. Finally, the services should record sufficient age-disaggregated information to be able to monitor and improve performance.

The gold standard for AFHS is that they are effective, safe and affordable, and they meet the individual needs of adolescents so that they will return when they need to and recommend the services to friends. However, making services adolescent-friendly is not primarily about setting up separate dedicated services. The greatest benefit comes from improving the existing health services in local communities, and the competencies of all health workers to deal effectively with adolescents.

The characteristics of AFHS were discussed during a global consultation initiated by WHO in 2000, which were continued and built on by the Expert Group convened by WHO in Geneva in 2001. These characteristics are intended for application in each country, taking into consideration the cultural, social, economic and political context and the available resources.

## Characteristics of adolescent-friendly health services

**Adolescent-friendly policies** fulfil the rights of adolescents, take into account the special needs of different sections of the adolescent population, give adequate attention to gender issues, guarantee privacy and confidentiality, and make provision for services to be free or affordable.

**Adolescent-friendly procedures** ensure privacy and confidentiality, short waiting times and consultations with or without an appointment.

**Adolescent-friendly health workers** are trained and supervised to provide services to adolescents.

**Adolescent-friendly support staff** are understanding and considerate, treating clients with respect, and are competent, motivated and well supported.

**Adolescent-friendly health facilities** provide a safe environment at a convenient location with an appealing ambience, and provide information in the community to generate demand and community support.

**Adolescent involvement** means that adolescents are well informed about services and rights, and involved in service assessment and provision.

**Community involvement and dialogue** promotes the value of health services and encourages parental and community support.

**Community based, outreach and peer-to-peer services** increase coverage and accessibility.

**Appropriate and comprehensive services** address each adolescent's physical, social and psychological health, and development needs and provide a comprehensive package of health care and referral.

**Effective health services for adolescents** are guided by evidence-based protocols and guidelines.

**Efficient services** which have and use a management information system, including information on the costs of resources.

*Adapted from the Orientation Programme on Adolescent Health for Health-care Providers (WHO 2003), Module D. Adolescent-Friendly Health Services*

## 4.6 Characteristics of the health worker in AFHS

While all these characteristics of AFHS are important, the most critical component of a health-care delivery system that is responsive to the needs of adolescents is the characteristics of the staff. Adolescents report that they look for staff who are able to combine technical skills with a sympathetic professional approach that demonstrates respect, patience and non-judgemental attitudes. It is essential that health workers who provide care for adolescents must like adolescents. There is no substitute for this basic quality. Professional staff who respect and genuinely like young people will make the effort to bridge differences in race, culture and class, and develop competence in fully appreciating the unique challenges facing adolescents.

Health workers do not need to abandon their own belief systems or values when faced with an adolescent whose behaviour they find challenging. However, they do need to understand a situation from an adolescent's point of view and not allow their own views or values to dominate the interaction and advice.

### **Adolescents need health workers who:**

- are technically competent in adolescent-specific areas, and offer health promotion, prevention, treatment and care relevant to each client's maturation and social circumstances;
- have good interpersonal and communication skills;
- are well motivated and supported;
- are non-judgemental and considerate, easy to relate to and trustworthy, as well as devote adequate time to clients or patients;
- act in the best interests of their clients, and respect confidentiality;
- treat all clients with equal care and respect;
- provide information and support to enable each adolescent to make the best choices for his/her specific needs.

## KEY POINTS OF SECTION 4

- 1. Based on the transmission period, there are essentially two main groups of adolescents living with HIV:**
  - adolescents who acquired HIV perinatally
  - adolescents who acquired HIV as adolescents.
- 2. There are differences between these two groups that determine how and when an adolescent first visits the health services, and their feelings and needs.**
- 3. Factors related to the health worker or the health services may encourage or discourage adolescents from returning. It is important to consider how to encourage adolescents living with HIV to return to the health centre for treatment, care and support.**
- 4. Peer support at the clinic is important for adolescents living with HIV. Peers have experience in coping with HIV and can offer practical and appropriate help on how to live positively.**

## Notes

[illegible]

# 5

## Section 5:

# Introduction to using the *Adolescent job aid*

### LEARNING OBJECTIVES

- to provide an overview of the *Adolescent job aid*
- to outline the section of the *Adolescent job aid* that focuses on HIV.

## **Overview of the *Adolescent job aid* and its use in providing services to adolescents living with HIV**

WHO has developed the *Adolescent job aid*, which is a user-friendly desktop reference for health workers. It can be used to assist health workers in dealing with questions that adolescents or their accompanying adult frequently ask. The responses to these questions are presented as algorithms that the health worker can follow when dealing with an adolescent client.

In Annex 4 of this Manual there are selected excerpts from the *Adolescent job aid*, including the algorithm “Do I have HIV?”. In addition to this algorithm, in Annex 4 there is also a copy of the table of contents, which provides an overview of the *Adolescent job aid*, and an excerpt from Part 1 of the *Adolescent job aid* which provides guidance on obtaining information from adolescents in order to be able to respond effectively to their problems (HEADS).

### **KEY POINTS OF SECTION 5**

#### ***The Adolescent job aid:***

- **is a handy desk reference to enable health workers to respond to their adolescent patients more effectively and sensitively;**
- **has a section dealing specifically with the question “Could I have HIV” and also includes a number of sections dealing with sexual and reproductive health issues, in general;**
- **provides health workers with tips about taking a history and examining an adolescent patient;**
- **includes information that should be provided to adolescents and their accompanying adult.**

# 6

## Section 6: \_\_\_\_\_

# Communicating with adolescents

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### LEARNING OBJECTIVES

- to review basic counselling skills and discuss the special counselling needs of adolescent patients;
- to identify important points for successfully communicating with adolescents.

Good communication is a core component of counselling. The health worker's attitudes towards adolescents in general and their manner of communicating with them are crucial. Participants should consider their reactions and responses to questions 6 and 7 in the spot checks to help them assess their attitudes towards adolescents, particularly those living with HIV. Participants should identify any attitudes that they may have that can create barriers and prevent good communication with adolescents.

Part of the normal adolescent development is “breaking loose” from adults in general, and parents in particular. This need for separation and independence may interfere with the relationship and good communication between the health worker and the adolescent, especially if the health worker treats the adolescent in a manner that reminds the adolescent of a dominating parent.

As children enter adolescence, their parents are still largely responsible for all aspects of their health, and the main communication is often between the health worker and the parent or guardian. By the end of adolescence, health issues will be almost entirely the responsibility of the adolescent. The challenge for the health worker is to maintain an effective and consistent clinical relationship, when the primary responsibility for issues such as adherence shifts from the parents to the adolescent. It may be important to meet adolescents alone, as well as with their parents or guardian.

Health workers need to consider how they will communicate with accompanying adults in a manner that is respectful both to the rights of the adolescent and to their parent or other caregiver. Do not exclude parents/caregivers, but make it clear that the adolescent is the centre of the consultation. Do this routinely as a way of respecting the adolescent's rights and maintaining their trust.

Each situation needs to be managed and assessed individually in light of the circumstances and the legal situation in the country. Practical guidelines should be made available to health workers, which provide information about national policies and legislation relating to the provision of services to adolescents, including issues of consent.

The following points can remind health workers of good practices and how to communicate respectfully with adolescent clients. Many of these points apply to successfully communicating with any patient, but some are especially important when communicating with an adolescent patient.

## 6.1 What to *do* and what to *avoid* when communicating with adolescents

DO	AVOID
■ Be <b>truthful</b> about what you know and what you do not know	■ Giving inaccurate information (to scare them or to make them “behave”)
■ Be <b>professional</b> and technically competent	■ Threatening to break confidentiality “for their own good”
■ Use words and concepts which they can understand and relate to. Assess if they <b>understand</b>	■ Giving them only the information that <i>you</i> think they will understand
■ Use pictures and flipcharts to explain	■ Using medical terms they will not understand
■ Treat them with <b>respect</b> in terms of how you speak and how you act	■ Talking down to them, shouting, getting angry, or blaming them
■ Give all the information/choices and then help <b>them decide</b> what to do	■ Telling them what to do because you know best and they “are young”
■ Treat all adolescents <b>equally</b>	■ Being judgemental about their behaviour, showing disapproval, or imposing your own values
■ Be understanding and supportive even if you do not approve of their behaviour	
■ <b>Accept</b> that they may choose to show their individuality in dress or language	■ Being critical of their appearance or behaviour, unless it relates to their health or well-being

### Life skills

An important part of normal adolescent development is learning life skills. Life skills include problem solving, critical thinking, communication, interpersonal skills, resolving conflict and coping with emotions.

Health workers cannot teach adolescents the full range of life skills as they neither have the time nor the capacity to do this. But, they should know where life skills are taught in the community, so that they can refer adolescents living with HIV to them and support the programmes. However teaching adolescents life skills that relate to specific health issues (e.g. how to delay sexual debut, how to negotiate safe sex, and how to use a male and female condom correctly) is part of the health worker’s responsibility. Such skills help adolescents deal with the difficult challenges of being an adolescent and living with HIV.

Basic counselling skills can be found in the IMAI Acute care guideline module in the section “Advise and Counsel”.

Everyone is entitled to have opinions on the range of issues that are raised by HIV, including sexual activity and substance use. However, it is important for health workers to explore their own attitudes and values in order to identify those that may be a barrier to providing care and support to adolescents living with HIV.

Workshop participants may have reflections from this session for their future work, which can be written here.

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## KEY POINTS OF SECTION 6

- 1. Good communication is an essential component of counselling.**
- 2. Health workers may need to examine their attitudes, values and manner of communicating to work successfully with adolescents. As with all people, adolescents need to be treated with respect so that they act on the information given to them.**
- 3. Adolescents may find that their peers are better able to give them support and offer practical and appropriate advice on living with HIV. Health workers should assist in the training of peer educators, and help peer educators to start support groups for adolescents living with HIV.**

# 7

## Section 7:

# Prevention and support for adolescents living with HIV

### LEARNING OBJECTIVES

- to identify the questions and discuss issues that are important for adolescents living with HIV;
- to identify the prevention priorities and support that health workers can provide to adolescents living with HIV.

## 7.1 Special challenges in providing prevention, care, treatment and support for adolescents living with HIV

### SPECIAL CHALLENGES IN PROVIDING PREVENTION, CARE, TREATMENT AND SUPPORT FOR ADOLESCENTS LIVING WITH HIV

CHALLENGES	Adolescents who acquired HIV perinatally (often younger age: early adolescence)	Adolescents who acquired HIV during adolescence (usually older age: 15 plus years)
<b>BENEFICIAL DISCLOSURE</b>	<ul style="list-style-type: none"> <li>■ If not yet discussed, disclosure to adolescent</li> <li>■ Peers</li> </ul>	<ul style="list-style-type: none"> <li>■ Need support to tell chosen family and friends</li> <li>■ Will benefit from others knowing so they can get support</li> <li>■ Fear of stigma/blame</li> </ul>
<b>POSITIVE PREVENTION</b>	<ul style="list-style-type: none"> <li>■ Not yet sexually active</li> <li>■ Preparing for sexual activity</li> <li>■ Wanting sexual relations and pregnancy in the future</li> </ul>	<ul style="list-style-type: none"> <li>■ Already sexually active</li> <li>■ Changes in health risk behaviour(s)</li> <li>■ Wanting marriage and children</li> <li>■ Need life skills, peer support</li> </ul>
<b>CONSENT AND CONFIDENTIALITY</b>	<ul style="list-style-type: none"> <li>■ Living with family/guardian</li> <li>■ No longer a compliant child</li> <li>■ Needs to start taking responsibility for own treatment</li> </ul>	<ul style="list-style-type: none"> <li>■ Legal position on age of consent</li> <li>■ Concern about confidentiality</li> <li>■ Desire for independence and need for support</li> </ul>
<b>DEVELOPMENTAL DELAYS</b>	<ul style="list-style-type: none"> <li>■ Delays in skeletal growth and puberty</li> </ul>	<ul style="list-style-type: none"> <li>■ Normal development</li> </ul>
<b>TRANSITION OF CARE</b>	<ul style="list-style-type: none"> <li>■ Paediatric to adolescent</li> </ul>	<ul style="list-style-type: none"> <li>■ Adolescent to adult</li> </ul>
<b>ART AND ADHERENCE</b>	<ul style="list-style-type: none"> <li>■ Choice of regimens</li> <li>■ Adherence: no longer a child</li> </ul>	<ul style="list-style-type: none"> <li>■ When to begin ART</li> <li>■ Choice of regimen</li> <li>■ Adherence</li> </ul>
<b>LIVING WITH A CHRONIC CONDITION</b>	<ul style="list-style-type: none"> <li>■ May be an orphan</li> <li>■ Acceptance of the condition may change as the adolescent develops</li> </ul>	<ul style="list-style-type: none"> <li>■ New diagnosis</li> <li>■ Depression and anger</li> <li>■ Lack of experience and resources</li> </ul>

## 7.2 Important questions asked by adolescents living with HIV

People who work with young people living with HIV say that the following questions and comments represent common concerns of adolescents living with HIV:

### **(a) “Will anyone want to have sex with me if they know I am HIV-positive?”**

Adolescents need to know that it is possible to enjoy a healthy sexual life while living with HIV.

- For most people, sexual activity begins during adolescence, and in general sex is an important part of the lives of young people. A positive HIV test will not stop an adolescent’s sexual development, so they will need practical information and support to deal with their questions, concerns and fears about being HIV-positive and having or wanting to have sexual relations.
- Fear that they will be rejected as a sexual partner (unless they remain silent about their serostatus) may discourage many adolescents living with HIV from disclosing their status. Health workers can help them explore the benefits of revealing their HIV status to selected people.
- Health workers may find it hard to raise and discuss these sensitive issues. However, they should provide accurate and current information on prevention for positives. Peer counselling and support from other adolescents living with HIV will help adolescents understand their risks, opportunities and options.
- Couple counselling should be encouraged, although an individual’s situation may make this impossible and the counsellor needs to support the client’s decision.
- Promoting consistent and correct use of male and female condoms is an essential part of counselling. The prospect of using condoms all their life can seem an impossible challenge to some adolescents, so it is important that they understand the implications of not using a condom, for themselves and their partners. Condoms are crucial to slowing the HIV epidemic and important as dual protection (i.e. prevention of STIs including HIV and prevention of unplanned pregnancy).

