

*HIV and adolescents: guidance for HIV testing and counselling and care for adolescents living with HIV*

**ANNEX 8: Decision-making tables**

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PICO 1
<p><b>1. Topic for analysis:</b> Should HTC be offered to adolescents from key populations in all settings?</p>
<p><b>2. Background:</b> Previous WHO guidance on HTC has concentrated almost exclusively on supporting provider-initiated or client-initiated HTC for individuals in general, with recent guidance issued in 2011 focusing on HTC for couples. UN guidance addressing the particular situations, challenges and needs of adolescents (10-19 years) and their health-care providers has not been developed. Access to and uptake of HTC by adolescents is lower than for many other groups, leaving them disadvantaged in terms of seeking prevention, treatment and care services. Late diagnosis of HIV infection for perinatally infected adolescents is increasingly being recognized as a significant problem leading to delayed initiation of ART, again highlighting the need to provide more effective HTC for adolescents. Late diagnosis is also an issue for adolescents from key populations who are infected horizontally but who are often reluctant to seek services due to stigma, discrimination and the potential for legal consequences.</p>
<p><b>3. DRAFT recommendation:</b> HIV testing and counseling with linkage to prevention, treatment and care is recommended for adolescents from key affected populations in <u>all</u> settings (generalized, low and concentrated epidemics).</p>
<p><b>4. Summary and quality of evidence:</b> Despite the low quality of evidence, the values and preferences as well as programme experience and expert opinion pointed to significant benefits when adolescents from key populations have improved access to HCT.</p> <p>The quality of evidence was VERY LOW. The RCT data was graded down for risk of bias, serious indirectness and very serious imprecision.</p> <p>The observational data was downgraded for serious indirectness as it was a testing intervention only and very serious imprecision was present due to the small sample size.</p> <p>Limited studies in adolescent populations. Two RCTs and one observational study of adolescents were identified. The two RCTs were conducted in public STI clinics in the USA and in a substance misuse clinic in the UK.</p>
<p><b>5. Risks/benefits</b></p> <p><b>Benefits</b> Data from a sub-group analysis of the adolescent data (ages 14 to 20) in the USA study demonstrated that HTC compared with no HTC lowered STI incidence at 12 months.</p> <p>The UK RCT found that participants who received HTC might be more likely to attend follow-up at a STI clinic after one week, were more likely to receive HIV, HAV and HCV testing, and might be more likely to receive all three doses of HAV and HBV vaccine at 1 week follow-up.</p> <p><b>Risks</b> Stigma, discrimination and legal consequences for adolescents from key populations if HTC not conducted according to existing WHO guidance on HTC and adhering to the 5 C's: Consent, Confidentiality, Counselling, Correct test results, Connections to treatment, care and prevention services.</p>

Based on available evidence, overall benefits judged to be potentially greater than potential harms.

## 6. Acceptability, values and preferences

<b>Community</b>	Adolescent participants report strong desire to test, motivations to test and awareness of responsibilities and benefits of testing
<b>Health-care workers</b>	Offering effective HTC services and encouraging adolescents to access them is considered to be a high priority for service providers as they recognize that adolescents are at high-risk of HIV infection. Services and policies around HTC are not often geared specifically towards adolescents and their needs are underserved.
<b>Other</b>	Legal issues and barriers exist in some settings which need to be considered – e.g. compulsory notification of certain risk behaviours and HIV test results, mandatory testing and criminalization of transmission

### In favour

- Adolescents who perceive themselves to be at risk for HIV want accessible and acceptable HTC services.
- Empowers adolescents to get life-saving care.
- Gives adolescents access to what is really happening to their bodies- the test doesn't give them HIV but the opportunity to do something about it, either immediately or in the future.
- Observed benefits of earlier access to HIV treatment and care and support for informed decision-making around prevention.
- Sense of responsibility to protect themselves and others.

### Against (Expressed as barriers to HTC)

- Fear
- Implications of a positive diagnosis
- Association with 'bad' and high risk behaviour
- Stigma and its consequences
- Attitudes of health workers
- Accessibility and acceptability of services
- Age of consent issues unresolved in many countries

### Pros

Significantly underserved population that is systematically neglected in many public health programs, thus recommendation to provide accessible and acceptable services for these key populations is critical to provide linkage to care and prevention.

### Cons

- Concern about possible repercussions in settings where key populations face criminal prosecution, stigma and discrimination.
- There was a strong sense of certainty about the importance of increased access to HTC for adolescents among community consultation participants.
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## 7. Equity, ethics and human right implications

Age of consent to test varies across countries and presents the greatest challenge to implementation of this recommendation. National consent policies can discourage uptake of services by adolescents and constrain providers who may have concerns about legal consequences for themselves and emotional consequences for adolescents who may not be able to cope with the implications of a positive diagnosis and who may not have adequate support in the home.

Mandatory or coerced testing is never appropriate. It is particularly important in that health workers are sensitive to the particular needs of adolescents and that they understand the issues and challenges facing adolescents, especially

those from key populations.

Many people with HIV have experienced discrimination and stigma following diagnosis. Adolescents from key populations in particular often face hostile legal environments as well as emotional and physical violence, and their needs for services and support must be addressed as part of HTC services. Providers of services for adolescents must receive training on human rights and protection issues and be aware of all relevant support services for timely and appropriate referrals.

Adherence to fundamental principles of human rights is foremost among all considerations when providing HTC services for adolescents. Most importantly:

- HTC is always voluntary.
- Privacy and confidentiality must be protected for adolescents as for adults.
- Adolescents have a right to make decisions and seek services in the interest of their own health and well-being.

### **8. Cost/resource use**

HTC services for key populations need adequate resources for supply of quality test kits, quality assurance measures to ensure correct test results, training of counsellors/service providers to make sure that HTC is delivered in a supportive and acceptable way and links provided to HIV prevention, care, support and treatment services.

The costs of providing HTC services for adolescents from key populations need to be calculated, but these costs can be estimated with certainty. Population size estimates and demand estimates are less certain and will need to be considered for each setting.

### **9. Cost-effectiveness**

In resource-constrained countries it will be especially important to distinguish between sub-national epidemics to avoid diversion of scarce resources and prioritize service coverage according to epidemiology and need.