### **(b) “Will I be able to have children?”**

Like all people, adolescents living with HIV have the right to choose for themselves whether they want to have children or not.

To do this they need to have access to sexual and reproductive health information and services, including counselling. This will help them be aware of their reproductive choices and the possible health risks for them and their child. They can then make informed decisions. For this to be possible, sexual and reproductive health services and HIV care services need to be linked.

### **(c) “Will I die soon?”**

Some adolescents may not understand the difference between HIV and AIDS. They may think that a positive test result means they will die soon.

- Health workers should tell them that with earlier detection, effective drug regimes and a healthy lifestyle, it is possible to remain alive and healthy for many years.
- They also need to know that without treatment and good adherence to treatment, they are not likely to live as long as they would with treatment compliance.
- Emotional and spiritual support can help alleviate depression, prevent suicidal ideas and the strong emotions associated with living with a chronic and fatal condition.

### **(d) “I am too young to have a chronic disease. My life isn’t worth living any more.”**

Many adolescents and young people live healthy and productive lives despite being HIV-positive. They need to meet others who are coping well with HIV, so they can understand that it is possible to live positively.

- Learning that you must live with HIV is shocking news at any age. For adolescents it can be hard to imagine how they are going to live their whole lives with a chronic disease, when they feel that they have only just begun to live. All their dreams for relationships, family life and career are overshadowed by the news.
- The health worker plays an important role in providing hope to young people

and in helping them develop the perception that life can continue, and be meaningful, even in the presence of HIV infection.

- Health workers should also provide referral to peer support groups. Adolescents living with HIV often understand each other's situation better than anyone else, and are well placed to educate, counsel and advise one another. Around the world, wherever HIV is present, young people living with HIV have established support and advocacy groups and networks. Health workers have a role in encouraging adolescents to begin, or become part of an existing network. Meaningful involvement with networks and groups can give them support and purpose. Increasingly, members of these groups are called on to participate in policy and decision-making forums.
- Health workers need to assess the mental health of adolescents living with HIV to determine if they are depressed or are considering suicide. They should also assess if adolescents are involved with substance use. If so, the adolescent should be referred to mental health or substance use programmes, where these are available, and followed up carefully in terms of their care and adherence.

**(e) “I am afraid that people will reject me, shun me or be violent towards me.”**

Many of those living with HIV, or affected by HIV, experience stigma and discrimination. Acts of discrimination can range from inappropriate comments to violence. Support groups can help people cope by giving them practical support and personal expertise in dealing with stigma and discrimination.

- Information and education about HIV can help moderate fears and misconceptions in society about the disease, and hopefully lead to less stigma and discrimination.
- In places with high rates of HIV, as more people learn their HIV status, being HIV-positive may become less stigmatizing.
- Adolescents will need support and advice on disclosure and on the implications of this disclosure for their future opportunities. HIV can have an enormous impact on access to education and work opportunities.
- Adolescents living with HIV may experience stigma, discrimination and isolation. They may lose friends because they are HIV-positive. They may also be wary of revealing their status to anyone (e.g. sexual partner, peers, family members, school officials) because of the possibility that disclosure may

ruin their image, or even their relationship, because of the stigma associated with HIV. Although this may be true for anyone, it may be harder for adolescents who may base their self-worth on what other people think of them. Through counselling, they can be made aware of the benefits of disclosing their HIV status to selected people who can support them to live positively.

**(f) “I can’t tell anyone that I am HIV-positive.”**

Many people are fearful of telling family, friends and sexual partners that they are HIV-positive. Friends and family can provide essential support if they know that the adolescent they love is HIV-positive, and if they themselves are adequately informed. If family and friends do not know, they will not understand the physical and emotional changes that they see. There is more information on beneficial disclosure in Section 7.3.

- Adolescents should be encouraged to understand the benefits of revealing their HIV status to family and friends, as they need their support to help them cope with living positively.
- They will also benefit from the support of other young people living with HIV, through peer support and group counselling. However, adolescents will need support to do this, and all concerned must be aware that there may be a risk associated with disclosure of HIV status in unsupportive settings.

**(g) “I am afraid you will tell my parents: will you?”**

This raises issues of consent to treatment and confidentiality with minors, which are discussed in Section 7.5. Health workers should know what they are obliged to do by law, how existing laws and policies are translated into practice and, if necessary, how they can work with the adolescent to help them understand the value of engaging parents and guardians in their long-term care.

**(h) “How was I born with HIV?”**

Adolescents with perinatally acquired HIV may feel anger and resentment towards their mothers and/or fathers, and blame them for transmitting HIV (and to complicate things, the parents may also blame themselves). Health workers can advise parents or guardians that the outcome is likely to be better if these issues are raised and discussed when the child is still young, using plain language and with an absence of blame.

Workshop participants may raise other questions and comments, which can be written here.

[illegible]

### 7.3 Beneficial disclosure

All people living with HIV need support to cope with living positively. Support from family and close friends can be particularly important for adolescents who may lack the maturity, experience or resources to cope with their diagnosis by themselves. They will only be able to access this support if trusted family members and close friends know their HIV status.

Having people who know their HIV status, and who can support them to live positively and help them to cope with their diagnosis, is an essential part of positive prevention. This support is likely to be especially important for adolescents living with HIV.

Counselling can help them understand the benefits of disclosing their HIV status. They may be reluctant to tell anyone, and may need help from health workers to think this through, and to practice, using role play for example, how to tell trusted people who can provide support, and how to deal with negative responses if these arise. They can also benefit from joining peer support groups and sharing experiences with other adolescents who have disclosed to parents and/or friends.

However, health workers need to be aware that there is a risk for adolescents in disclosing their HIV status in an unsupportive setting, in particular for young women who are married and who may be at risk of domestic violence. Adolescents also need to consider how revealing their HIV status can impact their future opportunities for training and employment.

### **KEY POINTS ON BENEFICIAL DISCLOSURE**

- 1. Support from family or a guardian is particularly important for adolescents because they are still young, inexperienced and usually still close to their family.**
- 2. Health workers can help adolescents understand the benefits of disclosure, and also practice how and when to disclose to selected family members and close friends.**
- 3. Health workers can help adolescents understand the importance of disclosure through counselling and peer support groups.**
- 4. Adolescents with perinatally acquired HIV are able to cope better if they were told about their HIV status at a young age.**
- 5. Health workers need to be aware that there is a risk when disclosing HIV status in an unsupportive setting, in particular for young women who may be at risk of domestic violence.**
- 6. Involving adolescents living with HIV who have already successfully disclosed their status may be helpful in working through the challenges of beneficial disclosure with adolescents thinking about disclosing their HIV status.**

## 7.4 Positive prevention

Prevention by HIV-positive young people includes all strategies that increase their self-esteem, motivation and confidence, with the aim of protecting their own health and avoiding transmission of HIV to others, or becoming re-infected. There are three key components to positive prevention: (1) healthy living, (2) healthy sexual activity, and (3) the involvement of people living with HIV.

- People who are living with HIV do not lose their desire to have sex and have children. Health workers need to provide clear information and respond frankly to the sexual and reproductive health needs of adolescents living with HIV.
- Peer support groups can help adolescents access practical and appropriate information on living with HIV, and provide them with the support that they need to live positively. Health workers have a role in helping to start new peer support groups, and in training and supporting existing groups.
- There are many social and cultural factors that influence whether adolescents use condoms; it is not just non-availability or lack of knowledge that prevents their use. Studies show that young people assess a potential partner's disease risk, and the need to use a condom, by their appearance and how well they know them socially. Health workers need to address this during condom counselling, as well as help adolescents learn and practice using a condom correctly and developing condom negotiation skills.
- Age difference (of more than five years) between adolescent girls and their older sexual partners is significantly associated with unprotected sexual activity. Health workers should reinforce the importance of correct and consistent condom use during every sexual encounter.
- Adolescents may enter health services with poor self-esteem and no belief that they will be able to master the skills that will be required to stay healthy. It is important that adolescents have the opportunity to learn how to discuss prevention behaviour, such as abstinence, sex and condom use, through interaction with health workers or through discussions in peer groups.
- Prevention is especially important for adolescents living with HIV who are using psychoactive substances. Adolescents need counselling to help them understand that drinking alcohol increases the risk of unplanned and unprotected sex, and that injecting drugs carries a high risk of HIV transmission, unless sterile needles and syringes are used every time.

Adolescent injectors need access to harm reduction programmes, including needle–syringe programmes, opioid substitution therapy and counselling, and information on safer sex.

- During adolescence, nutrition patterns can change and become chaotic. As adolescents begin to make more independent decisions about the food they eat, and are influenced by their peers and advertising, the quality and regularity of their eating can result in a poor diet. This can be the same for adolescents living with HIV. The health worker should be aware of this, and should regularly make a nutritional assessment and provide guidance on good nutrition.
- Prevention by HIV-positive adolescents requires the meaningful involvement of adolescents living with HIV in the planning and implementing of HIV strategies and policies.

Health workers need to consider that the two groups of adolescents (those that are perinatally infected and those that acquire HIV during adolescence) may have different concerns about sex and HIV. Health workers must be respectful, not assume that the adolescent is or not sexually active, and ask the adolescent's permission to talk about these sensitive issues.

**Adolescents with perinatally acquired HIV** may not yet be sexually active but may be planning to be, or have questions related to having sex. The health worker may not know if a particular adolescent is or is not sexually active. Many adolescents say that their first sexual experience is unplanned, so it is important to talk with the adolescent about sex and condom use *before* that first sexual encounter, if this is possible.

Tell adolescents that everyone has the right to refuse unwanted sexual advances. They may need support and assistance on how to negotiate and say “no” to unwanted sex. Tell them that if they are uncomfortable with the sexual attention of another person they have a right to refuse.

**Adolescents who acquired HIV during adolescence** may already be sexually active and are now considering the implications of the diagnosis on their sexual activity. Health workers must be prepared to discuss sexual and reproductive health options with adolescents. They can use the WHO *Reproductive choices and family planning for people living with HIV: Counselling tool* to assist them.

There is also information on sexual and reproductive health in other IMAI materials. Section 11 of the *IMAI-IMCI Basic HIV care with ART and prevention*

guideline module provides information on positive prevention for all people living with HIV, including adolescents; the WHO *Reproductive choices and family planning for people living with HIV: Counselling tool* is also relevant to young people; and the *IMAI Flipchart for patient education* has two pages on the adolescent patient (1–12 and 1–13).

It is important that health workers discuss the following points with adolescents when talking about sex.

### Discussion points on sex for adolescents living with HIV

1. Do not feel rushed into having sex.
2. If you have not yet had sex, consider delaying it. Do not begin a sexual relationship until you are ready. Talk together and agree on the limits of your physical intimacy.
3. If you are with a new partner, find other safer ways of giving each other pleasure until you are ready to have sex in this relationship. Enjoy other activities together.
4. When you have sex, **use a condom correctly every time**, even if your partner is also HIV-positive. Condoms prevent HIV transmission and also prevent unplanned pregnancy.
5. Drinking alcohol and substance use increase the risk of unplanned and unprotected sex.
6. Avoid situations or people that may put you at risk of unwanted sex.
7. Reduce the number of people with whom you have sex.
8. Consider disclosing to trusted people that you are living with HIV, so that they can support you.

## 7.4.1 Using condoms

The major transmission route for HIV globally is sexual intercourse. Abstinence and condoms are the only dependable ways of avoiding sexual transmission of HIV during penetrative sex. For sexually active adolescents living with HIV, condoms are the surest way to prevent the transmission of HIV and other sexually transmitted diseases to sexual partners and loved ones (apart from secondary abstinence). When used correctly and consistently, condoms provide an effective barrier, blocking the pathway of HIV by preventing the exchange of body fluids during sexual activity. Condoms also prevent unplanned pregnancy.

Many young people report consistent condom use with casual sexual partners, but often do not use a condom with steady partners. Factors influencing condom use include risk perception, social support and accessibility. Risk perception (whether the adolescent thinks that their behaviour puts them at risk of a negative outcome) is difficult to change in adolescents. Accessibility to condoms is more easily changed than attitudes towards condoms. Use of condoms is higher in countries where condoms are easily available in youth friendly establishments than in countries with limited condom availability.

Many adolescents, despite having adequate knowledge about HIV transmission, do not have the negotiating skills to demand condom use, and may be placed at risk of acquiring or transmitting HIV despite their best intentions. They may feel embarrassed or fearful to demand or insist on condom use with their partner. If they say that they do not like using condoms, the health worker should ask them their reasons for not liking condoms (e.g. smell, sensation) and ask them to seriously consider the consequences of not using them (e.g. HIV transmission, STIs, pregnancy).

Adolescents need information on the importance of using a condom correctly every time they have penetrative sex, on how to negotiate condom use, and on how to use a condom correctly. They need this information in words that they can understand and to which they can relate, they need a demonstration and they need an opportunity to practice. They also need easy access to condoms from a source that is reliable and adolescent friendly.

Health workers should encourage adolescents living with HIV to return for counselling with their sexual partner. Couple counselling can strengthen the support for the individual who is living with HIV, reinforce prevention for positives and help avoid the situation where the partner who receives a positive test result is blamed for the result. It is also an opportunity to discuss condom use and, in discordant couples, to provide support to the HIV-negative partner to cope with the situation. However, it is also important to recognize that there are situations when couple counselling is not possible.

## **KEY POINTS ON POSITIVE PREVENTION**

**Successful prevention for adolescents living with HIV requires their meaningful involvement in the planning and implementing of HIV services and policies.**

- 1. Adolescents living with HIV do not lose their desire to have sex and children. Health workers need to be able to discuss sensitive issues with them in an informative and non-judgemental manner.**
- 2. The two different transmission groups of adolescents may have different concerns about sex, depending on whether they are already sexually active or are planning to be sexually active.**
- 3. Prevention is especially important for adolescents living with HIV who are injecting drug users. Adolescent injectors need access to harm reduction programmes and information on safer sex.**
- 4. Peer support groups can help adolescents access practical and appropriate information on safer sex, and provide support for living with HIV positively.**
- 5. Adolescents need access to condoms. They also need information and the negotiating skills to ensure that they use condoms correctly and consistently.**
- 6. Adolescents living with HIV may express feelings of anger and depression. The health worker can help them talk about their feelings and refer them to other services as necessary.**

## **7.5 Consent and confidentiality**

Ideally, until the age of majority, an adolescent should be accompanied to the health centre by a parent, guardian or other responsible adult who can give informed consent for treatment. In practice, however, adolescent minors may not live with their parents or other caregivers, may be married, and/or may not want to involve their parents in their HIV prevention, treatment or care.