In countries with low and concentrated epidemics, prioritization of HTC services for adolescents from key populations will be significantly more cost effective than provision of HTC for all adolescents. In countries with generalized epidemics there are often adolescents from key populations who are not reached by interventions for the general population and because of the significantly higher HIV prevalence and incidence rates in these groups it will be cost effective to provide services specifically tailored to their needs.

### **10. Feasibility and constraints to implementation**

The recommendation is feasible pending:

- Review and modification of the legal environment, especially regarding criminalization of certain practices common to adolescent key populations
- Age of consent to test issues resolved
- Training of health workers in working with adolescents and key populations
- Availability and acceptability of related services

There is some uncertainty to the feasibility of this recommendation in settings with legal issues that are not compatible with WHO recommendations on HTC.

### **11. Relevance to different settings/populations**

**Key affected populations include:**

- Adolescent men who have sex with men
- Adolescents who use drugs
- Adolescents who are sexually exploited including in the context of sex work
- Transgendered adolescents

**Settings:**

- Depending on the setting and context, there may be additional populations who have increased

vulnerability for HIV and who also need targeted interventions to improve access to HCT – these may include orphans and sexual partners of key populations. It is advised that ‘increased vulnerability’ be the distinction for key populations in order to ensure that additional groups (certain groups of adolescent girls – e.g. girls in child-headed households, incarcerated youth and orphans) are included in programme planning.

## 12. Gaps, research needs, comments

Issues that need to be addressed in order to assess the degree to which the needs of key populations are understood and addressed in HTC, treatment and care programmes include:

- How do existing national data collection systems support targeting and monitoring those who need HIV services most?
- What are the characteristics of marginalized individuals who do not fit into currently understood KP groups?
- M&E / documentation of successful models and best practice of community-based delivery of services for key populations.

## 13. Final comment(s)

In developing these recommendations, the panel placed high value upon:

- Increasing access and acceptability of HTC services for adolescents from key populations
- Reduction of HIV transmission in all epidemic settings
- Improved linkages to supportive services (prevention, treatment and care)
- Caution, particularly in low and concentrated epidemic settings, not to overtly single out key populations when promoting services
- Monitoring and evaluation as part of all interventions.

Targeting key populations can be extremely stigmatizing, and for this reason, the Guidelines Group emphasized:

- The recommendations need to be clear that access to testing is for everyone. In concentrated epidemics, testing should be available if an adolescent asks for it, but in general there should not be specific campaigns promoting testing for the general adolescent public as this is not likely to be cost-effective or adequately reach adolescents from key populations.
- Approaches to testing must be non-judgmental if HCWs are to gain the confidence of adolescents from key populations; special sensitivity training may be needed.
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## 14. Rationale for recommendation:

HIV testing and counselling is an essential component of efforts to achieve universal access to HIV prevention, treatment, care and support. It is the key entry point for many HIV prevention interventions and it is essential for access to treatment and care. Regardless of HIV acquisition route, underutilization of testing and counselling services results in late diagnosis, and increasing uptake of HTC will lead to earlier diagnosis and more effective care. Due to the increasing availability of ART and prevention interventions, early diagnosis can reduce transmission and improve health outcomes, thereby decreasing morbidity and mortality.

Late diagnosis of HIV infection for perinatally infected adolescents is increasingly being recognized as a significant problem leading to delayed initiation of ART, and poor linkages to and retention in care, support for sustained treatment adherence, and LTFU are challenges in many settings.

Adolescents who learn that they have HIV infection can learn to reduce the risk of transmitting HIV to others, as well as to obtain HIV treatment and care. Early access to care can help them to feel better and to live longer than if they were to present for care when their disease is already at an advanced stage. Early access to care can also help adolescents to reduce on-going transmission. As for adults, HIV testing and counselling can serve as a means for adolescents to be diagnosed and to receive treatment and care as early as possible. Access to HTC is also important for adolescents to help them make decisions about HIV prevention choices.

Adolescents from key populations are of critical importance in that they are more vulnerable to abuse, stigmatization, exclusion and legal consequences than other adolescents. For this reason, they are more likely to avoid HTC services and therefore be excluded from the benefits of testing, counselling and related prevention,

treatment and care services.

### 15. Strength of recommendation

Strong recommendation, very low quality evidence

## PICO 2

### 1. Topic for analysis:

Should HTC be offered to all adolescents in generalized epidemic settings?

### 2. Background:

Previous guidance on HTC has concentrated almost exclusively on supporting provider-initiated or client-initiated HTC for individuals in general, with recent guidance issued in 2011 focusing on HTC for couples. UN guidance addressing the particular situations, challenges and needs of adolescents (10-19 years) and their health-care providers has not been developed. Access to and uptake of HTC by adolescents is lower than for many other groups, leaving them disadvantaged in terms of seeking prevention, treatment and care services. Late diagnosis of HIV infection for perinatally infected adolescents is increasingly being recognized as a significant problem leading to delayed initiation of ART, again highlighting the need to provide more effective HTC for adolescents.

### 3. DRAFT recommendation:

In generalized epidemics, HIV testing and counselling with linkage to prevention, treatment and care is recommended for all adolescents.

### 4. Summary and quality of evidence:

Despite the low quality of evidence, there was strong consensus that based on strong values and preferences, a strong recommendation was warranted.

The quality of evidence was VERY LOW. The evidence review showed that there are no studies comparing testing to no testing in adolescent populations. In addition, there are very few studies in adults that have looked at critical outcomes of interest such as linkage to treatment and care.

### 5. Risks/benefits

#### Benefits

One RCT found that HTC reduces STI incidence in the 6 months following HCT.

One RCT found that HTC reduces reported unprotected sex with a non-primary partner at 6 month after HCT.

One RCT found that HTC increases uptake of pre-ARV care at 5 months follow-up.

#### Risks

One RCT found that HTC may reduce attendance at HIV clinics and reduce survival at 6 months following HTC.

Based on available evidence, overall benefits judged to be potentially greater than harms.

### 6. Acceptability, values and preferences

<b>Community</b>	Adolescent participants report strong desire to test, motivations to test and awareness of responsibilities and benefits of testing
<b>Health-care workers</b>	Offering effective HTC services and encouraging adolescents to access them is considered to be a high priority for service providers as they recognize that adolescents are often at high-risk of HIV infection. Services and policies around HTC are not often geared specifically towards adolescents and their needs are underserved.

**Other**

Legal issues and barriers exist in some settings which need to be considered – e.g. compulsory notification of certain risk behaviors and HIV test results, mandatory testing and criminalization of transmission

**In favour**

- Adolescents who perceive themselves to be at risk for HIV want accessible and acceptable HTC services.
- Observed benefits of earlier access to HIV treatment and care and support for informed decision-making around prevention.
- Sense of responsibility to protect themselves and others.

**Against** (Expressed as barriers to HTC)

- Fear.
- Implications of a positive diagnosis.
- Association with ‘bad’ and high-risk behaviour.
- Stigma and its consequences.
- Attitudes of health workers.
- Accessibility and acceptability of services.
- Age of consent issues unresolved in many countries.

**Pros**

- HTC empowers young people to get tested.
- HTC gives a sense of responsibility to adolescents.
- Ensures that adolescents have access to health-care services (enshrined in the UN Convention on the Rights of the Child).
- Both HCWs and adolescents desire better access to HTC for adolescents.
- Cost of NOT testing adolescents in a generalized epidemic results in increased morbidity, mortality and fewer opportunities for prevention.

**Cons**

- Stigma.
- Judgmental HCWs and perceived lack of confidentiality.

**7. Equity, ethics and human right implications**

Age of consent to test varies across countries and may present a significant challenge to implementation of this recommendation. National consent policies can discourage uptake of services by adolescents and constrain providers who may have concerns about legal consequences for themselves and emotional consequences for adolescents who may not be able to cope with the implications of a positive diagnosis and who may not have adequate support in the home.

Mandatory or coerced testing is never appropriate. It is particularly important in that health workers are sensitive to the particular needs of adolescents and that they understand the issues and challenges facing adolescents.

Many people with HIV have experienced discrimination and stigma following diagnosis. Providers of services for adolescents must receive training on human rights and protection issues and be aware of all relevant support services for timely and appropriate referrals.

Adherence to fundamental principles of human rights is key among all considerations when providing HTC services for adolescents. Most importantly:

- HTC is always voluntary.
- Privacy and confidentiality must be protected for adolescents as for adults.
- Adolescents have a right to make decisions and seek services in the interest of their own health and well-being.

**8. Cost/resource use**

HTC services for adolescents need adequate resources for supply of quality test kits, quality assurance measures to ensure correct test results, training of counsellors/service providers to make sure that HTC is delivered in a supportive and acceptable way and links provided to HIV prevention, care, support and treatment services.

The costs of providing HTC services for adolescents need to be calculated, but these costs can be estimated with certainty.

### 9. Cost-effectiveness

In countries with generalized epidemics Improving access to HTC for adolescents will increase short-term costs but can be integrated into existing testing services.

### 10. Feasibility and constraints to implementation

Adding HIV testing onto other clinical services has already been shown to be feasible, e.g. in ANC settings, and so it should be feasible to add adolescent testing into other clinical services, such as contraception services and primary health and inpatient care. However many adolescents do not attend clinical services routinely and other community-based approaches may need to be considered. Will need to train existing health-care workers who provide testing to tailor approaches towards adolescents. There are many examples of community-based approaches which have been shown to be feasible and countries should be encouraged to choose a range of these approaches to best suit the needs of their populations.

### 11. Relevance to different settings/populations

#### Settings:

- In generalized epidemic settings, access to acceptable HTC services is relevant to all adolescent populations.

### 12. Gaps, research needs, comments

- Cost-effectiveness of routine HTC in generalized epidemics.
- Screening tests for tests (risk screens).
- Comparative effectiveness and cost-effectiveness of interventions to improve access to HTC/linkage to care in different settings.
- Feasibility, acceptability, ethics, effectiveness of self-testing.
- Feasibility, acceptability, ethics of school-based testing.
- Research is needed in countries where the age of consent to HTC has been lowered to determine that this has not led to adverse consequences following HTC for adolescents.

### 13. Final comment(s)

In developing these recommendations, the panel placed high value upon:

- Increasing access and acceptability of HTC services for adolescents in generalized epidemic settings;
- Reduction of HIV transmission in generalized epidemic settings;
- Improved linkages to supportive services (prevention, treatment and care);
- Monitoring and evaluation as part of all interventions.

#### Key considerations:

- Ensure that testing is linked to a defined package of services including prevention, treatment and care, as well as other SRH services;
- Essential to review the national age of consent for HTC to enable HCWs to offer testing without requiring parental/guardian consent. National programs should acknowledge evolving capacity of adolescents, especially for vertically infected adolescents;
- Sensitization around both vertically and horizontally infected adolescents;
- Ongoing dialogue with caregivers to encourage testing of adolescents;
- Research around risk assessment for testing;
- Offer testing to adolescents as a matter of routine in health facilities linked and integrated into existing testing services, and ensure that providers are continuously reminded to offer testing and sensitized in “adolescent friendly” service delivery;
- Community-based testing approaches need to be adapted/tailored for adolescents;

- Support positive adolescents to disclose to friends and family – a supportive environment is key to successful treatment outcomes;
- In the case of minors who attend with a caregiver, support for the caregiver will also be needed, particularly in the case of vertical transmission.

#### 14. Rational for recommendation:

HIV testing and counselling is an essential component of efforts to achieve universal access to HIV prevention, treatment, care and support. It is the key entry point for many HIV prevention interventions and it is essential for access to treatment and care. Regardless of HIV acquisition route, underutilization of testing and counselling services results in late diagnosis, and increasing uptake of HTC will lead to earlier diagnosis and more effective care. Due to the increasing availability of ART and prevention interventions, early diagnosis can reduce transmission and improve health outcomes, thereby decreasing morbidity and mortality.

Late diagnosis of HIV infection for perinatally infected adolescents is increasingly being recognized as a significant problem leading to delayed initiation of ART, and poor linkages to and retention in care, support for sustained treatment adherence, and LTFU are challenges in many settings.