Where issues of sexual and reproductive health are concerned, adolescents are understandably often reluctant to allow parents or guardians to be informed. Therefore, alternative models of health-care delivery may be required (although sometimes this may not be possible without changes in the law).

A minor under the law is a person who is not yet a legal adult (i.e. has not yet reached the legal age of majority). This is usually determined by age but can also be determined by other factors, such as marital status.

It is important for health workers to know if there are national or local laws that exist on consent to treatment for minors. However, even if there are laws, they may not stipulate the age of majority for independent access to health services. In addition, the age at which adolescents are allowed to give their own consent may vary for different procedures. For example, adolescents may be able to consent to be tested for HIV or to receive condoms at a younger age than they can consent to a surgical procedure.

## **7.5.1 Evolving capacities and competence**

Some countries make special allowances for adolescents who are designated as “mature” or “emancipated” minors (e.g. those minors who are married, pregnant, sexually active, living independently, or who are themselves parents), who are able to provide informed consent for themselves for some services, despite being a “minor”.

In other places, adolescents who are thought to be competent or sufficiently mature are able to give informed consent to, or refuse medical treatment. They need to show that they understand and appreciate the nature and consequences of the procedure, and the implications of their decision. It is necessary to take into account the evolving capacities of the adolescent, their increased maturity and their capacity to make and understand the implications of decisions. Details about their daily life and experiences are particularly helpful for determining their competence. For example, adolescents who have been living and/or working independently from the age of 15 years and are accustomed to making their own decisions, are more likely to be able to make decisions about health care than 15-year-olds who have been living at home and for whom the majority of important decisions are being taken by their parents or guardians.

## **7.5.2 Best interests**

Making decisions about an adolescent’s maturity will often be the responsibility of a health worker, and they will be called upon to make decisions about the “best interests” of the adolescent. These issues should be decided locally, case-by-case, on the basis of the best information available, following clearly understood procedures.

The well-being of the adolescent must be the foremost consideration, which is consistent with the human rights concept of the “best interests” of the adolescent.

The “best interests” are usually determined by reference to particular circumstances. For example, the question could be “Would it be in the best interests of this adolescent minor to test him for HIV without the knowledge of his parents or guardians?” Determination of the adolescent’s best interests must be decided based on the facts of a particular case, taking into consideration relevant policies and legislation.

### 7.5.3 Confidentiality

The General Comment on Adolescent Health and Development within the context of the *United Nations Convention on the Rights of the Child* (CRC) states that:

**In order to promote the health and development of adolescents, States parties are also encouraged to respect strictly their right to privacy and confidentiality, including with respect to advice and counselling on health matters (art. 16). Health-care providers have an obligation to keep confidential medical information concerning adolescents, bearing in mind the basic principles of the Convention. Such information may only be disclosed with the consent of the adolescent, or in the same situations applying to the violation of an adult’s confidentiality. Adolescents deemed mature enough to receive counselling without the presence of a parent or other person are entitled to privacy and may request confidential services, including treatment.**

This of course applies equally to adolescents living with HIV. Unfortunately, confidentiality for adolescents is not always respected. Maintaining confidentiality is an essential skill for all health workers (and other clinic staff) and should be addressed in training. In general, people are entitled to expect that health workers will not disclose information about them to other people. However, adolescents can face many legal and informal restrictions to accessing confidential health-care, including testing and counselling for HIV. Some countries have laws that oblige health workers to notify guardians or national authorities about HIV and STIs in all minors. Requirements for spousal consent for such testing may also deny confidentiality to married adolescents.

The importance of preserving confidentiality is greatly influenced by culture. However, an adolescent who has shown the initiative to seek out services for HIV prevention, care and treatment should have their confidentiality respected. A reputation for being an “adolescent-friendly” service will develop only when clients trust the service. Unfortunately, many adolescents do not seek care because they do not think that the services will treat information about them in a confidential way.

## 7.5.4 Privacy

Privacy is primarily about a person's entitlement to limit access by others to aspects of their lives that they do not wish to share with others. Privacy is connected with confidentiality. Concerns by adolescents about privacy can prevent them from accessing health services, can affect which health centre adolescents visit and can influence whether or not they communicate openly with health workers. All health facilities should have a space where adolescents can be assured of privacy in their interactions with health workers. This may be particularly important for adolescents living with HIV.

### KEY POINTS ON CONSENT AND CONFIDENTIALITY

- 1. Ideally, until the age of majority, an adolescent should be accompanied by a responsible adult who can give their consent for treatment and provide subsequent support. This is not always possible and may also be contrary to the wishes of the adolescent.**
- 2. It is important for health workers to know if there are national or local laws on consent to treatment for minors. However, the laws may not explicitly state the age for independent access to HIV treatment or care.**
- 3. In some countries, the law states the age at which adolescents are judged competent to decide for themselves. Where there are no laws, health services may develop their own protocols, based on the best interests of the child and a minor's evolving capacities to make decisions about things that affect their lives.**
- 4. Most legal systems recognize "mature minors" (e.g. married adolescents) as having adult rights for medical consent.**
- 5. Maintaining confidentiality is an essential skill for all health workers and a key component of adolescent-friendly health services. Unfortunately, many adolescents do not think that they have access to confidential care. As for all people, confidentiality for adolescents should be respected.**

## 7.6 Developmental delays

Adolescents who acquired HIV perinatally may present with slow skeletal growth and delayed pubertal maturation. This is due to the affect that HIV has on metabolic and endocrine functions. This delay in growth and sexual maturation may also have an impact on the psychosocial development of the adolescent concerned.

These delays are common among adolescents who acquire HIV perinatally, and may cause them strong feelings of frustration and anger because they look different from their HIV-negative peers.

### KEY POINTS OF SECTION 7

**1. Adolescents living with HIV have many concerns and questions that relate to:**

- acceptance of their diagnosis
- disclosure of their diagnosis
- feelings of isolation and stress
- coping with HIV in addition to the normal challenges of adolescence.

**2. The health worker should:**

- listen carefully to their questions and answer them respectfully
- provide them with support and appropriate information
- assist them to access existing sources of support through linkages and referrals
- encourage them to learn life skills that will help them live positively
- help set up new support groups and services.

# 8

## Section 8:

# Treatment and care for adolescents living with HIV

### LEARNING OBJECTIVE

- to present aspects of treatment and care that are of particular importance to adolescents living with HIV.

## 8.1 Clinical status when entering care

The HIV transmission pattern of the two groups of adolescents living with HIV (those who acquire HIV perinatally and those who acquire HIV during adolescence) is an important factor in determining:

- **when** the adolescent enters clinical care
- **their clinical status** when they enter care
- **the health problems** which they present with when they enter care.

The health problems that adolescents with HIV may have when they present for care also depend on:

- their general health
- their nutrition
- the socioeconomic conditions in which they live
- other infectious diseases prevalent in their community (e.g. tuberculosis, STIs).

Adolescents with perinatally acquired HIV are likely to have been receiving treatment and care from an early age. However, those who acquired HIV as adolescents are likely to visit the health centre either because they are unwell and experiencing the symptoms of immune dysfunction, or because they have been referred or have concerns following a positive HIV test, in which case they may still be asymptomatic.

### 8.1.1 Perinatally acquired HIV

Adolescents who acquired HIV perinatally are emerging in increasing numbers, particularly in countries where paediatric services exist and ART for children has been rolled out. As treatment becomes more widely available there will be a steady growth in the number of babies perinatally infected with HIV who survive into adolescence.

#### Clinical status when entering care

- They may present with delays in growth and sexual maturation, which may also have an impact on their psychosocial development.
- They may have begun ART during early childhood because of rapid progression of HIV disease, and may have experienced various ARV regimens by the time they reach adolescence.

A small number of babies who are born with HIV will remain asymptomatic and survive to adolescence without any treatment (although they are likely to experience developmental delays). These are known as “late progressors”.

### **8.1.2 HIV acquired during adolescence**

Those who acquire HIV as adolescents are generally asymptomatic for many years following infection, and many may remain unaware of their HIV status. They visit health services for problems common to their age group, although these problems may have been occurring more frequently or more severely than expected (for example respiratory tract infections).

#### **Clinical status when entering care**

- The infection can remain asymptomatic for a longer period of time in adolescents than in adults. There appears to be an inverse correlation between age at infection and the length of the asymptomatic period (i.e. the younger the age at infection after puberty, the longer the virus remains asymptomatic). Studies suggest that HIV-positive adolescents have a greater immunologic reserve than adults. There may also be comparatively more capacity in adolescents than in adults to expand or regenerate immune cells.
- Those adolescents who acquired HIV as adolescents usually enter care without symptoms. They are more likely to be in WHO Clinical Stage 1 or 2, not requiring ART but requiring prevention, care, support and preparation for future treatment.

## **8.2 Transition of care**

Adolescents who acquired HIV perinatally will usually have attended paediatric clinics for many years. These clinics may not be able to provide care for them after they reach a certain age, and this transition from the care with which they are familiar to an adult care setting may be a difficult time for an adolescent.

There are differences between paediatric and adult care models, and in resource-poor settings there are few health facilities that are set up specifically to serve adolescents living with HIV. However, it is possible for adolescents to receive adolescent-friendly services within adult or paediatric clinics. The success of such services depends on the attitudes of health workers towards adolescents, their understanding of adolescents’ special needs and the organization of the clinic.

## **Differences in HIV care models: Paediatric vs. adolescent vs. adult**

### **PAEDIATRIC:**

- family-centred medical model of care with paediatric expertise
- health worker has a more long-standing relationship with parent/guardian
- HIV care integrated into primary care approach
- may or may not address issues of HIV disclosure to child
- parent or guardian usually available for right to consent.

### **ADOLESCENT:**

- adolescent-centred and multidisciplinary care;
- HIV care integrated into primary care approach;
- adolescent is the client and may choose whether to disclose HIV status to family;
- issues of confidentiality and consent are addressed if the patient is still legally a minor;
- care should be offered in an adolescent-friendly setting;
- comprehensive adolescent services available (including STI diagnosis and treatment, reproductive health and family planning);
- frequent contact and networking with adolescent peers at the clinic.

### **ADULT:**

- adult-oriented care based on medical model;
- adolescent's transitional issues will usually not be given any systematic specialized focus;
- clinics tend to be large and it is easy for transitioning patients to "slip through the cracks" unless very motivated health workers are involved.

Frequently, adolescents receive their HIV care, support, treatment and prevention through either paediatric services or adult services.

## **8.2.1 Transition from paediatric care**

The following points can assist health workers in planning with an adolescent for their transition from paediatric care.

1. Discuss future transition of care early: during childhood and as the young person grows up.
2. Acknowledge the issues and concerns of adolescent patients and their parents, guardians and caregivers.
3. Identify colleagues who have an interest in adolescents and young adults.
4. Select a health worker who can supervise the transfer and provide continuity of care.
7. Organize a meeting when the adolescent can meet with the new health-care team and visit the clinic.
6. Secure a follow-up plan.
7. Identify other adolescents already in the new clinic who can provide support.

### **KEY POINTS ON TRANSITION OF CARE**

1. **Adolescents may not feel comfortable visiting either paediatric or adult clinics. There are few places where adolescent specific HIV clinics are available. However, it is possible for adolescents to receive adolescent-friendly services within adult or paediatric clinics, depending on the attitudes of health workers towards adolescents, their understanding of adolescents' special needs and the organization of the clinic.**
2. **HIV-positive adolescents who were infected perinatally need adequate preparation and support from health workers while transitioning from the paediatric clinic to the adolescent or adult clinic.**

## 8.3 Antiretroviral therapy

IMAI states that for all patients living with HIV, there are seven requirements for initiating ART at the health centre.

1. HIV infection confirmed by written documentation
2. Medical eligibility
3. Patient fits criteria to be started on ART at the first-level facility
4. Any opportunistic infection has been treated/stabilized
5. Patient is ready for ART
6. Supportive clinical team prepared for chronic care
7. Reliable drug supply.

(Source: IMAI-IMCI Basic HIV care with ART and prevention, 8.1, pages H25-26).

These same seven requirements also apply to adolescent patients.

- readiness for ART
- adherence preparation
- mental health (more information in *IMAI-IMCI Basic HIV care with ART and prevention* guideline module, page H28)
- need for support.

It is also important to review previous prescriptions and the adolescent's adherence record as a way of identifying personal strengths or weaknesses. The health worker needs to become aware of the circumstances of an adolescent's life and discuss which regimen could provide the "best fit", based on dosage requirements and the side effects profile.

When the health worker and the adolescent have decided to start therapy, a period of actual drug-taking skills-building begins. The adolescent can try tasting the agents in the proposed regimen first and be advised on how to mask the flavour. Some adolescents may need training to learn how to swallow the larger pill sizes of some medications.

Letting the adolescent try a "surrogate pill regimen" made up of pills or tablets, such as calcium carbonate, can help the adolescent determine the specific difficulties involved in the real regimen. The surrogate pill regimen should contain the same number of pills and in the same schedule, with the same provisions

(e.g. refrigeration) as the ARV regimen will require. During this trial period, the adolescent can keep a journal to identify the specific difficulties encountered. Special calendars and pillboxes may be used as reminders for pill taking. For adolescents needing more support, a treatment supporter or family member can provide the necessary encouragement.

### **8.3.1 Dosing and choice of ARV regimen for adolescents**

WHO recommends using the Tanner scale to determine the adolescent's physical maturity when deciding whether he/she should receive an adult or paediatric ARV regimen and dosage. The Tanner scale (see Annex 2) outlines the stages of physical development in adolescence. The scale provides physical measurements of development, based on external primary and secondary sex characteristics. The stages are based on observing the development of breasts in girls, development of genitalia in boys, and the growth of pubic hair in both sexes.