Adolescents who learn that they have HIV infection can learn to reduce the risk of transmitting HIV to others, as well as to obtain HIV treatment and care. Early access to care can help them to feel better and to live longer than if they were to present for care when their disease is already at an advanced stage. Early access to care can also help adolescents to reduce on-going transmission. As for adults, HIV testing and counselling can serve as a means for adolescents to be diagnosed and to receive treatment and care as early as possible. Access to HTC is also important for adolescents to help them make decisions about HIV prevention choices.

#### 15. Strength of recommendation

Strong recommendation, very low quality evidence

### PICO 3

#### 1. Topic for analysis:

Should HTC be offered to adolescents in low and concentrated epidemic settings?

#### 2. Background:

Previous guidance on HTC has concentrated almost exclusively on supporting provider-initiated or client-initiated HTC for individuals in general, with recent guidance issued in 2011 focusing on HTC for couples. UN guidance addressing the particular situations, challenges and needs of adolescents (10-19 years) and their health-care providers has not been developed. Access to and uptake of HTC by adolescents is lower than for many other groups, leaving them disadvantaged in terms of seeking prevention, treatment and care services. Late diagnosis of HIV infection for perinatally infected adolescents is increasingly being recognized as a significant problem leading to delayed initiation of ART, again highlighting the need to provide more effective HTC for adolescents. Late diagnosis is also an issue for adolescents from key populations who are infected horizontally but who are reluctant to seek services due to stigma, discrimination and the potential for legal consequences.

#### 3. DRAFT recommendation:

We suggest that in low and concentrated epidemics, HIV testing and counseling with linkage to prevention, treatment and care be accessible for adolescents.

#### 4. Summary and quality of evidence:

The quality of evidence was very low, but there was broad consensus that testing of adolescents even in low and concentrated epidemics would be of value. However, the recommendation was conditional based on the fact that



resource constraints may make this a lower priority. In these settings, priority should be given to ensuring access for adolescents from key affected populations. In addition, while this was a conditional recommendation for low and concentrated epidemics, it is important to recognize that in some countries, there are generalized epidemics where wider testing of all adolescents may be of value (see Recommendation 2).

The quality of the evidence was very low. No RCTs were identified. The literature was graded down for very serious indirectness (self-reported outcomes) and serious imprecision (very few participants).

## 5. Risks/benefits

### Benefits

One cross-sectional observational study conducted in a specialist HIV clinic in Thailand found that adults who received HTC compared with no HTC reported a reduction in the number of sexual partners in the previous 6 months

The same study found that those who received HCT compared with no HCT reported increased condom use in the previous 3 episodes of sexual intercourse

### Risks

None

## 6. Acceptability, values and preferences

<b>Community</b>	Adolescent participants report strong desire to test, motivations to test and awareness of responsibilities and benefits of testing
<b>Health-care workers</b>	Offering effective HTC services and encouraging adolescents to access them is considered to be a high priority for service providers as they recognize that adolescents are at high-risk of HIV infection. Services and policies around HTC are not often geared specifically towards adolescents and their needs are underserved.
<b>Other</b>	Legal issues and barriers exist in some settings which need to be considered – e.g. compulsory notification of certain risk behaviors and HIV test results, mandatory testing and criminalization of transmission

### In favour

- Adolescents who perceive themselves to be at risk for HIV want accessible and acceptable HTC services.
- Observed benefits of earlier access to HIV treatment and care and support for informed decision-making around prevention.
- Sense of responsibility to protect themselves and others.

### Against (Expressed as barriers to HTC)

- Fear.
- Implications of a positive diagnosis.
- Association with 'bad' and high-risk behaviour.
- Stigma and its consequences.
- Attitudes of health workers.
- Accessibility and acceptability of services.
- Age of consent issues unresolved in many countries.

### Pros

- HTC empowers young people to get tested.
- HTC gives a sense of responsibility to adolescents.
- Ensures that adolescents have access to health-care services and life-saving ART care (enshrined in the UN rights of the child).
- Both HCWs and adolescents desire better access to HTC for adolescents.
- In some countries with low and concentrated epidemics, there are generalized epidemics where wider testing of all adolescents may be of value.

**Cons**

- Stigma.
- Judgmental HCWs and perceived lack of confidentiality.

**7. Equity, ethics and human right implications**

Age of consent to test varies across countries and may be a barrier to testing for some adolescents. National consent policies can discourage uptake of services by adolescents and constrain providers who may have concerns, sometimes unfounded, about legal consequences for themselves and emotional consequences for adolescents who they fear may not be able to cope with the implications of a positive diagnosis and who may not have adequate support in the home.

Mandatory or coerced testing is never appropriate. It is particularly important in that health workers are sensitive to the particular needs of adolescents and that they understand the issues and challenges facing adolescents, especially those from key populations.

Many people with HIV have experienced discrimination and stigma following diagnosis. Adolescents from key populations in particular often face hostile legal environments as well as emotional and physical violence, and their needs for services and support must be addressed as part of HTC services. Providers of services for adolescents must receive training on human rights and protection issues and be aware of all relevant support services for timely and appropriate referrals.

Adherence to fundamental principles of human rights is foremost among all considerations when providing HTC services for adolescents. Most importantly:

- HTC is always voluntary.
- Privacy and confidentiality must be protected for adolescents as for adults.
- Adolescents have a right to make decisions and seek services in the interest of their own health and well-being.

**8. Cost/resource use**

Resource-intensive recommendation.

**9. Cost-effectiveness**

In resource-constrained countries it will be especially important to distinguish between sub-national epidemics to avoid diversion of scarce resources and prioritize service coverage according to epidemiology and need.

Unlikely to be cost effective given the low prevalence of HIV in the general adolescent population in countries with low and concentrated HIV epidemics. In countries with low and concentrated epidemics, prioritization of HTC services for adolescents from key populations will be significantly more cost effective than provision of HTC for all adolescents.

**10. Feasibility and constraints to implementation**

The recommendation is feasible pending:

- Review and modification of the legal environment, especially regarding criminalization of HIV transmission;
- Age of consent to test issues resolved;
- Training of health workers in working with adolescents and key populations;
- Availability and acceptability of related services.

There is some uncertainty to the feasibility of this recommendation in settings with legal issues that are not compatible with WHO recommendations on HTC.

**11. Relevance to different settings/populations****Settings:**

- In low and concentrated epidemics HTC should be available for adolescents who wish to test through clinical

settings and other venues where HTC is offered. Special HTC services should not be developed for adolescents.

## 12. Gaps, research needs, comments

- Cost-effectiveness of routine HTC in low and concentrated epidemics.
- Screening tests for tests (risk screens).
- Comparative effectiveness and cost-effectiveness of interventions to improve access to HTC/linkage to care in different settings.

## 13. Final comment(s)

In developing these recommendations, the panel placed high value upon:

- Increasing access and acceptability of HTC services for adolescents in low and concentrated epidemics who wanted to access HTC. While not promoting HTC for all adolescents, adolescents who wanted to access HTC should not be discouraged or excluded from HTC
- Reduction of HIV transmission in low and concentrated epidemic settings
- Improved linkages to supportive services (prevention, treatment and care)
- Monitoring and evaluation as part of all interventions.

In concentrated epidemics, testing should be available if an adolescent asks for it, but campaigns promoting testing for the general public should not be prioritized.

### Key considerations:

- Adolescents should be actively supported to test if they are seeking HTC at a testing site, but specific targeting of the general adolescent population is unlikely to be a cost effective strategy as prevalence will be very low; instead adolescent testing should be targeted to specific populations (see PICO1)
- As well as targeting adolescents from key affected populations (see Pico 1), important to also offer targeted services for other vulnerable adolescents including adolescents presenting with STIs, pregnant adolescents, orphans, and adolescents from families affected by HIV
- Community-based testing approaches need to be adapted/tailored towards adolescents
- Ensure that testing is linked to services
- Support positive adolescents to disclose to friends and family – a supportive environment is key to successful treatment outcomes

## 14. Rational for recommendation:

HIV testing and counselling is an essential component of efforts to achieve universal access to HIV prevention, treatment, care and support. It is the key entry point for many HIV prevention interventions and it is essential for access to treatment and care. Regardless of HIV acquisition route, underutilization of testing and counselling services results in late diagnosis, and increasing uptake of HTC will lead to earlier diagnosis and more effective care. Due to the increasing availability of ART and prevention interventions, early diagnosis can reduce transmission and improve health outcomes, thereby decreasing morbidity and mortality.

Late diagnosis of HIV infection for perinatally infected adolescents is increasingly being recognized as a significant problem leading to delayed initiation of ART, and poor linkages to and retention in care, support for sustained treatment adherence, and LTFU are challenges in many settings.

Adolescents who learn that they have HIV infection can learn to reduce the risk of transmitting HIV to others, as well as to obtain HIV treatment and care. Early access to care can help them to feel better and to live longer than if they were to present for care when their disease is already at an advanced stage. Early access to care can also help adolescents to reduce on-going transmission. As for adults, HIV testing and counselling can serve as a means for adolescents to be diagnosed and to receive treatment and care as early as possible. Access to HTC is also important for adolescents to help them make decisions about HIV prevention choices.

In low and concentrated epidemics the HIV prevalence rates among adolescents in the general population is often

extremely low and developing HTC service specifically for them or promoting HTC for adolescents through HTC campaigns or outreach is unlikely to be cost-effective. However HTC should be available for any adolescent who wishes to know their HIV status and offered in health-care settings for adolescents with symptoms suggestive of HIV infection (as per PITC guidelines).

### 15. Strength of recommendation

Conditional recommendation, very low quality evidence

## PICO 4

### 1. Topic for analysis:

Should adolescents be counselled about the potential benefits and risks of disclosure of their HIV status?

### 2. Background:

Disclosure is not an end in itself, but a means to obtaining more support.

There are many challenges related to “beneficial disclosure” (i.e. disclosure to a family member/peer to support coping with the diagnosis, access to care and adherence to treatment) and to disclosure to sexual partners since adolescents have different types of relationships (often intermittent and short-term) from those between adults (may be in longer-term, stable relationships, and have the knowledge and skills to deal with the difficult issues raised by disclosure to sexual partners including dissolution of the relationship).

For these guidelines, the primary importance of disclosure is to enhance the opportunities for support of the adolescent.

### 3. DRAFT recommendation:

We suggest that adolescents be counselled about the potential benefits and risks of disclosure of their HIV status and empowered and supported to determine if, when, how and to whom to disclose.

### 4. Summary and quality of evidence:

Despite the low quality of evidence there was consensus that the potential benefits of disclosure are usually greater than the potential harms.

### 5. Risks/benefits:

#### Benefits

Supportive effects on individual emotional and physical health, coping with a chronic illness, adherence to treatment, retention in care and preventive behaviour.

In one non-randomized trial from the US of HIV-positive youth, conducted in the pre-ART era, adolescents participating in small group discussions were less likely to report unprotected sex, compared to those receiving standard care, when measured at 15 months.

In one RCT from the US of HIV+ mothers and their children (age 6-12 years old), adults participating in four counselling sessions were more likely to disclose their HIV status to sex partners, compared to those receiving standard care, when measured at 15 months.

In one observational study from SA, more HIV-positive pregnant women who participated in structured support groups for HIV-positive pregnant women had disclosed their HIV status at 2 and 8 months, compared to before attending the support groups.

In one RCT from the US, conducted in the pre-ART era, HIV-positive parents participating in small group discussions with their adolescent children had lower mean depression scores than those receiving standard care at 15 and 24 months

In one RCT from the US, adults MSM participating in peer-led behavioural sessions among other HIV-positive MSM had a higher mean score in reporting that the intervention had motivated them to inform their sex partners of HIV status, compared to participants receiving standard care.

In one observational study from Mali, HIV-positive women who participated in women’s empowerment workshops for HIV-positive women had lower mean scores for the “weight of keeping their HIV status a secret”.

**Risks**

In one RCT from the US, conducted in the pre-ART era, HIV-positive parents participating in small group discussions with their adolescent children had higher mean depression scores than those receiving standard care when measured at 3 months.

A few observational studies (with no comparison group) reported higher levels of HIV stigma for those that reported disclosure as well as negative experiences such as abandonment, anger, blame, violence, and relationship dissolution

Potential for real or perceived harm to the family in the case of vertically infected adolescents (inadvertent disclosure of mother’s/parents’ HIV positive status)

Adolescents may face harsh discrimination and stigma as a result of being HIV-positive from peers, sexual partners, school, workplace and community.