Adolescents who are at Tanner scales 1, 2 and 3 are pre-pubertal, and should be treated with paediatric doses of ARVs. These patients require careful monitoring because this is the time of hormonal changes associated with the growth spurt. Adolescents who are at Tanner scales 4 and 5 are post-pubertal (considered to be adults), and should be treated with an adult ARV dose, with the same recommendations and special considerations that apply to adults. Adolescents with perinatally acquired HIV may have delayed development and stunting or wasting caused by progressive HIV illness, frequently exacerbated by malnutrition. For this reason Tanner staging, rather than only weight or height, should be used to determine whether to follow adult or paediatric ARV treatment guidelines.

In choosing an appropriate regimen, there is a need to go beyond considering maturity; simplification and anticipated long-term adherence are additional important criteria for selecting an appropriate first-line regimen for adolescents. Support from peers and family are especially important for adolescents who are beginning this lifelong treatment.

Health workers also need to consider whether to use efavirenz (EFV) and nevirapine (NVP) in adolescent girls. EFV should not be used in adolescent girls who are at risk of pregnancy (i.e. sexually active and not using adequate contraception) or in the first trimester of pregnancy. Symptomatic NVP-associated hepatic or serious rash toxicity, while uncommon, is more frequent in females than males, and is more likely seen in ARV-naïve females with higher absolute CD4 counts ( $>250$  cells/mm<sup>3</sup>). NVP should therefore be used with

caution in adolescent girls with absolute CD4 counts between 250 and 350 cells/mm<sup>3</sup>. If used in such adolescent girls, careful monitoring is needed during the first 12 weeks of therapy, preferably including liver enzyme monitoring. In situations where it is decided that both EFV and NVP should not be included in the first-line regimens for adolescent girls, the use of a triple nucleoside reverse transcriptase inhibitor regimen may be indicated.

### **KEY POINTS ON ANTIRETROVIRAL THERAPY**

- 1. There are seven requirements in IMAI to initiate ART at the health centre for all patients living with HIV. The same requirements apply equally to adolescents.**
- 2. The choice of regimen and dosing (adult or paediatric) of ART should be based on the adolescent's sexual maturity rating using the Tanner scale. Those who are at Tanner scales 1, 2 and 3 should be given a paediatric regimen and those who are at Tanner scales 4 and 5 should be prescribed an adult regimen.**
- 3. In choosing an appropriate regimen, there is a need to think beyond the Tanner scale. Simplification and anticipated long-term adherence are further important criteria for selecting an appropriate first-line regimen for adolescents. With adolescents, the health worker should be especially attentive to:**
  - **readiness for ART**
  - **adherence preparation**
  - **mental health**
  - **family and other support.**

## **8.4 Challenges in adherence to ART for adolescents**

Adherence to ART is important for all adults, adolescents and children. However, for adolescents living with HIV there are some additional factors and particular challenges in maintaining adherence to ART. Some of these factors relate to the adolescent (individual characteristics, including their stage of development) while others relate to their environment (family, peers and community).

The discipline of taking ARV medications in the way that they are prescribed

every single day represents a profound behaviour change for adolescents. ARV medications might also be a reminder of deceased parents, family or friends. Periods of relapse are to be expected and should be anticipated. They may occur when an adolescent just wants to feel like his/her peers, wants to forget his/her diagnosis for a time, or simply falls off the regimen and becomes discouraged. Adverse symptoms may also cause adolescents to stop taking the drugs. These types of temporary failures can have an intense and disproportionate affect on adolescents' sense of self-confidence. The health-care team needs to help adolescents understand that they have actually learned a great deal from the experience, and can benefit from the experience in being more successful next time.

Adolescents often report that their treatment interferes with their lifestyle. Similarly, changes in daily routines or spontaneous changes in their activities may interfere with the routine for taking ARVs. They need assistance in understanding and planning for these changes to avoid adherence problems.

### **Factors that may *improve adherence* to ART for adolescents living with HIV**

#### **The adolescent** (individual characteristics and stage of development)

- access to information that corresponds to the adolescent's maturational stage;
- treatment tailored to the adolescent's stage of development;
- information communicated in a straightforward way;
- a relationship of trust and respect with health workers;
- ART adapted to the adolescent's lifestyle (e.g. will the adolescent take medication at school?);
- adolescents involved with and consulted on changes in treatment (therapeutic alliance).

#### **Their environment** (family, peers, health services, community)

- support of siblings, parents/guardians, peers, support group, treatment supporter;
- consistent care and support from a range of sources over time;
- regular assessment for side effects and adherence in an appropriate manner;
- simplified therapeutic regimen;
- access to support groups led by peers who have successfully implemented and adhered to ART themselves.

### **Factors that may contribute to non-adherence to ART for adolescents living with HIV**

#### **The adolescent** (individual characteristics and stage of development)

- cognitive development (inability to understand the consequences of their actions)
- not understanding HIV or the medications and regimens
- inclined to live in the present rather than plan the future
- desiring their independence, feeling rebellious
- no disclosure, coping alone with the burden of HIV
- influenced by their HIV-negative peers, and wanting to be like them.

#### **Their environment** (family, peers, health services, community)

- how the family functions
- peer influence
- no treatment supporter
- unsupportive or unsafe environment where they live
- poor relationship with the health-care team; feel they are being “told what to do”
- complex treatment regimen
- treatment interferes with adolescent’s needs and lifestyle.

## **8.5 Living with a chronic condition**

Health workers often find that young people who have been managing well with a chronic condition (such as diabetes, asthma or haematological conditions such as sickle cell anaemia) in childhood, when they were more compliant and under the care of their parents, become “out of control” during adolescence. It can be the same for children who acquired HIV perinatally; when they reach adolescence their adherence to care and treatment can deteriorate.

As with any chronic condition, HIV may also continue to influence the adolescent’s development, for example their growth and pubertal changes, and their psychological development and socialization processes. This can affect the course and management of their condition, resulting in poor drug adherence, disease control, nutrition and planning, and an increase in health-related risk behaviours.

Adolescents who have recently acquired HIV have the challenge of coping with both their new HIV diagnosis *and* the normal developmental challenges of adolescence.

The management of any chronic condition during adolescence constitutes a major challenge for the individual, their family and the health-care team.

### **KEY POINTS ON LIVING WITH A CHRONIC CONDITION**

- 1. As with other chronic conditions (e.g. asthma, diabetes), normal developmental changes during adolescence can have an impact on the course and management of HIV (e.g. poor adherence, disease control, planning and nutrition).**
- 2. HIV may also influence the adolescents' development, especially growth and pubertal changes, psychological development and socialization processes.**
- 3. Adolescents who had been managing well with HIV in childhood (when they were more compliant and under the care of their parents or guardian) may appear "out of control" during adolescence, when their adherence to care and treatment may get worse.**
- 4. Those who acquired HIV as adolescents, have the complication of coping with the new diagnosis of a chronic condition in addition to the normal developmental challenges of adolescence.**

# 9

## Section 9: \_\_\_\_\_

# The 5 “A”s and the adolescent patient

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### LEARNING OBJECTIVES

- to review the 5 “A”s from IMAI and identify those issues that are particularly important for the adolescent patient living with HIV.

## 9.1 Guide for health workers:

### Using the 5 “A”s with adolescents living with HIV

The 5 “A”s (**Assess, Advise, Agree, Assist, Arrange**) are a key part of good chronic care. They are a series of steps used in the IMAI approach to chronic HIV care with ART, to guide health workers at each consultation. Here the 5 “A”s are presented with a particular focus on issues that are important for an adolescent patient living with HIV.

**NOTE:** If the patient is a minor, understand what is legally required of the health worker in terms of informed consent, bearing in mind the best interests of the adolescent and their evolving capacities. When providing treatment, care, support and prevention for adolescents, use appropriate language and attitudes.

#### ASSESS

- Assess the adolescent’s goals for this consultation: they may be different from yours.
- Assure them of confidentiality.
- Assess the patient’s physical and mental status, understanding that HIV may progress more slowly in adolescents than in adults.
- Review current treatments and assess adherence.
- Assess whether sexually active or not (or planning to become sexually active), and whether they are using condoms and/or other contraception.
- Assess young women for pregnancy.
- Assess other risk behaviours/factors for HIV transmission (e.g. injecting drug use, alcohol use, orphan, sex worker).
- Assess the adolescent’s knowledge, beliefs, concerns, and daily behaviours related to HIV.
- Assess support structures and who knows about their HIV status (e.g. partner, family, friends).

#### ADVISE

- Advise using plain, neutral and non-judgemental attitudes and language. Include parents or guardians in discussions, if the adolescent is agreeable.

- Correct any inaccurate knowledge and fill gaps in the adolescent’s understanding of his/her condition.
- Advise on being young and living with HIV (relationships, sex, alcohol/drug use).
- Advise on sexual activity, condom use, contraception and other aspects of positive prevention.
- Discuss couple counselling and the benefits of disclosing HIV status to chosen people, in order to develop support structures.
- Advise on peer support from other adolescents living with HIV.
- Advise on adherence.

**If you are developing a treatment plan:**

- Advise on options available to the adolescent (risk reduction, positive prevention, prophylaxis and treatment).
- Advise on the simplest regimen possible and evaluate the patient’s confidence and readiness to adopt and adhere to treatment.
- Take the adolescent’s developmental phase into consideration in prescribing ART (using the Tanner scale).
- patient’s specific concerns.

## **AGREE**

- Agree where the adolescent should choose to receive treatment and support.
- Agree to whom they choose to disclose their HIV status.
- Agree on how and when they wish to disclose their status, and the support they may need.
- Agree on the roles that the adolescent and others will play in their care and treatment.
- Agree on the treatment plan that has been developed.
- Agree upon goals that reflect the adolescent’s priorities. Ensure that the negotiated goals are:
  - clear
  - measurable
  - realistic
  - under the adolescent’s direct control
  - limited in number.

## ASSIST

- Provide a written or pictorial summary of the plan.
- Provide referrals to adolescent-friendly health workers and services in the community, as required.
- Provide links to support services for young people living with HIV in the community.
- Provide treatments and other medications (prescribe or dispense).
- Provide condoms and contraception, as required
- Provide skills and tools to assist with self-management and adherence, including adherence equipment (e.g. pill box organized by day, a calendar or other ways to remind and record the treatment plan).
- Address obstacles to adherence (e.g. side effects, weight gain, medication as a constant reminder of HIV status).
- Help patients to predict possible barriers to implementing the treatment plan and to identify strategies to overcome them.
- Assist with the patient's physical, mental and social health, including the provision of psychological support as needed; if an adolescent patient is depressed, treat for depression.
- Assist by strengthening the links with available support:
  - friends, family
  - peer support groups
  - community services
  - treatment supporter/buddy or guardian.

## ARRANGE

- Arrange what the adolescent will do in the time between visits to you.
- Arrange for the next appointment date: reinforce the importance of attending even if they feel well and have no problems.
- Arrange for referral for group counselling or relevant support group.
- Record what happened during the visit.

## **KEY POINTS ON THE 5 “A”S AND THE ADOLESCENT PATIENT**

- 1. The 5 “A”s are as relevant to responding to the needs of adolescents living with HIV as they are to responding to the needs of small children and adults.**
- 2. When thinking about the 5 “A”s with an adolescent patient, it is important to take into account specific issues such as:**
  - **stage of development, including sexual development;**
  - **knowledge and capacities (e.g. life skills);**
  - **mode of transmission (i.e. during the perinatal period or during adolescence);**
  - **needs for care, support and treatment preparedness for adolescents who are living with HIV but do not yet require treatment;**
  - **consent and confidentiality;**
  - **problems that may require specific attention, such as adherence, disclosure, discrimination and emerging sexuality;**
  - **available support structures.**

## Additional reading

*Adolescent health and development in the context of the Convention on the Rights of the Child*. Committee on the Rights of the Child, General comment No. 4 (2003).

*Adolescent job aid: a handy desk reference for primary level health workers*. Geneva, World Health Organization, 2009.

*Antiretroviral therapy of HIV infection in infants and children in resource-limited settings: towards universal access. Recommendations for a public health approach*. Geneva, World Health Organization, 2006.

*IMAI Acute care: Guidelines for first-level facility health workers at health centre and district outpatient clinic*. WHO/CDS /IMA I/2004.1 Rev. 3. Geneva, World Health Organization, 2009.

*IMAI-IMCI Basic HIV care with ART and prevention guideline module*. Geneva, World Health Organization, 2007 (<http://www.who.int/hiv/topics/capacity/en/index.html>, accessed 30 May 2009).

*Impact of HIV and sexual health education on the sexual behaviour of young people: a review update*. Joint United Nations Programme on HIV/AIDS, 1997.

*More positive living: strengthening the health sector response to young people living with HIV*. Geneva, World Health Organization/United Nations Children's Fund, 2008 ([http://www.who.int/child\\_adolescent\\_health/documents/9789241597098/en/index.html](http://www.who.int/child_adolescent_health/documents/9789241597098/en/index.html), accessed 30 May 2009).

*Orientation programme on adolescent health for health-care providers*. Geneva, World Health Organization, 2003.

*Reproductive choices and family planning for people living with HIV: counselling tool*. Geneva, World Health Organization, 2006.

UN Committee on the Rights of the Child (CRC), *CRC General Comment No. 4: Adolescent Health and Development in the Context of the Convention on the Rights of the Child*, 1 July 2003, CRC/GC/2003/4 (<http://www.unhcr.org/refworld/docid/4538834f0.html>, accessed 30 May 2009).

UNAIDS. *UNAIDS terminology guidelines (February 2008). Summary of preferred terminology* ([http://data.unaids.org/pub/Manual/2008/jc1336\\_unaids\\_terminology\\_guide\\_en.pdf](http://data.unaids.org/pub/Manual/2008/jc1336_unaids_terminology_guide_en.pdf), accessed May 31, 2009).

# Annex 1: Spot Checks

## INSTRUCTIONS

The purpose of the spot checks is to help you assess your gains in knowledge and understanding as a result of participating in this course.

The spot checks will not be collected, graded or checked by any of the facilitators. This is merely for your personal use at the beginning of the day.