Adolescents may face discrimination in terms of educational or employment opportunities.

Disclosure may be a particular problem among adolescents who are pregnant or delivering as there are potentially adverse outcomes when HIV status cannot be shared (with partner/parents/family) to support safe infant feeding and uptake of PMTCT interventions and HIV care when HIV status is not disclosed to the partner or supportive family members.

Disclosing to sex partners may cause harm in some settings where exposing individuals to HIV is considered illegal.

**6. Acceptability, values and preferences:**

<b>Community (adolescents)</b>	<p>Divided opinions:</p> <ul style="list-style-type: none"> <li>-- Disclosure is the right of the individual and should be the decision of the individual</li> <li>-- Disclosure can be a necessary means of support or it can expose the individual to rejection, marginalization and loss of relationships</li> </ul>
<b>Health-care workers</b>	<ul style="list-style-type: none"> <li>-- Challenging to discuss disclosure with adolescents, and so often not adequately discussed with adolescents</li> <li>-- Guidance or policy on how to support disclosure is weak or non-existent in many places</li> <li>-- Support for adolescents’ right to make decisions around disclosure; some support also for disclosure by providers to parents in the interest of ensuring the practical and emotional support that ALHIV will need to cope and adhere to treatment</li> <li>-- Need to take into account the willingness and readiness of each adolescent to disclose</li> </ul>

**In favour**

Important benefits to be gained from disclosure.

**Against**

Potential lack of support from society and peers; lack of coping skills.

### **7. Equity, ethics and human right implications:**

Confidentiality should be maintained unless there is a risk to the adolescent or others.

Who determines the best interest of the adolescent? Adolescent him or herself? The context will determine this – the provider may have some info that the adolescent may not have. Also there is the principle of evolving capacity. There is an onus on provider to advise where their best interest can be protected.

### **8. Cost/resource use:**

There is little published or descriptive data on the best ways to support adolescents to disclose safely and beneficially, so it is difficult to estimate costs and resources. Although unlikely to be costly there will be resource requirements for training counsellors and health workers and support for follow-up. There are therefore uncertainties about the costs.

### **9. Cost-effectiveness:**

If disclosure can be shown to increase uptake and adherence to treatment, prevention and PMTCT interventions (the limited data available suggests that this is the case) it is likely to be cost effective.

### **10. Feasibility and constraints to implementation:**

Emphasis on creating a supportive environment for adolescents to disclose to parents and/or peers.

Lack of clear guidance for providers on how to support adolescents to disclose.

Important to provide supportive pre AND post disclosure counselling.

### **11. Relevance to different settings/populations:**

Vertically infected adolescents are different from a cognitive and developmental perspective. Guidance must take into account these differences.

Can't recommend one model, because of lack of evidence in support of any particular approach but also because of the heterogeneity of country settings and epidemics and social and cultural context. Many models exist for HOW to deliver this type of support to adolescents including teen clubs, support clubs, peer support groups, using different strategies e.g. 6 sessions or more, incentive-based, role plays to encourage engagement of adolescents, dramas (some of these have been evaluated) - highlighted as case studies in the guidelines.

### **12. Gaps, research needs, comments:**

Supportive interventions to help adolescent decision-making about beneficial disclosure.

*Outcomes: Short and long-term psychosocial outcomes*

### **13. Final comment(s):**

Operational guidance is needed for health workers and peer counsellors to provide support for adolescents to make decisions about disclosure, including rights and responsibilities to disclose and *not* to disclose. Related to this, it is important to ensure that non-name-based reporting systems are in place to ensure confidentiality and protection. Forced or uninformed disclosure on the part of health-care workers can be a powerful deterrent for members of KPs and other ALHIV from uptake of HTC and can also undermine retention in care for individuals who have already been enrolled in care interventions.

While disclosure to sex partners is part of the ethical development of adolescents, and should be seen in the context of prevention, disclosing to sex partners may cause harm in some settings where exposing individuals to HIV is considered illegal.

Adolescents need to be empowered to determine if when how and to whom to disclose.

### **14. Rational for recommendation:**

Disclosure of HIV status to trusted individuals is considered to have significant beneficial effects that outweigh the potential harm of revealing one's status. The main reasons for disclosure are for the supportive effects on individual emotional and physical health, coping with a chronic illness, adherence to treatment, retention in care and preventive behaviour.

### 15. Strength of recommendation

Conditional recommendation, very low quality evidence

## PICO 5

### 1. Topic for analysis:

Should HIV treatment and care programmes include community-based approaches to improve treatment adherence and retention in care of adolescents living with HIV?

### 2. Background:

As with managing other chronic illnesses during adolescence, many ALHIV have serious problems with adherence to treatment and retention in HIV care (research shows that adherence and retentions are often more significant problems for adolescents than for adults); community-based services can mitigate some of the burden faced by adolescents who need accessible and low-cost services to support retention in HIV care and adherence to treatment.

While there is no single community-based model or approach that has demonstrated improved individual outcomes among HIV-positive adolescents across multiple geographic areas, community-based support strategies which address knowledge, motivation and skills of adolescents and caregivers; facilitate linkages into care; support the broader emotional and psychosocial needs of adolescents and reduce user costs in accessing care are likely to be of value.

### 3. DRAFT recommendation:

We suggest that HIV treatment and care programmes include community-based approaches to improve adherence to treatment and retention in care of adolescents living with HIV.

### 4. Summary and quality of evidence:

Regarding support for treatment adherence and retention in care through community-based interventions, there was no evidence in RCTs upon which to base the recommendation. The expert panel noted that RCTs are not very useful for behavioural studies, and that operational research is actually what is needed. They felt that the interventions in question are important enough that they be represented in the guidance as the best judgment of practitioners and advocates that will be used as the basis for further research focused on implementation trials.

Panel discussion highlighted conflict between extensive field experience with community-based services and lack of an evidence basis for the recommendation that resulted in a conditional recommendation.

The recommendation has a weak evidence base, but met the criteria for conditional recommendations. The recommendation was agreed by a majority, not unanimous, vote.

### 5. Risks/benefits:

#### Benefits

Greater accessibility / acceptability / affordability can also contribute to increased retention in care / reductions in LTFU.

#### Risks

There are many reports in the gray literature and experiences from members of the guidelines group of community-based care and support that is acceptable to adolescents with documented benefits; however, there are some community-based approaches that are of poor quality and may have little impact and/or deleterious effect.

## 6. Acceptability, values and preferences:

<b>Community (adolescents)</b>	Support provided nearer to the adolescent.  Potentially provides a wider range of emotional and psychosocial support to augment support from clinical providers.
<b>Health-care workers</b>	

### In favour

Facilitates involvement of adolescents in the planning and implementation of services, especially for peer support interventions.

Easier access to services, especially for adolescents who live far from clinic-based services and who will need multiple visits for treatment and care.

### Against

## 7. Equity, ethics and human right implications:

If access and accessibility increased, facilitates protection of the adolescent's right to health.

## 8. Cost/resource use:

There is little robust data on the costs of providing community-based services for adolescents (or for community-based services in general), so there is considerable uncertainty about the cost. As community-based services are often provided by lay providers, peers or volunteers, personnel costs may be less than providing support services through formal health facilities.

## 9. Cost-effectiveness:

As there is inadequate data it is not possible to make a considered judgment on this and formal costing and cost-effective studies are warranted.

## 10. Feasibility and constraints to implementation:

Community-based support should be seen as an adjunct to (and in partnership with) clinical care services. In general, it may be easier to make formal medical assessments in clinical settings, and adolescents on ART will need formal monitoring at least annually to review their HIV treatment, assess for toxicities and other clinical aspects of their care. Community-based support can, however, provide routine checks, dispense ART, support adherence, help identify potential problems and support early referral to clinics. Community support workers can also follow up adolescents who are lost to follow-up or default from care. There may also be important roles for community support workers or peers in helping adolescents cope with a range of emotional and psychosocial issues associated with their HIV infection, sexual relationships, family relationships, school issues and drug and alcohol problems. Peers may be ideally placed to support adolescents especially when health providers are overstretched and have insufficient time to devote to the complex needs of adolescents or lack sufficient empathy or skills to provide holistic and acceptable support.

Greater feasibility when working through existing community structures.

## 11. Relevance to different settings/populations:

Vertically infected adolescents (especially those who have often have started treatment late) often have different needs and more complex medical issues from a cognitive and developmental perspective, which may require psychological support in addition to clinical care. Horizontally infected adolescents will experience many of the same challenges as other adolescents (including sexual and family relationship issues) that may complicate coping with HIV.

There is a lack of evidence in support of any one particular community-based approach, as well as the heterogeneity



of country settings and epidemics and social and cultural context to consider. Many models exist for how to deliver this type of support to adolescents including teen clubs, support clubs, peer support groups, using different strategies e.g. 6 sessions or more, incentive-based, role plays to encourage engagement of adolescents, dramas (some of which have been evaluated) - highlighted as case studies in the guidelines.

**12. Gaps, research needs, comments:**

Identify effective components and combinations of community-based interventions that improve adherence, linkage and retention in care + proximal outcomes.

**13. Final comment(s):**

Will require particular attention to support for community-based service providers – systematic approach to recruitment, training and retention as well as ongoing training and supervision and support.

Important that these services operate within the context of existing national policies and guidelines related to community-based delivery of health services, are accredited and accountable, and have strong links to clinical services.

**14. Rational for recommendation:**

Increased access to services; increased opportunities for adolescents and their communities to be involved in services to support adherence to treatment and retention in care.

It is anticipated that improved access at the community level provides adolescents with a more acceptable/feasible option for managing their HIV care and may facilitate better adherence to treatment and retention in care.

**15. Strength of recommendation:**

Conditional recommendation, very low quality evidence

**PICO 6**

**1. Topic for analysis:**

Can training of health-care workers contribute to adherence to treatment and retention in care of adolescents living with HIV?

**2. Background:**

Negative attitudes of health workers affect adolescents more than adults, particularly young KPs. Studies show that adolescents often avoid engaging with health services due to distrust in health-care workers related to judgmental attitudes. However, for many adolescents, health-care workers are important sources of support, information and advice. To improve access to services and support retention in care and adherence to treatment, better understanding of the complex needs and issues which face adolescents living with HIV is required, as well as communication skills that foster openness and acceptance and non-judgmental interactions with adolescents.

It is acknowledged that the effective training for health-care workers should result in changes in behaviour, leading to attitudes and practices that facilitate better communication and more acceptable provision of services and support for adolescents. This, however, may not occur following a single training event. Training programmes for health workers that address adolescent issues may increase knowledge, but there is little available evidence that these result in significant changes in attitudes or the provision of services that are more acceptable to adolescents. The expert panel felt that it was important to have a recommendation for training as a starting point, as one component of working toward increased adherence to treatment and retention in care, with the implication of ongoing supervision and professional support as part of the behaviour change process. Additionally, programmes that provide training should assess its impact and document key elements that are effective in improving outcomes for adolescents living with HIV.

**3. DRAFT recommendation:**

We suggest that training of health-care workers contributes to improved adherence to treatment and retention in care of adolescents living with HIV.

#### 4. Summary and quality of evidence:

Regarding support for treatment adherence and retention in care through training of health-care workers, there was not sufficient evidence in RCTs or from other published or unpublished studies upon which to base the recommendation. The researchers reviewing literature relating to training of health-care workers to support better adolescent care also broadened their search to look at other clinical services for adolescents for which long-term support and adherence to therapy was critical (family planning, diabetes and asthma care), and no relevant studies were identified that could be used to help in the process of making a recommendation. A number of participants pointed out that it is often difficult to use standard research methods such as RCTs to explore the effectiveness of behavioural studies, particularly as models of implementation are often very context-specific, and that operational research approaches may be more appropriate in assessing effectiveness.

The expert panel felt that the intervention in question is important enough that it be represented in the guidance based on expert opinion and noted the need for further research focusing on implementation trials.

The recommendation has a weak evidence basis, but met the criteria for a conditional recommendation. It was agreed by a majority, not a unanimous, vote.

#### 5. Risks/benefits:

##### Benefits

Based on the expert opinion of the group, training of health-care workers can increase use of services and support adolescents to remain in care and adhere to treatment. Examples given were context-specific and there is a need to determine key elements that could be generalized.