The responses will be discussed at the end of the day.

**Respond to the following questions to the best of your knowledge and understanding.**

For many of the questions there is no right or wrong answer.

**1. How confident do you feel about providing treatment, care and support to adolescents living with HIV?**

☐ Uncomfortable    ☐ Not very confident    ☐ Confident    ☐ Very confident

**2. There are three stages of adolescent development. Can you name them and give the approximate ages to which they correspond?**

- i. \_\_\_\_\_
- ii. \_\_\_\_\_
- iii. \_\_\_\_\_

**3. Essentially, because of the mode of transmission, there are two groups of adolescents living with HIV. These two groups are:**

- i. \_\_\_\_\_
- ii. \_\_\_\_\_

**4. What do you think are the three most important questions that may be asked by an adolescent living with HIV in your community?**

- i. \_\_\_\_\_
- ii. \_\_\_\_\_
- iii. \_\_\_\_\_

## 5. What is particularly important in counselling adolescents?

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## 6. Read each statement and tick the box that reflects your point of view.

	I agree	I disagree
"Adolescents are not at risk of HIV in my community."		
"An adolescent with a positive HIV test who is still asymptomatic does not need any services."		
"Health workers must tell adolescents living with HIV how they should behave."		
"If a boy of 14 years came for HIV care I would tell him I could not help him unless he comes back with a parent or guardian."		
"If a young person tests HIV positive, it is my duty to tell their parents."		
"If a married adolescent who is living with HIV comes to my clinic, I am not obliged to tell their partner."		
"I find adolescents today hard to understand because they behave so strangely."		
"Prevention, care, treatment and support for adolescents living with HIV is no different from that for children or adults."		

## 7. Read the following brief scenarios. Consider your personal and professional feelings and reactions to each one and write some comments. You will not have to share these comments with other participants so try to be honest and explore how the adolescents in the scenarios make you feel and react.

- a) Jay, a 14-year-old boy, comes to the clinic alone with a cut on his head. He will not look at you. When you question him he answers with short responses in an angry voice.

**Your comments:**

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- b) Mai is a 15-year-old girl who comes to the clinic with her mother. The mother says that Mai has been missing school, sleeping late, shouting at her parents and staying out late with her boyfriend. They have tried punishing her and locking her in her room. Mai does not say anything, just keeps looking at the floor with her arms crossed while her mother speaks.

**Your comments:**

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- c) Pasco, a 15-year-old boy who is HIV-positive, comes to the clinic and asks for condoms.

**Your comments:**

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- d) Shaana, a 17-year-old girl, comes to the clinic and asks for contraception. She is not married and says she has had a sexual relationship with her boyfriend for two months.

**Your comments:**

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- e) A noisy group of young boys are standing at the clinic door talking and laughing loudly. They seem to be trying to make one of the boys in the group enter the clinic, pushing and joking with him.

**Your comments:**

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## Annex 2: The Tanner scale

The Tanner scale (or Tanner staging) provides a measure of physical development in adolescents. The scale defines physical measurements of development based on external primary and secondary sex characteristics. The scale is based on observing the development of the breasts in girls, the development of the genitalia in boys, and the growth of pubic hair in both sexes.

Due to natural variations, individuals pass through the Tanner stages at different rates. The Tanner scale cannot measure the entire course of puberty because the changes in internal reproductive organs begin much earlier and finish much later than the changes in visible external characteristics.

In ART, the Tanner scale is used to determine which treatment regimen to follow (paediatric or adult). Adolescents at Tanner scale 1, 2 or 3 should be started on a paediatric regimen, while adolescents at scale 4 or 5 should be put on the adult regimen.

### Tanner scale: Female breast

**Scale 1:** no breast tissue with flat areola



**Scale 2:** breast budding with widening of the areola



**Scale 3:** larger and more elevated breast extending beyond the areola








**Scale 4:** larger and even more elevated breast. Areola and nipple projecting from the breast contours








**Scale 5:** Adult size with nipple projecting above areola



**Tanner scale: Male and female pubic hair**

<b>Scale 1:</b> none	
<b>Scale 2:</b> small amount of long hair at base of male scrotum or female labia majora	
<b>Scale 3:</b> moderate amount of curly and coarser hair extending outwards	
<b>Scale 4:</b> resembles adult hair but does not extend to inner surface of thigh	
<b>Scale 5:</b> adult type and quantity extending to the medial thigh surface	

**Tanner scale: Male genitalia**

<b>Scale 1:</b> testes small in size with childlike penis	
<b>Scale 2:</b> testes reddened, thinner and larger (1.6–6.0 cc) with childlike penis	
<b>Scale 3:</b> testes larger (6–12 cc), scrotum enlarging, increase in penile length	
<b>Scale 4:</b> testes larger (12–20 cc) with greater enlargement and darkening of the scrotum; increase in length and circumference of penis	
<b>Scale 5:</b> testes over 20cc with adult scrotum and penis	

Source: Daniel WA, Paulshock BZ. A physician's guide to sexual maturity rating. *Patient Care*, 30 May, 1979. Illustration by Singh-Roy.

## **Annex 3: Identifying changes to improve services for adolescents at your clinic (section 4)**

### **Identifying changes to improve services for adolescents at my health centre**

Write down:

1. Three reasons why an adolescent living with HIV may be reluctant to return to my health centre:

i. \_\_\_\_\_

ii. \_\_\_\_\_

iii. \_\_\_\_\_

2. At least three changes that I could realistically make that would encourage adolescents to visit/return to my health centre:

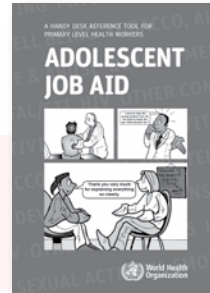
i. \_\_\_\_\_

ii. \_\_\_\_\_

iii. \_\_\_\_\_

# Annex 4: Excerpts from the *Adolescent job aid*

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How is the *Adolescent job aid* organized?

How is the *Adolescent job aid* to be used?

### PART 1: The clinical interaction between the adolescent and the health worker

1. The special contribution that you could make to the health and development of your adolescent patient
2. Establishing rapport with your adolescent patients
3. Taking a history of the presenting problem or concern
4. Going beyond the presenting problem or concern
5. Doing a physical examination
6. Communicating the classification, explaining its implications, and discussing the treatment options
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### PART 2: Algorithms, communication tips and frequently asked questions

#### DEVELOPMENTAL CONDITIONS

Delayed puberty: Male

Delayed puberty: Female

#### MENSTRUAL CONDITIONS

“I have a lot of pain during my periods”

“I bleed a lot during my periods”

“I have irregular periods / my periods have stopped”

### **PREGNANCY-RELATED CONDITIONS**

“I do not want to get pregnant”

“Could I be pregnant?” (suspected pregnancy)

“I am pregnant”

### **GENITAL CONDITIONS (INCLUDING SEXUALLY TRANSMITTED INFECTIONS)**

“I have a problem with the skin at the tip of my penis” (foreskin problems)

“I have pain in my scrotum/I have injured my scrotum”

“I have discharge from my penis/pain on urination”

“I have a sore on my genitals”

“I have a swelling in my groin”

“I have an abnormal discharge from/burning or itching in my vagina”  
(for non-pregnant women)

### **HIV**

“Could I have HIV?”

### **OTHER COMMON CONDITIONS**

“I have abdominal pain”

“I am too pale”

“I am tired all the time”

“I have a headache”

“I have acne”

“I am too thin/too fat”

“I am too short”

“I have been attacked”

“I cannot see very well”

## **Part 3: Information to be provided to adolescents and their parents or other accompanying adults**

Healthy eating

Physical activity

Sexual activity

Emotional well-being

The use of tobacco, alcohol and other substances

Unintended injuries

Violence and abuse

# Introduction

## **What is the *Adolescent job aid*?**

It is a handy desk reference.

## **Who is the *Adolescent job aid* intended for?**

It is intended for health workers who provide primary care services (including promotive, preventive and curative health services) to adolescents.

These health workers include doctors, midwives, nurses and clinical officers. The *Adolescent job aid* takes into account the fact that in most settings health workers provide health services to children and adults in addition to adolescents.

## **What is the purpose of the *Adolescent job aid*?**

Its purpose is to enable health workers to respond to adolescents more effectively and with greater sensitivity. To do this, it provides precise and step-wise guidance on how to deal with adolescents when they present with a problem or concern regarding their health and development.

## **What does the *Adolescent job aid* contain?**

It contains guidance on commonly occurring adolescent-specific problems or concerns that have not been addressed in existing World Health Organization (WHO) guidelines (e.g. delayed menarche). It also contains guidance on some problems and concerns that are not adolescent specific but occur commonly in adolescents (e.g. sexually transmitted infections) and highlights special considerations in dealing with these conditions in adolescents.

## **How does the *Adolescent job aid* relate to other WHO guidelines?**

It is consistent with and complementary to other key WHO guidelines including:

- *Integrated management of adolescent and adult illness*
- *Integrated management of pregnancy and childbirth*
- *Decision-making tool for family planning clients and providers*

## **How is the *Adolescent job aid* organized?**

Following this introductory section, it contains three parts:

**Part 1:** The clinical interaction between the adolescent and the health worker

**Part 2:** Algorithms, communications tips and frequently asked questions

**Part 3:** Information to be provided to adolescents and their parents or other accompanying adults

## **How is the *Adolescent job aid* to be used?**

Firstly, familiarize yourself with its contents.

**Part 1:** Go over the guidance that this part contains, carefully, thinking through its implications for your work. Where possible, discuss this with your colleagues.

**Part 2:** Go over the list of algorithms that it contains. Choose one presenting complaint that you commonly encounter in your work and go through the algorithm carefully, thinking through what it guides you to in the “Ask” and “Look/Feel/Listen” columns, in order to classify the condition. Then, go through how it guides you to manage each classification. After that, go over the information to be provided to the adolescent and the accompanying adult as well the responses to frequently asked questions.

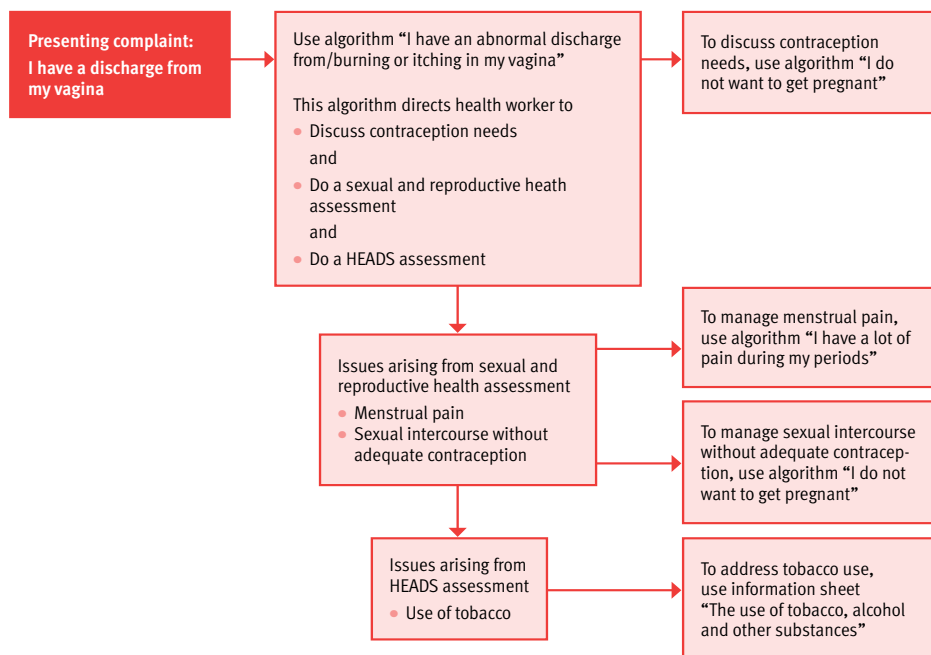
**Part 3:** Go over the list of topics that it contains. Choose any one topic and go over the messages it contains for adolescents and for their parents.

Secondly, begin using it in your work.

The starting point for each algorithm is the presenting complaint, either by the adolescent or by his/her parents. As you go through the “Ask” and “Look/Feel/Listen” columns, you are likely to be pointed to other algorithms to use. Go to them after you have completed the classification, defined the management approach to be used, provided information, and responded to questions, if any. In this way, the *Adolescent job aid* guides you to go beyond the presenting complaint to identify and deal with other problems that were not raised by the adolescent or his/her parents.

This is illustrated in the following chart.

### Example of entry points for use of algorithms, accompanying communication tips and information sheets in the *Adolescent job aid*



When you start using the *Adolescent job aid*, take the time to go through each algorithm and the accompanying communication tips carefully. With practice, you will be able to do this faster. You will also learn which issues you will need to spend time on, and which ones you could go through quickly or even skip altogether.

Lastly, although the *Adolescent job aid* contains 24 algorithms and communication tips on commonly occurring presentations, it does not cover all the presenting complaints that adolescents come with. This means that from time to time you will need to manage adolescents using other guidelines.

# Part 1

## The clinical interaction between the adolescent and the health worker

This part of the *Adolescent job aid* addresses the following issues:

1. The special contribution that you could make to the health and development of your adolescent clients/patients
2. Establishing rapport with your adolescent clients/patients
3. Taking a history of the presenting problem or concern
4. Going beyond the presenting problem or concern
5. Doing a physical examination
6. Communicating the classification, explaining its implications, and discussing the management options
7. Dealing with laws and policies that affect your work with your adolescent clients/patients

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### 1. The special contribution that you could make to the health and development of your adolescent clients/patients

#### ***What you should be aware of:***

1. Adolescence is a phase in life during which major physical, psychological and social changes occur. As they encounter these changes, adolescents have many questions and concerns about what is happening to their bodies. In many places, adolescents are unable to share their questions and concerns, and to seek answers from competent and caring adults.

**2.** While adolescence is generally considered as a healthy time of life, it is also a period when many behaviours that negatively affect health both during adolescence and later in life, start. Furthermore, many adolescents die every year – mostly from unintentional injuries (e.g. car crashes), intentional injuries (suicide and interpersonal violence) and pregnancy-related causes.

**3.** Health workers like you have important contributions to make in helping those adolescents who are well to stay well, and those adolescents who develop health problems get back to good health. You can do this through:

- providing them with information, advice, counselling and clinical services aimed at helping them maintain safe behaviours and modify unsafe ones (i.e. those that put them at risk of negative health outcomes);
- diagnosing/detecting and managing health problems and behaviours that put them at risk of negative health outcomes; and referring them to other health and social service providers, when necessary.

Health workers like you have another important role to play – that of change agents in your communities. You could help community leaders and members understand the needs of adolescents, and the importance of working together to respond these needs.

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## **2. Establishing rapport with your adolescent clients/patients**

### ***What you should be aware of:***

- 1.** Some adolescents may come to you of their own accord, alone or with friends or relatives. Other adolescents may be brought to see you by a parent or another adult. Depending on the circumstances, the adolescent could be friendly or unfriendly with you. Also, depending on the nature of the problem or concern, the adolescent could be anxious or afraid.
- 2.** Adolescents may be reluctant to disclose information on sensitive matters if their parents or guardians, or even spouses are also present.

### ***What you should do:***

- 1.** Greet the adolescent in a cordial manner.
- 2.** Explain to the adolescent that:
  - you are there to help them, and that you will do your best to understand and respond to their needs and problems;
  - you would like them to communicate with you freely and without hesitation;
  - they should feel at ease and not be afraid because you will not say or do anything that negatively affects them;
  - you want them to decide how much they would like to involve their parents or others;
  - you will not share with their parents or anyone else any information that they have entrusted you with, unless they give you the permission to do so.

3. If the adolescent is accompanied by an adult, in their presence, explain to the accompanying adult that:

- you want to develop a good working relationship with the adolescent. At some stage you may need some time to speak to the adolescent alone.

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### 3. Taking a history of the presenting problem or concern

#### **What you should be aware of:**

1. Many adolescent health issues are sensitive in nature.
2. When asked by health workers about sensitive matters such as sexual activity or substance use, adolescents may be reluctant to disclose information because of fears that health workers may scold or mock them.

#### **What you should do:**

1. *Start with non-threatening issues:* Start the clinical interview with issues that are the least sensitive and threatening. The *Adolescent job aid* algorithms contain many direct questions that health workers need to ask to determine classification and subsequent management. However, if you were to ask an adolescent, “*Are you sexually active?*” without first establishing rapport, the likelihood of obtaining any answer, let alone a true answer will be low. It is usually best to start with some introductory questions (e.g. about the adolescent’s home situation) before proceeding to more sensitive topics such as sexual and reproductive health. Then when one is ready to commence questioning about sexual and reproductive health, it is best again to start with the most non-threatening questions before proceeding to the more sensitive ones.
2. *Use the third person (indirect questions)* where possible: It is often best to ask first about activities of their peers and friends rather than directly about their own activities. For example, rather than ask an adolescent directly, “*Do you smoke cigarettes?*” you could ask, “*Do any of your friends smoke?*” If the adolescent replies, “*Yes*”, you could then ask, “*Have you ever joined them?*” This can lead to other questions such as, “*How often do you smoke?*” etc.
3. *Reduce the stigma around the issue by normalising the issue:* An adolescent who has an unwanted pregnancy or a sexually transmitted infection may feel embarrassed or even ashamed. You can reduce the stigma around the issue by saying to the adolescent that, “*I have treated a number of young people with the same problem you have*”.

#### **What you should be aware of:**

Even with adequate training, many health workers are uncomfortable discussing sensitive matters with anyone, whether adults or adolescents.

#### **What you should do:**

1. The first step in dealing with this is being aware of the issue, and then trying to overcome it. It may be useful to reflect that your discussions with the adolescents, although uncomfortable, will help you identify their needs and address their problems. It may also be useful to discuss your thoughts and feelings with a colleague.

2. Learn as you go along. In the beginning, you may use the questions listed in the *Adolescent job aid* as they are written. With time you may choose to modify them, using words and phrases that you are more comfortable with and a more relaxed conversational style. You will also find that you will get faster with practice, and will learn which issues to spend time on, and which other issues you can address quickly.

#### 4. Going beyond the presenting problem or concern

##### **What you should be aware of:**

1. When adolescents seek help from a health worker, they tend to volunteer information about the health problem that seems most important to them (i.e. the presenting complaint). They may have other health problems and concerns but may not say anything about them unless directly asked to do so. In such a situation, the health worker is likely to deal with the presenting complaint only (e.g. fever and cough) and go no further thereby missing other existing problems.
2. Further, adolescents may not volunteer information about a health problem or concern because they may be embarrassed or scared to do so, or because they may not be comfortable either with the health worker or the situation they are in.

##### **What you should do:**

You could consider using the HEADS assessment, which could assist you to:

- detect health and development problems that the adolescent has not presented with;
- detect whether the adolescent engages in behaviours that could put one at risk of negative health outcomes (such as injecting drugs or having unprotected sex);
- detect important factors in their environment that increase the likelihood of their engaging in these behaviours.

In this way, you would get a full picture of the adolescent as an individual and not just a case of this or that condition. It would also identify the behaviours and the factors in the adolescent's environment to address – yourself and in conjunction with other health and social service providers.

##### **HEADS is an acronym for**

- Home
- Education/Employment
- Eating
- Activity
- Drugs
- Sexuality
- Safety
- Suicide/Depression

The HEADS assessment is structured so that you can start the discussion with the most non-threatening issues. It starts by examining the home and the educational/employment setting. It then goes on to eating, and then to activities. Only then does it deal with more sensitive issues such as drugs, sexuality, safety and suicide/depression.

See the listing of “Information that can be obtained from a HEADS assessment” towards the end of this part of the *Adolescent job aid*.

If time does not permit you to do a full HEADS assessment, you will need to prioritize which sections of the HEADS assessment to do. You may choose to prioritize the sections which are most related to:

- Presenting complaint:

If an adolescent presents with an injury after a fall while drinking alcohol, you may prioritize the “Drugs” section of the HEADS assessment.

and / or

- Important health issues in your local area:

If you are working in an area of high HIV prevalence you may prioritize the “Sexuality” section of the HEADS assessment.

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## 5. Doing a physical examination

### **What you should be aware of:**

1. In order to make a correct classification, all the signs listed in the Look/Feel/Listen column of the algorithms need to be carefully checked for.
2. Some items in a physical examination are unlikely to cause embarrassment (e.g. checking the conjunctivae for anaemia); however, some other items are likely to do so (e.g. checking the vagina for the presence of abnormal discharge).

### **What you should do:**

1. Before doing a physical examination:

- If the adolescent is with an accompanying person, reach an agreement as to whether they want this person to be present during the examination.
- Inform the adolescent about what examination you want to carry out and the purpose of the examination.
- Explain the nature of the examination.
- Obtain the consent of the adolescent. (If the adolescent is below the legal age of being able to give consent, you will need to obtain consent from a parent or guardian. However, even if you have obtained consent from a parent or guardian, you should not proceed with the examination unless the adolescent agrees).

### **As part of the physical examination check the following things:**

- Temperature
- Pulse rate
- Presence of anaemia
- Presence of jaundice
- Presence of lymphadenopathy
- Presence of obvious over/under-nutrition
- Any abnormal health and lung sounds
- Any evidence of swellings or tenderness in the abdomen
- Presence of teeth and gum problems
- Presence of skin problems

2. During an examination:

- Respect local sensitivities regarding gender norms (e.g. whether it is appropriate for a male health worker to examine a female patient). If needed, ensure the presence of a female colleague during the examination.
  - Ensure privacy (e.g. make sure that curtains are drawn, doors are shut and that no unauthorized person enters the room during the examination).
  - Watch for signs of discomfort or pain and be prepared to stop the examination if needed.
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## **6. Communicating the classification, explaining its implications, and discussing the treatment options**

### ***What you should be aware of and do:***

1. Informing your adolescent patients about the classification and explaining its implications for their health can help them become active partners in protecting and safeguarding their health.
2. Informing them about the different treatment options and helping them choose the one that matches their preferences and circumstances will increase the likelihood that they will adhere to the treatment.

### ***What you should do:***

1. When you have made a classification, you will need to communicate it and explain its implications to the adolescent.

Before doing so:

- check whether they want to have the parent or other accompanying person present.

While communicating:

- demonstrate your respect and empathy to the adolescent through your speech and your body language (e.g. if the adolescent is with a parent or another accompanying person, address them);
- use language and concepts that they are likely to understand;
- periodically assess their understanding (e.g. by asking them to say in their own words what they understand about an issue).

2. Provide information on the implications of each treatment option and help the adolescent choose the one best suited to his/her needs.

While doing this:

- present all the relevant information;
- respond to questions as fully and honestly as you can;
- help them choose;

- respect their choice even if it is not the one you would have wanted them to make.
3. When providing medication, explain why they need to take it, and when and how they need to do so. If prescribing medication, make sure that they will be able to find the money to buy it.

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## 7. Dealing with laws and policies that affect your work with your adolescent clients/patients

### ***What you should be aware of and do:***

1. Ensure that you are fully aware of the national and local laws and policies.
2. Where appropriate, help your adolescent patients and their parents become aware of them.
3. As a health worker, just like all other citizens of your country, you have the responsibility to respect these laws and policies. As a health worker, you have an ethical obligation to act in the best interests of your adolescent patients. In your work with adolescents, you may find that in some situations, prevailing laws and policies may not permit you to do what is in the best interests of your adolescent patient (e.g. in some places, the provision of contraceptives to unmarried adolescents is illegal). In such situations, you may need to draw upon your experience and the support of caring and knowledgeable people to find the best way to balance your legal obligations with your ethical obligations.

### **Information that can be obtained from a HEADS assessment**

<b>Home</b>	Where they live With whom they live Whether there have been recent changes in their home situation How they perceive their home situation
<b>Education/ Employment</b>	Whether they study/work How they perceive how they are doing How they perceive their relation with their teachers and fellow students/employers and colleagues Whether there have been any recent changes in their situation What they do during their breaks
<b>Eating</b>	How many meals they have on a normal day What they eat at each meal What they think and feel about their bodies

<b>Activity</b>	<p>What activities they are involved in outside study/work</p> <p>What they do in their free time – during week days and on holidays</p> <p>Whether they spend some time with family members and friends</p>
<b>Drugs</b>	<p>Whether they use tobacco, alcohol, or other substances</p> <p>Whether they inject any substances</p> <p>If they use any substances, how much do they use; when, where and with whom do they use them</p>
<b>Sexuality</b>	<p>Their knowledge about sexual and reproductive health</p> <p>Their knowledge about their menstrual periods</p> <p>Any questions and concerns that they have about their menstrual periods</p> <p>Their thoughts and feelings about sexuality</p> <p>Whether they are sexually active; if so, the nature and context of their sexual activity</p> <p>Whether they are taking steps to avoid sexual and reproductive health problems</p> <p>Whether they have in fact encountered such problems (unwanted pregnancy, infection, sexual coercion)</p> <p>If so, whether they have received any treatment for this</p> <p>Their sexual orientation</p>
<b>Safety</b>	<p>Whether they feel safe at home, in the community, in their place of study or work; on the road (as drivers and as pedestrians) etc.</p> <p>If they feel unsafe, what makes them feel so</p>
<b>Suicide/ Depression</b>	<p>Whether their sleep is adequate</p> <p>Whether they feel unduly tired</p> <p>Whether they eat well</p> <p>How they feel emotionally</p> <p>Whether they have had any mental health problems (especially depression)</p> <p>If so, whether they have received any treatment for this</p> <p>Whether they have had suicidal thoughts</p> <p>Whether they have attempted suicide</p>

## **Sexual and reproductive health assessment**

Here is an example of how a health worker may do a sexual and reproductive health assessment.

### **Menstrual history**

- Have your periods started yet? If so, how old were you when your periods started?

### **Pain during the periods**

- Do you have pain with your periods?
- Does the pain prevent you from carrying out your daily activities?
- What do you do to ease the pain?

### **Excessive bleeding during the periods**

- How many days do your periods last when they come?
- How many pads (or equivalent) do you use a day?

### **Regularity of the periods**

- Are your periods regular? Do your periods come at the same time every month?
- How many days are there normally between your periods?

### **Knowledge about sexuality**

- Have you learned about sexuality at school, at home or elsewhere?

Note: Probe to find out whether the adolescent is knowledgeable about basic anatomy and functioning, menstruation, pregnancy and contraception, and sexually transmitted infections. Do this using questions tailored to the age, level of development and circumstances of the adolescent.

### **Sexual activity**

- Depending on the context, ask whether their friends have boyfriends/girlfriends, and then whether they do so themselves.
- Again depending on the context, ask whether their friends have had sex, and then whether they have done so themselves. (Be aware that the word “sex” may mean different things to different adolescents. Probe about penetrative sex, e.g. “Does he touch your genitals only?” and “Does he put his penis in your vagina/mouth?”)

### **Pregnancy and contraception**

- Do you know how one could get pregnant?
- Do you know how one could avoid getting pregnant?
- Are you currently trying to get pregnant?
- Are you currently trying to avoid getting pregnant?

- If so, what do you do to avoid getting pregnant?
- Do you know about contraceptive methods?
- If so, do you use any contraceptive method?
- Have you had sex in the last month?
- Is your period delayed? Have you missed a period?
- Do you have any of the following symptoms of pregnancy: nausea or vomiting in the morning, and swollen and sore breasts?
- When was the last time you had sex?

**If sexually active... Sexually transmitted infections**

- Do you know what a sexually transmitted infection is?
- Do you do anything to avoid getting a sexually transmitted infection?
- Do you know about condoms? Do you use them when you have sex? If so, do you use them always? If not, why not? Where do you get condoms?
- How many sexual partners have you had in last three months?
- Have you ever had an infection: genital sore, ulcer, swelling or discharge?
- If so, have you received any treatment for this?

**I. Laws and policies that govern health service provision:**

- laws and policies that specify the age at which diagnostic tests (e.g. an HIV test) or clinical management (e.g. provision of contraception) can be done with the independent consent of the adolescent;
- laws and policies on requirements to report infections (e.g. HIV) or assault (e.g. physical or sexual assault);
- laws and policies that require partner notification (e.g. in the context of a sexually transmitted infection);
- laws and policies that require a health worker to use government-approved standards and guidelines for clinical management.