Training of health-care workers was also noted by the expert panel to assist health-care workers to be better advocates with colleagues and other sectors (including community-based organizations) for recognizing the special needs of adolescents and adapting services accordingly.

##### Risks

Poorly conceived and conducted training can potentially waste resources and time, and there may be other opportunity costs.

Although the expert panel gave examples of specially trained adolescent health providers delivering quality services, specialization may deter health-care workers who are not trained from providing care to adolescents if and when the 'specialist' is not available.

#### 6. Acceptability, values and preferences:

<b>Community (adolescents)</b>	<p>Adolescents mention a number of positive aspects of care that would indicate the potential value of training:</p> <ul style="list-style-type: none"><li>• Sensitive and caring treatment;</li><li>• Interactions with providers who convey a sense of hope and optimism in a meaningful and realistic way.</li></ul> <p>Adolescents want health-care workers to be sensitive, supportive and attuned to their needs; this can be achieved through training.</p> <p>Support for adherence requires other knowledge, including technical knowledge as well as motivation, skills; performance improvement more generally is required and achieved through training.</p>
<b>Health-care workers</b>	<p>Service providers note that there is a lack of appropriate training in specific skills needed for working with adolescents, and they cite this as being a barrier</p>

to providing high quality care.

**In favour**

On balance, training for providers is welcomed by adolescents if it leads to better provider attitudes and communication, and health providers recognize that they need help to develop their skills to work more effectively with this group.

**Against**

Training, supervision and on-going support is resource-dependant.

**7. Equity, ethics and human right implications:**

Confidentiality should be maintained unless there is a risk to the adolescent or others.

Who determines the best interest of the adolescent? Adolescent him or herself? The context will determine this – the provider may have some info that the adolescent may not have. Also there is the principle of evolving capacity. There is an onus on provider to advise where their best interest can be protected.

**8. Cost/resource use:**

The expert panel noted that potentially lengthy residential workshops may be costly and require staff to be away from facilities without robust data to support the efficacy of this approach. In-service training and training supported and informed by adolescents may be less costly and more effective. The need for mentoring and ongoing support to improve adolescent skills with monitoring and feedback may be more appropriate, less costly and less resource-intensive in many settings. These views were based on expert opinion and therefore there is considerable uncertainty and no ability to generalize across different epidemic contexts and for different populations of adolescents.

*Please note: There is currently a lack of the staff need for the mentoring mentioned above. Some programs are exploring the possibility of peer mentoring and support between facilities in the context of skills sharing skills, information and experience. This is expected to develop a larger body of expertise in this area.*

**9. Cost-effectiveness:**

There is no directly relevant data on which to base discussions around cost effectiveness.

**10. Feasibility and constraints to implementation:**

Training for acquisition of technical skills is considered easier than for issues that require changes in attitude or behaviour (especially true in a culture that may promote or tolerate judgmental attitudes).

As noted in Section 8, in-service training approaches may be more feasible to implement.

Adolescent issues should be addressed in standard clinical training for all cadres of health workers. For example the specific needs of adolescents should also be considered in basic training of nurses, clinical offers etc.

**11. Relevance to different settings/populations:**

Health workers will require additional skills to provide care for adolescents from key populations. (See Section 13 for more detail.)

**12. Gaps, research needs, comments:**

Research is needed to identify effective interventions for sustained adherence to treatment and for improving linkage and retention in care for adolescents; results from this research will indicate areas requiring specialized training and supervision and the best ways in which to deliver this.

**13. Final comment(s):**

The expert panel felt that training of health-care workers should focus explicitly on:

- **Primary care:** Basic adolescent development and health; specific issues affecting ALHIV – chronic illnesses, co-morbidities, adolescent development – stunting/puberty delay;

- **Prevention:** Condoms, contraception, pre-conception advice and reproductive health issues, prevention of high-risk behaviours (e.g. alcohol and substance use);
- **HIV treatment and care:** Adherence, retention (e.g. loss-to-follow-up procedures, different service models such as youth-friendly services, transition to adult services), self-management, nutrition; special issues around adolescents who stop treatment, adhere poorly or experience treatment failure, long-term complications of ART, late presenters/slow progressors;
- **Recognizing psychological and emotional illness/issues:** Psychological and emotional problems are common for people with HIV, including adolescents. In addition, many ALHIV, particularly those in generalized epidemics, may live in households where other family members have HIV. They may have experienced or will experience the death of family members or they may be orphaned. These underlying family issues may not be initially disclosed to the health worker by the adolescent but may precipitate depressive symptoms or compound emotional problems that are common during all adolescence. Neurocognitive development will be different for each individual.
- **Disclosure:** There have been significant developments in terms of disclosure to children, so it is increasingly expected that by the time children reach adolescence they will have been disclosed to about their own HIV status and the status of their parents / guardians / caregivers. A major challenge remains around adolescents disclosing (a) to others in order to obtain the support they need, and (b) to sexual partners in order to contribute to safer sex / HIV prevention (although the priority for individuals should be adherence to treatment and correct, consistent condom use). Rights and responsibilities concerning disclosure in educational settings, the workplace and as well as personal relationships – these will be context-specific depending on national laws.
- **Communication skills:** Basic counseling skills, values clarification;
- **Young members of KPs:** Health-care workers must be trained to understand and address the particular needs of young members of KPs with sensitivity and discretion.

Training was considered by many in the expert panel to be a ‘package’ that includes follow-up, mentoring, supervising, and in-service training. Effective application of learning depends on supportive management structures in the clinics where training participants work and should be in line with MoH policies.

The expert group also considered that the health providers’ attitudes towards and desire to work with adolescents may be a critical element and that providers who were already empathetic to their needs and motivated to work with adolescents would benefit more from training. Therefore, careful selection of health workers to receive training should be considered. However, it was also acknowledged that as a principle of providing quality health-care to all in need, there should be general monitoring of the acceptability and quality of all health-care provided for adolescents and action taken if this was not provided in an acceptable way.

#### 14. Rational for recommendation:

Different / additional skills may be needed by health-care workers and lay counsellors for working with adolescents, with a particular emphasis on supporting treatment adherence and retention in care.

#### 15. Strength of recommendation

Conditional recommendation, very low quality evidence