**II. Laws and policies on social issues that could affect your work with adolescents:**

- laws and policies on protecting and safe-guarding minors;
- the stipulated age of consent for sex and the stipulated age of marriage (and any discrepancies between the two);
- the stipulated age at which tobacco and alcoholic products can be sold or purchased;
- laws and policies on the possession and use of psychoactive substances;
- laws and policies on homosexuality.

# Part 3

## Information to be provided to adolescents and their parents or other accompanying adults

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### 3. Sexual activity

Sexual activity often begins during adolescence, within or outside marriage. Many adolescents become sexually active before they know how to protect themselves from unwanted pregnancies and sexually transmitted infections.

Adolescents need help to understand the changes that their bodies are going through. They also need support to deal with the thoughts and feelings that accompany their growth and development, and to make well-informed and well-considered decisions on beginning sexual activity. They also need advice and support to resist pressure to have sex against their will. Adolescents need to be well aware of the problems they could face through too-early and unprotected sexual intercourse, and about what they could do to avoid unwanted pregnancies and sexually transmitted infections. They also need to be able to obtain the health services they need to avoid health problems, and to get back to good health, if and when they experience health problems.

#### Messages for adolescents

1. Many adolescents, including older adolescents, have not started having sexual intercourse (i.e. the insertion of the penis into the vagina, mouth or anus). The decision to start to have sexual intercourse is an important one. Wait until you feel ready to do so. Do not start just because other people want you to do so.
2. Even if you have had sexual intercourse in the past, you could decide to stop doing so until you feel truly ready for it.
3. Talk to your parents or other trusted adults about how to make decisions about sexual activity, and about how to resist pressure from others to have sex.
4. As far as you can, avoid being with people or in places where you could be forced to have sex against your will.
5. Be aware that there are ways of having and giving sexual pleasure that carry no risk of becoming pregnant or getting a sexually transmitted infection. This includes kissing, caressing and touching or rubbing the genitals. (Contrary to popular belief, handling your genitals does not lead to any negative effects.)

6. If you decide to have sexual intercourse, always use a condom from start to finish.
7. If you have had sexual intercourse without a condom or other form of contraception, it is possible that you could get pregnant or a sexually transmitted infection, including HIV. You should seek help from a health worker as soon as possible. With prompt action after sexual intercourse without a condom or other form of contraception, a possible pregnancy or HIV infection may be prevented. Most sexually transmitted infections can be treated with simple medicines.

### **Messages for parents**





#### *What you should know:*

1. While many adolescents wish that they could talk to their parents about their changing bodies and about sex, they feel uncomfortable to do so. So, they turn to other sources for information. Unfortunately, much of what they learn from other sources is misleading and incorrect.
2. Some people believe that talking with adolescents about sex will lead them to have sex. This is not true. In fact, adolescents who talk with their parents are more likely to postpone sex until they are ready, and to protect themselves and others when they do begin.

#### *What you should do:*


1. As your son or daughter grows and develops from childhood into adolescence, provide them with information on an ongoing manner about their changing bodies and about sex. Ask them if they have any questions or concerns. Show them that you are open to talk to them about this and other subjects.
2. Explain that sexual feelings are normal, but that having sex should be a well-thought through decision.
3. Explain that abstaining from sex is the only completely sure way to prevent pregnancy and sexually transmitted infections.
4. Talk to your son or daughter about how to prevent pregnancy and sexually transmitted infections, even if you have stressed the importance of abstaining from sex until they are ready. Explain that while there are different options for contraception, only condoms, if used properly, can reduce the risk of both pregnancy and sexually transmitted infections.
5. Discuss the pressures that they could face to have sex before being ready for it. Discuss how they could resist such pressures.
6. Encourage them to seek help from a health worker for advice and support, if and when they need to do so.

# “Could I have HIV?”

Ask	Look/Feel/Listen	Symptoms & Signs
<p> <b>TIP for the health worker:</b> Say that you are now going to ask him/her some personal questions and reassure him/her that information will be kept confidential.</p> <p><b>Why do you think you could have HIV?</b></p> <p> <b>TIP for the health worker:</b> Allow the adolescent to speak without interruption. This is an opportunity to learn about his/her understanding of how one could get HIV.</p> <p><b>Symptoms associated with HIV infection</b></p> <ul style="list-style-type: none"> <li>• Do you have/have you had recently           <ul style="list-style-type: none"> <li>– Noticeable weight loss</li> <li>– Prolonged diarrhoea</li> <li>– Prolonged cough</li> <li>– Prolonged fever</li> <li>– Painless purple bumps on your skin or in your mouth</li> <li>– White patches in your mouth</li> <li>– Painless swellings in your glands</li> </ul> </li> </ul> <p><b>Illness associated with HIV infection</b></p> <ul style="list-style-type: none"> <li>• Have you ever been diagnosed with tuberculosis?</li> </ul> <p><b>Risk factors for HIV infection</b></p> <ul style="list-style-type: none"> <li>• Do you use a condom every time you have sex?</li> <li>• Do you have/have you had many sexual partners?</li> <li>• Does your partner have/has your partner had other partners?</li> <li>• Have you had unprotected sex in last 72 hours?</li> <li>• Do you/have you inject(ed) drugs?</li> </ul> <p><b>Symptoms of STI syndromes</b></p> <ul style="list-style-type: none"> <li>• Do you have/have you had?           <ul style="list-style-type: none"> <li>– Sore/ulcer on your genitals</li> <li>– Discharge from your vagina</li> <li>– Discharge from your penis</li> <li>– Scrotal pain/swelling</li> </ul> </li> </ul> <p><b>Do a Sexual and Reproductive Health Assessment</b></p> <p><b>Do HEEADSSS Assessment</b></p>	<p> <b>TIP for the health worker:</b> Say that you are now going to examine him/her. Ensure privacy of the examination setting. For young women, have a female colleague present if needed.</p> <p><b>Signs associated with HIV infection</b> Check for</p> <ul style="list-style-type: none"> <li>• Weight loss of more than 10% (if previous weight is available)</li> </ul> $\% \text{ Weight Loss} = \frac{(\text{Old Weight} - \text{New Weight}) \times 100}{\text{Old Weight}}$ <ul style="list-style-type: none"> <li>• Kaposi lesions (painless purple lumps on the skin of the palate in mouth)</li> <li>• Fungus infection in the mouth</li> <li>• Generalized lymphadenopathy</li> <li>• Evidence of serious infection (e.g. respiratory infection)</li> </ul> <p><b>Signs of STI syndromes</b> Check for</p> <ul style="list-style-type: none"> <li>• Genital ulcer</li> <li>• Swelling in the groin</li> <li>• Discharge from the vagina</li> <li>• Discharge from the penis</li> <li>• Scrotal swelling</li> </ul> <p> <b>TIP for the health worker:</b> Current or past STI constitutes a risk factor for HIV infection</p> <p><b>Do a General Physical Examination</b></p>	<p>Any symptom associated with HIV infection or Any sign associated with HIV infection or Any illness associated with HIV infection (With or without identified risk factors)</p> <p>Any risk factor for HIV infection <i>and</i> No symptoms associated with HIV infection <i>and</i> No signs associated with HIV infection <i>and</i> No illness associated with HIV infection</p> <p>No risk factor for HIV infection <i>and</i> No symptoms associated with HIV infection <i>and</i> No signs associated with HIV infection <i>and</i> No illness associated with HIV infection</p>

**Adolescent:** I had sex last week and I am worried that I may have HIV. I have had this cough for two weeks. Could it be AIDS?

**Parent:** My son/daughter has been ill for sometime. Could he/she have HIV?

Classify	Manage	Follow-up
<b>Possible HIV infection causing symptoms, signs or illnesses commonly associated with HIV infection</b>	<p>Explain the classification</p> <p>If available on site, provide HIV testing and counselling</p> <p>If not available on site refer to a facility that offers HIV counselling and testing</p> <p>Provide counselling on safer sex/HIV risk reduction</p> <p>Treat any HIV related illness that have been identified (Refer to AMAI Guidelines)</p>	Agree on a follow-up visit or refer the adolescent elsewhere
<b>At risk for HIV infection</b>	<p>Explain the classification</p> <p>Provide counselling on safer sex/HIV risk reduction</p> <p>If available on site, provide HIV testing and counselling</p> <p>If not available on site refer to a facility that offers HIV counselling and testing</p>	Agree on a follow-up visit or refer the adolescent elsewhere
<b>HIV infection unlikely</b>	<p>Explain the classification</p> <p>Provide counselling on safer sex/HIV risk reduction in all cases</p> <div data-bbox="322 1177 801 1391"> <p> <b>TIPS for the health worker:</b></p> <p><i>Treat all classified STI syndromes using the appropriate algorithm.</i></p> <p><i>Encourage the adolescent to ask all partner(s) within the last two months to have themselves checked by a health worker whether they are symptomatic or not.</i></p> <p><i>Counsel regarding contraception and safer sex.</i></p> </div>	

## Information to be given to adolescents and accompanying adults

### ***Information to be provided and issues to be discussed before an HIV test is carried out:***

#### **1. Check the adolescent's understanding of key information on HIV.**

- What is HIV?
- How is HIV spread (and how it is not spread)?
- How could HIV infection be prevented?
- What are the effects of HIV on the body?
- What is it that health workers can offer to people who have been found to have HIV?

(If necessary, fill knowledge gaps and correct misconceptions.)

#### **2. Provide key information about the HIV test.**

##### *(i) What is an HIV test?*

An HIV test is a blood test which detects the presence of natural chemicals (antibodies) that the body produces in response to the presence of HIV germs in the body. These antibodies are produced by the body 8–12 weeks after being infected with HIV.

##### *(ii) What does a positive or a negative HIV test result mean?*

An HIV-positive test result means that the person who has been tested has HIV infection. An HIV-negative test result means that the person who has been tested does not have HIV infection. However, as mentioned above, the antibodies that are detected by the HIV test are not produced by the body until 8–12 weeks after infection with HIV. Therefore, in the three months after infection occurs, the HIV test can still be

negative although the person tested has HIV infection.

##### *(iii) What are the reasons for having an HIV test?*

There are at least four good reasons for having an HIV test:

- Health workers can provide effective medicines to prevent HIV germs from multiplying in the body.
- Health workers can provide medicines to prevent or treat other illnesses resulting from the effects of HIV on the body (e.g. tuberculosis).
- If a woman who is infected with HIV wants to have a baby, she can be given medicines to reduce the likelihood of the HIV infection passing from her body to that of the baby (in her womb).
- Knowing whether one is HIV infected or not can help one to take the necessary steps to protect both oneself and others from infection.

#### **3. Assure confidentiality and ongoing support.**

Firstly, assure the adolescent that the test results will not be shared with anyone. Secondly, assure the adolescent that if he/she is found to have HIV infection, every effort will be made to provide him/her with the needed care and support either on the spot or from other sources of care and support.

#### **4. Confirm the willingness of the adolescent to proceed with the test, and if so, obtain his/her informed consent to undertake the test.**

Informed consent means that the adolescent has been provided with key

information about HIV and about HIV testing, has fully understood it and has agreed to undergo the test. Ask the adolescent if he is willing to take the test and if so, ask him to clearly say that he consents to undergoing the test. Remember that the patient has the right to refuse an HIV test.

***Information to be provided and issues to be discussed before the HIV test results are disclosed:***

- recall the discussion on the meaning of a positive and negative test result;
- enquire whether the adolescent has considered whom to share the result with;
- empathize with the adolescent, saying that you are aware that waiting for the test result must have been hard. Assure him/her of your support.

***Information to be provided and issues to be discussed if the result is positive (i.e. it confirms that the person has HIV infection):***

- share the test result;
- appreciate that the ‘bad’ news is likely to trigger a strong reaction; empathize with and comfort the adolescent;
- check the adolescent’s understanding on the implications of the test result and provide further explanation if needed;
- discuss whom they would share the result with;
- explain what support services could be provided;
- explore what immediate support they need;

- indicate when they could come back for further discussion.

**Support disclosure:**

Tell the adolescent that it would be useful to consider whom he/she would inform if found to have HIV. Parents, other members of the family, as well as friends could be a valuable source of support.

Ask the adolescent to identify one or two people whom he/she likes, trusts and could turn to for help.

***Information to be provided and issues to be discussed if the test result is negative (i.e. it confirms that the person does not have HIV infection):***

- share the test result;
- appreciate that even hearing the good news is likely to trigger a reaction in the young person; give the adolescent some time to calm down;
- check the adolescent’s understanding on the implications of the test result and provide further explanation if needed;
- Stress the importance of taking steps to continue staying HIV-negative by protecting himself/herself and indicate what support you could provide for this.

***Tip for the health worker:***

In case the exposure occurred less than three months prior to the HIV test, explain that a negative result could mean either that the adolescent is not infected with HIV, or that infection has occurred but that antibodies to HIV have not yet been produced by the body. Advise a repeat HIV test in 6–8 weeks.

## **Annex 5: Scenarios using the 5 “A”s with an adolescent patient**

### **Instructions for group work**

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For their specific scenario, each group should:

- identify the important issues in relation to each of the 5 “A”s that the health worker needs to consider for the adolescent patient in their scenario;
- keep the particular needs and challenges of the adolescent patient in mind while working on the scenarios;
- use the 5 “A”s on the IMAI wall chart for guidance;
- write the important issues on the flipchart under each “A”. For some “A”s there may not be a particular issue to address in your scenario;
- remember to focus on what is different because the patient is an adolescent.

You have 15 minutes to work together and write your responses on a flipchart.

The facilitator will tell the groups to either report back to plenary as a presentation (with a participant using the flipchart in plenary) or as a role play (with two participants in a role play in plenary).

Each group should prepare a flipchart regardless of the method they will use to report back.

## **Scenario 1: Mary**

Mary is 17 years old. She has been married for one year. She went to the health centre two weeks ago for a follow up visit for contraception. The nurse told her that HIV testing was available at the clinic and asked her if she wanted to be tested. Mary talked with the nurse and decided she wanted to discuss HIV testing with her husband, Peter, who is a 25-year-old farmer.

Last week Mary and Peter came back to the clinic for testing. Both Mary and Peter had positive HIV test results. They are both asymptomatic. Mary says she has come to the clinic today because she has been having bad headaches. After examination and discussion, it is clear to the health worker that the headaches are most likely related to the stress that Mary is feeling since she learnt about her diagnosis.

## **Scenario 2: Franco**

Franco is 15 years old. He has lived on the streets ever since he left home three years ago. He works with a small bus company. He likes his life and often hangs out with a group of friends. They like to drink cheap alcohol together and occasionally inject drugs. When they have the money they pay women for sex.

He came to the clinic because he had heard of AIDS and is concerned for his health. Today his test result shows he is HIV-positive.

## **Scenario 3: Shanaz**

Shanaz is 13 years old. She was born HIV-positive. Her mother died of AIDS when Shanaz was four years old and she went to live with her grandmother. Her grandmother now looks after eight children.

Shanaz knows she is HIV-positive and has been visiting the paediatric clinic since she was a baby, and is well known as a patient. She is still on first-line treatment and is doing well. Generally, she is quite healthy although she gets infections easily.

She has come to the clinic today because she woke this morning with blood between her legs and this frightened her. After examining Shanaz, the health worker can reassure her that this is her menarche.

## **Scenario 4: Cheng**

Cheng is 19 years old. He has completed his high school certificate and has been working in a bank for a year. He says he enjoys parties and admits he has had many sexual partners.

He applied for a scholarship to study abroad and has been accepted. The scholarship is dependent on a medical examination and includes an HIV test. He has come to the clinic today for the results of his medical examination.

He was asymptomatic, but the HIV test result showed that Cheng has antibodies to HIV.

## **Scenario 5: Benton**

Benton is a 14-year-old boy with perinatal HIV. He has been brought to the health centre by his uncle. He is an orphan and lives with his uncle and his family. He is enrolled in school but rarely attends. His uncle says that Benton is often out all night and comes home drunk.

His family knows he is HIV-positive and they accept his diagnosis. His uncle is also HIV-positive. The family is upset with his behaviour and are afraid for him.

The uncle says that Benton used to be a good student and did well in school. Recently he has not even been taking his ARVs regularly. His uncle is angry with his nephew and says that he found medication thrown away in the outhouse. He wants the health worker to frighten Benton into taking his medication.

## **Scenario 6: Lisbeth**

Lisbeth is 19 years old. She tested positive for HIV when she was 16 years old. Lisbeth has been living with HIV for three years, has not been unwell during this time and has not begun ART. She did well in school and now has a good job. She lives at home.

Her family and a few close friends know that she is HIV-positive and she feels well supported. She has had a few boyfriends over the years and she says they always used a condom during penetrative sex. She has not told her boyfriends that she is living with HIV.

Lisbeth has come to the clinic today with a cold. The cold is not serious and it is clear to the health worker that Lisbeth’s real reason for coming is that she wants to talk. Lisbeth says she wants to get married in the future and is afraid she will never be able to get married or have children because of her HIV status.

Lisbeth has come to the clinic today with a cold. The cold is not serious and it is clear to the health worker that Lisbeth’s real reason for coming is that she wants to talk. Lisbeth says she wants to get married in the future and is afraid she will never be able to get married or have children because of her HIV status.

## Scenario 7: Georgio

Georgio is a thin, unwell-looking young man of 18 years. He comes to the clinic angry and upset. He tells the health worker that someone at the clinic must have told his mother that he is HIV-positive.

He shouts and bangs the desk. When he is calmer, the health worker asks him to say what actually happened. Georgio says that last night when he returned home from work his stepfather shouted at him to “take his filthy AIDS body away” and threw him out of the house. His mother was crying inside the house.

Georgio says he has not told anyone that he is HIV-positive since he was tested here at the clinic six months ago. So he feels that someone at the clinic must have told his mother or his stepfather.

## Scenario 8: Lena

Lena is 18 years old and has perinatally acquired HIV. She has been married to David for two years. He is also living with HIV. Lena is well. She has been taking ARVs for many years. She has come to the clinic today because she wants to have a baby.

### Important issues that need to be addressed in Scenario 1

Mary needs post-test counselling and continued support to help her understand and cope with her diagnosis. The health worker could use the *Flipchart for patient education* to explain basic information about HIV.

Mary needs to understand what is available for chronic HIV care (see *IMAI-IMCI Basic HIV care with ART and prevention* guideline module, pages H80–H84)

- Assess Mary’s headaches.
- Assess her understanding of the diagnosis.
- Assure confidentiality – she may need reassurance of this.
- Advise on fertility (see *IMAI-IMCI Basic HIV care with ART and prevention* guideline module, page H69): She is very young and has no children (is there pressure on her to have children?).
- Offer partner counselling: Is it a supportive relationship, or is there concern of domestic violence?
- Agree on disclosure: Discuss benefits of telling family or friends her concerns.
- Assist with positive test counselling, positive living and dual protection (see *IMAI-IMCI Basic HIV care with ART and prevention* guideline module, pages H72–73).
- Arrange a follow-up visit, and referral to a support group.

## **Important issues that need to be addressed in Scenario 2**

Franco’s social situation (living on the street, substance use, client of commercial sex worker) is a major factor in planning his support and care. His situation and behaviour will not necessarily change with his HIV diagnosis. The attitude of the health worker is key to successfully communicating with Franco (such as being non-judgemental, not telling him what to do). He is a minor without a parent or guardian present.

Franco’s personal concern for his health is an important entry point for behaviour change.

- Assess his reaction to the new diagnosis of HIV.
- Assess his knowledge of HIV, his support network and his concern for his health.
- Advise on positive prevention, relating to substance use, safe injecting and condom use.
- Agree on positive prevention.
- Assist with HIV information and support services, referring as necessary.
- Arrange a return visit.

## **Important issues that need to be addressed in Scenario 3**

Shanaz does not realize this is her menarche. She needs reassurance, education on sexuality and practical information about reproduction. She needs to be prepared for her emerging sexuality.

Her support network needs to be assessed (other family members, peer support).

Shanaz has come as an unaccompanied minor. Consider the best interests of this adolescent and encourage involvement of other supportive adults.

- Assess her knowledge of reproduction and sexuality.
- Assess adherence.
- Assess her support network, and encourage involvement of grandmother or others, as Shanaz wishes.
- Advise on maintaining general health (nutrition, hygiene, exercise, etc.).
- Advise on preparing for transition of care.
- Agree on disclosure; who else could/should know of her HIV diagnosis and can offer support.
- Assist with support network (e.g. peer group, school).
- Arrange a follow-up visit.

### Important issues that need to be addressed in Scenario 4

Cheng is asymptomatic and has received his HIV diagnosis today. His HIV test could prevent him from being able to accept the scholarship. He needs support at this time to cope with his new diagnosis and follow-up care to assess his mental state (there is an algorithm in the *Adolescent job aid* that deals with anxiety and depression). This was a mandatory HIV test that will impact on Cheng's immediate and future plans, and opportunities.

Whether his sexual partners are male or female may determine the peer support Cheng will need. Health workers should not assume sexual orientation and need to take care not to be judgemental in words or attitude when caring for patients of a different sexual orientation.

- Assess his reaction to the diagnosis.
- Assess his understanding of HIV.
- Assess his support network and mental state, and discuss disclosure.
- Advise on positive prevention including condoms.
- Agree on disclosure (to whom, how and when).
- Assist with referral to support services.
- Arrange a follow-up appointment with a health worker.

### Important issues that need to be addressed in Scenario 5

These important issues should be discussed either alone with Benton or with his uncle present, as appropriate. If discussed with Benton alone, the health worker needs to also talk later with the uncle present (having obtained Benton's agreement to this).

The health worker needs to give Benton information on how his behaviour will affect his health. The health worker also has to understand why Benton is not taking his ARVs, assess whether he would take his ARVs if the obstacles to his adherence were addressed, and give him the support he needs to maintain adherence.

- Assess treatment and non-adherence.
- Assess Benton's understanding of ART and his reasons for not taking his ARVs.
- Assess options for peer support to improve adherence.
- Assess risk factors (e.g. sexually active, substance use) – this should be done with Benton alone.
- Advise on adherence.

- Advise on positive prevention – with Benton alone.
- Agree on positive prevention (if sexual activity, offer condoms and demonstration of use).
- Agree on the treatment plan and Benton's role in maintaining adherence.
- Assist with Benton's obstacles to adherence and discuss possible future obstacles to adherence.
- Arrange links to peer support services or an adherence buddy.
- Arrange the next appointment.

### **Important issues that need to be addressed in Scenario 6**

Lisbeth wants reassurance from the health worker that she will be able to marry even if she is living with HIV. Lisbeth reports that she has been practicing safe sex and preventing the transmission of HIV to her boyfriends. She appears to be behaving responsibly and needs recognition for this and encouragement to continue.

The health worker can discuss the benefits of disclosing her HIV status to future boyfriends. If Lisbeth is looking for a husband, the relationship will need to be based on mutual trust from the beginning. Many people living with HIV get married to others who are also living with HIV or to those who are HIV-negative or to people who do not know their HIV status.

She may benefit from a support group where she can discuss these issues with peers who are living with HIV.

- Assess her support structure.
- Assess contraception (prevention of HIV transmission and pregnancy).
- Assess her understanding of HIV transmission routes.
- Advise attending an HIV support group.
- Discuss when and how to disclose her HIV status.
- Assist in skills to negotiate safer sex.
- Arrange a return visit and for couple counselling if she wishes in the future.

### **Important issues that need to be addressed in Scenario 7**

Georgio is angry at his situation and blames the staff at the clinic. The health worker may not know if his blame is justified, and should tell Georgio that “we do not know”. The health worker can suggest that they discuss Georgio’s situation now that his family knows his HIV status, rather than discuss blame. It is possible that his appearance may have alerted his family to his HIV status.

Later the health worker may need to discuss with the clinic staff whether there could have been a breach of confidentiality.

- Assess Georgio’s physical and mental health today.
- Assess his options for shelter and support today.
- Assess his health-risk behaviours.
- Advise on positive prevention and living with HIV.
- Agree on confidentiality and beneficial disclosure.
- Agree on immediate action plan for the social situation.
- Assist with referral to social support and peer support.
- Arrange a follow-up visit.

### **Important issues that need to be addressed in Scenario 8**

All people, including people living with HIV, have the right to reproductive choice (to choose to have or not have a baby). The health worker’s role is to explore and explain the risks for Lena and for the baby. If there is a PMTCT service, the health worker can refer Lena to the appropriate clinic.

- Assess Lena’s health and ART adherence.
- Advise Lena on the risks of becoming pregnant.
- Advise on the risks for babies of HIV-positive mothers.
- Advise on current recommendations for pregnant women living with HIV including breastfeeding.
- Advise Lena to discuss this information and risks with David.
- Assist with couple counselling if Lena wishes.
- Arrange referral to a support group.
- Arrange referral to a PMTCT clinic, if available.

# Annex 6: Individual action plan

Action Plan	
1. What changes do I plan to make in my everyday work with/for adolescents living with HIV?	<div></div> <div></div> <div></div> <div></div>
2. Why do I believe this change is important and who or what will benefit and why?	<div></div> <div></div> <div></div> <div></div>
3. How will I know if I have been successful and when will I know this?	<div></div> <div></div> <div></div> <div></div>
4. What personal or professional challenges do I anticipate in carrying out these changes?	<div></div> <div></div> <div></div> <div></div>
5. What help am I likely to need and who could provide me with this help?	<div></div> <div></div> <div></div> <div></div>

## **Annex 7: Scenarios for role play (for Optional Session)**

### **Role play demonstration and practice on the 5 “A”s – Optional Session C**

#### **Instructions for group work**

The objectives of this role play activity are to focus on the needs of adolescent patients and to give you an opportunity to consider the skills necessary to counsel an adolescent living with HIV.

The participants will be divided into four groups.

The facilitator will allocate one of the two scenarios below to each group.

Each group should decide who will play the health worker. An adolescent EPT or another participant will play the adolescent (if available)

Each couple acts out their scenario to their group. The role play will run for 3–5 minutes.

The other participants should observe what the health worker does or says that makes a difference to the way the adolescent reacts; what kind of “body language” is used by the health worker and the adolescent; what attitude the health worker displays towards the adolescent; and any difficulties the health worker experiences.

When they have finished, allow the two role players to come out of their roles and then discuss the interview. The health worker can speak first, then the adolescent and finally the rest of the group can give feedback.

Comments should focus on what happened in the role play, and not general issues that can be taken up later. Begin by having each of the role players say how they felt in the role (in addition to what they thought). When they have finished the group can respond. If necessary, refer to any behaviour that was significant and comment on it.

Give helpful positive and negative feedback. When the group has finished commenting, go back to the role players to give them a final feedback.

Consider what went well and what was difficult in the role play.

## Scenario One

Yugo is a 16-year-old boy who tested positive for HIV three weeks ago. He has come alone to the clinic today and appears distressed. He says he has not told anyone that he is HIV-positive and has felt both sad and angry much of the time since his HIV diagnosis. His girlfriend is upset with him because of the way he is behaving. His school work is getting neglected. His parents are worried and have tried to talk with him. He feels healthy. He does not know what to do.

## Scenario Two

Janine is a 15-year-old girl who acquired HIV perinatally. She has known she is HIV-positive for many years and has been coming to the health centre since she was a baby. She has been taking ARVs and generally feels well. She has had few problems with her health over the years.

Her mother died when Janine was seven and she has been living with her grandmother ever since. Her grandmother knows that Janine is HIV-positive but does not like to talk about it. Janine does not know her father. She has a close group of friends but none of them knows she is HIV-positive.

She has come today because she wants to talk about her friend Marco. He is a boy she likes very much and she knows that he likes her. She is worried because she does not want to put him at risk of acquiring HIV.

She has strong feelings for him. They have been arguing recently because she has been putting off having any physical contact with him. He has been trying to kiss her.

She has come today to ask your help to decide what to do.

## Notes





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*Participants Manual* – IMAI One-day Orientation on Adolescents Living with HIV

ISBN 978 92 4 159897 2



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